Report on the
People First
Coordinated Care Listening Forums

Karen Carpenter-Palumbo, LMSW, Commissioner
NYS Office of Alcoholism and Substance Abuse Services

Richard F. Daines, MD, Commissioner
NYS Department of Health

Michael F. Hogan, PhD, Commissioner
NYS Office of Mental Health

Diana Jones Ritter, CGFM, Commissioner
NYS Office of Mental Retardation and Developmental Disabilities

October 24, 2007
We wish to thank the many people and organizations responsible for making these Listening Forums a success. We want to express our most sincere gratitude to the many people who receive services, family members, advocates, providers, local governmental representatives, and those interested in quality health care that attended and shared their comments, questions, concerns and ideas. We want to thank the mental hygiene and health commissioners of the host counties where the forums took place. We want to thank the staff of the State University of New York at New Paltz, York College of the City University of New York, Roswell Park Cancer Institute, and Clinton Community College for welcoming us and providing valuable logistical assistance. We want to thank Karen Schimke from the Schuyler Center and James Tallon of the United Hospital Fund who ably facilitated the forum sessions. We want to thank the members of the Listening Forum Steering Committee and the dedicated regional, field office, and central office staff who assisted them in planning and conducting the Forums.

Commissioner Karen Carpenter-Palumbo
Commissioner Richard F. Daines
Commissioner Michael F. Hogan
Commissioner Diana Jones Ritter
In his seminal health care speech of January 2007, Governor Spitzer introduced his concept of a “Patients First” agenda that is “based on a single premise: patients, not institutions, must be at the center of our health care system. That means that every decision, every initiative and every investment we make must be designed to suit the needs of patients first.” To inform this agenda, Governor Spitzer announced the creation of “People First Coordinated Care Listening Forums,” to be held in the spring and summer of 2007 across the state by the Commissioners of Health, Mental Health, Mental Retardation and Developmental Disabilities and Alcoholism and Substance Abuse Services.

The Forums, which were subsequently held across the state in five locations, from the metropolitan New York City area to the North Country, provided an opportunity for individuals with multiple needs, and their caregivers, to describe their needs and their issues in navigating state and local service systems to receive necessary services. Over 2,200 consumers, family members, providers, community members, and local government representatives attended one or more of the forums. Nearly half of these completed a Comment Card to present concerns, questions, and experiences. The four agencies used the Comment Cards to identify major themes and issues for collaboration and attention.

This report summarizes the issues and information presented by health care providers, individuals, caregivers and other interested citizens at the Forums and presents some of the next steps and recommendations that the Commissioners are taking to improve and coordinate treatment and support for people who have needs across the four systems.

WHAT WE HEARD

We learned that people and their families experience a host of issues in trying to obtain quality health and mental hygiene services. People report experiencing the greatest difficulties and identify opportunities for improvement in:

- Accessing services and supports.
- Receiving quality, coordinated services and supports from a qualified workforce.
- Overcoming service barriers created by the systems themselves.

Accessing services and supports

The most frequently voiced area of concern among consumers and family members was in locating and accessing services that do not fit neatly into one agency’s area of responsibility. Agencies have specific mandates and populations to serve, but many people do not fit within rigid categories and get bounced from one system to another. Some find no agency that will accept them and are left without services or supports. Specifically, they pointed out the lack of readily available information and family support to get them started in navigating the systems.
People offered concrete examples of how the mental hygiene systems had failed them and their family members, and they often made recommendations to improve their ability to receive adequate services. Specifically, forum participants identified the following concerns:

- A lack of access to some critical clinical services across the state, for example, child psychiatry and special dentistry.
- Difficulty people with disabilities have in securing appropriate and affordable housing.
- Insufficient respite and crisis/emergency services.
- Not enough supports for people with physical and developmental disabilities, as well as those in recovery from mental illness or substance abuse, for becoming prepared for work, and then finding and maintaining jobs.
- Difficult, if not impossible, access to high quality medical, dental and related clinical services through the Medicaid system.

As one attendee said, “Accessing treatment is sometimes like climbing Mount Olympus,” with “insurance companies, government departments, medical establishments, and social agencies,” creating an “imposing never ending bureaucracy.” Once services are obtained, a number of people agreed that the quality was good and the services enabled them to pursue their life goals.

“We have multi-problem people seeking meaningful help in single-problem systems.”
— Forum Participant

We also heard about the unique problems in obtaining services in rural areas and ways that services could be improved. A major concern in rural areas is difficulty accessing services because of transportation issues. This is compounded by Medicaid regulations that preclude reimbursement for more than one service in a day. Solutions offered included the following:

- Taking services to where people are, including school-based health centers.
- Creating satellite clinics.
- Allowing Medicaid reimbursement for off-site treatment.

**Quality, coordinated services and supports**

Consumers, family members, advocates, and providers overwhelmingly agreed that integrated treatment should be an important goal of all systems. People described how services are being delivered in “silos” and indicated that there seemed to be no overall point of accountability. There were a number of suggestions to transform care and services including:

- Joint licensing and funding, and co-located services.
- Placing consumers and families at the center of services and care.

When a family is in need, one person poignantly described, it should not have to “knock on 20 doors to receive one service.” Rather, the family “should knock on one door and receive 20 services.”
Participants also emphasized the importance of addressing workforce issues that impact the quality of services, including attracting professionals in short supply and reducing staff turnover through salary and work incentives, cross-systems training and education, and preparation for “baby boomer” workforce retirements and related changes. Staff and provider organizations also need to be trained in the most contemporary person-centered support practices, with an emphasis on promoting quality of life outcomes that lead to community-based housing, meaningful employment, education, and self-determination.

**Service barriers created by systems**

Attention to how systems mature and evolve and the unintended consequences of these processes was another important theme among People First participants, with people describing barriers resulting from separate planning, regulatory, financing and licensing requirements and standards. Participants called for the following:

- Realigning agency structures and functions to simplify processes, diminish administrative complexity, increase flexibility, and thereby enhance service integration.
- Extending such efforts to include other state agencies that play a prominent role in meeting the educational, social, and health needs of New Yorkers.
- Improving collaboration with the criminal justice system and voluntary agencies.

People indicated that there is a pressing need to examine the Medicaid program’s policies and regulations to remove barriers to access and quality services. They called for:

- Permitting Medicaid reimbursement of telemedicine to reach more people with disabilities in rural areas where shortages of clinicians exist.
- Close monitoring of people who receive Supplemental Security Income (SSI) and are mandated into Medicaid managed care to assure barriers are not being created.

People also called for the removal of impediments to services created by the systems by restructuring funding models and pooling resources from different agencies.

**WHERE DO WE GO FROM HERE**

Work has already proceeded on several fronts, and will continue using the forum analyses as a foundation for moving forward. Immediate concrete steps being taken include:

1. At the Department of Health, Requests for Proposals/Applications (RFPs/RFAs) are being discussed with other agencies, and innovative ideas like co-located services are being included as standards of care.
2. Commissioners Hogan and Carpenter-Palumbo announced the creation of a statewide Task Force on Co-Occurring Disorders. It will provide the Commissioners
with recommendations that can be implemented in the short term to improve the care of people with co-occurring mental health and chemical dependency disorders.

3. Commissioners Ritter and Hogan are developing a new model for regional office collaboration directed toward people with both mental health and developmental disability diagnoses.

4. OASAS has begun sharing its County Planning System with OMH, OMRDD, and will include DOH in the future as a step towards coordinated planning efforts.

In addition to these steps, we propose a two-pronged approach for working toward the goal of coordinated health and mental hygiene across systems. Our first obligation and goal is to change the paradigm, as rapidly as possible, so that Department of Mental Hygiene agencies, not consumers and families, have primary responsibility for overcoming barriers to access caused by the current complex, confusing service system. Our second obligation is a sustained effort over time to unravel the complexities and barriers that have been created so the system becomes understandable and navigable.

These obligations are expressed in the two goals described below:

**Enable People with Disabilities and Family Members to More Readily Navigate the Existing Service Systems.**
- Create an integrated health/mental hygiene services directory to provide the basic information and assistance that people with disabilities and their families need to obtain services within and among these systems.
- Strengthen local capacity to assist people receiving services and families to get the supports they need from multiple systems. This will include county and regional mechanisms that improve communication and collaboration enabling issues to be resolved at the local level.
- Provide a single point of accountability within each State agency to serve as a liaison to coordinate information requests and follow up on more complex concerns, particularly when people have difficulty obtaining or maintaining necessary services.
- Develop specific mechanisms to involve people receiving services and families in the design of systems that help people find their way more easily within agency structures or across agencies.

**Systematically Eliminate Structural, Financing and Regulatory Barriers to Access and Services Coordination that Exist in the Service System.**
- Reinvigorate the Inter-Office Coordinating Council (IOCC), an existing structure charged with comprehensive planning, development, and implementation of all facets of prevention, treatment and rehabilitation of mental illness, mental retardation and developmental disability, alcoholism, alcohol abuse, substance abuse, substance dependence, and chemical dependence, as well as eliminating gaps in services to persons with multiple disabilities.
- Create an interagency committee linked to the IOCC to develop a work plan and time line to improve coordination, integration, and alignment of agency structures and functions to simplify processes, diminish administrative complexity, increase flexibility, and thereby improve outcomes and enhance the quality of services for adults, children and families. The Department of Health, while not a member of the IOCC, will participate in this committee to assure continued collaboration.
Develop recommendations to break down regulatory barriers to services and make recommendations regarding efficiencies that may be gained in the short run, strategies for overcoming more complex barriers, and methods for systematically examining proposed cross-system regulatory changes, including Medicaid reform, and ensuring efficiency and effectiveness.

- Build on existing efforts within each agency to examine and advance incentives to attract and retain a qualified workforce, share best practices, and increase the number of individuals who choose careers in the health and mental hygiene fields.

- Support the existing efforts of the State’s Most Integrated Setting Coordinating Council (MISCC) to improve access to housing and transportation for people with disabilities.

- Look for opportunities to expand cross-agency public health prevention and awareness and treatment public health campaigns through an interagency task force, beginning with a focus on Fetal Alcohol Spectrum Disorder (FASD).

**IN SUMMARY**

We appreciate the time many New Yorkers took to attend and participate in the Governor’s People First forums and the thoughtful feedback and suggestions for improvement. Clearly, there is widespread support for breaking down barriers to services and placing people once again at the center of health and mental hygiene services and care. We welcome the opportunity to provide the leadership necessary to institute immediate improvements that serve as the beginning of a series of steps to move us toward this new vision of unified, integrated services based on the principle that people and their health care needs come first.

Respectfully submitted,

Karen Carpenter-Palumbo, LMSW
Commissioner, NYS Office of Alcoholism and Substance Abuse Services

Michael F. Hogan, PhD
Commissioner, NYS Office of Mental Health

Richard F. Daines, MD
Commissioner, NYS Department of Health

Diana Jones Ritter, CGFM
Commissioner, NYS Office of Mental Retardation and Developmental Disabilities
Appendices

Appendix 1: Forum Methods and Participation
Appendix 2: Forum Press Release and Copy of Forum Announcements for Each Agency
Appendix 3: Copy of Blank Comment Card
Appendix 4: Thank You Letter to Participants
Appendix 5: Copies of Forum News Reports
Appendix 6: Summary of Interagency Collaborative Activities
Appendix 7: Summary of Agency Content Analyses from Forum Comment Cards
FORUM PURPOSES

The Listening Forums were designed to promote transformation of New York’s health and mental hygiene service systems. Specifically, the commissioners sought to do this by listening to the experiences and concerns of people using these systems, their families, advocates, providers, and local government. The commissioners were committed to drawing upon the collective wisdom of stakeholders and to using this knowledge to develop strategies for change.

FORUM STRUCTURE AND FEEDBACK MECHANISMS

The Forums were held in New Paltz, Queens, Buffalo, Syracuse, and Plattsburgh. Each was two hours in length, with most of the time devoted to dialogue between the commissioners and attendees. The Forums were advertised widely through e-mail listservs, agency web pages, word of mouth, and press releases (Appendix 1).

Approximately 2,200 consumers, family members, providers, community members, and local government representatives registered at the five Forums. An additional 4,000 unique URL addresses were counted; it is likely that this number is larger because groups often gathered to watch web casts. Finally, within each agency’s Listening Forum web page, there was a link to a mailbox where comments and concerns could be shared with the commissioners. The electronic mailboxes were developed to encourage people who were unable to attend the forums to participate in the process. Substantive concerns were raised by 179 persons who communicated by e-mail with the four agencies.

As part of the People First Forums, comment cards were made available on the agency web sites and upon registration at each Forum. On the comment cards, people recorded concerns, questions, and experiences to share with the commissioners. Additionally, the comment cards were used to organize the question-and-answer period at the forums where people asked questions of or expressed views with the commissioners. The comment cards hold a wealth of valuable information. They are the chief means by which the four agencies are identifying major themes and issues for attention and for which collaboration should yield improvements, particularly for people with complex needs that cross service systems. They are also the means by which each agency thanked most participants for being actively involved in the Forums. News reports from the various Forums are contained in the appendices.

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1 As specified under Section 5.01 of Mental Hygiene Law, the New York State Department of Mental Hygiene consists of three autonomous offices: the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities, and the Office of Alcoholism and Substance Abuse Service.
Table 1 provides a summary of participation in the process and the wide support for being heard, with nearly one-half of registrants completing and submitting comment cards.

<table>
<thead>
<tr>
<th>Forum Location/Host Agency</th>
<th>Number of Registrants</th>
<th>Number of Comment Cards</th>
<th>Number of Substantive E-Mail Comments Received by Host Agency</th>
<th>Total Comments (Cards + E-Mails)</th>
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<tbody>
<tr>
<td>Plattsburgh/OASAS</td>
<td>274</td>
<td>84</td>
<td>48</td>
<td>132</td>
</tr>
<tr>
<td>New Paltz/DOH</td>
<td>350</td>
<td>89</td>
<td>39</td>
<td>128</td>
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<tr>
<td>Queens/OMRDD</td>
<td>800</td>
<td>203</td>
<td>30</td>
<td>233</td>
</tr>
<tr>
<td>Buffalo/OMH</td>
<td>330</td>
<td>259</td>
<td>62</td>
<td>634</td>
</tr>
<tr>
<td>Syracuse/OMH</td>
<td>406</td>
<td>313</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>2,160</strong></td>
<td><strong>948</strong></td>
<td><strong>179</strong></td>
<td><strong>1,127</strong></td>
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FOR IMMEDIATE RELEASE:
April 26, 2007

SCHEDULE SET FOR "PEOPLE FIRST" FORUMS

State Agencies Seek to Improve Coordination of Health Services

Governor Eliot Spitzer today announced that Commissioner Richard F. Daines, M.D., of the Department of Health (DOH), Commissioner Karen M. Carpenter-Palumbo of the Office of Alcoholism and Substance Abuse Services (OASAS), Commissioner Michael F. Hogan, Ph.D., of the Office of Mental Health (OMH), and Commissioner Diana Jones Ritter of the Office of Mental Retardation and Developmental Disabilities (OMRDD) – will be conducting a series of Coordinated Care Listening Forums.

The Governor has directed these commissioners to travel the state, listen to the health care needs of New Yorkers, and provide recommendations on how to improve and coordinate support for people who have needs across the four systems.

“For far too long in this state, individuals with multiple needs have had to navigate through a complex myriad of state and local bureaucracies before they even begin to receive the care that they need, which is why a patient-centered system here in New York is necessary,” said Governor Spitzer. “Improved collaboration at all levels of government will be essential in moving our systems of care forward in the twenty-first century.”

The “People First” Coordinated Care Listening Forums are a starting point for new collaborative initiatives aimed at better serving New York’s residents. The forums are designed to listen to people who require services across various systems to better understand their needs with the goal of obtaining insight on how to improve quality and outcomes, as well as coordinate supports for individuals.

In each different area, the commissioners will be seeking feedback from local communities on access to resources, quality of care, interagency collaboration and coordination of care.

DOH Commissioner Richard F. Daines said, “Access to appropriate, high-quality care is our goal for all New Yorkers in need. Often the people using these services are in the best position to advise us on the changes they need. I look forward to hearing from the people in their communities to spark the innovative solutions we seek.”

OASAS Commissioner Karen M. Carpenter-Palumbo said, “Governor Spitzer has asked that my colleagues and I go directly to the residents of this great state and listen to their ideas on ways our health systems can better work together to move his vision of One New York forward. As commissioners, we are accountable for the services our agencies provide. We welcome the input from those who rely on our services, as it will help us improve the coordination of care for New Yorkers.”
OMH Commissioner Michael F. Hogan said: “Governor Spitzer’s vision is for a health system that is person-centered, not focused on the needs of institutions. We face that challenge within each of the service systems represented here, and additionally we must break down the ‘silos’ that create barriers to integrated care. We know that mental health is critical to overall health, but also that mental health recovery requires overall wellness.”

OMRDD Commissioner Diana Jones Ritter said, “New Yorkers who have multiple disabilities including developmental disabilities must have access to high quality care that assures their various and continuing needs are met. I am committed to working together with my sister agencies toward a more seamless service system that puts the person receiving services first and provides each individual with opportunities and choices for and about their own care. What better way to kick-start this effort than to go right to the people who receive or require these services? I look forward to hearing from our residents across the state on how we can better meet their needs.”

The Coordinated Care Listening Forums will be held on the following dates in the following cities:

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
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<tbody>
<tr>
<td>May 14</td>
<td>New Paltz</td>
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<tr>
<td>June 6</td>
<td>New York City</td>
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<tr>
<td>June 19</td>
<td>Buffalo</td>
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<tr>
<td>June 20</td>
<td>Syracuse</td>
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<tr>
<td>July 13</td>
<td>Plattsburgh</td>
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</table>

As details develop in regard to specific times and locations of the events, information will be made available at the following websites:

- [www.health.ny.gov](http://www.health.ny.gov)
- [www.oasas.ny.gov](http://www.oasas.ny.gov)
- [www.omh.ny.gov](http://www.omh.ny.gov)
- [www.opwdd.ny.gov](http://www.opwdd.ny.gov)

If you are unable to attend, but would like to provide feedback on how to enhance coordinated care in New York State, please email your thoughts to one or more of the following email addresses:

- OMH: [transformation@omh.ny.gov](mailto:transformation@omh.ny.gov)
- OPWDD: [public.affairs@opwdd.ny.gov](mailto:public.affairs@opwdd.ny.gov)
- OASAS: [public.affairs@oasas.ny.gov](mailto:public.affairs@oasas.ny.gov)
- DOH: [dohweb@health.ny.gov](mailto:dohweb@health.ny.gov)
FOR IMMEDIATE RELEASE

Wednesday, June 6, 2007

“PEOPLE FIRST” COORDINATED CARE LISTENING FORUM SCHEDULE
AT YORK COLLEGE IN QUEENS ON JUNE 6th
State Agencies Seek to Improve Coordination of Care Across Respective Systems

New York State Commissioners Diana Jones Ritter, of the Office of Mental Retardation and Developmental Disabilities (OMRDD); Richard F. Daines, M.D., of the Department of Health (DOH); Karen Carpenter-Palumbo, of the Office of Alcoholism and Substance Abuse Services (OASAS); and Michael F. Hogan, Ph. D., of the Office of Mental Health (OMH) will be conducting the second of five “People First” Coordinated Care Listening Forums on June 6, 2007 from Noon until 2:00 P.M. at York College, City University of New York in Queens.

The “People First” Coordinated Care Listening Forums were first announced by Governor Eliot Spitzer on April 26, 2007 as part of the Governor’s efforts to focus New York’s systems of care on the people they serve and to develop methods of improving and coordinating support for people who have needs across the four systems. The forums started in New Paltz and the Commissioners will travel New York State to gain grassroots input from people in order to develop a more seamless and collaborative system of care.

OMRDD Commissioner Diana Jones Ritter said, “These forums are giving us more insight into the cross-agency needs of real people in our state. All of Governor Spitzer’s cabinet is committed to working together to improve the access to and the quality of services for our citizens. Together, we will achieve the Governor’s vision of One New York. By listening to the voice of the people we will create a more seamless system of supports and services and assure that New Yorkers with mental health, developmental disabilities, alcohol and substance abuse addictions and other conditions get the care and treatment they need.”

DOH Commissioner Richard F. Daines said, “Access to appropriate, high-quality care is our goal for all New Yorkers in need. Often the people using these services are in the best position to advise us on the changes they need. I look forward to hearing from the people in their communities to spark the innovative solutions we seek.”

OMH Commissioner Michael F. Hogan, Ph. D. said, “Governor Spitzer’s vision is for a health system that is person-centered, not focused on the needs of institutions. We face that challenge within each of the service systems represented here, and additionally we must break down the ‘silos’ that create barriers to integrated care. We know that mental health is critical to overall health, but also that mental health recovery requires overall wellness.”

OASAS Commissioner Karen M. Carpenter-Palumbo said, “Just as New York's citizens are diverse, so are its health care concerns. Approximately 1.8 million New Yorkers suffer from a chemical dependence problem, and tens of thousands of those people have other health problems that cross multiple systems of care. The people taking part in our People First forums are helping us make a difference in New York to coordinate and improve care and to improve the lives of New Yorkers.”

Dr. Thomas R. Frieden, Commissioner of Health and Mental Hygiene for New York City said, “We salute our state partners for this important step. When different parts of our
health system fail to communicate, patients suffer. For example, substance abuse and mental illness are often so closely inter-related that it's impossible to identify either as the primary problem. Yet our health care system still rejects dual diagnoses. People with mental illness and substance abuse disorders may have to navigate two, three or four systems instead of one. Integrated care is more effective care. And through this forum, we affirm our commitment to making it a reality."

Thomas MacGilvray, Director of the Suffolk County Department of Health Services, Division of Community Mental Hygiene Services said, "While licensing and much of our funding originates in Albany, all services play out on the local level, and that's why we're encouraged to see that the Governor's Office and the new Commissioners have initiated this listening tour. When State Commissioners work together and work with us, it pays big dividends for the clients we all serve."

York College President Marcia Keizs said, "How exciting it is to have this historic event on the campus of York College with these four distinguished commissioners and their colleagues. Health Care is an area we care deeply about and it's one of our academic disciplines. We are sure that your "People First" Forums will touch the lives of many in New York City who have so much to say as we are home to a diverse population that has needs across all referenced systems of care on your program."

The Queens Forum is the second in a series of public listening forums being conducted around the state between May and July of this year. The first of these forums was held in New Paltz on May 14, 2007, and was an overwhelming success, with the live audience of some 400 people indicating that while they were somewhat satisfied with some of the services they were receiving, there was room for improvement. Approximately 1,000 additional individuals watched the forum through webstreaming on the Internet. Participants felt optimistic about the future of collaborative care in New York State based on the vision and mission of the public forums and on the presence of the four agency Commissioners and the interaction and discussion that ensued.

Additional “People First” Coordinated Care Listening Forums will be held as follows:

- June 19, 4-6 p.m., Research Studies Center, Roswell Park Cancer Institute, corner of Elm and Carlton streets, Buffalo.
- June 20, 2-4 p.m., Lafayette Theater in the Renaissance Hotel, 701 E. Genesee St., Syracuse.
- July 13, 1-3 p.m., Stafford Center for Arts and Technology, Clinton County Community College, 136 Clinton Point Drive, Plattsburgh.

The “People First” forums will be webcast live on the Internet. Links for viewing are available on each of the agency websites listed below. Driving directions for each Forum location are also available at these websites.

www.health.ny.gov
www.omr.ny.gov
www.opwdd.ny.gov
www.oasas.ny.gov

People who are unable to attend, but wish to provide feedback for any of the four commissioners involved in the “People First” Coordinated Care Listening Forums may do so by sending an email to any one of the following addresses:
Contacts:
Deborah Sturm Rausch (NYS OMRDD) 518-474-6601, Deborah.Rausch@opwdd.ny.gov
Claire Pospisil (NYS DOH) 518-474-7354, ctp02@health.ny.gov
Dianne Henk (NYS OASAS) 518-485-1768, DianneHenk@oasas.ny.gov
Jill Daniels (NYS OMH) 518-474-6540, Copajdd@omh.ny.gov
Nate Moore (York College) 718-262-2354, nmoore@york.cuny.edu
FOUR NEW YORK STATE COMMISSIONERS TO HOLD "PEOPLE FIRST" LISTENING FORUM JUNE 20 AT RENAISSANCE HOTEL IN SYRACUSE
State Agencies Seek to Improve Coordination of Care Across Systems

Michael F. Hogan, PhD, Commissioner of the New York State Office of Mental Health; Richard F. Daines, M.D., Commissioner of the New York State Department of Health; Diana Jones Ritter, Commissioner of the Office of Mental Retardation and Developmental Disabilities; and Karen Carpenter-Palumbo, LMSW, Commissioner of the Office of Alcoholism and Substance Abuse Services, will be conducting a "People First" Listening Forum on Wednesday, June 20 from 2:00 p.m. - 4:00 p.m. at the Renaissance Hotel in Syracuse.

"People First" Listening Forums are being conducted across New York State, to obtain grassroots input from the people who use multiple services in the areas of health care, addiction, mental health, and developmental disabilities and their families. Conducted in a "town meeting" format, they are part of Governor Spitzer's efforts to put people and their needs at the center of New York's systems of care. With better insight into people's needs, the Commissioners plan to develop methods of improving and coordinating support for people who have needs across the systems of care.

OMH Commissioner Hogan said, "Governor Spitzer's vision is for a health system that is person-centered, not focused on the needs of institutions. We face that challenge within each of the service systems represented here, and additionally we must break down the 'silos' that create barriers to integrated care. We know that mental health is critical to overall health, but also that mental health recovery requires overall wellness."

DOH Commissioner Daines said, "Access to appropriate, high-quality care is our goal for all New Yorkers in need. Often the people using these services are in the best position to advise us on the changes they need. I look forward to hearing from the people in their communities to spark the innovative solutions we seek."

OMRDD Commissioner Ritter said, "New Yorkers who have multiple disabilities including developmental disabilities must have access to high quality care that assures their various and continuing needs are met. I am committed to working together with my sister agencies toward a more seamless service system that puts the person receiving services first and provides each individual with opportunities and choices for and about their own care. The forums have been very informative and I look forward to receiving more grassroots input as we continue to hear from people across the state on how we can better meet their needs."

OASAS Commissioner Carpenter-Palumbo said, "Nearly halfway through the "People First" Forums, we have already learned a great deal from New Yorkers about the diversity of their health care needs. My colleagues and I appreciate the more than 1,200 citizens who have
attended the forums. Every comment is important to us and will help us put forth a comprehensive plan to improve access and quality of care for all New Yorkers, including the 1.8 million with substance abuse problems."

David Brownell, LMSW, Commissioner, Onondaga County Department of Mental Health said, "Governor Spitzer's "People First" vision is welcome news for consumers, families and providers. Change begins at the top but success depends on a unified vision at all levels. These "Listening Tours" are a great first step."

Cynthia Morrow, MD, MPH, Commissioner, Onondaga County Department of Health said, "The World Health Organization defines health as being a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity. I applaud the State Commissioners involved in this initiative, and Governor Spitzer for embracing this comprehensive definition and for bringing people together in an effort to create a more coordinated health care system that supports the health needs of all New Yorkers."

"People First" forums have already been held in New Paltz, New York City and Buffalo; in addition to the Syracuse forum, another is scheduled to be held in Plattsburgh on July 13.

The "People First" forums will be webcast live, and links for viewing are available on each of the agencies' websites. In addition, people who are unable to attend, but want to provide feedback on coordinated care in New York State, can send email directly to the following addresses:

OMH: transformation@omh.ny.gov
DOH: dohweb@health.ny.gov
OPWDD: public.affairs@opwdd.ny.gov
OASAS: public.affairs@oasas.ny.gov
FOUR NEW YORK STATE COMMISSIONERS TO HOLD "PEOPLE FIRST" LISTENING FORUM JUNE 19 AT ROSWELL PARK CANCER INSTITUTE

State Agencies Seek to Improve Coordination of Care Across Respective Systems

Michael F. Hogan, PhD, Commissioner of the New York State Office of Mental Health; Richard F. Daines, M.D., Commissioner of the New York State Department of Health; Diana Jones Ritter, Commissioner of the Office of Mental Retardation and Developmental Disabilities; and Karen Carpenter-Palumbo, Commissioner of the Office of Alcoholism and Substance Abuse Services, will be conducting a "People First" Listening Forum on Tuesday, June 19 from 4:00 p.m. - 6:00 p.m. at the Roswell Park Cancer Institute's David C. Hohn, M.D. Lecture Hall.

"People First" Listening Forums are being conducted across New York State, to obtain grassroots input from the people who use multiple services in the areas of health care, addiction, mental health, and developmental disabilities and their families. Conducted in a "town meeting" format, they are part of Governor Spitzer's efforts to put people and their needs at the center of New York's systems of care. With better insight into people's needs, the Commissioners plan to develop methods of improving and coordinating support for people who have needs across the systems of care.

Forums have already been held in New Paltz and New York City; and in addition to the Buffalo forum, others are scheduled to be held in Syracuse on June 20, and Plattsburgh on July 13.

OMH Commissioner Hogan said, "Governor Spitzer's vision is for a health system that is person-centered, not focused on the needs of institutions. We face that challenge within each of the service systems represented here, and additionally we must break down the 'silos' that create barriers to integrated care. We know that mental health is critical to overall health, but also that mental health recovery requires overall wellness."

OMRDD Commissioner Diana Jones Ritter said, "New Yorkers who have multiple disabilities including developmental disabilities must have access to high quality care that assures their various and continuing needs are met. I am committed to working together with my sister agencies toward a more seamless service system that puts the person receiving services first and provides each individual with opportunities and choices for and about their own care. The first two forums held in New Paltz and Queens have been very informative. I look forward to receiving more grassroots input as we continue to hear from people across the state on how we can better meet their needs."

OASAS Commissioner Karen M. Carpenter-Palumbo said, "Nearly halfway through the "People First" Forums, we have already learned a great deal from New Yorkers about the diversity of their health care needs. My colleagues and I appreciate the more than 1,200
citizens who have attended the forums. Every comment is important to us and will help us put forth a comprehensive plan to improve access and quality of care for all New Yorkers, including the 1.8 million with substance abuse problems."

DOH Commissioner Richard F. Daines said, "Access to appropriate, high-quality care is our goal for all New Yorkers in need. Often the people using these services are in the best position to advise us on the changes they need. I look forward to hearing from the people in their communities to spark the innovative solutions we seek."

Phil Endress, Commissioner of the Erie County Department of Mental Health said, "We are hopeful that as a result of the "People First Listening forums," the state agencies represented will encourage and support new and more integrated approaches to better address the complex health and behavioral health needs of all New Yorkers. By first listening, we are confident that the Commissioners will better understand these needs and the challenges that are faced by individuals accessing the current array of fragmented services. New integrated service models will be a major first step toward improving the overall health of Western New York."

Anthony J. Billittier, IV, MDFACEP, Commissioner, Erie County Department of Health said, "Governor Spitzer and his health and mental hygiene commissioners are to be commended for their bold and brave leadership efforts to bridge the gaps in services to individuals with complex, multiple needs. We cannot continue to treat individuals as separate pieces. Instead, we need to encompass the entire person in order to make that person whole again."

The "People First" forums will be webcast live, and links for viewing are available on each of the agencies' websites. In addition, people who are unable to attend, but want to provide feedback on coordinated care in New York State, can send email directly to the following addresses:

OMH: transformation@omh.ny.gov
DOH: dohweb@health.ny.gov
OPWDD: public.affairs@opwdd.ny.gov
OASAS: public.affairs@oasas.ny.gov
FOR IMMEDIATE RELEASE
Thursday, July 12, 2007

Contacts:  Dianne Henk, (OASAS) 518-485-1768
          Claudia Hutton, (DOH) 518-474-7354
          Jill Daniels, (OMH) 518-474-6540
          Deborah Sturm-Rausch, (OMRDD) 518-474-6601

"PEOPLE FIRST" COORDINATED CARE LISTENING FORUMS
TO CONCLUDE ON JULY 13 IN PLATTSBURGH

Adding to more than 1,100 comments and questions from New Yorkers across the state, North Country residents will have an opportunity to attend the fifth "People First" Coordinated Care Listening Forum in Plattsburgh on Friday, July 13, from 1 to 3 p.m.

Karen M. Carpenter-Palumbo, LCSW, Commissioner of the Office of Alcoholism and Substance Abuse Services, Michael F. Hogan, PhD, Commissioner of the New York State Office of Mental Health; Richard F. Daines, M.D., Commissioner of the New York State Department of Health; and Diana Jones Ritter, Commissioner of the Office of Mental Retardation and Developmental Disabilities will meet the public at the William H. Forrence Health, Physical Education, and Recreation Center, located at Clinton Community College.

The "People First" Listening Forums are designed to obtain grassroots input from the people who use multiple services in the areas of health care, addiction, mental health, and developmental disabilities. Conducted in a "town meeting" format, they are part of Governor Spitzer's efforts to put people and their needs at the center of New York's systems of care.

With better insight into people's needs, the Commissioners plan to develop methods of improving and coordinating support for people who have needs across the systems of care. A report will be submitted by the agencies to Governor Spitzer on the findings of the forums, along with plans for addressing the issues identified. Thus far, more than 2,000 New Yorkers have attended and hundreds more have participated via Webcast.

OASAS Commissioner Carpenter-Palumbo said, "These landmark forums have proven that New Yorkers all across the state want more of a say in their overall health care needs." I anticipate an excellent discussion between North Country residents and the leaders of four state systems at Clinton Community College, and look forward to receiving important feedback on health care issues affecting individuals and their families."

DOH Commissioner Richard F. Daines said, "The people using health care services are in the best position to advise us on ways to better meet their health care needs. I look forward to hearing from people in the North Country on what needs to be done to achieve our goal of providing all New Yorkers with access to coordinated, high-quality health care."

OMRDD Commissioner Diana Jones Ritter said, "New Yorkers who have multiple disabilities including developmental disabilities must have access to high quality care that assures their various and continuing needs are met. I am committed to working together with my sister agencies toward a more seamless service system that puts the person receiving services first and provides each individual with opportunities and choices for and about their own care."
The 'People First' approach is one that OMRDD fully embraces, and I look forward to receiving more grassroots input as we continue to hear from individuals about how we can better meet their needs."

OMH Commissioner Hogan said, "Governor Spitzer's vision is for a health system that is person-centered, not focused on the needs of institutions. We face that challenge within each of the service systems represented here, and additionally we must break down the 'silos' that create barriers to integrated care. We know that mental health is critical to overall health, but also that mental health recovery requires overall wellness."

The Plattsburgh forum is the fifth in a series that began in New Paltz and traveled to Queens, Buffalo and Syracuse. This week's forum will feature a Health Fair where local organizations will be offering free health care checks and information. The Clinton County Health Department, Clinton County Mental Health and Chemical Dependency, National Kidney Foundation, Behavioral Health Services North, Adirondack Tobacco-Free Network, National Alliance on Mental Illness and Champlain Valley Family Center will all be participating.

The Commissioners thanked Clinton County officials from the Departments of Health and Mental Hygiene Services, as well as the Community College, for their efforts on behalf of the People First Forums.

"Solving complicated health issues and having a coordinated health care system requires a multi-disciplined approach that includes all of our health care partners," said Paula Calkins Lacombe, Director of Public Health for Clinton County. "Health problems are tied to behaviors and lifestyle choices, as well as the health care system. To make a difference we need a comprehensive, coordinated, whole-body approach to health."

"This is an historic event and we are especially gratified and pleased that the commissioners will have the opportunity to hear first hand from our communities what is needed in our primarily rural area," said Sherrie Gillette, Director of Clinton County Mental Hygiene Services.

Maurice Hickey, President of Clinton Community College said the college was an ideal host for the forum because of its focus as a resource for the North Country community. "The presence of the four commissioners, the themes of access, quality, interagency collaboration and coordination of care demonstrates a commitment to putting the patient first in health care," said President Hickey. "We are proud to play a small role in that process."

The Forum will be Webcast live, and links for viewing are available on each of the agencies' websites. In addition, people who are unable to attend, but want to provide feedback on coordinated care in New York State, can send email directly to the following addresses:

OMH: transformation@omh.ny.gov
DOH: dohweb@health.ny.gov
OPWDD: public.affairs@opwdd.ny.gov
OASAS: public.affairs@oasas.ny.gov
"People First" Coordinated Care Listening Forums
Putting YOU at the Center of New York's System of Care

The purpose of these forums is to obtain input from the people who use multiple services in the areas of health care, addiction, mental health, and developmental disabilities and their families regarding their experiences. We also welcome input from providers and others. Our goal is to obtain insight on how to improve quality and outcomes, as well as coordinate support for people who have needs across multiple systems.

Please join these New York State Commissioners in a dialogue to discuss the needs and desires of individuals and their families and your ideas about ways to better serve New Yorkers.

- RICHARD F. DAINES, M.D.
  Department of Health (DOH)

- DIANA JONES RITTER
  Office of Mental Retardation and Developmental Disabilities (OMRDD)

- KAREN M. CARPENTER-PALUMBO, CSW
  Office of Alcoholism and Substance Abuse Services (OASAS)

- MICHAEL F. HOGAN, PH.D.
  Office of Mental Health (OMH)

"Our agenda is based on a single premise: patients, not institutions, must be at the center of our health care system. That means that every decision, every initiative and every investment we make must be designed to suit the needs of patients first. The result will be a high-quality health care system at a price we can all afford." - Governor Eliot Spitzer

The forums are a starting point for new collaborative initiatives aimed at better serving our citizens. We would like to hear from you regarding your experiences in accessing care, the quality of care you received and the ease of coordinating your care, and look forward to seeing you.

Theme 1: Access
1. Where have you experienced easy and effective access to services?
2. What problems have you experienced in accessing services?
3. Are these problems more difficult when you need to access services from more than one provider or system?
4. What services have been the most difficult to obtain?
5. Have you made decisions about you or your family's care based on medical cost instead of medical advice?

Theme 2: Quality
1. What does high quality mean to you?
2. What services do you feel are of high quality and meet your needs?
3. Where do you think quality could be improved when accessing services from more than one provider system?

Theme 3: Interagency Collaboration and Coordination of Care
1. Do you feel that your services are generally well coordinated?
2. Are there specific areas where care is well coordinated?
3. Do you have suggestions to help us improve coordination across systems?

Forums will be held statewide at the following areas and dates. Exact locations to be announced.

5/14/07 . 6/6/07 . 6/19/07 . 6/20/07 . 7/13/07

New Paltz Forum will be held at the SUNY New Paltz Lecture Center, 1 Hawk Dr., New Paltz, NY 12561. May 14, 2007
6:30-8:30 PM - 845-357-7869. Please arrive early as you will be asked to fill out a card with your feedback. The cards are also available online at any of the Websites listed below for you to complete in advance. Please bring two copies.

Directions: Take NYS Thruway (I-87) to exit 18. After toll booth, turn left onto Rt. 299. At the next traffic light turn left to S. Patt Corners Rd. Take a right onto Rt. 32. Take a left onto Southside Loop. Turn right on South Rd. Parking will be on the left in the Elting Main Parking Lot 5. The Lecture Center is one block from the parking lot. Please note: If you let the parking lot attendants know that you are attending the "People First" Listening Forum in the Lecture Center, the parking fee will be waived.

Please note: Space is limited, seating will be on a first come, first served basis. Forums will be broadcast live at each of the following agencies websites. If you are unable to attend and want to provide feedback, you may e-mail us at one of the following:

DOH Email: dohweb@health.state.ny.us
Website: www.nyhealth.gov

OMRDD Email: public.affairs@omr.state.ny.us
Website: www.omr.state.ny.us

OASAS Email: public.affairs@oasas.state.ny.us
Website: www.oasas.state.ny.us

OMH Email: transformation@omh.state.ny.us
Website: www.omh.state.ny.us
APPENDIX 3
Blank Comment Card and Online Feedback Form

People First

LISTENING FORUM

Please share your experiences about the services you received and any other information that you would like to bring to the attention of the New York State Commissioners regarding access, quality, and coordination of care between services in the areas of health care, addiction, mental health and developmental disabilities.

1) Select the group you represent:
   consumer   family/friend   service provider   advocate

2) For future follow up please provide contact information (optional):
   Name: ______________________________________________________
   Organization: ______________________________________________
   Address: __________________________________________________
   Phone: ___________________________________________________________________
   E-Mail: __________________________________________________________________

Please keep your comments within the space provided:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Dear Listening Forum Participant:

Now that we have traveled across the state, held five People First Listening Forums on behalf of Governor Spitzer, and heard from many individuals, families, advocates, service providers, and organizations, we are writing to thank you for participating in the regional forums. and to provide some feedback.

Approximately 2,200 people who receive services, family members, providers, community members, and local government representatives attended the Forums. An additional 4,000 watched the live web casts. We received 948 xx comment cards from more than xx people who attended the forums as well as an additional 179 e-mail messages. Many individuals and organizations offered very thoughtful comments and some even of you provided specific recommendations for change; we appreciate your input. Your comments covered an array of subjects and concerns. These ranged from individual descriptions of challenges experienced in one service system of care to complex issues that cut across services provided through all of the agencies participating in the forums. Comments also covered other areas including issues related to education, family assistance, and services for children and families that are provided through other State agencies. The feedback we received during the forums illuminated identified individual, family, local, and statewide needs. We also were pleased to hear many useful suggestions about how our systems can collaborate to improve quality of services and supports.

Please know that our staffs are working together to review every comment, letter, email message, and submission of formal testimony to identify major themes, to indicate where work is already under way, on the issues, and to determine strategies for moving forward collaboratively into addressing the issues and concerns you brought to our attention. We will continue to meet regularly and will periodically report our progress on the People's First Listening Forums web pages listed below:

  Department of Health
  http://www.health.ny.gov/events/listening_forums/

  Office of Alcoholism and Substance Abuse Services

  Office of Mental Health
  http://www.omh.ny.gov/omhweb/news/pr_people_first.html

  Office of Mental Retardation and Developmental Disabilities
  http://www.opwdd.ny.gov/hp_peoplefirst.jsp
We appreciate the time you took to offer your feedback and to participate in this process, and look forward to a fruitful collaboration that will enhance and improve vital services to New Yorkers.

Sincerely,

Karen M. Carpenter-Palumbo, Commissioner of Alcoholism and Substance Abuse Services

Richard F. Daines, MD, Commissioner of Health

Michael F. Hogan, PhD, Commissioner of Mental Health

Diana Jones Ritter, Commissioner of Mental Retardation and Development Disabilities
Appendix 5
Copies of Forum News Reports

“People First” Coordinated Care Listening Forums
Press Coverage

**Newspaper:**
*Daily Freeman 5/15/07* - Kingston, NY
**Advocates say state must refine health care delivery system** By William J. Kemble
Re: New Paltz Forum

*New York Nonprofit Press June 07*
**“We’re Listening” Commissioners Launch “People First Tour”** By Fred Scaglione
Re: New Paltz Forum

*Buffalo News 6/20/07* - Buffalo, NY
**State health officials emphasize collaboration at community forum** By Chrissie Thompson
Re: Buffalo Forum

*Syracuse Post-Standard* - Syracuse, NY
**A Dose of Reality** By James T. Mulder
Re: Syracuse Forum

*Plattsburgh Press Republican* - Plattsburgh, NY
**State officials to discuss health-care concerns** By Jeff Meyers
Re: Plattsburgh Forum

**Television:**
*WCAX News, Burlington Channel 3*
Re: Plattsburgh Forum

*WPTZ, Plattsburgh*
Re: Plattsburgh Forum

**Radio:**
*WAMC Radio - Albany, NY*
Re: Plattsburgh Forum
"We're Listening"

Commissioners Launch "People First" Tour

by Fred Scaglione

Several hundred members of the health and human services community, including providers, consumers and family members, turned out at SUNY New Paltz on May 14th to share their concerns and thoughts with the four new commissioners of New York State’s health-related agencies. Sitting at one table for the first of five “People First” Coordinated Care Listening Forums were Richard F. Daines, M.D., Commissioner of the Health Department; Michael F. Hogan, Ph.D., Commissioner of the Office of Mental Health; Commissioner Dianna Jones Ritter of the Office of Mental Retardation and Developmental Disabilities; and Karen M. Carpenter-Palumbo, CSW, Commissioner of the Office of Alcoholism and Substance Abuse Services.

The stated purpose of these forums is "to obtain input from the people who use multiple services in the areas of health care, addiction, mental health and developmental disabilities regarding their experiences…and to obtain insight on how to improve quality and outcomes as well as coordinate support for people who have needs across multiple systems."

WE'RE LISTENING continued on page 9
Commissioners Launch "People First" Tour

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The stated purpose of these forums is “to obtain input from the people who use multiple services in the areas of healthcare, addiction, mental health and developmental disabilities regarding their experiences... and to obtain insight on how to improve quality and outcomes as well as coordinate support for people who need access to multiple systems.”

WE'RE LISTENING continued on page 9

Providers often point to a lack of adequate funding as one of the root causes of problems confronting the system. Commissioner Carpenter-Palumbo doesn’t agree - at least not on a systems-wide level. “I was very clear with the Governor,” she says, “I really believe the money is there, that we have the money in the state. I have to make sure that it is being spent in the best possible ways.”

Exactly how much is there remains an open question. “I am working just to get an idea on how much we are spending on substance abuse in the state. I know we are spending $1.2 billion in this agency with Medicaid. But, there is money going into Parole, the Department of Correctional Services and Mental Health.”

Her goal is to reinvest resources into programs and services which have been proven most effective.

“Look at detox,” she says. “We spend $400 million on detox.”

“I think I could do quite a few things with $400 million in different ways to better serve clients.”

For example, the Commissioner points to variations in therapeutic community models. “Some do three month programs and some do 18 months. Do we need that? I certainly don’t want to see the message that everything should be the same but if we look at both of these programs, what is the return on our investment? What yields the best return in terms of recovery?”

Prevention programs offer similar opportunities for fine tuning or expenditures, she says. “Prevention is the first prescription for a healthy New York. We spend about $100 million on prevention right here in OSSA. We know what works. We have science based research and practice. We have to make sure that everyone is doing that. We really want to make it a priority. I don’t think it has been a priority for a long time.”

Carpenter-Palumbo is also hoping to build a substance abuse “recovery movement” in the state. “Compared to other fields like mental health or mental retardation, this field does not have a strong recovery movement,” she says. “That is a priority because we know it works. We know that if you have a mental health diagnosis and you are connected to a psychosocial club, you are more likely to stay out of the hospital. You are connected. You have someone to talk to, someone who can help you get treatment right there if you have a problem.”

“We need that on the substance abuse side,” she continues. “Historically there has been a stigma. But people have worked very hard to get into recovery. Why shouldn’t that be viewed as a badge of honor just like it is for a cancer survivor?”

Over the coming months, the commissioners and their staff will be conducting indepth reviews of current programming and developing plans for the future. She is asking non-profit providers to join her in this process.

“I want them to begin a review of their own practices, just as I am doing,” she says. “Are they doing the best work they can? What could they do differently, if...? I want to encourage people to be excited and to come to us with their ideas. Then, hold my feet to the fire. Some we will be able to implement. Some we won’t.”
WE'RE LISTENING continued from page 1

"For far too long, individuals with multiple health needs have had to navigate a complex and fragmented system," said Dr. Dennis, the formal host for the first of the Listening Forums. "All too often, there are disconnects between systems of care."

The mere presence of the four commissioners at a single event taking input and questions from the general public was seen as a major break from past practice. "This is historic, right?" commented OMRDD's Commissioner Ritter.

"I thought it was remarkable, if nothing else than for people across the state to have access to these four commissioners," said John Coppola, Executive Director of the New York Association of Alcoholism and Substance Abuse Providers. Coppola believes that the sessions could have a significant impact.

"I was very impressed with the commissioners," said Dr. James McGuirk, Executive Director of Astor Home. "Not only did I think they were open for feedback but I thought they were honest in their comments. I got the sense they were taking everything very seriously and that there was a genuine commitment to respond."

Each of the commissioners also acknowledged problems within their own service networks and the ways they interact with other systems at both the state and local level. "The implicit policy for the last 12 or 15 years has been defined by two essentially negative goals," said OMH Commissioner Hagan. "In community-based mental health care, we would do whatever Medicaid would pay for. Our goal with respect to hospitals has been to close them. Neither of these are particularly lofty goals."

An estimated 300 providers, consumers and family members turned out to share their thoughts and concerns with commissioners at the inaugural "People First" Listening Forum in New Paltz on May 21st.

Photo: Bill DeVita, Rehabilitation Support Services, Inc.
significant impact in shaping future policy and practice. “It gets my attention if a father of a 23 year old mentally-retarded young woman gets up and says I have exhausted myself trying to get through the regulatory boundaries and red tape.”

“I feel like I have been crawling through the desert for years and now I have found the oasis,” said Jane Elven, Director of HIV Prevention, Planned Parenthood of the Mid-Hudson Valley, Inc. “I just pray you are not a mirage.”

“We are all very optimistic about the future,” said OASAS Commissioner Carpenter-Palumbo who was credited for suggesting the joint listening forums. “We like each other. We have been ‘kumbaya-ing’ from here to there. But we are mostly about solutions. What is important is that we better serve the people who come in our front doors.”

The commissioners drew praise for their willingness to acknowledge and address community concerns.

“It was a powerful acknowledgement of what everybody says when you are out in the field,” said Cathy Doyle, CEO of Greystone Programs, Inc. “If you fit perfectly in one of these systems you get served, but if you have any kinds of needs that overlap, the systems

“Since coming to New York, I have never seen so many smart and committed people as I see working in this field who are so frustrated at the absence of a common vision, yet who have persevered in communities across the state,” Hogan continued stressing the need for State agencies to recognize and respond to innovative solutions at the local level.

Several themes were raised by members of the audience, including incompatible eligibility requirements which create gaps in services as clients move from one system to another, problems with managed care coverage and the need for affordable and supportive housing for clients in all of the health-related systems.

The second “People First” Coordinated Care Listening Forum will be held in New York City at York College in Jamaica Queens on June 9th. Subsequent sessions will be held in Buffalo on June 19th, Syracuse on June 20th and Pittsburgh on July 13th. All of the sessions are being broadcast simultaneously via the internet. For additional information on sessions and how to attend or provide feedback, visit the websites of any of the participating agencies: www.nyhealth.gov; www.omh.state.ny.us; www.oasas.state.ny.us; www.omh.state.ny.us.
State officials to discuss health-care concerns

By JEFF MEYERS
Staff Writer

PLATTSBURGH — Community members could have a say in what directions the state's health-care system may take in the near future.

Commissioners from the state's four major health-care agencies are concluding a series of unprecedented public-comment sessions across New York when they visit Plattsburgh on Friday, July 13, for a two-hour gathering at Clinton Community College.

"The aim of the forum is to allow regular people to come in and talk to the commissioners about their health-care needs," said Diane Henk, communications director for the Office of Alcoholism and Substance Abuse Services.

"People often need services from several agencies. There has got to be more focus on collaboration (between agencies), and this is a step in that direction."

Joining Office of Alcoholism and Substance Abuse Services Commissioner Karen Carpenter-Palumbo for the two-hour session will be Richard Daines from the Department of Health, Diana Jones Ritter from the Office of Mental Retardation and Developmental Disabilities and Michael Hogan from the Office of Mental Health.

"They have already begun responding to some of the issues they've heard" at four previous meetings in other regions, Henk noted, adding that questions and comments from the public are being collected and evaluated by the commissioners and their staff.

"The commissioners are very honest," she added. "They don't promise things. If there is no easy solution, they will say so. These issues have to be looked at intelligently, and that is what they are doing."

Participants in the session will have an opportunity to submit a question or concern, and then the commissioners will pick what they feel are the most significant or common concerns brought forward.

Those chosen will make their comments aloud during the session for the commissioners to respond to in person. Those questions or comments not chosen will be reviewed by the four agencies for the development of an action plan to be presented to Gov. Eliot Spitzer.

"The commissioners realize this is a huge challenge, but they know they have to listen to the people in order to put people at the center of the health-care system," Henk said.

"There will be results from these sessions. They are setting an agenda for the agencies to collaborate wherever and whenever possible."

Historically, the perception has been that general health-care services have been separate from mental health. The "People First" listening forums are attempting to bridge that gap and allow people to find appropriate services when their health-care concerns overlap both areas.
"It's a way for these agencies to discuss issues collaboratively and to work for the common good of everyone," said Sherrie Gillette, director of community services for the Clinton County Mental Health and Addiction Services.

"They want to hear from people who may have struggled for services," she said, adding that she had attended the forum in Syracuse and was deeply impressed with both the questions from the public and the responses from the commissioners.

The forum, originally scheduled for the Stafford Center auditorium at Clinton, has been moved to the gymnasium to accommodate everyone who wishes to attend. Participants will receive cards to write their comments on, and those chosen will be given two minutes to speak.

Themes for the event will focus on access to health care, the quality of health care and collaboration and coordination of care among agencies.

The commissioners are also welcoming comments from health-care providers.

The People First Coordinated Care Listening Forum will be held from 1 to 3 p.m. Friday, July 13, at Clinton Community College.

Registration for the event, which is free and open to the public, begins at 12:30 p.m. at the gymnasium.

E-mail Jeff Meyers at:

jmeyers@pressrepublican.com
A DOSE OF REALITY

Town hall audience diagnoses state health care's ills
Thursday, June 21, 2007
By James T. Mulder
Staff writer

About 400 people turned out Wednesday for a public forum in Syracuse to tell the state's top health care bureaucrats what's wrong with New York's system.

Members of the audience at the town hall-style meeting at the Syracuse Renaissance Hotel pleaded for more psychiatrists, dentists trained to care for the disabled, and more community-based alternatives to institutions for people with mental illnesses and developmental disabilities.

Nashwa Kahn, a youth advocate at the North Country Children's Clinic in Watertown, said children in her area who need psychiatric care cannot find any.

"We need to do something now or else it will be another dysfunctional generation," Kahn said.

The meeting was the fourth in a series of listening forums officials are conducting around the state to get feedback from patients, families and providers on how the state can better coordinate services.

The meeting was conducted by Michael F. Hogan, the state's mental health commissioner; Dr. Richard F. Daines, state health commissioner; Diana Jones Ritter, commissioner of the Office of Mental Retardation and Developmental Disabilities; and Karen Carpenter-Palumbo, commissioner of the Office of Alcoholism and Substance Abuse Services.

The forums are part of Gov. Eliot Spitzer's efforts to put people, not institutions, at the center of health care.

"We're not doing this with the assumption that we know best," Hogan said. "There has been a little bit too much of not listening to local needs."

He and the other commissioners said there are too many artificial barriers set up that make it difficult for people with multiple needs to access physical health services, mental health services, addiction treatment and disability services. They said government agencies historically have contributed to and perpetuated this problem.

Hogan and Daines said there are no easy solutions to the shortage of child psychiatrists, which they said is a national problem.

Daines said about half the doctors trained in New York leave the state after they finish training. Even if every child psychiatrist trained in New York stayed here, there still would not be enough, he said.

Hogan praised efforts under way in Onondaga County to provide more mental health training to pediatricians who are frequently asked to treat children's behavior problems.

Carpenter-Palumbo said she and her fellow commissioners are trying to change the mind-set that public health is just about physical health.

"One in 10 New Yorkers has a substance abuse problem," she said. "They are your neighbors."

James T. Mulder can be reached at 470-2245 or jmulder@syracuse.com.

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State health officials emphasize collaboration at community forum

By Chrissie Thompson NEWS STAFF REPORTER
Updated: 06/20/07 6:56 AM

The state’s top health officials received an unusual introduction Tuesday when they stopped in Buffalo on their tour of Western New York.

Phil Endress, commissioner of Erie County’s Department of Mental Health, told the Roswell Park Cancer Institute gathering not to expect too much from the state.

“The time that we come together and we say that we’re here from the state and we’re here to help you — I think it’s gone,” Endress said. “We have to work together so that things are done in a way that we are not pointing a finger at representatives from the state.”

Following the advice of Gov. Eliot L. Spitzer, the commissioners — Richard F. Daines of the Department of Health, Michael F. Hogan of the Office of Mental Health, Diana Jones Ritter of the Office of Mental Retardation and Developmental Disabilities and Karen Carpenter-Palumbo of the Office of Alcoholism and Substance Abuse — are conducting five forums across New York to hear community members who use state health services.

By the end of the two-hour event, Hogan told the audience he agreed with what he called Endress’ “funky comments.” Hogan said Endress was right to focus on collaboration between local and state agencies.

In fact, the theme of collaboration among the departments of the four officials dominated the discussion.

Helen Trowbridge Hanes, director of residential services for Aspire of Western New York, an agency that serves people with developmental disabilities, drew cheers from the crowd when she asked the four agencies to collaborate on providing one criminal background check system instead of each requiring its own. She termed the request “a real lowhanging fruit.”

After the forum, Trowbridge Hanes said she had been dreaming for years of seeing all four state agencies working together.

While the state officials seemed optimistic about making change, they spoke frankly about limitations to provide for every health need.

“We have the delusion that we’re going to be able to provide housing for everyone with mental illness. Forget about it,” Hogan said. “We’re never going to develop enough for everyone who wants a place to live.”
Hogan also said he did not think “the system” could solve the problem of transporting people with disabilities to community activities.

“I don’t think in a state with . . . the second-highest tax burden in the country, we’re going to solve this by buying more transportation solutions,” he said.

After the forum, Daines said he was “giving the roar” to others in his department to work on the concerns presented.

“We are changing, and people will see change,” he said.

But Ben Muller, 22, said he had doubts about the agencies’ addressing all concerns. A day after Healthcare Association of New York State announced a 36-doctor shortage at six Western New York hospitals, Muller’s mother, Christine, spoke about caregiver shortages for people like her son, who has Duchenne muscular dystrophy, which means his muscles will weaken as he ages.

“I think some of the things they know and they’re working on,” he said. “But some of the things don’t seem like they’ll change because they haven’t,” he said.

c Thompso n@buffnews.com
NEW PALTZ - Better procedures are needed to ensure people in need of health, mental health or substance abuse services don't miss out because of bureaucratic failings, speakers said Monday at a forum on the state's health care system.

The two-hour forum at SUNY New Paltz attracted about 200 people, and 15 speakers. Among the most frequent complaints is that proposed changes are not taken seriously or are considered a duplication of existing services.

"In 2006 Ulster County ... did a survey of seven school districts and who had developmental disabilities and mental health issues," said Sal Garozzo, director of clinical services for Ulster-Greene ARC. "What we identified was approximately 100 individuals needing services. We submitted a proposal to (the state Office of Mental Retardation and Developmental Disabilities) and the responses that we have been getting back is 'Why do we need a service that seems very similar ... to services that are available.'"

The panel leading the forum included state Department of Health Commissioner Richard Daines, state Office of Alcoholism and Substance Abuse Services Commissioner Karen Carpenter-Palumbo, state Office of Mental Health Commissioner Michael Hogan, and state Office of Mental Retardation and Developmental Disabilities Commissioner Diana Jones Ritter.

Attorney Trilby de Jung, representing the Empire Justice Center, said the commissioners need to develop a plan that allows people with multiple issues to receive help without being shuffled between departments.

"We've gotten ... several calls from attorneys in this region who have clients who have difficulties accessing health care services once they were enrolled in managed care plans," she said. "These are individuals with complex health needs that span your different agencies. It's enough to get us very worried, particularly in light of what we're hearing from New York City, where now mandatory Medicaid managed care has reached out to individuals who receive SSI (Supplemental Security Income), individuals with serious and persistent mental illness, children with serious emotional difficulties."

Diane Mueller, a parent advocate with the Mental Health Association in Ulster County, recommended working with the state Education Department so "we're seeing everybody at the table" in developing solutions.

"In the future, what are we doing to create a better system of care where the children are not being put into one system versus the other?" she asked.

Panelists were also asked to develop better health insurance laws to cover low income individuals.

"So many people are uninsured and as a result they don't seek care until they're very, very sick, and then they have to go to the emergency room and get emergency care, which is sometimes very costly because it's almost end-of-life," said Esther Nason, an advocate for universal health coverage. "If they were able to access the health care system when they were young, practice preventative medicine, they wouldn't reach that point."

The commissioners are scheduled to lead another four forums in the state before making recommendations later this year.
## APPENDIX 6
### Summary of Interagency Collaborative Activities Currently Under Way

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<tr>
<th>Initiative</th>
<th>OMH</th>
<th>DOH</th>
<th>OMRDD</th>
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<td>CMA User Group (Human Resources)</td>
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<td>Community Assessment Strategies and Impact Group</td>
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SUMMARY OF CONTENT ANALYSIS CONDUCTED BY DOH

There was overall consistency in the themes that emerged during each of the Listening Forums and through other comments submitted, indicating that the broad issues for consumers, their family members and other advocates, and the providers who serve them are similar, regardless of their location in New York State. Following is a summary of the predominant themes that were reported and that either pertained primarily to the Department of Health or that included the Department of Health.

- **Housing:** The need for affordable, safe, accessible, permanent, community-based and supportive service enhanced housing was the most frequently reported concern among Forum participants.

- **Access to Care:** There was a resounding call from Forum participants for better access to care for persons with special needs including but not limited to those with chronic illnesses, developmental disabilities, substance dependence and who face barriers such as lack of insurance, homelessness, and illiteracy.

- **Transportation:** Forum participants noted that transportation, particularly in rural areas, prevents access from many needed services including medical care. In addition, the current Medicaid prohibition against billing for more than one service per day exacerbates access by requiring consumers to travel on multiple days. This results in the need not only for transportation but often other supportive services as well such as child care and may also jeopardize the individual’s employment because of their need to take additional time off.

- **Prevention:** Many persons commented that there should be a much greater focus on prevention and risk reduction education in general and investment in efforts to intervene for consumers before their needs become insurmountable crises.

- **Planning:** Participants were encouraged by the appearance of four commissioners at the Forums and emphasized the need for more coordinated planning among the four agencies and among other key state agencies as well including the State Education Department, the Office of Temporary and Disability Assistance, the Office of Child and Family Services and the Department of Correctional Services.

- **Funding:** Forum participants suggested using more master contracts and integrated funding streams to fund services that cross agency boundaries and as a way to ensure more coordinated care.

- **Eligibility:** Many said that there should be one set of eligibility criteria for access to services across the full spectrum of services offered by the range of state agencies.
Data Collection and Analysis: Participants noted that it would be helpful to have consistent systems of data collection/reporting and analysis/evaluation across systems of care.

Regulations and Policies: Many Forum participants said that there needs to be a much greater effort to make regulations and policies consistent across state agencies.

Health Insurance/Medicaid: There was a call from participants for universal health care coverage for all New Yorkers. In addition to the Medicaid one service per day billing issue noted above, other Medicaid limitations, including new restrictions on case management and treating both primary and secondary diagnoses make it difficult to obtain needed services. Specialty care (oncology, urology, psychiatry) is reported to be difficult to access under Medicaid.

Participants said that current Medicaid reimbursement for children in foster care often results in fragmented care; coverage is needed for 18–21 year olds aging out of the foster care system.

There was a call for immediate Medicaid coverage for persons released from prisons and jails.

Some participants reported that managed care companies are denying coverage for inpatient chemical dependence treatment, even when medically necessary.

It was noted that the Medicaid system is not consumer-friendly for transgender individuals, forcing people to the black market for hormones.

Participants requested improved access to hospice services for persons covered by Medicaid and in long term home health care.

Medical Specialty Care: It was reported that particularly in rural areas, specialty medical, psychiatric, and dental care are difficult to obtain. Many suggested the use of telemedicine/telepsychiatry to address some of this need.

School-Based Health Centers: Participants expressed overwhelming support for these community-based health centers that provide care to many youth who might otherwise go without health care (including primary, preventive, mental health, health education and dental care); the expansion of these centers with enhanced fiscal support was widely recommended.

Health Education: Participants said that public health campaigns are needed to promote service availability at the state and local levels and to promote prevention and care options (cancer, HIV/AIDS, Lyme disease, FASD, preterm birth; availability of community health centers); a lifespan approach to health issues was suggested.

HIV/AIDS: HIV/AIDS service provider and consumers reported that coordinated care is essential for people living with HIV and AIDS. They noted that comprehensive care with wrap-around services is a best practice model. Some providers noted that there are increasing mental health issues for their clients with HIV/AIDS and said that there needs to be better coordination between health and mental health care service delivery, including coordination of HIV disease and psychiatric medications.

Stigma and Discrimination: Participants reported that stigma and discrimination are still significant issues for many people in need of services including those with mental illness,
chemical dependence, developmental disabilities and HIV/AIDS. Educational campaigns were suggested as a means to reduce stigma and discrimination.

- **Certificate of Need (CON) Applications**: Forum participants said that it would be helpful to have more effective collaboration among the agencies in reviewing CON applications.

- **Electronic Medical Records**: Participants expressed widespread support for implementation of health care technology including electronic medical record systems to improve overall service quality and improve information sharing by care providers.

- **Fetal Alcohol Spectrum Disorder (FASD)**: Forum participants requested greater interagency collaboration in service delivery for those affected by FASD and increased attention to the prevention of FASD.

- **Health Disparities**: Forum participants noted continuing disparities in access to and quality of care and requested renewed focus and collaboration among state agencies to eliminate these disparities.

- **Services for Youth**: Many participants noted difficulties in access to care for young people, particularly those not covered by insurance. It was noted that young people at increased risk for being without care including gay, lesbian, bisexual and transgender youth need particular attention, with improved access to care and sensitivity training for providers.

- **Other Supportive Services**: Forum participants frequently mentioned the need for additional supportive services to make services accessible including language interpretation, sign language interpretation, peer-delivered services, examination fixtures to accommodate individuals with physical limitations. It was also noted that literacy is key to access to care, particularly medical care.

- **Medical Care for Special Populations**: Participants noted that there need to be better health care options for persons with spina bifida, eating disorders and Alzheimer’s disease.

**SUMMARY OF CONTENT ANALYSIS CONDUCTED BY OASAS**

**PRINCIPLES**

- Consumers and families should participate in decisions about the services they receive.
- Services that support family members are important in improving the quality of care provided by the four systems.
- The four agencies are committed to providing individualized services that are developed with consumer and family involvement.
- There is no need to reinvent the wheel. Existing cross systems structures can be used to improve collaboration among systems and to improve services for consumers and families. These include the Coordinated Children’s Services Initiative (CCSI), Most Integrated Setting Coordinating Council (MISCC), and Inter-Office Coordinating Council (IOCC).
MAJOR THEMES

Cross-System Themes (DOH, OASAS, OMH, and OMRDD)

Housing

- The critical importance of housing was the most significant theme that emerged during the forums. The need for housing ranged across all disabilities and areas of the state. Housing is a critical component in the continuum of care and has a direct impact on the effectiveness of services. Forum participants called for safe, affordable, accessible, and integrated housing. Specific needs identified included transitional, supportive, and permanent housing.

Transportation

- The lack of transportation was identified as a major barrier to individuals accessing health care, chemical dependence, mental health, and mental retardation services. This issue is especially acute in suburban and rural areas of the state.
- **Solution:** Create a statewide cross-disability transportation task force that will oversee current efforts and develop a comprehensive transportation policy for all areas of the state.

Workforce

- Mental health, mental retardation, and chemical dependence agencies are experiencing a workforce crisis. Difficulties that providers have in attracting and retaining staff affect the quality of care. In the healthcare system, there are shortages of nurses and home health aides.
- **Solution:** Regular Cost of Living Adjustments (COLAs) are necessary to stabilize agency staff and provide quality services.
- Opportunities exist to train and mentor individuals with disabilities to address staffing shortages in provider agencies.

Prevention

- Increased services for children are the best form of prevention.

Planning

- There should be an overarching planning process that includes OMH, OASAS, OMRDD, and DOH. This would improve service delivery and reduce burdens on counties and providers.
- The Coordinated Children’s Services Initiative (CCSI) should be rejuvenated.

Funding

- State agencies should use master contracts, whenever possible, to foster service integration.
Stigma

- Educational efforts are needed to reduce the stigma faced by those with mental illness, chemical dependence, developmental disabilities, and HIV/AIDS.

Criminal Background Checks

- There should be one criminal background check that meets the requirements of all state agencies.

Certificate of Need (CON)

- There needs to be more effective collaboration in reviewing CON applications.

Agency-Specific System Themes

Health

- Universal healthcare coverage should be implemented in New York State.
- Individuals in the mental health, mental retardation, and chemical dependence systems have an array of healthcare needs.
- Concerns were expressed about the regulation prohibiting outpatient Medicaid billing of two services in the same day. In order for a provider to receive Medicaid reimbursement, patients are forced to travel to the same provider twice to obtain services. Medicaid will pay transportation costs for a patient to receive services on two different days.
- There are issues in accessing services by individuals covered under Medicaid, the AIDS Drug Assistance Program (ADAP), and Family/Child Health Plus. These include the lack of medical providers especially specialists who accept Medicaid, the need to better coordinate HIV services, and problems accessing services encountered by SSI recipients in New York City who were recently mandated into Medicaid Managed Care.
- There should be immediate Medicaid coverage for individuals released from prisons and jails.
- Managed care companies are denying coverage for inpatient chemical dependence treatment despite the fact that this level of care is medically necessary.
- School-based Health Centers (SBHCs) provide primary and preventive health, mental health, dental, and health education services for children and adolescents. Families have difficulty accessing SBHCs because there are only 200 of them throughout the state. Solution: To improve access, New York State needs to ensure a permanent funding solution that includes eliminating current financial barriers. SBHCs do not receive Child Health Plus reimbursement for HIV counseling and testing, which are reimbursable to other licensed health facilities.
- There should be an increase in HIV prevention and risk reduction programs.
- Comprehensive care with wraparound services is a best practice for those with HIV/AIDS.
- HIV/AIDS providers are experiencing more mental health issues.
Implementing health care technology including electronic medical records will improve collaboration among providers and give them the information to better serve individuals with disabilities. Electronic medical records would enhance history taking, reduce error and duplication, and facilitate timely referral.

The four agencies should collaborate on efforts to prevent Fetal Alcohol Spectrum Disorder (FASD) and to provide coordinated, integrated services for individuals and their families who are affected by FASD.

The strong relationship between physical and mental health highlights the importance of better coordination between the two systems.

There are racial, ethnic, economic, and language barriers to accessing healthcare services.

### Chemical Dependence

- There is a large body of research demonstrating that investments in prevention are cost-effective. Research has also identified evidence-based prevention strategies.
- Medicaid should reimburse off-site services for chemical dependence treatment. This would improve access to treatment for underserved populations.
- Timothy’s Law should be expanded to include chemical dependence.
- Adolescents experience difficulty in accessing appropriate chemical dependence treatment because they often lack health insurance coverage.
- There should be more focused efforts to educate parents and youth about the consequences of underage drinking.
- Additional funding for case management is needed to help coordinate needed care.
- There should be more treatment programs for women with children.
- Women in recovery are negatively affected by the lack of coordination among the social services, courts, child welfare, and labor systems.
- Current reimbursement rates do not meet the cost of providing crisis services in rural counties.
- There should be more vocational, educational, and job placement services for those in treatment and recovery.
- The savings from reforming detoxification should be reinvested in other chemical dependence services.

### Mental Health

- There is a shortage of child psychiatrists throughout the state especially in rural areas.

### Mental Health and Chemical Dependence

- There should be “no wrong door” to treatment for those with co-occurring mental health and chemical dependence.
OMH and OASAS have very different treatment approaches for dually diagnosed clients. The coordination of the regulations and service delivery systems is essential to developing evidence-based programs for this population.

OMH and OASAS regulations make it difficult to provide integrated treatment for those with co-occurring mental illness and chemical dependence. The two agencies should dismantle the regulatory barriers that prevent integration of these services.

Funded service providers need more financial flexibility to serve those with co-occurring mental health and chemical dependence. Financing models should be restructured to support integrated care and treatment.

Mental health and chemical dependence treatment services should be co-located.

There needs to be a new model for residential services for the dually diagnosed that incorporates harm reduction methods and traditional chemical dependence treatment.

There is a lack of services for Quadrant 4 individuals who have both a serious mental illness and a serious chemical dependency.

Eligibility for client services between OMH/OASAS needs discussion due to conflict of primary diagnosis for admission.

There are not any community residences that are licensed by both OMH and OASAS. Some OMH community residences will not accept a person with an addiction problem and some OASAS community residences will not take a person with an extensive mental health diagnosis. Solution: Start and fully fund some community residences for the dually diagnosed out of both budgets.

The OASAS “Gross Cost per Service Unit” policy makes it difficult for funded service providers to offer effective treatment to persons with co-occurring mental illness and chemical dependence.

Adolescents with severe dual diagnoses who require psychiatric stabilization to function, but do not pose a critical threat to themselves or others, find it nearly impossible to access an appropriate level of care.

Mental health services should be available in chemical dependence treatment programs.

The Credentialed Alcoholism and Substance Abuse Counselor (CASAC) exam should be offered more frequently.

Chemical Dependence and Criminal Justice

There is a need for better collaboration between the criminal justice system and treatment providers. This should include an appropriation of adequate resources for chemical dependence treatment providers who serve individuals involved in the criminal justice system.

Drug courts and the chemical dependence treatment system must work together better. Treatment providers should be reimbursed for the services they provide to drug courts.
SUMMARY OF CONTENT ANALYSIS CONDUCTED BY OMH

All comment cards were examined closely to identify issues that in any way included the OMH system of care. Comments were grouped according to concerns expressed solely, between and among systems of care as follows: OMH only, the OMH and DOH systems, OMH and OASAS systems, OMH and OMRDD systems, and three or more systems. Within these areas, domains identified as having challenges and presenting opportunities for improvement included access to services, coordination of care, financing issues, quality of care, regulatory and structural issue and workforce issues.

It is important to know that many issues were raised in each domain, but for the sake of summary, those that were raised often are recorded in summary format below: (An absence of mention of issues and concerns is not meant to imply that certain issues were not important to any one person or a few who were in attendance.)

Mental Health Only

Access

- Provide adequate support to rural counties that deal with unique capacity, structural, and resources and geographic barriers to care. Included were addressing limited public transportation to services, a lack of acute care capacity in close proximity to children’s home, long waits lists for care, insufficient services and treatment modalities for youth transitioning to the adult service system and for hospital-based treatment of children, and insufficient housing.

- Increase the number of child and general psychiatrists, psychologists, counselors, social workers, therapists and psychiatric nurse practitioners, especially in rural areas. Suggestions included offering fiscal incentives and funding to attract staff in short supply and removing statutory barriers, enabling nurse practitioners to provide preventative and school-based services.

- Help parents to better advocate for their children and meet their needs by stopping practices that hurt families and relying on those that support them. Included were calls to strengthen parenting skills, not set parents up to fail because they lack the support to succeed, and ensuring that parents have a voice in their children’s treatment.

- Promote family support to enable children and their families to obtain the information they need to secure services that best meet an array of needs, including respectful and compassionate care, respite services, including insurance and financing information.

- Improve access to school-based mental health services.

- Improve access to and capacity for the delivery of children’s services, particularly for low-income children and adolescents and for adolescents who are part of the Indian Nation.

- Provide specialty and permanent, decent, affordable housing to meet the varying levels of needs for children and adults in recovery.

- Maintain, promote and protect from funding cuts, especially in light of PROS implementation, the use of social clubs to reduce the impact of disability and to foster individual stability, skills development, independence, community, and recovery and less need for hospital care.
- Extend the benefits of Timothy’s law to every citizen, not just people covered by group health insurance offered through businesses.

**Financing**
- Permit Medicaid reimbursement of telepsychiatry services.

**Quality of Care**
- Continually monitor opportunities for clinical and administrative improvement and develop systematic responses aimed at raising quality and promoting accountability for the quality of care delivered. Included were suggestions for making consumers and families aware of where they could go to lodge complaints without fear of reprisal, improving physical health for persons with mental illness to reduce diabetes, heart disease, etc., and having HIPAA regulations not create barriers to family participation.
- Provide respectful, culturally competent treatment, particularly for underserved communities (e.g., GLBT, Latin).
- Promote individual, person-centered care and peer support.
- Provide public education to help reduce the stigma associated with mental illness.

**Workforce**
- Employ staff who have respectful attitudes, are professionals eager to work with families, and are well-trained, competent and experienced in case management and address workforce issues that erode the quality of care (e.g., high turnover, low salaries).

**Mental Health and Health**

**Access**
- Better integrate physical/mental health care and disease management (e.g., co-located services).
- Better meet the multiple needs of adult home residents (e.g., affordable housing, advocacy).

**Financing**
- Review Medicaid policies in relation to physical and mental health care to be certain they facilitate integrated and coordinated care (e.g., paying for more than one visit per day, addressing inequitable reimbursement rates, reverse policies that limit the ability of a person with a mental illness to obtain care).

**Mental Health and Alcohol and Chemical Dependence**

**Coordination of Care**
- Promote evidence-based simultaneous, integrated treatment of mental health and chemical dependence rather than breaking apart mental health and chemical dependence treatment programs and driving up the cost of care (e.g., more visits, more transportation costs).
Mental Health and Mental Retardation and Developmental Disabilities

**Access**

- Improve access to evaluation, coordination, of, and flexibility in service provision while reducing the probability that families, courts, and providers are left to resolve very difficult problems without adequate resources. Suggestions included addressing service coordination regulations that complicate care for persons approved for participation under the OMRDD waiver, breaking down structural and regulatory barriers that limit the ability of children with dual needs to be served in either system, addressing how best to serve children with autism spectrum disorders.

- Ensure appropriate and timely residential placements of children with mental illness and developmental disabilities and strengthen families’ ability to cope while awaiting placement.

- Improve in-state and regional access to appropriate residential settings and models of community care that promote family involvement in care.

- Ensure that persons with developmental disabilities have access to emergency psychiatric services, when indicated.

**Multi-agency Issues (Those Issues Identified as Cutting across the Four Agencies)**

**Access**

- Provide adequate support to rural counties that deal with unique capacity, structural, and resource issues and geographic barriers to care (e.g., rely upon school-based health centers to increase access, resolve transportation difficulties.)

- Provide appropriate, affordable housing to meet the needs of clients touched by the various systems of care, including older adults, persons with complex medical needs, and persons with co-occurring disorders, including creative strategies to facilitate placement such as shared housing among people served by different service systems.

- Reduce the waiting period from time of crisis or the identification of service need to first follow up appointment (e.g., implement a single point of access for care to people served across the systems of care).

- Rely upon telepsychiatry as an alternative service delivery method, particularly for children in need of child psychiatry services.

**Coordination of Care**

- Make information easily accessible and understandable so that consumers and their families may navigate easily between systems of care, understand vital health care and insurance documents, and readily know who to contact for problems or for additional information (e.g., names and phone numbers of point persons for each agency; a lead person with each agency to offer assistance).

- Invest more time, energy and dollars into cross-systems collaborations such as CCSI, based on principles truly in the best interest of children and their families, and where diverse (medical, social services, educational, etc.) needs are met.
Financing

- Monitor the care of persons with multiple disabilities who receive SSI upon mandatory enrollment into Medicaid managed care to be certain that they are not losing medically necessary services.
- Consolidate funding streams and mechanisms across the systems of care (e.g., blended funding, co-located models, pooled resources), along with regulatory reform, to allow cross-system service planning, coordination and service provision, and attention to person-centered service provision by “service coordinators.”

Quality of Care

- Promote person-centered services, peer-run and family supports and services, and respect for service recipients and their families, including inclusion of consumer and family members on advisory and governance boards.

Regulatory and Structural Issues

- Align agency structures and functions (e.g., reciprocal recognition of staff credentials) to simplify processes, decrease administrative complexity, increase flexibility, and enhance integration of services for adults, children and families within OCFS, OMH, OMRDD, SED, OASAS, CJ, other social service agencies, voluntary agencies and local departments of social services (e.g., accessing care not available in one system automatically when served in another system, give children what they need rather than spending resources qualifying them, streamline administrative requirements such as fingerprinting across agencies, standardize and minimize where possible documentation requirements).
- Lift regulatory restraints on providing integrated health, mental health, substance abuse, and aging services (e.g., creating a single license to authorize the provision of health, mental health, mental retardation, and/or substance abuse services).

SUMMARY OF CONTENT ANALYSIS CONDUCTED BY OMRDD

All comments cards, e-mails, and other correspondence for the five forums were reviewed; a total of 422 commentaries included issues of relevance to OMRDD. These comment cards usually had relevance for additional agencies and many cards identified more than one concern or issue. The number of specific issues identified totaled 566. Comment cards were reviewed for thematic content, and clustered according to the emergent themes. Frequency of comments associated with the themes was assessed and topics are organized in accordance with prevalence of comments.

While summaries by location of forum are available for the purpose of regional consideration, the following represents a summary for the entire state.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of Comments</th>
</tr>
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<tbody>
<tr>
<td>Special Populations</td>
<td>91</td>
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The needs of individuals with the dual diagnoses of developmental disability and mental health challenges were by far the most highly identified issue relevant to OMRDD. People with dual diagnoses were reported as often “bouncing” between systems, with neither OMRDD nor OMH taking leadership for coordination of supports and services. In addition to accessing integrated basic supports and services, needs for emergency housing, emergency psychiatric care and stabilization services were highlighted. Suggestions included the provision of regulatory changes that would allow for cross system service delivery and funding flexibility, higher reimbursement rates for case management, cross systems training, and increased collaboration between hospitals and residential service providers. It was also suggested that hospitals be allowed to bill for services while an individual is awaiting residential placement.

Another area of primary concern related to services for people with Autism Spectrum Disorders, particularly those with Asperger’s disorder, who have had challenges in documenting eligibility for OMRDD services. An increasing number of people with Asperger’s or learning disabilities are having difficulty accessing supports and services through the mental hygiene system, which may result in additional challenges due to possible involvement with the criminal justice system, substance abuse, and poor health coordination.

Other special populations identified included: people with Fetal Alcohol Syndrome, sexual offenders, medically frail, aging individuals, parents with disabilities, Native Americans, people with Prader-Willi syndrome, and people in need of transition to alternative “stepped” down services.

Unmet Service Needs

While the housing needs of people with developmental disabilities were identified frequently, suggestions were often made to develop housing with supports that could be universally available to any individual who is aging or has disabilities. In addition, the need for creative housing that is affordable and accessible, or supports that allow people to stay in their own homes were noted. The use of web-based technology for a housing registry was also suggested. Young people aging out of foster care were noted as a particular area of need in the New York City region. Married couples accessing supports from different agencies also noted the problems they have in coordinating their supports for housing between the agencies.

Respite (especially crisis respite) was an often noted need for families supporting individuals with developmental disabilities. Other service needs included employment supports, case management, assistive technology, self-directed services, crisis intervention, person centered planning, greater assistance for parents with disabilities, prevention, and increased funding for family supports and residential habilitation.

Overarching Need for Interagency Collaboration

Many people commented on the need for increased interagency collaboration to facilitate seamless service delivery. Often comments were offered about the positive vision being put forth for collaboration, and people spoke of their hopes for the future. The potential for achieving efficiency in government by reducing redundancy in application processes and duplication of services was noted.
The Offices of Mental Health, and Mental Retardation and Developmental Disabilities were cited most often as agencies that need to work together more collaboratively to assist people with dual diagnoses of mental health and developmental disability to access supports and services.

Another area of necessary heightened collaboration relates to the needs of youth. In particular, there are systemic issues related to coordination with the education system. There is a need for improved information sharing and planning, particularly at points of transition. Other points related to children with multiple and complex concerns, and incarcerated youth.

Several comments were made about the need to develop a centralized body to coordinate all disability-related services.

Other suggestions for collaboration included facilitation of clinical information and data sharing across agencies, perhaps through digital technology, development of a singular approach to criminal background checks across agencies, a universal waiver program for all disability groups, cross systems training, development of regulatory flexibility and dual certification/funding capacity, co-located services, common service language, and development of a system of single access/eligibility.

**Children’s Issues:**

Multiple service needs for children were highlighted repeatedly by commenters. Families of children with dual diagnoses of developmental disability and mental health spoke frequently of challenges in accessing behavioral health and child psychiatry services.

The need for quality education, cooperation with schools, access to school-based psychological assessment, and improved transition planning to effect seamless access to services between agencies were identified as concerns by a number of people.

The need for services for children in foster care who have developmental disabilities, after-school respite, child care, integrated recreation programs, and other family supports for families who have children with disabilities, especially those who have medical frailties, were also identified. Children who have PDD or Autism were noted to be particularly challenging for families.

**Workforce**

Comments related to workforce focused predominantly on challenges in recruitment, retention, provision of adequate compensation, and training for direct support professionals. Suggestions were made for pay equity between the voluntary and state sectors. A few comments related to supporting direct support staff to empower people with disabilities to have more choice and control in their lives.

Turnover of service coordinators and retention of nurses were additional areas of workforce concern.
Health Insurance

Many participants spoke of the need for universal health care. Challenges with accessing necessary supports through Medicaid and managed care were identified. Concerns were also expressed about being able to find qualified doctors and dentists that would be willing to accept Medicaid rates of reimbursement.

A specific concern noted by forum participants related to difficulties in obtaining durable medical goods. Problems were reported with the approval process, time frames for repairs, insufficient funding, and inability to access preferred equipment.

Billing allowances for transportation and same day medical services were seen as barriers to efficient service delivery in several locations.

Systems Management

A number of issues were identified that were related to the bureaucracy of services delivery. The complexity of the systems, paperwork, jargon language, levels of approval authorities, redundancies, licensing, billing, timeliness, transparency, corporate compliance requirements, cultural competency, and privacy were all raised as concerns.

The ongoing involvement of parents and self-advocates in services planning and agency oversight was stressed. It was also suggested that more local decision-making authority be supported.

Suggestions were provided for “master contracts” for flexible cross-systems services, and electronic records to facilitate paperwork reduction.

Eligibility

Restrictions on eligibility for OMRDD services, especially since the eligibility review clarifications were issued in 2005, were identified as problematic due to the “burden of proof” that is placed on individuals and families. People with Autism Spectrum Disorders, Tourette’s syndrome, learning disabilities, dual diagnoses, and others with borderline functioning are being excluded from services eligibility with multiple agencies. Without supports, these individuals are at increased risk of having other problems, such as substance abuse, health concerns, or involvement with the criminal justice system. Suggestions were provided for provisional/transitional eligibility, universal eligibility determination, different age cutoffs, and decentralization of the OMRDD eligibility process.

Individualized Services

The need for person centered service design and decision-making were noted as needed throughout all the agencies, although OMRDD was complimented for its initiatives in this area. An individualized approach to services, including consideration for more self-directed approaches, was promoted. Seamless access to services across the life-span using an individualized approach was seen as essential to simplifying the systems.
Suggestions were made for “roadmaps” and resource directories. The benefits of service coordination were noted, and a suggestion was made to develop a cross-systems form of case management to assist people in traversing the systems.

**Clinical Services**

Challenges in finding psychiatry services were frequently noted, in addition to other quality health care services, i.e., dental and medical. Suggestions were made for integrated clinics, satellite clinics, and integrated prevention/wellness education programs. Problems in changing providers of health-related services due to insurance limitations were also noted.

Consistent treatment and standards of care for all people, regardless of disability, were articulated as basic rights in need of respect by practitioners.

A suggestion was made to support Advanced Dental Hygiene practitioners to increase access to dental care in rural areas.

Another suggestion was made to provide more specialty practice training to health practitioners and counselors.

**Transportation**

More accessible, affordable, timely transportation options are needed, especially in rural areas. Transportation assistance is needed to get to medical appointments, to volunteer, to recreate, and to get to work. A suggestion was made to consider a statewide cross-disability transportation system.

**Deinstitutionalization**

The continued institutional bias of the long-term care system in New York State was noted. Transition from institutional settings is difficult due to the lack of housing and appropriate individualized supports. The need to continue to address closing of institutional settings was raised.