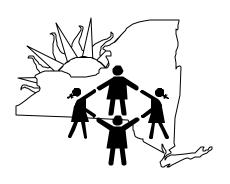
New York State Coalition for Children's Mental Health Services

A Children's Mental Health System of Care Blueprint







The New York State Coalition for Children's Mental Health Services

is a 501c (3) organization dedicated to the advancement of children's mental health services in New York State. The Coalition represents the interests of children and youth, family members and providers who seek to inform and educate policymakers about the need for the development of a children's mental health system of care.

The Mission

To promote quality mental health services for New York's children with serious emotional disturbance and their families by leading the service provider community in identifying effective practices and participating in planning and implementing a continuum of services that are family-focused, comprehensive, cost-effective, culturally responsive, coordinated and appropriately funded.

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The New York State Coalition for Children's Mental Health Services

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Executive Summary

A System of Care Blueprint for the Children's Mental Health System

September 2003

The New York State Coalition for Children's Mental Health Services

"Today, service to children and families is rationed."

The New York State Coalition for Children's Mental Health Services commissioned a white paper to articulate a vision that would set a clear direction for children's mental health services in New York State. The primary stakeholders involved in the process are youths, families, providers, local government mental health officials and state government mental health officials. Opinions were solicited from these stakeholders to inform the development of the Coalition's vision of a comprehensive mental health system of care for children and families.

To begin to redesign the system, we must continue to drive toward a complete, efficiently functioning mental health system of care for all of New York State's children and their families. We must also link that system to all of the other children's service systems as many children and families move from one system to another or are served by more than one system simultaneously.

This report crafts a new future for the children's mental health system based on collaboration and partnerships. We articulate our vision for the future now recognizing the positive effect of new services currently developed by the emerging "family-government-provider partnership" in New York State.

Action Steps Necessary to Develop a System of Care

The Coalition identified Action Steps for development and implementation to achieve its collective vision. Recognizing this, the Coalition's activities, resources and member's actions will support the initiatives which will act as a stepping stone for initial change in the system of care.

- Formalize and fund the role of families in the system of care
- Identify and build the service array
- Ensure immediate access to education
- Create a system of care management for multiple service users
- Build a young adult service continuum that bridges the children's system and the adult system
- Organize the "service silos" into a system of care
- Rebuild service models and finance models as needs and approaches change
- Create cross-system service eligibility
- Build an outcomes-oriented information system



Executive Summary

A System of Care Blueprint for the Children's Mental Health System

September 2003

The New York State Coalition for Children's Mental Health Services

Values

The vision outlined in the Coalition's report builds upon the Children and Adolescents Support Services Programs (CASSP) principles. These principles are recognized nationally as the accepted conceptual framework for children's mental health services. However, the CASSP principles alone cannot move the system forward without further consideration of the perspectives of government, providers and families. The Coalition established the key values outlined below to be used as a framework for development of a true system of care.

- All children and families are entitled to the full array of culturally competent mental health services when they need them;
- Absence of parity and other policy barriers to care must be removed;
- The system of care begins and ends with the family or guardian;
- Youth should be full participants in their treatment and the design of the system;
- Service access must be clear, easy and swift;
- Responsibility for the system of care is a local, regional and state responsibility;
- Service funding must enhance the functioning of the system of care, support effective service models and support a diverse, skilled workforce;
- Cross-systems children require a true cross-systems approach;
- "Service Silos" require planning and cooperation;
- Linkage with the other children's service systems is necessary; and
- Information guides service system decisions.

"We hope to see a day when children and families will have access to a range and volume of mental health care equal to that available today in physical health care; that is, a day when a child afflicted with depression or any other mental health problem, will be treated as quickly and effectively as a child with a broken bone or a fever."

The growing commonality of beliefs about what can be achieved for a children's mental health system is powerful.

We join others who believe that by working together, we can achieve much.



ntroduction

The New York State Coalition for Children's Mental Health Services commissioned this paper to articulate a vision that would set a clear direction for children's mental health services in New York State. Opinions were solicited from various children's mental health stakeholders to inform the development of the Coalition's vision of a comprehensive mental health system of care for children and families.

Across the country, efforts to develop systems of care are gaining momentum. The concept of a system of care has arisen over the past several decades from a set of experiences and beliefs. This set of experiences includes the realization that as programs and services grow in size, scope, and specialization, the coordination of these programs and services become more difficult. While each program might function in the best interests of the children and families it serves, the resultant inefficiency in the overall system can result in less than optimal outcomes.

In New York State, we have seen the array of services to children and their families grow, with a particular emphasis on community-based services. We have also seen growth in a myriad of versions of the Single Point of Accountability/Accessibility for selected children's mental health services. Although some significant steps have already been taken in the direction toward a system of care, much work is still needed

As recently as 1999, the 27.8% of New York State's population that was under the age of 18 constituted only 18.4% of the recipients of mental health services in the state. Children were just 14.6% of those receiving emergency care, 11.1% of those receiving inpatient service, and only 9% of those receiving non-residential community support ("Patient Characteristics Survey, 1999", New York State Office of Mental Health). This is not to say that resources should be withdrawn from adults and redirected to children, but rather to point out that children's services remain enormously inadequate at this time.

To begin this transformation, we must continue to drive toward a complete, efficiently functioning mental health system of care for all of New York State's children and their families. We must also link that system to all of the other children's service systems as many children and families move from one system to another or are served by more than one system simultaneously.

This report crafts a new future for the children's mental health system. We are encouraged to articulate our vision for the future now because of a growing body of hard evidence that documents the positive effect of new services that have been developed by the emerging "family-government-provider partnership" in New York State.

This document presents various implementation strategies and begins with a series of values, which will guide the actual framework of the system. In so doing we advance a wide range of values, policies and recommendations that will fundamentally transform our children's mental health system and convert our current array of services into a true system of care.

"To begin this transformation, we must continue to drive toward a complete, efficiently functioning mental health system of care for all of New York State's children and their families."

"The CASSP principles have become the foundation for system of care initiatives ... values built upon these principles must quide our efforts to transform the current array of services to a true system of care."

Child and Adolescent Service System Program (CASSP)

Brief History

A national study in 1982 found that two-thirds of all children with severe emotional disturbances were not receiving appropriate services. These children were "unclaimed" by the public agencies responsible to serve them, and there was little coordination among the various child-serving systems. To address this need, Congress appropriated funds in 1984 for the Child and Adolescent Service System Program (CASSP), envisioned as a comprehensive mental health system of care for children, adolescents and their families.

CASSP Core Principles

CASSP is based on a well-defined set of principles for mental health services for children and adolescents with or at risk of developing severe emotional disorders and their families. These principles are summarized in six core statements.

Child-centered: Services meet the individual needs of the child, consider the child's family and community contexts, and are developmentally appropriate, strengths-based and child-specific.

Family-focused: Services recognize that the family is the primary support system for the child and participates as a full partner in all stages of the decision-making and treatment planning process.

Community-based: Whenever possible, services are delivered in the child's home community, drawing on formal and informal resources to promote the child's successful participation in the community.

Multi-system: Services are planned in collaboration with all the child-serving systems involved in the child's life.

Culturally competent: Services recognize and respect the behaior, ideas, attitudes, values, beliefs, customs, language, rituals, ceremonies and practices characteristic of the child's and family's ethnic group.

Least restrictive/least intrusive: Services take place in set settings that are the most appropriate and natural for the child and family and are the least restrictive and intrusive available to meet the needs of the child and family.

Values

The first "systems of care" were established to serve children and families based on Children and Adolescents Support Services Programs (CASSP) principles developed by Stroul and Friedman (Stroul, 1993). The CASSP principles have become the foundation for system of care initiatives around the country and generally receive consensus support as the appropriate conceptual foundation for the development of a children's mental health system of care.

Building upon these principles, the Coalition believes the following additional values must guide our efforts to transform the current array of services to a true system of care.

1. All children and families are entitled to the full array of culturally competent mental health services when they need them.

Children and families receive mental health services if they need them and the mental health system has those services available. In many areas, necessary services do not exist or there are long waiting lists for those services. Schools cannot refuse to educate children because of lack of capacity and county departments of social services cannot refuse to serve neglected or abused children. The children's mental health system must take similar responsibility to ensure that the full array of services is available to all children and families across New York State. This array should reflect the cultures of the children and families receiving services. It should be equally available to children with and without families.

2. Absence of parity and other policy barriers to care must be removed.

Insurers and managed care companies should bring the mental health benefits in line with physical health benefits. Families should not have to pay higher co-pays for mental health services than for physical health services. The number of visits should reflect need rather than a set benefit and should allow for flexibility of service type, rather than outpatient and inpatient services only. The Medicaid cap, affecting the expansion of mental health services, needs to be lifted to allow necessary growth to ensure that the mental health needs of the state are met.

3. The system of care begins and ends with the family or guardian.

For the most part, families are now invited to participate in treatment planning for their children within each mental health service provided. This is insufficient. Families must drive the service planning for their children, across levels of care, and across funding streams with close cooperation and consultation from service providers. Additionally, service providers, county, and state government must each support and assist the families in developing and exercising their skills in service planning and advocacy. Families must also be full partners in the design and operation of the system in which they are served.

"Schools cannot refuse to educate children because of lack of capacity and county departments of social services cannot refuse to serve neglected or abused children."

"What parent knows the mental health system well enough to know whether their child needs school-based mental health services, a private practitioner, outpatient services, **Intensive Case** Management, Waiver, etc.?"

4. Youth should be full participants in their own treatment and in the design of the service systems.

It is important that youth have the opportunity to work in partnership with their families and providers in their own service plans. Youth, who are or have been service recipients, should also participate in the design and oversight of the children's mental health service system.

5. Service access must be clear, easy, and swift.

If a family lives in an area where service choices are many and varied, they will have many choices. Unfortunately, such choices may be limited by capacity and very complicated admission requirements. What parent knows the mental health system well enough to know whether their child needs school-based mental health services, a private practitioner, outpatient services, Intensive Case Management, Waiver etc.? How many professionals in the community can even list what services exist and how to obtain them? Our mental health system needs to assure comprehensive assessments and knowledgeable triaging into the array of services. If a child does not have a family, the legal guardian should have the same level of access to necessary services.

6. Responsibility for the system of care is a local, regional, and state responsibility.

A full array of services organized into a system of care cannot be accomplished by any entity alone. Many services can and should be provided and organized at the local or county level. Other lower volume, higher cost services will need to be delivered regionally and organized regionally. The state, the county, the provider, and the families must share ownership to ensure that services are developed, organized, and operated in a manner that allows the system of care to function smoothly within a county and across many counties.

7. The service funding system must enhance the functioning of a system of care, support effective service models, and support a diverse, skilled workforce.

Some children's service models mirror adult models (e.g. outpatient, community residence), have highly complicated and regulated admission and service delivery requirements (e.g. Waiver, RTF), and have rate methodologies that do not adjust annually to cover costs (e.g. Community Residence, Outpatient Mental Health, Family-Based Treatment). These models need to be redesigned to ensure adequate reimbursement that supports effective children's clinical models and ensures salaries that will attract and retain high quality staff.

8. Cross-systems children require a true cross-systems approach.

It is currently very difficult to obtain adequate services for children and youth whose needs require services from multiple systems. One system frequently denies service by shifting the child to another system even though the child's needs require the services of both systems. Developmentally disabled children, for example, may spend nine to twelve months in acute hospital beds, crisis residential pro-

grams, or the juvenile justice system because no services can be found that meet both their mental health and developmental disabilities needs. All of the child serving systems must cooperate to forge a solution to this problem.

9. "Service Silos" require active planning and cooperation.

Regulatory and funding bodies typically separate services into silos (mental health, social services, etc). No system of care in the country has been able to eliminate all silos of service. Regulations, federal funding requirements, multiple service providers, and the array of services itself introduce silo walls that impede smooth and easy transition from one service to another. All system of care stake holders (families, counties, regions, providers, state) share the responsibility to design linkages that work easily and rapidly.

10. Linkage with the other children's service systems is necessary.

This paper addresses the development of a Mental Health System of Care – it does not formulate a plan for a multi-funded system of care. However, many children and families move across funding streams; the proposed Mental Health System of Care must provide dependable and simple linkages to the other systems to ensure that the most complete service package may be offered as needed. This is particularly true for children who are in the custody of a county department of social services, but need mental health services.

Linkage to the adult system is also critical to ensure that necessary mental health services are provided to aging out youth as they move from the children's system to the adult system.

11. Information guides service system decisions.

Information should be gathered that shows what the service delivery system looks like, geographically, by service type, across multiple system funding streams. New York invests heavily in information systems that exist within small silos and do not communicate with each other. It is difficult, if not impossible, to look at services and utilization across the state across multiple funding streams. Consequently, it is difficult to make informed service development investment decisions.

"Information should be gathered that shows what the service delivery system looks like, geographically, by service type, across multiple system funding streams."

Action Steps

- 1. Formalize and Fund the Role of Families in the System of Care
- 2. Identify and Build the Service Array
- 3. Ensure Immediate Access to Education
- 4. Create a System of Care Management for Multiple Service Users
- 5. Build a Young Adult Service Continuum that Bridges the Children's System and the Adult System
- **6.** Organize the "Service Silos" into a System of Care
- 7. Rebuild Service Models and Financial Models as Needs and Approaches Change
- 8. Create Cross-Systems Service Eligibility
- 9. Build an Outcomes Oriented Information System

Action Steps

Given the beliefs and challenges noted above, there are action steps that we can take now to continue the building of a statewide mental health system of care linked to the other child service systems.

1. Formalize and Fund the Role of Families in the System of Care

Clear roles and responsibilities for families should be written for use at the regional, state, and the county level. Family support should become part of each service model package with FTEs allowed in the rate methodology. Extensive training should be provided to counties, regions, families, and providers that delineates the power and possibilities of family involvement in service planning.

2. Identify and Build the Service Array

No system of care can deliver on the promise that children and families are entitled to prompt access to the full array of mental health services unless the array is developed to allow access. The array should be built from the county level to the regional level. For larger counties, this design should happen in county sectors to ensure that families do not have to drive too far for services.

County-based services

The keystone to our vision of an effective system of care is the Unified Access Center: Access staff would know the entire child service system and can offer advice to families and other professionals about what might work and how to obtain it. These access centers would be available 24 hours a day, 7 days a week. They would be staffed by trained staff who would have the ability to triage calls to the necessary service. The Unified Access Center could be the SPOA or could be linked to the SPOAs, but would need to have access to all of the services available in a county as well as the regional services. Some counties may choose to create one well-trained access center that would cover multiple counties. Parents or professionals would only need to make one phone call to link to the required service. Rapid linkage to or provision of assessment services would be critical. This Center either offers assessments or refers to other providers for assessments. It also has immediate access to the crisis service system. Access to prevention and flexible outpatient services could occur through the Access Centers, but direct access to those services for incidental use would be encouraged.

Front Line Mental Health Services

- Assessment services
- Prevention services
- Early intervention services
- School-based services
- Flexible clinic outpatient services

Care Coordination Services for Higher Need Children and Families

- Crisis system (24X7):
 - telephone (Unified Access Center)
 - mobile crisis
 - in and out of home respite
 - Home-Based Crisis Intervention Services
- Wraparound services approach (like Waiver) of varying intensity based on need.
- Family support and advocacy services
- Family-Based Treatment
- Natural community supports

Regional Services

- Day Treatment
- Community Residence
- Crisis Residence
- Acute In-Patient
- Residential Treatment Facility
 - Regular
 - Intensive
 - Specialty (Sex Offender etc.)
- Intermediate In-Patient (State)

3. Ensure Immediate Access to Education

Access to appropriate educational services has been a challenge for children with intensive needs who are returning to their previous school or are entering a new school. When such children and youth return to their communities from a placement, they may be required to accept one hour of home tutoring for significant periods of time while decisions are being made regarding school placement.

Children and youth should be registered in the new school 30 days prior to starting school. The school must provide appropriate educational services at the conclusion of the 30 day notice or OMH will authorize and pay for an interim day program. This day program cost would then be billed back to the education system.

4. Create a System of Care Management for Multiple Service Users

Care management would be available to all children and families utilizing more than one mental health service (similar to OMRDD's Medicaid Service Coordination). The care coordinator would assist the family in managing the service package across multiple levels of care (including residential) and would have access to a flexible package of services (similar to the Waiver) as well as access to flexible dollars for the non-traditional service needs of a family.

5. Build a Young Adult Service Array that Bridges the Children's System and the Adult System

Currently, many youths aging out of the children's system at age 18 are placed in facilities with middle aged adult roommates who have very different service needs. The service array should include services specifically designed for the 18 to 25 year old and should be formally linked to both the children's system and the regular adult system.

6. Organize the "Service Silos" into a System of Care

County level

Create written protocols that uniformly build durable linkage protocols between all elements of the service system – families, providers, Local Governmental Units (LGU), and others. These protocols should clearly outline how the system of care should work including referrals, admissions, wait times prior to service, discharges to the next service etc. These protocols should ensure that the service array operates without observable walls or barriers. All parties, but particularly the Unified Access Center staff must become expert in the protocols.

Each county should convene a group of system of care stakeholders (families, youth, funders, providers) which has shared oversight responsibility for how the system is working. This group should be able to review the data regarding service provision and work on ensuring that the system is working as defined by the protocols. It must be clear that this group has responsibility for appropriate services for all children and their families. There should be no rejection unless another service system has taken responsibility for planning and service provision.

Regional Level

Written protocols should also be completed between all regional services, OMH regional field offices and LGUs. These protocols should delineate standard expectations across all counties for regional services and visa versa. They should be standard for each service type for each region. Once again, the protocols should make all barriers to service invisible to the family.

Each region should have an oversight body composed of the system of care stakeholders (funders, families, youth, providers, regulators) that examines the system operations to ensure that it is operating according to the established protocols. The CCSI legislation may provide a platform upon which these county and regional planning and oversight capabilities can be built.

State Level

The state should review the statewide data on how effective the system is with a particular focus on the following:

- Does the service array exist at the county and regional levels?
- Access: Are children and families gaining access to the services they need within appropriate time frames?
- Do regulatory requirements interfere with swift service delivery (such as the current PACC system for RTF youth in some regions)?
- Do services provided meet acceptable quality standards?

7. Rebuild Service Models and Financial Models as Needs and Approaches Change

Many of the existing service models were constructed years ago and there is no established procedure to ensure that service and financial models remain up-to-date. Each service model should periodically be re-examined by the system of care stakeholders to ensure that the model accomplishes the usual service model requirements as well as the following:

- Family support is included and is funded.
- Youth are included as participants in service delivery.
- Staff salaries are at a high enough level to attract and retain a quality workforce.
- The financial model clearly supports the clinical model.
- The financial model is responsive to cost changes annually which ensures that the service remains viable.
- Linkages to the system of care are clear and delineated.

8. Create Cross-Systems Service Eligibility

Based upon an agreed upon assessment, any child that qualifies as a "cross-systems" child would receive a cross-systems care manager and a *services passport* that immediately qualifies that child and family for services from the needed service systems. No other system eligibility would be required. For example, a Seriously Emotionally Disturbed child who is also Developmentally Disabled would qualify for required services in either of the two systems.

9. Build an Outcomes Oriented Information System

Create an information system that delineates the service needs of children and families, the services provided, and the outcomes achieved. This outcomes management system would contribute to county, regional, and state decision making based on reliable outcome and cost data. It should not be limited to one episode of care at one service level (i.e. one FBT admission and discharge), but should track the impact of the system of care over time for multiple levels of service provided to each family.

"We hope to see a day when children and families will have access to a range and volume of mental health care equal to that available today in physical health care; that is, a day when a child afflicted with depression or any other mental health problem, will be treated as quickly and effectively as a child with a broken bone or fever."

Conclusion

This vision for the future of mental health services for children and families stands on a foundation of need, opinion and hope as expressed by stakeholder groups in the first section of the paper. We believe the vision is realistic and necessary for the children and families of New York State.

We hope to see a day when children and families will have access to a range and volume of mental health care equal to that available today in physical health care; that is, a day when a child afflicted with depression or any other mental health problem, will be treated as quickly and effectively as a child with a broken bone or a fever. On that day, parents' concerns for their children's mental health will be addressed by a wide array of preventive and intensive mental health services, just as their physical health concerns are addressed now by well-child care, by nurses in schools, by doctors in offices, and by specialists in hospitals. On that day, mothers and fathers won't need to worry about enough care being available. On that day, they won't be confused about where the help is, or how to get it.

We are far from realizing this vision now. The Surgeon General of the United States, commenting on research into the provision of children's mental health service, has said:

The foremost finding is that most children in need of mental health services do not get them....The conclusion that a high proportion of young people with a diagnosable mental health disorder do not receive any mental health services at all (Burns, et. al., 1996) reinforces an earlier report by the US Office of Technology Assessment (1986) which indicated that approximately 70% of children and adolescents in need of treatment do not receive mental health services.

Mental Health: A Report of the Surgeon General, Department of Health and Human Services, US Public Health Service, 1999

The President's New Freedom Commission on Mental Health discovered similar substantial problems in the national mental health service delivery system, stating in their 9/29/02 letter to the President:

...America's mental health service delivery system is in shambles. There are so many programs operating under such different rules that is it often impossible for

families and consumers to find the care that they urgently need....the Commission

affirms the President's position that Americans deserve a health care system that treats their mental illnesses with the same urgency as it treats their medical illnesses. The Commission is united in the belief that the mental health service delivery system needs dramatic reform. It is becoming clear that the mental health service system does not adequately serve millions of people who need care....The "mental health maze" is more complex and more inadequate for children.

Despite some valuable recent improvements in New York State's mental health care for children, we must acknowledge that our current situation is not materially different from that reported at the Federal level. As recently as 1999, the 27.8% of New York State's population that was under the age of 18 constituted only 18.4% of the recipients of mental health services in the state. Children were just 14.6% of those receiving emergency care, 11.1% of those receiving inpatient service, and only 9% of those receiving non-residential community support ("Patient Characteristics Survey, 1999", New York State Office of Mental Health). This is not to say that resources should be withdrawn from adults and redirected to children, but rather to point out that children's services remain enormously inadequate at this time.

Today, service to children and families is rationed. Intensive case management "slots" and RTF beds are distributed until they run out, and then the waiting begins. Other forms of care are meted out according to severe eligibility requirements; e.g. the necessity of observable danger to self or others prior to some hospital admissions. The current Medicaid cap prevents the expansion of all services, and contributes directly to the fact that only 130 children in the entire state—out of 5.2 million—were reported by OMH to have received school-based mental health support during the reporting week in November, 1999. In the absence of effective mental health care, too many of our children find themselves shunted by default into juvenile justice programs, into child welfare, into private boarding schools which operate free of mental health standards and oversight, or transferred entirely out of the state for service elsewhere.

We are encouraged to articulate our vision for the future now because of a growing body of hard evidence that documents the positive effect of new services that have been developed by the emerging "family-government-provider partnership" in New York State. Home and Community Based Waivers, Single Points of Accountability, RTF transitional staff, expanding family support and a wraparound process, strength-based assessment—these techniques and others are changing the outlooks and futures of children and their families in ways that were unimaginable two decades ago. As confidence in the power of our methodologies grows, so too does our determination to keep the promises implicit in the presentation of children's mental health care.

Although we may not at the moment have a broad-enough array of approaches, or sufficiently well-articulated systems of care to achieve the vision implicit in our statement of values, we can certainly see that the vision may be achieved one day in the not so distant future. The commonality of beliefs about a children's mental health system of care across the various stakeholder groups is powerful. It is now up to each of us to help create a new reality in children's mental health.

The commonality of beliefs about a children's mental health system of care across the various stakeholder groups is powerful."

Appendix I

PRINCIPLES OF SYSTEMS OF CARE FROM MULTIPLE PERSPECTIVES AND TENSIONS WITHIN THE CHILDREN'S MENTAL HEALTH SYSTEM

Summary of Findings

Based on field research conducted by

John S. Lyons, Ph.D. Dana A. Weiner, Ph.D.

This summary describes a series of focus group interviews conducted across the state with representatives from the New York State Office of Mental Health, local county mental health, families, and providers. The interviews surfaced both common ground and divergent perspectives that help describe statewide thinking about a mental health system of care.

The concept of a system of care has arisen over the past several decades from a set of experiences and beliefs. This set of experiences includes the realization that as programs and services grow in size, scope, and specialization, the organization and management of these programs and services become more difficult. While each program might function in the best interests of the children and families it serves, the resultant inefficiency in the overall system can result in less than optimal outcomes.

The first "systems of care" were established to serve children and families based on Children and Adolescents Support Services Programs (CASSP) principles developed by Stroul and Friedman (Stroul, 1993). These programs were funded by the Robert Woods Johnson Foundation and later by the Center for Mental Health Services. These principles have become the foundation for system of care initiatives around the country and generally receive consensus support as the conceptual foundation for systems of care for children and adolescents with mental health challenges. Few would argue with the proposition that services for children and families should be designed with these principles in mind.

While the CASSP values and principles represent an important area of consensus within the children's mental service system, these principles represent only the focus of service delivery and do not establish principles for the system of care from the multiple perspectives of providers, administrators, or government agencies. There is no attention within these principles for county, regional or statelevel considerations. Nor are there any considerations of the business aspects of service delivery. Therefore, it is necessary to establish and understand the unique core values and guiding principles of each of the partners in a system of care. Using an approach consistent with the CASSP philosophy, we can derive principles that incorporate other perspectives to guide the development of New York State's system of care.

As stated previously there is a great deal of consensus that these statements outline the appropriate conceptual framework for the development of a system of care.

The CASSP guiding principles require the following of a system of care: a comprehensive and culturally competent array of services that are integrated, coordinated and managed, to be provided in an individualized way while keeping the child in the least restrictive environment possible. Family

members should be fully involved in all aspects of the system. The rights of children and families must be respected.

Although this approach to the system of care is widely accepted, tensions arise from discussion of how to get to this idealized system. Tensions are a natural aspect of all systems. In service systems, tensions arise from the fact that different partners within service system have different perspectives. The honest pursuit of one's own perspective can easily place one in conflict with another partner's perspectives. Tensions resulting from honest disagreements may arise from different perspectives about treatment and care. These tensions cannot be completely eliminated, but they can be managed. Creative management of these tensions can be the source of energy for innovation and positive service system evolution.

The first step on the creative management of tension in a system of care is to explicate the additional principles under which system partners operate. In the development of this white paper, we will begin that process for state, county, family, and provider perspectives.

In order to inform the presentation of each perspective, a series of focus group discussions were organized with representatives of each of these perspectives. The organization of these focus discussions was that a draft of each perspective was written and these were provided to each focus group representative to review prior to the discussion. The focus group discussion then featured a review of the general presentation of the perspective, the draft of additional principles, and a discussion of perceived areas of common ground and disagreements with other perspectives.

Common Ground

All representatives endorsed the CASSP principles as a foundation for the public children's mental health service system. Maintaining a child and family focus to the service system that is culturally competent and empowers parents to be and stay involved in their children's lives was seen as crucial. A focus on providing services that help children and families is seen as the appropriate priority for the system. The only area related to CASSP principles that appears to generate some disagreement is the criteria that might be used to define appropriate decisions about least restrictive environments.

State Government Focus Group Perspective

The key issue for understanding the perspective of state government is that it operates in an essentially political environment as the messenger/executor of the government as directed by the Governor and Legislature. The state government represents all of the residents of the state and is responsible for the just allocation of tax revenues across all of the competing options. The Office of Mental Health primarily serves to implement the directives of the state government. To some degree OMH also represents citizens and residents with mental illness and their families within the state: however, this representation is by no means exclusive as many other advocacy organizations and individuals citizens communicate with the state government.

TABLE 1. State Government Perspective Principles.

1. The State of New York is responsible for the well-being of all of its residents and must weigh all decisions within the broad context of the overall

benefit to residents, citizens and taxpayers.

- 2. The Office of Mental Health represents the State of New York to residents of the state, those with mental health challenges and their families, and providers who address these challenges. OMH must operate within the legal, regulatory, and policy directions established by the Governor and the Legislature.
- 3. The OMH has limited resources and must allocate those resources based on need within a complex political environment.

For the most part, OMH is responsible for funding and monitoring services and the service delivery system. This places OMH in an oversight role with the county-level management of local systems of care. The one exception to this general rule is that OMH does provide direct services through the state-operated hospitals. The dual oversight and service provision role may complicate some aspects of local decisionmaking since OMH as both oversight authority and a provider (i.e. a state hospital) could, at least conceptually, benefit from specific decisions made by the local decision-makers.

In sum, representatives of the state perspective report looking for value with their investments. They desired greater accountability and demonstrable outcomes.

County Government Focus Group Perspective

County government shares the three principles of state government in that the county represents the residents, citizens, and taxpayers of the county and must make decisions within that broad political context. County agencies are bound by the directives of county elected officials. Local elected officials must allocate limited re-

sources within a political environment. The big difference between county and state level government is that counties often have less discretionary revenue from local sources and therefore rely on state revenues. In addition, county government involves fewer people allowing for more personal relationships. Closer relationships offer both advantages and disadvantages to developing systems of care. Wide variations in the size and scope of county governments, including, geographic size and topography, population density and demographics also limit options for system of care development. All these factors of composition influence what is possible and de-

In addition county governments are focused on the service delivery system as it applies to the residents of that county. There is an inherent limitation built into a system that allows a single county to dictate the service delivery system according to its residents' needs when the service delivery system must operate on a regional basis and meet the needs of other counties' residents as well.

Counties report that, under the SPOA model, they are likely to have much greater control over decision-making related to access to intensive community services. Many counties are also direct service providers. When the county directly provides the intensive community services and operates the SPOA, this represents a noteworthy deviation from the essential SPOA model as it might place the county in a potential conflict of interest. A similar potential conflict can exist if a provider agency operates the SPOA and provides the intensive community services. Also, if the SPOA were structured independently from the county operated service delivery either structurally or contractually, potential conflicts of interest could be moderated.

TABLE 2. County Government Perspective Principles.

- 1. There are no exclusions from a system of care. All children and families should be eligible. Similarly, there are no extrusions from a system of care. You cannot terminate or discharge a child or family from a system of care.
- 2. Child serving agencies must work in partnership at the local level, directed by the parents or substitute parents to address the needs of children. These partnerships take time to develop.
- 3. Service planning should be based on identified needs and strengths - not on what services are available in a specific geographical region.
- 4. A primary goal of a system of care should be to help children remain in their community. Success in this goal should alleviate the need for residential placements.

In sum, representatives of county mental health administrators reported a desire for greater control over decision-making. They perceive themselves as middle-managers between the state and providers and desire greater autonomy from the state and more authority than the state over providers. More than any other perspective, county administrators report interest in effective collaborations between public mental health services and other child serving agencies, particularly child welfare and juvenile justice.

Family Focus Group Perspective

Families with children who have serious emotional and behavioral problems face enormous challenges. The time involved in addressing the individual needs of the child is substantial. Often schools require a parent to come in each time a child acts out. Suspensions and expulsions may require a parent to stay with the child when they are not in school. Attendance for clinical services can result in scheduling and travel complications. All of these factors make keeping a high-need child at home difficult for the parent/caregiver. As such, in addition to an individualized, coordinated array of services, families often require additional help in overcoming barriers to access. The Surgeon General has identified stigma as one of the most significant barriers to services. For parents with children who have emotional and behavioral problems, this stigma can include feelings of inadequacy and blame. Consequently, stigma, access, lack of information all present major barriers to service delivery.

TABLE 3. Family Perspective Principles

- 1. Parent's knowledge about and understanding of their children should be recognized and valued.
- 2. Services should be provided at the convenience of the family. Barriers to access should be identified and minimized.
- 3. Families should have choice in services and providers. Family decision-makers should be given the information they need to make informed choices.
- 4. Services should be provided in a way that respects individual family members and does not blame families for the presence of mental health problems.

In sum, representatives of parents and youth expressed the desire for a greater level of respect and increased choice. They wish to have both more options for services and more control over which options they choose to exercise. Families desire greater collaboration among child serving agencies so that redundancies are reduced in assessment and service delivery.

Youth Focus Group Perspective

Two in-person focus groups have been held. The first group was held in Albany with a state-wide youth advocacy group. A second group was held in a county in the Hudson River region. In this focus group, youth were asked to discuss the strengths and problems with the public system from their perspective. All of the youth representatives expressed a wish for a stable and supportive school environment. One representative felt he was getting just such an experience at a special school with a vocational focus. Other representatives felt that in both regular class rooms and special education, the lack of discipline and support was a major problem.

TABLE 4. Youth Perspective Principles

- Schools should provide environments that support learning and achievement.
- 2. Youth deserve to be in a loving and supportive family environment.
- 3. Services should focus on developing recreational options and vocational options.
- 4. The 'stigma' of having mental health needs should be reduced or eliminated.

In addition to a stable and supportive school environment, youth identified wanting three basic things: someone who cared about their health and well-being, more recreational options, vocational options

While these youth reported varied experiences with foster parents some very caring and some very strict and some just not very nice—it appears from listening to these youth that the type of caring they seek is something that comes from family. One participant described their experience of essentially being adopted by the parents of the person with whom they had become romantically involved. These parents became surrogate parents to this youth and had a major impact on them turning things around in their life.

In terms of recreational options, the participating youth expressed a great deal of pleasure from sports activities and a need for options to be used to structure leisure time.

In terms of vocational options, the youth expressed a desire to work and make some money. While none of the participating youth expressed a need to work in order to meet basic needs, they felt their quality of life was improved dramatically if they had at money to spend on other things (e.g. leisure activities). The focus of their concerns appeared to be relatively immediate (i.e., a job), rather than long-term (i.e., career development).

Several of the youth expressed frustration with the stigma (not their word) that comes with having mental health problems. They felt either that there was a tendency to make them feel different or that they were in fact different and the circumstances appear to highlight their differences from others. They felt that once identified as problems, they were exposed to a much higher level of scrutiny as compared to their 'undiagnosed' peers. This leads into a cycle of continuing to have problems and being unable to escape these problems as they become 'expected' by others. A related problem is that they tend to be placed together with other youth with problems. As one

youth in the Albany group stated "I never knew you could throw a desk at school until I went to day treatment. As soon as I saw that, I wanted to give it a try".

There was some evidence of developing institutional dependence even within the participants of these groups. For example, one participant described a perspective that they should not have to purchase their own food even when living independently. This participant was working and wanted to use personal earnings to purchase clothes and other items.

In general, these youth were not particularly focused on services. They did not appear to view them as a particularly important part of their lives. One participant had seen five different counselors in the past few years and thought some were pretty good and some were not so good. The youth liked the new therapist but had only seen her one time so far.

The results of these two youth focus groups suggest that the youth perspective is quite different than the other perspectives. Concerns of youth are more immediate and they primarily want a family life with love and support but without too much intrusion.

Provider Focus Group Perspective

Providers are often confronted with dual priorities. On the one hand, service delivery is a business and like any other business must be financially operational, stable and viable in order to, at a minimum survive and under the best circumstances, excel. On the other hand, clinical decision-making should be based on both the proper assessment of problems and knowledge of the most effective treatments. This decisionmaking is thought to exist outside of any business considerations. New York's child mental health

services system should be guided by a set of principles that emphasize clinical judgment exercised within an environment that responds to family wishes and financial pressures, with an equitable distribution of risk.

TABLE 5. Provider Perspective Principles

- 1. The system of care should support the ability of providers to exercise their clinical judgment consistent with family wishes, and professional, ethical and evidence-based standards.
- 2. It is desirable and often necessary to establish an expected flow of service recipients to allow for appropriate program planning and staffing. Other system partners should be aware of and support provider's operational needs in this respect.
- 3. Reimbursement for services, regardless of the specific funding mechanism, should be sufficient to support the recruitment and retention of high quality staff.
- 4. Business models for specific programs should be designed to be consistent with the clinical objectives of those programs.
- 5. Competing demands from different system partners should be resolved between those partners and providers should not be financially penalized when competing demand and conflicts result in referral barriers, transfer delays, reserve bed mandates and other problems that result from these conflicts.

Perhaps the clearest example of financial penalties to providers resulting from other system partners problems involves extended stays in the psychiatric hospital. Children who are wards of DSS can end up hospitalized past medical necessity because of problems establishing a discharge placement. Similar problems occur with transfers from community hospitals to state hospitals. Hospitals sometimes must swallow the costs of providing medically unnecessary days when they have no control over discharge planning.

A second example of both the fourth and fifth principles involves transition to community from residential. Several residential providers have noted an unwillingness of intensive community providers to become engaged with a child and family until the child has been discharged from residential treatment because the community provider cannot be reimbursed until the child is living in the community. Similarly, school placements cannot be accomplished in many situations until the child is living in the community following discharge from a facility. Home tutoring is then provided for a couple of hours per day until a plan can be worked out by the school. This is completely inconsistent with the appropriate clinical model of smooth transitions. While interventions such as the RTF Transition Coordinator system can successfully create residential treatment facilities ability to support this transition, it would be more likely to succeed if community services and relationships could be established prior to the child's physical move.

In sum, representatives of providers expressed a wish for well-paid staff that remains with the agency. In addition, providers desired more resources to fully fund service models, less regulation, and more autonomy from both state and county oversight. Representatives of providers also express interest in improved collaborations among child serving agencies to reduce redundancies and reduce negative outcomes for chil-

dren and youth generated by the lack of collaboration between child serving agencies.

CURRENT TENSIONS IN THE SYSTEM OF CARE IN NEW YORK: FOCUS GROUP FINDINGS

Through review of the principles established above and experiences with the service system in New York we have identified a set of existing tensions. The following is a discussion of these tensions. Innovative strategies to manage these tensions will be necessary in order for the children's public mental health system in New York to continue to evolve.

County Control and Clinician Autonomy

The SPOA demonstrates some of these tensions. A central component to the SPOA model is granting a locally designated entity the authority to oversee the assignment of seriously emotionally disturbed children into several programs including supportive case management, intensive case management programs, home and community-based services waiver programs, and family-based treatment. Once a SPOA is created, however, it would be a natural process for it to assume greater involvement in managing access to a range of other services. In some counties SPOA are fully integrated in county-wide decision processes.

In order to effectively implement SPOA, the SPOA will likely need to exert a greater level of control over decision-making at the individual child and family level. While in most, if not all, of the SPOA designs, clinicians serve critical roles in the process, this may present some tensions for other clinicians who are serving children and families that become involved with the SPOA process. Individual service providers are sometimes required by profes-

sional standards and, in some cases, by law, to make service delivery decisions regarding children and families. It is possible for multiple clinicians involved with the same family to find themselves at odds with decision priorities as a result of the different professional ethics, governance directives and their perceptions of family needs.

System management, as practiced by managed behavioral healthcare firms, provides excellent examples of the potential problems with this approach. The industry is replete with stories of service denial based on little or no consideration of the needs of the service recipient. If decision-making is not accomplished in a fashion that is clinically sophisticated or if the decision-makers do not have the information they need to fully understand the needs of the children and families under consideration, then poor decision-making is likely to occur. Even when good decision making is used, if the decision-making process is not inclusive and the criteria for decisions are not well communicated, then perceptions of poor decisionmaking can be developed.

The advantage of county control is that centralized authorities, such as SPOAs, can manage limited resources over the population of eligible individuals in need. Individual clinicians operate without resource constraints in situations of third party payment. Historically, this has created the potential for conflicts of interest among providers.

System Management and Service Provision

Some counties are already major providers of mental health services to resident children and families. If the design of the SPOA overlaps with the service delivery components that are owned and operated by the county, then the SPOA's assertion of authority over

access to high-end programs may create conflicts of interest between the county's service delivery and system management responsibilities. Responsibility for both system management and selective service provision by a single entity may not be compatible with optimal quality of care. Alternatively, integration of system management with service delivery might offer opportunities for a high level of accountability and/or increased efficiencies and conveniences.

There are a variety of examples of how this potential conflict of interest might manifest. A county SPOA might favor access to highend programs for children within their service system who present management problems over children involved with non-county programs. This preference of the SPOA to choose SPOA operated services could reduce family services choice. In this scenario, the SPOA becomes a management tool for the county service delivery system rather than a tool for all the residents of the county.

Local autonomy and centralized consistency

One of the tensions of local control is that comparability and consistency become secondary considerations. The great advantage of local control is that opportunities exist for creativity to identify and meet local needs with approaches that are consistent with local wishes and sensibilities. However, the resultant local variations across counties pose challenges to regional providers. This is a potentially serious problem for providers who serve children across a number of different counties. If each of these counties creates entirely different policies and operating procedures for their SPOAs, the multi-county, regional providers must manage their services across this potentially confusing landscape.

Additionally, county governments or their designees (SPOA) are primarily concerned with the service delivery system and responsiveness to the residents of their own county. There is an inherent limitation built into a system that allows each individual county to dictate the service delivery system according to its residents' needs when the service delivery system must operate on a regional basis and meet the needs of other counties' residents as well. Without a centralized check and balance system, the inconsistencies between services available to residents of different counties become a huge

Full array of services and low volume of service recipients

New York State has an extensive diversity on many dimensions across its counties. Some counties are enormous in population but relatively small in geography. Some are geographically large but sparsely populated. A principle of a system of care is to have services available for those children and families in need. Realizing such a structure across diverse situations is a challenge, particularly in counties with smaller populations. In New York City, the challenge is a problem of magnitude. The counties in NYC are so large and diverse that a 'single' point of anything runs the risk of becoming a bottle neck that limits access rather than rationalizes services.

A service array model for a system of care is very different from a program model. In a program model, the intention is to have available slots in each program. System management involves matching children's needs to available program slots at both program entry and exit so that the system is managed efficiently. Priorities should be to get children into programs in a timely fashion, and then to transition them to different programs or out of the system once their needs have been

addressed.

In a service array model, services are individual commodities to be used based on the individual needs of the child and family. There is no concept of 'slots' in a service array model. The volume of services needed is simply the number of children and families who have been identified as having the relevant and requisite needs. This flexibility is consistent with the CASSP principles but it makes the business operations of service delivery exceptionally complex. This is less of a problem in areas where providers can expect high volumes so variability in specific volume has less impact on the functioning of the service. For low volume services or in areas where demand for services is intermittent, this may be an impossible challenge to overcome. Only natural supports have this level of flexibility; contract service providers cannot.

Prevention and eligibility for services

While everyone agrees that preventing a child from developing a serious emotional or behavioral disorder is an important priority, there are a number of tensions in the existing system that work against this objective. One of the major complications is that eligibility for services, particularly the more expensive services, must be based on the level of need.

The argument for service eligibility goes something like this: Without gate-keeping access to services based on levels of needs, children in greatest need might not get services while those with lower needs who may be easier to serve do receive services. Thus establishing eligibility for services based on the level of need is a critical component of a well-managed system of care.

The counterpoint to this argument is that when a child must have a specific level of need to become eligible for services, then they may be denied services until they develop that level of need. This is entirely counterproductive from a prevention perspective, as it may fail to prevent and in fact may encourage the exacerbation of problems while lower intensity services are being provided.

Quality of care and cost efficiency

There is currently no evidence that providing more money for services necessarily increases the quality of those services. However, quality can be limited by the absence of services, or by reimbursement rates that are so low that no service providers can be found. Operating in an environment of limited resources, there is always a tension between doing the best possible job and doing that job within the confines of available resources. Higher quality is sometimes associated with higher costs. As such, high quality services can be expensive. Simultaneously optimizing quality and efficiency is a significant challenge, particularly as we enter a period where available resources may shrink.

In public mental health, most systems respond to this challenge by fixing the price and then trying to increase the quality of care. While this is the simplest strategy in a limited resource environment, it has some important implications. For example, when cost and quality are not allowed to vary, one is unable to estimate the relationship between these two constructs. It is then impossible to determine what the upper limit of quality will be for a specific cost, or how easily quality might be improved by additional investments. When the cost/reimbursement is determined in the absence of information about quality (or expected outcomes), it is impossible to know what the constraints on quality (or outcome) will be.

Perhaps an example from outside the behavioral health field will be illustrative to this complex issue. The price of automobiles is widely variable across the spectrum of available cars. One can purchase a new car for a little as \$10,000 or as much as \$300,000. There are clear quality differences in the automobiles across this range of prices. However, one also can identify real values in which a relatively high quality car can be purchased at a lower price than numerous cars of lower quality. If a regulatory agency were to fix the price of all cars, the variability of quality would likely decline but some variability would still exist. However, in all likelihood, no knowledge of the possible upper range of quality would be available.

Flexible Funding and Traditional Clinical Services

Increasingly, system of care interventions have provided families with financial resources that can be used to address very unique needs. This flexible funding operates outside of the usual reimbursement for services and can be used to pay for anything from eye glasses, to cabinet locks, to music lessons. Such flexibility challenges traditional service delivery in a number of ways. First, concerns can develop regarding the appropriate use of flexible dollars. Second, because agencies are not used to spending money in this fashion, the bureaucracy of the agencies can experience difficulties. Third, clinicians are not used to thinking about how to best use flexible funds and families may be uninformed about the availability and possible applications of these funds.

Use of non-professionals and clinical specialization.

The use of individuals without specialty mental health training within the system of care is both an important innovation of the

past decade and a significant challenge as we evolve a larger knowledge base on effective practices for specific circumstances. The goal of the wraparound process philosophy has been to develop natural supports that will be there when services are no long provided. Therefore, involving neighbors and extended family members in initial service delivery can be a positive factor in long term success with a particular child. In addition, nonprofessionals can be less stigmatizing and more approachable to children and families. They are certainly less expen-

The problems associated with the use of nonprofessionals include concerns about skills, ethics, and safety. Children with complicated needs sometimes need the assistance of skilled individuals who have been trained in specific techniques. Evidence-based practice approaches often require specialized training for effective implementation. Training can serve as a screening process; people with insufficient ethics or interpersonal problems often fail to complete training. The lower the training 'bar', the greater the potential that individuals become involved who might not be able to consistently understand and act with the best interests of the child and family in mind.

Focus Group Addendum Summary

It is clear that the perspectives of state government, county government, families, youth, and providers challenge us to design and deliver a children's mental health system that meets their varied, but critical, requirements. It is also clear that this variety of perspectives creates tensions in the system that must be creatively managed as we move to the creation of a system of care for children's mental health.

Appendix II

OMH PCS, 1999/2001

0-18 SERVICES RANKED BY NUMBER AND PERCENT

	1999	Number	Percent
1.)	Outpatient Clinic	22,262	71.9
2.)	Day Treatment	2,594	8.4
3.)	ICM	1,577	5.0
4.)	Gen. Hospital Psy Unit	560	1.8
5.)	Inpatient Psy Unit	560	1.8
6.)	Cert. Men. Ill Hospital	559	1.8
7.)	RTF	463	1.5
8.)	FBT	248	<1.0
9.)	Waiver	142	<1.0
10.)	CR	135	<1.0
11.)	School Based	132	<1.0
12.)	Respite	77	<1.0
13.)	SCM	61	<1.0

	2001	Number	Percent
1.)	Outpatient Clinic	21,180	68.1
2.)	Day Treatment	2,785	9.0
3.)	ICM	1,598	5.1
4.)	Gen. Hospital Psy Unit	597	1.9
5.)	Cert. Men. Ill Hospital	568	1.8
6.)	Inpatient Psy Unit	542	1.7
7.)	RTF	486	1.6
8.)	Waiver	421	1.3
9.)	School Based	345	1.1
10.)	FBT	246	<1.0
11.)	SCM	227	<1.0
12.)	Respite	153	<1.0
13.)	CR	133	<1.0

RS:lw 7/22/03

OMH PCS, 1999/2001

DIFFERENCES IN NUMBER AND PERCENTAGES OF CHILD CLIENTS PER AGGREGATED CATEGORIES OF SERVICE FROM 1999 to 2001

	Number of Clients, 0-18		Percent of All 0-18 Clients		0-18 Clients, Percent of All Clients*	
	1999	2001	1999	2001	1999	2001
Emergency ¹	850	1,027	2.7%	3.3%	11.2%	12.9%
Inpatient ²	2,027	2,162	6.5%	7.0%	14.6%	15.8%
Outpatient ³	25,023	24,076	80.8%	77.5%	21.7%	21.4%
MH Residential ⁴	565	662	1.8%	2.1%	2.9%	2.9%
Community Support 5	3,919	5,019	12.6%	16.1%	11.5%	13.4%

^{* 24.7%} of NYS population is 0-18, per U.S. Census.

Observations from the OMHPCS 1999/2001

- OMH offers about 75 discrete services; 50 of these serve 5 or more children.
- \bullet The total number of under- 18s served increased by 90 (<1%) from 1999 to 2000, but the number of all clients served went down by 596 (-3.6%)
- Using MHPAC and SED statistics, a total of 787,446 children may need MH service. In November 2001, 31,507 kids were actually being served.
- Children are 24.7% of the child population in NYS. In 2001 they comprised 18.8% of all MH recipients during the census week. This is up .2% from 1999.

¹ 11 services, 10 serving 0-18

² 4 services, all serving 0-18

³ 6 services, 5 serving 0-18

⁴ 18 services, 9 serving 5 or more 018 clients

⁵ 36 services, 22 serving 5 or more 0-18 clients