

Summary of Proceedings - October 8, 2008
Most Integrated Setting Coordinating Council (MISCC) Meeting

MISCC Meeting Participants

Diana Jones Ritter, Chair

Commissioner, New York State Office of Mental Retardation and Developmental Disabilities

Deborah VanAmerongen

Commissioner, New York State Division of Housing and Community Renewal

Nancy White Martinez

Director of Strategic Planning and Policy Development (representing Gladys Carrion, Commissioner, New York State Office of Children and Family Services)

John Allen

Special Assistant to the Commissioner, New York State Office of Mental Health

Dr. Rebecca Cort

Deputy Commissioner, VESID (representing Richard Mills, Commissioner, New York State Education Department)

Dr. Edward Placke

Assistant Commissioner, VESID

Marcus Harazin

Deputy Director (representing Michael Burgess, Director, New York State Office for the Aging)

Jane Lynch

Chief Operating Officer, Commission on Quality of Care and Advocacy for Persons with Disabilities

Mark Kissinger

Deputy Commissioner (representing Richard F. Daines, MD, Commissioner, New York State Department of Health)

Ron Epstein

Director, Statewide Policy Bureau (representing Astrid C. Glynn, Commissioner, New York State Department of Transportation)

Bill Panepinto

Director, Bureau of Housing & Employment Services, New York State Office of Alcoholism and Substance Abuse Services

Public Members

Patricia Fratangelo

Executive Director, Onondaga Community Living

Karen Oates

President and CEO of the Mental Health Association of Rockland County

Kimberly T. Hill

Director of NYS Assembly Task Force on People w/Disabilities

Mathew Mathai

Representing Harvey Rosenthal, NY Association of Psychiatric Rehabilitation Services

Commissioner Ritter welcomed everyone to the Most Integrated Setting Coordinating Council (MISCC) meeting.

Commissioner Ritter stated that today at sundown begins Yom Kippur, and it was the only date that could be arranged for this meeting in this room, and she noted that some people may not have been able to attend because of this. She apologized for that calendar challenge.

Commissioner Ritter hoped that they would view in on the webcast and will send along their comments on the MISCC Draft, and hoped people still feel that they are valued and embraced and were part of the process.

Commissioner Ritter introduced Michael Seereiter from the Governor's Office; she commented that he was a friend to the MISCC. She stated that Michael Seereiter has not missed a meeting and she is happy to have the Governor represented by him.

Commissioner Ritter stated at the last MISCC meeting that she had a mission to transform human services so that persons with all disabilities have the same opportunities to live with dignity in their home community as the rest of the residents in the community. She stated, under the leadership of Governor David Paterson, that MISCC continues that mission and dedication to the mission with increased energy.

Commissioner Ritter stated that the MISCC's commitment was to pickup the ball and move it forward; and to have progress on facilitating and implementing the intent of Olmstead and the principles therein.

Commissioner Ritter stated that she is excited that the Council has demonstrated commitment to this milestone meeting where we have worked together over the last year to bring together a draft report that shapes some of the things it has done and part of that is there is more work to be done and more progress to be assured and that the Governor is awaiting results. She noted, the Legislature will use this report to understand what the MISCC has been doing given the fiscal environment, and where it is going.

Commissioner Ritter stated that each of the member agencies has reported on its internal progress. Each agency report also delineates its stakeholder group, which is there to advise each agency as it develops, implements and annually updates its most integrated set of implementation plans. She stated many of the member agencies have a long history of advocacy participation in planning and in implementation of policy. She noted, some agencies like the Department of Transportation are more bricks and mortar related, and have not had the same experience but have been aggressive in taking steps to establish stakeholder input so we all did not start at the same place but we are certainly moving in the same direction.

Commissioner Ritter said the Draft MISCC Annual Report includes the report of the three MISCC Committees established to tackle cross-systems issues related to Housing, Employment and Transportation.

Commissioner Ritter commended Deborah VanAmerongen, Commissioner of the New York State Division of Housing and Community Renewal for her staff's report which was excellent and for the fact that it was submitted on time.

Commissioner Ritter stated over the next five to six weeks the Council will be seeking feedback on this Draft Plan. The report was posted on the MISCC website for review and comment. She noted it will also offer paper copies of the report to those who do not have access to the internet and will provide Braille copies, courtesy of OCFS, to those who need it.

Commissioner Ritter commented on the severe stress of the State and the nation's financial condition which will clearly impact every aspect of what is done in New York State and what is done in governmental operations.

Commissioner Ritter stated that she believes the Council can still move forward towards making certain that the intent of Olmstead, and the principles committed to, are underlying the movement in the agencies going forward. She noted, the importance of getting stakeholder input, particularly now under these tight fiscal conditions. The MISCC should continue to get input and understand the challenges of people with disabilities and what the barriers are. Particularly, what are the priority needs? "While going forward, we will be tasked as agency leaders to set priorities to look at tightening our belts but to preserve the principles of this administration's Governors' commitment", she said.

Commissioner Ritter stated that she thinks that all of us have done that due diligence but we need to continue to do it and by asking the stakeholders, the people who are recipients of our programs and services what they think we could do better and where they think we could be more efficient and how we still can achieve more with the resources that we have.

Commissioner Ritter said that today we will spend the bulk of our meeting discussing the report submitted by the Housing, Employment and Transportation Committees. She affirmed that the MISCC Plan will be completed and submitted to the Governor and the legislature by December 16, 2008.

Commissioner Ritter announced that the first MISCC Agenda item we have will be a presentation from the Office for the Aging regarding its stakeholder group. She noted that there are some handouts that have been provided by them at the registration desk.

Commissioner Ritter stated it is important to note that we were committed to making sure that each member agency took time on the MISCC Agenda to discuss their stakeholder group, and when this presentation is done we would have completed the

first round. Commissioner Ritter stated she thinks that too is an important milestone for celebration.

She said once again the constituent discussion period has been moved to the end of the MISCC Agenda so we can receive feedback on their expectations and context of this draft. Commissioner Ritter reiterated for those present who don't know, there is a sign up sheet at the registration desk for those who are present and would like to speak. She pointed out that since we have so many people requesting to comment, we will be limiting remarks so we can have as many people speak as possible.

Commissioner Ritter noted that if you do not have time to speak, your comments can be made through the opportunities we have for each of our agencies and on our websites for comments and you can write directly to her with any comments you have.

Commissioner Ritter introduced Marcus Harazin, who is representing Michael Burgess, to present the Office for the Aging stakeholder report.

Marcus Harazin stated due to the time constraints he will present the highlights. He noted each of the agencies was required to use each of the principles of the MISCC to examine its program. As was discussed at prior meetings, NYSOFA, because of its broad mission of working with elders and their family members, chose the area of caregiving as the focus of its examination.

Harazin reported caregivers and family members supply the long-term care needs of persons who are disabled in the community. He noted also the recognition of demographics of the growing number of older persons and a shrinking number of caregivers of working age is going to drive New York State to examine what it is doing in the area of caregiving.

Harazin noted that they found the MISCC guidelines and framework useful when looking at their caregiver program. He noted that the handouts on the registration table are available on their website at www.aging.state.ny.us. He pointed out that the handouts included the following: *The Caregiver Toolkit, Resources for Caregivers in New York State, NYS Caregivers Elder Support Program and NYSOFA Caregiver Initiatives*; and that these handouts provide a broad overview of what NYSOFA is doing in the area of caregivers.

Harazin stated that NYSOFA provides funding for 59 area agencies on aging through the National Family Caregivers Support Program. He said NYSOFA has State funding for a limited number of caregiver resource centers across New York State. As approved in the Budget, NYSOFA is going to be implementing a Regional Caregiver's Center of Excellence.

Harazin noted that in addition to the MISCC another State level policy group, the Family Caregiver Council, has been meeting since last year to develop

recommendations for the Governor regarding caregiving. He noted this group represents caregivers of all ages and will be making recommendations for policy that is problematic. He said the MISCC process comes at a good time for NYSOFA and it can feed into this policy initiative as well as into its program development initiatives. He said the tack that NYSOFA took with this was to involve stakeholders with its Family Caregiver Council. Using the principles of MISCC, NYSOFA had the requirement that 50 percent or more of that council be caregivers themselves. Harazin noted that has been truly helpful with the dynamics of those discussions.

Harazin stated for the purposes of this assessment NYSOFA was looking at the caregiver process. It involved a wide range of stakeholders from across the State which included consumers and consumer advocates as well as some of NYSOFA's network of area agencies of aging and community-based providers, and had them systematically go through using the principles of the MISCC, to look at NYSOFA's assessment processes for working with families that it uses to assist the agency to develop care plans and service development. He noted the agency has garnered quite a few recommendations through that process.

Harazin stated that based on the input from stakeholder groups, that NYSOFA decided to do a couple of surveys:

- survey of the providers that are within the system to find out what's going on; and
- a random survey of caregivers themselves.

Harazin noted that the results of those surveys will be coming out in November and NYSOFA will share them with the MISCC. He shared with the group that the surveys will provide the demographics of who the agency serves, average age, etc.

Harazin spoke about NYSOFA and DOH's participation in the New York Connects Program, which provides access to systems for Long Term Care. He states that each one of those programs have a council at the local level and NYSOFA interviewed providers to find out their awareness is of caregiver services and how to access the services.

Harazin shared with the MISCC that NYSOFA recently received a grant from the Administration on Aging for nursing home diversion along, with its partners from the Department of Health, which will be testing some consumer-directed models to help divert people from nursing homes.

Harazin shared the data that, under the Federal Caregivers Act, NYSOFA serves 20,000 caregivers annually and at least 1,000 are grandparent caregivers caring for children. He noted \$15M is spent on that caregiver initiative, which provides respite care, supplemental services and a variety of services to help a person remain independent, to sustain caregiver information and assistance, as well as counseling

and support groups. He thanked the MISCC for the opportunity to present at today's meeting.

Commissioner Ritter asked if there were any questions and stated she would like to have the NYSOFA survey results on the upcoming agenda.

Commissioner Ritter introduced Commissioner VanAmerongen.

Commissioner VanAmerongen thanked everyone for the opportunity to be there today. VanAmerongen thanked Commissioner Ritter for the credit given but she noted that the credit really goes to the people who spent a lot of time and effort putting the report together over the past 18 months; she wanted to recognize Lorrie Pizzola, Lisa Irizarry and Maureen Freehill. She thanked them for all the work they did and stated if DHCR's report looks good, it's all due to them. Commissioner VanAmerongen thanked Carl Letson for his help and leadership in putting together the report. She stated it was very helpful for us to have input on format and to keep DHCR on track in terms of the preparation of the report.

Commissioner VanAmerongen gave the Housing Committee report as provided in the Draft MISCC Annual Report. She noted as a MISCC Committee it has tried to be goal oriented and to incorporate its objectives into the everyday work of the respective agencies and organizations.

Commissioner VanAmerongen stated that in previous reports she has shared the work of the Housing Committee and some of the steps taken at DHCR to ensure accessibility and opportunity for both supportive and accessible housing. She stated the Committee asked itself how it could apply itself in a way that relates to the tangible challenges in its own programs and policies. She reported from the first meeting, the Committee discussed its individual understanding of what is the most integrated setting and what does it mean to the members of the Housing Committee and from that it formed a mission statement.

Commissioner VanAmerongen stated the Committee believes the MISCC Plan should focus on realistic outcomes that can be achieved and as Commissioner Ritter has noted, and the group took it as its charge, that there is a very difficult financial environment that we are operating in and these challenges continue to grow. She said the Committee is trying to relay objectives that are truly obtainable. The Committee also tried to structure recommendations that are succinct, and formatted in such a way to identify clear performance measurements. The Housing Committee will hold itself to these standards and are asking for the help of all agencies who have been members of the working groups to help the Committee to achieve all the goals that are in the report.

Commissioner VanAmerongen noted the three working groups; Housing Subsidy, Data and Education. She commended those groups and particularly Shelly Nortz

from the Coalition for the Homeless and her co-chair Michael Newman from OMH. She noted they worked tirelessly and she thanked them for all their efforts.

Commissioner VanAmerongen introduced Shelly Nortz to present the Draft Report for the Housing Subsidy Workgroup. Commissioner VanAmerongen stated she wanted to share DHCR's time with Shelly Nortz. She said that the Housing Subsidy Workgroup took their charge very seriously and worked very hard over the past several months.

Shelly Nortz referred the group to Appendix A of the MISCC Draft Report for the Housing Subsidy Workgroup. Shelly noted the findings on Page 186 speak for themselves and they are worth reading. Nortz stated it reflects that there is a major crisis in the area of housing for people with disabilities in New York State and that is costing the State of New York enormous sums of money.

Shelly Nortz stated those costs could be addressed through housing subsidy recommendations that the group came up with, which were aimed principally at that goal.

Nortz briefly overviewed the Housing Subsidy Workgroup to the MISCC and thanked everyone for their time and interest.

Commissioner VanAmerongen thanked Harvey Rosenthal who led the Data Workgroup and Vera Prosper who led the Education Campaign Workgroup.

Commissioner Ritter asked members if there were any questions or comments.

Mathew Mathai thanked the Commissioner VanAmerongen for the wonderful report and stated that it focused on something he wanted to highlight, in particular, which is the data collection. He stated that the priority to determine what unmet needs are and, from a grassroots advocacy perspective, that it is meaningful information that is needed to know who gets what and to determine if progress is being made. He noted a real Olmstead Plan would do that. He said he was happy to see the data, regulation and finance noted in the report.

Commissioner VanAmerongen stated that DHCR were not the holders of most of this information and that they were glad to work with other agencies.

Bill Panepinto stated he was very grateful and excited in the recommendation to bring the Office of Temporary Disabilities Assistance (OTDA) to both the Housing Committee and the broader MISCC. It is really important for OTDA to be able to contribute and be part of the dialogue especially around homelessness and risk-to-homelessness for people with disabilities.

Dr. Karen Oakes thanked Commissioner Ritter for the work that she has done. Dr. Oakes wanted to commend Commissioner Ritter on the format of the report and what she incorporated into it.

Commissioner Ritter introduced Dr. Edward Placke from SED/VESID to report on the Employment Committee. Dr. Placke thanked her for the opportunity to Chair the Employment Committee. He stated he wanted to thank Joanne Bushart from OMRDD as Vice-Chair who was intricate to the process. He also wanted to acknowledge Frank Coco from VESID, who played an incredible role in regard to technical support towards developing the final report.

He commenced by noting that there were two concepts that drove the Employment Committee's work:

1. Unemployment rate of people with disabilities which currently is at 66 percent and has grown over the last ten years; and
2. Without work, you do not have dignity.

Dr. Placke stated that the MISCC needs to make the commitment to the people of New York State that it will close that employment gap and will find jobs for people with disabilities because they can be a large part of the workforce.

Dr. Placke outlined the common values established by the Employment Committee:

1. All individuals with disabilities can work with the correct amount of support and guidance; and
2. Work is normative and an expected activity of New Yorker's with and without disabilities. The preferred option is integrated employment, working shoulder to shoulder with workers who are not disabled.

Dr. Placke said the Employment Committee identified five recommendations/outcomes for collaborative opportunities for a more effective way to provide benefits to individuals with disabilities while they are engaged in work activities:

1. Benefits -- looking at enhancing the infrastructure for benefits and work incentives;
2. Marketing -- letting employers throughout New York State know that people with disabilities make excellent employees;
3. Focusing on reviewing the data and funding; and looking at retrofitting funding from segregated environments to more integrated environments;
4. Looking at 55a, 55b and 55c programs and how do to enhance those for people with disabilities who qualify for those programs; and
5. Because individuals with disabilities have multiple needs in regard to employment, a single portal to access services needs to be established.

Dr. Placke stated those points essentially became the driving force for the Employment Committee. He noted that the goal was to close that gap of the more than 30 percent of adults with a disability who live in poverty in New York State.

Dr. Placke noted that the Education Committee membership is 40 strong, with representation from across New York State. He said it consists of stakeholders from consumer groups, advocacy groups, statewide organizations, including community rehab groups, independent living centers, public schools, colleges (both four and two year) as well as businesses, State agencies and trade associations.

John Allen (Office of Mental Health) thanked Dr. Placke and the Employment Committee for its assistance, and all the agencies, in helping to put together the Medicaid Infrastructure Grant Application. He noted that it was a huge task that everyone participated in and that Dr. Placke's leadership was very helpful with getting the Employment Committee behind it.

Commissioner Ritter commended the Employment Committee for getting alot done in a limited time.

Commissioner Ritter introduced Ron Epstein, DOT, to provide the Transportation Committee report. Ron Epstein thanked Commissioner Ritter for putting together the report and that there was a lot of excellent information for all the agencies to review.

Ron thanked the Transportation Committee and commented that they had some long and strong deliberations over the topics. He commented that while the Transportation Committee report doesn't represent everything to everybody, he thought it is a very sincere start to a long process that will address the recommendations put forth today.

Epstein stated that one of the next steps he sees with moving forward is the expanding participation. He stated OTDA is one of the agencies that administer funding for transportation for low-income individuals. He commented that OTDA is seen as a natural fit for the Transportation Committee and he would like to bring them in. He noted as a result, the Transportation Committee would be restructured as it moved forward.

Ron Epstein stated DOT is not a traditional health and human service transportation-related agency. He shared with the MISCC that he has dealt with an older individual (parent) who had both cognitive and physical disabilities and did not live locally. He said on a personal level he can understand the separation of family, the loss of community, and understands the barriers personally and that is what is guiding some of his judgment.

Ron Epstein reviewed the Transportation Committee report as provided in the Draft MISCC Annual Report. Ron noted the Transportation Committee mission statement. He said the Committee is committed to promoting and advocating for the

accessibility, reliability and affordability of transportation alternatives for individuals with disabilities. He reviewed the following Transportation Committee findings:

- Effectively leveraging of federal, State and local funding for health and human service transportation. He stated the Committee needs to develop a comprehensive health and human services transportation policy at the State level;
- Without reliable and accessible transportation services, individuals with disabilities are faced with a diminished quality of life and there is a need to focus on programs that eliminate the service gaps; and
- No one type of delivery methodology supports transportation solutions. He stated a varied transportation network is needed that can meet the requirements of individuals with disabilities.

Epstein stated what the MISCC is trying to do is to provide greater economic independence, healthy living and an improved quality of life. The Transportation Committee selected three recommendations this group should embark on immediately.

1. Establish a person in each agency, a transportation czar, who will become the point of contact for knowledge on the programs that are delivered in that agency which have transportation benefits. Because transportation itself is not the core function of many agencies, it is imbedded in the service delivery mechanism and perhaps it is not broken out individually in a way to identify costs or other issues. The transportation point person, ("czar"), could help the Transportation Committee to understand the intricacies of each agency's transportation programs, the revenue streams that support it, and help the Committee have insight on how it can better consolidate, coordinate or effectively disseminate information on those programs.
2. There is a private-sector component to this as well that could be publicly supported, which is accessible taxis. The Transportation Committee believes that accessible taxis are essential to addressing the transportation gaps that exist and especially some of the gaps in the Americans With Disabilities Act. The Transportation Committee is recommending that a bill be developed that combines the civic milestones and incentives to mainstream the deployment of accessible taxis and private taxi fleets. The Transportation Committee thinks it will add to the sense of community and the dignity that will be needed to travel where and when they need too.
3. Providing the incentives necessary on a local level to establish a mobility manager or a health and human services transportation coordinator in each county, somebody to improve the availability, accessibility of transportation services, while still maintaining and maximizing choice. The Transportation Committee foresees that a mobility manager would work with the individual to obtain services, that best meet individual's needs, and can be provided in the most efficient way as possible.

The Transportation Committee noted other recommendations:

- Public transportation paratransit services -- there needs to be review and recommendations made to the federal government on how this can be done in a way that provides a greater benefit to all.
- It was also determined that there needs to be more sensitivity training in the public transportation sector regarding the transportation needs of disabled individuals.
- Regarding transportation that specifically relates to employment services, the Transportation Committee will develop future recommendations that will help leverage some of the low income and employment related services that are available to better serve the needs of individuals with disabilities.

Ron Epstein extended thanks to the staff involved; Matt Haas, Tom Vaughan, Jen Simpson and Carl Letson.

Commissioner Ritter thanked Ron Epstein for his presentation and asked if there were any member comments.

Dr. Karen Oakes reiterated the importance of transportation. She stated that a local human service person would be great in counties where there is a point person to talk about rate reimbursement, etc. She said that DOT and Epstein's efforts are key to the provision of services.

Commissioner Ritter stated that the MISCC was going to expand on the Transportation Committee representation. She asked all the member agencies to ensure that if there are others that want to join the group they can and to make sure advocacy groups are represented as well.

Commissioner Ritter thanked Ron Epstein for what he brought to the MISCC.

Commissioner Ritter requested that due to the large number of people who signed up for speaking to limit it to three minutes to respect everyone's wishes to speak. Commissioner Ritter stated we are looking for comments on our MISCC deliberations, our progress-to-date, and specifically comments on what you have seen or heard about in the Draft MISCC Annual Report.

Commissioner Ritter opened the public comment portion of the Agenda.

Matt Canuteson from NYAPRS wanted to thank John Allen and Joe Swinford for their hard work in putting all the recommendations that came from the OMH stakeholder groups into the report. He stated he appreciated the proposals in the report that focus on data collection in housing, employment, regulatory changes, and specifically in the use of person centered plans to overcome funding obstacles to employment. Lastly, he said, in moving forward with the current budget situation and

encourages us to redirect resources from institutional settings into community based services.

Oscar Jimenez introduced himself as the Chairperson of the statewide campaign "We Can Work." He voiced his appreciation to the support of OMH. He stated "We Can Work" is a grassroots initiative for the purpose of building hope and capacity among people with psychiatric disabilities to achieve meaningful employment and true economic integration. He congratulated the enormous effort put forward in the preparation of the report for ensuring that employment is a priority to the MISCC. He stated the MISCC needed to ensure that data be available for the level of economic integration achieved by people with disabilities in New York State. The group knows that more than two-thirds of individuals with disabilities are unemployed, more than one-third lives in poverty, and many people who are employed work less than twenty hours per week in employment that is not meaningful to them such as the food industry and cleaning industry. He stated we also do not know how many people with disabilities are employed in lesser levels of integration as far as employment. We also do not know how many people are in sheltered workshops who would like competitive employment. He noted that many of those individuals feel trapped by the lack of additional supports. He said employment must stop being segmented or compartmentalized by silo vocational funded employment. He stated that people with disabilities can work and want to work and want to contribute to the economic structure of our State.

Commissioner Ritter requested that Oscar Jimenez submit a copy of his comments to Dr. Placke.

Kaseem Moultrie, Local 200 SEIU, identified himself as a family member of someone who is receiving disability services and he has concerns around the area of incident reporting. He stated he has been working in human services over two years and is concerned about the fact that numerous workers have been fired for reporting incidents to their employer in regards to abuse that they witness. He asked what can the MISCC do to enhance oversight and protect workers from being retaliated against by their employer when they are actually doing their jobs.

Lordi LaRouge, Medicaid Service Coordinator, stated through her job she is an advocate for the individuals she serves and she states she is here for them more than herself. She noted all of your work is to no avail if the direct service providers do not receive a living wage, if they do not receive benefits, and if they cannot keep their jobs long enough to follow through on the plans that have been set before them. She thanked the MISCC for their work and for how far they have come together, but it cannot be implemented by people making \$9.50 per hour.

Andrea Campbell stated that she used to work at Ulster ARC and after 10 years she had come to the realization that she could not afford to work there anymore and she became an employee for SEIU to try to advocate for those members to get a living wage and she noted that it was a sad thing that after ten years they lost a very

dedicated employee but that she could not afford to feed her three children on the money she made. She commented that State agencies get a lot more money and better benefits than the private agencies.

Bruce Darling, ADAPT stated that the Draft MISCC Annual Report was much more out of the MISCC since its inception. He noted that back at home with ADAPT's Board of Directors, which is a consumer-controlled board is struggling with the question what do we do as a Board, how do we function, how do we step up and what is our role. He noted one of the things they found was that one of functions of the Board is to provide a sense making opportunity for the staff. He said it's a time where the staff would stop and write a report explaining in some rational way what they are doing, why they are doing it, and where they are going. He stated the MISCC was developed to provide that sense making opportunity for the State agencies to focus on the fact that people with disabilities and seniors want to live in the most integrated setting and this is the opportunity for us all to step back and make some sense of what is going on around us. He wanted to applaud the MISCC because it is moving in a direction where it is beginning to make some sense of what's going on. He commended the honesty in the Executive Summary. He stated it was quite striking and something we have not seen previously from the State. He said we need to see more hard data, specific targets, timelines and what progress has been made. Bruce thanked the MISCC from the bottom on his heart for all the thousands of people locked into institutionalized settings. He stated thank you for moving this process forward and we stand with you in going forward.

Diane Coleman stated she just moved here from Illinois where she was working for the Director for the Center for Independent Living for about 12 years. She stated she was involved with the State Long Term Care Council, Money Follows The Person Advisory Council and spent a lot of time working on long term care. She stated she would like to bring up two points of comparison that she was able to find out about in her first two months. She was glad to see in the report the importance about consumer directed personal assistance program as a very important element of whatever we do and she really applauds that. She noted that there is something really good about CDP in New York State compared to the CDP in Illinois that the one in New York State is available to people of all ages; she noted that in Illinois it's available only to the working age community. She noticed that in New York State 10,000 people are in the CDP and in Illinois there are over 30,000. She said the other point of comparison is the really large roles for the Centers for Independent Living in community reintegration and transition work. She commented that the state of Illinois asked the Center for Independent Living to be the first transition providers over a decade ago. She stated after the first 900 people were moved into the community, at that point they were able to compare apples with apples about the cost in a facility to the cost for the same people living in the community. She said they found out that those first 900 people saved the State of Illinois 55m. She noted they increasingly acknowledged our expertise in doing this even though we did not have the educational degrees. She pointed out that when the aging community started working on the same thing they called it "Home Again" and they made the Centers

for Independent Living a mandatory partner with area agencies on aging to get the job done. She wanted to emphasize the way Centers for Independent Living can be a resource because that is what we are doing, living everyday in the community and figuring out how to make it work.

Gene Spinney, President for the Center for Disability Rights, commented that at the last MISCC meeting he asked for support on getting membership in our local Long Term Care Program and we still don't have that. He noted some efforts were made on their behalf but as of this date we still do not have representation. He also stated that he wanted to speak on unemployment for disabled individuals. He asked that regarding the Medicaid Buy-In he was looking for exemptions for people on the trial work period so they don't have to lose money. He stated there is no easy way around the system and would like to know how to fix it. He noted that sometimes it takes up to ten months to get on it.

Sue Stahl, ADAPT, indicated that she is a Consumer Representative. She thanked the MISCC for all their work in the Draft MISCC Annual Report and she was impressed that it was done. She said that her impression was that the MISCC was really doing nothing. She stated this report is showing her you are doing something and we need a way to inform consumers that with all this work in the end they can get out of nursing homes. She noted in the end they can get out of the group home. She felt the need for concise and simple ways to tell someone that if I use these services and I am eligible for these services, I can get them and they can help me get out of the nursing home. She said we need to remember that the most integrated setting is a wonderful concept but if you never simplify it to the person who is in the group home or nursing home, you are working very hard and not getting the point across.

Leah Farrell, Center for Disability Rights, wanted to commend the MISCC on the Draft Report and she felt it is definitely a great first step. She noted earlier she had passed out one of their position papers on reforming long term care services in New York State. She encouraged everyone to look at it. She said the next issue will focus on the most integrated setting. She commented that the goals set by the MISCC are fundamentally issues of civil rights. She said although we recognize the fact that every agency is under budgetary constraints, we don't want to see plans for more plans. She said we can't tell people in facilities that they have to wait for their rights. She stated we really need to get them out of institutions and keep them out. Forcing people into institutions to receive services is a form of segregation and discrimination. This is a civil rights issue for people with disabilities.

Terrie Lincoln wanted to reiterate on the consumer directed program. She shared with the MISCC that she moved to New York State from Ohio a year ago. She said it took awhile to get into the Medicaid Buy-In Program. She said that in Ohio she was in a traditional job program and at first they would send me aides that were elderly and could not lift and she would often be stuck in bed until her family or friends came over to help her. She said or they would go to the other extreme and send some young untrained aide who could not lift thirty pounds. Eventually she had to get her

family and friends to go into that program so she could have reliable care. She shared with the MISCC that when she moved to Rochester she was hooked up to a CDP Program where she got to manage, select and dismiss her own attendants at her will, and she gets to train them based on her care needs. She really appreciates the program and hopes that it is something everyone uses or will use.

Dean DeRusso wanted to thank the MISCC for having an interpreter at the registration desk and that it was very helpful. He stated he would like to request something to put his papers on because he uses his hands to communicate. Commissioner Ritter committed to providing a stand for the next meeting. He wanted to commend Dr. Placke for his Employment Committee presentation. He stated we want to integrate employment opportunities because right now there are a lot of people in sheltered workshops and people are still being isolated and that needs to stop. He said they don't have the social, recreational and political opportunities that non-disabled people have, so we need to stop that. He said the money that is being used for the workshops could be used for other services in the CDP Program. He said we need to look at 55a, 55b and 55c programs and he noted that Veterans that come back with disabilities get a higher rate of employment than people with disabilities. He stated that the CQCAPD program for the deaf, hard of hearing and blind said it was progressing and that they were looking at different issues. He said five people have been appointed and three people haven't yet been chosen. He asked the Governor's staff to look into it and get those three last appointments. He shared with the MISCC that we cannot forget the deaf and that this organization needs to focus on resources because the deaf are stuck in nursing homes as well. He thanked the MISCC for their work.

Frank Kimmes stated he was an advocate for housing for deaf senior citizens. He told the MISCC that he would like to see some help for the deaf American senior citizens and deaf people who are living in different parts of New York State who need a sign language friendly environment so they can meet other people like themselves and have a quality of life where they can sign and socialize. He said we need people who could help them coordinate services for the deaf and socialize with other deaf. He stated that these seniors have paid taxes and now is the time for them to get something back. He stated that he believes that the MISCC needs to advocate for housing for the deaf senior citizens. He thanked everyone for their time.

John Smaitis, Center for Disability Rights, stated he works in the Consumer Directed Assistance Program. He noted that to get people out of nursing homes that the housing is just not available and they can't afford \$900 per month. He stated that the DSS takes so long to assess the people that the waiting time is four to six months and it takes way too long. He stated the waiting list for a program right now is 45 to 50 people and it needs to get a lot shorter.

Rashem Broughton, Hiring Specialist at the Regional Center for Independent Living in Rochester, he wanted to comment on accessible, affordable and integrated housing. He stated he works with people on a day-to-day basis to try to find housing and the

problem they are running into is that there is just no accessible housing. He said sometimes people have to cut back on their medicine or personal care to get housing. He said landlords are often willing to put in wheelchair ramps but then we can't find the funding to get into the home. He noted when there is no funding for a wider doorway or a roll-in shower that is a problem we run into with accessible housing. He stated that when you only receive Social Security on a monthly basis you are not able to actually live in a good community where you don't have to worry about crime and drugs. He said there should be more affordable housing throughout the city and suburbs. He also wants integrated housing for people with disabilities just because we have to use four wheels instead of two legs we shouldn't have to be put in a certain quarter of the city or just be out of sight and out of mind. He said he wants to live in a community with everybody else and he wants to live next to able bodied people.

Hillary Cudmore stated she was a former employee of Schoharie ARC. She stated she was recently let go after reporting abuse that she witnessed. She would like to know what OMRDD can do about workers who are being retaliated against and to prevent retaliation cover ups. She shared with the MISCC that at the end of the investigation the report was unfounded even though a co-worker and I were witness to it. She stated that she believes that all investigations of abuse should be done by the State or an outside agency to protect the rights of the consumers so no staff or consumer needs to fear retaliation.

Kathy Stevens, Baker Victory Services, mentioned that she met Commissioner Ritter in June at the Millennium Hotel and she did keep a promise to me to give me a call about meeting with us and a SEIU union representative. She stated we have a lot of caring workers and we have high turnover problems. Commissioner Ritter agreed to visit their site sometime in the future.

Commissioner Ritter stated that this is about accountability.

Mike Lmigro stated that the Local 200 SEIU put together a public policy position statement on how future wage, benefit and retirement structures could be created for direct support professionals so they would have a stable employment situation in direct care settings because their employment situation is the living situation of the recipients of services to stabilize one you enhance the other. Lmigro stated he would like the position statement to be included in the final drafting of the 2008 MISCC Annual Report and have it included in Appendix C in the Employment Committee report.

Commissioner Ritter responded that he can forward it to her and we will consider it.

Josh Twedt Spoor stated for five years he has worked at the Schoharie ARC. He stated that they were severely understaffed and the workers are underpaid. He stated he works at a total support place where we take care of individuals who can't speak and many are profoundly mentally retarded and he thinks of them as family. He said

that the administration has taken the television out of the living room, taken away consumer outings because of short staffing and because they don't want to pay the workers. He stated you cannot afford to work at Schoharie ARC and asked the MISCC what they were going to do about this situation.

Catherine Hough, UGARC in Kingston stated she is a Resident Specialist for the past thirteen years. She stated she is finding it harder to do the work that is expected of her when she can go to Walmart's for the same amount of money. She said we have a large turnover of staff due to the fact that wages are so low and the benefits are so poor. She stated that everyone who was present today gives all they can give everyday and needs to be paid fairly.

Dawn Clary, Local 200 SEIU stated that in regards to transportation, the report did a lot to addressing some of the issues consumers face but it does not address the issues the workers face. She stated workers are forced to drive their own vehicles with consumers in them and sometimes with consumers who act out and it can become a very dangerous situation. She said wages are a huge problem and most of the workers that are here today are being paid just over the federal poverty rate wages, which are not getting reimbursed, and are working in an unsafe situation. There has to be some regulation we can work on in regards to that. She was impressed to see the Transportation Committee report was looking into rural areas in Upstate New York. She stated that many of the staff in the private agencies have stated that many consumers come out of school settings where they get one-on-one attention and they thrive; the short staffing in vocational training facilities; they no longer receive one-on-one attention.

Commissioner Ritter stated that workforce issues are challenging and the MISCC is aware of the impact. She stated in regard to the MISCC report there is a lot the Council has to do. For it to really support people in integrated settings, the agencies have to make sure they have the staff to support them in those areas. She said the MISCC could strengthen its report to ensure it is inclusive of the comments that were received from all today and the Council will take a look at how we are going to do that.

Commissioner Ritter said let's make sure we have the data, make sure we are measuring our progress and that's where we take the next level. She said we have this framework and that while it is progress, the Council has to build on it. She said we are all committed to measurable results in this area.

Commissioner Ritter stated that the unions will hold the MISCC accountable as well as other advocates who all along have been supporting, encouraging and demanding responses.

Commissioner Ritter thanked everyone who came forward. She noted that these are both challenging and exciting times. She noted challenging because the State is facing very uncertain financial times with the impact of Wall Street, and the national

finances which is creating a very uncertain environment. She stated there will be growing competition for very limited resources, which will require the MISCC to prioritize and listening to voices as we have heard today.

Commissioner Ritter stated it is exciting because of under the leadership of Governor Paterson, the MISCC has been reenergized.

Commissioner Ritter stated we will be moving forward to see how much more creative we can be about using the resources that we have.

Commissioner Ritter stated one of the items in the packet is a list of our MISCC meeting dates for 2009. The next meeting is scheduled for Monday, January 5, 2009, at 1:00 p.m. at the Empire State Plaza Meeting Room 6.

Commissioner Ritter spoke about an advocate at previous meetings who was frustrated about how long it took for someone who was living in a nursing to get out of the nursing home and to live in the community. Commissioner Ritter reported that the team got together and found there was more we could do and that by crossing systems and by working on the individual's needs, that there was something we could do and she held up a picture of the house that the individual will be moving into in March.

Commissioner Ritter thanked each of the members for working so hard to put together our first draft report and will be working on comments and getting them out to you for review. She said although we are not meeting until January 2009 we still have the December 16, 2008 deadline.

Commissioner Ritter asked for member comment.

Kim Hill wanted to thank Commissioner Ritter for all the work she has done since taking over the MISCC. She wanted to thank the advocates for all their years of putting the MISCC's feet to the fire. She stated she was hoping next year's meeting will have even more examples of people moving out of institutions.

John Allen wanted to echo Kim Hill and to thank her personally but also to her staff that graciously assisted other agencies who were not always cooperative with deadlines. He stated thank you for your staff and the leadership you have shown in this process.

Mathew Mathai congratulated the MISCC, Commissioner Ritter and everyone involved. He stated the theme of the next steps is about transparency and the willingness to be so.

Pat Fratangelo shared with the MISCC how a family who was given the power to find a home of their choice in their community for their disabled daughter, who was taking college courses, advertised for a roommate who was a college student and in

exchange for board provided assistance to their daughter. She stated this is how funding can be obtained and the individual can make the choices.

Commissioner Ritter adjourned the meeting.