WE THE PEOPLE:
MANAGING OUR BEHAVIORAL HEALTH CARE

OVER 100 CUSTOMERS VOICE THEIR EXPERIENCES AND VALUE RECOVERY!

Waterville, Maine
February 25, 2006
WE THE PEOPLE ...

In February 2006, the Judge David L. Bazelon Center for Mental Health Law and the Federation of Families for Children’s Mental Health responded to a call for technical assistance by Maine’s two statewide networks dedicated solely to representing behavioral health customers.

WE THE PEOPLE ... is a consensus report of responses by adult consumers and families of children and youth who gave voice to their experiences and the value of recovery to inform DHHS’ consideration of managed care.

This report was generated from the various tools used to collect information, and points of discussion that generated almost 300 comments. During afternoon discussions, I roamed among the groups to glean a sense of the environment, assist facilitators if necessary, and record additional observations. I hope I have aptly reflected the proceedings of this event and the messages of those who attended.

Pat Hunt, FFCMH
Office of Policy Reform
Continued budget constraints and the demand for coordinated services for consumers and families encouraged the Maine Department of Health and Human Services (DHHS) to seek changes in the behavioral health care delivery system. DHHS’ vision of the system includes increased responsiveness to the needs of Maine behavioral health care consumers and their families, increased creativity, and more efficient service delivery mechanisms. In order to improve the design and delivery of publicly funded behavioral health care services the Maine Behavioral Health Managed Care Program has been established and a concept paper has been developed (December 9, 2005). This paper described a process and a concept to improve the design and delivery of publicly funded behavioral health care services in Maine. The paper was written to communicate to stakeholders, funding sources, and decision makers much of the work that has occurred since October 2005 by staff of the Department of Health and Human Services.

The concept paper also represented a DHHS commitment to periodically offer opportunities for interested behavioral health stakeholders to provide input into the design of this new system of service delivery. It assured that various planned public meetings with Department personnel would be held for the purpose of hearing public reaction, and responding to questions and suggestions. Additionally, it proposed regularly scheduled meetings of the Consumer Advisory Group, the Quality Improvement Council, and Maine Association of Peer Support and Recovery Centers be used to solicit public involvement.

DHHS has encouraged interested persons to read and critique the concepts in their paper. The paper reflects the initial thinking of the Behavioral Health Work Group. DHHS has welcomed and encouraged comments and feedback as they continue the process of creating a single behavioral health service delivery system throughout Maine. Once comments are received and considered, DHHS committed to revising the paper to serve as the basis for development of a request for proposals (RFP)/Contract and for further development of the single behavioral health system described in this paper. The purpose of this Targeted Technical Assistance event was to assist DHHS customers to be better informed in order to provide feedback relevant to the concept presented and to effectively participate in subsequent events outlined in the paper.
The Advocacy Initiative Network of Maine and the GEAR Parent Network are statewide, consumer-driven and grassroots in nature. Both networks are solely dedicated to the behavioral health of Maine adults and children (respectively). They are connected to local customers throughout Maine as a result of their advocacy, education, support and leadership development. A landmark occasion, this event was their first jointly coordinated public policy response for children and adults. Their outreach resulted in over one hundred and twenty participants. Both organizations reported turning away potential participants because resources would not accommodate a greater number. Participants included families of Maine’s children and youth with behavioral health needs, transition age youth, adult customers of its behavioral health services, families and state policy makers. Strategies for increasing consumer and family knowledge about this event included, but were not limited to, contact with members of the Consumer Advisory Council, Statewide Quality Improvement Council, social clubs, peer centers and support groups. A flyer created by families and consumers was widely disseminated throughout Maine to ensure broad knowledge of this opportunity to provide feedback to DHHS regarding its concept paper for managing care.

**AGENDA**

**MANAGED BEHAVIORAL HEALTH CARE MEETING**

**FEBRUARY 25, 2006**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Facilitator</th>
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<tbody>
<tr>
<td>8:00</td>
<td>Registration</td>
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<tr>
<td>9:00</td>
<td>Welcome and Overview</td>
<td>Melinda Davis, AIN</td>
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<td></td>
<td></td>
<td>Carol Tiernan, GEAR</td>
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<tr>
<td>9:20</td>
<td>Transforming A State System Using Managed Care</td>
<td>Chris Koyanagi, Bazelon Center</td>
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<tr>
<td>10:45</td>
<td>More on Managed Care</td>
<td>Chris Koyanagi</td>
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<tr>
<td>11:30</td>
<td>Maine: Where We Are Going &amp; Why</td>
<td>Chris Zukas-Lessard, DHHS</td>
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<tr>
<td>12:00</td>
<td>Challenges and Concerns</td>
<td>Pat Hunt, FFCMH</td>
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<tr>
<td>1:00</td>
<td>Your Recommendations</td>
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<tr>
<td>2:15</td>
<td>Report Out &amp; Consensus Building</td>
<td>Pat Hunt</td>
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<thead>
<tr>
<th>GROUP</th>
<th>ROOM</th>
<th>FACILITATOR</th>
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<tbody>
<tr>
<td>Yellow</td>
<td>Conference Room 221</td>
<td>Chris Koyanagi</td>
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<tr>
<td>Green</td>
<td>Colby – Thomas</td>
<td>Steve Hoad</td>
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<tr>
<td>Red</td>
<td>------</td>
<td>Melinda Davis</td>
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<td>Blue</td>
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<td>Liz Carignan</td>
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<tr>
<td>Orange</td>
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<td>Lydia Richard</td>
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THE PROCESS

DHHS expressed a commitment to hold forums for public input and feedback to the concept paper released in December 2005. Planning for Targeted Technical Assistance included Chris Zukas-Lessard and several other representatives of DHHS, Melinda Davis (AIN), Chris Koyanagi (Bazelon), Pat Hunt (FFCMH), and Carol Tiernan (GEAR). Planning with technical assistance providers was accomplished through conference calls and e-mail. The event was designed in such a manner that the process and protocols could be replicated throughout Maine. By providing the same information and posing the same questions for feedback to stakeholders throughout Maine, DHHS will have access to a vast and collective voice regarding its managed care concept.

Pre-event activities included designing post cards and checklists intended to gather maximum participant input. Prior to the event, skilled facilitators met to increase their familiarity with the materials, experience the process, and discuss strategies for meeting challenges to their task.

Participants were provided general information about managed care by Chris Koyanagi, Policy Director, Bazelon Center for Mental Health Law. Chris Zukas-Lessard, DHHS Medicaid Special Projects Manager, provided information about the status and focus of Maine’s planning efforts. This information helped participants be better prepared to use the following means to say what they think:

- Questions and comments for presenters
- Endorsement of principles
- Facilitated workgroup discussions containing 3 guiding questions
  - How should consumers and families of children and youth be involved in managed care reform?
    - Operations of the plan?
    - State planning, implementation and oversight?
    - Monitoring performance?
  - To what outcomes do you think the state should hold the contractor accountable?
  - What should we do when things go wrong?
- 2 Post Cards - 44 responses received for each
  - “If managed care worked for me / my child I would know it because…”
  - “One thing I would absolutely not change about my/ my child’s services is --- because ---“
- Checklists to identify which services to be covered are important
- Signature cards to participate in future managed care work

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1 Appendix i
2 Appendix ii
3 Adapted from Consumers’ Role in Contracting for Public-Sector Managed Mental Health and Addiction Services Partners in Planning
A FEW KEY MESSAGES ABOUT THE CONCEPT

Please include us in the development of the concept.

A thoughtful, informed and inclusive process cannot be accomplished by July 1, 2006.

Do not cut the budget or try to institute managed care WHILE stretching resources $30 million thinner.

If you want a consumer-driven program, you have to let us in the driver’s seat.

We want to hang onto what’s working!

We want all money saved by these changes to be reinvested in our community-based services.

Let’s make sure our values are toward the same direction, e.g. – eliminate incentives for residential services, commitment or medication.

If managed care is a good idea, isn’t it a good idea for all services – including Intensive Case Management, state hospitals & medications?
WE THE PEOPLE ... ENDORSE THESE PRINCIPLES

Managed Care Event – Waterville, ME (2/25/06)

I believe the following principles are important for a strong managed care system in Maine and hope they will guide the work of DHHS throughout the process.

- Consumers and families of youth must have meaningful and substantial involvement in the design, delivery and monitoring of the system, and the involvement must take place up front and on a continuing basis.
- The development of a managed care contract must be an open process and a matter of public record.
- The provision of a comprehensive system of care must not be compromised or lost when public agencies turn to managed care for their mental health and substance abuse systems.
- Consumers and families of children and youth should be hired to provide assistance to people enrolled in the plan and should participate as part of the MCO’s (ASO) governing board.
- Funding must not be reduced in anticipation of managed care savings, but only after such savings have materialized.
- It is the public agency’s obligation to maintain a comprehensive system of services and supports that are community-based and promote prevention, treatment, rehabilitation, recovery and integration into community life.
- All individuals must have access to affordable, comprehensive, and effective care based on clinical need, without arbitrary limits.
- Narrow interpretations of medical necessity must not be used to deny treatment to people who need and could benefit from that service.
- Consumers and families of children and youth must be treated with dignity and respect; their views and wishes about their treatment should be an integral part of all decisions about their care.
- MCOs should have procedures in place to ensure that services are delivered in an appropriate manner for those who need them.
- All planning and delivery of services should be culturally and linguistically responsive to ethnically diverse populations and the communities where they live.
- Coordination with other agencies and providers must be established to ensure access to health, dental, vision care, housing, job training, education, social services, etc.
- Individual rights must be explicit and must not be compromised.
- Clear, easily accessible and user-friendly procedures must be in place for timely resolution of consumer grievances and appeals.
- Confidentiality must be protected.
- The contract must avoid giving the MCO any incentives to seek commitment.
- Consumer choice and satisfaction must be a driving value in the mental health and substance abuse systems and the MCO must be accountable to external stakeholders for meeting the needs of the people it serves.
- Consumers should have clear, easy to understand information that describes their rights, covered services, how to access services, how to lodge complaints, and where to find help when they are dissatisfied with the plan.
- Public agencies should use flexible funding and other arrangements so as not to encourage under-serving.
- Consumers should be fully engaged in monitoring and oversight of the managed care arrangement.
- Managed care plans must address the issues unique to children and provide services based on each child’s and family’s strengths.
- Families must be seen as partners in the planning and delivery of services to their child.
- The concept of a system of community-based care for children and adults must be retained under managed care.

I believe in these principles! ___________________________ (Signature)
FEEDBACK FROM DISCUSSIONS

This event was structured to both provide information to and get input from Maine’s customers of behavioral health services. The nature and level of concern expressed by participants was affected by various current events:

- Consumers who had received notice that their Maine Care coverage was being terminated;
- Families who had learned that their children would no longer qualify for Katie Beckett; and
- Those who described struggling without adequate services and a lack of accountability in the current system.

Participants did not understand the reason for losing the vital support of their insurance.

Conversely, many participants described experiences that contributed to their feedback as:

- Being satisfied with the services we have and fear at the thought of them being interrupted;
- Having the ability to choose services that consider my personal views and decisions;
- Having services that keep families together

Presenters encountered a landscape of uncertainty, mistrust, frustration and hesitation in which to sow seeds of encouragement and hope for a better system. Insightful, expansive and fervent discussions followed the presentations – proving that both participants and presenters were equipped for the task at hand.

PRE-CONTRACT CONCERNS & RECOMMENDATIONS

CONCEPT, DEADLINE & WORKGROUP - DHHS customers were distressed that they were not involved in the early stage of concept design. Their call to “start over and ask for a new deadline” was loud and clear. They were enthused about the stated value of their inclusion and eager to take part in the design of all aspects of managed care. They expressed concern at the composition of an impending managed care stakeholder workgroup – citing their lack of knowledge about the group’s existence and the selection process for membership. Participants discussed the importance of selecting their own group representatives to speak for them. DHHS presented vital information regarding the process they had used for selection and timing of the first meeting, and welcomed the opportunity to expand membership of the group and future sub-groups. Participants sent one another a clear message - they intend to hold members accountable for recommendations made at the table. They explored ideas for more effective communication among themselves in order to have a collective voice at this policy table. They indicated a desire to “stop the press” – “get rid of the stakeholders group” and cancel meetings planned for March. They discussed strategies for being more involved as participants and overseers of the ongoing process. They continuously struggled with the question of who will be responsible for those people who are uninsured and homeless.
Participants cautioned DHHS to “RESTORE money cut from the budget before managing care”. They endorsed an ASO model that would “reinvest the savings” back into their community-based services. There was NO support for a MCO. Participants viewed the MCO as an opportunity for the state to shift responsibility without accountability; for customers to experience undue interruption in their quest for services; and for care decisions to be based on the incentive of an MCO to keep savings rather than improve the quality of life for customers. They endorsed DHHS plan for dealing with the issue of “capitation”.

Participants described a need for funding to follow their changing need for service, rather than be tied to the services they must select. DHHS described plans that fit with such a model. Customers also identified their roles in policy and planning to include:

- We should have input on how our money is going to be spent. We must have involvement in the actual planning and budget process for defining where the money is going to go.
- Planning should be around consumer choice and the money should support it.
- Focus of services should be effective and efficient – not cheaper

CONTRACT DEVELOPMENT/ASO - Maine consumers and families of youth expressed questions, concerns and ideas regarding the process and contract for managing their care:

- People who have received state delivered services must be the ones who define whether and when current state-delivered services are included in the plan. Participants endorsed a strong state role in public policy, quality and oversight. They described little accountability in the current system and shared an expectation that managed care provide more avenues for holding people responsible. They recommended building on the strengths and skills of state staff who excel and using their expertise to train and support others.
- We must be meaningfully involved in developing the RFP or contract, reviewing applications, and selecting the winning proposal. We have not seen enough information to be persuaded that a “sole source” contract will result in best practices for managing care. We are concerned that there is an “agency in waiting” and do not know if it has a well-known, proven track record. We recommend a competitive process and make the following observations and recommendations:
  - Full inclusion of customers who are working on managed care design and implementation requires information in advance for meaningful and informed representation - We need to know when and where to get the prep materials so our input is relevant and timely.
  - Consumers and families of youth must define and participate on the governance body of the selected ASO organization and be members of all final decision making committees.
  - Hired administration must be qualified, but given preference if they are consumers and families of youth from Maine (the Veterans Administration was cited as an example).
  - Contract must respect cultural experience, rural differences and address transportation issues. Our cultural experiences ARE central to our individualized services.
Contract must eliminate incentives for residential services, commitment procedures and undue reliance on medication
Maine must include medication IN the managed care contract, to avoid cost shifting to the medication management agency and inappropriate reliance on medication as a treatment solution
Significant numbers of customers must be employed for the daily operations of the organization, including those assisting with the grievance process, quality assurance and service satisfaction.
Contract must include all supports for peer to peer surveys
Contract must require customer involvement in interpreting survey results and data, and in developing solutions for those things that need improvement
Must have clearly published policy and procedures made available on all managed care systems, services, operations and state contract
Policy and procedures must be published in understandable formats by all agencies for all services offered
Hiring preferences within the ASO must be extended to Maine citizens, consumers and families of youth with behavioral healthcare needs
Customer service requires trained customers
Contract must include customers as vital component of care manager team & peer specialists and parent partners as a covered service.

**FORUMS**
- Participants were eager to let others know about DHHS pending forums. They offered to assist in activities and provide peer support to others who may wish to attend. Their two most significant questions for this topic were:
  - How will we be notified of the public forums?
  - How and when will we receive information about the input gathered at these forums?

**IMPLEMENTATION CONCERNS & RECOMMENDATIONS**

**LINKAGE BETWEEN PUBLIC AGENCIES – PRIMARY HEALTH/MENTAL HEALTH**

Customers of DHHS behavioral health services referred to the vital need for services that are consistently delivered wherever they require them. Services must be available wherever consumers and youth live, work and play – and be integrated with primary health appointments, hospitals, elder or nursing facilities, as well as schools, housing arenas, and juvenile justice and correctional facilities. In other words “community services come to us when we need them – we can’t always get there”. Dependent care issues, physical constraints, transportation, and incarceration seriously interrupt and/or prevent access to services. Customers stated that services need to “build better bridges” between the adolescent and adult worlds and treatment must be coordinated with their primary physicians. To look at behavioral health needs in isolation from diabetes, circulatory problems and other health issues does not offer helpful, appropriate, effective or clinically sound treatment – “sometimes our meds cause these problems”.

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ACCESS

Consumers and families of youth said they need to clearly know whether they qualify for access to services and why - and how to access the services when they need them. They expressed confusion, frustration and disappointment when eligibility criteria are not openly shared. When the criteria appear “secret”, they experience distrust and are left to wonder about the means used to determine who gets what. Additional input included:

- Consumers and families must be involved in determining the criteria for eligibility.
- We must have input on the timeliness of services under the contract
- We must be able to select our treatment providers.
- We need to know how and where to get what we need.
- Denial of any service must be reviewed by a person of competencies equal to those of the person who initially recommended the service.

Data must be collected to track the successes and challenges of obtaining services. Customers say it is important to have factual information about ease of entrée and availability of service in order to inform any changes necessary to the managed care contract. Recommendations included such data be available electronically and widely shared in a timely fashion and understandable and usable format. This information must be easily accessible to customers and advocates and contain the date, process used for collection and identify the reporting source. One customer best summed it up by saying, “This is about us being able to get what we need – when we can’t, we should at least know why and have a way to change what doesn’t work”.

SERVICES INFRASTRUCTURE

Participants expressed concern about the possibility of losing services that are important to them for the sake of managing money. They recommend DHHS be more aggressive about service quality and quantity, and not simply cut services by category. Their message was clear that ensuring provider quality and accountability will prevent waste and allow for crucial services to be available. They also made the following recommendations:

- No elimination of categories of services for at least 2 years
- 24 hour a day crisis and warm lines available to ALL consumers – NOT split hours between warm line programs
- All consumers can easily access “Peer Respite Resource Centers”
- All consumers have choice of and access to psychologists, in-patient and community-based care
Perhaps the best summation of participant discussion regarding outcomes came from one recorded statement: "We should define the kind of care we receive --- it's our body, it's our life". Consumers explained that the ISP (Individualized Support Plan), when appropriately implemented, is the yardstick by which success should be measured. When ISP goals are met, outcomes have been achieved. Additional discussion indicated that integrity to the ISP process varies among workers within agencies, as well as among agencies. Participants agreed that they have a role in supporting one another and providers with training about individualized planning. They also identified the following goals as important to them:

**ADULTS**

Reside in our own homes or living arrangements of our choice  
We are working  
Have good physical and mental health  
Feel safe  
Have no/or less involvement with the legal system  
Have friends and social opportunities  
Fully realize activities associated with our daily living  
Have an Advance Directive

**FAMILIES & YOUTH**

Success in school, home and community  
Communities and families are connected with and invested in all youth  
Physically and mentally healthy  
Enjoy activities, peers and a social life  
Have someone to talk to that we trust  
Live at home and in the community  
Reduce/eliminate residential placement  
Services promote and support peace and harmony in our homes  
No involvement with the JJ system  
Access to job training and higher ed  
Better identification of mental health issues of teens  
Reduce all wait lists  
NO teens “fall through the cracks” when transitioning to adult services

**BOTH GROUPS**

Increase community based services  
Fewer people with mental health issues in criminal justice system / jails  
More consumers and youth successfully mainstreamed in regular education & schools  
Emergency Department services yield a ONE-HOUR resolution to assessment and placement(whether home, respite, hospital, etc.)  
Reduction in homelessness  
Decreased need for intensive services  
Increased level of customer involvement demonstrated in state and local agency planning and oversight
Participants agreed that a managed care system cannot be successful without clear commitment to the role of its customers to design and carry out training and share crucial information. They talked of needing written materials, posters and handbooks that are written by them, for them and for their care providers. Materials must be developed with and reviewed by consumers before publication.

**Provide Training:**
- Training and mentoring for ASO-MCO, providers (including case managers), consumers and peer facilitators in proven recovery models
- Make sure the people who do utilization review are trained in proven recovery models
- Training for consumers to be care managers
- Peer training regarding grievance process
- Train peers to support others through grievance process
- Consumers and parents given updated training concerning grievance opportunities
- Disease education geared towards consumer understanding

**Create Written Materials**
- A manual for guiding providers in decision-making regarding our managed care will be available to us and written in language we understand (Understanding the limitations of covered care, number of visits, reimbursement, etc. allows us to share responsibility for care decisions.)
- Consumer/family/youth manual
- HANDBOOK regarding grievance containing language for and reflective of diverse cultures
- Publicly funded materials and contractors must use person-first language (i.e. we are not “the mentally ill”, “mentally ill offenders”, or “bi-polars and schizophrenics”, etc.)

**Create Public Awareness**
In order to establish a greater level of public trust, successes and challenges must be openly shared with Maine citizens, our Legislature and other policy makers. A public relations campaign focused on garnering additional resources and greater community buy-in must use current events to promote behavioral HEALTH. Publicly funded PR messages must reflect and endorse our vision and values. Resiliency and recovery deserve greater public attention. Public information about catastrophic life experiences must be balanced by responses that eliminate bias and unfriendliness toward us, and value us as members of our communities. Ideas for greater public awareness also included:
- Public forums for ongoing feedback
- Media campaign that show faces of success (pictures of mental HEALTH include children in school, adults working, empty jails, etc.)
- Posters, brochures, and other materials that represent resiliency & recovery
- Events that include our talents
WHAT DO WE DO TO KEEP THINGS WORKING RIGHT?

**CONTINUOUS FEEDBACK**

Participants stated that it is important to know what is working well and to promote and recognize excellence. Their idea of a system that works well is one that builds on its strengths and meets its challenges. Many customers are pleased with the quality and quantity of their services. They recommend routine assessments of the system to provide consistency and ensure that what works will continue to thrive. They want a system that measures its success and provides accountability so services available to them are not defined by the agendas of others. ASO/MCO must have a customer service component that employs people with lived experience to ensure recovery model is core to all services and programs.

Below are some of the methods customers identified a role in:

**QUALITY REVIEW & MONITORING**

The system must provide a role for customers to:
- Shape service satisfaction tools and surveys
- Conduct interviews
- Participate in analysis and interpretation of quality feedback information
- Design forms and protocols regarding integrated electronic health records and personal information systems
- Participate in all phases of contract negotiation and renewal
- Gather broad peer feedback to inform system decisions

Institute a separate monitoring council that is comprised of a significant majority of customers (51% consumers – 49% state, providers and ASO/MCO). We should be involved in developing the guidelines for the MCO & DHHS. The Council must have a role and authority for ensuring that customer feedback results in the change requested.

**REMEDY & GRIEVANCE**

Participants said it is important for them to have various methods available for trouble shooting prior to filing grievances. They depicted the process and time it takes for grievance resolution as too often burdensome, confusing and intimidating. By the time their service problems reach the mark for grievance, they described facing fear of retribution, diminished relationships with their providers, and bearing additional undue stress. They described an imbalance of power as they are left to struggle alone for remedy, while agencies have an infrastructure to support staff and administration in their decisions.

Some of their ideas for early response to problems include a toll free telephone helpline, e-mail and web based options. They also cited training as important for both
customers and providers in order to be better able to communicate and mutually develop solutions. Other ideas included:

- **Process:**
  - Grievance process must be accessible, publicized and easy to understand
  - Include process for going to the source (MCO, state, providers) to find out what the problem is Consumer review & decision panels – not provider driven
  - A toll free number for access to all advocacy programs
  - Peer support or case managers be paid to provide support in process
  - Peer advocates supporting and guiding us through the process of grievance and resolution
  - When I have a problem I want *them* to come see me – “just like the Sear’s repairman” – not expect me to meet all the challenges of finding day care, etc. to find them.
  - 24 hour response to receipt of grievance – 7 business days for a solution
  - When filing an appeal the customer must have access to an independent advocate with relevant expertise at no cost to the customer
  - Consumer with grievance has opportunity to attend all discussion and decision-making meetings
  - Build in protections from retribution
  - Disability Rights Center must be available to talk with consumers and document the problems for any grievance, not just those with the potential for litigation
  - We need legal advocacy available for the completion of advance directives

- **Outcomes:**
  - Our grievances and complaints must be accompanied by the opportunity to CHANGE things – (not just go through a process with no lasting outcomes)
  - Customer involvement in all aspects of the grievance process – at the table when and where decisions about us are made
  - Data must be collected and used to justify crafting incentives, instituting financial rewards and penalties, and terminating contracts

- **Data:**
  - Monitor all data regarding grievances to identify early warning system and create interventions for problems
  - A designated consumer organization should get the grievance data – possibly consumer councils

- **Ombudsperson:**
  - Ombudsperson must be a separate contract – NOT a state employee or an ASO/MCO employee
  - Ombudsperson must be employed, housed and supervised by an independent customer-run agency
  - 24-hour access to Ombudsman program
Adult consumers and those who are parenting youth with behavioral health issues must be supported for effective involvement in all aspects of the service system, including public policy. This arena must afford customers an opportunity to shape policies that affect their behavioral health services based on their collective experiences. Setting practice standards, recommending process and protocols, creating forms, defining criteria, developing the contract for the ASO/MCO, and educating legislators are a few of the ways that Maine customers plan to be involved in a managed care system.

Governance bodies of state and local agencies and advisory groups must have customer membership that reflects the diverse experiences of the people they serve. Participants were quick to indicate additional roles:

- Participation in development of all state agency plans that affect our lives
- Defining the outcomes for contracts and service delivery
- Identifying services to be available
- Determining Medicaid reimbursable services
- Providing information for RFP specifications
- Making sure that public funding supports the kinds of services we know we need
- Ensuring system institutes changes based on our experience and recommendations
- Assuring appropriateness of state access to federal funds for supporting consumer delivered programs
- Ensuring that program design/development is congruent with vision and values of customers
- Designing and adopting forms and protocols regarding integrated electronic health records and personal information systems
- Making recommendations regarding evidence-based practices, and influencing whether new models are adopted
- Awarding, negotiating and renewing contracts
- Identifying promising practices for service development
- Gathering information on complaints and working with policy makers to solve the problems by changing the system

Participants acknowledged they, and the agencies that serve them, need to be supported with training, information and strategies for effectively achieving their mutual goals.
A) Participant responses to “One thing I would absolutely not change about my/my child’s services is ….. because…”

B) Participant responses to “If managed care worked for me/my child I would know it because …. .”

Condensed summary of input regarding DHHS behavioral health services proposed to be covered under managed care.

C) Adults

D) Children’s
### A) One thing I would absolutely not change about my/my child’s services is

<table>
<thead>
<tr>
<th>Services</th>
<th>Because</th>
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<tbody>
<tr>
<td>The behavioral workers (though some need to be better trained)</td>
<td>Because of the help they are providing.</td>
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<tr>
<td>All of my son’s services</td>
<td>They are helping us right now – he has lots of help</td>
</tr>
<tr>
<td>Case management, counseling, crisis, meds, in-home supports</td>
<td>Without them my child would be hospitalized</td>
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<tr>
<td>Current plan of care should not be diminished or services lost</td>
<td>It would put his stability in jeopardy</td>
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<td>Coverage for medication and services</td>
<td>My daughter will continue to need ongoing services throughout the years</td>
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<td>Our freedom of choice and grievance opportunity</td>
<td>My culture and background are important to me – our/my personal views and decisions</td>
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<tr>
<td>The freedom to choose providers and services as our family needs without 8 referrals</td>
<td>All cases are unique and no 1 or 2 plans will work for all – we have enough appointments to go to.</td>
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<tr>
<td>Provider choice and access</td>
<td>Parents are better at determining the best provider</td>
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<tr>
<td>The ability to make decisions about his mental health care needs myself</td>
<td>(name of agency) providers lack the expertise (diagnosis) to make those decisions for me.</td>
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<tr>
<td>His eligibility for Katie Beckett</td>
<td>It allows him to remain at home. However 2 weeks ago, after 10 years we received a letter saying he is no longer eligible. Nothing has changed regarding his need. We are in shock.</td>
</tr>
<tr>
<td>In home support services</td>
<td>Without it he would be in residential placement, my family would be split up, and I would not be able to work-- hence lose my health insurance, and place my family on state aid and Maine Care.</td>
</tr>
<tr>
<td>Access to case management services</td>
<td>They help me obtain the services my child has needed and continues to need.</td>
</tr>
<tr>
<td>Length of BS1 services</td>
<td>My son has had BS1 services for 2 years ---- 3 months is not enough</td>
</tr>
<tr>
<td>BS1 services need to stay the way they are now</td>
<td>Children need to have ISP and the length of service needs to be the same as now</td>
</tr>
<tr>
<td>Respite care services</td>
<td>It works for our family and we don’t have to deal with the bureaucracy of DHHS all the time.</td>
</tr>
<tr>
<td>Respite and family support</td>
<td>I could and can always use extra hands and some friends who understand.</td>
</tr>
<tr>
<td>My child’s health services with her temper</td>
<td>She throws things and (illegible)</td>
</tr>
<tr>
<td>A) One thing I would absolutely not change about my/my child’s services is</td>
<td>Because</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Case management services</td>
<td>Their grievance process fired one and hired another</td>
</tr>
<tr>
<td>DBT services, peer support programs</td>
<td>They help a lot</td>
</tr>
<tr>
<td>The doctors, case manager, counselor</td>
<td>I need this on a continuing basis</td>
</tr>
<tr>
<td>My drug plan saves me hundreds of dollars</td>
<td>New co-occurring mental health – I see (names).</td>
</tr>
<tr>
<td>I have had a good doctor for 10 years – she is great and I hope I don’t have to change</td>
<td>For 2 months it has worked like a charm because I signed up early.</td>
</tr>
<tr>
<td>My mental health services</td>
<td>I would be lost without them</td>
</tr>
<tr>
<td>The way I receive the services</td>
<td>I like having my options open</td>
</tr>
<tr>
<td>Now after 17 years I’m getting Intensive Case Management</td>
<td></td>
</tr>
<tr>
<td>The now Medicare Part D and Maine Care pill services</td>
<td></td>
</tr>
<tr>
<td>My doctors or other health care providers</td>
<td>I don’t deal with changes good</td>
</tr>
<tr>
<td>Caseworker, (name of agency and provider)</td>
<td>I need my workers</td>
</tr>
<tr>
<td>Med clinic</td>
<td></td>
</tr>
<tr>
<td>My doctor, counselor &amp; case manager</td>
<td>I have been seeing them for almost 5 years and I like them. I have a hard time expressing my problems and concerns to strangers. If I have to change my health care provider then I feel it would be like starting all over from scratch.</td>
</tr>
<tr>
<td>The treatment plan that I currently follow</td>
<td>It works with my “meds” to make me grow!</td>
</tr>
<tr>
<td>Meds</td>
<td>I need them</td>
</tr>
<tr>
<td>My clubhouse</td>
<td>It helps me to feel so much better – they look at what I am good at, not at what my illness is. Helps my depression.</td>
</tr>
<tr>
<td>Supported living</td>
<td>They help me with medication and daily living</td>
</tr>
<tr>
<td>The freedom to choose my providers</td>
<td>Not all people fit well/perfectly.</td>
</tr>
<tr>
<td>Flexibility in choice of service providers and services</td>
<td>Some providers stop meeting my needs – conflicts arise over complacency.</td>
</tr>
<tr>
<td>My ability to choose providers not connected to an agency</td>
<td>Choice is important for me in getting the services that work for me.</td>
</tr>
<tr>
<td>Choice of psychiatrist / mh clinic</td>
<td></td>
</tr>
<tr>
<td>My psychiatrist (name) at (agency)</td>
<td>He helps me enormously.</td>
</tr>
<tr>
<td>There is nothing I wouldn’t change</td>
<td>Services are in some way stipulated as is.</td>
</tr>
</tbody>
</table>
### B) If managed care worked for me/my child I would know it because:

<table>
<thead>
<tr>
<th><strong>ADULT</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>There would be supports to find and keep housing, schooling, and work – and we would have approval for ALL meds that work!</td>
</tr>
<tr>
<td>I could work ½ time, which is the max I can</td>
</tr>
<tr>
<td>All that has been said today would happen and stay that way – and would happen rather quickly</td>
</tr>
<tr>
<td>I would have the services necessary to feel safe and healthy in the community with natural and systems supports and valuable things to do – give back to the system.</td>
</tr>
<tr>
<td>I want to get back braces not wait for months – please do your job right – this is what I need</td>
</tr>
<tr>
<td>I would have better services</td>
</tr>
<tr>
<td>Go from child to teen to adult - myself only one doctor to take care of the items I need</td>
</tr>
<tr>
<td>There would be major changes in the system</td>
</tr>
<tr>
<td>My life would be living the road of recovery for the best possible way to daily living</td>
</tr>
<tr>
<td>Would feel better – wouldn’t go into the hospital – feel better about ourselves</td>
</tr>
<tr>
<td>Crisis intervention, betterment, more services for long term care, better care for disabled people with mental illness</td>
</tr>
<tr>
<td>My agency in Bangor would help me</td>
</tr>
<tr>
<td>All services would be cooperative as groups</td>
</tr>
<tr>
<td>I lost my Maine Care January 1ˢᵗ 2006. I need to get Maine Care back – I utilize many services</td>
</tr>
<tr>
<td>Because I would (not) be denied specialist for G-2 colonoscopy, varicose leg vein surgery, and heart doctor for bad ventricle.</td>
</tr>
<tr>
<td>I would see an overall improvement in the m h system – RESULTS as opposed to repetitive gatherings with out solutions.</td>
</tr>
<tr>
<td>I would find that my life would become more healthier, happier and more satisfying</td>
</tr>
<tr>
<td>I would not be isolated in the community</td>
</tr>
<tr>
<td>I would get the services I have now plus more – like more supported living apartments - some for life</td>
</tr>
<tr>
<td>I would feel comfortable with my health care providers – and comfortable talking with them about my situation with them.</td>
</tr>
<tr>
<td>I wouldn’t be denied meds I need and services I require to keep me mentally healthy.</td>
</tr>
<tr>
<td>I could go to the (name) clubhouse – it helps me to feel productive and like I matter, learn new skills and can work.</td>
</tr>
</tbody>
</table>
B) If managed care worked for me/my child I would know it because:

<table>
<thead>
<tr>
<th>(ADULT CONTINUED)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would be busier and feel better</td>
</tr>
<tr>
<td>(I would get) meds</td>
</tr>
<tr>
<td>My mental illness is depression but I can manage and take care of myself; I live alone and it gets lonely.</td>
</tr>
<tr>
<td>I would not need services as often as I would have learned to control / manage my mental illness.</td>
</tr>
<tr>
<td>I would be getting my services</td>
</tr>
<tr>
<td>I would have the services I need by the provider I choose.</td>
</tr>
<tr>
<td>I would be getting the services I need and when I need it,</td>
</tr>
</tbody>
</table>

**CHILDREN & YOUTH**

Because we would have a voice and actual services would listen and work towards meeting our child’s goals and objectives to make her daily life more successful for the entire family – not just for providers and department staff at DHHS to pad their pockets by being able to bill for services they don’t follow through to provide. ......... we want to regain control of our lives as a family.

<p>| My child could continue to access the services he needs to be under control and maintain and better himself. |
| My son would receive the services he needs to progress at home and in the community. |
| My son would have all the services he needs and the wait time for appointments would not be long. |
| There would be no disruption in care – services would be available – I could choose and change services when needed. |
| We would grow healthy as a family and receive the right services at the right time – without adversity and extreme stress. |
| There would be an increase in services and providers available within my area. |
| My child would be receiving the services needed to become a healthy, self-sufficient adult without having to travel out of state. |
| DHHS would have become proficient in over seeing and administrating service contracts. |
| There would be timely access to a full array of services that provide a system of care for my child based on treatment and recovery. |
| His behavior would be better |
| We would have better workers for all ages in all care services – Family voice would be in all services – no more financial cuts – new services available |
| We would feel happy in our homes and community at least 15 days out of 30. |</p>
<table>
<thead>
<tr>
<th>Services important to me</th>
<th>3 Services I would most like to self-select</th>
<th># OF THOSE WHO DID NOT ID SERVICE AS IMPORTANT, BUT WOULD LIKE TO SELF SELECT</th>
</tr>
</thead>
</table>

**C)**
ADULT BEHAVIORAL HEALTH SERVICES PROPOSED TO BE COVERED UNDER MANAGED CARE

<table>
<thead>
<tr>
<th>SERVICES</th>
<th># OF TIMES MENTIONED</th>
<th>RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMMUNITY SUPPORT</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>PHYSICIAN SERVICES (BY A PSYCHIATRIST)</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>SPECIALIZED GROUP SERVICES THAT FALL UNDER COMMUNITY SUPPORT</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>PSYCHOLOGICAL SERVICES</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>PSYCHIATRIC FACILITY SERVICES</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>LICENSED CLINICAL SOCIAL WORKER, LICENSED CLINICAL PROFESSIONAL COUNSELOR AND LICENSED MARRIAGE AND FAMILY THERAPIST SERVICES</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>HOSPITAL SERVICES</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>MENTAL HEALTH SERVICES</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>PRIVATE NON-MEDICAL INSTITUTION (PNMI) SERVICES</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>HOME HEALTH SERVICES</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>LABORATORY SERVICES</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>SUBSTANCE ABUSE TREATMENT SERVICES</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>PRIVATE DUTY NURSING AND PERSONAL CARE SERVICES</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>CASE MANAGEMENT FOR PERSONS WITH PSYCHOACTIVE SUBSTANCE ABUSE DEPENDENCE</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>NURSING FACILITY SERVICES</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

One service important to me that I do NOT see listed is:

<table>
<thead>
<tr>
<th># OF TIMES MENTIONED</th>
<th>RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Voc Rehab Help!</td>
</tr>
<tr>
<td>1</td>
<td>Consumer level disease education</td>
</tr>
<tr>
<td>2</td>
<td>Adult activities - cooking, art, sewing, ceramics, handcrafts, drawing, writing, exercise, (dietary) food intake, sleep habits, stress (management),</td>
</tr>
<tr>
<td>1</td>
<td>Integration of cross disability services i.e. MR &amp; MH, physical &amp; MH, etc.</td>
</tr>
<tr>
<td>1</td>
<td>Advocates who physically and verbally apply themselves to represent consumers on an individual basis rather than &quot;passing the buck&quot; and referring consumers from one agency to another with no concrete results.</td>
</tr>
<tr>
<td>1</td>
<td>A A</td>
</tr>
</tbody>
</table>
D) CHILDREN’S BEHAVIORAL HEALTH SERVICES PROPOSED TO BE COVERED UNDER MANAGED CARE

<table>
<thead>
<tr>
<th># OF TIMES MENTIONED</th>
<th>RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recreational</td>
</tr>
<tr>
<td>1</td>
<td>BS1 services outside of home</td>
</tr>
<tr>
<td>1</td>
<td>Non-traditional services</td>
</tr>
<tr>
<td>1</td>
<td>School services</td>
</tr>
<tr>
<td>2</td>
<td>Peer support</td>
</tr>
<tr>
<td>2</td>
<td>Respite</td>
</tr>
</tbody>
</table>

20 RESPONDENTS

<table>
<thead>
<tr>
<th>X</th>
<th>X</th>
<th>X</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>18</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>18</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>15</td>
<td>0</td>
<td>2</td>
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<tr>
<td>15</td>
<td>2</td>
<td>2</td>
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<tr>
<td>14</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>12</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

CHILDREN’S MENTAL HEALTH SERVICES
LABORATORY SERVICES
PHYSICIAN SERVICES (BY A PSYCHIATRIST)
CASE MANAGEMENT FOR CHILDREN AND ADOLESCENTS WITH EMOTIONAL DISTURBANCE, BEHAVIORAL DISORDER, MENTAL ILLNESS, MENTAL RETARDATION, OR PERVASIVE DEVELOPMENTAL DISORDER
HOSPITAL SERVICES
HOME-BASED MENTAL HEALTH SERVICES
PSYCHOLOGICAL SERVICES
DAY TREATMENT
DEVELOPMENTAL AND BEHAVIORAL CLINIC SERVICES
PSYCHIATRIC FACILITY SERVICES
HOME HEALTH SERVICES
LICENSED CLINICAL SOCIAL WORKER, LICENSED CLINICAL PROFESSIONAL COUNSELOR AND LICENSED MARRIAGE AND FAMILY THERAPIST SERVICES
CASE MANAGEMENT FOR PSYCHOACTIVE SUBSTANCE ABUSE
PRIVATE NON-MEDICAL INSTITUTION (PNMI) SERVICES
PRIVATE DUTY NURSING AND PERSONAL CARE SERVICES
SUBSTANCE ABUSE TREATMENT SERVICES
This event prompted difficult, ardent and valuable discussion. It promoted a new level of understanding about DHHS plans and the desires of its customers. It sparked a commitment to advance greater customer involvement, both from consumers and DHHS. It offered encouragement for mutual trust to emerge, unified policy goals to be set, common outcomes to be explored, and for the topic of accountability to achieve significant attention.

Customers shared their heartfelt hope and eagerness to participate as profoundly as they shared their experiences. Their early meeting demeanor of fear, frustration and mistrust was tendered by the knowledge that Chris Zukas-Lessard had not only heard their messages, but welcomed their voice throughout further managed care efforts.

DHHS received important information about services that customers value, and which ones they desire to self-select. At days end, responses from 35 participants provided a pool of potential managed care committee members who are better prepared to make informed recommendations and support one another in these efforts.

Maine customers were clear – the managed care train has left the platform. Whether or not they agree with the destination, the journey is about \textit{\ldots WE THE PEOPLE\ldots}
What Is Managed Care?

In simple terms:

- Managed care means an organized system for delivering comprehensive mental health services that allows a managed care entity to determine what services will be provided to the individual (and when) in return for a pre-arranged financial payment.

- In Maine, the state plans to pay the managed care Plan a flat fee per month for every person covered. (State will explain more fully who is covered, but will include all those on Medicaid and others).

In the managed care world, plans like to describe managed care as:

*negotiated* quality of care for an identified population for a negotiated *price*.

I translate this as, *you get what you pay for*.

**Introduction:**

Four key factors affect success:
- well written contract
- planning and transition into the new system
- oversight
- active involvement of consumers, families and other advocates

As you start to discuss issues, keep in mind:

- What parts of the current system work well
- What aspects need improvement
- What are the key gaps

This is an opportunity to address shortcomings in the current system (and to do it outside the political process).
Threats and Opportunities of Managed Care:
Page 6, Partners in Planning

**Threats:**

- Managed care systems with capitated payments have an incentive to deny services.
- MCOs Practice Guidelines often make heavy use of medications as a cheap and simple solution (a medical model, not a recovery model).
- MCOs are less familiar with people with serious disorders. Those working in public systems understand better what helps people.
- Managed care plans have far less familiarity with non-traditional services.
- Unqualified case reviewers may make poor decisions on the need for care.

**Opportunities:**

- Control the use of inpatient and residential services.
- Increase use of outpatient/community services.
- Move from a provider-driven system to one that creates the opportunity to consider the consumer a customer.
- Greater consumer choice among services.
- Changes in provider practices towards evidence-based practices.
- Shift resources from services systems currently over rely on (state hospital, medication, psychotherapy) towards less traditional interventions.
- Provide opportunity to measure progress and outcomes.

To take advantage of the opportunities while avoiding the threats is the key. Takes careful planning, diligent oversight and the active involvement of consumers and families.

Bottom line is: you want to manage care, not manage costs.
Process

- Department will explain this more, but the concept paper you have seen (modified and expanded to reflect input and further state thinking) will form the basis for a request to the federal government to allow Maine to shift consumers into managed care.
- Once that approval is obtained, Maine will most probably issue a Request for Proposals, following the outline presented to the federal government in its waiver request and taking account of public input.
- One or more managed care plans will then bid on the RFP, and one will win. State needs federal approval to have only one plan.
- The state then has the opportunity to further negotiate the details to change some of the things the Plan said it would do when it bid, and so reach a final agreement.
- Once the contract is signed, the state can monitor the Plan’s performance, but only hold it to the conditions in the contract.
- The state can (if the contract lays this out) apply sanctions for failure to perform certain tasks adequately or award incentives for good performance.
- Normally, contracts are for 3-years, after which the contract can be re-bid. Another plan could then come in and win, but the pattern around the country is for the same Plan to win again unless it has seriously under-performed.

Best opportunity to influence is early in process like now. Once the RFP is issued, outsiders have little role (except, possibly, in monitoring).

What Should Be covered in the RFP (and then the Contract)

Clarifying System’s Values to the MCO:
Page 26, Partners in Planning

Maine has outlined its Guiding Principals in the Concept Paper. Consumers/families should review and comment.

In other states, value statements include reference to the need for:

- Recovery and resiliency.
- Strengths-based assessments and plans.
- Consumer-driven services, directed towards goals of the individual consumer and with real choices.
Comprehensive service array, including non-traditional services.
Least restrictive setting.
Protection of consumer rights.
Culturally competent system.

These values not only for the Managed Care plan, but also for state and providers. Training of providers, consumers/families as well as MCO will be needed.

**Service Issues**

Maine does not intend to change its services as the shift is made to managed care. Service issues you may still want to consider are:

- Incentives to Plan to use savings to develop non-traditional services that may not now be available (respite care, peer support, family support, warm lines, drop-in centers, supported employment).
- Specific requirements that services be consumer- and family-driven, with real choices among effective options.
- Choice of provider (vote with your feet).
- Timely delivery of services and timely response to requests for assessment.
- Meaningful case management that provides linkages and follow up advocacy with respect to benefits and services individual is entitled to (Soc Sec, IDEA identification, housing, job training, etc.).
- Children have a single, interagency plan of care and a single team across agencies.
- Services are culturally competent.
- Services are appropriate for each age group: very young children, grade school aged children, adolescents, transition-aged youth and young adults, adults and elders.
- Strong linkages with primary care providers. Plan responsible for contracting with primary care providers to co-locate in mental health day programs (rehab, clinic etc.). Primary care providers bill for services through Plan (preferred) or directly to Medicaid and other payers.
- Plan educates providers on advance directives (community providers so they can assist consumers; institutional providers on their responsibilities regarding consumers expressed wishes).
- Maine is unusual in including drugs in the contract. Will be essential to calculate the costs of medications correctly or other services likely to be reduced.
**Access:**

A Medical necessity determines what is authorized:

- State needs to define this term.
- Should be driven by clinical need, and recommendation of treating provider should carry significant weight.
- Definition must take account of disability need to maintain and improve functioning, prevent relapse and enhance the quality of life, not merely a focus on symptoms.
- Plans rules for providers (Practice Guidelines) must make clear that often more than one type of service is appropriate and that services must be individualized and responsive to consumer/family choice.
- Medical necessity definition should reference and take account of the EPSDT mandate for children (children have the right to any federally-covered Medicaid service as needed). (Note, new Medicaid bill just signed by President does not alter this.)

To be sure this medical necessity definition is appropriate, Plan must be required to disclose it to the State for approval and make public its practice guidelines for providers.

In addition, plan must be required to have qualified individuals making medical necessity decisions as they review requests for services. No denial should be made by anyone other than a reviewer with the same credentials as the provider (in other words, only a psychiatrist can deny a psychiatric service, and so on).

**Ensuring Good Results**

- State does not reduce spending levels when transitioning to managed care (a more efficient service system is created, not a cheaper one).
- Savings are reinvested in creating new services.
- Plan responsible for creating effective jail diversion services and working with law enforcement to create jail diversion programs.
- Outreach to homeless is required.
- Plan responsible for linkage (and follow up) with agencies providing other key services, such as housing, job training, education.
- Plan pays for all inpatient care, including involuntary placements in state hospital.
What Are Good Results?

Measure process and outcomes (Pages 66 and 82, Partners in Planning)

Examples of Outcome measures:

- **Adults**: living arrangement, employment status, physical health, rates of arrest, hospitalization rates, have a social support network, satisfaction.

- **Children**: living situation, school attendance, rates of placement in residential treatment, rates of placement in therapeutic foster care, rates of contact with juvenile justice system, number of parents losing custody,

Examples of process measures:

- **Time to treatment (access).**
- **Telephone response time.**
- **Follow up times (e.g. how long until seen in community after discharge).**
- **Individualized service plans with specific consumer goals.**
- **Linkages with other systems.**
- **Grievance system data.**
- **In focus groups run by consumers/families, individuals report satisfaction.**

**Consumer Rights:**

Pages 54-55 and 62-64 of Partners in Planning.

- To be fully involved in all treatment decisions, to make choices among effective service alternatives, to choose their providers and case managers.
- Give or withhold consent to service plan and have amendments considered at their request.
- To live as independently as possible in the community (adults) or to live at home or in a home-like setting (children) whenever possible.
- To file a grievance at any time and to:
  - receive a response within 24-hours;
  - to have grievance resolved in an expedited manner (same day) in emergencies;
  - to have urgent care grievance issues resolved within 7 days;
  - to have other grievances resolved within 15 business days.
  - to continue to receive services until grievance is resolved.

- Medicaid-enrolled individuals must retain their rights to a Medicaid appeal, and be informed of those rights. Medicaid-enrolled individuals should be able to bypass MCO grievance procedures and go straight to a Medicaid appeal.
• Have the right to be represented in any grievance or appeal proceedings.
• Not be penalized due to refusal of treatment, missed appointments, etc.
• To draw up an advance directive and/or appoint a health care agent and to have providers in the system take account of their wishes as laid out in the AD or by the agent.
• To be assured of confidentiality, and to have access to their records.

The state should also consider contracting for an outside entity to serve as an independent watchdog over the plan and the system by:

  o Establishing an Ombudsman program specific to the managed care plan, or contract with an existing rights advocacy organization (such as the Protection and Advocacy System for people with disabilities).

  o Monitor data on grievance and appeals in early stages (SAMHSA Early Warning System) to catch problems early on.

**Funding Issues:**

Full capitation and full-risk is risky; Soft capitation (shared risk) is better.

• ASO better yet (ASO, Administrative Services Only, where MCO responsible for administrative tasks, such as approval of services, network development, utilization review, but does not pay for services. Therefore, no benefit to plan in denying care.

• Maintain current spending level in first year; plan for increases, not decreases.

• All funds saved stay within the mental health care system. Do not build roads with inpatient dollars.

• Limit the plans profit margin and its administrative costs: these come off the top.

**Consumer Information:**

Consumers need information on the plan, its grievance and appeal procedures:

• Plan provides educational materials that are easy to understand that describes its services, how to access them.

• Plan must provide written-jargon free information on rights and how to use its grievance procedures and how to file a Medicaid appeal.
**Enforcement:**

- Sanctions and incentives built into contract.
- Incentivize: developing new, non-traditional services, lower institutional placement rates, higher consumer satisfaction, improved performance in responding to requests for assessments, and other desired outcomes.
- Sanction: poor discharge planning, high recidivism rates, untimely inpatient admissions, inappropriate referrals that dump people on another system (especially juvenile and criminal justice), delays in service approval or payments to providers.
- Use intermediate sanctions: monetary penalties, appointment of temporary management to oversee operation.
- Profits margin allowed to increase if rated as good or superior performance.
- Plan can receive specific extra payments or non-financial rewards (recognition, one-year contract extension, fewer or less frequent reporting requirements).
- Contract should stipulate that in extreme case it can be canceled for repeated substandard performance.

**Monitoring the Plan**

- State needs management information system capacity to track and monitor the plan.
- Site visit monitoring.
- Data on the use and outcome of the Plan’s grievance procedures should be collected and made public.
- Have outside evaluation studies by universities are a good source.
- Involve consumers/families in monitoring.

**Consumer/Families Critical Role in Process:**

Consumers/families know more about treatment, services and system problems than do many government employees who will design the contract. Consumers and families should:

- Be on planning group that is drafting the RFP.
- Be on state-level consumer oversight board following award of contract.
- Participate on the Board that governs the operation of the contract by the MCO.
- Staff a Consumer Rights Office within the Plan to assist people enrolled.
- Hired as service providers (consumer/family organizations contracted with for certain services; individual consumers with appropriate training and credentials hired as providers).
Conclusion

- Managed care changes role of state agency as watchdog, monitor, planner, evaluator. No longer funder of direct services.

- Need to ensure that essential principles are met. See Principles throughout *Partners in Planning* (also listed on pages 86-87)

- Be assertive. Corporations know exactly what they want. Those who purchase on behalf of the public should do the same.

Good luck.
Maine: Where are we going and why?

Some issues with the current delivery system for behavioral health care:

- services are often fragmented and uncoordinated
- it is difficult to access some services
- positive or improved outcomes are lacking
- confusing to navigate
- Department’s budget/funding doesn’t always allow for smooth transition from children’s services to adult services

The Department’s goals and expected outcomes of managed care are to:

- develop a system that is customer and family directed,
- committed to recovery and resilience,
- able to integrate services across multiple systems,
- is accessible in a timely manner and is community based.

Over time, the department wants to see some specific system results. These results are listed in the concept paper that was published last December. Some of them are:

- Access to the right service in the right amount at the right time to meet the needs of individuals receiving mental health or substance abuse services; (this could very likely mean that different services are available that can better meet the needs of consumers and families.)
- Coordinated funding that will be flexible enough to promote a more efficient system of services and supports.
- Assurance of an adequate number and distribution of appropriately credentialed behavioral health care providers
- Implement of evidence based and best practice service approaches
- Improved access to all needed services, with an emphasis to substance abuse services
- Continuity of care for people with mental illness that allows for a smooth and timely transition from hospital to community and through appropriate levels of care
- Ability to meet state, state judicial and federal mandates.

**What has been done so far?**

1. The Department has an internal working group that is doing work and research necessary to complete the waiver. The waiver is the document that outlines the details of the managed care program that we submit to the federal government. They review that document and once it is approved, it gives the Department permission to operate a managed care program.

   The waiver requires certain things; some of them are:
   - standards for grievances and appeals
   - cultural competency requirements
   - specific detailed information to consumers.

2. We have created a Managed Care Stakeholder Group. It is made up of consumer and family organizations; advocacy organizations; and provider representatives. The group will work the Department on the implementation of the managed care program and continue to work with us as managed care continues in Maine.

3. We are looking at what we need as a State to run a managed care program. The Department’s role changes under managed care.
   - shift from purchasing services to oversight of the managed care organization—and working with the managed care organization to be sure it is moving the behavioral health system in the direction we want.
   - what types of performance do we want to build incentives for—two that come to mind are dual diagnosis treatment and stakeholder involvement. How the Department pays the managed care vendor will impact who they respond.

4. We are drafting our quality plan. What outcomes do we want for consumers from a managed care program? What reports do we want from the managed care organization? How do we make sure that we are attaining a recovery orientation? We will be looking for your input in this area.
As we have begun our work on this program we have some recommendations and things for you to think about:

We’d like all behavioral health services currently paid for under MaineCare will be part of this waiver, except

- ICM
- State hospitals
- Drugs related to mental illness or substance abuse

Would like another contract for management of the State grant dollars for those same types of services for individuals who do not have MaineCare.

We are recommending that wrap services, or non-traditional services like respite, not be included in the program right now. Those services would still be covered separately by the Department as it does now, through contracts with providers. These services could be included in managed care later.

We want all MaineCare members would be part of this system. At this point, we are recommending that there be no excluded populations. However, if a person is an inpatient at Riverview or Dorothea Dix, if the State hospitals aren’t in managed care, the person would not be part of the managed care system until they have been discharged.

The State can decide to allow consumers to self refer (not have to get permission from the managed care organization) to certain services. The services we are recommending for self referral are:

- Assessments
- Crisis services
- Inpatient hospital services for substance abuse detox
- Case management
- Outpatient services (until a certain number services are used)
(After a certain number of visits, the managed care organization could require that the provider seek authorization for more visits.)

We want the managed care organization to coordinate with the consumer’s primary care physician. And if the consumer doesn’t have a primary care physician, to help them find one.

We want to require the managed care organization to provide non-English language written translation of materials to the same extent as the Department provides that translation. And we want oral translation to be available to all enrollees regardless of the language spoken. Sign language would also be included in the translation requirements.

Each managed care organization must have a complaint and grievance system. We are recommending that the members of this system use this system before they use the State’s system. The complaint and grievance system would be in compliance with the requirements of
the Medicaid program, but would also incorporate provisions of the consent decree for class
members as well as the rights of recipients of mental health services.

**This afternoon will be answering some questions that will help us write the waiver document and the contract with the managed care vendor:**

- What other services do you think people should be able to get without prior authorization or a referral?

- What should be the access standards for service? Meaning, what is the maximum amount of time a person should have to wait for the different types of service.

- The quality of services. How would you measure whether you or your family member is getting quality services?

- What kind of input do you want to see as a consumer or family member into the managed care company’s operations?