



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

~ Minutes ~
October 16-17, 2012 Meeting

Participants

Ex officio Members and Representatives:

Edward Anthony

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

Susan Aramaki

Representing the Honorable Rebecca Blank, Secretary, U.S. Department of Commerce

Michelle Aronowitz

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

Jewel Bazilio-Bellgarde

Representing the Honorable Wendy Spencer, Chief Executive Officer, Corporation for National and Community Services

Gary Blumenthal

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

Leola Brooks

Representing the Honorable Michael J. Astrue, Commissioner, Social Security Administration

Serena Lowe

Representing the Honorable Hilda Solis, Secretary, U.S. Department of Labor

Mary Kay Mauren

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

Yvette Rivera

Representing the Honorable Raymond L. LaHood, Secretary, U.S. Department of Transportation

Citizen Members:

James T. Brett, Chair
Annette McKenzie Anderson, Ph.D.
Peter H. Bell
Clay Boatright
Micki Edelsohn
Ann Hardiman
Alison A. Hillman de Velasquez
Carl M. La Mell

Julie Ann Petty
Carol Quirk
Susana Ramirez
Deborah M. Spitalnik, Ph.D.
Lillian Sugarman
Liz Weintraub
Carol Wheeler
Sheryl White-Scott, M.D.

Presenters:

Edo Banach
Max Barrows
Suzie Bosstick
Chuck Bruder, Ph.D.
Maureen Casey
Merrill Freidman

Dohn Hoyle
Ari Ne'eman
Jami Snyder
James Toews
Lynda Zeller

Special Guest:

Kathy Greenlee, Assistant Secretary for Aging, and Administrator of the Administration for Community Living

ADD-PCPID Staff:

Sharon Lewis, *Commissioner*
Jamie Kendall, *Deputy Commissioner*
Laverdia Taylor Roach, *Senior Advisor*
Madjid "MJ" Karimi, *Program/Policy Analyst*

Sheila Whittaker, *Program Assistant*
Sara Vogler, *Administrative Supports Assistant*

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

October 16, 2012 (Day One)

Greetings, Call to Order, and Presentation of Chairman

Sharon Lewis

Commissioner, Administration on Intellectual and Developmental Disabilities (AIDD)

The October 16-17, 2012 meeting of the President's Committee for People with Intellectual Disabilities (PCPID) was called to order by Sharon Lewis, PCPID Designated Federal Official, and Commissioner of the Administration on Intellectual and Developmental Disabilities (AIDD).

Deborah Spitalnik, Ph.D., shared with the Committee that the report of the Blue Ribbon Panel, recommending the establishment of the President Committee on Mental Retardation (PCMR) was delivered to President John F. Kennedy, fifty years ago. She circulated the copy of a photo, taken in 1962, of the Panels' delivery of the report to President John F. Kennedy.

Welcoming Remarks and Meeting Overview

James T. Brett

PCPID Chair

Chairman James Brett welcomed PCPID members to the meeting and thanked them for making time to participate. He indicated that the Committee was scheduled to receive presentations in the area of *Managed Long-Term Services and Supports (MLTSS)* from subject-matter experts in the field of Intellectual and Developmental Disabilities, advocates, and family members during the meeting.

Approval of Agenda and Minutes (August 09, 2012)

PCPID Chair

Chairman Brett requested a motion to approve minutes of the August 09, 2012 Committee Conference Call. Liz Weintraub made a motion to approve the minutes. Lillian Sugarman seconded the motion. All the members voted in favor of approval of the minutes.

Managed Long-Term Services and Supports (MLTSS)

Managed LTSS 101

James Toews

Senior Social Scientist Analyst, Administration for Community Living

Mr. James Toews began his presentation by defining *Managed Care* as a way of paying for delivering health care and/or Long-Term Services and Supports (LTSS). He noted that in early days of managed care, many seniors and people with disabilities were critical of the system, because they felt that managed care was often out to save costs and not focus on quality. In

reality, managed care has improved throughout the years and in many states, it has offered better access to care for seniors and people with disabilities, in particular. Mr. Toews added that in recent years with exceptions of Arizona and a couple of other states, managed care has been introduced into LTSS.

Mr. Toews pointed out that 30-40% of people with Intellectual and Developmental Disabilities (ID-DD) are eligible for Medicare, mostly through their parent's records. If their parents retire or die, individuals with ID-DD will be eligible for Medicaid in addition to Medicare (i.e., dual eligibility). Mr. Toews mentioned that in most cases; people with ID-DD have been "carved-out." This means that they are not included in LTSS, and that the state developmental disability agency is still operating under the system of fee-for-services. Under fee-for-service, the person chooses his/her doctor, the hospital, or the clinic, and the insurance pays for part or all of the cost according to a schedule laid out in the policy. Mr. Toews indicated that, generally, a payer gives a Managed Care Organization (MCO) a capitated or fixed monthly payment per member, which the MCO uses to provide services and supports to its members. MCOs, however, assume and manage some or all of the financial risks for their members. As such, they have a financial incentive to keep members healthy and coordinate members' care.

Mr. Toews shared with the PCPID members that in a high-performing state, approximately 70% of the Medicaid budget is spent in the community, whereas in a low-performing state, this amount is recued to only 10%. These estimates are somewhat different on the developmental disability side. The only state that spends less than 50% of all its dollars in community services is Mississippi. All remaining states spend a majority of their long-term services dollars for people with ID-DD in the community. There are huge waiting lists and the service system and its dollars only reach a minority of people. It is, therefore, important to come up with ways to serve people on the waiting lists and support people that will have complex needs.

Round Robin Questions and Comments related to Managed LTSS 101

PCPID Members

Ms. Julie Ann Petty asked if the above-mentioned information is indicative of the fact that people like to move away from long-term services and embrace managed care. Mr. Toews responded, "No." The managed care, over the years, has been about medical services, doctor visits, hospital stays, drugs, and pharmacy costs. There is a move to include long-term services (e.g., in-home supports, and 24-7 residential care) in managed care. Ms. Liz Weintraub requested clarification on the concept of "dual eligibility." Mr. Toews replied that dual eligibility means that one receives both Medicaid and Medicare, if that person lives with ID-DD and is under age 65 and have no parents or guardians. Mr. Gary Blumenthal added that with respect to the long-term services, the potential for cost savings in the dual program on the medical side is understandable. There is justifiably, however, some anxiety about how to achieve cost savings on long-term services, while respecting the needs for people with ID-DD and protecting their right to services. Mr. Blumenthal raised concern that there are some states that spent in LTSS in institutional care settings; and that there are other states that support the same population for half of the cost. He presumed it is perhaps accurate to say, if you can support people in less restrictive environments, you can achieve cost-savings.

Ms. Carol Wheeler asked Mr. Toews to share his belief regarding systems that allow individuals to carve themselves out of the participants' pool. Mr. Toews responded that this is a huge issue

as we continue hearing terms about mandatory, passive, and active enrollments. These concepts mean that after managed care is setup, the participant can go through an educational period of deciding his/her choices and go through an enrollment period. If the person does not enroll during the timeframe, then the state automatically puts the individual in a plan. The person will also have a period to opt out of the plan if he/she is not satisfied. Mr. Toews added that, in such instances, there would be a guarantee that the individual could still maintain the same relationship with his/her provider for an extensive period of transition.

Mr. Clay Boatright expressed belief that in states with no carve-out options for institutions, managed care can help accelerate the deinstitutionalization process. Ms. Ann Hardiman shared with the members that New York State is in the middle of designing a long-term care and acute care system. She raised concerns with respect to complex transition and deficiencies with direct support professionals. Mr. Toews noted that in many states people with disabilities and seniors can hire their own support workers, including family members.

Dr. Deborah Spitalnik shared with the Committee that, for a while, the state of New Jersey was running both a fee-for-service acute care system and a managed care system. She added that this made it difficult for the state to realize some of the benefits of managed care. She encouraged members to think about what they know in DD service system, what is important to them, what is important to people they work for; what they see as the challenges down the road, whether it is direct support, people determining their own lives, or people living in the community. She expressed belief that the Committee's task is to think about what supports people with ID-DD the best, and be able to translate the findings to a managed care delivery system. Mr. Toews agreed and stated that one of the things that the Committee needs to consider is the need for a separate layer of consumer protection. He expressed belief that the Federal Government and states, whenever possible, should fund consumer protections and stay involved in the planning process.

State Panel: State Perspective Regarding Managed LTSS Planning and Implementation

Jami Snyder

Administrator, Arizona Long Term Care System, Arizona Health Care Cost Containment System

Ms. Jami Snyder began her presentation by sharing with the PCPID members that the state of Arizona does not have a big history around transition from fee-for-service to managed care model. She pointed out that the state receives approximately 3,000 applications for LTSS each month. In order to qualify medically for LTSS, an individual has to demonstrate through an assessment process that he/she is at immediate risk of institutionalization. In providing services to people with ID-DD, Arizona contracts with its sister state agency as well as three MCOs (i.e., Bridgeway Health Solutions, Advocare Select, and Mercy Care Plan).

Administrator Snyder pointed out that if one is enrolled into the long-term care program, from a long-term care managed care organization, he/she receives not only long-term care services, but the person also receives acute care services and behavioral health services though the same contractor. She added that the Division of DD in Arizona does subcontract out with acute care health plans for the provisions of acute care to members and with the Division of Behavioral

Health Services, another state agency for the provision of behavioral healthcare. The state of Arizona provides care services, nursing facility services, hospice, and behavioral healthcare. The state is also committed to offering the continuum of care, from in-home care, which is the foundation of the system, assisted living and DD group home care. Member individuals who are elderly or have physical disabilities are about 51% of the population; individuals with ID makeup 49% of the population. Approximately, 73% of members either are in their own home or in alternative residential settings, mostly assisted living homes, some assisted living centers, and 27% are in nursing facilities. The Home and Community-Based Services (HCBS) replacement rate is approximately 86% for a combined program between elderly/physical disability and DD.

Ms. Snyder emphasized that Arizona's Program Administrators believe in incorporating acute care and behavioral healthcare with the long-term care system, so that members have optimal care coordination. This is to ensure that managed care entities not only understand the long-term care needs of the individuals, but also understand what medical conditions might be affecting their long-term care needs as well as behavioral health issues. Ms. Snyder added that the "rate setting methodology" has been a key component to incentivizing HCBS in Arizona. The methodology is a blended capitation rate in that the percentages of individuals in nursing facilities are multiplied by the cost of providing services to an individual in a nursing facility setting. The State of Arizona has a community transition services fund, which is up to \$2,000 per member for individuals moving from nursing facilities into HCBS placement. In terms of monitoring and compliance, the state has clear standards around time and distance standards for pharmacies.

Ms. Snyder noted that it is important to recognize that every individual member in the Arizona system has a case manager. The state is currently pursuing a dual demonstration to enhance care coordination for dual members (i.e., elderly/physical disability). She ended her presentation by sharing her belief that creation of an independent entity or ombudsman, which could act as the first line of interface for members, is a way that Arizona can enhance its system of care.

Lynda Zeller

Deputy Director of the Behavioral Health and Developmental Disabilities Administration (BHDDA), Michigan Department of Community Health

Deputy Director Zeller reported that the State of Michigan is about 15 years into managed care for a broad base of individuals, not limited to people with ID-DD. She mentioned that Michigan's last public intermediate care facility was closed in 2009. Michigan calls its managed care system on the community mental health side, as the community mental health boards are in charge of managed care. Ms. Zeller added that, in Michigan, most people with ID-DD are living independently or with relatives; followed second by people in specialized residential programs.

Ms. Zeller noted that managed care has to be a system that carefully considers which tools should be used for what purpose, how they fit together, and what are the intended/unintended consequences of putting those power tools together. She added that the state has to set the direction for the delivery of services, and it has to think beyond Medicaid and Medicare. Ms. Zeller explained that the recipients of public mental health services could choose from a choice of providers, which is important in the Michigan system. She noted that the consumer protections, including grievance and appeal, are very crucial in this system. Ms. Zeller

mentioned that the emphasis is on delivery of supports and services in the community, not in congregate, segregated settings for housing or employment.

Deputy Director Zeller reported that Michigan supports family caregivers. She added that for the individual members who live with their families, respite services, assistance with inclusion and participation, family training and other services are important. They allow individuals to be richly engaged and empower their communities in powerful ways. Michigan serves people without waiting lists. The service array is broad, flexible, and community-focused. Ms. Zeller noted that the entities that are taking the responsibility for managed care are required to make sure people get access and choice. The Michigan system must have sufficient capacity to address crises within regions, rather than relying on state institutions, which requires oversight of a decentralized service delivery system.

Deputy Director Zeller reported that Michigan would be submitting a state plan amendment to cover applied behavioral analysis for children with autism in the near future.

Chuck Bruder, Ph.D.

Assistant Director, Division of Disability and Aging Services, Vermont Department of Disabilities

Dr. Chuck Bruder shared with the Committee that the intent through managed care, in Vermont, is to provide greater flexibility and a broader range of services to the constituents. The state is granted authority to have its agency of human services operate as it was a private MCO. Vermont was the first in the nation to be able to offer enrollment to virtually all Medicaid enrollees throughout the entire state. Dr. Bruder noted that the requirement was that the Department fulfill the same standards as the federal partners on MCOs that primarily has to do with risk, and reserve or emergency services and quality improvements. The appropriation that comes to the Department from the state legislature, as well federal partners, is given to the agency of Human Services, which then pays for the state Medicaid agency.

Dr. Bruder pointed out that the state started with a budget of \$850M in FY 06 and is currently approaching a budget of \$1.4B for Medicaid 1115 program. The entirety of the state's Medicaid program operated under generally one 1115 demonstration project, entitled "Global Commitment." He added that there is a second 1115 project that state is intending to merge with the *Global Commitment* that serves the elderly and operates as a nursing home diversion project. Dr. Bruder commented that the statutes contain statutory eligibility requirement, which get the participant in the front door, but it does not get them any funding. For funding, the state has a separate process whereby funding priorities are established in what is called the *Vermont State System of Care Plan*. Dr. Bruder also described different payment methodologies. For instance, within developmental services, he mentioned the possibility of a daily rate as well as annual budget that is divided by 365.

Additionally, Dr. Bruder shared with PCPID members that in order to receive HCBS services, one needs to fulfill statutory funding requirements and meet funding priorities, which are detailed in the state's system of care plan. The state provides services to 4,029 individuals. The total appropriation this coming year is approximately \$154 million. There are 2,539 individuals receiving HCBS services, an addition of 1,068 individuals receive flexible family funding, and

422 receive bridge and Targeted Case Management (TCM) funding. The bridge and TCM are state plan services, and the state plan has become part of *Global Commitment* entity. Dr. Bruder noted that in Vermont, 54% of individuals are receiving resident support living with their own families. In 2012, the United States Cerebral Palsy Association ranked Vermont as the top state in the nation in terms of keeping families together.

Round Robin Questions and Comments related to State Panel

PCPID Members

Mr. Clay Boatright asked panel members if they foresee any trends or changes for people with ID-DD to be willing not to live with their families. Ms. Snyder responded that, in recent years, an upswing in terms of placement in either DD group homes or assisted living placements has been seen in Arizona. Dr. Bruder added that the genesis of shared living program in Vermont happened when Brandon Training School started paying the staff members, who had spent their entire lives living with individuals that remained at Brandon, to take these individuals home to live with them.

Mr. Gary Blumenthal asked why the developmental disabilities system was carved-out in Arizona. Ms. Snyder responded that this was due to programmatic problems revolving around elderly/physical disability groups as well as acute care population. Arizona will issue a Request for Proposal in couple of months to look at implementation date for the demonstration projects for January 2014.

Ms. Carol Wheeler asked panel members how do they explain the financial benefits of the managed care operations to people with ID-DD. She asked what types of facts are being used to explain managed care to people with ID-DD. Ms. Zeller responded that it is important to look at the whole system for cost savings.

Ms. Yvette Rivera, Department of Transportation ex officio representative, shared with the Committee that a significant change in MAP-21 is the combination of the Elderly Individuals and Individuals with Disabilities Program and the New Freedom Program, which provides formula funding for people with disabilities, into a single program. The new combined program is called the Enhanced Mobility of Seniors and Individuals with Disabilities Program. This program is authorized at \$255 million in FY2013 and \$258 million in FY2014 compared with \$226 million for the Elderly and Disabled and New Freedom programs combined in FY2012.

Ms. Lillian Sugarman asked panel members to elaborate on the MLTSS consumer satisfaction facts. Dr. Bruder responded that Vermont conducts consumer satisfaction surveys, annually, and added that, so far, customer satisfaction has been 90%. Ms. Zeller mentioned that Michigan uses national core indicators, which is a good tool to identify consumer satisfaction but it is extremely resource intensive. Ms. Snyder added that Arizona allows its MCOs to establish their own survey mechanisms.

Mr. Carl La Mell asked about the residential costs per person. Ms. Snyder responded that the average cost of an institutional placement in Arizona is about \$5,500 per month. The average cost of an HCBS placement, which is blended rate between in-home and alternative residential, is approximately \$1,700 per month. Mr. La Mell asked how Arizona deals with abuse and

neglect issues in shared residential settings. Ms. Snyder responded that her office works closely with the Department of Licensure in the State of Arizona to connect with MCOs and look at alternative placements.

Dr. Spitalnik commented that under the Affordable Care Act, there is a requirement for state maintenance of efforts in terms of the amount that may be invested in services. Ms. Zeller agreed and added that states have to plan with expansion. They need to take into account what does maintenance of effort look like if federal or state directions change.

Managed Care – Payer Perspective

Merrill Friedman

Vice President, Advocacy, Amerigroup

Ms. Merrill Friedman began her presentation by highlighting the importance of independent living philosophy and principles of self-determination for people with ID/DD. She stated that, with the passage of healthcare reform, budget costs, and the economy, many states are relying on managed care to increase access and services. This is while they are taking into account managing budgets, alleviating and eliminating waiting lists, and having to enhance the capacity within the community. Ms. Friedman pointed out that engaging people with disabilities, their families, and other stakeholders at all levels are the keys to success in managed care. She expressed belief that seniors should be able to age in the community, if that is their choice. People with disabilities should also be able to live independently.

Ms. Friedman pointed out that currently 28 states are looking at LTSS by contract structures and for services that are needed to be developed. She described transparency, flexibility, self-direction and self-advocacy that focus on the community and eliminating the institutional bias, and increased oversight and accountability, as integral part of a managed care system. She expressed belief that the goal of managed care is to improve the coordination, access to quality and efficient services, and shifting and rebalancing of costs for the state to move forward. Ms. Friedman stated that looking at what managed care should ultimately do should help in ensuring that Medicaid is sustainable for people who rely on such services and supports. States would like to ensure that MCOs are designing a *benefit program* that is responsive to the needs of consumers.

Ms. Friedman shared that in 2009, Amerigroup, in collaboration with the National Advisory Board, developed a white paper that outlined six principles for how to sustain the infrastructure of managed care, and how each principle could fit into LTSS. She noted that enhancing self-care through improved coordination where people are empowered to take an active role in self-direction, encouraging community integration, and expansion of the accessibility of services and supports were included in this white paper. The Amerigroup has also partnered with disability, community-based and faith-based organizations to ensure that “it is moving the needle on elimination of the institutional bias.” Since 2007, Amerigroup has transitioned approximately 1,400 individuals from institution to the community, and diverted over 4,000 people from ever having to go into an institution. Ms. Friedman suggested building capacity within the communities to ensure that the services and supports are available and still being built toward

quality of life for people with ID-DD. She added that this requires educating community providers.

Ms Freidman ended her presentation by emphasizing that managed care should be de-medicalized. If the process is de-medicalized for people with ID-DD and the focus is on choice and outcome, it is going to bring the managed care costs down.

Round Robin Questions and Comments related to Managed Care - Payer Perspective PCPID Members

Dr. Spitalnik commented that people are concerned that State Plans do not address individual needs that may vary from one population-based model. Therefore, any program should be built from the roots (i.e., children). Any system should be designed with kids in mind first and then be modified to meet needs as the individual ages. Ms. Carol Quirk agreed and added that the purpose of transition planning for students with disabilities is to ensure that they leave the entitlement system with a plan in place, and hopefully the service providers support them to continue their life in the community. Ms. Freidman stated that her organization (Amerigroup) supports students during the school day; for instance, it provides healthy menus and immunizations.

Ms. Friedman commented on the infiltration of the provider education system as an important technique. She added that Amerigroup is committed to providing training through webinars and other communication tools to get the providers engaged and provide them with managed care education. Ms. Susana Ramirez noted that this is very important as avoiding “restricted future” for individuals with ID-DD, and this should be the focus. She suggested that providers should work with parents towards this focus.

Mr. Blumenthal asked what could encourage other MCOs to function to their full potential as Amerigroup. Ms. Freidman replied that not all MCOs are operating in the best way for people with disabilities. CMS can help oversee them. Other advocates or groups (e.g., America’s Health Insurance Plans) and agencies can engage MCOs in dialogue in order to improve their services for people with disabilities. Ms. Ann Hardiman and Ms. Alison Hillman de Velasquez spoke about the concerns that exist over placing non-medical LTSS in the hands of medical model MCOs. They shared the belief that individuals with ID-DD need to be supported holistically, and that MCOs must have employees who understand non-medical support models as well as independent living needs of the population.

(Break for Working Lunch)

Centers for Medicare and Medicaid Services (CMS) Perspective Regarding Managed LTSS

Suzie Bosstick

Deputy Director, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services (CMS), Center for Medicaid and CHIP Services

Ms. Suzie Bosstick started her presentation by expressing that managed care has a consistent theme, value and requirement regardless of the population being served. She added that there are many states are pursuing MLTSS to the goal of changing a large fee-for-service system to a managed system of care. For the first time, through the Affordable Care Act, LTSS is no longer being carved-out of managed care delivery system. They are, indeed, carved-in with all the other state plan services. Ms. Bosstick noted CMS observation of an upsurge in state requests to develop and/or enhance LTSS, so the agency hire a contracting firm (i.e., Truven Health Analytics) to gather information for states about the growth of MLTSS.

Ms. Bosstick shared a slide presentation that compared the number of enrollees in MLTSS from 2004 to 2012. She noted that in Texas more than 50,000 individuals receive LTSS through managed care delivery system; whereas, in Pennsylvania, the data shows only 100 people who are enrolled in the managed care delivery system. Ms. Bosstick added that many people are fearful that implementation of MLTSS may put an end to self-direction. CMS believes that MLTSS should not put an end to self-direction, as the number of states incorporating self-directions in their programs is growing. Ms. Bosstick pointed out that there are education programs in community and state plans to ensure that self-direction is not lost in the move to MLTSS. She noted that there has also been concern about the role of managed care in continued rebalancing and systems transformation. What CMS is noticing in many states is an awareness, not only of the need of continued principles like self-direction, but also of the need to think about how to incorporate money follows the person and the desire to rebalance MLTSS. The home- and community-based services waivers have been the primary driver for long-term care reform in states. Ms. Bosstick noted that Texas STAR PLUS waiver, for example, has been delivering HCBS through a managed care delivery system for over a decade.

Deputy Director Bosstick shared with the PCPID members that, based on an interview conducted by Truven Health Analytics, some of the quality parameters that states are including in their MLTSS are: timelines of completing level of care assessments; turnover rates; person-centeredness; and institutional admissions. She reported that 70% of Medicaid dollars are now spent inside managed care delivery system, and fee-for-services, as the predominant delivery system, has gone away. The thinking should, therefore, be focused on how to monitor a fee-for-service and how to ensure that all the services have been provided to the individuals and paid appropriately. Ms. Bosstick pointed out that the states can perform a delivery system reform through 1115 demonstration waiver. CMS has seen, in the past two years, an increase in a number of states that are incorporating MLTSS as a part of their 115 healthcare reforms. This is, however, not the only way for a state to perform MLTSS. A state can, essentially, overlay a managed care delivery system to its home- and community-based waivers. States can also use their existing home- and community-bases waiver authorities in Medicaid, and an existing 1915(b) waiver. Ms. Bosstick noted that states can put these two authorities together and submit an application for a concurrent (b) (c) waiver. Many states are currently focusing on integrated health (e.g., primary, acute, institutional, behavioral, pharmacy, and LTSS).

***Centers for Medicare and Medicaid Services (CMS) Perspective Regarding Managed LTSS
Edo Banach***

Senior Advisor, Medicare-Medicaid Coordination Office, Centers for Medicare and Medicaid Services (CMS)

Mr. Edo Banach began his presentation by highlighting that Section 2602 of Affordable Care Act created the Medicare-Medicaid Coordination Office within CMS. The purpose of the office is to improve quality of care, reduce cost, improve the beneficiary experience, and ensure that people with Medicare and Medicaid have access to government services. The office is set to improve the coordination, develop innovative care coordination and intubation models, and eliminate financial misalignments. Mr. Banach noted that individuals with Medicare and Medicaid are sometimes caught between these two systems. CMS has, therefore, published a list of 30 different misalignments areas in which Medicare and Medicaid do not work well together. CMS has also attempted to provide Medicare data sources to states. Additionally, CMS has created the *Integrated Care Resource Center*, a center to provide help to states that are interested in integrating care for people with Medicare and Medicaid. The goal of the Center is to focus on person-centered models that promote coordination, easily navigable systems, and robust network adequacy and evaluation.

Mr. Banach pointed out that, in order to make systems navigable to consumers, CMS requires states to have continuity of care provisions (e.g., one identification card for all benefits and services, one appeal system for both Medicare and Medicaid, etc.). Thirty-six states have submitted letters of intent for *state demonstration development processes*. The State of Massachusetts has had its demonstration approved. Seventeen states are pursuing capitated models, six states are following a managed fee-for-service model, and two states (i.e., North Carolina and New York) are seeking to attain both models. Mr. Banach mentioned that it is important to note that some states (i.e., South Carolina and Tennessee) propose to carve-out services received by the individuals with ID-DD, but not carve-out individuals themselves.

Mr. Banach shared with PCPID members that states have come under scrutiny from individuals and groups seeking to be carved-out of the demonstration processes. The goal of CMS is to create a system in the long-term to provide the most integrated and seamless benefits to as many people as possible.

Round Robin Questions and Comments related to Centers for Medicare and Medicaid Services (CMS) Perspective Regarding Managed LTSS

PCPID Members

With respect to carve-outs, Mr. Blumenthal asked why the CMS do not take a strong position and simply say no to exclusions of people with ID-DD in the system. Mr. Banach replied that the CMS' position recognizes the existing limitations of each state's structure and their intentions to carve- out or carve-in ID-DD. This is a demonstration that allows states to "test" as service design. He added that the CMS requires states to engage "stakeholders" (including, groups and individuals) if a state has not, then the advocates need to communicate this to the CMS.

Ms. Liz Weintraub asked if self-advocates are involved with helping the states to set up waiver demonstrations. Mr. Banach responded that it is the CMS' requirement that states engage all level of stakeholders in the process. He added that individuals with disabilities are the real source to developing indicators regarding consumer experiences. Ms. Hillman de Velasquez asked if people with ID-DD were also engaged with the contractors charged to develop the

indicators for members' experiences. Ms. Bosstick responded that the CMS has developed tools with feedback from panel of technical advisors that included advocate groups; including, *Self Advocates Becoming Empowered*.

Dr. Spitalnik expressed belief that, when writing recommendations in the *PCPID 2012 Report to the President*, having outcome measures in terms of individuals and group beneficiaries in the field of ID-DD can be a big struggle. Ms. Bosstick responded that things like community integration and meaningful employment are type of measures that will fundamentally tell CMS about the impact of managed care and LTSS inside a community. She agreed with Dr. Spitalnik and added that some of the outcomes from MLTSS require collaborations from other federally funded programs. Ms. Bosstick emphasized that no matter how good the MLTSS system is; there will be gaps if "collateral" supports are missing or are weak.

Family and Advocate Perspective

Maureen Casey

Early Intervention Policymaker and Parent, Arizona

Ms. Maureen Casey stated that she has been actively involved in providing supports and working with people with disabilities. She stated that regulations, policies, and funding are important to ensure that families have the access to the services and supports they need. She expressed belief that as the states move from institutionalization to managed Medicaid, the community services and fiscal efficiency become important. Ms. Casey pointed out that in Arizona; families are enrolled in health plans as there are a number of different plans. The long-term care system is run by Medicaid program and contractors work to develop disability system to provide acute and primary care services to DD population. In Arizona, there is a separate contract with the Health Department for Behavioral Health and another with the medical plans.

Ms. Casey stated that support coordinators, in Arizona, are 95% state employees. In addition to the state DD office being the MCO, the support coordinator comes from the state as well. She added that children could enter the DD system through the state early intervention program. Ms. Casey expressed her belief that the issues around employment in Arizona is exclusive of the Medicaid manage care system. The state is going to make sure that people have jobs.

Ms. Casey talked about stakeholder involvement in Arizona. She shared that the state has sustainability workgroups that will look inside the DD system and its programs. It is important to educate families as well as the providers about how they can be flexible and responsive. Ms. Casey cited accountability as another important factor.

Despite the fact that there are no waiting lists in Arizona, network capacity problems have been seen in the DD system. The State funds the *Parent Training and Information Center* to educate self-advocates and families regarding their rights and the appeal process. All contractors are required to provide performance measures and later report on them. Ms. Casey expressed belief that "we really have to have a grand vision" that people with ID-DD are going to have enviable lives. To do so, we have to embrace cross agency collaboration.

Dohn Hoyle

Executive Director, The Arc of Michigan

Mr. Dohn Hoyle noted that the Arc of Michigan is an advocacy organization at both the local and the state levels. Managed care, in Michigan, has provided increased access, including access to specialty providers. Mr. Hoyle observed that managed acute health care in Michigan is significantly better than it was in previous years.

Mr. Hoyle indicated that the “Howell” consists of a group of people from across the system to research how system change can occur in Michigan. He stated that one of the goals from the state’s earlier waivers in moving toward managed care was to stop the constant assessments of people. Mr. Hoyle noted that there were seven different assessments in state assurance to Medicaid and CMS. He added that it was true, people needed certain assessments depending upon their circumstance, but they did not need to undergo seven different assessments every year. There were, however, more principles for adopting into managed care. For example, the implementation of a single funding stream, in which it eliminated going to a number of different places to get money in order to make a plan for a person. The state also accepted the capitation as long as the growth was seen. Additionally, Mr. Hoyle stated that believing in local discretion, shared risk, and stop loss were as important.

Mr. Hoyle stated that proposals are made to the state of Michigan to fulfill the promise of the code (i.e., mental health) revisions, individualized supports, elimination of barriers, and contain the cost for services that add value and provide needed and desired services for those in waiting lists. The state also adopted a person-centered planning statute. Mr. Hoyle mentioned that the managed care system for people with DD, is carved-out and administered through local entities. He noted values that are incorporated in the application for participation in managed care system for people with ID-DD, including: right, empowered exercise choice and control over all aspects of their lives; involvement in meaningful relationships with family and friends; and support to live with their family when they are a child.

Mr. Hoyle ended his presentation by saying that Michigan learned that the model of services in a group setting is similar to the model of services in an institution, and it is difficult to change that. The state is, therefore, encouraging individuals to live in their own places.

Max Barrows

Outreach Coordinator, Vermont Statewide Self- Advocacy Organization

Mr. Max Barrows described that, in 2005, Vermont converted out 1915 waiver program for people with ID-DD to a managed care system run by the state. Initially the state wanted to follow a “one size fits all” approach for programs for the elderly and people with ID-DD. Mr. Barrows stated that through advocacy, however, people with ID-DD and their families played a major role in maintaining a person-directed approach. They kept the same outcomes and indicators as developmental service system moved into managed care. Mr. Barrows cited himself as an example of an individual being able to choose the people he wants to work with, such as service coordinators, job assistance and community support staff.

Mr. Barrows mentioned that he is aware of some frustrations with service systems, including not getting enough employment supports, not having their confidentiality fully respected by support staff and, perhaps, not being fully in charge of the individual support agreement. He observed that Vermont does not have a big waiting list, but occasionally the state face problems with people not getting the services they need. According to Mr. Barrows, approximately 25% of individual who are eligible for service receive services they need. Each year about 100 new adults with ID-DD enter the service system. Mr. Barrows added that money for services is also available for students graduating from high school. He suggested that states using a managed care system keep track of the real needs of people with ID-DD.

Mr. Barrows stated that Vermont has no ombudsman for persons with ID-DD; but there is an ombudsman for elders. Vermont has also faced budget cuts. State employees responsible for quality assurance and technical assistance for developmental services have been reduced to 75% over the past few years. Mr. Barrows mentioned that, as other states convert to a managed care system, the key should be “nothing about us without us.” To build a system that meets the needs of people with ID-DD, self-advocates need to be involved at all levels. Mr. Barrows noted that each provider and state board by law, in Vermont, has to cover at least 51% persons with ID-DD.

Mr. Barrows ended his presentation by stating that self-advocacy is strong, diverse, and well-supported in Vermont. He added that despite being a rural state with a relatively low population, Vermont holds 21 local self-advocacy and advocacy groups with 600 plus active members.

Round Robin Questions and Comments related to Family and Advocate Perspective PCPID Members

Mr. Clay Boatright asked about the kind of residential option that is available in the states of Michigan and Vermont. Mr. Hoyle responded that smaller settings are available and more effective in supporting individuals with significant needs, and added that less staff turnover in smaller settings contributed to success in Michigan.

Ms. Carol Wheeler commented that although no major waiting lists exist in Vermont, the “real needs” of Vermonters with disabilities are not adequately addressed if they are not eligible for a specific service due to prioritization of need or functional eligibility requirements. Mr. Hoyle added that in Michigan, if one has developmental disability and is on Medicaid, the person is entitled to all available services as state has redefined “medical necessity.” Ms. Casey mentioned that Arizona has also defined medical necessity to enable MLTSS to pay for services necessary to avoid a more severe issue later. She noted that individual choice enables a person to choose but churning impacts a case coordinator’s ability to stay current on all common resources, as too much choice can add a layer of complexity.

(Day One Recess)

October 17, 2012 (Day Two)

Call to Order (including introduction of contractor supporting staff on FY12 report)

James T. Brett, Chair

The October 17, 2012 meeting was called to order by Chairman Brett who welcomed the Committee members. Chairman Brett introduced the meeting's special guest, Ms. Kathy Greenlee, Assistant Secretary for Aging and Administrator of the Administration for Community Living.

Welcome and Greetings

Kathy Greenlee
Assistant Secretary of Aging
Administrator
Administration for Community Living

Ms. Kathy Greenlee thanked PCPID Designated Federal Official (DFO) and staff for arranging the meeting. She briefly described the mission of the Administration for Community Living (ACL). Ms. Greenlee expressed belief that the creation of ACL will fill the gap between aging and disability. She talked about how unique this opportunity is for Department of Health and Human Services (DHHS) to undertake the efforts to enhance community living. She suggested that PCPID Members contact her directly if they have any suggestions or comments. Ms. Greenlee ended her remarks by thanking everyone for looking into issues that revolve around *Managed Long-Term Services and Supports for People with Intellectual Disabilities*.

Ms. Sugarman asked Ms. Greenlee if ACL is planning to connect with the Administration for Children and Families (ACF) to not only focus on children with ID at birth, but also throughout their entire lifespan. Ms. Greenlee responded that she would like to see that the lifespan approach be taken. She encouraged that the administration rely on University Centers for Excellence in Developmental Disabilities (UCEDD) to continue their work on research. Ms. Greenlee further stated that the best opportunities might be difficult to find, however, the ACF Acting Assistant Secretary has been supportive of ACL.

Mr. Blumenthal commented that when people within the ID community enter into managed care, they might need to understand these systems, and be able to navigate through private insurers. He asked if the role of the Protection and Advocacy (P&As) groups would be expanded. Ms. Greenlee responded that through establishing ACL, CMS has played a significant role in supporting states. She pointed out that from the ID-DD perspective, those P&As agencies exist; however, for the aging community, P&As do not exist.

Ms. Liz Weintraub asked if self-advocates have a role in supporting the elderly population? Ms. Greenlee responded "yes," people living in communities have a way of helping everyone else out, and by working with self-advocates, a healthy community supportive system is promoted. Ms. Leola Brooks, Social Security Administration (SSA) ex office representative, wondered if any opportunities for collaboration between Social Security Administration and other agencies were available. Ms. Greenlee mentioned that representative payee at SSA is a huge issue at Administration on Aging (AOA). Another issue that is being dealt with is disability insurance system at SSA. However, these are larger than ACL issues and more a DHHS level conversation. Ms. Brooks asked if there are any opportunities for disability

research. Ms. Greenlee replied that she would get back to her on that because ACL has been cooperating with National Institute on Disability and Rehabilitation Research (NIDRR) while also working together with National Institutes of Health and National Institute of Aging. Ms. Spitalnik added that participatory action research is important and impactful to both self-advocates and benefactors. She underlined Ms. Sugarman's point about life course issues. Dr. Spitalnik stated that there is great opportunity in creating collaborations and coalitions within communities while weaving similar elements together. Additionally, she noted that it is important to have federal partners at the table because of the complexity of the LTSS issues. Ms. Greenlee agreed and added that there is great need in translational research across the fields of disability and aging. Ms. Greenlee used an example where she was asked a question in regards to the research of Alzheimer and people with Down syndrome. The likelihood of receiving the disease is four times likely than the general populace. Ms. Julie Ann Petty commented that sometimes the research that is compiled is not understandable to many self-advocates.

Discussion and Review of Day One (*development of additional questions for the National Council on Disability (NCD) and for discussion*)

PCPID Members

Ms. Wheeler asked if it is possible to learn lessons from states that are already involved in LTSS, or not. For example, she mentioned a situation in Wisconsin, which is in stark contrast to what is occurring in Minnesota, where someone is suing somebody. Commissioner Lewis explained that Wisconsin was one of the first states to do LTSS. She noted that Wisconsin has created entitlement in their waiver as well as a self-directed waiver. She mentioned that advocates have pursued legal action. Ms. Wheeler further stated that getting costs down and getting advocacy organizations to live their lives and not worried about charts or risk assessments is important.

Ms. Petty asked a clarifying question about the ability to save money and if fee-for-service could be explained. Commissioner Lewis explained that fee-for service is a structure that exists in many states. She went into detail about the provider who will cater a service and it is based on "X" amount of money for the hours that are paid for a service. Moreover, she stated that, in a managed care system, the rate would be based on people's needs. Dr. Spitalnik added that the capitation fee is based on flexibility so that the person decides what they want and need. Ms. Petty reiterated that capitation is about flexibility. Ms. Spitalnik responded that it is about flexibility and delivering a service that is coordinated and it gives the opportunity to be a person-centered system.

Ms. Weintraub commented that self-advocates are a part of the public, and need to be able to understand the language in the *PCPID 2012 Report to the President*. Commissioner Lewis suggested that PCPID develop a glossary of terms and ideas to incorporate into the Report to make it understandable for people with ID-DD. Mr. Peter Bell concurred.

Dr. Anderson spoke about how educating parents, teachers and students about managed care should be addressed in the *PCPID 2012 Report to the President*. Mr. La Mell commented that a problem with managed care is how to control costs. He shared with the PCPID members that in five years timeframe, there will be fewer services, which will continue to exclude people due to changing eligibility requirements. Ms. Wheeler mentioned that there are funding priorities that exclude people. She noted that only 25% of individuals with developmental disabilities in

Vermont are covered. Commissioner Lewis pointed out that this occurred only in "24 hours a day, 7 days a week" residential services. Ms. Wheeler suggested that the Committee should think in general terms of how to provide services for a larger population. Ms. Yvette Rivera agreed, and stated that there is a lack of diversity among the demographic population and suggested that the topic of diversity be addressed in the report.

Prior to introducing the next presenter, Chairman Brett acknowledged the presence of former PCPID Chair, Ms. Madeleine Will, who served two terms in the previous Administration as well as a nationally recognized advocate for the National Down Syndrome Society. Chairman Brett mentioned that Ms. Will has made enormous contributions to the field of Disability as the previous chairperson to PCPID.

Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Intellectual Disabilities

Ari Ne'eman

President and Co-founder of the Autistic Self Advocacy Network
The National Council on Disability (NCD)

Mr. Ari Ne'eman began his presentation by sharing that he was representing the National Council on Disability (NCD). He explained that NCD's role is to advise Congress and the Executive Branch of the government on disability policy issues. Mr. Ne'eman mentioned that NCD will be releasing a toolkit on deinstitutionalization, as well as how to make managed care work effectively for people with disabilities. He continued by describing the history of managed care. Mr. Ne'eman pointed out that managed care has been used effectively for people with disabilities, including people with ID-DD. He mentioned that there is growing push towards inclusion within the disability community and LTSS. Mr. Ne'eman explained the fee-for-service methodology and its effects on managed care. Another issue that he talked about was the importance of allowing people to make their own decisions about services within LTSS. Mr. Ne'eman also described different kinds of models of managed care, such as voluntary managed care, managed care in a passive enrollment basis, and mandatory managed care. He described the Medicaid infrastructure that could be done through different waivers such as 1915 (B) and (C). He explained that states could engage with the Medicaid agencies, and make a case to the CMS by explaining what should go into the waiver application. Mr. Ne'eman noted that many advocates have raised concerns with financial alignment demonstration, which are passive enrollments that will place people in a position where they have to shift away from a managed care plan. Mr. Ne'eman stated that there are some potential benefits for managed care, such as clear and specific systems change like employment and its desired outcomes. He referred to the National Core Indicators (NCI) as a great model for states to utilize in incorporating quality that takes into account outcomes for LTSS. Mr. Ne'eman noted the importance of building an ombudsman into states and making sure that it is in the state's application. He pointed to the NCD's recommendations to the CMS and state governments to manage LTSS as community living, quality measures, family support, employment, and provider sufficiency.

Mr. Ne'eman ended his presentation by stating that questions, such as whether or not people need to play a role in designing the framework, should be posed when looking at MLTSS. He also stated that there needs to be a mechanism for innovation and ensuring that MCOs will be making long-term investments.

Round Robin Questions, Comments, and Discussion with NCD PCPID Members

Ms. Liz Weintraub asked whether managed care is for people with real jobs or people working in sheltered workshops. Mr. Ne'eman responded that it depends on the state, and the way that its managed care system is designed. He mentioned that sheltered workshops could be included in the managed care framework because this is how quality measures are developed. Commissioner Lewis added that the best way is around quality and accountability, which equals to outcomes. Ms. Weintraub reflected that her bottom line is real jobs for everyone. Mr. Ne'eman agreed and explained that the role of MCOs is to improve quality and costs. He would like to see the focal point be moving away from institutions and into community living. He explained that this result could be completed by providing more funding to the community side. Mr. Blumenthal raised concern that there are mixed messages coming from the CMS because the agency is allowing for "carve-outs." This can cause much confusion. Referring back to Ms. Weintraub's point, Mr. Blumenthal pointed out that NCD has a definitive statement on sheltered workshops, and asked Mr. Ne'eman to spend some time explaining those positions. Mr. Ne'eman responded that he would rather schedule a time to do a full briefing to explain NCD plan to phase out 14(C). If PCPID members are interested, Mr. Ne'eman would hold a session on the NCD plan around 14(C).

Ms. Quirk stated that the emphasis in managed care seems to be person-centered planning, self-direction, a variety of options customizing for the individual and driven by the individual and his/her family. From what she has heard, it is not about managed care versus fee-for-service as much as it is about funding availabilities. Ms. Hardiman viewed the goals as individualized and customized choices. She raised a question about the purpose of a managed care model. She also asked why individuals have to pay a managed care organization. Mr. Ne'eman responded that managed care is a broad administrative vehicle. He stated that most states have adopted managed care structures that rely on nonprofits rather than private companies. He noted that the real emphasis must be on quality improvement(s). As a brainstorming technique, Mr. Ari Ne'eman posed the following questions for PCPID members' consideration:

- How do we move away from sheltered workshops?
- How do we move to a system where state and service provisions are not connected?
- How do we move to a system where HCBS are fully implemented?

Mr. Ne'eman stated that managed care is occurring; the choice to make sure individuals are using this mechanism to advance the Committee's priorities, or individuals being placed under a framework that does not understand their shared needs or issues, is something that may be dealt with now. He stated that a good managed care framework could get individuals further than the current fee-for-service. Mr. Bell asked how does one come up with the amount of money that an individual has within a managed care organization. Mr. Bell commented that the disability population is no different from the non-disabled population and the choice of living arrangements should be available. He concluded that he would not like to lose that sense of choice or option. Mr. Ne'eman responded to the first question, suggesting that it deals with risk adjustment and determining capitated payments. The acute care side is well developed by the formulas. It is important to get the assessment structure correct because the services that are

being used at the end of life are different and have different cost implications. All these factors have to be figured into the capitated payment infrastructure. Mr. Ne'eman continued that other measures have to come out of the DD community that has more experience with acute care and the elderly populations. He concluded that it makes more sense to use available waivers towards other populations. Dr. Spitalnik mentioned that there are no absolutes here, and different states construct their building blocks differently. She stated that whatever individual scores on their strengths or needs assessment, then states can make a decision on how much money they will assign to people in a particular way. Another point she made was that the recommendations that are being developed involve what kinds of assessments are being conducted. Finally, Dr. Spitalnik went back to the point raised by Ms. Weintraub about Medicaid and whoever is eligible for Medicaid, then Medicaid should be willing to pay. She asked the Committee to not only look at big systemic issues, like capitation, but also to consider the construction of what the individual will use in that system. Dr. Spitalnik mentioned that these should be meaningful recommendations about educating people and identifying places where the Committee would like advocates and stakeholders to be involved.

Mr. Ne'eman concurred with Dr. Spitalnik's comments and added that people would like the right kind of services that will increase their health and quality of life. There are few states, such as Oregon, that have two home community-based waivers and one for entitlement. Mr. Ne'eman emphasized that choice was never supposed to be one person or one time. He stated that the range of choice, when looking at research, is more significantly biased towards higher levels of choice and decision making at every single level of cognitive disability. Mr. Ne'eman noted that it is important to build the structural arrangements and legal rights to ensure people have the opportunity to experience choice and self-determination on a daily basis.

Ms. Rivera asked Mr. Ne'eman what would be his three wishes that the Committee could accomplish. Mr. Ne'eman cited his three wishes as follows:

- That the Committee will deliver to CMS a clear message about what this community wants and does not want. The Committee needs for CMS to be vigilant so that they can ask hard questions, and CMS needs to understand and advocate the Committee's priorities;
- that the Committee promote and support active engagement of the ID-DD community in state level discussions on managed care; and
- that the Committee understands that it is critical to involve self-advocacy groups; particularly, around quality and choice.

Ms. Wheeler referred to remarks made by the first speaker, James Toews, who suggested that the new area of managed care is complicated and that people cannot depend on typical groups to handle this on their own. She continued that Mr. Toews spoke about advocacy organizations needing to reach out to actuarial and insurance people. Ms. Wheeler asked Mr. Ne'eman what was his understanding on this; and does the Committee need to be mandating new bodies to make sure this happen? Mr. Ne'eman replied that there is a real opportunity to engage with the larger healthcare advocacy community, and look beyond the disability community. Replying to the second question, Mr. Ne'eman suggested that the Committee needs to consider the P&As and the availability of supplementing funding.

Ms. Quirk asked what is the difference between managed care and fee-for-service in terms of outcomes. She presented two scenarios on different individuals who will be affected by the services, and wondered which will be better for them. Finally, Ms. Quirk commented that the choices are different for each individual. Mr. Ne'eman responded that one of the challenges in fee-for-service system is that there is not a huge incentive on the part of the provider. He mentioned that the main financial incentive is that providers are driven by more than just financial services – the main way is to find a way to bill services. Mr. Ne'eman pointed out that the disadvantages are that the cheapest provider would be chosen, and people will be pushed into restrictive settings. He noted that engaging with the person's family is the best way, so that the family can provide support. Mr. Ne'eman concluded that both sides of the equation need to define outcomes as well as how individuals shift from a system in which individuals pay for services that are provided to a system that people pay for quality of outcomes that are delivered.

Mr. Ne'eman noted that it is possible to build in strong incentives for community integration, de-institutionalization, and addressing concerns of the immediate aftermath of de-institutionalization. He made it clear that his concern is hybrid systems. Mr. Ne'eman explained that HCBS system take into account managed care and leave the institutions and/or fee-for-service because this will mean that MCOs will have incentive to take the least expensive people to serve, and push people who are costly into institutions where they will be under fee-for-service. MCOs will not be responsible for those people. He concluded his presentation by noting that the continuum of services in the residential services is very important, and suggesting that including a population into managed care may drive de-institutionalization.

Dr. Spitalnik reminded members that people want, need, and have the right to live in the community, and that managed care can be a tool for rebalancing systems. She continued that if the Committee agreed that community living is important, then it can advocate for institutions to be part of managed care and that money can be reinvested into the community. Commissioner Lewis agreed and stated as the Committee moves further along into the report discussion, this can be talked about further. Ms. Petty wanted to know if Mr. Ne'eman agreed that managed care was more about outcomes. Mr. Ne'eman responded that it depended on if it is a bad managed care system or a good managed care system. He reiterated that managed care is an administrative vehicle. Mr. Ne'eman mentioned that a good managed care system can do things that current fee-for-service cannot, and a bad managed care system will lose things that people have gained in the current system. Ms. Petty asked for an example of this and stated she is not familiar with what this looks like. Mr. Ne'eman commented that quality should be a factor in the managed care contract. He stated that at the end of the day, it is matching money and it all comes down to outcomes.

Ms. Hillman de Velasquez asked if Mr. Ne'eman could address issues of legal capacity; she recognized that people have the right to be supported in their decision-making process, and that this will eventually turn away from a guardianship system. Mr. Ne'eman responded that he would be in favor of supported decision-making system. He mentioned that HCBS would prioritize greater decision-making power, including for people who have cognitive impairments or those who struggle with communication. Mr. Ne'eman stated that research shows that smaller residential settings provide more choice and decision-making at every single level of ID. He concluded that right kinds of supports are needed in a value-neutral way to be delivered to the supported decision-making properly. Ms. Hillman de Velasquez commented that reforming state guardianship laws is what is needed most. Mr. Ne'eman provided one example of these specifics

to Ms. Hillman de Velasquez's point. He explained that, in September 2011, an informational bulletin stated that the CMS stated that people have to differentiate between group-supported employment and individual-supported employment. Mr. Ne'eman introduced a new service definition called career planning which is a kind of support that people are going to be requesting if people moved away from a system that does not recognize people's employment options.

Prioritizing Focus Areas of 2012 Report to the President on Managed LTSS

PCPID Members

Commissioner Lewis stated that the Committee needs to identify central themes that the members would like to consider for developing recommendations in the report. She stated that each citizen member would provide two main ideas and then staff would record big themes and secondary ideas. Commissioner Lewis noted that the secondary list should be 10-15 themes that so that smaller groups can work on it later in the afternoon. She reiterated a point that Mr. Ne'eman mentioned that the Committee does not need to repeat any recommendations that NCD have proposed or duplicate any other reports that have already been published.

Dr. Spitalnik pointed out that some ideas need to be referred to from the NCD report. Commissioner Lewis agreed and clarified that if the Committee ended up with ten principles that everyone needed to follow, then collaboration may be done with another independent organization. She strongly suggested that the analogy of "train-has-left-the-station" is not a productive recommendation. The Commissioner stated that managed care is a fact of everyone's life, and the Committee will have to use managed care systems as a tool so that systems can be more effective. She repeated the process that everyone will state his or her two broad themes and then everyone will break for lunch.

Ms. Petty asked if there is already NCD data on managed care LTSS. Commissioner Lewis answered that yesterday; speakers spoke on data and qualities that are not similar to the acute side. She continued that there are different measurements that are used such as National Core Indicators or the caps tool used by CMS and these measurements are not a consistent data source for long-term supports and services. Ms. Weintraub added that the core indicators and personal outcome measures are two tools that the Committee should consider. Commissioner Lewis agreed and added that national core indicators can be used for one set of things and then there are different kinds of indicators that can be useful for quality.

Chairman Brett shared two themes that he has been listening to: consumer protection, and ombudsman language. Chairman Brett concurred with the Commissioner on the theme of good quality measurements, which are nonexistent at present time.

Dr. Spitalnik mentioned her two recommendations are: 1) the importance of understanding these types of issues and the importance of these issues to people with ID, their families and others; and 2) the complexity of these issues and making them accessible. She emphasized the need for participation of self-advocates and their families in decision-making and planning at every level.

Mr. Bell mentioned his two recommendations are keeping it simple and maximized choice/options. Lastly, he added that measurements and outcomes are important too.

Ms. Petty mentioned her two recommendations are people should have control over their own choices, and everyone needs support. She also suggested that direct support workers should have a meaningful wage and career.

Dr. White-Scott mentioned her two recommendations are: education, and consumer protections. She also pointed out the importance of having an independent ombudsman that is separate from the federal government.

Ms. Ramirez concurred with others on the use of simple language. She mentioned a type of guide to provide self-advocates and families in terms of dual process and their rights as well as communities of color to address a sense of urgency to make sure that linguistic and cultural barriers were removed. She noted that it is difficult when different states have different standards, and she would like to see some guidance on acquiring one national standard.

Ms. Weintraub mentioned her two recommendations are simple language and choices.

Mr. La Mell mentioned his two recommendations are: to stop managed care, and the need for an independent, third-party evaluation of each state's results.

Ms. Sugarman mentioned her two recommendations are: real choices, and lifelong continuity of services.

Ms. Hillman de Velasquez mentioned her two recommendations are: highlight competence, and incorporate a supported decision-making model.

Ms. Quirk mentioned her two recommendations are: a qualification on measurements of success while addressing the impact on family, and that this movement be related to IDEA transition planning.

Ms. Wheeler mentioned her two recommendations are importance of accessibility of the Report and asking the CMS to make some requirements when it comes to setting basic standards for state plans.

Dr. Anderson mentioned her two recommendations are: broad based education for stakeholders to understand the concept of managed care, long-term supports and services, and their direct involvement in the implementation of managed care; and that the Committee members listen to self-advocates.

Mr. Boatwright mentioned his two recommendations are: variety of choices without limitations, and a mechanism to protect the self-determination of the individual.

Ms. Edelson mentioned that her two recommendations are: keeping all the choices on the table, and consumer protection and quality; and emphasis on the development/education of direct support professionals.

Ms. Hardiman mentioned her two recommendations are: avoid medicalization, and reinvest in services for people.

Dr. Spitalnik admonished that the Committee leapt over healthcare and focused only on long term supports. She emphasized the importance of healthcare and blending meaningful supports to promote participation. Ms. Weintraub mentioned the importance of “nothing about us without us” meaning self-advocates should be involved in this process. Mr. Edward Anthony, Department of Education ex officio representative, responded by adding transition, the Individuals with Disabilities Education Act, and employment per Rehabilitation Act, which also adds to choice and consumer choice. Ms. Rivera added that a robust public engagement model is of importance. Ms. Brooks added that collaboration should be a key factor in this discussion. Commissioner Lewis commented that there are 18 broad themes and that the Committee does not have the capacity to have that many workgroups. She asked if anyone was willing remove his or her ideas from the list.

Dr. Spitalnik asked if the Committee could take the time during lunch to look at the list and consolidate ideas. Commissioner Lewis agreed and suggested if anyone has any suggestion on the list that may be a secondary theme. Dr. Spitalnik requested that her ideas might be put in the preamble or introduction that highlights the importance of these points. Dr. White-Scott mentioned cultural competence should be underlined in anything the Committee does. Commissioner Lewis stated she has post-it notes and then everyone will get into small groups after lunch.

Ms. Weintraub asked if removing “nothing about us with without us” is an elementary discussion. Commissioner Lewis interjected that this idea has been implemented with meaningful participation and engagement. Mr. La Mell said he would remove his idea. Ms. Hardiman suggested stating it in another way. For example, Ms. Hardiman offered the lack of data that exists. Ms. Quirk pointed out that she sees five clear themes: choice – participatory decision-making, person centered planning, choices without limits, quality measures, oversight/self-advocacy involvement, education and communication, and state/local implementation. Commissioner Lewis agreed, and asked each member of the committee to take post-it notes and write two themes that he/she would like to see discussed in the afternoon. She stated that the goal is to have three workgroups. Dr. Anderson asked if the five themes (consolidated by Ms. Quirk) would be considered. Commissioner Lewis replied that everyone would vote on pieces they put forward.

(Break for Working Lunch)

Discussion and Deliberation Regarding Report Recommendations/Framework

PCPID Members

Committee members put forth the following four topic areas, with accompanying recommendations and suggestions, regarding the framework for the Report:

- 1) Ensure understandability of issues for people with intellectual and developmental disabilities and their families**

- Prior to preparation of the *2012 Report to the President*, there needs to be a dialogue of understanding of what the charge will be. There also needs to be a clear understanding of long-term services and supports for individuals with ID.
- Recommendations should be stated using simple and clear language.
- The Report should include a glossary of definitions that are comprehensible (508-compliant)
- There should be an exploration of alternative formats of information, such as the “companion document” used in the Committee’s 2004 Report. Websites, resources, DVD and/or persons who will explain MLTSS will ensure the understandability factor.
- The overall Report should include collaborations between federal partners and the CMS. The *PCPID 2012 Report to the President* should be “a living document.”

2) Ensure real choices

- Ensuring choices and options are an independent service. There are two large subsets: legal (i.e., rights to informed consent), and personal choice/self-determination.
- The legal side is honoring and supporting decision-making processes for people with ID-DD.
- The right to make mistakes and the concept of dignity is vital. Personal choice should include an individual choice for adequate providers. There should be ongoing coordination in supports and services that honors the person’s evolving needs.
- Ensuring continuity with the choice of provider(s) as reflected in contracting and network, including natural supports.
- Any information that be disseminated should include quality of supports and services. The information conveyed in the Report should be available and accessible in various formats (e.g., Internet, phone, and by the use of assistive technology).
- Language access should be available so that the audience for which the Report is informed about managed care companies and activities they provide.

3) Consumer protection

- Quality indicators should be used as benchmarks to measure services and outcomes (based on person-centered planning).
- The federal and state governments should be separate from the MLTSS independent groups. The independent groups should include self-advocates and their families. There should be no conflict of interest.
- Two approaches should be used: 1) proactive, and 2) reactive. In the proactive approach, rules and data from quality measures should be reviewed. The reactive approach should highlight the development of a complaint department.
- An ombudsman should serve to ensure confidentiality (trainings should be provided to the ombudsman officer). The ombudsman should have a different role from the Protection and Advocacy Systems (P&As). The ombudsman and P&As should work together.

4) Participation of self-advocates and their families in planning at every level

Community level

- Ensure broad input from community members, including transparency of input and membership, who is invited, of how information is processed and included, and assurance that self-advocates, advocates, and family members receive support to participate, including alternative communication, transportation, and additional funding to make broad participation possible.
- Institute federal guidance that requires states to delineate how meaningful citizen involvement in developing the plan was obtained. There should be demonstration of citizen collaboration with the state in identifying priorities, including summary of the dialogue. Federal government could also suggest what a meaningful citizen involvement could look like.
- Submission of state plan should include documentation of the dialogue, of input, and consensual decision making through transcripts and/or minutes.
- Fund consumer groups to get involved in the process, maybe through Projects of National Significance. Emphasize the need for universal state-level financial support.

Individual level

- Adequate funding and to create flexible process to address needs and desires of the individual through a coordinated systems, development of individual plans, built in flexibility for change as a person's situation changes (e.g. a new housing option, a hospital stay), with a flexible rate schedule in plans that can adapt to changing needs and desires - persons input isn't relevant if there are no funds to support the expressed needs and desires - rethink the contracting process between states and providers to build in flexibility for this change.
- Conduct period review of the plan, supports, and services, to involve the individual, family and other significant people or organizations.
- Ensure a well-trained and competent workforce that is paid competitively to ensure a flexible system that is well implemented. Demonstrate the cultural respect for people with disabilities and the workforce through training and education for individuals and the professionals who serve them.

PCPID-AUCD Dialogue Regarding Report to the President

PCPID Members and the Association of University Centers in Disabilities (AUCD) Representatives

Dr. George Jesien, AUCD Executive Director, indicated that the PCPID meeting has been a learning/growth experience for him. He pointed out that PCPID and AUCD should collaborate to prepare and submit a report to the President that can make everyone proud. Dr. Joe Caldwell, Author of the *PCPID 2012 Report to the President*, shared with the Committee that the *PCPID 2012 Report to the President* needs to be delivered to the White House at the end of February. He emphasized the importance of having concise framework as well as recommendations. Dr. Caldwell requested that the members always submit their comments/suggestions to him through PCPID staff (Laverdia Taylor Roach).

PCPID Chairman, Jim Brett, entertained a motion to adjourn the meeting. Ms. Weintraub made the motion. Ms. Hardiman seconded it. The motion passed unanimously. Chairman Brett announced that the meeting was adjourned.

Action items:

PCPID Staff:

- 1) Share the informal notes taken during the meeting with the Committee members by Tuesday, October 23, 2012.
- 2) Convert the meeting transcript into minutes by Monday, November 19, 2012.

Committee Members:

- 1) Submit their travel invoices and receipts to the PCPID Budget Officer within three business days after the meeting.
- 2) Communicate with the author of the *PCPID 2012 Report to the President* through the Committee's Senior Advisor, Laverdia Taylor Roach.
- 3) Submit any suggestions and comments to PCPID Senior Advisor.
- 4) When interested, request that the PCPID staff invite Mr. Ne'eman to hold a session on the NCD plan around 14(C).