

PUBLIC COMMENTS TO THE DRAFT 2010 MISCC PLAN

Comments from Individuals

1. I think that it goes without saying that since Commissioner Ritter has taken over leadership of the MISCC that we have taken gigantic steps forward. The fact that we have an initial plan is testament to that. For that, I am extremely grateful. However, those of us who have been with the MISCC since the start have great expectations for the content of this document. We have worked for too long for the complete data we need, yet still do not have. And unfortunately, while the plan contains many great sentiments, it is severely lacking in implementation actions and goals that are measurable. For example, one of the recommendations is to increase the number of people participating in the Nursing Home Transition and Diversion (NHTD) Waiver Housing Subsidy. This goal is admirable, but the plan contains no recommendations that specify how many more people we plan to move into the waiver, and by when. Without that information, there is no way to determine if we are truly moving more people into the waiver. Nor do we set up concrete goals for ourselves. And this is only one example of a recommendation that lacks a way to measure or monitor it. Without being able to measure our goals, we have no way of knowing how successful we will be. While I am thrilled that we have a plan to discuss, I really think that we do not go far enough to ensure that we will live up to our obligation to ensure that people with disabilities are living in the most integrated setting appropriate to their needs. I look forward to continue working with the many committed individuals who are a part of the MISCC to ensure that in the very near future we amend this plan to include concrete, measurable implementation actions and goals that will finally begin to move people with disabilities into integrated settings at a reasonable pace.
2. A most critical piece of the plan is a review of the direct care workforce. The shortage of workers will only worsen if efforts are not made by ALL entities to take action to improve wages and benefits, working conditions, and training. A key will be to eliminate the existing variations in training and certification of aides in favor of a certified Universal Worker. I urge the coordinating council to make this a major focus of their plan.
3. Well, my *initial* comments are that yes, it's a start, but how does that cliché go? "We've lost the forest for the sight of the trees" or something like that ... In the long term care realm, where DOH rules supreme, we have now relegated the MISCC's responsibilities to rest on the workings of the DOH stakeholder group. At the last MISCC meeting I brought up concerns about the fact that there is no MISCC focus on long term care – as there is for the other subcommittee focuses: Housing, Employment, Transportation. I expressed concerns of duplication of effort via the DOH stakeholder group. Commissioner Ritter and Commissioner Daines pointed to the work of the DOH stakeholder group. Whereas I've seen a

drastic shift in DOH's commitment to involving the *entire* DOH (previously the Office of Long Term Care was shouldering the burden) and have seen the development of subcommittees from the main stakeholder group – these are great improvements that can be the start of something worthwhile ... And yet, there is a distinct vision – a *12 month vision* – that is informing the process. No more, ... I know the email references a two year period ... There is also a clear understanding that it is not the stakeholder group's (or the subcommittees') role to create, contribute to, etc. a New York State Olmstead Plan ... that role is the main MISCC's responsibility ... So, if the MISCC is the *mothership* then the DOH is an integral crew member, I chose Spock, in ensuring the mothership doesn't crash – there is no way to divorce DOH's exclusive membership as part of the whole – and when it comes to the long term care arena – that's Spock's home planet ... My point is cautionary in the fact that what I liked about the Virginia Plan was it's 10,000 mile high / long range systems change perspective (and it was gorgeous in its level of specificity) ... I'm relieved to have *something* in writing – a starting point – but as much as it is a “plan” (small “p”) – New York State is still tasked with the development of an Olmstead Plan (big “P”) and our current process isn't necessarily going to do anything to get us there ... Which leads us back to the MISCC proper – as the oversight entity – the vehicle of change driving us through to the other side of institutional bias ... look, the bus won't move without a driver, fuel and a GPS ... we need to stay vigilant with our eyes on the prize! ...

Independent Living, Inc

MEMO

To: Commissioner Ritter, Office of the Developmental Disabilities Service
Office of New York State

From: Douglas Hovey, Executive Director, Independent Living, Inc.
5 Washington Terrace
Newburgh, NY 12550

Re: MISCC Draft Plan 2010-2011

Date: December 2, 2009

After having read the Draft Plan 2010-2011, while there is a great deal of inconsistency related to the plan format and irrelevant content (to Olmstead), particularly in the ‘implementation actions’, some of the big picture outcomes are laudable. Also noted, there seems to be a lack of understanding and consistency related to the creation of specific and measurable outcomes. While some of the big picture ‘goals’ are focused on Olmstead, the ‘outcome measures’ lack specificity and therefore are doomed to not succeed. We encourage the MISCC to edit the ‘goals’ into Strategic Goals and the ‘measurable outcomes’ into S.M.A.R.T. Objectives (Specific, Measureable, Aligned with Olmstead, Realistic and Time-Framed). Moreover, we suggest that the ‘implementation actions’ must be more specific and aligned with the goals and measurable outcomes and become agreements between a responsible agency/representative and the MISCC, and held accountable for following through by a

specified and agreed upon time frame. There needs to be a clear connection between the GOALS (STRATEGIC GOALS), MEASUREABLE OUTCOMES (SMART OBJECTIVES) and IMPLEMENTATION ACTIONS (AGREEMENTS).

Housing Committee – ‘goals’, ‘measureable housing outcomes’ and ‘implementation actions’ are in line with Olmstead in terms of the big picture and each is clear in what it intends to accomplish. However, each intended measurable outcome needs an implementation action that is S.M.A.R.T. – Specific, Measureable, Aligned with Olmstead, Realistic, Time-framed. Also, the ‘implementation actions’ have no time line or assigned responsible party. As a result, there is no way to measure success or accountability to ensure completion. Instead, these are nice ideas floating in outerspace.

For example: “Increase the number of people with disabilities who live in community based settings” should read: Increase the number of people with disabilities who live in the home of their choosing based upon informed decision-making by 10% per year over the next 10 years. This is Specific, measureable, aligned, realistic and time-framed (S.M.A.R.T.).

Also the shift that should occur would allow or enable all persons with disabilities to use ‘their’ funding to secure the housing of their choice. For example: the total funding used to support someone who lives in a group home or community residence will be made available to the individual for purchasing or renting their own home, giving rise to 100% informed opportunity for people to choose their living situation. This shift should have a specified time frame for implementation.

Employment Committee -- measurable outcomes are similar to the Housing Committee, goals are clear in terms of their intended outcomes, but do lack specific necessary information. It is recommended that they be edited to be S.M.A.R.T. For example: “Increase the number of people with disabilities who are placed in employment in integrated settings by the member agencies.” This needs to identify the projected number of individuals (or percentage) that will be served and by what date. Furthermore, it will require a specific measureable time-framed objective for shifting funding to enable provider agencies to move people into integrated employment. For example: Day Habilitation Centers will become Integrated Employment Programs, creating expectation and opportunity for all to become gainfully employed, as this is the new default expectation within the public school setting and publicly funded agencies.

As for the second ‘measurable employment outcome’ for employment, *“Identify the employment status of persons transitioned from sheltered workshops, day treatment centers, and day services programs into integrated employment programs, including supported employment programs and other competitive work placements. Through the Medicaid Infrastructure Grant (MIG), develop a five year cross agency strategic employment plan and establish a disability employment platform for New York State,”* this makes no sense in the context of Olmstead.

For more clarification on setting Strategic Goals and S.M.A.R.T. Objectives, please refer to the attached definitions sheet.

Attachment

Definition of Strategic Goals and SMART Objectives

Strategic Goal: Broad spectrum, complex, organizational, indication of program intentions.

S.M.A.R.T. Objectives: Specific (defined), Measurable, Aligned, Realistic, Time-framed. Must be operational, simple steps that are clear and concise. Objectives contribute to the fulfillment of specified goals. Complete with a beginning and an end.

Goals and objectives are statements that describe what your *Vision Statement* will accomplish, or the results that will be achieved.

Goals are high level statements that provide overall context for what the Vision Statement is trying to achieve, and should align to its components.

Objectives are lower level statements that describe the specific, tangible products, deliverables and fruits that will be delivered; and must be S.M.A.R.T.

The definition of goals and objectives is more of an art than a science, and it can be difficult to define them and align them correctly.

Strategic Goals

Because the goal is at a high-level, it may take more than one objective to achieve. It may take many objectives over a long period of time to achieve the goal.

Generally, non-measurable: If you can measure the achievement of your goal, it is probably at too low a level and is probably more of an objective.

If your goal is not achievable through any combination of objectives, it is probably written at too high a level. It may instead be a vision statement, which is a higher level statement showing direction and aspiration, but which may never actually be achieved.

S.M.A.R.T. Objectives

Objectives are concrete statements describing what the project is trying to achieve. The objective should be written at a lower level, so that it can be evaluated at the conclusion of a goal to see whether it was achieved or not. Goal statements are designed to be vague. Objectives should not be vague. **A well-worded objective will be Specific, Measurable, Aligned, Realistic and Time-bound (SMART).**

- Note that the objective is much more concrete and **specific** than the goal statement.
- The objective is **measurable** in terms cost, speed, quantity and / or quality.
- We must assume that the objective is **achievable** and **realistic**.
- The objective is **time-bound**, and should be completed by a specific date.

Objectives should refer to the deliverables of the goal. If you cannot determine what deliverables are being created to achieve the objective, then the objective may be written

at too high a level. On the other hand, if an objective describes the characteristics of the deliverables, they are written at too low a level. If they describe the features and functions, they are requirements, not objectives.

Public Comments on the Draft MISCC Plan
By the Center for Independence of the Disabled, NY
December 2, 2009

Overall, the plan represents a step forward, detailing specific actions to be taken by State actors to address compliance with the “most integrated setting” mandate. We have several general comments about the plan.

First, it is our perspective that implementation, evaluation and progress would be greatly enhanced by coordination through an agency that represents people with all forms of disability of all ages. We welcome OMH; SOFA, and OMRDD’s commitment to improving opportunities for community integration through their programs. At the same time, it must be understood that these programs reach a segment of New Yorkers living with disabilities. Our focus will be on the initiatives that have the potential to improve the independence and community integration of all people with disabilities.

Second, apart from its endorsement of specific limited initiatives in support of improved housing, employment, transportation, long-term care, and community-based treatment plans, the MISCC should include one implementation action for all agencies. It should endorse the creation of state-agency ADA policies that ensure that people with disabilities have “equal opportunity to participate in and benefit from programs and services,” “reasonable modifications” “methods of administration with a discriminatory effect,” “equal access,” “meaningful access.” This is a critically important step. The chain of events leading to institutionalization is often set in motion by state, local district, non-governmental entities’ policies and practices that fail to comply with federal civil rights laws.

- The ADA policies should contain this broad sweeping language of the law and then explain and illustrate these broad concepts and requirements with concrete examples that are relevant to the agency’s programs.
- It should require modification of policies practices and procedures that deny equal access to persons with disabilities.
- The state agency policies should speak of *Olmstead* and the “most integrated setting” requirement, and provide examples of the types of policies and practices, particularly in the Medicaid program, might violate the requirement.
- Since many state agencies provide direction to local social service districts concerning the administration of programs or contract with non-governmental entities to administer some aspects of their programs, the ADA compliance plans should require that agreements between state and local governments or non-

governmental contractors include detailed guidance on steps that must be taken to comply with the ADA.

- The plan should require that the state agencies provide technical assistance, monitor and oversee compliance.
- It should be made clear that while referrals to disability-specific programs are often an appropriate accommodation for individuals with disabilities, that local districts and non-governmental contractors cannot meet their ADA obligations merely by referring their clients elsewhere (such referrals may violate the ADA if they are the only step taken).
- The state agencies policies should provide guidance to these entities concerning the content of policies the local districts and non-governmental contractors should themselves adopt, this could be accomplished by promulgating model policies. Having a written, comprehensive ADA policy is only a first step. State agencies must themselves come into compliance with their policies and must ensure that local districts and non-governmental contractors come into compliance as well.
- People with disabilities must be informed of their rights. They must be advised that they are entitled to reasonable accommodations from public programs and that the failure to accommodate is considered under the law to be a type of discrimination, which is therefore prohibited.

Our comments regarding specific provisions in the plan follow:

- In the MISCC Housing Plan, there are no actions that would clearly result in the creation of new housing units serving people with any type of disability. There will be only 125 new units produced, all for OASAS consumers, who must be people with substance abuse problems.
- We are concerned about the proposed increased collaboration between the Access to Home program, the NHTD program, and the OMRDD E-mod program, because it is likely to direct limited Access to Home money into programs that have their own funding to make e-modifications
- The MISCC Employment Plan shows examples of actions undertaken by individual agencies that should be undertaken by all relevant agencies to give equal opportunities to people with different types of disabilities. For example, NYSOFA is planning to work with the NYS Dept. of Labor One-Stop Centers to get their employment training structure to share with agencies serving older adults with disabilities. However, the One-Stop Centers and their employment training structure do not share enough with agencies serving younger people with

disabilities, either. The initiative should include more agencies, like VESID, OMH, OMRDD and OASAS.

- The Community-based Treatment Plan should include provisions for case management for people with disabilities through Medicaid Managed Care plans. It should require that new models, such as the medical home, be designed to coordinate care for people with disabilities so that they may avoid institutionalization.
- Finally, there is a division between long-term care and community-based treatment within the MISCC committee structure. Perhaps this should be revisited at this point. In order for long-term care to take place in the most integrated setting, it must provide community-based treatment.

Western New York Independent Living, Inc Comments on the Draft Plan for the New York Most Integrated Setting Council for Fiscal Year 2010-11

Western New York Independent Living, Inc. (WNYIL) is pleased to provide comments on your plan to assist citizens of New York with disabilities to live more independently in the community. WNYIL, as part of the New York network of independent living centers, considers community integration one of our agencies key purposes.

In reviewing the plan, we applaud the Council in considering such a broad array of topic areas that relate to community integration. Should issues be achieved in all these areas, significant benefits are possible for entire communities.

We are concerned about the vague, somewhat-recycled nature of some of the goals in the plan. As an independent living center, funded by the New York State Education Department, goals we would write in these areas would be required to be more specific than a number of goals presented here. We encourage the Council to identify more specific levels and timelines within each goal area so that community partners would be able to assist you in achieving the plan's success. Additionally, we encourage the creation of additional assurances that all goals are cross disability in nature. While the general goals would apply to all persons with disabilities, it appears the specific departmental goals may leave some disability areas out.

In specific, we make the following recommendations:

- Within the housing area, we have a concern regarding the use of "Access to Home" program dollars. Access to Home can also be perceived as a very important activity to promote the *prevention* of persons with disabilities currently living in the community from being institutionalized. We're concerned by placing this priority in the plan; you may be eliminating the ability of the program to serve its community purpose. We recommend that the Division of Housing and

Community Renewal investigate additional safeguards to prevent all of the programs dollars being used for nursing home transition rather than prevention.

- Within the long-term-care area, we must recommend that the state Department of Health identify regulatory safeguards and enforcement that promote the concept that any person with a disability who requests nursing home release has the right for community advocates to investigate, and provide services for releases under Olmstead provisions. Quite often advocates are prevented from assisting consumers to achieve transition due to a facilities desire to maintain funding for that individual based on Medicaid or other health insurance payment. A simple goal in this area would go a long way in facilitating other goals currently in the plan.
- Within the employment area, we express concern over State Education Department goals that conflict with current operating policy within VESID. These are perfect examples of where goals need to be more specific in order to facilitate completion of Council objectives. Currently, high school students await involvement of VESID until the last marking period of their senior year of high school *by current VESID practice* (based on personnel and caseload concerns), which would conflict with the stated goal. Providing a more specific percentage or numerical target may serve as a better way of measuring success.
- Within the community based treatment area, while we applaud the commitment to appropriate physical and mental health standards for children in family-based care, it is the belief of WNYIL that the most effective treatment for children involves living at home with family. Consistent with this standard, goals relating to the foster care system must include commitments that identify the mission of foster care to be family reunification whenever safe and feasible for a child, rather than permanent relocation.
- We applaud the Council's mention of the Medicaid Buy-In, but recommend that additional state departments should be involved with the promotion of the program. All MISCC agencies should be promoting the use of the program, and the Department of Health should place a priority on training and technical assistance of County officials involved in the application and approval process for the buy-in. Even after all this time, significant errors still exist requiring buy-in applicants to find trained advocates who can walk them through the process and deal with the innumerable errors and delays.
- Finally, we want to remind each MISCC agency that with any goal constructed in this plan, funding (and funding alternatives) should be identified to allow for successful completion. Goals with no expectation of being able to fund them are the equivalent of empty promises to our community in relation to our freedom.

RESOURCE CENTER FOR ACCESSIBLE LIVING, INC.

November 30, 2009

Comments on the Draft 2010-11 MISCC Plan

MISCC Housing Plan

The first two recommendations under housing dealing with livable communities are too broad, and are a city planning , rather than a NYSOFA function. Creating more “...livable communities for older people, younger-aged people with disabilities, families and caregivers.” Is equivalent to the typical life cycle for the entire population. An emphasis on the life-cycle of individuals and families should result in more support for housing that is physically accessible to all.

MISCC Employment Plan

Why are education, training and outreach related to the Medicaid Buy-In for Working People with Disabilities targeted to the OMH population, to the exclusion of persons with physical disabilities? Furthermore, why isn't DOH taking a much needed leadership role, specifically in ensuring the county Medicaid workers follow established procedures for systematically evaluating eligibility for this program?

VESID should support summer employment for high school students with disabilities before students reach their senior year. This is essential to achieve a goal of increasing the number of young adults who transition directly from high school into employment.

**New York Association on Independent Living's Response to the MISCC
Draft 2010-2011 Plan**

The New York Association on Independent Living (NYAIL) is a statewide membership organization of Independent Living Centers, community-based providers of services and advocacy that are run by and for New Yorkers with disabilities of all ages. NYAIL works to remove barriers to community integration and promote the civil rights of all people with disabilities.

NYAIL commends the MISCC for its effort to move towards creating an actual MISCC “plan”, rather than issuing another “report.” Though most of the action items in the draft plan are vague, the plan will serve as a foundation for a more detailed Olmstead plan as required by the MISCC statue. We look forward to seeing more detailed implementation plans proposed in the coming months. As the council develops the more extensive and detailed plan, NYAIL urges its members to consider the following:

The MISCC should look across systems, state agencies, and funding silos at ways to shift state funding from segregated to more integrated programs to remove barriers to full community integration for people with disabilities. The MISCC employment subcommittee has made great strides in collecting data related to the use of funding for employment of people with disabilities. The subcommittee's number one priority is to direct or re-direct resources toward integrated employment. A similar implementation step must be made a priority for all MISCC agencies and with all funding streams.

Furthermore, MISCC agencies should not be able to limit their plans to those issues they choose to address and not others. For example, though OMRDD has identified "decreasing the number of people with developmental disabilities living in Developmental Centers and stopping the acceptance of new admissions" as an implementation action for housing, it has not acknowledged that large group homes are also segregated settings, but continues to move forward with plans to create at least four new such facilities across the state. For the more detailed plan expected to be produced during the first quarter of calendar year 2010, the MISCC should direct all agencies to submit plans to reduce the number of people in all forms of segregated facilities and programs. This detailed plan should show timetables, specific numbers of people to be moved or transitioned, closure dates for segregated congregate facilities, and dollar amounts to be reallocated from those facilities and programs to integrated, individualized services. Finally, no effort has been made to look across systems, state agencies, and funding silos at ways to address systemic reliance on segregated versus integrated services and shift state funding across systems accordingly. This effort must begin now.

The MISCC must authorize the creation of a Long Term Care subcommittee. While we commend the MISCC for including implementation actions directly related to long term care, we must question the process through which these actions were included in the plan. To date, there is no subcommittee of the MISCC focusing solely on long term care, as there is in the areas of housing, employment and transportation. Yet, this issue is key to the purpose of the MISCC. Recently, the Department of Health stakeholder group has been serving as an impromptu MISCC subcommittee developing recommendations related to long term care. In using its stakeholder group as a make-shift subcommittee, DOH is limiting the purview of a true subcommittee as well as taking away from the responsibilities associated with a true stakeholder group. Other MISCC stakeholder groups are comprised primarily of consumer of services, but the subcommittees on housing, employment and transportation include all stakeholders and relevant state agency staff. These subcommittees are where much of the work of the MISCC has been taking place, often with positive, real results. The issues relevant to the long term care system have not been addressed directly in the existing subcommittees. In addition, DOH has limited the work of the stakeholder group to short term outcomes achievable within 12 months and has avoided addressing the underlying systemic and regulatory issues that exist as barriers to community integration for people with disabilities. A new long term care subcommittee should be created, and NYSOFA should be substantially involved or co-chair of the subcommittee.

The draft plan also includes “Community-Based Treatment Plan” implementation actions. We have no idea how this section of the draft plan was created or by whom. There is no subcommittee on “community-based treatment,” nor should there be. These proposals should not be in the draft plan. The issues, apparently raised by the state agencies noted as responsible, OCFS, CQCAPD, SED and DOH, should be addressed within the most relevant subcommittees.

NYAIL, in collaboration with the Center for Disability Rights and the Consumer Directed Personal Assistant Association of New York State, recently issued a paper entitled, “Proposals that reduce NYS spending and promote the independence and integration of seniors and people with disabilities.” The paper was disseminated to the legislature, the Governor’s Office, and the Department of Health, and included detailed budget-related proposals to cost-effectively serve more seniors and people with disabilities in the most integrated setting. The paper is attached. The disability community has offered many proposals for systemic changes that would help the state meet its obligations under the Olmstead decision and remove barriers to full community inclusion, including a recent paper by the Center for Disability Rights, which we understand was included with CDR’s comments, and which offers detailed recommendations to the state. These proposals and recommendations should be considered for inclusion in the final 2010-2011 MISCC plan.

We look forward to working within the MISCC subcommittees in the coming months to develop a comprehensive statewide plan to ensure that people of all ages with all disabilities receive supports and services in the most integrated setting appropriate to their individual needs.

**Proposals that reduce NYS spending and promote the independence and integration of seniors and people with disabilities Prepared by the Center for Disability Rights, the New York Association on Independent Living, and the Consumer Directed Personal Assistance Association of New York State
November 13, 2009**

The state’s Independent Living network and disability community have been advocating for policy changes in New York that would increase the independence of seniors and people with disabilities. Despite the fact that these proposals were cost-effective and save money, the administration has been slow to act on the advocate proposals. Even in the face of serious financial difficulties, New York State has an unprecedented opportunity to improve the lives of seniors and people with disabilities to support them living in the most integrated setting as mandated by the Supreme Court’s Olmstead decision. Unfortunately, instead of developing state policy that promotes savings through people receiving services in the most integrated setting appropriate for their needs, the administration has simply proposed manipulating the Medicaid rates to generate savings.

The administration’s approach has the potential to backfire and reverse progressive state policy, ultimately costing the state more in institutional care.

Recommended Policy Changes and their Associated Savings

Proposed Policy Change	Non-Federal Share Savings
1. Increase utilization of the Nursing Facility Transition and Diversion Waiver to transition people from nursing facility placement to community living	\$85.7 million
2. Divert people from nursing facility placement using the Nursing Facility Transition and Diversion Waiver	\$84.2 million
3. Shift people currently receiving Certified Home Health Care to the less costly Consumer Directed Personal Assistance Program	\$43.4 million
4. Shift people currently receiving Traditional Personal Care to the less costly Consumer Directed Personal Assistance Program	\$26.6 million
5. Expand the pool of direct care workers to match the federal rules for family caregiving to promote the use of more cost-effective services	\$39.4 million
6. Utilize assistive technology to contain costs	\$ 7.7 million
Total Savings from the Proposals	\$287.0 million

Policies that promote community-based services save money!

National research has demonstrated that states which shift from using institutional care including nursing facilities to community-based models of care are leveling out their long term care costs. States that are not making this transition are continuing to see their long term care costs escalate.

New York has taken some steps in the direction of promoting more effective use of community based alternatives, but overall New York’s system is still institutionally-biased. According to the most recent spending data from Thomson Reuters (formerly Medstat), in 2007 60.71% of New York’s Medicaid spending for long term care for seniors and persons with physical disabilities was for institutional nursing facility care. Other states are making the shift. The state of Washington has steadily reduced its spending for nursing facility care while investing in community based alternatives. Compared to New York during the same year, Washington State only spent 44.42% of its Medicaid long term care dollars serving seniors and physically disabled for nursing facility care. In terms of per capita spending, New York also spent dramatically more for

nursing facility care at \$349.80 compared to less than one-third of that amount in Washington State (\$91.96). In fact, only one state spends more per capita on nursing facility placement – Connecticut which spends \$351.99, and only one other state spends more than \$300 – Pennsylvania which spends \$311.13.

New York State should implement the following recommendations.

1. Increase utilization of the Nursing Facility Transition and Diversion (NFTD) Waiver to transition people from nursing facility placement to community living for a potential annual savings of \$85.7 million in the non-federal share.

According to the 2009 3rd quarter report of CMS' Minimum Data Set (Q1A), there are currently 22,027 New Yorkers living in nursing facilities that indicated they wish to return to the community. Institutionalizing these individuals despite the fact that they want to live in the community costs over \$2.5 billion. The Nursing Facility Transition and Diversion Waiver was expected to have 5,000 enrollees by the end of year three. As of September 25, 2009, more than half way through year two, the waiver enrollment was 231 individuals. NYS could achieve significant cost savings by increasing utilization of the NFTD Waiver and transitioning more individuals out of costly institutions and into community based settings.

While the Department of Health has clearly worked to implement the waiver, its bureaucracy has slowed progress and the waiver is only one of many confusing and sometimes contradictory DOH initiatives. Department staff – at times – have micro-managed implementation and tended to over-medicalize the program slowing implementation despite the fact that this model has the potential to create significant savings. Although the NFTD waiver is too new to get good cost-savings comparisons, the TBI waiver has demonstrated a cost savings of just over \$29,000 per individual, per year in the non-federal Medicaid share compared to the cost of institutionalizing these individuals.

Even if the state only realized 85% of the TBI waiver's savings and only transitioned 25% of the MA-eligible individuals who have expressed a desire for community-based living, we estimate NYS would \$85.7 million. If over four years, the state transitioned all of these individuals, the cumulative savings in the non-federal share would be \$857 million.

2. NYS should immediately establish an expedited enrollment process for the NFTD and TBI Waivers to divert people from nursing facility placement for a potential annual savings of \$84.2 million in the non-federal share.

Too often, people leave the hospital and go into a nursing facility immediately following a hospital stay and then are unable to leave that costly setting to return to the community. Because the enrollment process for waiver services is lengthy, people often are placed in nursing facilities. The New York State Health Department should create an expedited

enrollment process that allows seniors and people with disabilities to immediately return home from the hospital. This approach would promote the concept that the individual is expected to be independent and help them return home with more cost-effective services.

Based on the assumption that the state could divert 25% of 13,187 Medicaid nursing facility admissions and save 85% of the established savings under the TBI waiver, New York State could save \$84.2 million in the non-federal share and promote the independence of these individuals by avoiding long-term institutionalization.

3. NYS should implement a plan to shift some people currently receiving Certified Home Health Care to the less costly Consumer Directed Personal Assistance Program for a potential annual savings of \$43.3 million in the non-federal share.

Advocates have demonstrated that the Consumer Directed Personal Assistance Program (CDPAP) is the most cost-effective model for assistance in the home because the per-hour rate for CDPAP is cheaper than other home care services. When consumers self-direct their nursing tasks, the savings are significant. Compared to Certified Home Health Care, CDPAP reduces Medicaid spending by \$9.52 for every hour of service. Assuming an average of 5 hours of service a day, by shifting about 5,000 people from Certified Home Health Care to CDPAP, the state would reduce Medicaid spending by approximately \$86.8 million (a savings in the nonfederal share of \$43.4 million).

In reviewing the national data, it seems that there is significant room for making such a shift. In New York State, Certified Home Health Care accounts for 14.75% of the state's Medicaid long term care spending for aged and physically disabled individuals. In comparison, Certified Home Health Care in Washington State is just 2.04%. State law provides for expanded participation in CDPAP through contracts with peer based programs to provide education and outreach to eligible individuals and training for discharge planners, LDSS' and others. In addition, the CDPAP statute was amended to require county enrollment targets and annual implementation plans, to promote consistency regarding approved service levels across the state. Unfortunately, the administration has not fully implemented these proposals and has therefore failed to generate the potential saving from this paradigm shift.

4. NYS should implement a plan to shift some people currently receiving Personal Care Services to the less costly Consumer Directed Personal Assistance Program for a potential annual savings of \$26.6 million in the non-federal share.

CDPAP is also cheaper than traditional Personal Care services. Although the savings are not as dramatic, they are significant. On average, CDPAP is 6.89% cheaper than traditional personal care with a per hour Medicaid savings of \$1.46. Assuming an average of 10 hours of service a day, by shifting about 10,000 people from Personal Care to CDPAP, the state would reduce Medicaid spending by about \$53.3 million (a savings in the non-federal share of \$26.6 million).

The state could take additional steps to realize increased savings by promoting the shift from medical model approaches to the more cost-effective consumer-directed model.

The state should set aggressive county enrollment targets for CDPAP. The state has begun to receive reports from individual counties about their usage of CDPAP and plans for how they intend to promote the use of that program. Under current law, the State is required to set county enrollment targets. By setting aggressive enrollment targets for counties and approving their plans, the State has control over assuring Medicaid savings are realized from this initiative.

The state should expand consumer direction into the Nursing Facility Transition and Diversion and Traumatic Brain Injury Waivers. Currently, counties are forcing people off of CDPAP because they are eligible for Home and Community Support Services (HCSS) under these waivers even though those services may, in fact, be more expensive. In Monroe County, a man receiving services on the TBI waiver is being told that he will be removed from CDPAP. Now he may not personally be able to manage his own services, but his wife – who is a nurse – can. And they like the idea of managing who comes in and out of their home.

Even when consumers are not being forced to drop their CDPAP services, the logistics of having both HCSS staff from an agency and consumer-directed attendants make the choice unworkable. Disability groups have urged the Department of Health to provide consumer direction as an option within these waivers, but they have not moved forward with these plans. This is particularly frustrating because attendants under the CDPAP model can do a variety of health related tasks that would otherwise require a nurse. HCSS provides safety monitoring which is a far less skilled task and could easily be done by a CDPAP attendant. Expanding CDPAP into the waivers will give consumers more control and reduce Medicaid spending.

The state could realize additional savings by relaxing the requirement that consumers physically visit their doctor within thirty days of the reauthorization. This is not to say that physician assessments are not important; it is simply a costly requirement that is burdensome for personal care consumers. The State should amend the regulation to require individuals to visit their physician once a year, which is common for an annual physical. Such a change is permissible by CMS. According to the State Medicaid Manual, Pub. No. 45, Chapter 4, Section 4480, "...nor does Federal law require that a physician prescribe the services in accordance with a plan of treatment. States are now permitted the option of allowing services to be otherwise authorized for the beneficiary in accordance with a service plan approved by the State" (Centers for Medicare and Medicaid's State Medicaid Manual). This allowance can be found in 42 CFR § 440.167 for Personal Care Services. The regulation states:

§ 440.167 Personal care services.

Unless defined differently by a State agency for purposes of a waiver granted under part 441, subpart G of this chapter—

(a) Personal care services means services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease that are—

(1) Authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State;

For example, in 2006, Idaho passed S. 1339 that amended the existing law to remove the standard which requires that personal care services be ordered by a physician or authorized provider. New York State can and should make this regulation amendment.

5. NYS should expand the pool of direct care workers in the Consumer Directed Personal Assistance Program to match the federal rules for paid family care givers, which would promote the use of this cost-effective service for a potential annual savings of \$39.4 million in the non-federal share.

The relationship between an attendant and the consumer is essential to the success of the any home care service, but the ability to select who comes into your home is a critical component to the success of the Consumer Directed Personal Assistance Program. To increase the savings generated by using CDPAP, the state needs to implement policies which would promote the use of that model. Because of the type of assistance that is being provided, individuals with disabilities, particularly seniors, often prefer having a family member serve in this role. Family often make the choice to institutionalize a senior because they do not want to have strangers in their homes.

Federal regulations [42 C.F.R. § 440.167], state that personal attendants cannot be a family member who is “legally responsible” for the care of an individual. This is interpreted to include spouses and legal guardians (parents) of minors. However, New York State regulations [18 NYCRR § 504.14(h)(2)] are much more restrictive than federal regulations and expand the prohibitions on attendant employment to certain members of the consumer’s family to include spouse, parent, child, son-in-law, or daughter-in-law. If the NYS regulations were amended to expand the definition of personal attendant to match the federal regulation, we estimate that 3% of the Medicaid nursing facility population would transition into the community and New York State would save \$78.8 million annually in institutionalization costs (\$39.4 million in the nonfederal share).

This approach also addresses a critical shortage of home care workers that stalls efforts by states to shift toward a community-based model of long term services and supports. Previous efforts in New York State to address the need for direct care workers have not focused on significantly expanding the pool of workers, but have focused on making the job more appealing to people interested in this work by providing improved benefits or a career ladder. While these efforts have had some impact, they have generally drawn from the same pool of workers, rather than expanding it.

By expanding the ability to pay family members to provide assistance, the State would be drawing in workers who would not generally want to be an attendant with the potential for significantly increasing the pool of workers and addressing a critical barrier to moving toward a cost-effective community-based model and reduce the state's Medicaid spending.

The state could require that the State Education Department work with the network of Independent Living Centers to develop and implement a model for training people with disabilities to become attendants to realize further savings both by promoting the shift from medical model approaches to the more cost-effective consumer-directed model and by providing employment to these individuals. Although generally not considered as potential workers, many people with certain types of disabilities (i.e. psychiatric or developmental disabilities) often already provide some level of personal assistance on an informal basis. Direct care employment may be a good fit for this population because they tend to be comfortable with basic tasks and are committed to the concept of supporting people who want to live in the most integrated setting. Ultimately, this approach creates opportunities for people with disabilities to be competitively employed and expands the pool of potential direct care workers. The disability community has been suggesting such an approach for about seven years. The difficulty in getting such an initiative started is that it is difficult to get one state agency to invest in a model that creates savings in another area. The Independent Living network – because it is a consumer controlled model that hires people with disabilities – is most likely to implement such a model successfully.

6. NYS should better utilize assistive technology to contain costs for a potential annual savings of \$7.7 million in the non-federal share.

While there are options for assistive technologies under the waivers and through vocational rehabilitation, generally this type of assistance has been overlooked by the NYS Department of Health which oversees much of New York's long term care system. Discussions about the use of technology and equipment have generally focused on tele-health as opposed to meeting more basic needs of individuals who want to live independently. Technology, however, has the possibility of significantly reducing long term care costs. For example, people who require 24- hour or overnight home care because they are unable to get out of bed independently to open the door for the morning attendant could potentially reduce hours if they were provided with assistive technology which allows them to open the door. Assuming that the state only provided such assistive technology to 250 people and reduced their need for personal care by 8 hours a day, the state could reduce Medicaid spending by \$15.4 million.

To make technology more readily available, the Department of Health should use the next round of HEAL funding to expand the Technology Related Assistance for Individuals with Disabilities (TRAID) program. TRAID is a federally-funded project administered by the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities. In New York, the TRAID dollars have been used to establish

regional technology centers that are providing information, borrowing, and referral services for persons with disabilities. The TRAIID Centers work to improve people's access to assistive technology equipment and services. Under the NYS Commission on Quality of Care and Advocacy for Persons with Disabilities, the TRAIID program provides coordination of assistive technologies for assistance in education, employment, community living, and information technologies. There are twelve Regional TRAIID Centers (RTCs) across the state. While this provides a strong foundation, the State needs to expand this program. The next round of HEAL funding provides a funding mechanism for expanding the TRAIID program. The state could then coordinate the efforts of the TRAIID project with the Regional Resource Development Centers for the waivers to enhance the use of technology in promoting the independence of people.

The state can address the deficit by promoting independence and consumer-direction!

Independent Living and disability rights advocates have identified specific barriers that push people into institutional settings who could otherwise benefit from community living and suggested ways New York State could address those barriers so individuals with disabilities and seniors can both live in the most integrated setting and help control New York's Medicaid spending. We have also demonstrated the potential savings of shifting to the consumer directed model for providing long term services and supports.

The legislature is in a position to implement simplistic cuts proposed by the administration that tinker with rates and have the potential to backfire with increased institutionalization costs or implement progressive reforms that promote independence and reduce unnecessary Medicaid spending. New York's disability community is looking to our leaders in Albany to make the right choice.

**CENTER FOR DISABILITY RIGHTS' RESPONSE TO THE MISCC'S DRAFT
2010-2011 PLAN
December 2, 2009**

The Center for Disability Rights, Inc. (CDR) is a non-profit service and advocacy organization devoted to the full integration, independence and civil rights of people of all ages with all types of disabilities. With services in 13 counties in New York State (NYS) and offices in Rochester, Corning, Geneva and Albany, CDR represents the concerns of thousands of people with disabilities.

Under the direction of Commissioner Ritter, the Most Integrated Setting Coordinating Council (MISCC) is shifting gears and this new direction is clearly evident in the MISCC's Draft 2010-2011 Plan. While there are, of course, many areas that need improvement, this draft plan has demonstrated the State's progress toward a real Olmstead plan. We recognize the efforts of the MISCC agencies to provide real action items with targeted years of completion and we commend the State agencies for not submitting another report that lists the agencies' existing community-based initiatives.

It is evident in some of the Workgroups' missions, visions, and values that some of the agencies are truly beginning to understand the purpose of the MISCC; such as, the Housing Workgroup's stated vision, "...to provide leadership, guidance and a collaborative forum for stakeholders to impact policy changes..." This type of big picture vision is precisely what this Workgroup should be doing: impacting policy changes. The MISCC, through its Workgroups and various members, should be impacting all programs of the State that could foster people with disabilities' independence. The Employment Workgroup took this a step further and stated in its mission, "...through executive, legislative, and budgetary action." Yes! This is what the members of the MISCC should be doing. In order for NYS to comply with the Olmstead decision, the MISCC should be making recommendations to the Legislature, Executive, and Division of Budget. The State agencies are only one piece of the Olmstead puzzle.

Most of the action items are vague and require more details, such as "engage in six initiatives"[Housing] or "engage in four activities" [Employment] or "identify potential replication of four models" [Transportation], etc. However, CDR recognizes that this draft plan states that "during the first quarter of calendar year 2010, more detailed implementation plans will be created that include specific goals, timetables and key performance data in order to monitor progress." We presume that these action items will be fleshed out and we look forward to these detailed plans that will be released by March 2010.

The MISCC's 2010-2011 plan is organized based on the workgroup areas. The following are recommendations for the draft plan, and ultimately for the State to implement in order to promote people with disabilities' independence and remove barriers for people to receive services in the most integrated setting.

Housing Workgroup

Under the direction of SOFA, the State will complete a technical assistance resource manual for communities to use as a tool in development. CDR believes that this manual could have great implications for expanding the pool of accessible and visitable homes in the state. However, this has been well underway since September 2008. While this should be a part of the plan, it is important for people with disabilities and seniors to be more actively involved in the development of the manual.

The Action item that focuses on TR Aid is certainly on point. Assistive technologies that allow people with disabilities to live independently at home can reduce institutionalization and home care costs. CDR supports the MISCC's efforts to expand TR Aid; however, this item in the plan is not an action item at all, but rather a statement of fact. It states, "though there is no additional funding available, it is estimated that the program will have at least a 5% increase in utilization..." Is this a directive to the agency or a report by the agency? If it is a report, which it appears to be, then we can deduce that the need for assistive technologies is increasing; however there is no plan for meeting the

increased demand for services. (See the attached paper for more recommendations regarding assistive technologies.)

Most notably, one of the action items identified by the Housing Workgroup is to “increase the number of people participating in the Nursing Home Transition and Diversion (NHTD) Waiver Housing Subsidy.” Multiple reports conclude that housing has been identified as the number one barrier for people with disabilities to live in the most integrated setting. All of the home care services in the world will not support people with disabilities in the community without accessible, affordable, integrated housing. There are a few ways that DHCR and DOH could explore to maximize the waiver’s home modification funding:

- Require Access to Home providers to be Medicaid waiver providers.
- Establish a process for Access to Home grantees to set aside working capital for waiver home modification services, thus drawing down federal dollars. It would be reimbursed via the waiver’s modification funding stream.
- Mandate that providers of Access to Home refer applicants to the local Regional Resource Development Center (RRDC) as potential eligible waiver participants. Thus, Access to Home (DHCR) becomes a portal to the NHTD Waiver (DOH).

The MISCC is the legislatively formed body charged with implementing the Olmstead decision in New York State. However, the MISCC agencies often pick and choose what areas they would like to focus on and omit others from the discussion. The action item to “decrease the number of people with developmental disabilities living in Developmental Centers and stop the acceptance of new admissions” is a bold statement that CDR supports, though there should also be percent targets for decreasing the Developmental Centers. In addition, the draft plan fails to make this same charge for other congregate settings, such as adult homes and large group homes, and the State is moving forward with the development of four new facilities.

The disability community has pushed for a user-friendly resource for identifying accessible, affordable, integrated housing. The relatively new site, NYHousingSearch.gov, is a step in the right direction and DHCR deserves some accolades for developing this system. While the registry could be a very useful tool, in order for it to be effective, it must be updated frequently and constantly promoted so that users will actually receive a comprehensive list from their search. The draft plan calls to “improve the impact” of the registry. What does this mean? CDR recommends the following:

- Provide an option for “Resources to make your home accessible” that would link directly to a list of local providers that do home modifications; removing the PDFs that can make websites inaccessible for screen reading and screen magnification software.
- Since there is a handy list of assisted living options, there should also be an equally useful list of fully integrated apartment units—in addition to the more in-depth search options available on the site. Although there is a segment of the senior population who prefer assisted living, these facilities too closely resemble

nursing homes and should not be presented in a way that confuses people searching for fully integrated units.

The housing registry, NYHousingSearch.gov, has the potential to be a strong tool; however, without a significant number of current listings, it will continue to be another tool with flash and no substance.

Employment Workgroup

To begin, the proposed MISCC Employment Workgroup's values are excellent. They affirm the advocates' language that all people – regardless of disability or no disability – can work. They remove the disability-focused agenda from the directive of the group and they call for State policy shifts.

The first action item, which calls on the responsibility of all MISCC agencies, is extremely broad and vague to be considered a measurable action item. "Directed or redirected resources toward increased expectations and capacity for integrated employment, based on a cross program information system that accurately reflects data and funding." How are the member agencies supposed to go back to their respective staffs and create results with this directive?

The proposed action item that could have major implications and assist the State toward reducing costs is "Examine health care workforce issues including: finding ways to employ people with disabilities as aides; educational and training requirements for aides; improving the job satisfaction of aides; and providing health care workers with universal skills that enable them to move seamlessly from facility care to community care; and assisting aides to work successfully within the consumer directed and non-medical models." This is not only a means for the State to comply with Olmstead, but it also offers significant cost savings for the State. For example, the first point that offers finding ways to employ people with disabilities as attendants not only addresses the problem of low attendant pools, but it also reduces the employed person's reliance on public assistance, while promoting the independent living, peer based model. The points that follow in the plan's action items promote community-based services, which are less costly than institutional settings.

Transportation Workgroup

The Transportation Workgroup's vision appears to be incomplete. The vision should be: "All people, regardless of disability, should have equal access to quality transportation services to provide access to housing, employment, health care, education, community services, recreation and other activities necessary for daily living."

CDR commends the Transportation Workgroup for proposing the establishment of a Mobility Manager/Health and Human Service Transportation Coordinator within each county. This could be a vehicle, pun intended, for advocates to get through to the local transportation authorities on issues such as paratransit. The concern, however, is that this may be difficult within the context of the State's hiring freeze.

The action item that refers to enhancing the volunteer system through NYSOFA's Community Empowerment Initiative to produce additional transportation resources for older adults should be expanded upon to include non-elderly people with disabilities. These types of volunteer driving networks can be very successful if implemented correctly but this effort should not exclude anyone who needs transportation in order to remain in the community.

Long Term Care Plan and Community Based Treatment Plan

Reviewing the Long Term Care Plan and Community Based Treatment Plan, CDR asks the question: what are these? Are these new workgroups? Are they truly distinct from one another? CDR recommends merging these two areas together under one Long Term Services and Supports Workgroup. Just as the Housing Workgroup is administered by DHCR, Employment Workgroup is under SED, and the Transportation Workgroup is lead by DOT, the Long Term Services and Supports Workgroup should be lead by DOH. This is clearly the direction that the MISCC is heading because the DOH stakeholder group, formed from the long term care restructuring group, developed the goals for the "Long Term Care Plan" in the draft MISCC plan. Clearly, the State Office for the Aging should also play an integral role in this Workgroup as SOFA has developed a myriad of progressive community-based programs over the past couple of years. Though, it must be noted that the 2010 action items for NYSOFA under the long term care plan section of the draft plan are not action items, but rather they hearken previous MISCC "plans" that simply required the State agencies to report on their current community-based programs. The Community Living Program Grant, Community Navigator Program, NYS Family Caregiver Council, NY Elder Caregiver Support Program, and NY Connects are all existing SOFA programs. While these are undoubtedly programs that support NYS' efforts to comply with Olmstead, we need to be careful to maintain the integrity of the 2010-2011 MISCC plan as a Plan, not a report. Perhaps if these programs could be expanded or replicated by other long term care agencies (OMH, OMRDD, DOH), then that could potentially be a goal of SOFA for the 2010-2011 plan. The same is true for components of the "Community Based Treatment Plan" section of the draft MISCC plan that basically amounts to OCFS reporting on existing programs.

Under the Long Term Care Plan section, the first action item is to create a "long term care work plan that addresses the following areas: increased access to community care, improved quality assurance and accountability of health programs, transition of care from segregated to integrated settings, increased workforce opportunities and elimination of barriers that prevent individuals with disabilities from living in the most integrated settings." These four areas were identified by the DOH stakeholder group to be the focus for the MISCC. The phrase "nothing about us, without us" is the mantra of the disability self-advocacy community and it remains true within the stakeholder groups. Providers and State agency staff, while definitely important to the discussion of long term care, are not stakeholders. The Department of Health charged the Workgroup's sub-groups with developing concrete recommendations to remove barriers for people with disabilities to receive services in the most integrated setting.

The meetings for these sub-groups have begun and it appears as though the direction of the groups is already shifting away from advocates' recommendations. Thus, in order to respond to the requests of the Department of Health to develop real action items, attached is a paper developed by advocates, "Recommendations for the Department of Health MISCC Stakeholder Group: Priorities and Action Items," that provide concrete action items for the State to facilitate the independence and integration of people with disabilities. The recommendations in the attached paper should be considered for inclusion into the final MISCC 2010-2011 Plan.

- Attachment -

**“Recommendations for the Department of Health MISCC Stakeholder Group:
Priorities and Action Items”**

National research has demonstrated that states which shift from using institutional care, including nursing facilities, to community-based models of care are leveling out their long term care costs. States that are not making this transition are continuing to see their long term care costs escalate. New York has taken some steps in the direction of promoting more effective use of community-based alternatives, but overall New York's system is still institutionally-biased. According to the most recent spending data from Thomson Reuters (formerly Medstat), in 2007 60.71% of New York's Medicaid spending for long term care for seniors and persons with physical disabilities was for institutional nursing facility care. Other states are making the shift. The State of Washington has steadily reduced its spending for nursing facility care while investing in community-based alternatives. Compared to New York during the same year, Washington State only spent 44.42% of its Medicaid long term care dollars serving seniors and physically disabled for nursing facility care. In terms of per capita spending, New York also spent dramatically more for nursing facility care at \$349.80 compared to less than one-third of that amount in Washington State (\$91.96). In fact, only one state spends more per capita on nursing facility placement – Connecticut, which spends \$351.99 - and only one other state spends more than \$300 – Pennsylvania, which spends \$311.13.

It has been ten years since the landmark U.S. Supreme Court's Olmstead decision and under the leadership of Commissioner Ritter, the State's Most Integrated Setting Coordinating Council (MISCC) has finally begun to develop a plan to support people living in the most integrated setting. Each State agency on the MISCC is responsible for developing a stakeholder group charged with identifying priority areas for 2009 activities, while the full MISCC develops a comprehensive Olmstead Plan for the State. The Department of Health's MISCC Stakeholder Group has identified four key priority areas: (1) Transition of Care, (2) Workforce, (3) Improving Access to Community-Based Services, and (4) Quality Assurance. Outlined below, stakeholders, representing people with disabilities who want to live in the most integrated setting, have identified specific recommended action items (in no particular order) for each of the identified priority areas. These recommendations will assist the State in its efforts to comply with the Olmstead decision and remove barriers to community-based services.

I. PRIORITY AREA: TRANSITION OF CARE

General Problem Statement: *Many people are transferred from hospitals to nursing facilities and become “trapped” there due to unnecessary barriers and inefficient process that operate to preclude the provision of appropriate and cost-effective home and community-based services.*

Issue: Many people are placed in a nursing facility directly from the hospital because the process for securing home and community-based waiver services under the Nursing Facility Transition and Diversion (NFTD) Waiver and the Traumatic Brain Injury (TBI) Waiver takes too long.

Recommended Action:

The Department of Health (DOH) should create an expedited enrollment process for the TBI and NFTD waivers. An expedited enrollment process would allow people to transition directly from the hospital to their homes; it would provide a mechanism for people who do go to a nursing facility for rehabilitation to be able to quickly return to the community; and it would increase the number of enrollees on the waiver, as well as allow the State to draw down Money Follows the Person (MFP) funds. This approach would promote the concept that the individual is expected to be as independent as possible and help them return home with more cost-effective services.

According to the 2009 3rd Quarter report of CMS’ Minimum Data Set (Q1A), there are currently 22,027 New Yorkers living in nursing facilities who indicated they wish to return to the community. Institutionalizing these individuals, despite the fact that they want to live in the community, costs over \$2.5 billion. The NFTD Waiver was expected to have 5,000 enrollees by the end of year three. As of September 25, 2009, more than half way through year two, the waiver enrollment was 231 individuals. NYS could achieve significant cost savings by increasing utilization of the NFTD Waiver and transitioning more individuals out of costly institutions and into community based settings.

In order to establish an expedited enrollment process, the RRDC would complete a 60- day “conditional” enrollment whereby the RRDC would identify only basic service needs, such as Service Coordination and Home and Community Support Services (HCSS). The consumer could immediately begin to receive these supports in conjunction with State Plan services (i.e. personal care). No other services would be offered during the conditional period of 60 days.

The RRDC would be responsible for determining which local agencies that provide service coordination could immediately accept new consumers. The Initial Service Plan (ISP) would need to be submitted to the State within 30 days. The RRDC would complete the intake paperwork and the newly created “expedited enrollment form,” which would serve as the catalyst for enrollment

into the waiver and release from the nursing facility. If personal care and basic waiver services could be put in place immediately as an interim measure pending the final approval of a care plan, the State would realize considerable cost savings by avoiding more costly institutional placements—and complying with the Olmstead decision.

In order for the expedited enrollment process to be successful for people transitioning out of nursing facilities, there needs to be a symbiotic relationship between the nursing facilities and the Regional Resource Development Centers (RRDC) that administer the home and community-based waivers. The connection should occur at the time when a person is transitioning from rehabilitation to long term care, in order to avoid unnecessary long term institutional placement. DOH should mandate referrals to RRDCs and the RRDCs could then review the person during this transitional period, rather than relying on local Departments of Social Services to complete the assessment.

Recommended Action (for people transitioning back to PCA/CDPAP):

Consumers in CDPAP who require hospitalization are removed from the program and required to re-enroll. This creates a disruption in services. In addition, the potential for losing a personal assistant increases because they could take alternative employment in the interim. While people may be able to directly re-enroll, in certain cases counties are requiring consumers to first receive Certified Home Health assistance through Medicare, further delaying the ability of the consumer to re-establish their community-based supports.

To address this issue, the discharge paperwork from the hospital verifying continued need (i.e. the person's disability status and general needs have not changed) could replace the formal physician's order. The local Department of Social Services would then be required to complete the assessment in the hospital, eliminating the gap in coverage and the need to re-enroll in the Program.

Issue: While care coordination is considered to be a critical service for controlling the cost of long term services and supports, it is typically limited to Medicaid programs and senior centered EISEP. There are no resources for non-elderly, non-Medicaid individuals who require general care coordination, unrelated to medical needs.

Recommended Action:

Care coordination helps individuals and families navigate complex systems of care, but it is not necessary for care coordinators to be medical professionals. In fact, medically modeled care coordination can overlook cost-effective solutions for meeting day-to-day needs. Independent Living Centers (ILCs) have demonstrated expertise in meeting this need and have an established statewide infrastructure. They can also provide this service at a much lower cost than a medical professional (i.e. a CHHA nurse), but this network lacks the financial

resources to address this need. The State should fund the ILC network to provide care coordination.

Issue: The State recognizes the importance of electronic records; however, the system focuses on medical and institutional settings such as hospitals and nursing facilities. The system does not include non-medical community-based services. This is not a holistic approach and ultimately leaves parts of consumers' services off of the grid. HCBS waiver services, PCA, and CDPAP are excluded from this system which means hospitals may be completely unaware that there are community-based service providers working with the individual.

Recommended Action:

There is potential for the State to extend the implementation of electronic medical records to include non-medical home and community-based services. Electronic information about waiver enrollment and service authorizations are already available through the eMedNY and other systems. Providers are connected through the Department of Health's HPN system. At least parts of the data and infrastructure are already in place, so the State should consider linking the data and those systems into the health information networks. This would allow hospital discharge planners to be aware of the community-based services that the consumer was receiving prior to hospitalization and be able to prepare them to return to the community, as well as provide a mechanism for community-based service providers to be aware of consumers' hospitalizations.

Issue: New York State is focusing its efforts on developing a single point of entry (POE) through NY Connects. This program is modeled on the Aging and Disability Resource Centers. Nationally, it has been recognized that this model has only effectively met the needs of younger persons with disabilities when disability organizations were included as equal partners through the design and implementation phases. Although well intentioned, NY Connects is inconsistently administered by the counties and the State has been unwilling to provide oversight to assure that the county programs address the needs of younger people with disabilities. Advocates are concerned that the single point of entry model, in the absence of adequate state control, has the potential to become an inappropriate gatekeeper for services depending on how it is administered by counties. Additionally, DOH is currently developing Regional Long Term Care Assessment Center demonstrations, which will serve as additional points of entry for services.

Recommended Action:

Instead of using a single point of entry approach, the State should change its model to "no wrong door." While the aging network is an expert on senior services, it does not fully understand the issues facing younger people with disabilities. Thus, the Independent Living Center network should be incorporated into this model. To assure that the various potential points of entry provide consistent information, the State should use HEAL Phase 14 monies to develop necessary technological infrastructure and training for this system.

Additional Recommended Action:

NY Connects is operational in most regions; excluding New York City, Oswego, Madison, and Seneca Counties. Clearly there are gaps here, but since NY Connects is moving forward in the other regions across the state, NY Connects should be collecting Olmstead-related data. Currently, data is collected on age, gender, payer source, and information requests on: consumer and caregiver supports, home-based services, facility-based services, insurance/benefit information, protective services, housing and home modification, and transportation. Information is not collected on type of disability. The Department of Health has worked with the Office for the Aging, but it is unclear to what extent DOH has collaborated with the development of the data collection tool. DOH, consumers, and advocates should be involved with the evaluation of the data collection tool because if it is not comprehensive, it could be a missed opportunity for the State to collect concrete numbers of people seeking long term care information.

Issue: The re-authorization requirement for Medicaid personal care services (under State Plan) is every six months. With this, there is a requirement that consumers must be seen in the physician's office within thirty days of the re-authorization in order to get the physician's approval of the re-authorized services. Requiring consumers to physically go to their doctor's office twice a year is costly and can be very challenging for people with disabilities.

Recommended Action:

The State should relax the requirement that consumers physically visit their doctor within thirty days of the re-authorization. This is not to say that physician assessments are not important; it is simply too burdensome for many personal care consumers. The State should amend the regulation to require individuals to visit their physician once a year, which is common for an annual physical. Amending the regulation would not only resolve the concern of consumers, but it is also allowable by CMS. According to the State Medicaid Manual, Pub. No. 45, Chapter 4, Section 4480, "...nor does Federal law require that a physician prescribe the services in accordance with a plan of treatment.

States are now permitted the option of allowing services to be otherwise authorized for the beneficiary in accordance with a service plan approved by the State" (Centers for Medicare and Medicaid's State Medicaid Manual). This allowance can be found in 42 CFR § 440.167 for Personal Care Services. The regulation states:

§ 440.167 Personal care services.

Unless defined differently by a State agency for purposes of a waiver granted under part 441, subpart G of this chapter—

(a) Personal care services means services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care

facility for the mentally retarded, or institution for mental disease that are—

(1) Authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State;

For example, in 2006, Idaho passed S. 1339 that amended the existing law to remove the standard which requires that personal care services be ordered by a physician or authorized provider. New York State can and should make this regulatory amendment.

II. PRIORITY AREA: WORKFORCE

General Problem Statement: *The systems are not in place to recruit, train and maintain sufficient community-based direct care workers necessary to support people with disabilities and seniors in the community.*

Issue: There is a lack of direct care workers necessary for community-based services, particularly attendants. It is essential for the State to expand the pool of attendants in order to give people with disabilities the opportunity to live in the most integrated setting.

Recommended Action:

The relationship between an attendant and the consumer is essential to the success of the any home care service, but the ability to select who comes into your home is a critical component to the success of the Consumer Directed Personal Assistance Program. To increase the savings generated by using CDPAP, the State needs to implement policies which would promote the use of that model. Because of the type of assistance that is being provided, individuals with disabilities, particularly seniors, often prefer having a family member serve in this role. Family members often make the choice to institutionalize a senior because they do not want to have strangers in their homes.

The State should amend NYS regulations regarding payment to family members for attendant services to be consistent with federal regulations. According to federal regulations [42 C.F.R. § 440.167], personal attendants cannot be a family member who is “legally responsible” for the care of an individual. This is interpreted to include spouses and legal guardians (parents) of minors. New York State regulations [18 NYCRR § 504.14(h)(2)] are more restrictive than federal regulations and expand the prohibitions on attendant employment to certain members of the consumer’s family to include spouse, parent, child, son-in-law, or daughter-in-law.

Previous efforts at addressing the need for direct care workers have not focused on significantly expanding the pool of workers but have focused on making the job more appealing to people interested in this work by providing improved

benefits or a career ladder. While these efforts have had some impact they have generally drawn from the same pool of workers rather than expanding it. By expanding the ability to pay nonlegally responsible family members to provide assistance, the State would be drawing in workers who generally would not be doing this type of work with the potential for significantly increasing the pool of workers and addressing a critical shortage.

Additional Recommended Action:

Develop a program to train people with certain disabilities to join the workforce as personal care attendants. According to the U.S. Bureau of Labor Statistics, the September 2009 unemployment rate of people with disabilities was 16.2 percent, compared with 9.2 percent for persons with no disability. Clearly, the unemployment rate among people with disabilities is significant and this group of people represents an untapped resource for direct care workers and attendants. Although generally not considered as potential workers, many people with certain types of disabilities (i.e. psychiatric or developmental disabilities) already provide some level of personal assistance on an informal basis. Direct care employment may be a good fit for this population because they may be more comfortable assisting with basic tasks and more committed to the concept of supporting people who want to live in the most integrated setting. Ultimately, this approach creates opportunities for people with disabilities to be competitively employed and expands the pool of potential direct care workers. The disability community has been suggesting such an approach for about seven years. The difficulty in getting such an initiative started is that it is difficult to get one state agency to invest in a model that creates savings in another area. The Independent Living network – because it is a consumer controlled model that hires people with disabilities – is most likely to implement such a model successfully.

Issue: There is a lack of consumer control in HCBS waivers.

Recommended Action:

Consumer directed services are less costly to the State than medical-model service provision, which reinforces people's dependence. If you assume an individual is going to be as independent as possible, they will be. The State should expand consumer direction into Medicaid waiver services so that a consumer or designated surrogate is empowered to hire the people who provide assistance, including their family members. Under current State policy, individuals enrolled in Medicaid HCBS waivers may be able to select, manage, and dismiss people who provide personal care and health-related activities such as tracheostomy care, but must use licensed home care services to provide safety monitoring, which is a far less skilled task and could easily be done by a CDPAP attendant. Expanding consumer direction into the waivers will give consumers more control and reduce Medicaid spending.

Issue: Informal caregiver burnout is an ongoing problem.

Recommended Action:

While, NYS should not mandate informal caregiver supports, it should provide support to those networks. In 2000, Under the Older Americans Act, Congress established the National Family Caregiver Support Program. New York’s Family Caregiver Support Program is available for informal caregivers supporting seniors—leaving a clear systems gap for informal caregivers for people with disabilities. According to NY Connects, “services for caregivers include: individual counseling; organization of support groups and training for caregivers to assist them in making decisions and solving problems related to their caregiver roles; respite care to enable caregivers to be temporarily relieved of their responsibilities; and other supplemental services. The goal is to enable persons caring for an elder to continue their important work by providing them support based on their unique circumstances” (NYConnects.org). The State should promote these supportive programs.

According to AARP, while some of these supports may exist, there are vast disparities in availability and implementation across the state. “Despite a broad array of available services, local access to program information or services varies considerably. Programs may make services available in one part of the state but not others, or they may use differing eligibility criteria and service limits. Therefore, even within the same state, caregivers may not find the same package of services available and may have difficulty determining where to go for help” (*Family Caregiver Support Services: Sustaining Unpaid Family and Friends in a Time of Public Fiscal Constraint*. Lynn Friss Feinberg, Sandra Newman, and Wendy Fox-Grage, AARP Public Policy Institute, April 2005). At the very minimum, the Department of Health should offer the following services to informal caregivers of people with disabilities:

- Respite;
- Information on how to balance the consumer’s needs with those of the informal support provider; and
- Community-integration counseling for family members of consumers.

III. PRIORITY AREA: IMPROVE ACCESS TO COMMUNITY-BASED SERVICES

General Problem Statement: The traditional model of long term care services emphasizes a medical model approach to meeting needs, often involving high cost professionals. The current system is fragmented based on classifications of diagnosis and age – reflecting an outmoded and impractical approach to meeting very real human needs. Furthermore, the State inconsistently enforces regulations and the counties make erratic decisions, sometimes directly in violation of Federal and State mandates.

Issue: The current long term care system in New York State over-emphasizes a medical approach – requiring high cost professionals to deliver services and supports.

Recommended Action:

The State should de-medicalize the system and promote independent living models of assistance, which are not only preferred by consumers but are more cost-effective. Amend the Nurse Practice Act (NPA) and the waivers, where necessary, to allow more opportunities for non-medical workers to provide services, such as medication administration. Since family members are allowed to provide a skilled service than so should direct care workers under the supervision of the consumer or family member.

Recommended Action:

The first step toward this goal would be to make consumer directed services the first option that people are given. By giving people control over their services, we create the expectation that they are independent and promote autonomy and self-reliance rather than dependence. Instead of perpetuating the current system that provides traditional medical-model care to people with disabilities, the State needs to expand the consumer directed model. Additionally, the State should develop approaches that build different levels of consumer direction within the traditional model of home care. For example, personal care providers and certified home health agencies (CHHAs) could be required to offer the opportunity for basic self direction so that consumers could develop those skills and eventually move to complete consumer direction of their services, thus reducing the cost of their services.

Issue: Home and community-based waivers are structured based on diagnosis and age, rather than functional need.

Recommended Action:

On June 22, 2009, the Center for Medicare and Medicaid Services (CMS) issued CMS-2296-ANPRM, an advance notice of proposed rulemaking to recommend changes to the home and community-based services, 1915(c) waiver program. The advocacy community fully supports CMS' effort to remove regulatory barriers to allow states to develop HCBS waivers based on functional need, not diagnosis.

The Department of Health's comments on the ANPRM submitted to CMS clearly indicate that DOH recognizes that the current silo'ed system of service delivery based on age and diagnosis, not need, needs to be reformed (Letter to CMS from Deborah Bachrach, August 21, 2009). While it is evident in DOH's comments that DOH is concerned about unintended consequences of the proposed changes, such as "possibility of service dilution for unique populations," it is important for the State to bear in mind that while CMS has only proposed changes to HCBS, the bigger take-away is that the feds recognize that the system is flawed. Given the interest of CMS in moving toward a 1915(c) waiver construct that allows the state to mix populations, DOH should begin discussing this approach with disability advocates. Ideally, the State would move to a generic 1915(c) that incorporates

the service menu of all the various waivers. To be clear, we are not advocating for the development of an 1115 megawaiver, which the State had proposed as an apparent mechanism for eroding community-based services. Rather, this approach would consolidate services for people who meet the institutional level-of-care requirement, thus reducing the administrative costs associated with managing multiple 1915(c) waivers.

This approach would significantly increase the pool of waiver participants, thus reducing the difficulty associated with budget neutrality on smaller programs, allowing more people with significant needs to enter the waiver and receive services in the most integrated setting. This would also expand the options available under the waivers. For example, people with development disabilities who must live in group settings such as Individual Residential Alternatives (IRA) may now have options to receive services in other more integrated community-based settings.

In the short term, the Department should fold the TBI Waiver into the NFTD Waiver for the same reason as mentioned above. It would not only save the State significant administration costs, but it will also increase the pool necessary for cost-neutrality budgeting. This should be allowable within CMS formulas because individuals on either the TBI or NFTD Waiver would be eligible for the same level of institutional care.

Issue: There are significant county-to-county disparities with personal care and CDPAP, which violate the State's obligation to comply with CMS' requirement for statewideness, often forcing people into unnecessary nursing facility placement.

Recommended Action:

Even though Federal law requires that Medicaid State Plan services be available statewide, many counties implement the long term care programs differently. The Department of Health has addressed the inconsistencies in the Medicaid eligibility determination process, but has not addressed the inconsistency in the authorization of the long term care services. There are dramatic differences between upstate and New York City, and even among upstate counties. The State needs to determine a consistent application of the regulation that will be implemented across the state and stop the counties from creating their own rules and requirements. One way to increase consistency is to remove the counties from their existing role and allow the contracts for personal care to be held directly by the State. Counties would serve as fiscal agents and would administer the contract, but the State would ultimately still be the holder of the contracts with the service providers.

It should be noted that in recognition of these county disparities, the Department of Health established the Long Term Care Assessment Center demonstration. Advocates across the state worked with DOH to ensure that the development of the assessment centers would not simply be a mechanism for cutting hours in

New York City. DOH assured advocates that one of the assessment centers would be upstate – where there is a strong prevalence of counties limiting hours. Unfortunately, DOH selected Orange/Ulster Counties as the “upstate” region in the Request for Proposal (RFP No.0907070849), proving that the Department of Health does not understand or propose to address this issue inflicting the upstate region. The State cannot continue to condone these inconsistencies by the counties and advocates will continue to work with the State to ensure that people receive the hours necessary to maintain people in the most integrated setting.

Issue: Home care agencies do not always accept people with complex long term needs and the proposed home care prospective payment system (PPS) exacerbates this problem.

Recommended Action:

The proposed home care prospective payment system (PPS) appears to be more about reducing hours of home health services than it is about reimbursement reform. Clearly, the proposed system will create financial disincentives to treat the highest cost outlier cases, which will ultimately shift this long term care population from home care toward more costly institutions. As recommended by Consumer Directed Choices and Selfhelp Community Services, the two consumer advocate representatives appointed to the home care reimbursement workgroup, “we urge the delay of implementation of a new reimbursement methodology until such time that the enacted assessment changes are in place and measured for consumer outcomes and their ability to address consumer need” (Comments from Selfhelp Community Services and Consumer Directed Choices, October 21, 2009). The assessment center demonstration, the proposal to eliminate subcontracting between CHHAs and LHCSAs, and the proposed PPS appear to be mechanisms to control costs under the guise of long term care reform that, if done correctly, could benefit people with disabilities. The State should not reform the entire home care reimbursement methodology in an attempt to harness spending by the identified seven agencies. More analyses of the proposed PPS – and ultimately the assessment center demonstration and subcontracting arrangements – is necessary before the State makes drastic changes to a system that could result in unnecessary institutionalization of people with disabilities.

Issue: Assistive technologies are essential to removing barriers to community-based living and can offer solutions that reduce dependence on home care services, yet these are underfunded and underutilized.

Recommended Action:

While there are options for assistive technologies under the waivers and through vocational rehabilitation, generally this type of assistance has been overlooked by the NYS Department of Health which oversees much of New York’s long term care system. Discussions about the use of technology and equipment have generally focused on telehealth as opposed to meeting more basic needs of individuals who want to live independently. Technology, however, has the

possibility of significantly reducing long term care costs. For example, people who require 24-hour or overnight home care because they are unable to get out of bed independently to open the door for the morning attendant could potentially reduce hours if they were provided with assistive technology which allows them to open the door. Emergency home response systems provide safety for individuals at risk of falling.

To make technology more readily available, the Department of Health should use the next round of HEAL funding to expand the Technology Related Assistance for Individuals with Disabilities (TRAID) program. TRAID is a federally-funded project administered by the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities. In New York, the TRAID dollars have been used to establish regional technology centers that are providing information, borrowing, and referral services for persons with disabilities of all ages. The TRAID Centers work to improve people's access to assistive technology equipment and services. Under the NYS Commission on Quality of Care and Advocacy for Persons with Disabilities, the TRAID program provides coordination of assistive technologies for assistance in education, employment, community living, and information technologies. There are twelve Regional TRAID Centers (RTCs) across the state. While this provides a strong foundation, the State needs to expand this program. The next round of HEAL funding provides a funding mechanism for expanding the TRAID program. The State could then coordinate the efforts of the TRAID project with the Regional Resource Development Centers for the waivers to enhance the use of technology in promoting individual independence.

Issue: CHHAs may decide not to serve individuals because they do not have sufficient staff to meet the individual's needs, forcing people into institutional placements without the opportunity to be considered for services when additional staffing may be available.

Recommended Action:

The State should develop a system that tracks the approvals and denials for home care services and allows people who have been denied services to be placed on a waiting list. The creation of a waiting list would assure that homecare agencies are not "cherry picking" easy-to-serve consumers while people with more significant assistance needs are forced into institutional placements. The waitlist would provide a mechanism for identifying people who could readily transition from an institution back to a community-based setting.

IV. PRIORITY AREA: QUALITY ASSURANCE

General Problem Statement: *Under current models, short term hospitalization for acute care disrupts the relationship between the direct home care worker and the individual.*

Issue: Seniors and people with disabilities do not get the services they need when they

transition from a community-based to a hospital-based setting. Due to Medicaid laws that prohibit double-billing, attendants cannot provide services in a hospital.

Recommended Action:

As Vince Reiter, from the Independent Living Center of the Hudson Valley, mentioned at the last two DOH MISCC Stakeholder meetings, he had a CDPAP consumer who went into the hospital and went hungry because there was insufficient hospital staff to feed him. Generally, hospitals do not have the staff to assist people with significant disabilities. In addition, consumers have difficulty maintaining employment of their attendants while they are hospitalized, which disrupts their services when they return to the community. CMS allows for a “hold payment” to attendants for people on HCBS waivers when they enter the hospital; however this payment mechanism is not available in the State Plan. For consumers receiving services in CDPAP, the State should allow consumers to enroll into the NFTD Waiver to receive service coordination and the discrete service of a “hold payment.” This would create an increase in enrollees in the NFTD Waiver and would allow for consumers in the CDPAP to maintain their attendants through hospitalization.

At the last Department of Health MISCC Stakeholder meeting, DOH was very amenable to advocate recommendations, which was very encouraging. Though the representation of stakeholders was quite diverse, the group was able to arrive at a consensus on four priority areas: (1) Transition of Care, (2) Workforce, (3) Improving Access to Community-Based Services, and (4) Quality Assurance. The above recommendations in each priority area provide concrete action items for the State to remove barriers to community integration. As they are implemented, the State will continue toward compliance with the Olmstead decision’s requirement to provide services in the most integrated setting appropriate to individuals’ needs.

**Southern Tier Independence Center, Inc.
Comments on the Draft 2010-11 MISCC Plan**

Introduction

Southern Tier Independence Center, Inc. (STIC) is a Center for Independent Living located in Binghamton, NY. In operation since 1983, STIC provides several programs and services, including not only core Independent Living services but also Service Coordination, HCBS Waiver RRDCs, Day Habilitation, a TRAIID Center, an Early Childhood Direction Center, a supported employment program, a CDPA program, and a sign-language interpreter referral program. We serve a very large geographic area of the state, and well over 3000 people annually. In our comments last year we provided more detail on STIC’s expert qualifications on all areas of disability services and policy. In the interests of brevity, we won’t repeat that here.

In preparing comments this year we tried to obtain information on various projects mentioned in the plan but were hampered by the extremely short notice (less than three

weeks, which included the long Thanksgiving holiday) required for comments. Also, the three links to documents related to the MISCC's October 5 meeting on the MISCC website were dead as of November 25.

General Principles

STIC is pleased to see that this year's document is a "plan" rather than a "report", that its format enables identifying systems change objectives with time frames and lines of responsibility, and that a few of the specific items therein appear to be constructive. We understand that the MISCC intends to flesh this out with much greater detail during the coming year.

However, the content of this document shows that the MISCC continues to engage in several of the same undesirable patterns of behavior that we identified in our comments last year. Rather than discuss them in detail everywhere they appear in the plan, we've laid out some general points here which, had they been followed while the plan was being developed, would have resulted in a much better product. The MISCC needs to follow these principles in the future.

Legal Framework

MISCC members should study the recent US District Court decision in *DAI v Paterson*, which includes three important findings: First, illegal "unnecessary segregation" under ADA Title II is not determined by the size or location of facilities, but by the restrictions and limitations they impose on the people who are in them. Second, "*most* integrated setting" is a serious mandate; if it is possible to provide a setting that is more integrated than what is currently available, even if the current setting has some integrated elements, states are in violation of the Americans with Disabilities Act unless and until they provide that setting. Third, states must reallocate existing funds if needed to comply with these requirements. The court found that integrated options are cheaper than segregated options in the aggregate. A state cannot claim that it "costs too much" to increase availability of integrated options that it already provides in some amount if, at the same time, it also pays for more expensive segregated options to meet the same kinds of needs.

Basic Principle 1: Reallocation of Existing Funds

Effective reform of NY's disability service systems will require major reallocation of existing funds. In many cases this means moving funds from less efficient segregated congregate programs to more efficient individualized integrated services. The state will then be able to serve more people with the same amount of money. Therefore the current fiscal crisis is not an important barrier to achieving significant reforms, and the MISCC should stop citing it as a reason for offering limited initiatives. Instead it should lay out plans and timetables to reallocate existing funds to decrease use of segregated congregate modalities and increase the availability of integrated individualized services. Where legislative reappropriations are necessary to achieve these results, the MISCC should not hesitate to recommend the appropriate legislation.

Basic Principle 2: Plan for the Future

The MISCC Plan should consist solely of goals, action steps, timetables, and measurable indicators for future activities that address documented high-priority needs.

Basic Principle 3: Comprehensive Planning

Implementation items in the plan should be the result of analysis and deliberation by the entire MISCC. They should reflect a comprehensive effort to ensure that all of the resources that all of the state agencies have available for services for people with disabilities have been prioritized and directed toward achieving the goal of maximizing the ability of people with disabilities to receive supports and services in the most integrated settings. Items already on the agenda of a state agency should be in the plan only if they are the best use of resources to meet a high-priority need; items that don't meet these criteria should not only not be in the plan, they should be dropped by the relevant agency and their resources reallocated to higher-priority items.

Specific Items

Housing

NYSOFA

NYSOFA has three items targeted toward “communities”: “recommendations that will help facilitate the ability of communities to address development barriers and challenges related to housing, planning, zoning, universal design, green building, energy alternatives, mobility, transportation, and livable communities;” “complete a technical assistance resource manual as a tool to assist communities in creating more livable communities;” “regional or community educational and technical assistance events related to the areas of housing, planning, zoning, universal design, green building, energy alternatives, mobility, transportation, and livable communities.”

It is unclear what “communities” means in this context. The housing issue can be simply defined: there is a lack of accessible, affordable housing for people with disabilities, especially in the more dense urban areas of the state. The only viable solution to the problem is to build more housing, and that costs money. “Communities” don't have money and they don't build housing. Governments and private real estate developers do. When it is difficult to get low-income housing built in certain areas due to zoning issues, laws can be passed to correct the problem. Neither the MISCC nor NYSOFA are grass-roots housing advocacy agencies; they are arms of state government. Their role is not to organize “communities” to build housing, their role is to recommend to state government that it enact laws and appropriate funds to build housing and/or to create effective incentives for private developers to build housing.

Existing funds can be reallocated for this purpose. For example, the latest estimate of the cost of keeping a single person in a developmental center for a year is \$1.2 million. Quite a few accessible, affordable housing units could be built, or existing units renovated for accessibility, or individual housing subsidies provided, with that money.

There is value in promoting universal design. However, appropriate educational materials for this already exist and creating more doesn't seem to be a good use of scarce state dollars.

CQCAPD

The TRAIID Project item does not comply with Basic Principle 2, above. It is a report on past activities. It contributes nothing of value to the plan and should be removed. If the entire MISCC, after careful consideration, decides that expanding TRAIID would increase access by people with disabilities to supports and services in the most integrated settings enough to justify the expenditure of resources, then an item calling for such expansion should be included in the plan, along with a description of how funds will be reallocated for the purpose..

OASAS

The two OASAS items on increasing the availability of "Permanent Supportive Housing" are very good examples of how implementation items should be phrased. They are specific and measurable. They also *appear* to respond constructively to the overall goal of enabling people with disabilities to receive supports and services in the most integrated settings; i.e., "apartments" rather than "group homes" will be created.

However, some of these programs are congregate residential facilities, and others, though called "scatter-shot", actually are clusters of several apartments within the same building. Neither of these qualifies as the most integrated setting for many people with substance abuse disabilities. "Permanent" in this context appears to mean "not time-limited"; there is mention of people taking over program apartment leases from the provider agency once they have enough income. However, it's not clear what happens to the case management and other services at this point, nor are many people likely to want to stay in a congregate facility once they no longer need support services. Many people with substance abuse issues don't need intensive supports for their entire lives and should be able to "graduate" into completely typical lifestyles at some point.

Given the entire spectrum of needs of people with disabilities in New York State, we are also unsure whether these proposals, constructive as they may be in isolation, would truly be the best use of limited state funds. We are fairly sure that they did not result from comprehensive consideration of all needs, priorities, and available funds as prescribed in Basic Principle 3, above. They appear to be a subset of OASAS activities that "fits" within the MISCC mission. If this is a high priority, perhaps a greater percentage of OASAS funds should be allocated to it, and other OASAS activities curtailed, so that more people can be served. Perhaps housing homeless people with disabilities, regardless

of diagnosis, is a high enough priority that all of the state agencies should be reallocating more funds in that direction.

OASAS does provide some more truly integrated housing supports. And we know that some of this comes from a well-intentioned effort to leverage existing program models and funding to get some new housing units, which are definitely needed, built. But we must emphasize that there is no substitute for modifying state policies, priorities, and funding allocations in order to simply build and/or renovate more accessible low-and-moderate income housing, with no services attached, in urban areas. It must be understood at the highest levels that this isn't just a disability-service-agency problem to solve; it is the responsibility of state government as a whole.

OASAS housing data provided to the MISCC in September 2009 mistakenly conflates facility size with level of integration. As the *DAI v Paterson* decision makes clear, integration is not related to the size of a facility; it is determined by the extent to which residents have independent freedom of action, and the ability to interact and form relationships with nondisabled people who are not paid to serve them. The fact that a facility has "24 beds or less" does not make it more integrated than a "large facility". All segregated congregate residential facilities of any size have a low level of integration.

DDPC

The two DDPC items do not define useful measurable outcomes. They state that DDPC will carry out a specific number of "activities" but they do not project measurable benefits to people with disabilities from those activities.

That being said, we realize that the DDPC is essentially a research body; it funds demonstration projects that may or may not be replicated if successful. Many DDPC projects have directly and constructively responded to the goal of enabling people with developmental disabilities to receive services and supports in the most integrated settings, including enabling them to have greater control of their own lives. The MISCC could most effectively make use of the DDPC's limited resources by directing OMRDD to allocate significant resources to replicating some of the DDPC's most successful projects on a widespread basis.

DOH

We applaud the DOH and DHCR item to "Increase the number of people participating in the Nursing Home Transition and Diversion (NHTD) Waiver Housing Subsidy."

We dispute the claim in the DOH housing data provided to the MISCC in September that the integration level of "assisted living" is "medium". Many assisted living facilities are indistinguishable from nursing facilities except for the intensity and range of services available in them. They are not in any sense integrated. The correct level for "assisted living" is "low". However, DOH also called the integration level of hospice services "medium", and labeled personal care services as "high" while marking CHHA services as

“medium”. Hospice services are often provided in the person’s home; their correct integration level is “varies”. DOH should be asked to break out data for in-home and facility-based hospice services. Both personal care and CHHA services are delivered in the person’s home and/or workplace. The main difference between them is the extent to which the services provided are truly medical. The integration level for both should be “high”. Perhaps DOH confused “integration” with “medical intensity”?

DOH’s housing data lumps “scattered site” and “congregate” supportive living services into one category and gives it a “high” integration level. This is incorrect. Congregate residential programs are not highly integrated. The correct designation here is “medium”. DOH should review the *DAI v Paterson* decision and reconsider its designations. DOH should also be required to break out numbers separately for scattered site and congregate programs.

OMRDD

We support the OMRDD item to “Decrease the number of people with developmental disabilities living in Developmental Centers and stop the acceptance of new admissions.” However, this is a very limited response to a very significant problem.

MISCC members may not know that the term “developmental center”, in OMRDD parlance, no longer refers to a building; it is purely a programmatic designation. This item does not commit OMRDD to reduce the number of people in large congregate institutions or to stop admitting new people to them. OMRDD is dividing its large institutions into multiple programs. Portions of the buildings allocated to “developmental centers” are decreasing. But portions allocated to other equally undesirable congregate institutions, such as “Local Intensive Treatment” (LIT) units, are remaining static or expanding. The MISCC should direct OMRDD to submit items to reduce the number of people in all forms of segregated congregate facilities, regardless of size or location. The detailed plans produced next year should show timetables, specific numbers of people to be moved, closure dates for segregated congregate facilities, and dollar amounts to be reallocated from those facilities to integrated individualized services.

We cautiously support the OMRDD item to “Increase the number of people with developmental disabilities who live in a home or apartment of their own.” However, in the absence of additional information, we must raise serious questions.

First, it is not clear that this item refers to anything more than expanding—or perhaps only continuing at current levels—OMRDD’s “Home of Your Own” program, which is narrowly targeted to establish trust funds and other mechanisms to enable a relatively small number of families to purchase homes (houses or condominiums) for their relatives with developmental disabilities. This would be a good thing to do, of course, but given all other relevant factors, it may not be the most appropriate way to make use of the resources involved.

If, however, this item actually means that more of the people served by OMRDD will live in individual integrated settings regardless of ownership, OMRDD can easily meet the goal by putting one more person into an apartment between now and December 31, 2011. The forthcoming detailed plans must include a specific, significant projected numeric or percentage increase in people living in these situations in order for this item to have credibility.

Also, it's unlikely in this fiscal climate that significant new funds will be provided for this purpose. In order to have a credible plan and comply with Basic Principle 1 above as well as with the spirit of *DAI v Paterson*, and save the state the expense and embarrassment of further legal challenges, OMRDD will have to reallocate significant amounts of funds currently used for segregated congregate residential services. It will not be acceptable for OMRDD to scale down projections, or delay implementation of this item, on grounds that no new money is available.

“Step down” group homes and “backfills” are not acceptable. OMRDD has had a legal obligation to prepare the people living its institutions for true community integration for over two decades. The fact that in many cases it has failed to do so is not an allowable excuse for further delaying the integration to which these people are legally entitled. OMRDD must quickly roll out a “train-in-place” model and move people directly to fully integrated individualized living situations, with appropriate supports as necessary. As part of this reform, OMRDD must cease its practice of discharging “voluntary” residents from developmental centers without putting adequate individualized integrated supports in place for them, and must also cease its practice of terminating service eligibility for people who have been dependent on its institutions for their entire lives on the basis of “new evidence” indicating no developmental disability. The detailed plan to be provided in the next year must include timetables for the transfer of both money and people from segregated congregate facilities of all sizes to integrated individualized residential supports, as well as closure dates for segregated congregate residential facilities of all sizes.

Projects to build or renovate any new segregated congregate residential facilities that have not already broken ground must be cancelled, and those funds used for new integrated individualized residential supports for people moving out of segregated congregate facilities until those facilities can be closed and their funding reallocated. The only allowable exception on this point would be temporary respite or crisis-response facilities, which OMRDD sorely lacks—though policies and procedures for these facilities must strictly prohibit long-term stays.

It is disturbing that OMRDD, probably the largest operator/funder of housing for people with disabilities in the state, did not provide any housing information to the MISCC as part of the September “MISCC 2009 Housing and Employment Data” document. Why did OMRDD fail to identify the integration levels, numbers of people served, and amounts of money spent, on its various housing programs? How is it possible that the Chairperson of the MISCC, who requested this data from the other member agencies, was permitted to skip furnishing this information about the agency she heads? How can the

MISCC possibly produce a coordinated, centrally prioritized plan without this information? Who in New York State government is responsible for requiring OMRDD to produce this data and make it public?

DHCR

It is remarkable that, given the centrality of DHCR to any viable state effort to increase the availability of affordable and accessible housing for people with disabilities, there are so few DHCR implementation items in the Housing section of the plan, and those items are extremely limited in potential impact. We applaud DHCR's previous efforts to create greater incentives for housing developers to build accessible, adaptable, and/or visitable housing units. However, there is a need to monitor and evaluate the effectiveness of those efforts; this should be a plan item. Also, NY is under a court order to find individual integrated housing options for some 4300 adult "home" inmates as soon as possible. It should be a high priority to reallocate at least some existing housing construction funds for projects that haven't yet broken ground to meet this need.

In this context, we're unsure what value the proposal to increase inter-agency "collaboration" on the Access to Home program will have. It would be much more productive to reallocate some existing funding from relatively low-priority projects to expand this undeniably helpful program. And quite frankly, we have yet to see any significant benefits result for people with disabilities from repeated efforts to boost "inter-agency collaboration" in New York State. A better use of resources would be to reorganize programs so that their administrations do not cross agency lines. "Collaboration" then would no longer be necessary and instead there would be clear lines of responsibility and accountability for failure to deliver services properly.

Improving the impact of www.NYHousingSearch.gov is a nice idea. However, there are other more pressing needs, such as construction of additional housing units, that are more urgent.

Unaddressed Housing Issues

The plan's Employment section contains a commitment to redirect resources to increase integrated employment for people with disabilities. The Housing section should also commit all of the agencies that operate or fund housing for people with disabilities to redirect resources away from segregated congregate housing to individualized integrated housing supports.

Employment

All MISCC Agencies

We applaud the commitment to redirect resources as needed to increase integrated employment. Although this is only one of several employment implementation items, in

the current fiscal climate it is the most critical to achieving significant improvement in employment for people with disabilities, and it should be given the highest priority among employment goals.

We expect detailed plans and timetables for how this will be done. These plans should state how funds will be redirected away from sheltered workshops, “enclave”-style supported employment, “affirmative businesses”, and other work and day programs that either are segregated congregate facilities, exist primarily to provide jobs to people with disabilities, or both. There must be a commitment from every agency to do this, including CBVH. In addition, the MISCC must direct CBVH to stop promoting workplaces for people with disabilities that are sheltered, segregated, and/or exist primarily to employ people with disabilities, and also to stop advocating with RSA to loosen its restrictions on use of such programs to achieve acceptable “employment outcomes”.

It won’t be possible to develop such a plan without complete data, however. In September the MISCC received employment data from its member agencies. Most agencies provided complete information on segregated and integrated programs, with numbers of people served and amounts of funds allocated. But the state’s two vocational rehabilitation agencies, VESID and CBVH, did not provide complete data. Although VESID can’t use federal funds for services that don’t lead to integrated “employment outcomes”, those are not the only funds VESID has. We believe VESID uses some of these other funds to directly or indirectly support segregated programs and should be required to provide information about it. CBVH proudly promotes its use of sheltered, segregated, and/or special-purpose disability employment programs, but didn’t provide any data on them to the MISCC. It said only that its undifferentiated “vocational rehabilitation” program has a “high” integration level. This is demonstrably false. CBVH defines “integrated setting” to include segregated congregate facilities in which some program staff do not have disabilities, but this definition is not allowable under federal regulations and should not be accepted here. CBVH must provide accurate information on the integration levels of all of the employment programs that its clients are in, the numbers of clients in them and the money spent to support them.

Training workers in the disability field on best practices to ensure integrated employment is a good idea. However, if funds are not redirected as described above, the training will achieve very little. Most supported employment providers already know how to achieve results; what they lack is sufficient funds to meet the needs.

We support the idea of “Development of employment focused policy across State agencies and community partners that reflects the expectation that all individuals, including youth, can work when the proper supports and services are provided.” We think special attention should be paid to school-to-work transition. School districts are required by federal and state law to provide this service, and VESID is required to see that they do so. However, most school districts do not have effective programs to move graduating students with disabilities who are not college-bound into integrated competitive employment, and VESID has done very little to enforce the law.

NYSOFA

Two items involve strategic planning grants to enable older workers to stay in the workforce. While this is a laudable goal, we must point out that in a state where over two-thirds of people with disabilities of typical working age are unemployed and dependent on public assistance, it would seem that scarce resources would be better spent elsewhere. We realize these are specific grants for a particular purpose. This is why the MISCC should follow Basic Principle 3 above to establish unified statewide priorities and funding recommendations, *before* grants are applied for, rather than simply uncritically inserting various agency “pet projects” into the plan. If NYSOFA has NYS funds available for this effort, they should probably be redirected into VESID supported employment services.

There is an item to “Enhance the working relationship/collaboration between the New York State Department of Labor Workforce Investment Board’s One-Stop-Centers and older worker employment programs supported by the New York State Office for the Aging to produce sharing between New York State’s employment training structure and those agencies serving older adults with disabilities.” This item as stated is not measurable, and we don’t see how it could be restated to become measurable. As we’ve said, numerous “cross-agency collaboration” efforts undertaken in the last two decades have failed utterly to produce significant results.

In any case, the “One-Stop-Centers” have a poor reputation in the field. When it comes to serving people with significant disabilities, they aren’t “one-stop” at all; when such people go to them they are invariably sent somewhere else. This is appropriate. Overcoming widespread discrimination, and providing appropriate supports, to enable people with significant disabilities to achieve integrated employment is a very specialized activity. Funds for training employment service providers on geriatric disability issues should be used to train the actual people who serve that population, and not diffused through a little-used referral mechanism.

OMH

Regarding: “OMH will work to promote and increase the number of Employment Networks for persons participating in the Ticket to Work Program, provide technical assistance to sheltered workshop programs to assist them in transitioning to other forms of employment support, and promote SSA and other work incentives.”

Only the part about increasing Employment Networks here is measurable. Unfortunately, like “One-Stop Centers”, “Employment Networks” and the “Ticket to Work” program have poor reputations. Putting more money into them would be sending good money after bad. Instead, all employment services for people with disabilities should be centralized under VESID, and OMH funds used for that purpose should be redirected to VESID.

There are two other completely different issues in this item: sheltered workshop transition and promoting work incentives. These should be separate items, restated in measurable

terms with dollar amounts by which support of these activities will be increased and numbers of people who will benefit.

“Technical assistance” will be of some use to organizations that are converting from sheltered to integrated employment services, but the real need is to temporarily subsidize their existence during the transition, when neither dwindling numbers of sheltered clients nor slowly increasing numbers of integrated clients generate enough funding to keep either program in operation. The way to do this is to move per-capita funding for integrated supports closer to parity with that for sheltered work. We expect to see that as part of the “all agencies” plan for redirecting resources.

Promotion of work incentives should probably be combined with the next OMH item, to promote use of the Medicaid Buy-In. And all MISCC agencies that are involved with employment services, not just OMH, should be promoting the Buy-In and other work incentives.

VESID

Improving the Supported Employment Memorandum of Understanding is a dead letter. That MOU should have kept OMRDD from unilaterally trying to foist certain supported employment consumers onto VESID and its contractors, without a concomitant transfer of funds, on two occasions in the last few years—yet it didn’t. Meanwhile, VESID’s focus has moved away from people with the most significant disabilities. In an apparent effort to quickly maximize “employment outcomes”, resources have been diverted to serve those with the fewest needs. This has left many people with developmental disabilities cooling their heels in segregated congregate day activity programs or sheltered workshops while on waiting lists for VESID services.

“Interagency collaboration” is a failed model. There is no mechanism for establishing unified priorities, no one is held accountable for implementing it, and it does not significantly improve outcomes for people with disabilities. It should be scrapped. Instead, all supported employment services and funding should be solely administered by VESID. Then VESID officials could be held accountable for all aspects of service quality and outcomes.

This applies to school-to-work transition too. The federal Individuals with Disabilities Education Act makes VESID responsible for enforcing transition requirements. VESID does not do this well, but diffusing lines of responsibility and accountability across state agencies will make things worse by both confusing school district administrators and enabling them to play agencies off against each other. All programs and funding related to school-to-work transition for students with disabilities should be moved to VESID. VESID must revamp policies and redirect resources to create an effective enforcement system that motivates school districts to obey the law.

As for direct transition services, VESID’s change of focus has led it to emphasize financial aid for college-bound students and “direct placement” for people who need very

little help. Students with the most significant disabilities are placed on waiting lists for intake and/or services, and referrals to supported employment have dropped. The MISCC must direct VESID to refocus on serving people with the greatest need for specialized employment services, including students in transition.

And finally, there is no reference anywhere in the plan to the impact of special education services on employment outcomes for people with disabilities.

School districts in New York State still rely too heavily on BOCES programs, “alternative schools”, and segregated classes within neighborhood schools. These programs produce poor academic results compared to integrated classes, and therefore graduate large numbers of students with disabilities who are ill-prepared for working life. VESID does not devote enough resources to its IDEA enforcement responsibilities, and it is reluctant to confront school officials.

VESID does not effectively enforce IDEA requirements for schools to provide positive behavioral supports for students who need them. It does not have effective policies to limit overuse of restraints and seclusion, to prevent abuse of students with disabilities by school employees, or to investigate and prosecute abuse when it occurs. These failures cause or exacerbate emotional, mental, and even some physical (such as TBI) disabilities, further reducing employability. VESID needs to modify policies and redirect resources to ensure effective enforcement of IDEA provisions for positive behavioral supports.

The MISCC needs to endorse and join efforts by advocates to obtain strong state and federal legislation to limit use of restraints and seclusion and provide effective mechanisms to identify and prosecute abusive school employees. Certain actors have spread misinformation to the effect that SED’s new “aversive treatment” policy adequately addresses this issue. It does not. It does not limit school districts’ abilities to use physical or mechanical restraints or long-term “time out” in response to students whose behavior is not an immediate significant physical threat to themselves or others, nor does it provide a quick and effective response to documented reports of abuse by school employees that prevents further abuse or retaliation.

OMRDD

All three of OMRDD’s employment items are measurable goals. However, the term “integrated” is noticeably absent, including from the item about “businesses”; it’s important to be specific here because so-called “affirmative businesses”, which exist primarily to employ people with disabilities and are therefore not typical real-world workplaces regardless of whether nondisabled people work there, are not acceptable. And, all of these items are misplaced.

For the most part OMRDD does not fund job placement or intensive supported employment; therefore it can’t have a notable impact on the number of people with developmental disabilities who get jobs. It can assist them to keep those jobs once they

have them through its funding of “extended” long-term employment supports, but that is not what is being proposed here.

Compared to VESID and its subcontractors, OMRDD lacks expertise in achieving employment placements and the funds would be better used by VESID. Also, overlapping administration of employment services between OMRDD and VESID continues to result in unresolved eligibility conflicts and service delays. The state’s continued failure to reorganize its systems in a decisive manner to correct major administrative problems is not acceptable.

DDPC

We realize that the DDPC funds demonstration grants and has little ability to affect actual service quality or availability.

Regarding the item to “Create four additional customized employment services or resources to assist individuals with developmental disabilities obtain and maintain their employment.”: The real problem with “customized employment services” is lack of funding, not lack of effective methodologies. In the absence of redirected funding, such a project is not likely to survive after the grant runs out. It would be a better use of the DDPC’s resources to address issues that aren’t as well understood as how to provide supported employment services.

On the “Address policy, practice or funding barriers that will result in 500 young adults w/DD obtaining employment and receiving services and supports needed to maintain employment.” item: Addressing funding barriers is essential, since that is the major problem with employment supports for people with disabilities. We don’t see how DDPC can do this since it doesn’t fund ongoing services, but we’ll be interested in what they come up with.

The Project Search and post-secondary programs look worthwhile.

On the item to “Engaged [sic] in four activities that improve the capacity of generic employment services to assist individuals w/DD to obtain and maintain employment including implementation of a volunteer initiative in collaboration with the NYS Commission on National & Community Service that will assist 200 individuals with DD to move into community volunteer opportunities which may also serve to increase employability skills for participants.”: We don’t think efforts to get generic employment services to work with people with significant disabilities will bear much fruit. Such efforts have been underway for well over a decade without real results. At best, such services make referrals back to real disability employment agencies. Most people with significant disabilities won’t bother seeking real job assistance from generic services, let alone volunteer work. Those services don’t have the expertise people with disabilities need. Any incentive a DDPC project could create in this direction would be eclipsed by the services’ primary responsibility, which is to help nondisabled people find jobs, and for which they are underfunded as it is. They will never be adequately funded to assist

people with disabilities beyond providing an inefficient mechanism for referring them to the programs that actually can assist them. DDPC funds would be better spent elsewhere.

Once again, to the extent that DDPC grants have produced effective replicable models for employment services, the MISCC should examine them and direct that the best ones be replicated by the appropriate agencies on a broad basis.

Transportation

All MISCC Agencies

Having a “Mobility Manager/Health and Human Service Transportation Coordinator” in each county is a good idea. We think this is an important step toward replicating the Erie County model of mandatory accessible transportation coordination in every county—which should be the ultimate goal. We question why this is under the “all agencies” rubric rather than DOT, though. Giving each state agency a finger in this pie would impose an unnecessarily complex regulatory and reporting burden on these offices. We’ve seen DOT’s frightening organizational chart of agencies that are involved in transportation for people with disabilities. DOT should function as a firewall between that confusion and the actual implementors of transportation services. Appropriate transportation-related funds should be redirected from the other state agencies to DOT, and DOT should set goals and oversee performance for these county offices.

We do think it’s good to collect information from all possible sources on priorities for service expansion and legal and regulatory enforcement issues.

NYSOFA

While it’s a good idea to try to get volunteers and more social service agencies involved in increasing transportation options, we want to emphasize that this will only really be productive if those entities are required to participate in county-wide coordination systems to ensure that the resources are used most effectively and efficiently.

OMRDD

“Increase access to transportation opportunities for participants in the Home Of Your Own (HOYO) program” is the only OMRDD item here. This seems odd. HOYO participants, it would seem, would have access to generic transportation services to the extent that their homes are in communities that offer them. It would be preferable for them to maximize use of those services because they are integrated.

Meanwhile, a major criticism of OMRDD’s group “homes” is that the people who live in them often don’t have truly individualized and integrated community activities because transportation is limited. Instead, they tend to be taken in groups to the same places in the “house van” whether that’s where they’d really prefer to go or not. A better use of any available OMRDD transportation funds would be to beef up the ability of the very large

number of OMRDD group “home” residents to go where they want when they want, instead of focusing on the relatively small number of HOYO participants who have better transportation options to start with.

Long Term Care

DOH

Regarding “Creation of a long term care work plan that addresses the following areas: increased access to community care, improved quality assurance and accountability of health programs, transition of care from segregated to integrated settings, increased workforce opportunities and elimination of barriers that prevent individuals with disabilities from living in the most integrated settings.”

Long term care in its various incarnations is what the entire MISCC is about. Most of the member agencies provide long term care, and the impact of the long term care services that DOH provides on people with disabilities and their ability to benefit from the other agency services is pervasive. For these reasons DOH should not produce this work plan alone. This must be a joint MISCC effort driven by a unified policy direction, unified priorities and a unified funding plan.

“Workforce opportunities” must not be a priority in this kind of planning. People with disabilities do not exist to provide employment opportunities, and neither do state agencies. Job creation is a side-effect, not a goal. State governments must “balance” various interests, but the civil and legal rights of people with disabilities to the supports they need in the most integrated settings must not be abridged for any reason. This is a big industry that employs a lot of people. So is the automobile industry, and its approach to workers has had to change dramatically over the years. Technologies and consumer demand change; the industry must follow them, and what happens to workers is secondary. There certainly are things that can be done, such as retraining institutional staff to work in individual integrated settings. However, in order to meet the need, service unit costs must be decreased; that is an unavoidable fact. It will be completely unacceptable to limit or delay availability of services in order to maintain wage scales in a situation where the demand for services is escalating much faster than the available funding.

The rest of this item essentially restates the mission of the MISCC. We hope there will be much more detail in the coming year on how: nursing facilities will be downsized and closed (not converted to “assisted living”); county CDPA enrollment targets will be expanded, monitored and enforced; and Medicaid HCBS waivers combined under more effective administration. The MISCC should give serious consideration as well to the opportunity provided by the federal government in 2005 for states to create HCBS services as a Medicaid State Plan option, and/or to add the “Community First Choice” option if it is enacted as part of national health care reform.

NYSOFA

A “consumer-directed” option for the EISEP and CSEP programs seems like an excellent idea. How it works out in practice depends on how it is implemented. Consumer freedom of action must be maximized, and intrusions upon personal privacy must be minimized. Some “consumer-directed” program models don’t do those things, so we await details with great interest.

The items related to the Caregiver Council and the Community Navigator program appear to address important priorities as the percentage of the population that is elderly is increasing and there are fewer younger people who can provide care. This demographic trend, however, is so significant that the entire MISCC should assign it a very high priority and reallocate resources accordingly. Measurable objectives and timelines for this need to be in next year’s plan.

We are skeptical about the effectiveness of a state agency plan to organize consumers to advocate for what they need. Typically this type of approach results in agency-defined needs being represented as the priorities of consumers when those consumers in fact have other priorities. We think state agencies should leave community organizing and advocacy to actual community advocates.

CQCAPD

Regarding “The vigorous advocacy activities of the Protection and Advocacy Programs in representing the interests of persons with disabilities seeking least restrictive placements pursuant to their rights under Olmstead and the ADA will continue to be supported. Specific outcome measures will be reflected in their programs' annual reports.”

This is very interesting. Recently two of these PADD programs sued OMRDD for refusing to turn over to them information that they were legally entitled to receive in the course of an investigation of allegations of abuse and neglect in two developmental centers. CQCAPD sided with OMRDD and disavowed the PADD agencies. We don’t know what “continue to be supported” means here, but with friends like this, those PADD programs don’t need enemies.

Also, the term in the *Olmstead* decision is “most integrated setting”, not “least restrictive placement”. These terms are not equivalent; for one thing, a “placement” is an artificial construct designed for service provision, while a “setting” is a natural environment. “Least restrictive placement” is a term reserved for special education.

The wording of this item sidesteps CQCAPD’s ultimate responsibility for carrying out its most important role, which is to be an independent watchdog on the state “mental hygiene” agencies, including OMRDD, OMH and OASAS. Under Commissioner Clarence Sundram, CQC had an activist agenda to investigate and bring to light systemic deficiencies in the agencies it exists to monitor. This plan item appears to be designed to let CQCAPD take credit for PADD actions that don’t raise hackles elsewhere in Albany,

while distancing itself from those that do. This is unacceptable. CQCAPD collects trend data on complaints about the activities of the “mental hygiene” agencies. It should analyze that data and devote significant resources to at least one high-profile independent investigation each year.

Community Based Treatment

OCFS

Regarding “Improve the foster care and juvenile justice system’s capacity to meet children’s mental health, development and health needs in order to keep more children in family based care as an alternative to placement in higher level programs. In addition, enhance mental health and substance abuse services for youth in facilities and provide continuity of such services as youth transition back to home and community.”

The first sentence could be made into a measurable objective if next year’s detailed plan includes data on how many children are in “family based care” as opposed to “higher level programs”, and also includes a projection of how many children will be moved from the latter to the former, and/or a projection that shows that the percentage of total children served in the former will increase while that in the latter decreases. The second sentence doesn’t indicate anything measurable. Much more specific information should be provided in the plan to indicate what is meant by “enhance” and what resources will be allocated/reallocated to getting what specific number of youth “back to home and community”.

Concerning the Bridges To Health Waiver: STIC has become a provider for this program, because it offers essential services that are not available under other waivers to some children. However, we remain highly critical of the program design. This is essentially three separate Medicaid HCBS waivers, one for developmental disabilities, one for mental health disabilities, and one for physical disabilities. It is administered jointly by two state agencies. Regardless of the good intentions of its administrators, this will inevitably create regulatory entanglements, eligibility conflicts, and service delays. Most of the children served will likely be children with developmental disabilities who live in foster homes. We don’t see anything in Medicaid law or the OMRDD HCBS waiver regulations that would preclude children with developmental disabilities from remaining on that agency’s waiver when they move to foster care. However, if there were real limitations in OMRDD’s waiver that caused children to be dropped, why, when OMRDD was revising its waiver for reauthorization at the same time Bridges To Health was being designed, did OMRDD not simply make the necessary changes so foster children with developmental disabilities could stay on the OMRDD waiver with the service coordinators who know them? This is a classic example of the dysfunctional nature of the “interagency collaboration” model, and of the MISCC’s failure to carry out an effective oversight role.

While we are on the subject of HCBS waiver design, this seems as good a place as any to discuss the new opportunities that the federal Centers for Medicare and Medicaid Services (CMS) are about to make available.

CMS wants to change the HCBS waiver regulations to permit states to design waivers that would serve people with disabilities based solely on functional need, without regard to diagnosis. In comments provided to CMS, this excellent idea received a cautious and specious response from DOH, representing all NYS agencies. There certainly is no merit to DOH's claim that a consolidated waiver, properly organized and administered, would be more expensive to operate than several separate waivers. STIC filed extensive comments on the proposed changes; we won't take the space to repeat them here in detail but they are on the CMS website and all MISCC members should read them. The MISCC should publicly endorse this change. If the change is finalized, the MISCC should produce a phased plan to consolidate all of New York's statewide Medicaid HCBS waivers into a single waiver that includes all of the service types that are in the separate waivers, and which determines eligibility based on functional need, not diagnosis. This combined waiver should be administered by a new Office of Disability Services.

CMS also proposed to identify a method to define the term "home and community-based". If a so-called "stakeholder process" to do this occurs in NY, the MISCC should support a consumer-controlled process: That is, the majority of participants should be people with disabilities who do not work for or represent organizations that operate segregated congregate facilities; state agencies and nondisabled family members should constitute a minority of participants and may only be ex-officio (non-voting) members; at least one statewide advocacy organization that is governed and operated by people with disabilities should participate; "voluntary" operators of segregated congregate facilities must not take part at all because it would be an obvious conflict of interest.

The stakeholders should be guided by the *DAI v Paterson* decision: The proper definition of "home" is: A place where a single person, a married or cohabiting couple (with or without children), or a group of no more than four unrelated adults who have freely chosen their housemates, lives; and in which the residents (or if they are legally incompetent, their legal guardians) make all the rules, have privacy in their bedrooms and bathrooms, individually choose their schedules and activities inside and outside the home, are not involuntarily subjected to "treatment", and receive sufficient individual supports to enable them to operate in a completely autonomous manner. The proper definition of "community-based" is: The *same places* in the community that nondisabled people frequent to work, learn, shop and play. Facilities established primarily for the purpose of providing services or activities to groups of people with disabilities are not "community-based", regardless of size or location.

Returning to the plan, and the CBVH item: We recognize that CBVH provides some non-vocational services. However, the fact that this, and not the Employment section, is the only place that includes a CBVH item is symptomatic of that agency's ongoing dysfunction. The agency exists primarily to assist adults with visual disabilities to obtain integrated employment, yet it proposed to do nothing in the Employment section. Instead,

it is here under “Community Based Treatment” proposing merely to expand some undefined “services” in a portion of New York City, and to provide “cultural competency” training to its staff.

In an era when over 2/3 of adults with disabilities are unemployed and people with significant visual disabilities are one of the most underserved groups within that cohort, is this really all CBVH could think of to do to help reform the state’s disability service system and ensure compliance with the US Supreme Court’s *Olmstead* decision? Is this all the MISCC, which is responsible for setting statewide cross-agency priorities, needs CBVH to do? In the “2009 MISCC Employment and Housing Data” document prepared for the October meeting at which this plan was discussed, CBVH provided very incomplete information. On whose authority was CBVH excused from providing complete data?

The MISCC should recommend to the Governor and Legislature that CBVH be disbanded and its employment services and funding transferred to VESID. Its other services should be moved to a new “Office of Disability Services”.

CQCAPD

As we’ve said, we are skeptical of projects wherein government entities propose to train people regarding their rights to advocate against said government entities. The best advocates are independent advocates who get their training “on the streets”. Although many Deaf people believe it is important for their particular disability to receive special mention, given the scarcity of resources in New York at present, we don’t think a schedule of trainings is the best use of funds. There are higher priorities for the Deaf community, including improving the academic quality of primary education and increasing the availability of assistive technology, that would be more worthy of this expenditure.

VESID

We’d like to thank VESID for proposing to promote Independent Living programs through some sort of literacy program—though we can’t see why that would be a useful venue for such promotion. In any case, more people would benefit if VESID would refrain from such extraneous activities and use the money to beef up IDEA enforcement in the public schools and/or increase rates and referrals for supported employment services.

Missing Priorities

Three critical aspects of the systems reform needed to ensure that people with all disabilities can receive necessary supports and services in the most integrated settings are entirely missing from the MISCC plan. One we’ve already discussed in detail: the failure to address special education issues. The others are the ongoing “dual diagnosis” problem,

and the need to simplify, revamp, and combine regulations and administrative structures to achieve maximum efficiency and responsiveness.

The Dual-Diagnosis Problem

Across New York, people whose multiple disabilities cross state-agency boundaries continue to be denied sufficient services by all of the agencies involved. MISCC members are aware of this problem. State agency heads conducted a “People First Listening Tour” that collected testimony from thousands of people about it. The agency heads announced that they would be ensuring that everybody would work together to get this problem solved. A bit later, they announced that in every region of the state, there would be joint OMRDD/OMH troubleshooting committees that would accept individual cases and quickly figure out how to get the people served.

Since then, virtually nothing has changed. We have tried to access our local “troubleshooting committee” but it doesn’t seem to exist. The director of the local CPEP (“Comprehensive Psychiatric Emergency Program”) refuses to serve anyone with a developmental disability diagnosis no matter how severe their psychiatric issues; he holds the obsolete view that it is impossible for people with low IQs to have mental illnesses, they can only have “behavior problems”, and his supervisor won’t retrain, discipline or replace him. That supervisor, the County Commissioner of Mental Health, much of whose department is funded by OMH and who therefore should be held accountable by that state agency, insists that OMRDD should serve anybody with a developmental disability and mental health issues in an Article 16 clinic. The local Article 16 clinic has extremely limited resources and is not equipped to deal with severe and persistent mental illness issues. Our DDSO, despite the fact that it has heard repeatedly for decades from large numbers of people that intensive behavior crisis intervention services are needed, has only this year taken a step to address the need (though the available funds are insufficient to serve more than a handful of people). And since behavior crises are really a community mental health problem, not a state MR/DD agency problem, this small amount of help is coming from the wrong place. We know there is a “Memorandum of Understanding” that says people with dual DD/MH diagnoses should be able to get services from both agencies, but the local MH Commissioner says he only heard about that MOU “a few months ago” and he has clearly indicated that he isn’t planning any system or personnel changes to comply with it.

Over the years this foot-dragging, turf-warring situation has produced many tragedies for people with disabilities in our region. Here are two recent ones:

A child with autism-spectrum disorders and several psychiatric disabilities was forced out of his parents’ home into a segregated residential facility. The parents were desperate to keep him home and struggled for years to do so. They pleaded with the DDSO for respite and behavioral intervention services but their pleas were ignored. As the child’s behavior became more violent and dangerous, they were unable to get appropriate medication evaluation and management services from anyone. The CPEP program responded at first by telling these parents, whose child had threatened to kill them and himself and had

brandished a knife to do it, to take him home and calm him down. After repeated visits, CPEP staff forbade the parents to bring the child there ever again. In the end, the segregated facility was the only remaining option.

An adult who had spent his entire life in the OMRDD system, and who had inappropriate social behavior issues as well as multiple psychiatric diagnoses, eventually became a “voluntary” resident of the developmental center. When he learned he could leave with 72 hours’ notice, he announced his intention to do so. His advocate asked him to wait and pleaded with the DDSO to arrange ongoing integrated individual supports for him in the community. The DDSO said the only thing it would do is try to find a group “home” slot for him within a period of months or years. The person refused to wait that long and moved into an unsafe situation with disreputable characters. He committed a minor crime, was arrested and spent some time in jail. Meanwhile the DDSO did a new IQ test and found his IQ to be above the MR threshold, so they declared him ineligible for services. (We later learned that the DDSO staff had “coached” him so he would get a higher score.) When advocates tried to get mental health services for him, the local county MH/OMH program did its own “reevaluation” and found that on the basis of his most recent, rather mild diagnosis, he wasn’t eligible for mental health services either. Instead, a MH official said, OMRDD should have held him in the developmental center indefinitely, despite his legal right to leave. He is without services and at risk for all kinds of troubles to this day.

These are just two examples; we could provide many more.

Although the “interagency collaboration” effort to address the dual-diagnosis problem was heavily promoted by the MISCC in previous years, there is nothing about it anywhere in the plan. Once again, “interagency collaboration” has completely failed to produce useful results. The MISCC must get serious about removing eligibility conflicts and turf issues from the system. One way to do this would be to endorse CMS’s proposal to take diagnosis out of the HCBS waiver design process and, when those new regulations come out, combine all of the state’s HCBS waivers into a single waiver under a single “Office of Disability Services”. Establishing such an office and putting non-waiver services for people with developmental and/or mental disabilities into it as well would create a single administrative structure in which specific individuals could be identified as responsible, and held accountable, for ensuring that people with both DD and MH diagnosis get all of the services and supports they need.

Regulatory Barriers and Conflicts

At a MISCC meeting earlier in 2009, MISCC Chairperson Diana Jones-Ritter said she planned to create a new MISCC committee to examine state agency regulations and identify how conflicts, redundancies, and barriers could be removed to ensure that people with various disabilities were not denied services in the most integrated settings purely due to regulatory irrationality. This is an absolutely essential element of the MISCC’s job. In addition to the dual diagnosis issue, there are a multitude of problems related to differing eligibility rules for people who need employment services from both VESID

and some other agency; service discontinuities resulting from age-boundary “handoffs” for children moving from DOH Early Intervention to VESID preschool education; problems caused by local entity noncompliance with state and federal law, regulations, and directives; and more. Yet there is no mention of this anywhere in the plan, and we don’t even know if the MISCC committee was ever formed.

This issue must be a priority and it must appear in the plan.