



November 14, 2011

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### Introduction:

Commissioner Burke welcomed people to the meeting and provided a brief synopsis of recent activities related to waiver development, making the following points:

- Six informational briefings on the waiver were held in late October/early November. They included a presentation on the waiver and a time for questions.
- The 5.07 Plan hearings were held Nov. 9 and generated a lot of interest and questions about the waiver.
- OPWDD has prepared a draft document summarizing and addressing the major concerns expressed at the hearings and the recent waiver briefings and invited the Steering Committee to review and discuss this document during the meeting. This document is referred to as the “Response to Key Issues.”
- The Request for Information (RFI) will be issued November 15. Its purpose is to gather information and ideas that will support development of the subsequent Request for Applications (RFA) that will result in waiver pilot projects.
- At the request of CMS, New York submitted an application to further the federal review process. It will be updated to reflect the 5.07 plan input and will be published once we have the opportunity to review the document with CMS.

### Discussion and Guidance on Risk Management:

This discussion was intended to generate ideas and thoughts around the topic of managing the increased risk or perceived increase risk associated with serving people in most integrated settings, in particular those individuals who desire or were once served in more restrictive settings. Key points that were raised during the discussion included:

- People often assume that more integration equals greater risk. That’s a big assumption. In reality, congregate settings have often led to less desirable outcomes for people. When people live in less restrictive settings, the result is often fewer incidents. The more important determinant in outcomes is the relationships that each person has – with staff, with others in their life and the community.
- There is also an assumption that if OPWDD moves people into less restrictive settings, it will also reduce its oversight for these individuals; it will audit less. People assume this change will not be managed well.
- Switching providers actually adds costs because the changes disrupt relationships and may require new providers to learn how to best serve the new person and the person being served to adjust and become comfortable with the new provider. Additional visits/services may be necessary, and progress may be interrupted or slowed during the transition.
- It is not always true that the more restrictive settings are safer. We need to market the ability to keep people safe and support them to achieve good outcomes in less restrictive settings.
- Implementing real person-centered planning helps people understand how less restrictive can also be safe. Involving people in the planning process helps them become open to more options.
- Risk is not always bad. Sometimes it’s good for people because it is a more natural situation.
- Exposing people to new situations and decision-making means some will make bad decisions. We need to explore and clarify what the liability will be for service providers.



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- The waiver will allow the development of individualized supports to protect people's safety and mitigate risks.
- Providers will need flexibility in staffing levels to allow individuals to assume greater independence as they progress and gain confidence and skill.
- As we develop the waiver, we should collect information on best practices related to individual decision-making and agency responsibility and response.
- A workforce development initiative is needed to ensure all the skills that are needed are available within the direct support workforce.

### Key Discussion Questions to Inform Pilot Projects

**Question #1** – Given that participation in the demonstration projects will be on a voluntary basis, how can OPWDD incentivize participation for individuals, their families, and provider agencies so that they will want to be included?

- The primary question is: With no new money, where will the system find the money to serve new people while still supporting those currently receiving services?
- A SWAT Team might help providers figure out how it can work.
- It is likely that volunteers for the pilot projects will be people who do not fit well into the current system.
- Participation in pilot projects must not jeopardize people's long-term care services.
- OPWDD must choose the pilot projects carefully and must include some that use both Medicaid and Medicare funding.
- Participation in pilot projects must also not jeopardize service providers by making them liable for higher costs, as occurred during the transition to the current HCBS waiver.
- OPWDD must encourage providers to understand that spending money differently will show where the money can come from. In the 1970s there was much resistance to deinstitutionalization. As people moved to community-based services, however, the concept became more acceptable.
- OPWDD must assure people that the pilots will not put people at risk. Instead, they will test out the "money follows the person" concept and examine the results for people. Pilots do not all need to be replicated for all specific groups of people.

**Question #2** – How can OPWDD best ensure and require real person-centered planning to happen in order to drive individual outcomes achievement for all based on a person's strengths, interests and needs?

- Person-centered planning should be "organic," reflecting where an individual is at any given point in time. What someone needs may change from day to day. Person-centered planning cannot be delegated to a vendor to make it happen once for a person.



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- Person-centered plans must be co-produced with the individual being supported. To say they are customized is to suggest they are pre-determined.
- Tools exist to measure the person-centered planning approach and evaluate DISCOs' and providers' performance and should be used.
- Person-centered plans must be living documents. They cannot go on the shelf and be ignored.
- Perhaps the system could provide a combination of some "off the shelf" service packages that people may like as well as personalized planning options.
- Programs like PACE (Program of All-Inclusive Care for the Elderly) are unknown and untested in the developmental disabilities field. Providers will need to partner with parties with experience in managed care.
- The new waiver will have to support preparation of an organic plan of services, including plans to meet people's need for home care. People who deliver home care services are now wondering who will coordinate these services for people with developmental disabilities.
- We need to elicit a dialogue around how to combine medical, home care and long-term care services and reveal successful models from across the country.
- We must move to managed care to increase efficiencies and accommodate fiscal realities, but we must remain separate from a medical model because developmental disabilities are not illnesses. People with developmental disabilities are not patients that recover. The system needs to respect the reality that providing services early on in someone's life does not eliminate the need for long-term services.
- Pilot projects must be bold and test creative ideas.
- The new system must spread the financial risk so that no one provider or DISCO supports the most expensive individuals. In some areas, the Cash and Counseling model has worked well, preserving resources by providing stipends directly to families.

Question #3 - How can OPWDD ensure and encourage the development of home and community-based clinical supports, particularly for individuals transitioning from state-operated institutional settings to community residential options and for individuals who reside at home?

- Community-based clinical supports refer to services that will support people who transition out of institutional settings, people with autism spectrum disorders, and people who are experiencing crisis and are at risk of moving into a developmental center.
- There are some agencies in New York State that have crisis expertise and can demonstrate best practices in this area.
- The Commission on Quality of Care and Advocacy for Persons with Disabilities' resource on surrogate decision-making may offer good insight.
- A pilot project should work with county mental health departments to build capacity across systems.



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- A SWAT team might help families successfully navigate the system during a crisis. Rural areas might need special considerations regarding how to provide this kind of support.
- Community-based services must also provide things like “homemaker services” that can be very important in allowing someone to return home from the hospital by freeing their family members to care for them at home. This kind of service saves money.
- The workforce will need additional training to meet greater needs in community settings. OPWDD’s workforce training consortium will need to intersect with the development of these system reforms.
- Technology and financial planning assistance for families will also help people to be served in community settings.
- Not everyone needs clinical services on a regular basis delivered in a clinic setting. In some instances, clinical services can be effective when provided on a consultant basis as in the past.
- Development of community-based capacity should examine all available data related to serving people with developmental disabilities and not just OPWDD data. Comprehensive data will provide a better, more accurate picture of what works and what can improve efficiency and effectiveness for people.

**Question #4** – What kinds of administrative efficiencies, streamlining or other initiatives such as regulatory reform should OPWDD foster, including those between providers that support the direction of the 1115 waiver and may also provide cost savings?

- The volume of regulations is staggering. Agencies currently need multiple departments to process a tremendous amount of paperwork. Regulatory reform could free up resources.
- Providers can form groups to share administrative function costs, but will need to determine how to share the cost savings.
- Providers will need clarity regarding what Medicaid standards they are accountable to. Knowing this could help them identify potential efficiencies. The fear is that DISCOs will push the obligation to demonstrate standards down to the providers.
- Perhaps providing an economic incentive to providers to join together could achieve efficiencies. When combining agencies, however, we must be careful not to create a higher-cost operation.
- The waiver should explore the possibility of matching Section 8 housing funds to support people’s housing and the possibility of the private sector partnering with DISCOs to provide housing.
- OPWDD should provide cost data to provider agencies to help them prepare and organize to form new DISCOs.

### Next Steps

Commissioner Burke outlined the immediate next steps in the waiver development process:

- Finalize Response to Key Issues document.
- Issue the Request for Information, analyze responses.
- OPWDD to facilitate provider dialogue, data sharing.
- OPWDD to work with New York State Department of Insurance to address issues related to risk sharing.



## Steering Committee Meeting Summary

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- OPWDD to examine regulations and their impact on flexibility and effectively responding to people's needs.
- OPWDD to develop strategy for continuing the advisory function of the Steering Committee and a strategy for soliciting ongoing feedback and input from individuals and families across the state.