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Comment Line: 1-866-946-9733
E-mail: people.first@opwdd.ny.gov

This document summarizes the feedback received from 14 groups of workshop participants on three presentations made by collaborating groups of service providers. Workshop participants included individuals with developmental disabilities, family members, and representatives from service providing agencies.

Advance of Greater New York
Aspects Workshop Participants Liked Best
<i>Defined plan to move forward together with specialized topic committees</i>
<i>Focus on person-centered planning and putting person's needs at center</i>
<i>Involvement of smaller agencies</i>
<i>Collaboration with multiple agencies to become a DISCO</i>
<i>Committee structure</i>
<i>Diversity, inclusiveness and choices due to involvement of many agencies</i>
<i>Collaboration with many will save costs, for example in training expenses, group buying</i>
<i>Clear objectives</i>
<i>Openness to accepting new agencies</i>
<i>Focus on preventative care</i>
<i>Decreased reliance on emergency room visits</i>
<i>Cultural diversity</i>
<i>24-hour access to medical care other than emergency Rooms</i>
<i>Expansion of Article 28 clinics' hours</i>
<i>Centralized database with things entered in real time</i>
<i>Intensive care coordination</i>
<i>Use of information technology to help people be more independent, for training</i>
<i>Active study of managed care now</i>
<i>Clearly defined benchmarks against which to measure improvement</i>
Aspects Participants felt would be a Challenge to Implement
<i>New information technology will be expensive.</i>
<i>In other areas of the state the agencies aren't specialized so there is no opportunity to have competition and offer choices.</i>
<i>Small agencies may lack the infrastructure needed to form a managed care organization.</i>
<i>In other places, there is not much public transit that is accessible, and it can take a long time to get from place to place.</i>
<i>Getting doctors to participate and engage in care coordination</i>
<i>Effective governance, decision making and costs given the size of the collaboration</i>
General Concerns Noted
<i>Activities are not concrete.</i>
<i>More input from families and individual involvement is needed.</i>
<i>Supporting the Direct Support Professionals is a good idea, but what are the resources for training and</i>

<i>paying them more?</i>
<i>No mention of serving specific subpopulations such as people who are deaf</i>
<i>Concern about loss of relationships as people must receive services from people they don't know. Will that impact ability to make changes and adhere to care plans?</i>
<i>Concern about ability to sustain services during transition to managed care operations</i>
<i>Shift to data-driven quality measurement may take away from quality of services.</i>
<i>Is the collaboration truly culturally diverse?</i>
<i>Smaller agencies that are not in a network may not survive.</i>
<i>People lose jobs when functions are combined.</i>
<i>Not clear on what the innovation is.</i>
<i>Concern about loss of individualized services</i>
<i>The collaboration lacks a service provision proposal and needs more specifics.</i>
<i>Who are the 30 participating agencies?</i>
<i>Sometimes less expensive care can feel like fewer services. Are we creating unrealistic expectations?</i>
Promising Aspects Noted
<i>Focus on information technology and standardization of information to increase efficiency</i>
<i>Ability to let providers and Care Coordinators know when someone is in the hospital</i>
<i>Shared purchasing</i>
<i>Emphasis on sensitivity to cultural and language differences</i>
<i>Collaboration of so many agencies to form a network linked by effective communication</i>
Alliance Care Network
Aspects Workshop Participants Liked Best
<i>Identifying needs and creating plans to meet them</i>
<i>Focus on behavioral health</i>
<i>Integration of behavioral health and community services</i>
<i>Focus on chronic disease management</i>
<i>24/7 care model and partnering with urgent care centers</i>
<i>Staff training manuals and instruction booklets for individuals and families</i>
<i>Incorporation of the Health Home model</i>
<i>Focus on preventative care</i>
<i>Development of metrics to indicate quality</i>
<i>Use of technology - Smart houses can allow staff to spend time with those they support, Medical alert system to indicate when independent people receive health care services</i>
<i>Single point of accountability</i>
<i>Partnership in pursuing dreams</i>
<i>Use of uniform protocols and nationally accredited standards</i>
<i>Investment in frontline staff</i>
<i>Increasing the knowledge of medical providers and their staff</i>
<i>Focus on developing a unique care coordination model that makes individuals part of the planning</i>
<i>The collaborating agencies' experience with mental health and developmental disabilities services</i>
Aspects Participants felt would be a Challenge to Implement
<i>Getting medical providers to take Medicaid and extend their availability</i>
<i>Finding doctors with familiarity with developmental disabilities, training providers to understand the special concerns and needs related to developmental disabilities</i>
<i>Providing sufficient staffing to ensure people get the right kinds of health care and needed medical</i>

<i>follow-through with staff supports</i>
<i>Securing the needed financial commitment to develop the information technology</i>
<i>Coordinating 24/7 model of care</i>
<i>Using technology throughout all the agencies and coordinating data on a Web-based system</i>
<i>Providing information to care givers in different languages and at different reading levels</i>
<i>Ensuring people follow preventative care</i>
<i>Obtaining reimbursement for services and completing Medicaid paperwork</i>
<i>Cross training the Direct Support Professionals (different service needs and systems)</i>
General Concerns Noted
<i>Literature must be translated into the languages needed.</i>
<i>Size of the collaborative – perhaps too big</i>
<i>Smart technology could be too much for some.</i>
<i>Would like to see clinic services expanded</i>
<i>Failure to target special populations</i>
<i>Direct Support Professionals being the point persons for the triage process. Triage people need clinical training.</i>
<i>Focus on mental health could also be a liability.</i>
<i>Want to hear more about day habilitation and employment</i>
<i>Would medical providers be within a reasonable distance after hours?</i>
<i>Access to outside network providers - can people keep their current providers?</i>
<i>How will HIPAA impact shared records?</i>
<i>Who is really advocating for the person? And who is advocating for the agencies?</i>
<i>Want to hear more about specialty medical services</i>
<i>Will family support money be available?</i>
Promising Aspects
<i>Availability of 24/7 medical care</i>
<i>Focus on wellness of the person</i>
<i>Engaging the Direct Support Professionals</i>
<i>Urgent care medical centers will provide better access and decrease emergency room use and hospitalization.</i>
<i>The use of information technology and tele-medicine</i>
<i>Integrating medical and developmental disability services to eliminate fragmented services</i>
<i>Health Home model</i>
<i>Focus on prevention rather than reactive care</i>
New York Integrated Network
Aspects Workshop Participants Liked Best
<i>Evidence-based concepts and use of national indicators</i>
<i>Comprehensive nature of the proposal, coordination with medical care</i>
<i>Use of metrics</i>
<i>People aging in place</i>
<i>Focus on retention and quality DSP workforce, training and ongoing communication</i>
<i>Patient-centered Medical Home model</i>
<i>Collaboration with mental health and other services, intensive care coordination</i>
<i>Outcome measurements</i>
<i>Information technology, electronic records, and use of Web site</i>

<i>Empowerment Center model, especially using community buildings, vocational focus, peer advocacy</i>
<i>Primary care team</i>
<i>Partnering with urgent care and health care centers</i>
<i>After-hour care</i>
<i>Diversity</i>
<i>Decreased hospitalizations and emergency room visits (decreased costs)</i>
<i>People being served in many places</i>
<i>Letting families share information and resources</i>
<i>Transportation training</i>
<i>Family outreach</i>
<i>Involvement of Self Advocates</i>
<i>Strong commitment of participating agencies</i>
<i>Collective experience of participating agencies</i>
<i>Participating agencies' shared values and mission</i>
<i>Combination of back office functions such as purchasing – has potential for many benefits</i>
<i>Person-centered planning process that includes the individuals with developmental disabilities</i>
<i>Same day primary care visits</i>
<i>24/7 primary care provider access</i>
Aspects Most Challenging to Implement
<i>Empowerment Center</i>
<i>Person-centered planning for people who can't advocate for themselves, requires training</i>
<i>Organizational commitment at all levels</i>
<i>Getting technology to everyone</i>
<i>The work order day</i>
<i>Peer supports can be difficult to implement.</i>
<i>Transportation training - due to costs</i>
<i>Incentivizing doctors and dentists to accept Medicaid</i>
<i>Serving the large number of people planned</i>
<i>Records sharing</i>
General Concerns Noted
<i>Lack public transit limits what can be done.</i>
<i>Sample size of 100 people is too small to elicit good data.</i>
<i>How will those who can't communicate be respected?</i>
<i>What are the outcome measures for kids?</i>
<i>Clubhouse model seems like traditional day habilitation.</i>
<i>Need to educate Self-Advocates about what can be different</i>
<i>People who are not assertive may get lost in the shuffle.</i>
<i>Can there really be cost savings with customized model?</i>
<i>Never forget to make sure people don't lose ground from where they are today.</i>
<i>Must include people with cognitive and behavioral challenges</i>
<i>Lower costs may lead to lower quality.</i>
<i>How do existing agencies that are not part of a DISCO fit in?</i>
<i>Hard to implement it in areas with smaller agencies and vast geographic areas</i>
<i>Don't use word consumers.</i>
<i>Small size of collaborative</i>

<i>Lack of specialty services</i>
<i>Challenges of getting people into managed care. If they're stable now, you don't want to upset that. Transition is key.</i>
<i>Some people do not have computers. Some can't read.</i>
<i>Where is choice?</i>
<i>Having enough people to hire in rural areas</i>
<i>Costs of transportation in rural areas</i>
<i>Moving out of group homes could result in loneliness</i>
Promising Aspects
<i>Chat Room</i>
<i>Clubhouse model - if broken away from traditional onsite services and in community</i>
<i>Family forums</i>
<i>Recognizing the Direct Support Professionals with training, pay, and benefits</i>
<i>Living, working and loving model - It's not just a medical model, but a more global view.</i>
<i>alliance with health care providers</i>
<i>Peer mentoring</i>
<i>Web-based training</i>
<i>Willingness to do transition planning</i>
<i>Electronic records systems and tele-medicine</i>
Concerns Voiced about all Three Presentations
<i>Need to address crisis services</i>
<i>Must include seriously disabled and children</i>
<i>Must include provisions for addressing conflict of interest</i>