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

~ Minutes ~
September 26-27, 2011 Meeting

Participants

Ex officio Members and Representatives:

Mark Gross
Representing the Honorable Eric H. Holder, Attorney General, U.S. Department of Justice

William D. Falsey
Representing the Honorable Kenneth L. Salazar, Secretary, U.S. Department of the Interior

Alexa Posny
Representing the Honorable Arne Duncan, Secretary, U.S. Department of Education

Jewel Bazilio-Bellgarde
Representing the Honorable Patrick Corvington, Chief Executive Officer, Corporation for National and Community Services

Charlene Wills
Representing the Honorable Shaun L.S. Donovan, Secretary, U.S. Department of Housing and Urban Development

Susan Aramaki
Representing the Honorable Gary Locke, Secretary, U.S. Department of Commerce

Caffin Gordon, Yvette Rivera, and Michael Caliendo
Representing the Honorable Raymond L. LaHood, Secretary, U.S. Department of Transportation

Richard Balkus and Robert Weathers
Representing the Honorable Michael J. Astrue, Commissioner, Social Security Administration

Mary Kay Mauren
Representing the Honorable Jacqueline A. Berrien, Chair, Equal Employment Opportunity Commission

Gary Blumenthal
Representing the Honorable Jonathan M. Young, Chair of the Board, National Council on Disability

Citizen Members:

James T. Brett, Chair
Annette McKenzie Anderson, Ph.D.
Peter V. Berns
Clay Boatright
Micki Edelsohn
Ann Hardiman
Alison A. Hillman de Velasquez
Carl M. La Mell
Carol Quirk
Susana Ramirez
Deborah M. Spitalnik, Ph.D.
Lillian Sugarman
Liz Weintraub
Carol Wheeler
Sheryl White-Scott, M.D.

Guest Speakers/Presenters:

Ken Capone
Lisa Ekman
Cathy Ficker-Terrill
Marty Ford
Phyllis Holton
Richard Kogan
Bill Krebs
David Mank, Ph.D.
George Sheldon
Leigh Sutherland
Nancy Thaler
Paul Van de Water, Ph.D.
Jane West
Tracy Wright

Special Guest(s):

Charles Lakin, Director, NIDRR
Sue Swenson, Deputy Assistant Secretary, OSERS

Constituency Group Representatives:

Marty Ford, Arc of the United States
Sue Swenson, OSERS
Nancy Thaler, NASDDDS

Other Guests:

Charles Acree
Patricia Brett
Dawn Carlson, NIDRR
Angela Childers, ASL Interpreter
Mandy Haltrecht, DOT
TJ Sutcliffe, the ARC

ADD-PCPID Staff:

Sharon Lewis, Commissioner
Madjid “MJ” Karimi
Pamela O’Brien
Laverdia Taylor Roach
Genevieve Swift
Sheila Whittaker

~ SUMMARY OF PROCEEDINGS ~
(Meeting Agenda at End of Summary)

Greetings, Call to Order, and Presentation of PCPID Chair
Sharon Lewis, ADD Commissioner and PCPID Designated Federal Official

The September 26-27, 2011 meeting of the President's Committee for People with Intellectual Disabilities (PCPID) was called to order by Sharon Lewis, Designated Federal Official, and Commissioner of the Administration on Developmental Disabilities (ADD). Commissioner Lewis reviewed the agenda and highlighted issues to be discussed, including the Budget Control Act and Congressional funding decisions.

Welcoming Remarks and Introduction of Special Guests
James Brett, PCPID Chair

The PCPID Chair, Jim Brett, thanked Carol Wheeler for hosting a reception for Committee members at her home. Mr. Brett also acknowledged several meeting attendees, including Dawn Carlson of NIDRR and Gary Blumenthal, ex officio representative from NCD and former PCPID Executive Director.

Approval of Agenda and Minutes (June 16-17, 2011; July 19, 2011; and August l6, 2011)
James Brett, PCPID Chair

Chairman Brett requested a motion to approve minutes for the June 16-17, 2011, July 19, 2011, and August l6, 2011 Committee meetings. A motion was made. Mr. Brett gave the Committee the opportunity to discuss issues pertaining to the content of the minutes. No discussion was raised. The Committee voted, unanimously, to accept all three minutes of the three meetings.

Meeting Overview and Orientation
James Brett, PCPID Chair

Mr. Brett thanked Sharon Lewis and the PCPID staff for developing the agenda and arranging presentations. He noted that Committee members would hear from experts regarding the five focus areas (Employment, Income Support, Long-term Services and Supports/Community Living, Education, and Healthcare/Medicaid) of the Report to the President. He added that, following these presentations, a panel of self-advocates and family members of individuals with intellectual disabilities (ID) would address the Committee.

The Chair reminded members that during the August 16, 2011 conference call, several decisions were made by members regarding the content of the report and the process for preparing the document. It was decided that Committee members should compose a brief report to the President for 2011, based on the Budget Control Act and its impact on discretionary funding to people with ID. The Committee decided to focus on the impact of potential cuts or elimination of funding to programs in five identified areas, listed on the agenda. Experts would be asked to help Committee members gather knowledge in the specified areas. On the second day of the meeting, a facilitator would assist members in putting together the report. In order to have an impact on the decisions to be made by the Joint Selection Committee on Deficit Reduction (JSC), "Super Committee", the report would need to be completed by the end of October.

Sharon Lewis suggested the Committee take time to dialogue and give ex officio members the opportunity to ask questions. Mr. Brett listed the five focus areas (Employment, Income Support, Long-term Services and Supports/Community Living, Education, and Healthcare/Medicaid) and four key questions submitted to presenters:

1. What are the core fundamental values that PCPID should consider about the importance of this priority issue for people with ID?
2. What are the risks in the current economic and political environment related to programs, services, and policies supporting people with ID under this priority issue?
3. What are the opportunities in the current economic and political environment related to programs, services, and policies supporting people with ID under this priority issue?
4. What is the potential economic impact of changes in policy and funding related to this priority issue?

Members expressed hope that some of the subject matter experts would be available to provide expert advice to help working groups put together priorities.

Deborah Spitalnik provided an explanation of how the Committee decided to focus on the Budget Control Act and discretionary funding and how these programs are crucial to the lives, well-being, and productivity of people with ID. She emphasized that ensuring the protection of current programs is necessary for full community inclusion.

Alison Hillman de Velàsquez mentioned that during the last ACA/Medicaid call, the speaker suggested that the Committee members focus on essential principles to underlie necessary supports, rather than dissecting policies. As follow-up to that speaker, PCPID staff sent out a document with principles identified in previous Committee meetings. This idea is something the Committee expressed interest in considering. The Chair liked this idea, and suggested that it be discussed on the second day of the meeting.

Peter Berns pointed out a number of possible budget outcomes. He asked Sharon Lewis to share her understanding of the government's plan for these outcomes. Commissioner Lewis explained that preparation strategies vary by agency. She stated that, fortunately, most contingency plans are already in place, due to the anticipated government shutdown last spring, and added that offices are planning FY12 expenditures using the President's budget.

Gary Blumenthal voiced concern that the solution to the budget issue might be worse than the problem. He suggested that the Committee may wish to raise its profile and work with constituency groups to alert people to the impact that cuts would have at the ground level.

Carol Wheeler asked Sharon Lewis how Super Committee discussions have progressed. Ms. Lewis replied that there has not been much progress, but that speakers could provide more complete information on that point.

Deborah Spitalnik suggested that Committee members consider how success would be constituted. She expressed belief that if the Super Committee reaches an agreement, current proposals will have a significant impact on people with ID. Government supports will most likely change dramatically and the kinds of supports that Committee members consider essential will receive considerably less resources. Dr. Spitalnik admonished that Committee members need to be optimistic and proactive, regardless. Commissioner Lewis added that the variability

among states will become more pronounced, since states set their own priorities related to waivers and optional services based on state budgets. As a result, more responsibility and advocacy are necessary at the state level.

Mark Gross emphasized how important state issues can be. He noted that the Committee's tone will be picked up by the states. Mr. Gross shared his belief that this meeting needs to focus on what to send out in the short-term.

Gary Blumenthal suggested that the Committee focus on how maintaining community services for people with ID can be efficient. Sharon Lewis noted that aligning efficiency with values and advice is part of the Committee's role. Carol Quirk agreed. There is a notion that the current structures, including day programs and other programs, are the most cost efficient but other, more cost-efficient possibilities exist, which advance our values in the community. Clay Boatright agreed. He also suggested that the Committee focus on how to move the discussion beyond government resources. Mr. Boatright added that a large percentage of support for people with disabilities has come out of federal and state budgets, and that people with ID should not be subject to political whims for support because that is unsustainable long-term. He expressed belief that the Committee should look to other avenues of support, such as faith-based or commercial organizations. Liz Weintraub advised that this could be accomplished by helping individuals with ID get jobs.

Overview of the Budget Control Act and Implications for People with Intellectual Disabilities
Richard Kogan, Senior Fellow, Federal Fiscal Policy, Center on Budget and Policy Priorities
Paul Van de Water, Ph.D., Senior Fellow, Federal Fiscal Policy, Center on Budget and Policy Priorities

The Center on Budget and Policy Priorities is a nonpartisan organization that works on behalf of low-income individuals. According to Mr. Kogan, the Budget Control Act is a partial resolution of the debt limit crisis in the spring and summer of this year. It has two parts. First, it dealt with votes in Congress on a Constitutional Balanced Budget Amendment and allowed an increase in the debt limit, to avoid an immediate monetary crisis was until 2013. Second, it set two rounds of budget cuts in place. Round one limited the money that the Appropriations Committee could appropriate for the next ten years and divided that statutory ceiling between defense-related activities and non-defense activities. The non-defense ceiling is about 6 percent less than current funding levels. Because the Appropriations Committee will decide how to allocate the cuts, PCPID will need to persuade them to minimize cuts to discretionary programs for people with ID. Cuts have historically meant that all ongoing programs suffered about equally, so programs for people with ID will likely be affected. Round two mandates an additional $1.2 trillion. This can be done by lowering the caps further, cutting entitlement programs, and raising revenues. Mr. Kogan explained the legislative process surrounding a bill from the JSC. Due to the possibility that the JSC may not to reach a consensus, a backup system was created to serve as an incentive for cooperation and a remedy for potential failure. If the joint committee process achieves less than $1.2 trillion in savings, more spending cuts will automatically go into effect to make up for the short coming. These cuts will be evenly divided between defense and non-defense programs, mostly affecting discretionary appropriation. The defense caps will be lowered starting in 2013, the first year that automatic sequestration would occur, running through 2021. Non-defense caps will be further lowered. Certain entitlements will be automatically cut,

and there is no discretion about how the President will order those cuts. An estimated $123 billion will come out of Medicare, through a cut of 2 percent in reimbursements to providers and plans. There will not be cuts on beneficiaries. This may actually benefit beneficiaries because the cost of premiums to buy Medicare Part B will be slightly lower. Other non-exempt mandatory programs will be cut by an estimated 9 percent. Mr. Kogan advised that most mandatory programs are exempt. Non-exempt programs include basic state grants, Title 20 grants to states for social services and vocational rehabilitation. These will be cut by an estimated 9 percent if there are no joint selection committee savings. As mentioned before, non-defense discretionary programs will be capped by 6 percent in 2012, growing to 9 percent by 2021. This means that, by 2013, they would reach 13 percent off of existing funding and 14 percent by 2021. Mr. Kogan went on to explain how he reached these percentages. Depending on what the public wants, these percentages may not be strictly adhered to over the course of the decade.

Mr. Kogan showed a slide describing different sequestration outcomes, based on the amount that the JSC is able to save. The higher the savings from the JSC, the lower the cut percentages.

Mr. Van de Water continued the presentation addressing the Budget Control Act and implications of possible to supports and current benefits for people with ID. He began by stating that programs for persons with disabilities are seriously threatened by cuts. Many programs are exempted from sequestration, but not possible cuts from the JSC. If the JSC produces a package of recommendations, it will almost certainly include cuts to Medicare and will likely include cuts to Medicaid as well. Hopefully, there would be no significant cuts to SSI. All federal spending programs are under serious threat. The Committee should think about the big picture, not just individual programs. Everything needs to be on the table, including tax increases, as in the President's recent proposal. Unless revenue increases are included in the final package, cuts in spending will be severe.

Mr. Van de Water note that two points need to be emphasized in the case for revenue increases. First, income growth in the bottom 90 percent of the population over the last thirty years has been roughly stagnant, but in the top 1 percent growth has been large. This implies room for upper income individuals to share in reducing deficits. Spending cuts mainly affect middle and lower income individuals. A balanced package can only be put together with the inclusion of revenue increases. The second point is the fact that federal income taxes are currently quite low compared with recent history.

Mr. Van de Water expressed belief that exaggeration about the growth of federal disability programs may make these programs a target for cuts. He added that while discussion has focused mainly on Social Security disability programs and SSI, exaggeration could impact all disability programs. Much of the recent growth in Social Security and SSI reflects the aging of the population, increasing the percentage of the population insured for disability benefits and the number of workers in their disability-prone years. There has also been an increase in proposals for work requirements in disability programs. A recent proposal included work requirements for both adults with disabilities and parents of children with disabilities in the SSI program. Other proposals would turn SSI back to the states. Some have suggested using block grants to make programs more efficient. Given the current budgetary environment, proposals for block grants are not supposed to be neutral with regard to the level of spending, but are a way of cutting federal and state spending. Other proposals have suggested providing services rather than cash

to the families of children with disabilities, limiting decision-making opportunities for individuals with disabilities.

(Presenter-Committee Dialogue)

Clay Boatright requested more information about the proposed work requirements. Dr. Van de Water explained that some people view the work requirements and time limits in TANF as a good model for SSI. TANF worked well during prosperous economic times. Now that jobs are much harder to find, the idea of work requirements needs to be reevaluated.

Deborah Spitalnik talked about PCPID's previous recommendation to maintain SSI cash benefits, which had implications for the Social Security Administration. She stated that this example illustrates the current policy environment and demonstrates a way to reach beyond the requirements of the report and advise other agencies. Dr. Spitalnik noted that SSI is an important issue because it supports people with ID in living with their families and prevents institutionalization due to financial hardship. In order to avoid institutionalization, SSI needs to be protected. Carol Wheeler added that, if individuals with disabilities are driven into institutions, costs will go up as a result.

Peter Berns commented that the least damaging scenario is one in which no agreement is reached, automatic sequestrations occur, and the Bush tax cuts expire. When the Bush Tax Cuts expire, new revenue will become available and another large budget dispute will likely ensue. Mr. Kogan pointed out that the sequestration would occur in January of 2013, at the same time as the next debt limit crisis and the expiration of the Bush tax cuts. Therefore, the next Congress and President will be in a position to leverage certain supports for people with disabilities against one another and potentially eliminate some of those supports. Even if the Bush tax cuts did expire, it would take legislation to apply any additional funds to any budget holes.

Mr. Van de Water added that no proposal from the JSC is preferable to a bad proposal. From an economic perspective, it does not matter whether cuts are automatic or enacted by the JSC.

Chairman Brett voiced belief that doctors would stop accepting patients with disabilities if Medicare and Medicaid was cut by 2 percent on the service provider end. Mr. Kogan added that the 6 percent cut enacted in other discretionary programs could contribute to the same type of problem among those programs. He also noted that the percentage will likely increase to 13 or 14 percent if the JSC does not propose another solution or 10 to 30 percent if it does.

Chairman Brett discussed why the JSC will likely not be able to come to a compromise. He also asked how much of the $900 billion will start taking effect in the FY12 budget. Mr. Kogan did not have the numbers or dollar amounts, but the amount is approximately a 6 percent cut.

Mark Gross asked how the expiration of the 2013 Bush tax cuts would translate into revenue. Mr. Kogan answered that the value of the cuts is about 2 percent of GDP or approximately $300 billion per year at current levels. Mr. Gross then asked that Mr. Van de Water translate his slide with the growth over the past six decades from percentages into actual income, particularly the income for the top 1 percent. Mr. Van de Water offered to send the income cut offs to staff for transmission to Committee members. The increase for the top 1 percent was 280 percent, which translates to a huge amount of actual income, illustrating why those with higher income can

afford to pay more in taxes. These individuals are becoming much richer and are paying moderately higher taxes, causing their after tax income to explode.

Carl LaMell inquired whether the 2 percent cut to Medicare would be a one-time or yearly decrease of 2 percent. The cut will total 2 percent and will not increase beyond that point.

Deborah Spitalnik pointed out that the lack of growth at the lower end of the economy also represents growth in the number of children living in poverty. She stated that the Committee has not focused on programs that prevent ID, and it is well within the Committee's purview to do so.

Mark Gross asked if there was a way to get figures showing the dollar amounts of program cuts and revenue enhancement. The revenue enhancement figures will likely be higher. Mr. Kogan answered that that information is already available to some extent and explained how that figure could be calculated. Mr. Gross clarified that he was talking about calculating the cuts to specific programs. Mr. Kogan explained that most of the programs of concern to PCPID are exempt from automatic cuts. Clay Boatright agreed that this was a good framework on a macro level and suggested including the number of people that would be affected by cuts to each program. He also voiced his concern that a suggestion to increase revenues would politicize the report when the issues related to disabilities are largely bipartisan in nature.

Carol Quirk asked whether the Committee could get data, by race, on the impact of poverty on disability. Mr. Van de Water suggested that HHS staff was in a better place to provide that information, but poverty rates are certainly higher among selected racial and ethnic groups. Sharon Lewis added that PCPID could get this information from census data. The Committee may even be able to gather information about specific programs to some degree, as Clay Boatright suggested. The difficulty is that each state prioritizes in terms of optional services, so it becomes exemplary but does not have a clear if-then relationship. The Committee, however, can still talk about some of the scenarios and their real impact.

Micki Edelsohn suggested trying to contact other Congressmen or Representatives who could influence JSC members rather than sending a report to the JSC, which is likely to become deadlocked. Chairman Brett agreed, but said that the mandate was to report to the President. Mr. Kogan advised PCPID not to write anything in the report that could be misused or misinterpreted to the Committee's detriment.

Mr. Kogan and Mr. Van de Water will be happy to answer follow-up questions from PCPID in the next few weeks.

Mr. Brett welcomed attending who had recently joined the meeting, including Sue Swenson, Assistant Secretary in the Office of Special Education and Rehabilitative Services at the Department of Education, and Marty Ford, Director of Public Policy for the ARC.

(Brief recess)

Employment Issues that Impact People with Intellectual Disabilities
David Mank, Ph.D., Director, Indiana Institute on Disability and Community

David Mank began his presentation by acknowledging that the unprecedented political and economic climate presents a good opportunity to discuss employment for people with ID, investment and change and produce a positive outcome. He highlighted the 2009 PCPID report to the President, "Dignity Through Employment," because unemployment has not improved significantly in the last few years and the goals of the report are still relevant. Dr. Mank read a portion that illustrates the impact of personal stories, but also emphasized the importance of drawing attention to the hundreds of thousands of people who are not working in the community and are able to do so. The employment situation for people with ID has remained roughly the same for thirty years, although several states are doing better than others. There is solid research about the ability of individuals with ID to work and clear intent in the last three decades of state and federal policy to provide them with opportunities.

Dr. Mank went on to discuss the 13 recommendations from the 2009 PCPID report:

1. Issue a Presidential call to double the number of people with ID working in integrated jobs by 2014.
2. Create a national public awareness campaign to build a new wave of employment expectations.
3. Expand implementation of existing legislation and federal policy with a specific focus on employment outcomes.
4. (No longer relevant) Continue to invest in the New Freedom Initiative
5. Create employer incentives and demonstrations.
6. Promote employment of people with ID in the public sector workforce.
7. Promote large-scale demonstration projects based on innovations of the last ten years.
8. Endorse and expand state Employment First agendas.
9. Promote national and community service for young people, fully integrating young adults with ID in the effort, as a means for transition to adult life.
10. Expand investment in the Individuals with Disabilities Education Improvement Act of 2004 and the Rehabilitation Act's focus on transition plans for all youth with ID, including full federal funding of the Act.
11. Expand investment in the Rehabilitation Services Administration related to funding supports for transition from school to adult life.
12. Increase incentives to work and remove income limits governing benefit programs for people with ID, and promote these incentives.
13. Refocus existing resources to promote integrated employment.

In Dr. Mank's opinion, reinvestment of existing resources towards employment and the involvement of self-advocates are two potential "game changer" on this issue.

(Presenter-Committee Dialogue)

Jim Brett asked which foundational values PCPID should consider with regards to the importance of this priority issue for people with ID. Dr. Mank answered that the value base of PCPID is just fine, it but may wish to work on redefining words like "productivity" (how fast a person can work) in favor of "contribution" (indicates a valued role and full participation).

Jim Brett asked what the risks are in the current economic and political environment, related to programs, services, and policies supporting people with ID in employment. The biggest risk is complacency because of the current economic environment, in which the general unemployment rate is high. Carol Wheeler requested the unemployment rate for people with ID, in order to spread awareness by using a concrete figure to draw outrage. Dr. Mank was uncertain, but estimated 22 to 25 percent. Sharon Lewis thought the unemployment rate was slightly lower. However, that rate excludes the underemployed and individuals who are not actively seeking employment. The participation rate of 76 to 78 percent might be a better indicator because it is extremely low for people with disabilities, relative to the general population. For each person with intellectual or developmental disabilities (IDD) who is working, there are at least five to seven others that do not have the opportunity for a job. A survey from the ARC of the United States found that 85 percent of individuals with ID were not working. Clay Boatright suggested focusing on the fact that employment for individuals with the capability to work can free up services for others who are not capable of working. David Mank pointed out that, while government money is saved when individuals go to work, the parts of government that pay for employment supports are not the parts that benefit financially from employment outcomes.

Liz Weintraub asked whether the 22 percent includes those working in sheltered workshops and segregated day services. That figure only includes integrated community employment.

Liz also asked how to handle situations in which individuals with ID want careers rather than jobs without advancement. Dr. Mank acknowledged that the problem has not really been addressed and suggested that PCPID might be in a good position to address the issue.

Mark Gross pointed out that, while government can be influenced by policy to hire more individuals with ID, the private sector will not necessarily follow suit unless doing so is at least cost neutral. Dr. Mank responded that, if individuals are well matched to a job, the data indicates no increased costs or insurance rates. The circulation of stories and videos of individuals with ID working in various fields has helped to open up opportunities in new industries.

Jim Brett asked what the opportunities are in this economic and political environment, related to programs, services, and policies supporting people with ID in employment. Dr. Mank said that most employees, with or without ID, start at the entry level. Despite the current economy, entry-level positions are still available, so there is still opportunity for employment.

Jim Brett posed the following question: what is the potential economic impact of changes in policy and funding in employment? As Clay Boatright commented earlier, employment can allow for reduced supports over time and can allow improvement in general health.

Jim Brett inquired which states were doing betting in hiring people with disabilities and what those states have done differently. Vermont, Oklahoma, and Washington have higher employment rates for diverse reasons. Vermont made a policy decision that people with IDD belong in the community and eliminated their segregated day settings. The state of Washington made employment a priority for the state IDD agency in the 1970s, so they have had decades to invest in innovation and build the structure for training and technical assistance. Oklahoma, has a Medicaid waiver that pays the providers of services for the number of hours that people with IDD work beyond the number of hours it takes the provider to support them. In addition, the waiver says that group placements are equivalent to individual placements, causing an over-reliance on group placement such as crews or enclaves.

Gary Blumenthal asked Dr. Mank if he knew of any data examining the impact of employment on the economic stability of families of individuals with ID. Since many people with ID live with family, the burden of support often falls on the family if an individual is unemployed during the day. Deborah Spitalnik noted that the Family Support Coalition of New Jersey collected family to-do lists, which demonstrate the kinds of accommodations that families have made. She offered to provide the reference. Peter Berns mentioned the ARC survey results that indicated one out of five families had a family member leave work to stay home with an adult child with disabilities. One of the employment areas that has grown for people with disabilities is preferred-source contracting: AbilityOne on the federal level and state preferred-source contracting.

Gary Blumenthal asked Dr. Mank to comment on the shift away from center-based work, towards service types of employment. Dr. Mank responded that he knew the numbers of opportunities were in the twenty-thousands. There has been a shift from the center-based contracting to more of the service-based contracting at Air Force bases. He acknowledged the importance of asking how those particular programs can move toward an integrated community job arrangement, as opposed to group approaches. He recommended focusing on moving programs towards jobs of choice, the direction suggested by the self-advocates. The AbilityOne program tends to pay very well, but could be improved by moving toward a more integrated employment focus.

Carol Quirk pointed out that the response to Mr. Bern's question spoke to the 13th recommendation in the 2009 Report to the President, about refocusing existing resources. She asked what the biggest barrier was for service providers switching over to community-integrated employment models. David Mank identified two barriers. The first barrier is the impact of Medicaid and Medicaid waivers, which determine supports for people with ID (underscoring the importance of September 16th CMS memo, stating a preferred outcome). Second, as long as the economic realities favors non-integration, it will continue to be difficult. Dr. Mank noted that, additionally, some economic disincentives keep prevent integrated programs and this needs to be addressed. The economic opportunity should be on the community employment side. It needs to work from a business standpoint, which is not currently the case.

Mark Gross asked for Dr. Mank's opinion on why these issues had gone for thirty years without many successes or changes. Dr. Mank named three possibilities: 1) continuance of an existing structure that does not promote employment of people with ID as the first outcome; 2) when people did work, they were often encouraged to maximize their benefits and only work a little bit, as opposed to working enough to earn a higher income, reduce their benefits, and be better off over time; and 3) economic disincentive have prevented providers from moving in the direction of integrated employment. Changing incentives is the one thing that has not been done for the last 20 years. When the financial incentives remain unchanged, the problem should not be expected to change. He reiterated the significance of the CMS memo, calling it the beginning of an incentive that moves in the direction of the value statements of every piece of legislation about disability over the past thirty years. The vast majority of state and federal money supports non-integrated employment. As long as that is the case, there will be non-integrated employment. Carol Wheeler asked for the CMS memo to be circulated. Sharon Lewis agreed to resend the memo, if people did not receive it.

David Mank noted that, six months ago, in order to encourage states to move towards integrated employment, the Administration on Development Disabilities (ADD) issued an RFP urging state-level projects, systems-change efforts that emphasize integrated employment. That is the kind of effort that helps create the incentives discussed. Dr. Mank thanked Commissioner Sharon Lewis. Ms. Lewis reported that ADD will be able announce those states later in the week. The Commissioner related the hard work of CMS to get the letter out and its positive reception from the community. The core service definitions will begin to capture some of the data that will help make those distinctions. Ms. Lewis acknowledged that many self-advocates were concerned that CMS clearly stated that pre-vocational services should be time limited. She argued that people should not be entering sheltered workshops and be in pre-vocational services long-term, as is often the case. If the program is pre-vocational, it should be preparing individuals towards something that is vocational. Many were very happy to see CMS making that distinction. However, CMS regulations continue to support minimum wage as a component of these supported employment services.

Deborah Spitalnik asked Dr. Mank whether there was legislation, TEAM or TRAIN, about the Developmental Disability system and the Vocational Rehabilitative system being more involved in transition, so that individuals move directly from school to employment. She stated that she believes this was pending and not a current legislation. Dr. Mank responded that the legislation helps; the incentives matter hugely. He reemphasized getting the business side of this right. He concluded with a quote, by Dan Thompson, a self-advocate, and his mother, Margaret Lee. She says, "whatever the problem is, a job is a big part of the answer. You want more friends? Get a job. You want to go on vacation? Get a job. You want to get better healthcare, either buy it or get it from your employer? Get a job. You want to feel like you contribute to society. Get a job."

Income Support
Marty Ford, Director of Public Policy, The Arc

Marty Ford, Director of Public Policy for the Arc of the United States, informed the Committee that income supports involved two programs: 1) Old-Age, Survivors, and Disability Insurance program (OASDI) which is the Title 2 of the Social Security Act; and 2) the Supplemental Security Income (SSI) program which is Title 16 of the Social Security Act. Summing up the goals and core values of the OASDI program, she cited a quote from President Roosevelt saying that "one can never insure 100% of the population from 100% of life's hazards but attempted to frame a law that would give protection to the average citizen and family against job loss and against poverty-ridden old age." (Social Security Act 1935)

Ms. Ford gave an overview of OASDI or Social Insurance, stating that people share risk of common life events and each worker's record provides benefits for different family generations and guaranteed monthly payment. She pointed out that the OASDI program was linked to Medicare and funded by the payroll tax contributions under the Federal Insurance Contributions Act. In 2011, 55 million would receive Social security OASDI benefits, and more than one third of all monthly checks would go to non-retired people. Ms. Ford named three benefit categories including: retirement, survivors and disability. These categories insure against poverty, dependents after retiree dies and loss of work due to a disability. Disabled Adult Children are eligible for all three types of benefits if they have a severe disability before age 22, significant work limitations, and are single. This is based on earning records of a parent who was disabled, retired or died and they rarely leave the program. Ms. Ford discussed OASDI Program Strengths

as fixed monthly payment, flexibility to move among three programs, work history, age and eligibility category, and pays multiple family members based on one worker's earnings. She stressed that over 11 Million people with disabilities and their spouse and children receive OASDI benefits. She noted that SSI is a shortcut reference for people with disabilities in the Title 2 program or the Disability Insurance program. Technically, they were not all in the Disability Insurance Program. She cautioned members, when writing the 2011 Report, to remember to use the larger terms of Social Security disability programs. Ms. Ford described how people who received adult child benefits rarely left the program and often started receiving SSI benefits and Medicaid. When a parent became disabled, or retired, he/she moves into the status of receiving a disabled adult child benefit and Medicare, and may end up keeping all four benefits: SSI, Medicaid, Title 2, Social Security, and Medicare. Illustrating the complexity, Ms. Ford pointed out that, if a parent died, it may move them up to a higher cash benefit and loss of SSI, but they would keep the other three. She described OASDI's parameters for the average monthly payment to beneficiaries as well as the Social Security Disability Insurance (SSDI) or the "DI" part of the Social Security OASDI program. Ms. Ford stated that SSDI pays benefits to 8.4 million workers, who are unable to work due to illness or impairment. She confirmed that only workers who met a strict definition of disability under federal law and have earned enough work credits would receive benefits. She also gave an overview of the Supplemental Security Income (SSI) program. As a federal income supplement, it was designed to help people who are aged, blind, or have disabilities and have no income. It was designed to provide cash to meet basic needs for food, clothing, and shelter and was administered by the Social Security Administration. She reported the two were linked: funds for SSI come from the general tax revenues and Medicaid was its health benefit. In December of 2010, almost 8 million people received SSI, including a little over a million children and adults with ID under age 65. According to Ms. Ford, the average federal SSI benefit for all beneficiaries was $501 per month. For people with ID, it was $530 per month.

Ms. Ford discussed the differences between OASDI and SSI. Title 2 was funded through payroll taxes, while Title 16, general revenues. Title 2 paid benefits to other family members, while the SSI program did not. The SSI program only paid the individual. The SSI program was needs based, while the Title 2 program was not. Title 2 went with Medicare. SSI went with Medicaid.

Ms. Ford addressed the concerns of people with ID and their families about OASDI and SSI. She emphasized that both of them included delays in benefits: a very complex application process, long processing times for SSDI and SSI, a 5 month wait for eligibility for SSDI benefits and a 2 year wait for SSDI beneficiaries for eligibility for Medicare. This is part of the law, and even if SSA was able to process applications immediately, there would still be a 29-month waiting period before Medicare would kick in and average payments would be low and often insufficient to meet basic needs. Ms. Ford acknowledged that there were marriage penalties built into the system for people with disabilities.

Next, Ms. Ford presented the Risks and Opportunities. Social Security Reform was on the Horizon, citing the Social Security Trustees Report: Social Security was able to pay full scheduled benefits through 2036. Modest adjustments could ensure long-term solvency without reducing benefits because of the contributions from payroll taxes.

In addressing the Budget Control Act Risks, Ms. Ford stated that people with disabilities stand to lose a great deal from any benefit cuts. Adults with disabilities have a very low employment rate.

She then discussed principles for Social Security reform. They include: addressing reform separately from deficit reduction; keeping the basic design based on payroll taxes; preserving social insurance for disability, survivors and retirement; guaranteeing monthly benefits adjusted for inflation; preserving current and future benefits; and restoring the program's long term funding.

Ms. Ford discussed opportunities for work incentives: allowing ongoing presumptive re-eligibility for SSDI; allowing continuing eligibility for Medicare for SSDI beneficiaries; establishing earnings offsets for SSDI beneficiaries that are similar to SSI earnings offsets; and strengthening work incentives programs. She mentioned a couple of current legislative opportunities, the SSI Savers Act and the Achieve a Better Life Experience Act. There are opportunities for improving benefits, supporting the Social Security Administration's efforts to improve the application and payment process, eliminating the five-month wait for SSDI, eliminating marriage penalties, increasing the SSI asset limits and indexing to inflation, creating opportunities for savings, improving work incentives, and eliminating the two-year wait for Medicare. Ms. Ford advocated for permanent premium-free access to Medicare for Title 2 disability beneficiaries. She acknowledged that there are several proposals in the President's budget, a permanent attachment to the Title 2 disability program and premium-free access to Medicare for Title 2 beneficiaries called the Work Incentive Simplification Program (WISP). The WISP would be a tremendous improvement in Title 2, and could alleviate problems in the Title 2 program and help make it more like the SSI program.

(Presenter-Committee Dialogue)

Carol Wheeler asked Ms. Ford if she could repeat what was in the President's budget as it relates to Title 2. Ms. Ford noted there was a pilot, WISP, proposed in the budget, and advocates would like to work with Social Security and with the Congress to explore it further and try to get it passed. That would allow people who are in the Title 2 disability programs, the Social Security disability programs, to have a more permanent connection to the cash benefit so that, as their income rose, they would not lose their connection to the program. When their income went down again, they could automatically get back into the program without the long application process, the long waiting times, and the fear of not being able to get back in. The permanent connection to Medicare is also important for the same reasons, so that if they do not have a job that comes with health insurance, they are covered.

Ms. Ford noted that some fears of losing Medicare or Medicaid, facing the long application process, and being ejected from the cash benefit roles kept people from taking the risk of going to work once they have tried and failed.

Ms. Bazilio-Bellegarde asked if there was any intersection between these benefits and what a veteran with disability might receive.

Ms. Ford replied that there are some intersections, but she could not talk about the veterans benefits aspect of it. She confirmed that veterans were eligible for some of these benefits and there would be intersections with the benefits they're eligible for under the Department of Defense and Veterans Administration. The Consortium for Citizens with Disabilities had some organizations, like Paralyzed Veterans of America, who could answer her questions.

Peter Berns asked Ms. Ford to discuss one of the proposals that would potentially have unintended consequences, if the retirement age changed from 65 to 67. Ms. Ford answered that increasing the retirement age was considered a reduction in benefits for people because it will take longer for anyone to be able to receive a full benefit.

Marty Ford noted that Arc did not have a fact sheet for self-advocates on benefit laws.

Dr. Spitalnik asked two questions. First, she asked if Ms. Ford had any suggestions about changing the public tendency to lump Social Security with Medicare and Medicaid when speaking about deficit reduction. This seemed erroneous to Dr. Spitalnik. She wanted to know if Second, some of these issues intersect with the Affordable Care Act. If the Class Act were implemented, there would be less pressure for early retirement and less pressure on Medicaid. Did Ms. Ford have any suggestions for engaging in this discussion in a productive way, since these are not popular topics at present?

Agreeing with Dr. Spitalnik, Ms. Ford stressed that the Social Security trust funded the Social Security System. She stated the Social Security surplus was very significant, $3½ Trillion. After that is depleted, it could still pay 75 percent of promised benefits if no changes were made in the law due to payroll taxes.

In response to Deborah's second question, Ms. Ford affirmed that the Class Act, the Community Living Assistance Services and Supports Act will help take the pressure off the Medicaid program by helping people avoid the need to become impoverished in order to become Medicaid eligible to cover long-term services and supports, or long-term care. Among programs, Medicaid sustains most of the long-term care.

Chairman Brett remarked that Marty Ford was right on the Social Security issue and he appreciated her input. In 1936, when Social Security was passed, there were about 160 contributors to each recipient. The wisdom of Franklin Delano Roosevelt, was that he made Social Security eligible for people at 65 years, when the average lifespan of a male in 1936 was 63 years. The program has gone from 160 contributors for each recipient, to three contributors for each recipient and increased life expectancy. There will be enough funds to go to 2036.

Longterm Services and Supports/Community Living
Nancy Thaler, Executive Director, National Association of State Directors of Developmental Disabilities Services

Nancy Thaler began with an overview of the Long-term Services and Supports/Community Living, noting evidence of significant change across the country, from institutional to community care. Soon, eleven states would have no publicly funded institutions. Ms. Thaler noted in that group, Alaska and Oregon currently have no privately funded institutions, and they seemed to be doing just fine.

Ms. Thaler reported that major problems face the states. The national structural budget deficits will combine with the recession and Baby Boomers reaching retirement age. Medicare and Medicaid are expected to rise rapidly while Social Security shrinks, and the demographic shift reflects a growing demand for services, and a lack of growth in the number of care givers. Ms. Thaler stressed the necessity of confronting reality. Public funding growth will slow, while the workforce will not keep pace with the demand, and waiting lists will increase. Many states, do

not keep waiting lists at all. Reality calls for reevaluating current services. Citing Lakin's data, the average costs of an ICSMR, public and private combined, cost $225,000 per year per person. The contrast was one person in ICFMR or five people living with their family. This is significant in understanding where the most benefit can be found and the most people served for the money.

When people talk about long-term care services, generally it is in the aging system. When people enter Medicaid, the average length of stay is somewhere between 18 and 24 months. There is not a long-term cost per each person because they are not in the system very long. She contrasted this to people with IDD, who stay a lifetime. The impact of making a decision for a person with IDD early in life had tremendous longitudinal implications.

This idea is nudging the system to be person-centered, to support families, and involve people in the community for the lowest cost. The question was whether people and their families will struggle alone or have a great life because the supports were there for them. The type and amount of support provided to families opened their homes because they had the supports.

Ms. Thaler then responded to the Committee's four questions, describing basic human and civil rights as core foundational values, and emphasizing the premise that people with IDD want to live like typical citizens.

Subsequently, she identified the following risks: congregating people on the false premise that it saved money and reducing services based on the assumption that people and their families have other alternatives to public services. People with IDD can't buy private insurance for long term supports and few can pay privately for a life time. Reductions in services, based on assumptions that families can care for family members without assistance, and pressures to solve the dual eligibility problem will push people into long-term care systems not designed for them.

Ms. Thaler outlined the opportunities including: elimination of the institutional bias in Medicaid and creation of an entitlement to community services; creation of incentives to get people jobs; and provision for self-advocates and families to gain more control over services and development of built-in accountability for outcomes.

She concluded by describing the potential economic impact of changes in policy and funding, related to long term services and supports/community living. She suggested reducing the growth curve by substituting community services for institutional services, strengthening families and reducing costs as people achieve employment. Then, she solicited questions. The question and answer period was extensive. Some included the following:

(Presenter-Committee Dialogue)

Mark Gross stated that he had an overriding concern about everything that she said today. He has a 29-year-old child with Down's Syndrome. The family goal, from the beginning, was to have him get a job and live in a group home. From Ms. Thaler's presentation, it sounded like government was going to force families to keep adult child at home forever to minimize costs. He was familiar with the Arc's saying, "a life like yours," encouraging people with ID to have a life like everyone else. He assumed that was also for the parents of individuals with ID. He found the whole approach very, very troubling. Ms. Thaler clarified that she was not promoting the idea that people should live with their families indefinitely. The inability to expand

residential services means that the waiting list for those residential services gets longer and longer.

Mr. Boatright seconded the sentiments expressed by Mr. Gross. One thing that stood out to him, and that he felt was indicative of the advocacy community as a whole, was the extreme of choice. The options seemed to be either institutional care or live with parents until everyone dies. There does not seem to be a lot of room in the middle for various options.

Ms. Thaler responded that, whether the options can be created, goes back to cost. Some families have devised options that don't require 24-hour staffing, such as pooling resources and having a mother-in-law apartments. Some individuals don't need 24-hour services, so they live with another friend in an apartment. These are all options. However, about eleven states use the approach of individual budgeting,.

Ms. Edelsohn was in agreement with Mark and Clay. She thought it was dangerous because the government was giving people an "out" by saying, "we can do it cheaper in the families." She told of her 39 years old son who had lived in a group home since 1994. She asked Ms. Thaler to consider the idea that it should be self-determined.

Ms. Thaler acknowledged what their point. However, when looking at a waiting list with over half a million people and 23 states reducing the amount of money they invest in the system, she could not say they could figure it all out. The data was overwhelming at the state level that the 12 percent growth seen in residential services in the last 10 years had already stopped.

(Mid-Morning Recess)

Education
Jane West, Ed.D., Political Advocacy Consultant, American Association of Colleges for Teacher Education and Higher Education Consortium for Special Education

Dr. Jane West commenced a discussion of education by outlining the meaning of education policy affecting students with intellectual disability. First she summarized the Elementary and Secondary Education Act, $14.8 Billion. This program is often known as No Child Left Behind (NCLB), which was the current iteration of the Elementary and Secondary Education Act, on the radar screen for Congress and for this Administration in terms of reform. The President held an event at the White House Friday, announcing changes in NCLB, which he proposed through waivers to states. Waivers were important for students with IDD, as they were included in the assessment and accountability system under ESEA. That has been a very significant policy shift over the last decade, and there has been a lot of gain to students with IDD, from that shift.

Second, Dr. West discussed the Individuals with Disabilities Act (IDEA), part B, the state grant program, about $11.5 Billion. The federal government promised, when this was enacted 35 years ago, to pay for 40 percent of the cost of educating students with IDD. It currently at 17 percent and a perennial challenge to get up to where it should be.

Third, she noted that the IDEA pre-school program, is at $374 Million. The infant and toddlers program is at 439 Million. Transition programs didn't have their own set of funding, which made them vulnerable. The funding came through IDEA, the Vocational Rehabilitation Act, many of the state DD services, Medicaid, and Social Security.

She also discussed the Pell Grant programs, which provided scholarships to low-income college students. For the first time, there was eligibility for students with ID who were in approved programs in higher education for scholarships to low-income college students. Lastly, was the model Individuals with Disabilities demonstration programs in higher education, S11Million, which Mrs. Shriver initiated.

She followed with a discussion of the Core foundational values in education. Equal access and zero rejection, Dr. West listed first, stating IDEA was founded on those principles. Next, she cited full inclusion, integral to school programming, including accountability and assessment. Equal access to general education was third, with need for improving capacity of general educators to work with students with ID. Fourth, was high expectations. Students with ID want the same outcomes that all students want: post-secondary education, employment, and independence.

Afterwards, she discussed the risks including: budget cuts at the federal and state level such as teacher lay-offs, which impacts class size and makes a difference in terms of teachers' willingness to address students that have ID; tuition increases in higher education; early learning and transition services; ESEA reauthorization, risks with the waivers or the potential for schools described as successful with some of their subgroups such as students with IDD; concerns over the 1% and 2% cap; threat of being marginalized; skilled teachers; IDEA; maintenance of effort waivers; and sustainability of Pell Grants.

Subsequently, she identified opportunities like Charter schools as bipartisan components of ESEA reauthorization. She stated that legislation passed the House that strengthens the provisions related to students with IDD. Typically, students with IDD were not included or were in charter schools, only for students with IDD. This is a popular reform strategy, but what does it mean for the kids with ID. The current budget climate requires a grassroots activism, making sure students are part of the equation: strengthen teacher skills; universal design; improve the 1% & 2%; growth models; enact restraint and seclusion legislation; educate the public and congress concerning progress; strengthen implementation of post-secondary programs for students with ID; prepare for IDEA reauthorization.

Dr. West concluded with a discussion on the potential economic impact of policy and funding changes. She reported that students with IDD would be less prepared in terms of the outcomes for post-secondary education and work and would become less independent. She noted that increasing the SSI rolls might result in fewer taxpayers and increased dependence on family. Finally, consolidation cuts and investing in capacity were needed where students with IDD should be included, and a federal role of equity and access to opportunity was important.

(Presenter-Committee Dialogue)

Gary Blumenthal, asked Jane West how she evaluated the effectiveness of the federal government in monitoring states' compliance with inclusion. Regardless of the administration, the discussion had been the same for the past 30 years. Dr. West agreed with Mr. Blumenthal. However, she noted that, because the role existed, there is potential for some kind of bar that, theoretically could be pushed.

Answering Carol Quirk's question on teacher, preparation, Ms. West stated that ESEA and IDEA do have a lot to do with teacher preparation because they define what a highly qualified and effective teacher looks like. That drove the skills with which teachers were prepared. State certification was the other key role in the skills that teachers attained. University preparation programs were aligned with state certification. The shift to promotion of inclusion implied a shift in the special educator's role.

Carol Quirk explained that she partnered with universities and heard the need to prepare teachers across states for their realistic roles in segregated school systems. Dr. West agreed.

Carol followed-up with a question: how could universities be cutting-edge and produce leaders, if they didn't change teacher preparation? Dr. West responded that it was a push-pull relationship, where universities felt pressure. For example, New York City had a separate district for students with IDD and had one program, Teachers' College, preparing people for inclusive settings, which they did not have. There was push in teacher preparation to train them for the real world and for a new world. She suggested investing in programs partnering with K-12 districts and studying the effect.

Mark Gross asked why the federal government should enforce this area instead of the local school districts. Dr. West replied that the federal role had asserted itself as protecting inclusion.

Ms. West indicted that throughout the US history, many people have had to fight their way into schools. Susan Ramirez added that, as a parent of a child with ID, she believes that advocacy at the local and grassroots levels is important in the area of education. Ann Hardiman added that getting jobs after any educational experience is also vital to this target population.

Healthcare/Medicaid
Lisa Ekman, Senior Policy Advisor, Health and Disability Advocates

Ms. Ekman stated that Medicaid is the backbone of services that allow people with ID to live independently in the community. That independence needs to be maximized through a spectrum of publicly and privately funded healthcare services and supports. Healthcare services should always include informed consent so that people with ID and their families can make decisions about their own healthcare. Getting good information to people with ID and their families is vital, as healthcare services need to be consumer-directed and based on informed choice. She added that Medicaid is very expensive for states. There is a misperception that the Affordable Care Act (ACA) will not affect people with disabilities who are eligible for Medicaid, but this only applies to those who receive SSI. In the ACA, there are risks regarding the new Medicaid expansion, what will go into exchanges and what is in the essential benefit package. The ACA created a new Medicaid eligibility group, often referred to as the adult only group, for people between the ages of 19 and 65 who make up to 133% of the poverty level for their family size. The first time a childless adult without a disability is eligible as a mandatory category, states must cover under Medicaid. The risk is that people with disabilities are being put into the new adult category and will not have access to what is required for independence. In next few weeks, the Institute of Medicine will send back a framework for essential benefits to Health and Human Services (HHS), and HHS will develop the minimum set of benefits for anyone offering a qualified health plan through the new state level exchanges. Another risk is the lack of a clear federal policy on outcomes for Medicaid investments, especially related to employment.

Opportunities available under the ACA include the Community First Choice option and Money Follows the Person. The Community First Choice is an option that states can adopt, which provides funding for people to live independently in the community. The Super Committee need to knows about the importance of Medicaid for people with disabilities, as well as the importance of federal standards and guidelines for people with disabilities in Medicaid, which protect gains in independence for people with disabilities. Dr. Spitalnik stated that the policymakers in New Jersey are looking to comprehensive waivers not only to improve care, but also to deal with shortfalls in state budgets, particularly around Medicaid. We do not know how many new people will be eligible, their service needs or what their utilization of basic healthcare will be because many have been uninsured long-term. Ann Hardiman stated that the state of New York is working on 1115 waiver for people with ID and is moving towards personalized services.

Welcome and Greetings
George H. Sheldon, Acting Assistant Secretary, Administration for Children and Families, US Department of Health and Human Services

Chairman Brett introduced ACF Acting Assistant Secretary, George H. Sheldon. Mr. Sheldon thanked Committee members and PCPID staff. He pointed out that the critical pieces in the field of ID are knowledge of the rights of individuals with ID and empowerment of those people to use individual bargaining power and decision-making. Employment is a key component. Mr. Sheldon ended by thanking the Committee for their hard work.

"Voices of Advocates"
Ken Capone, Public Policy Coordinator, People on the Go of Maryland
Tracy Wright, Project Manager, Self-Advocacy Network
Leigh Sutherland, Parent
Bill Krebs, Regional Representative**,** Self-Advocates Becoming Empowered
Phyllis Holton, Advisor**,** Project Action

Phyllis Holton began by emphasizing the importance of employment to promote the self-worth of self-advocates. Her organization, Project Action, takes individuals with ID to employment fairs to prepare resumes, interview, and learn other employment basics. The organization focuses on the capabilities of individuals with disabilities. Project Action members also train service coordinators to provide services through the District's Department on Disability Services.

Bill Krebs introduced himself and talked about the employability of people with ID. He believes that some of these individuals will never be able to work, but can volunteer and get credit for doing what they are able to do. He then talked about his personal experiences in a workshop, getting a job in school, and losing his job after a short period of time. He shared with the Committee that he has filed for unemployment and his paperwork has been accepted.

Tracy Wright introduced herself and thanked Liz Weintraub for inviting her to speak at the meeting. She talked about her journey through her current job. She was not getting raises, health insurance, or opportunities for professionally growth due to her disability. The most difficult parts of Tracy's job are earning the respect of her employer and feeling that she is as highly valued as employees without disabilities.

Mr. Ken Capone introduced himself and added that the organization that he works for, People on the Go, is a statewide self-advocacy group that is supported by the ARC of Maryland. The

organization believes all people with challenges should be included in school, work, and the community. He reiterated his love of advocacy work. Ken's big concern for people with disabilities is employment. It took him 17 years to get a job. His other concern is affordable, accessible, integrated housing.

Leigh Sutherland is a parent and advocate for her daughter, Alexandra, who has a genetic condition called Angelman's Syndrome. People with Angelman's Syndrome require full-time, 24-hour care. Alexandra is in a day program called *Community Support Services*. Part of Community Support Services' goal is to get all people employed in the community for part of the day and has been creative about how they get adults with disabilities employed. Most people with disability, in this setting, work in restaurants. Alexandra enjoys preparing coffee every morning as a part of her job. However, the *Community Support Services* is in need of additional funding to help further train their aids and upgrade the equipment on the coffee cart, but the goal is within the next two years to get Alexandra and her friends out in the community.

Liz Weintraub asked the panelists to share one or two things that they would like the Committee to report to the President. Ms. Holton and Mr. Capone were concerned with maintaining funding support for people with ID. Mr. Krebs would like to tell the President to stop putting Medicare dollars into workshops because people with ID want to work and be integrated in the community. Ms. Wright added that it is important to try to cut out as much red tape as possible.

Chairman Brett announced that Ms. Cathy Ficker-Terrill would be a Facilitator to Develop PCPID 2011 Report to the President during the second day of the meeting. Ms. Ficker-Terill is the CEO of the Institute on Public Policy for People with Disabilities, and also an adjunct professor at the University of Illinois and Elmhurst College.

(Afternoon Recess)

DAY TWO

Call to Order
James T. Brett, Chair
The June 17, 2011 meeting was called to order by Chairman Brett who welcomed the Committee members. He turned the meeting over to Cathy Ficker-Terrill, the facilitator of the Committee Meeting.

Overview and Framework for Discussion Leading to Development of Report to the President
Cathy Ficker-Terrill, CEO, the Institute on Public Policy for People with Disabilities

Ms. Ficker-Terrill started her presentation by stating that she believes the PCPID report is not just a report to the President, but to Congress, the nation, and states. It is also a report to people locally, and it is a report that will be read internationally. The PCPID audience is multigenerational. Ms. Ficker-Terrill conducted a comprehensive brainstorming exercise, which involved all of the PCPID Committee members. She then summarized the opportunities and risks addressed by the members under each priority area.

(The comprehensive report prepared by Dr. Ficker-Terrill is cited in a separate summary at the end of the transcript.)

Chairman Brett thanked Sue Swenson for coming and asked if she would be interested in helping the Committee on the education portion. Ms. Swenson nodded affirmatively. Gary Blumenthal expressed concern regarding the timeframe in which the Report to the President could go through the clearance process. Dr. Spitalnik inquired if PCPID could count on Deputy Assistant Secretary Swenson for help with clearance, which was better than writing. Ms. Swenson agreed to help with clearance, but stated that it will be a long-term process. Committee members then asked Laverdia Roach about the shortest timeframe that she could have cleared the reports in the past. Laverdia responded, six weeks. Dr. Quirk stated that she was concerned that the Committee had been operating for the last two days with the idea that they were writing a report within two weeks. However, based on from the timeframe that Laverdia shared, it is not realistic to expect to produce such a document before the Super Committee has to make a decision. Ms. Roach responded that she did not know the degree to which the ADD Commissioner could facilitate the movement of the report. She reiterated that historically, the report was not cleared in less than six weeks because of the process; it was unlikely that the report will be cleared in two weeks. Cathy Ficker-Terrill thought the Committee could take some of this information and cull it into a letter from the Chair, identifying the highlights and key points. Laverdia Roach responded that the Committee has done it in the past, and sometimes it was a position paper or a letter. Carol Quirk suggested, because of the overlap in risks, opportunities, and values that the Committee develop a policy paper that would go from the committee or from the Chairman to whomever they selected. Laverdia Roach responded that it went to the Commissioner. Carol Quirk remarked that this would make it shorter. She noted that the Committee could identify the five areas, core values, and common areas that cut across each. They would produce a more extensive report that detailed data demonstrating the actual impact with personal stories.

Committee could produce data and personal stories accompanying each category, and have two documents, one shorter and an actual report later in 2011, just not done in the next two weeks.

Sue Swenson had a question of process. She noted that, as Chair of the Interagency Committee on Disability Research, she knew that her Committee had multiple departments. As such, the clearance process always involved getting clearance from each the federal partner.

Laverdia nodded agreement, noting that PCPID would need clearance from all of its 13 federal partners. According to Sue Swenson, that process could take a year. Carol Quirk again suggested that, for this reason, they should send a letter and put together the 2011 report later. In agreement with Carol Quirk, Mark Gross suggested that Chairman James Brett should select five members to write the report. The five will write a few paragraphs, on each of these areas, send them to Jim, and circulate to the Members. He thought it was the Chairman's prerogative to turn it into a letter from the Chairman to the JSC or whomever he chose and put together a longer, more thorough report later. The last two days' information could be turned into long-range plans for the 2012 report. Carol Wheeler agreed with Mark and Carol Quirk but suggested including stories as an attachment. There was additional discussion on timing of the submissions and whether is should be called a letter or a report.

Dr. Spitalnik asked if the Chair could find out if Commissioner Lewis was on board with the letter. Work needs to be done quickly, and then the decision needed to be made whether the resulting document should be called a report or policy paper. The document's real power in, this situation, is making the recommendations and raising the issues. Peter concurred with Carol. He asserted that the outline already produced worked for a letter or a report, no matter what it was called, the content was the same.

After lengthy discussion, Mark Gross made the motion to draft a letter, based on the input the Chair received from the Committee on the five principles, and to send the letter out. Liz Weintraub seconded the motion. Chairman Brett asked all in favor, all responded aye, and the motion was unanimously passed.

Sue Swenson warned that, if the Committee sent it to Congress, not to sign any federal officers because they cannot write to Congress, without clearing it with their agencies' government affairs office.

Dr. Spitalnik noted that people had worked very hard and it was important to leave feeling that they had accomplished something. Liz tagged on to Deborah's point, stating that, as a self-advocate, she was reassured that so many people in the government in major departments were advocating for them.

Dr. White-Scott expressed her gratitude to Cathy Ficker-Terrill, in terms of facilitating a group. She efforts were helpful in ensuring that everyone's voice was heard. She noted, whether it was the letter or not, that the Committee should look at alternative mechanisms to distribute the document because the written part was not as powerful as Facebook or YouTube, per Cathy's suggestion.

Mark Gross recommended that, after Jim's letter went out, it was going to be a great advocacy piece for the Committee to use in other venues. Once it was made public, sent to Congress, it

could be used by any of the Members in any other venue and should be. He suggested that local, state, and federal representatives would help circulating it that way.

Chairman Brett updated Commissioner Sharon Lewis on the Committee's decision to send a letter on the five principles, as opposed to an actual 2011 report due to time constraints with the decisions being made by the JSC and deficit reduction personnel. He noted that Sue Swenson indicated her interest in helping in the education portion. A draft letter would be developed, to be sent to those members in the next two weeks. Additionally, the 2011 report would be written later in the year to expand on everything heard in the meeting and be a more meaningful and in-depth.

Commissioner Lewis joined the meeting and apologized from the members for being in and out of the meeting.

A lengthy discussion ensued between the Commissioner and the Committee regarding the following issues: the use of a letter versus a report, the sign-off and clearance process, the necessity of voting on the content of the letter, FACA Committee rules and voting on the letter, whether the Chair was signing it with Citizen Members only, the option for Ex officio Members to abstain from voting, if there was a downside to Ex-officio Members abstaining, and how the vote would be taken. Commissioner Lewis agreed that the committee could send a letter.

Sharon Lewis noted that voting on the content of the letter was necessary. The letter will have to be approved to go out on PCPID letterhead from the committee. Each federal member will then have to determine their course of action in voting on the letter, consistent with their agency's counsel.

Five volunteers will submit their inputs on the five principles to the Chair for the purpose of producing a persuasive letter. Then, the Chair will convene a conference call of the Committee members to approve the letter. Federal officials will abstain at this time, if they choose to do so Otherwise, they will present the letter to be approved.

Commissioner Lewis stated that the Committee could not require the letter to go through clearance prior to the committee voting upon it. As a FACA Committee, PCPID has a right to bring a document forward, take a vote, and each federal official must determine their course of action in either voting yes, no, or abstaining on such a document. If you have an adequate number of members who voted yes on such a document, then you can put the document forward.

Sharon Lewis said she would check with counsel on whether they could produce a letter that was on behalf of the Chair and the Citizen members of the Committee, but thought they would have a hard time with this, since there was an open deliberation of excluding ex-officio members from a vote.

Commissioner Lewis stated that there was not a downside to the federal officials abstaining as long as the Committee votes with a minimum of the quorum, and has a majority that wins the vote.

Chairman Brett asked Peter if he would be willing to serve as a chair of this working group and use his outline as a guide. Sharon Lewis said staff will help support the drafting process in whatever way needed. Liz Weintraub offered to help with the draft.

Sharon Lewis reported that she would work on getting some clarity in terms of whether or not that the federal members do not participate in the support of the letter. She thought the Committee would have to give them the opportunity to either oppose, support or abstain.

The Commissioner said, what will happened is that the letter will go forward, and even though federal officials abstained, it will be a letter from the Committee at large that it does not say who opposed it. The Committee had to have a quorum, or not.

Jim Brett stated he would like to entertain a motion that they adjourn. Liz Weintraub made the motion, and Mr. Brett asked for a Second. Micki Edelsohn seconded it, and the motion passed unanimously.

Chairman Brett announced that their public meeting was adjourned.

Meeting adjourned.

Action items:

PCPID Staff:

1) Share the informal notes taken during the meeting with the Committee members.
2) Convert the meeting transcript into minutes.
3) Sharon Lewis will check with the HHS General Counsel on whether the Committee could produce a letter that was on behalf of the Chair and the Citizen members.
4) Sharon Lewis will request, and share with members of the Committee, information regarding the clearance process and estimated time to clear the Report/Letter to the President.

Committee Members:

1) Submit their travel invoices and receipts to the PCPID Budget Officer within three business days after the meeting.
2) Help with the following tasks in order to finalize the PCPID 2011 Report (Letter) to the President:

Annette McKenzie Anderson

1) Will help with promoting report creatively after it is done
2) Will provide public relation support and overall editing

Peter V. Berns

1) Will edit of the entire document; or
2) Will write one of the 5 sections of the report

Clay Boatright

1) Will provide testimonials
2) Will develops creative visual cues (word clouds)
3) Will edit

Micki Edelsohn

1) Will show how to build and modify group homes
2) Will provide testimonials

Ann Hardiman

1) Will provide testimonials
2) Will help write the Long-term Community Supports and Services

Carl M. La Mell

Will help to promote the report and strategize how Committee can best use the Report (Letter)

Carol Quirk

1) Will edit; use Wordle
2) Will write/contribute to education piece

Susana Ramirez

1) Will help with the education aspect of report
2) Will provide feedback/input/edit

Deborah M. Spitalnik

1) Will write the introduction of the report
2) Will help write about how Medicaid affects people with ID healthcare

Lillian Sugarman

1) Will provide testimonials
2) Will edit

Liz Weintraub

Will provides testimonials

Carol Wheeler

1) Will help with whatever is most needed, including writing the employment or education section
2) Will Edit

Sheryl White-Scott

1) Will provide testimonials
2) Will edit

Mark Gross

Will write one section of the letter—preferably housing

Yvette River

Will help by providing innovative and creative ideas to make the report compelling

Michael Caliendo

Will help by editing, formatting, graphing data, and performing any required research

Jewel Bazilio-Bellegarde

Will reviews and edit draft as needed

Robert Weathers

1) Will write the income support section
2) Will edit

Mary Kay Mauren

Will help with editing

Employment

Core values

- People with intellectual disabilities deserve full and lifelong inclusion in all aspects of community living, including integrated employment opportunities and the chance to earn and maintain financial resources.
- Individuals with intellectual disabilities, when given appropriate support, achieve strong competitive employment outcomes aligned with their personal goals.
- All individuals, including people with intellectual disabilities, can work in integrated settings for competitive wages, and should be supported to pursue employment consistent with their strengths, talents, gifts and interests.

Opportunities

1. **Employer incentives for hiring people with IDD**
   - Create employer incentives for hiring people with ID
   - Create opportunities to support, incentives; inform the attitudes of employers and potential employers
   - Both public sector and private sector (for profit and non-profit) should have incentives for employing people with IDD
   - Create incentives and/or tax breaks to hire people with ID
   - Establish tax credits for small business employers to hire people with ID
   - Promote employer incentives, models, and demonstrations of "customized" person centered work options
   - The fiscal supports should provide incentives for gainful employment for individuals with IDD
   - Create employer incentives and employer demonstrations.

2. **Prepare people with disabilities for work**
   - Increase employment for people with ID partnerships and training (strengthen pre-employment skills) to include family involvement, school, home
   - Expect that all PWD want to work and prepare them to work
   - Create opportunities to demonstrate, practice, build skills, grow networks that can lead to employment, ex. National Service, paid internships, volunteering

3. **Refocus majority of existing funds away from congregate/sheltered workshop/settings to integrated and competitive employment.**
   - Federal policy and programs should focus on employment first and provide financial incentives to providers to move toward integrated employment.
   - Refocus majority of existing funds away from congregate/sheltered workshop/settings to integrated and competitive employment.

- Create incentives for day program providers to move people to employment.
- Refocus existing day resources to promote employment.
- Federal resources must be used effectively and efficiently for the outcome of employment for people with disabilities.
- Schools need to better prepare people with ID for employment.
- Talk to kids and students about employment at the high school levels.
- Refocus existing resources to promote integrated employment, starting at transition.
- Maintain and expend investment in IDEA and Rehab Act to focus on transition to adult life, including employment for youth with ID/DD.
- Transition from school to work, present system to future system, should be the focus of collaborative and creative areas of education/ private/ government and community systems.

4. Remove economic disincentives to employment.

- Abolish disincentives to employment for PWD.
- Remove income limits governing benefit programs.
- Increase incentives to work and remove income limits for benefit programs for individuals w ID.
- Remove economic disincentives to employment.

5. Create a national public campaign to build awareness of employment

- Create a national public campaign to build awareness of employment, find ways to create employer incentives in hiring
- An effort is made to highlight companies and businesses that are already hiring people with ID (Walgreen's, B of A, Marriott, Project Search, and encourage others.
- Create diverse vehicles for encouraging employers to hire People with Intellectual Disabilities. ex. a visual narrated production, a talk show on employment with an inclusive and a performing arts presentation.
- Provide grants/incentives programs to help train people with intellectual disabilities to perform skilled work. In addition, provide funds and resources to market the skilled potential employees. (get the word out)
- Emphasize public awareness through the media and a variety of different techniques relative to the critical needs of employing people with intellectual disabilities.

6. Include people with intellectual disabilities in the nation's commitment and to putting people to work

- All people need an opportunity to become as independent/self sufficient as their abilities allow.
- Include people with intellectual disabilities in the nation's commitment and to putting people to work.
- Preserve avenues to integrated employment opportunities.
- Pursuing traditional employment for people w/IDD reduces their demand for government. Supported frees up funds to support those more severely affected.
- All individuals with intellectual disabilities can contribute to the communities in which they live.
- Give all people a chance to have jobs/careers of their choice.

7. **The federal government should model more forcefully the hiring of people with ID**
   - Encouraging MOV's between RSA, DOL, and OPM to create a searchable database of vocational rehabilitation consumers for use by Federal and private hiring managers and HR professionals. (Gov. is currently spending money on private companies to do smaller scale data bases when we could use workforce recruitment program model receiving/benefiting from Federal subsidies)
   - The federal government should model more forcefully the hiring of people with ID by creating more useful tools and databases containing resumes of such Americans

8. **Preserve some supported employment opportunities like enclaves for those unable to achieve independent employment**

9. **The federal government should ensure that meaningful metrics are in place to hold senior leaders accountable for the recommendations in this report**

10. **Public Private sector**
    - Promote employment of people with ID in the public/private workplace
    - Work with public and private sector to promote employment opportunities for persons with intellectual disabilities

11. **Transportation**
    - Employment opportunity needs supports, ie. transportation, accessibility, accommodations, training
    - By strongly supporting the efforts of the US Department of Transportation to spear head accessible and safe transportation systems, Americans with intellectual Disabilities have more opportunities to American's jobs

12. **Importance of maintaining educational programs and transition programs that have employment as a clear end goal**

13. **Employment of people w/IDD creates a more loyal workforce, which also inspires the traditionally developing employees**

14. **Identify and invest in innovative approaches that have proven effective in helping persons w/IDD obtain sustained employment**

15. **Call for increasing or doubling integrated employment by 2014**

16. **Equal Opportunity for Work**
    - Promote equal opportunity in employment
    - Importance of employment and to quality of life for individuals and ultimately to decreasing financial burden on the government and maintaining programs that achieve it
    - Employment for adults with ID is essential for a life of dignity
    - All people regardless of disability have the opportunity to work in the community with equal pay
    - People with ID have as much to give and are as dedicated to work as those in the general population they deserve meaningful employment and of course equal pay for their work as all others
    - People with intellectual disabilities should have the same opportunities to participate in employment as all Americans

17. **Any reforms of entitlement programs or discretionary programs should support growth in employment opportunities for people with I/DD**
    - Improve coordination of federal programs that are aimed at improving employment outcomes of persons with ID
    - Endorse and expand state employment first agendas with a focus on self-determination
    - Employment addresses more than simply reverence revenue generation, such as: establishing friendships, improving sense of self-worth, huge step towards true community integration, its natural not constructed
    - Any reforms of entitlement programs or discretionary programs should support growth in employment opportunities for people with I/DD

18. **Create opportunities for continuing vocational training into adulthood**

Risks

1. **Lose a richly diverse and productive staff**
    - Lack of training to prepare for employment, loss of trained workforce
    - Employees will lose a richly diverse and productive staff persons if unable to employ

2. **Wastes millions spent in education of children**
    - Removing incentives to employment will increase deficit
    - Limiting employment opportunities wastes millions spent in education of children with intellectual disabilities as a result of IDEA

3. **Limit opportunity for pwd's to generate assets**
    - Limiting employment eliminates tax revenue spent by people with ID who earn
    - Cuts in employment programs limit opportunity for pwd's to generate assets

4. **No public awareness**
    - Budget cuts will decrease funding for increased public awareness relative to employers hiring more readily, people w IDD

5. **Waste of an important national resource**
    - Increase employment, decrease dependence on benefits
    - What is lost when people are not employed, when people with ID have dignity are productive, contribute, pay taxes and are citizens of communities
    - Waste of an important national resource for no product with IDD
    - The country won't come to have the goal of putting people back to work
    - Cutting funds that allow PID's to engage in employment preparatory activities results in whole groups of people who cannot contribute to their community, to the GDP, etc. who receive but aren't able to contribute

6. **Non-disabled family members to lose jobs**
    - Cutting back on entitlement/discretionary programs that support families will force more individuals to leave workforce to stay home as caregivers
    - Medicaid LTSS cuts could force non-disabled family members to lose jobs to care for loved ones, further increasing unemployment and recessionary pressures

- Family members may have to quit their jobs to care, this reducing tap revenue and increasing HHS costs
- Cutting employment programs not only limit possibility for pwidd- families often are unable to work because pwidd is at home needs supervision
- Without employment people would become less or fully dependent on family

7. Increased need for government subsidiary, housing, health, income

8. More ID people will be in the streets and emergency rooms, shelters etc.

9. People with ID would not be able to work

- People won't have jobs
- People with IDD will be less likely to secure competitive employment thus increasing their reliance and cost of HSS support services
- Decreased opportunity and actual experiences of equitable life situation (personal)
- Supports for individuals with IDD to engage in gainful employment, decreasing reliance on government funded services could be eliminated
- The ID will be thought about last because of the crisis in jobs (lack thereof)
- More homelessness and increased health problems (societal)
- Cutting Medicaid investment and H.C.B.S. and V.R etc, will lead to the higher rates of unemployment many PID- of whom 85% are already not employed and increase long term costs
- Cuts in employment programs and minimal job opportunities in the private sector would force people to remain at home
- People with ID would not be able to work and become fully dependent on benefits not contribute to society
- People with IDD will get lost in the shuffle as policy makers focus on lowering the 9.2% unemployment rate- their needs/rights will be at bottom of priority list
- ID will never achieve their goal of independence and self-sufficiency
- People working with those with ID in programs lose their jobs

10. Eliminating employment opportunities results in isolation

- If employment opportunities for PID are severely limited, we will create a class of people who may become shut-ins we will diminish economic opportunities for communities and for the United States, and we will create long-term health effects on caregivers
- Eliminating employment opportunities results in isolation

11. The support staff will be unemployed, taxes, and needing new skill set to change jobs

12. The human rights of ID will be taken from them if employment opportunities do not exist

- If employment opportunities for PID are severely limited, we will create a class of people who may become shut-ins we will diminish economic opportunities for communities and for the United States, and we will create long-term health effects on caregivers

Income Support

Core values

- In this time of difficult economic decisions, supports to people with intellectual disabilities must be maintained as a critical component of our humane social safety net.

Opportunities

1. **Simplify the system**
   - Simplify the system and access points especially for different communities
   - Develop guidelines/rules to eliminate interpretation of them at the local SS office
   - Simplify work incentives wise
   - Uncomplicated system to make it easier to navigate services and provide better supports to individuals and families trying to access benefits
   - Modify to increase work incentives, continue health eligibility, programs and simplify
   - The system should be simplified so people with ID can understand how the system works
   - All processes for receiving benefits need to be simplified
   - Simplify processes including eliminating 2yr wait for Medicare
   - Recommendation within SSI and DI programs simply work incentive programs so that people with ID can clearly understand
   - Keep it simple

2. **Increase allowable assets and earnings**
   - Increase allowable assets and earnings for SS and SSI
   - People with ID should receive benefits when they have a job, regardless of the number of hours they work
   - Remove mitigate negative impact of eligibility for other benefits- e.g. national service stipend
   - Eliminate regulations which require people to impoverish themselves and are disincentives to savings
   - Allow ID individual to work with no limitations to income
   - Change Social Security system to remove disincentives to work be people with IDD (financial and Medicaid, Medicare)

3. **Lift the $2000 cap**
   - Lift the $2000 cap on SSI and maximum allowed monthly earnings
   - Individuals with ID shouldn't have to be limited to have 2K to keep eligibility
   - Lift the $2000 cap on SSI
   - Substantially raise income and $2000 assets for cap on SSI
   - Remove cap of $2000 assets limits for SSI

4. **Breakdown/show how income support comes back to the community, think like an economist**

5. **Preserve income benefits**
   - Preserve income benefits and index for inflation
   - Both the income maintenance and access to Medicaid compensates of SSI are essential for the children and adults with IDD to live as contributing members of the families and communities

6. **Simplify the work incentive provisions**
   - Simplify the work incentive provisions within both SSI and DI programs so that individuals with ID understand them and can attempt work knowing how it will affect their benefits
   - Work incentives earning salaries allow ongoing presumptive re-eligibility for SSDI
   - Simplify people moving into and out of system as circumstances change
   - Eliminate 2 year wait for Medicare

7. **The limits placed on receiving benefits need to reflect the costs of living**

8. **Shorten the waiting list for benefits**
   - Shorten the waiting list for benefits
   - Reduce the time limits for waiting for eligibility for services
   - Eliminate waiting periods for SSDI and Medicare
   - 2 year wait for Medicare for SSDI beneficiaries
   - Link of Medicaid to non-employment status

9. **Eliminate marriage penalties**
   - Eliminate marriage penalties
   - People with ID should not lose their government benefits when they marry

10. **Engage the SSA inspector general to understand unintended results from the support we are providing**

11. **Promote work, extend benefits and allow PWD to transition into job and economic security**

12. **Improve Medicaid buy-in-to enhance incentive to work**

13. **PASS**
   - Encourage use of SSI program to achieve self-support (PASS)
   - Recommendation for people w ID to achieve self support encourage the use of SSI programs

14. **SSA reform needs to be considered separately from deficit reduction**
   - For pwidd SSI and SSDI are essential supports that make it possible for pwidd to live as part of their families and communities
   - SS reform needs to be considered separately from deficit reduction

15. **Provide assistance to youth with ID receiving SSI, make successful transition to employment as an adult**

Risks

1. **Families will fall over into deeper poverty**
   - Entire families will fall over into deeper poverty
   - Budget cuts for income support will definitely end to limited resources for supporting self and family relative to basic needs (food, clothing, shelter)
   - Extra strain on families
   - Family stress and lack of productivity and poverty
   - Decrease opportunities, increase hardships (food, shelter), increase living at home, decrease independence
   - Greater hardships on families
   - Income, increase stress on families
   - More cost to families
   - Lack of finical support would lead to increased dependence on families (lack of housing =homelessness)
   - Increase in poverty rate, homelessness and poor health (physical and mental) which increases the burden on families and local communities
   - Financial responsibility of families (who are aging)
   - Lack of basic needs, food, transportation, housing options, lack of asct. Technology
   - Diminished life/equality for families
   - Family members of people with ID may have to stop working to take care of the person in the family with ID
   - Families impacted
   - Loss of income will return people to their family's home

2. **Will add to the homeless population**
   - No income leads to homelessness
   - People with ID won't be able to live in the community
   - Inability to function independently, live on their own, pay rent, will become homeless
   - Will add to the homeless population
   - Homelessness, families into poverty and dependence on other public programs
   - Poverty and homelessness
   - Total loss of housing, employment, homelessness
   - SSI program provides important support to low-income individuals. Erosion in protections will shift burden to other programs
   - Increase in homelessness and hunger

3. **Isolation and institutionalization**
   - Increased demand for institutionalization
   - Isolation and institutionalization
   - Isolation and lack of community and not productive members of society
   - Limited access to activities all the rest of us enjoy
   - Cannot afford to feed themselves
   - Early death
   - DI trust funds will become insolvent within next decade- changes to program that increases costs will be difficult
   - Businesses will lose customers

- The collateral impact will be suffering by small businesses in our communities where PIDS live
- Less active consumers in the economy

Long Term Services and Supports/Community Living

Core Values

- ❖ We must continue pursuing and publicizing best practices of supporting people with intellectual disabilities as full and equal participants in society.

- ❖ People with intellectual disabilities have the right to be supported in living, learning, working, playing, and having meaningful, fulfilled, lives in the community, just as other citizens.

- ❖ Appropriate home and community-based living options for people with disabilities with a range of functional and support needs should be available nationwide.

Opportunities

1. **direct support professional**
   - Build a real direct support professional net work to support community living wherever a person chooses to live
   - Programs/incentives to bring in caregivers
   - Skilled, well trained and well paid staff must be available to provide the supports needed
   - Develop new ways to provide social networks and home based coaches in community settings (using funds re-allocated from institutional and large group settings)
   - Address the issue of available qualified direct service providers better training and better compensation
   - Develop programs to create direct support professionals

2. **convert congregate settings to community-based**
   - Ways to reduce or close large state institutions
   - Invest limited dollars wisely by closing state institutions promote federal policy to implement Olmstead reduce FFP for institutions
   - Provide incentives for service providers to convert congregate settings to community-based supported living options
   - Closing of institutions will enhance the fiscal bottom-line in supporting community based services
   - Encourage states to eliminate spending in large congregant institutions
   - Economic impact, reduce the growth curve by substituting community services for institutional services and strengthen families

3. **Eliminate institutional bias in Medicaid**
   - Remove the institutional bias in Medicaid funding

- Eliminate institutional bias in Medicaid and create entitlement to community living in customized settings (person-centered planning)
- Remove the institutional bias living
- Eliminate the institutional bias with Medicaid and create an entitlement to community services
- Medicaid should be reformed to eliminate the institutional bias and make HCBS more readily available to all who need them

4. maximum flexibility to individuals and families

- Give self advocates and families more control over services
- Empower Americans to provide input into our own services, specifically for those in communities that transition from relying on family to move traditional support services start now before it becomes a necessity
- Support and value family members w ID with a system that is person centered taking into consideration their own values and choice
- Ways to increase direct support services
- Long term services must be person-centered, giving self-advocates and families control
- Adapt individualized budgeting systems to allow maximum flexibility to individuals and families in creating a system of support that best meets their needs
- Ensure that long term supports are available to individuals and that supports are person-centered, support families and involve community

5. public/private partnerships

- Need to build public/private partnerships with families and others to help offset costs
- Encourage and incent non-government entities such as faith-based and commercial businesses to partner in creating long term supports
- Encourage public-private partnerships to grow housing opportunities
- Proactive Planning, involve important stakeholders such as planning commissions, the association of Realtors, commerce associations and others to create win-win communities throughout US

6. varied living arrangements

- There should be a menu of choices for all types of community living, including neighborhood group homes and apartments
- Many and varied living arrangements for those with ID/DD/PD must be available in every community
- Maintain current living arrangements but increase ability to move according to individual choices

7. Incentives for creating smaller and more integrated community opportunities

- Recommendation all persons with ID should have increased accessibility to long term community living
- Recommendation long term community living is vital to ensure increased accessibility to people with ID relative to employment, health care, transportation, technology and education
- Incentives for creating smaller and more integrated community opportunities

- Recommendation community living for people with ID is a primary goal that must be ascertained so that their daily interaction will be on a level playing field with all citizens

8. protect current community choices

- Maintain Medicaid funding to ID
- Protect community services protect current community choices as system evolves and changes provide choices

9. tax exempt long term support savings accounts

- Allow the creation of tax exempt long term support savings accounts where contributions are tax deductible, income support
- Families with IDD should be able to save for the future of their son/daughters with IDD in like manner as available to families saving for college

10. create long-term buy-in use all forms of media

- Awareness and education for communities about people with ID/DD to be provided thru the media so all will be welcome in all communities
- To create long-term buy-in use all forms of media, such as social networks sites, to highlight success stories, enlist private sector in this work

11. maximum benefits with supports for best possible outcomes

- Services and facilities for general population must be accessible to pwid
- Long term services should not be based on managing risks (worst case scenario) but provide maximum benefits with supports for best possible outcomes
- Remove regulations which restrict the creation of residential and other long-term support options

12. Create opportunities to contribute to community life and communities through volunteering, change the paradigm to being viewed as valuable contributors

13. a right to live just like typical citizens

- People with ID should have access to appropriate home and community based services based on their individual needs and desires choice-access to life
- People have a right to live just like typical citizens as part of a family and community Programs and policies should be focused on supporting this right
- Ensure that PWID have the opportunity to choose their place of residence and where and with whom they want to live on an equal basis with others and are not obligated to live in any particular arrangement
- Ensure that PWID have access to a range of services and supports necessary to support living and inclusion in the community and that community services and facilities for the general population are available on equal basis with others
- People with ID should have the right to live with supports in the community and home of their choice

14. Family supports include considering all members of the family equally- ie, person with ID/DD as well as parents and siblings

15. The Class Act

- Support the class
- Employers should be actively encouraged to make the class program available to employees

16. Access to community supports should not require years on a wait list

17. help people get integrated jobs at competitive wages

- People should get off Medicaid so they can have real jobs
- Decrease the need for services by supporting government programs that help people get integrated jobs at competitive wages

Risk

1. Warehousing and homelessness

- Budget cuts may lead to limited accessibility for community living (housing)
- People living independently with fund support will not be able to keep their homes creating more homelessness
- Increased institutionalization
- Realizing the rights pwidd under Olmstead is threatened by the lack of available community services
- Return inhumane institutional (large scale) living conditions- personal decrease choice decrease self determination
- Long term need for institutional care reversing Olmstead
- Stated will return to warehousing people in institutions as parents/caregivers die or are no longer able to provide for loved ones
- People with IDD will become homeless
- No safety net back to institutions and or homelessness
- Increases in homelessness
- Institutions will be growing

2. Families will be torn apart as resources to support lived ones become scarce

- Cuts in Medicaid funding will impact directly individuals with IDD and their families with limited care and adverse outcomes
- Eliminating community housing opportunities for people with ID can limit options for family members
- Families will be torn apart as resources to support lived ones become scarce
- Progress made to date in supporting p w IDs to live in community is at risk- lack of support for families- caregiver burn out no/longer able to provide care
- Increased pressure on families decrease health and decrease lifespan of family, members, inequitable burden on families, low respect/regard for people with ID, societal
- People unnerved in families that became highly stressed unemployed economically effected
- Family members could lose their jobs and also be on public benefits themselves, economic impact beyond disability
- Increase in people living with family members and related family stress

3. **people will not have choices**
   - Eliminating options reduces an element of individual choice and self-sufficiency
   - ID people will not have choices to live as the rest of the population lives
   - People and families won't get to have choices in the community
   - Individuals with IDD will have limited choices with budget driven options

4. **isolation**
   - Eliminating housing causes isolation
   - Long term risk isolation

5. **"least expensive" options will be favored**
   - The cost cutting efforts will lead to fewer choices for residence and supports and "least expensive" options will be favored without consideration of quality and appropriateness
   - Fund cuts will likely cut the most costs efficient supports and services, ex family supports, community housing options, home on your own

6. **People with ID won't have independence**
   - The ID will not gain opportunities for being part of a free and open society
   - People with ID won't have independence

7. **Community programs will become mini institutions w horrible situations that we don't want**

8. **People providing services to those needing community support will lose their jobs**

9. **Current wait lists to supports would be to nowhere**

10. **Increased financial drain on US economy, decreased productivity, increased health costs, increased individual care costs**

11. **The US design firms and businesses lose out in the global economy because they will not be able to export, among other things, architecture and planning services**

12. **Smaller communities will face burdens of unsupported citizens**

Health Care/Medicaid

Core Values

- ❖ Disparities in access to appropriate, quality healthcare, including dental care, must be addressed for people with disabilities.

- ❖ Healthcare delivery systems must continue to move towards person-centered care that respects self-determination and choice.

Opportunities

1. **Better training for medical professionals**
   - Training of health care professionals especially for the adults with ID population
   - Collaborate with medical schools, universities and medical professional organizations to increase awareness of treating people with IDD within the entire medical community
   - Better access and training of medical and dental professionals in healthcare for ID and incentives to locate in rural underserved areas
   - Health care providers at all levels are trained to attend the PWIDD an ensure informed consent in all health care decisions
   - Professional schools should do more training in treating people with ID
   - Better training for medical professionals in all areas of practice so they are better equipped to work with individuals with IDD
   - Medical schools should do more training in the field of disabilities
   - Awareness and training of issues related to health should be implemented in training programs backed by mandate

2. **health care is person focused not money driven**
   - Must not lose sight of importance of person centered services as attempts to cut costs
   - Require states to provide services that demonstrate a person centered focus with customized supports as a minimum
   - Ensure that health care is person focused not money driven
   - CMS must monitor state /waiver applications and state plan amendments to ensure that the health and long term care needs of PWIDD are addressed in a person-centered community based manner and choice
   - Individuals who are dual eligible shouldn't have "to be managed" in a cost effective system that is not person centered and back to a medical model
   - Encourage money follows the person model

3. **the ACA is fully implemented**
   - As ACA is implemented monitor how features affect people with IDD and ensure that they have access to health care that they need
   - Recommendation ensure that the ACA is fully implemented so as to increase the accessibility of health care services, primary health care for people with ID
   - Ensure that the benchmark health exchange plan provides adequate coverage for DME therapeutic services and other services needed by people with ID
   - Implementation of the Affordable Care ACT should include full inclusion of individuals with IDD
   - People with ID need to have opportunity to have access to all care needed not the care that the individual state provides by their definition of services available
   - ACA includes PWIDD
   - Ensure essential benefit packages in insurance exchanges address the needs of people with ID
   - Fully implement the ACA
   - PCDID should provide advice/guidance to the President relative to developing credible policies and practices for people with IDD in implementation phase of ACA

4. **the necessary information to make appropriate choices about their healthcare**
   - The healthcare system is just too complicated for people with ID to understand it needs to be simplified
   - Local government must help families locate health care for family members with ID
   - Informed accessible support mechanisms to navigate health and benefits and eligibility requirements
   - Ensure people with ID (and their families)have the necessary information to make appropriate choices about their healthcare

5. **effective oversight of state plans**
   - Federal government must exercise careful and effective oversight of state plans to ensure that individuals with IDD receive the services intended by the Affordable Care Act
   - Monitor impact upon PWIDD of changes to services for all eligible

13. **Develop incentives for doctors such as forgiving med school loans if they have at least 50% of their clients w IDD for at least 5 years**

14. **avoid the medicalization of IDD**
   - Closely regulate managed care to avoid the medicalization of IDD and prevent profit motive from decreased services
   - The move to managed care around the country is not necessarily a good fit for the lives of people with ID. More demonstration that it works is necessary
   - Don't allow managed care to negatively impact long term support services

15. **Protect health care access for all/people do not lose their healthcare**
   - As appropriate people with ID should not lose their Medicaid if they get employed
   - Maintain maintenance of effort to ensure people do not lose their healthcare
   - Maintain current health care Medicaid funding until 2014

16. **The federal state system structure we have is broken. We cannot continue with band-aid fixes that create more inefficiencies**

17. **access to preventive health services**
   - People with ID who don't have Medicare and cannot afford health care but need medical care should receive government aid for such care
   - Ensure access to preventive health services under ACA for people with IDD
   - People with IDD should have access to affordable healthcare under ACC
   - Individuals with IDD should have access to comprehensive coordinated covered health services

18. **All Health services are accessible**
   - Ensure that insurance companies that the general public can access provide equal opportunity and quality care for all
   - All Health services are accessible to PWIDD on an equal basis with others

19. **Dental schools create forgiveness program to dentists who go into the field of disabilities**

20. **Healthcare for people with ID cannot be tied to full-time employment**

21. **People with ID that want technology is should be available and funded to improve health care**

22. **Emphasize the impact of Federal cuts on States, domino effect**

23. **Ensure that state and federal budget cuts do not affect health care services available for people with IDD**

Risks

1. **not person centered**
   - Movement to limited managed care options will halt and undo gains in better services geared to individuals needs
   - Managed care options are not person centered and accountable for needs of individuals with IDD

2. **Rationing of services and more disenfranchised as a group**

3. **Healthcare premiums skyrocketed for all**

4. **Reduction of productivity for economy**

5. **Decrease in levels of payment**
   - Medicaid cuts limit access to care and finical disincentives for serving individuals with IDD
     Decrease in levels of payment reduces already scarce medical services

6. **Families unable to pay for medical care**
   - More dependent on family insurance and/or family care
   - Financial impacts on parents and siblings
   - Bankrupt families
   - Families unable to pay for medical care
   - Enormous strain on families and their budgets

7. **Decrease in preventive care equates increase in illness**
   - Cuts in wellness services will mar the view of Americas' workers. This will impact the ability to attract global forms to the US
   - ID folks will not be willing to participate in prevention or follow-up examinations, x-rays etc.
   - Decrease in preventive care equates increase in illness

8. **Decreased personal health**
   - Poorer health outcomes lead to decrease life expectancy
   - Lives will be cut short as people are unable to receive adequate care
   - Prohibitive out of pocket costs expenses for families and individuals, no or postponed care , increased mortality
   - Decreased personal health

- Short life span
- People's disabilities might get worse resulting in physical health or death
- Health outcomes can lead to increased morbidity and mortality for individuals with IDD and their families
- Limited health care services for PID and their families, cost will go up people will die

9. emergency room usage will be greatly increased

- Increased health care costs from poor health and emergency care result in higher costs for everyone
- Reduction in available doctors emergency room usage will be greatly increased increasing overall med costs for all citizens
- More visits to emergency room at hospitals and increase in cost dollars
- Unhealthy and more disabled conditions will prevail, use of emergency room more frequent
- Increased cost in emergency services, high costs substandard health care for people with ID
- Losing health care ends up costing more because people use emergency rooms as primary care
- Increased actual costs of health care, emergency acute and life-saving measures
- Continued health dispensations PWIDD require more expensive care

10. Creating increased reliance in more costly institutional and nursing home care

11. If lose benefits people won't be independent

Education

Core Values

- ❖ Students with disabilities are, first and foremost general education students who need high expectations, presumptions of competence, access to the grade level content and meaningful curriculum. All teachers (not just special education teachers) should be prepared to work with diverse learners, including students with intellectual disabilities in order to truly achieve inclusion and successful academic outcomes for students.

- ❖ Individuals with intellectual disabilities should have access to educational opportunities, including college, which will enable them to attain employment, housing, and the quality lives they desire.

- ❖ We have a responsibility to ensure that current and future generations of children, youth and adults with intellectual disabilities can expect the goals of the ADA—of equal opportunity, full participation; independent living and economic self-sufficiency—can be achieved.

Opportunities

1. Transition from school to adult work

- Expand investment in transition services
- Recommendation Paramount to success for people with ID, the educational program must provide an infrastructure that leads to a post-age 21 transition component emphasizing specific career paths, job skills, community employment and post secondary education options
- Focus on the goal of employment early in the IEP process with emphasis on internships and workplace experiences in the last years in the public school system
- Implore "transition to work" education in schools
- Transition from school to adult work activities need to be enhanced with person centered focus
- Better school to work preparation for students with ID transitioning to adulthood
- Seriously improve the transition from school to work with better work preparation in school
- Ensure transition entitlement promotes employment for students with IDD
- Post-secondary transition raise expectations of students with ID transition plans should not be just a box to check. There should be meaningful goals that provide transferable skills for integrated employment and college attendance

2. post-secondary programs for students with intellectual disabilities

- Strengthen implantation of post-secondary programs for students with intellectual disabilities
- Recommendation PSE programs must be continued and publicized widely
- Provide more post-secondary education and training (including volunteering) opportunities to meet needs of growing population of individuals with IDD who are aging out of the guaranteed services under IDEA
- Enhance college prep and secondary ed to college transition programs for all
- Early education is needed to ensure that opportunities are available equitably for secondary and post secondary school success
- Expand options for students with ID to attend post secondary education leading to employment
- Increase post secondary experiences as they improve employment chances
- Strengthen access and implemented on post-secondary programs as a path to employment for people with ID
- Parents and families need to "think college" and have high expectations

3. Incentives school districts to expand use of developing technology for students with disabilities

4. Enforce existing federal IDEA laws

- Enforce existing federal IDEA laws, hold states and local districts accountable
- Maintain accountability of schools for outcomes of students with IDD

5. ensure inclusion and meaningful participation of all children in the classroom

- Require schools to pay attention to inclusive educational settings
- Recommendation an inclusive educational setting pre-21 that promotes family involvement and community partnerships, while emphasizing on academic program that initiates the development of basic employment skill is vital

- Ensure individuals with ID are gaining access to general curriculum and not being excluded due to performance standards
- Focus IDEA discretionary funds systemic improvements to increase inclusive placements for students with ID
- Needs to be inclusive education with everyone
- Expect/ensure inclusion and meaningful participation of all children in the classroom by providing supports children need to thrive and learn
- Less restrictive environment for students with ID is the foundation for community living students with ID must have access to meaningful education classes, liked to see disaggregated LRE data for students with ID

6. Improve skills of teachers

- Better to teach all students in inclusive classrooms
- Better training of classroom aids to support not only the student but the teacher
- Improve skills of teachers to teach ID individuals in their classroom
- Promote truly inclusive education by training all teachers to teach the range of diversity of the human experience
- Provides teachers with information on the needs of individuals with ID so that they can provide effective education
- Education and training of all teachers general and special ed needs to address curriculum revisions for preparation of students for 21st century
- Train teachers in general school education to address being inclusive of all students and their varying learning styles
- Require teacher prep programs (general and special ed) to demonstrate they are producing "highly qualified" teachers who know: collaboration, differentiation, positive behavior support, individual student, planning for students with ID
- Training for all teachers to be able to teach/tutor people with ID
- People need to have proper supports to have education for all

7. Promote Ameri Corps national service as a means to transition to post-secondary education, employment

8. Reform IDEA a la Sue Swenson

9. an improved workforce

- Teacher para-professional training support link between general education and special education
- Use IDEA discretionary funding and state pass through, develop an improved workforce for service provided in general education settings

10. teach to the genius of people with IDD

- Create a race to the top type program specifically armed special education services
- Rethink the educational paradigm; teach to the genius of people with IDD

11. Better coordination between educational institutions and government agencies

- Have state education superintendents and HHS agency meet each other
- Better coordination between educational institutions and government agencies and support systems to make possible needed education and training opportunities

- Achieving educational outcomes for students with ID involves multiple funding streams, need to ensure that Medicaid supports services to students in schools that transcend to employment adult life are supported

12. **In the conversation of education ensure that leaders of diverse the underserved communities are at the table**

13. **adult education to improve employment opportunities**
    - Engage providers of continuing learning to think of the pwidd community in course offerings
    - Help states and localities to provide adult education to improve employment opportunities for adults with DD

14. **Stop weakening of special education maintenance of effort**
    - Ensure maintenance of efforts at state level don't expire
    - Stop weakening of special education maintenance of effort requests

15. **Incentivize teachers and parents to include service learning experiences to IEP's**

16. **Better education of public- families and their school age children about people with intellectual disabilities**

Risks

1. **Decrease employability equals decrease income, decrease independence, decrease self-actualization**

2. **Lower education levels that result from decreased opportunities will increase dependence on income support programs**

3. **Civil rights violated without EI-ECSE there would be an increase in severity of disability**

4. **decreased preparation less prepared for workforce and alternative options**
    - Less training for employment opportunities
    - Students with IDD would have decreased access to inclusive education leading to decreased preparation less prepared for workforce and alternative options
    - Halt to progress in availability of more PSE programs—which are vital to the prospects of employment and long term redirection of need for government support services
    - Lack of support for transition students with IDD leave school not prepared for employment in need of costlier programs
    - Loss of transition services loss of skills students with IDD stigmatized and excluded
    - Lack of employment preparation, lack of jobs
    - Innovative programs will not exist- post secondary service, internships as examples
    - Transition from schools will be less painful and chances for employment will be reduced
    - Loss of good, appropriate education leads to dead and adult life

- Limiting funding will lead to a decrease in effective educational programs across all age groups, including PSE
- Even fewer students will graduate and be prepared for adult life
- Without supports dropout rate will increase

5. **Less diversified workforce**

6. **Lack of education or limiting "opportunities" will limit job possibilities**
   - People won't be productive members of society
   - Lack of education or limiting "opportunities" will limit job possibilities

7. **Students will suffer abuse and neglect**
   - Continued segregated experiences, low access to equality education opportunities
   - The valued progress integration in the classroom will be reversed, class size increased
   - Training of educators will decrease students will not receive effective inclusionary education
   - Students will be isolated and segregated in schools

8. **Sub-par teaching leading to lower outcomes, less employment and greater reliance on high cost social services**

   - It will lead to creation of a class of untrained and undereducated Americans. The existence of such a class will denigrate American value of independence and self-sufficiency
   - Limiting anyone to education possibilities contributes to the status of the US as being a lower rambling country in the global picture
   - Less exposure to inclusive settings
   - Back to 1944 institutions mind set prior to IDEA- segregation
   - Continued disrespect in the upcoming generations for people with ID
   - People with ID getting sub- standard education keeps them "in the shadows"
   - People's dream won't be able to be reached
   - Teacher preparations would loss incentives (money) for improved and creative programs for serving individual with ID
   - Loss of experienced gained over time of how we can assist children and youth reach potential
   - Decreased access to new technology and personal to support students with IDD
   - Budget cuts, monies allocated for teaching will be a very limited thus leading to ineffective academic programs, speech and language interventions and job training
   - Does not allow people with ID to be fully participating members of the society
   - Much less enthusiasm of local school districts to use innovative educational practices
   - Loss of full participation in civic and social life.

Draft Meeting Agenda
September 26-27, 2011

U.S. Department of Health and Human Services
The Hubert H. Humphrey Building (HHH Bldg.)
200 Independence Avenue, S.W., Conference Room 505-A
Washington, D.C. 20201

Day One: Monday, September 26, 2011

8:30 a.m. – 8:35 a.m.	**Greetings, Call to Order, and Presentation of PCPID Chair** Sharon Lewis Commissioner Administration on Developmental Disabilities PCPID Designated Federal Official (DFO)
8:35 a.m. – 8:40 a.m.	**Welcoming Remarks and Introduction of Special Guests** James T. Brett PCPID Chair
8:40 a.m. – 8:50 a.m.	**Approval of Agenda and Minutes (June 16-17, 2011; July 19, 2011; and August l6, 2011)** PCPID Chair
8:50 a.m. – 9:05 a.m.	**Meeting Overview and Orientation** James T. Brett PCPID Chair
9:05 a.m. – 9:15 a.m.	Chair-Committee Dialogue
9:15 a.m. – 9:45 a.m.	**Overview of the Budget Control Act and Implications for People with Intellectual Disabilities** Richard Kogan Senior Fellow Federal Fiscal Policy Center on Budget and Policy Priorities Paul Van de Water, Ph.D. Senior Fellow Federal Fiscal Policy Center on Budget and Policy Priorities
9:45 a.m. – 10:10 a.m.	Presenter-Speaker Dialogue
10:10 a.m. – 10:20 a.m.	***REFRESHMENT BREAK***

10:20 a.m. – 10:40 a.m.	**Employment Issues that Impact People with Intellectual Disabilities** David Mank, Ph.D. Director Indiana Institute on Disability and Community
10:40 a.m. – 11:05 a.m.	Presenter-Committee Dialogue
11:05 a.m. – 11:25 a.m.	**Income Support** Marty Ford Director of Public Policy The Arc
11:25 a.m. – 11:50 a.m.	Presenter-Committee Dialogue
11:50 a.m. – 12:10 p.m.	**Longterm Services and Supports/Community Living** Nancy Thaler Executive Director National Association of State Directors of Developmental Disabilities Services
12:10 p.m. – 12:35 p.m.	Presenter-Committee Dialogue
12:35 p.m. – 1:25 p.m.	***LUNCH (on your own)***
1:25 p.m. – 1:45 p.m.	**Education** Jane West Political Advocacy Consultant American Association of Colleges for Teacher Education Higher Education Consortium for Special Education
1:45 p.m. – 2:10 p.m.	Presenter-Committee Dialogue
2:10 p.m. – 2:30 p.m.	**Healthcare/Medicaid** Lisa Ekman Senior Policy Advisor Health and Disability Advocates
2:30 p.m. – 2:50 p.m.	Presenter-Committee Dialogue
2:50 p.m. – 3:00 p.m.	**Welcome and Greetings** George Sheldon [Invited] Acting Assistant Secretary Administration for Children and Families US Department of Health and Human Services

3:00 p.m. – 3:15 p.m.	***REFRESHMENT BREAK***
3:15 p.m. – 4:15 p.m.	**"Voices of Advocates"**

Moderator: Sharon Lewis
Commissioner
Administration on Developmental Disabilities

Presenters: Ken Capone
Public Policy Coordinator
People on the Go of Maryland
Annapolis, Maryland

Tracy Wright
Project Manager
Self-Advocacy Network
Annapolis, Maryland

Leigh Sutherland
Parent
Chevy Chase, Maryland

Bill Krebs
Regional Representative
Self Advocates Becoming Empowered
Philadelphia, Pennsylvania

Phyllis Holton
Advisor
Project Action
Washington, DC

4:30 p.m. – 4:55 p.m.	Presenter-Committee Dialogue
4:55 p.m. – 5:30 p.m.	**Summary Discussion and Wrap Up** James T. Brett PCPID Chair
5:30 p.m.	***RECESS*** ***(See transportation details for Committee on page 6)***

Day Two: Tuesday, September 27, 2011

9:00 a.m. – 9:05 a.m.	**Call to Order** James T. Brett PCPID Chair
9:05 a.m. – 9:10 a.m.	**Introduction of Meeting Facilitator to Develop PCPID 2011 Report to the President** PCPID Chair
9:10 a.m. – 10:00 a.m.	**Overview and Framework for Discussion Leading to Development of Report to the President** Cathy Ficker-Terrill CEO The Institute on Public Policy for People with Disabilities
10:00 a.m. – 10:25 a.m.	Facilitator-Committee Dialogue
10:25 a.m. – 11:00 a.m.	**Discussion and Committee Acceptance of Priority Areas Recommended to Comprise 2011 Report to the President** Deborah Spitalnik and Peter Berns
11:00 a.m. – 11:25 a.m.	Presenter-Committee Dialogue
11:25 a.m. – 11:35 a.m.	***REFRESHMENT BREAK***
11:35 a.m. – 12:15 p.m.	**Discussion of Content, Outline, and Format of PCPID 2011 Report to the President** Full Committee
12:15 p.m. – 1:00 p.m.	***LUNCH (on your own)***
1: 00 p.m. – 2:00 p.m.	**Development of Statements in Selected Priority Areas and Formation of Related Ad Hoc Work Groups** Full Committee
2:00 p.m. – 3:30 p.m.	**Meeting of Ad Hoc Work Groups on Each Priority Area** Committee Members
3:30 p.m. – 3:40 p.m.	***REFRESHMENT BREAK***

3:40 p.m. – 4:05 p.m.	**Presentation of Ad Hoc Group Reports to Full Committee (five minutes, each)** Ad Hoc Group Leaders
4:05 p.m. – 4:30 p.m.	Presenter-Committee Dialogue
4:30 p.m. – 5:15 p.m.	**Discussion and Approval of Priority Area Statements and Recommendations for Inclusion in the 2011 Report to the President** Cathy Ficker-Terrill and Committee Members
5:15 p.m. – 5:30 p.m.	**Next Steps (Assignments, Timelines, and Products)** PCPID Chair
5:30 p.m.	***ADJOURNMENT***