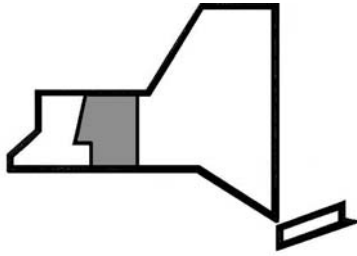


**MONROE COUNTY
CHILDREN'S SYSTEM OF CARE
TASK FORCE**

Finger Lakes Health Systems Agency
December 2004

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Rochester, NY**

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December 2004

On behalf of the Finger Lakes Health Systems Agency, we are submitting the Monroe County Children's System of Care Task Force Report. The report represents the work of a Task Force that was appointed to assess the service delivery systems in place to support emotionally disturbed children and their families, identify barriers to accessing needed services and supports and recommend approaches for responding to these barriers through design of a new system of care for Monroe County. The work of the Task Force was based upon the key principles of:

- **Active involvement of families and the larger community**
- **Recognition of the strengths of youth, families and communities**
- **True collaboration among multiple child-serving systems and constituencies**
- **Cultural competence.**

Based upon a series of Task Force meetings that engaged key individuals in professional and leadership positions from various community constituencies, this report is seen as an initial step that the Monroe County Office of Mental Health will be using to re-design the way in which children with emotional disturbances and their families access and receive necessary services and supports in the community through the development of a system of care. We trust that it will be of value as a planning tool.

Sincerely,

Bonnie DeVinney

Roger Gardner

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MONROE COUNTY CHILDREN'S SYSTEM OF CARE TASK FORCE

EXECUTIVE SUMMARY

The Children's System of Care Task Force convened by the Finger Lakes Health Systems Agency (FLHSA), in conjunction with the Monroe County Office of Mental Health (MCOMH) and Coordinated Care Services, Inc. (CCSI), was charged with:

...assessing the service delivery systems in place to support emotionally disturbed children and their families, identifying barriers to accessing needed services and supports and recommending approaches for responding to these barriers through design of a new system of care for Monroe County.

The work of the Task Force is based upon the key principles of:

- Active involvement of families and the larger community*
- Recognition of the strengths of youth, families and communities*
- True collaboration among multiple child-serving systems and constituencies*
- Cultural competence.*

The Task Force met from March 2004 through September 2004, with its work culminating in the issuance of this Report. This Task Force is one of the initial steps in a local planning process being conducted by the Monroe County Office of Mental Health to redesign the way in which children with emotional disturbances and their families access and receive necessary services and supports in the community through the development of a system of care.

The Task Force used the definition of a system of care as defined by the Child and Adolescent Service System Program (CASSP) and adopted by the federal system of care movement. A system of care is defined as

A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.

The system of care should be:

- ***child centered and family focused***, with the needs of the child and family dictating the types and mix of services provided.
- ***community based***, with the locus of services as well as the management and decision-making responsibilities resting at the community level.
- ***culturally competent***, with agencies, programs and services that are responsive to the cultural, racial and ethnic differences of the populations served.

These values are further articulated in CASSP's Guiding Principles:

- *Children with emotional disturbances should have access to a comprehensive array of services that address their physical, emotional, social and educational needs.*
- *Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.*
- *Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.*
- *The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.*
- *Children with emotional disturbances should receive services that are integrated with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.*
- *Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner, and that they can move through the system of services in accordance with their changing needs.*

- *Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.*
- *Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.*
- *The rights of children with emotional disturbances should be protected and effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.*
- *Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.¹*

In terms of services to children who are emotionally disturbed and their families, the Task Force recognized that there are significant strengths in Monroe County: there is a wealth of high quality services available to children and their families, and there is a long history of organizations and families working together to address issues. Nevertheless, in its deliberations which were based upon member perceptions, the Task Force yielded a number of key findings with regard to barriers/issues in the current children's service delivery systems. The Task Force also identified strategies to address these barriers. It should also be pointed out that although this report discusses barriers/issues to care and proposes strategies, there are limitations. These include:

- The report is not data-driven: it is based upon perceptions of Task Force members.
- Participation was uneven: not all Task Force members were present at every meeting and therefore, the tone/content of the meetings was colored by the composition of those present. The report attempts to present themes—barriers/issues and strategies—that were frequently discussed over the course of the meetings. If an issue was brought up for the first time during the Task Force's review of the report, it was not included.

¹ From Stroul, B., & Friedman, R. (1986) *A system of care for children and youth with severe emotional disturbances*. (rev. ed., p. 17), Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

- Group process evolves and is living: perceptions changed during the course of the meetings.

The key issues and barriers in the current system identified by the Task Force are as follows:

- **System Issues:** *There is no consistent vision and driving philosophy for the current systems that serve children, resulting in barriers and difficulties that prevent the needs of children and their families being fully addressed. This is especially true for children whose needs cross multiple systems.*
- **Prevention/Early Identification/Early Intervention:** *The child-serving systems are focused on providing treatment rather than prevention/early identification/early intervention. Prevention/early identification/early intervention services related to mental illness among younger children are not routinely incorporated into the systems serving this population. (E.g., primary health, early intervention, preschool and elementary education.)*
- **Accessing Services:** *Currently, the child-serving systems are complex with multiple points of entry which often require restrictive entry criteria. Barriers related to availability also impede access.*
- **Family Engagement/Involvement:** *The current systems do not adequately empower families or engage them meaningfully in dialogue about their own needs, the needs of their family members, and the larger systems' needs.*
- **Service Array for Families:** *The current systems do not offer families an appropriate array of services and supports to meet their multiple needs.*
- **Service Options and Flexibility:** *The services that are offered do not cover the broad spectrum of needs and are not matched to the populations they are intended to serve.*
- **Navigating Services/Continuity of Care:** *Continuity of care is lacking; the systems are complicated and difficult to navigate. This is particularly true for those whose needs cross systems and/or are transitioning between systems.*
- **Data Needs/Evaluation:** *There is a lack of comprehensive information regarding how multiple systems work and how effective they are in addressing the emotional and social well-being of the children.*
- **Training:** *Training of personnel from all child-serving systems lacks a comprehensive*

focus as each system trains according to its own needs and requirements. Families, youth, and the broader community are not consistently offered training opportunities which are coordinated and, thus, would maximize effectiveness.

The Task Force developed a series of strategies to address these barriers, as follows:

- **System Issues:** *A consistent vision and philosophy, for a system of care that includes all those who work with children and families, should be developed*
- **Prevention/Early Identification/Early Intervention:** *The system of care should incorporate prevention, routine screening for early identification of mental illness and access to early intervention services for children of all ages and their families. Education and awareness are seen as vehicles that will assist in reducing stigma.*
- **Accessing Services:** *Access to the system of care should be through a user-friendly mechanism that offers families timely entry into appropriate services that meet their needs.*
- **Family Engagement/Involvement:** *The system of care must view families as partners and offer them a greater level of respect and choices. The term “family” should be uniquely defined by each participant in the system of care.*
- **Service Array for Families:** *The system of care should offer families an array of flexible traditional and non-traditional services and supports to meet their needs.*
- **Service Options and Flexibility:** *The system of care should consist of a full range of traditional and non-traditional service and support options to meet family needs. Such services and supports should be flexible, culturally competent, and offered by a variety of organizations in a variety of settings.*
- **Navigating Services/Continuity of Care:** *Each family in the system of care should have access to a primary case manager/care coordinator who has the responsibility of assisting the family with its needs and who remains with the family through transitions.*
- **Data Needs/Evaluation:** *The system of care should be data-driven, with evaluation and continuous quality improvement processes that meaningfully involve staff, families and clients.*
- **Training:** *A coordinated and comprehensive training approach should be developed that offers education/training regarding system of care values, principles and practices to family*

members, youth and the community, as well as to staff at all levels within organizations. Targeted training in specific areas should also be offered.

Next Steps

This process of identifying issues and barriers and proposing strategies is one component in the needs assessment and planning phase necessary to design a system of care for children and their families. The information in this report will become the basis for continued planning, and will be used as a foundation for further dialogue with additional community constituencies. It is expected that this report and the information gathered through additional dialogue and analyses will be combined with current and relevant data to present a full picture of services, gaps and barriers to care for children with emotional disturbances and their families in Monroe County. From this base, strategies for redesign of the way children with emotional disturbances and their families access and receive services and supports will be further developed, resulting in the design of a system of care for Monroe County. The Monroe County Office of Mental Health, together with Coordinated Care Services, Inc., will take the lead in bringing the community together to plan, design and implement such a system of care.

MONROE COUNTY CHILDREN'S SYSTEM OF CARE TASK FORCE

INTRODUCTION/BACKGROUND

In March 2004, the Children's System of Care Task Force was convened by the Finger Lakes Health Systems Agency (FLHSA), in conjunction with the Monroe County Office of Mental Health (MCOMH) and Coordinated Care Services, Inc. (CCSI) and was charged with:

...assessing the service delivery systems in place to support emotionally disturbed children and their families, identifying barriers to accessing needed services and supports, and recommending approaches for responding to these barriers through design of a new system of care for Monroe County.

The work of the Task Force is based upon the key principles of:

- *Active involvement of families and the larger community*
- *Recognition of the strengths of youth, families and communities*
- *True collaboration among multiple child-serving systems and constituencies*
- *Cultural competence.*

In terms of services to children who are emotionally disturbed and their families, the Task Force recognized that there are significant strengths in Monroe County: there is a wealth of high quality services available to children and their families, and there is a long history of organizations and families working together to address issues. Nevertheless, in its deliberations, which were based upon member perceptions, the Task Force yielded a number of key findings with regard to barriers/issues in the current children's service delivery systems. The Task Force also identified strategies to address these barriers. It should also be pointed out that although this report discusses barriers/issues to care and proposes strategies, there are limitations. These include:

- The report is not data-driven: it is based upon perceptions of Task Force members.
- Participation was uneven: not all Task Force members were present at every meeting and

therefore, the tone/content of the meetings was colored by the composition of those present. The report attempts to present themes—barriers/issues and strategies—that were frequently discussed over the course of the meetings. If an issue was brought up for the first time during the Task Force’s review of the report, it was not included.

- Group process evolves and is living: perceptions changed during the course of the meetings.

The convening of this Task Force is one of the initial steps in a local planning process being conducted by the Monroe County Office of Mental Health to redesign the way in which children with emotional disturbances and their families access and receive necessary services and supports in the community. It is anticipated that the outcome of this larger planning process will be the design of a system of care for children and their families, based upon community consensus that embraces the core values and principles that are inherent in the federal system of care movement.

At the federal level, (a project of) the Child and Adolescent Service System Program (CASSP) has defined the system of care concept and philosophy, providing a conceptual framework for system of care development in communities. The CASSP core values and guiding principles have been embraced nationally. CASSP has defined a system of care as:

A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.

Central to the system of care are three core values. The system of care should be:

- ***child centered and family focused***, with the needs of the child and family dictating the types and mix of services provided.
- ***community based***, with the locus of services as well as the management and decision-making responsibilities resting at the community level.
- ***culturally competent***, with agencies, programs and services that are responsive to the cultural, racial and ethnic differences of the populations served.

These values are further articulated in CASSP's Guiding Principles:

- *Children with emotional disturbances should have access to a comprehensive array of services that address their physical, emotional, social and educational needs.*
- *Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.*
- *Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.*
- *The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.*
- *Children with emotional disturbances should receive services that are integrated with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.*
- *Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.*
- *Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.*
- *Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.*
- *The rights of children with emotional disturbances should be protected and effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.*
- *Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.²*

² From Stroul, B., & Friedman, R. (1986) *A system of care for children and youth with severe emotional disturbances*. (rev. ed., p. 17), Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

TASK FORCE PROCESS/METHODOLOGY

In order to effectively carry out their charge, it was necessary for Task Force membership to be representative of the various systems that work with children and families in Monroe County, as well as of the community at-large. Staff from the Monroe County Office of Mental Health (MCOMH), Coordinated Care Services Inc. (CCSI) and the Finger Lakes Health Systems Agency (FLHSA) identified key individuals in professional/leadership positions from various community constituencies to join the Task Force, which was chaired by the director of a local charitable foundation. The membership included family members, representatives from mental health service providers, schools, early intervention programs, youth-serving and other community organizations, the medical community, nursing schools, health insurers, Monroe County Human and Health Services Department divisions (Children and Family, Youth Bureau, Mental Health), Monroe County Probation, Monroe County Public Health Department, and regional representatives of the New York State Offices of Alcoholism and Substance Abuse Services (OASAS) and Mental Retardation and Developmental Disabilities (MR/DD). (Appendix A: Task Force Roster.)

Efforts were made to identify representatives from other key constituencies, including the faith community, higher education, additional family members, and youth. Although these efforts were not successful in identifying Task Force participants, strategies to effectively involve them in the process in the future are being explored and developed.

In addition to the Task Force itself, three workgroups were formed to address specific key areas, with the work of these groups being incorporated into the Task Force's activities and this report. The groups and their purposes are as follows:

1. Youth Work Group – Created to gain youth perspectives on services, gaps, needs and most effective approaches to engage young people.
2. Family Advisory Group – In addition to family representatives on the Task Force, this group was formed to gain broader family perspectives. This group will be on-going and evolve into a Family Advisory Group, with family members from this group being involved in all aspects

of the system of care. The Family Advisory Group reviewed all of the system issues that were identified by the Task Force and commented on them as well as on the preliminary strategies that were proposed. The full text of their comments is included as Appendix C.

3. Older Adolescents in the System of Care Work Group - This group was created in response to the unique challenges faced by youth transitioning between the child and adult systems and was asked to support a process of identifying barriers and potential strategies for transition to the adult system and/or independent living.

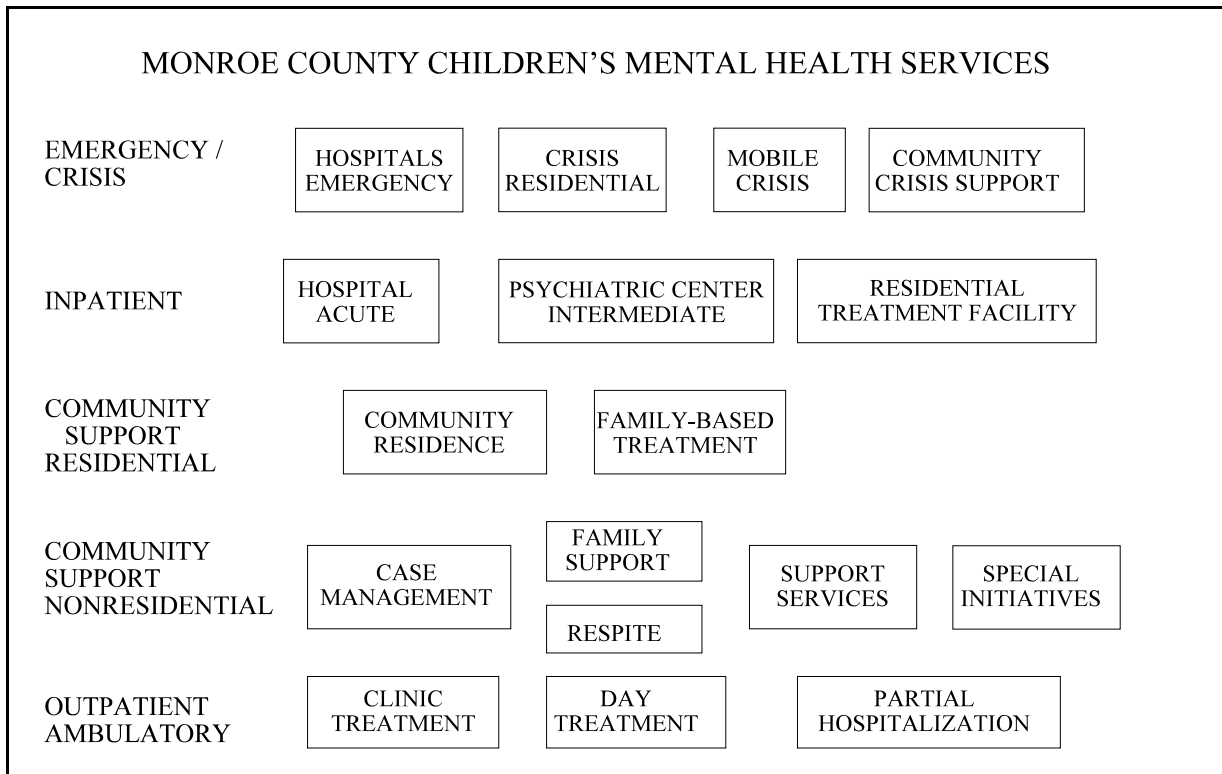
The barriers/issues that the Task Force identified were categorized into the following major themes:

- System Issues
- Prevention/Early Identification/Early Intervention
- Accessing Services
- Family Involvement/Engagement
- Service Array for Families
- Service Options and Flexibility
- Navigating Services/Continuity of Care
- Data Needs/Evaluation
- Training

The Task Force then identified potential strategies to address the barriers. Strategies suggested addressed the major themes; there was no attempt to suggest a strategy for each barrier identified. The full list of barriers and strategies identified as a result of this process is attached as Appendix B.

CURRENT MENTAL HEALTH SYSTEM

The current mental health service system for children in Monroe County is organized along a continuum, with multiple providers (including hospital systems, community-based agencies, and state psychiatric center) and multiple entry points. It is funded through state, federal and local government support, third party reimbursement, grants and other funds. A diagram of the current mental health services in Monroe County is presented below. It reflects the available service options—not the relationships between and among them.



In addition to the mental health service system, other systems affect children with emotional disturbances and their families. These systems include child welfare, public health, education, juvenile justice, developmental disabilities and chemical dependency. Each of these systems, too, have multiple programs, entry points, and funding streams. A graphic description of the complete “system” that incorporates all of the services, their interrelationships, and their interrelationships does not exist.

A challenge faced by this Task Force has been to try to understand the many issues faced by children with emotional disturbances and their families in obtaining optimal care in the face of such complexity.

KEY FINDINGS: BARRIERS AND PROPOSED STRATEGIES

System Issues

BARRIERS

There is no consistent vision and driving philosophy for the current systems that serve children, resulting in barriers and difficulties that prevent the needs of children and their families from being fully addressed. This is especially true for children whose needs cross multiple systems.

Often, children with emotional disturbances and their families are involved in more than one system, each with its own purpose, goals, requirements, and funding streams. Thorough communication between the systems and with the children and family members receiving services, does not consistently occur and can be challenging for many reasons. The Task Force stressed the lack of consistent collaboration among systems involved in providing services for cross-systems children.

There are different roles governing how each system works. Some service systems cannot refuse to provide care for children and their families. This is the case, for example, in child protective situations or in Juvenile Justice (PINS), which are mandated services. In mental health, there are no mandated services. At times, families may seek services from those (non-mental health) systems mandated to serve the child when they are unable to obtain the service from the mental health system due to such factors as long waiting lists and/or inability to pay high co-pays for the service. This may involve surrendering a child to foster care or filing a PINS petition.

STRATEGY

A consistent vision and philosophy for a system of care that includes all those who work with children and families should be developed by all agencies and institutions serving children who are mentally ill and their families.

A key strategy for consideration is the development of a consistent vision and philosophy for a system of care that includes all those who work with children and families. This vision and philosophy should incorporate the core values and principles of the federal system of care movement. The system should be data-driven, and utilize best practices and evidence-based practices. In addition, a common language should be developed to facilitate improved communication between families, agencies and programs. While recognizing that local services may not be able to change the rules and processes of the various systems, a coordinating mechanism should be developed to facilitate the delivery of services for all children, regardless of where they enter, or receive services.

The Task Force identified the need to address strategies regarding the lack of parity for mental health services, requirements for obtaining services, reimbursement limitations and shortages of services as significant barriers.

For cross-system children and their families, it is imperative that all of the systems involved work together collaboratively, and that the provision of services becomes seamless. Individualized care planning with the child and family, including all systems that are involved, is a potential strategy to address issues on the individual participant level. In addition, mechanisms for effective communication, collaboration and coordination among the systems must be built into the system of care infrastructure to ensure that such individualized care planning occurs, and that barriers are identified, addressed and resolved.

Prevention/Early Identification/Early Intervention

BARRIERS

The child serving systems are focused on providing treatment rather than prevention/early identification/early intervention. Prevention/early identification/early intervention services related to mental illness among younger children are not routinely incorporated into the systems serving this population (e.g., primary health, early intervention, preschool and elementary education).

The Task Force recognized that there is a lack of sufficient funding for prevention/early identification/early intervention services in most child-serving systems, which may lead to costly treatment options. Often, entry to services is based upon specific eligibility criteria, such as a diagnosis (or “label”) having been made. Due to a system’s mandate to serve children meeting the eligibility criteria, it may not view prevention/early intervention services as within its purview for development and/or funding.

Early identification strategies, such as screening for mental illness, are not routinely incorporated into primary care or other early childhood settings. It was noted that the lack of time, reimbursement and expertise, impact the ability of primary care practitioners to routinely screen for mental illness. Similar barriers exist for early intervention and preschool providers, with such providers noting difficulties in maintaining children with behavioral problems within mainstream services.

STRATEGY

The system of care should incorporate prevention, routine screening for early identification of mental illness and access to early intervention services for children of all ages and their families, as well as education and awareness to reduce stigma.

The Task Force recommended that mental health screening and education become routine and integrated into normalized settings for all children in Monroe County. The introduction of assessment tools to support this process should be encouraged. The use of tools which have already been proven successful, reliable and valid should be supported. In addition, the focus should be on encouraging the development and use of tools that have been normed on multi-cultural populations.

Preventive outreach and primary prevention, which also raise public awareness and decrease stigma associated with mental health problems, should be expanded, with programs offered throughout the community in a variety of settings. Schools, early childhood community programs, community based organizations and the faith-based community may also provide a useful arena to reach the broader community for screening and early intervention. These options should also be integrated into the system of care.

Pediatric health care professionals--physicians and nurses--and early education and care professionals have a critical role to play in the early detection of potential mental illness, and the Task Force recommended that their knowledge and skills be enhanced to enable them to serve as possible resources to conduct screening as well as early interventions and referrals for mental health issues. Issues related to reimbursement for the time spent in conducting mental health screenings in primary health care and other sites is an area that would need to be addressed. The University of Rochester's "Pediatric Links to the Community" should be approached as a potential source of providers to pilot and test screening approaches.

Effectively meeting the needs of younger children, in particular those aged birth to five, requires that coordination and collaboration occur with systems that historically have not related to the mental health system. The Task Force recommended that linkages be made with the Early Childhood Direction Center and the Task Force on Behavioral Supports to build upon the work already begun in the community related to the mental health needs of this young population and their families.

Accessing Services

BARRIERS

Currently, the child-serving systems are complex with multiple points of entry, which often require restrictive entry criteria. Barriers related to availability of services also impede access.

Few individuals—families or professionals—have an understanding of all the child-serving systems, the options available, how to move across systems, and their requirements. Additional access barriers include the limited number of providers who specialize in care for children (particularly the lack of child psychiatrists), waiting lists for services, lack of transportation, limited sites for services, inconvenient/limited hours of operation, and the lack of culturally competent and bilingual providers who are representative of minority communities and reflect the values of those communities.

In some instances, when access is delayed, or generally unobtainable, families face the dilemma of surrendering their child to foster care in order to obtain the services they need

Additionally, the Task Force echoed statewide and national discussions about the lack of adequate insurance coverage, high co-payments for mental health services and lack of parity with physical health coverage, as access barriers.

STRATEGY

Access to the system of care should be through a user-friendly mechanism that offers families timely entry into appropriate services that meet their needs.

A user-friendly, culturally competent, central entry system with 24-hour response capability should be developed. This may include a toll-free telephone number and/or walk-in sites to respond to mental health issues identified by children and/or their families. At an entry point, the

child/family should be able to obtain an assessment of needs and secure a referral or linkage to support services that could meet those needs. Linkage with family advocates would be built into the entry process at the earliest possible point. Persons staffing these entry points would be knowledgeable about program options and availability across systems including eligibility criteria, payment requirements, and waiting lists. This central entry system would also incorporate mechanisms to respond to crisis situations.

Recognizing the system is complex, the Task Force noted that the creation of a system of care and a central point of entry mechanism will not completely eradicate the complexity; nevertheless, it was agreed that entry should be made as simple as possible for the system's users, i.e., children and their families. Necessary services and supports should be easily accessible and transitions (both within the system and between systems) should be smooth and efficient. It is the various systems' responsibility to ensure that the complexity is minimized for the consumers.

Family Engagement/Involvement

BARRIERS

The current systems do not adequately empower families or engage them meaningfully in dialogue about their own needs, the needs of their family members, and the larger systems' needs.

Although family members have a great deal of knowledge and understanding about their child(ren) and their needs, many families and providers agree that this knowledge and understanding is not consistently taken into consideration when the systems are planning for mental health care at both an individual and system-wide level. In addition, the active participation of family members and children is not always sought in the development of treatment/care plans, in program planning/development, and in evaluation.

Communication delays and gaps between families and providers are common, which may further impede family involvement in developing care plans.

Confidentiality may also be an issue: many family members have expressed the desire to know the details pertaining to their child's care and treatment, while some providers have expressed a firm commitment to the rights of privacy for the child, therefore choosing to disclose little or nothing at all to parents.

STRATEGY

The system of care must view families as partners and offer them a greater level of respect and choices. The term "family" should be uniquely defined by each participant in the system of care.

The system of care must view families as partners and give them a greater level of respect and increased choice. Families should be involved in all aspects of the system of care – planning, development, implementation, operation, and evaluation. Families should also have a broader

array of options for services, and should have more control over which options they choose to exercise. The system must promote greater collaboration among child-serving agencies to reduce redundancies in assessment and service delivery, thereby reducing the stress placed on families.

The Task Force believes that within the system of care, each child has the right to an attachment to a caring adult and/or family. The term “family” should be uniquely defined by each participant in the system of care and should not represent one way of thinking about the concept of family. Whenever possible, a child’s family should incorporate those persons that the child identifies. Where family relationships do not exist, the system of care should strive to support and facilitate the development and maintenance of secure attachments for the child.

Service Array for Families

BARRIERS

The current systems do not offer families an appropriate array of services and supports to meet their multiple needs.

The Task Force acknowledged the need to expand the availability of current services that were effective; however, they also identified numerous service gaps including programs that effect smooth transition from inpatient to the community to more residential levels of care, to lack of after school and vacation programs.

The Task Force identified the need for service flexibility and a family-centered approach in all systems that provide services to children. Family members, both parents and siblings, who may often be in need of services themselves, cannot access assistance through the same mechanisms as their “identified” child because they are not the “designated patient/client”. Often, families must begin a separate process to obtain services for other family members.

STRATEGY

The system of care should offer families an array of flexible, traditional, and non-traditional services and supports to meet their needs.

The need to develop and fund alternatives to traditional services was repeatedly emphasized throughout the process. The Task Force recommended supporting families in developing their own informal, neighborhood-based support networks which promote normalization and independence from the various services and systems as appropriate.

The Task Force and Work Groups identified the need to develop new services, alternatives to traditional approaches, and/or expand current service offerings, such as dual diagnosis services,

respite, mobile crisis, skill builders, supervised programs before/after school and during school vacations for children with behavioral problems, recreation activities, and support groups. It was also stressed that services should be culturally competent and responsive to the participants' needs.

Increased service flexibility and a more family-driven approach were suggested as strategies, with the Task Force identifying examples such as providing additional evening and weekend hours, or service delivery at multiple locations (including the home). The Task Force also stressed that those children with emotional disturbances should be more integrated into existing opportunities in the community. It was suggested that mainstream services for both be enhanced to accommodate youth with emotional disturbances.

Service Options and Flexibility

BARRIERS

The services that are offered do not cover the broad spectrum of needs and are not matched to the populations they are intended to serve.

The Task Force noted that although mental illness can be a long-term issue, there are few, if any, long-term supports available for the child and family. Mental health needs are treated with short-term, system-oriented services which are not comprehensive and do not focus on recovery. Additionally, the Task Force noted that among the gaps in current services are respite, skill building, varied levels of residential options, and recreation.

It was the perception of the Task Force that services are designed to meet the convenience of providers, agencies, and systems (in terms of available hours and locations), rather than the needs of children and their families. There are also waiting lists for many needed programs.

The Task Force recognized that culture affects the manner in which families seek and respond to services, yet services have not been customized for particular cultural groups. Further, the lack of cultural competence within the systems and among providers likely impacts the diagnosis/label that minority children receive.

The community is very service driven, and at times fails to identify the underlying needs of children and families and respond to them in creative and flexible ways. Currently, existing models do not adequately make use of, or capitalize on, non-traditional methods or informal support responses. Funding also shapes how services are delivered. Currently, most insurers, including Medicaid, do not routinely reimburse for alternative services, with reimbursement tied to a medical model of service delivery.

STRATEGY

The system of care should consist of a full range of traditional and non-traditional service and support options to meet family needs. Such services and supports should be flexible, culturally competent, and offered by a variety of organizations in a variety of settings.

Services should be provided in a variety of settings and in collaboration with a variety of active partners within the community that may include schools, health centers, community-based organizations, faith-based organizations, neighborhood centers, etc. Once the child/family has entered the system of care, a variety of services and supports should be made available that meet the needs of the child/family and are provided at their convenience (e.g., evenings, weekends, neighborhood-based).

The Student-Family Support Centers in schools should be multi-service centers, developing more effective ways of connecting children attending these center programs to mental health services, other systems that may need to become involved, and community organizations. A goal of all Student-Family Support Centers should be reduction of the amount of time that the child spends out of the classroom.

Crisis intervention services that are immediately available, regardless of whether a mental health diagnosis has already been made, were also suggested by the Task Force. Communication should occur with the family as soon as possible, once it has been determined that a crisis situation exists. Social and emotional support for the family should be available during and after the crisis.

Navigating Services/Continuity of Care

BARRIERS

Continuity of care is lacking; the systems are complicated and difficult to navigate. This is particularly true for those whose needs cross systems and/or are transitioning between systems.

As has been pointed out in other sections, there is no single system of care for children and their families. It is difficult for families to navigate “through the maze.” In order to ensure continuity of care, the system must be easy to navigate, removing barriers that relate to access, transitions between programs and service systems, funding, and timeliness, to name but a few issues.

Currently, children and their families must relate to multiple individuals as they move from program to program and from system to system. Due to the fact that there are numerous persons from different systems communicating with the family, there is no “constant” voice for the family to follow, and often messages are inconsistent or contradictory. In addition, each time the child enters a different system, the family is put into the position of needing to “start again from the beginning”. This problem is particularly acute for children who are placed out-of-home, and at times out-of-county, as planning for community and family reunification is not always appropriately integrated into the treatment plan.

STRATEGY

Each family in the system of care should have access to a primary case manager/care coordinator who has the responsibility for assisting the family with all needs and who remains with the family through transitions.

Children and their families should have a consistent, continuing, knowledgeable person who is their point of contact with the system(s) and who acts as a coordinator. Case managers/care

coordinators are an integral link between clients and resources, and they must be easily and immediately accessible. They should be able to cross systems and help plan to support the child and family and their needs over time. The Task Force placed a particular emphasis on the need for care coordination for children placed out-of-county to ensure that families are involved in the care plan and discharge planning from the start.

Relationships with natural, neighborhood and extended family support systems, (i.e., those systems that exist in the family's environment) should be developed, which can support the child and family over time, thus reducing the reliance on the formalized system whenever possible. Planning for the use of these natural supports should be integrated into the individualized plan of care from the start.

Data Needs/Evaluation

BARRIERS

There is a lack of comprehensive information regarding how multiple systems work and how effective they are in addressing the emotional and social well-being of children.

Although children and families receive services across systems, information is collected by individual systems, each with its own requirements and definitions. It is difficult to obtain a total picture of the services, outcomes and cost of care a family receives. Currently, the various systems do not routinely collect, analyze and report data in a manner which allows for comprehensive or comparative analysis and bench marking. Each system has its own performance measures and outcomes based on this mandate.

Evaluation activities tend to be focused on individual programs or services, and are not system-wide in nature. When such evaluation does occur, families and consumers are not consistently involved in designing the evaluation tools or in the evaluation of programs themselves. In addition, evaluation tools are generally not normed on multi cultural populations. Best practices are not routinely identified and information about them is not routinely disseminated nor shared across systems.

STRATEGY

The system of care should be data-driven, with evaluation and continuous quality improvement processes that meaningfully involve staff, families and clients.

Data collection and evaluation should be a continuous process with family involvement a critical component. Community wide performance measures which include consumer satisfaction need to be developed and implemented. In addition, standard, consistent assessments and assessment tools should be developed and utilized. The process should culminate in an understanding of the

efficacy, efficiency and gaps in the current system. This information should be widely disseminated and serve as the basis for quality improvement efforts.

Training

BARRIERS

Training of personnel from all child-serving systems lacks a comprehensive focus as each system trains according to its own needs and requirements. Families, youth and the broader community are not consistently offered training opportunities which are coordinated and, thus, would maximize effectiveness.

The lack of in-depth training regarding system of care philosophy was identified as a major issue. The workforces of all systems that provide services to children and families will need to be trained in the system of care core values and guiding principles so that they will be able to see the inherent value in the changes and understand the potential gain or benefit of implementation of a new paradigm for children and families. Among the key areas for values based change are recognizing and valuing the role of families as partners in all aspects of the system of care, and infusing cultural competence into all aspects of the new system.

Children/youth and family members do not currently have access to training opportunities that allow them to develop a more comprehensive understanding of the system, its philosophy or its practices. Additionally, youth and family members are not routinely offered training or orientation related to their participation in systems planning, development or evaluation activities. There is also a lack of offerings to enhance family understanding of mental illness, appropriate skills to use with their children, stigma, advocacy and other areas of interest.

At the community level, there is also a lack of education/training available for the general population related to mental health awareness and stigma. Because training is offered and provided by multiple organizations, there is currently no effective way to consistently offer and coordinate training opportunities for consumers.

STRATEGY

A coordinated and comprehensive training approach should be developed that offers education/training regarding system of care values, principles and practices to family members, youth and the community, and to staff at all levels within organizations. Targeted training in specific areas should also be offered.

The Task Force recognized that in order for the new system of care to be successful, a coordinated and comprehensive training approach must be created at multiple levels which should include the family, children, the broader community, health and mental health personnel, leadership, the medical community, schools, etc. A major emphasis of this training must be the philosophical shift required by true system of care work.

In addition, the Task Force identified several other areas of needed training which include enhancing the skills of primary health care providers and early education and care providers to screen for mental illness; community-wide prevention/education regarding mental illness to reduce stigma; and training for child care workers, teachers, school personnel and staff within community organizations to better understand and manage behaviors associated with mental illness in children. Family members and clients should be offered the opportunity to enhance their own knowledge base on areas of concern for them, such as specific mental health diagnoses, the use of medications, signs and symptoms to be aware of, or managing their child in the home.

Next Steps

Monroe County has embarked on a process to develop a system of care for children with emotional disturbances and their families. The work of this Task Force is one component of this process. The information that has been gathered from the Task Force will be used as a base for additional work to more clearly define the barriers and propose strategies into the system of care that will address them. This Task Force Report will become the base for continued dialogue with the community regarding how best to design a system of care that meets the needs of children with emotional disturbances and their families. The findings of this Task Force will be broadly disseminated to the community. The Monroe County Office of Mental Health will coordinate a process to obtain additional community involvement through presentation of the Report's findings to various community groups, with the intent of incorporating additional community input into the design of the system. Preliminary findings of the Report have been presented to several groups thus far, which has resulted in linkage to additional constituencies for further input.

Appendix A - Task Force Members

MONROE COUNTY CHILDREN'S SYSTEM OF CARE TASK FORCE

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Appendix B - Barriers and Strategies

(Note: The barriers and strategies as presented in this Appendix represent the discussions of the Task Force prior to the report having been written. After the Task Force reviewed the first draft of the report, there were changes made in some of the categories, e.g, Families, Training. The report itself reflects those changes.)

System Issues

Summary: There is a lack of consistent vision and driving philosophy for the current systems that result in barriers and difficulties that prevent addressing the needs of children. This is especially true for children who cross multiple systems.

- Mental illness is a chronic condition, like a chronic physical illness (e.g., diabetes), and requires long-term personal management. However, mental illness is not treated in a similar manner.
- Reimbursement issues drive how services are delivered. There is a need to train/educate re: how to obtain payment for various aspects of services.
- Inadequate community consensus to change the way things are being done.
- There is no “image” of what the system should look like.
- Mental Health services are not an entitlement (like DSS, education); even when a child/family is identified as needing services, the services may be unavailable, and so the client may have a long wait to gain access, etc..
- Parents do not see primary care providers as appropriate sources of support around mental health issues.
- For “cross-system” children—there are issues of who pays for services and what service options are available to them.
- For “cross-system” children, coordination and communication is very difficult and inconsistent.
- Staff burnout and inadequate compensation are significant contributory factors to turnover and the lack of consistency in relationships between youth/families and providers.

STRATEGIES:

- **There is a need for a “plan”/vision that crosses systems.**
- **There is a need to look at all children, especially those with high needs.**
- **The strategy developed should not be so broadly defined that what gets done is meaningless.**
- **The system of care should adopt the CAASP principles (CAASP principles: are they appropriate for our community? What modifications are necessary? Add the values from the Children’s Mental Health Coalition.) Wherever possible, these principles should be incorporated into other child-serving systems that touch on the system of care.**
- **Definitions must be consistent across systems. Among the terms that need to be defined: behavioral, crisis intervention, disruptive.**

Families

Summary: The current systems do not adequately address the multiple needs of families or empower them to engage meaningfully in dialogue about their own needs, the needs of their family members, and the larger systems' needs.

- From the probation standpoint, it is difficult to convince/engage parents to get mental health services for their children.
- Parents fear losing child to CPS.
- Siblings (not the designated client) often “victim” of mental health issues in the family, but cannot receive care. (Often care is only provided to designated patient/client and not to the entire family.)
- Care should involve the active participation of the child in developing his/her treatment plan. This includes young children.
- Child(ren) may have parents with psychiatric disabilities; however, children may not receive any care/attention because he/she is not the identified “patient”.
- Families/parent may need to place kids in foster care when parent has need for inpatient or residential treatment.
- Treatment is usually directed towards one member of the family.
- Parents/children should be involved in evaluation of programs/services.
- Treatment plans should include parent/youth involvement. Families should receive written copies of treatment plans.
- Confidentiality—in terms of what information must be shared vs. what information cannot be shared with parents.

STRATEGIES

- **Broaden definition of the concept of “family”— the child should be asked to define who should be included in his/her “family”. Definition should also consider cultural perspective in defining the family.**
- **Every child has a right to have an attachment to a caring adult. Where this relationship does not exist, the system of care should strive to assist in its development (using “natural supports”; schools; etc.).**
- **Natural supports (community) should be included in any planning for services.**
- **Families may also have needs and the system must have the ability to work with the adult systems to assist in meeting those needs.**

Prevention/Early Identification/Early Intervention

Summary: The child serving systems are focused on providing treatment rather than prevention/early identification/early intervention.

- Prevention, to keep kids out of the system—is difficult. There is no funding attached to it—we tend to prevent placement vs. preventing mental health issues.
- Screening is inadequate. Primary care providers generally do not do mental health screening, nor do they necessarily have the skills to do mental health screening. There are significant constraints on PCP time.
- Many parents do not understand what “mental health” issues are, what mental health services are, and what services will benefit their child(ren). Diagnosis or label required for early intervention/care. Many parents are resistant to having child labeled.
- Earlier intervention than is currently available is needed. People need to learn when bad behavior becomes a mental health issue.

STRATEGIES

- **Expand the role/ability/expertise of primary care physician to identify and intervene early. Provide physician training. Include training of nurses (who are underutilized) to do screening. Provide tools for including social/emotional screening into medical services. (Note: reimbursement and amount of time available are challenges.)**
- **Link Primary Care Providers to the system of care that is developed, particularly in screening, referrals, and follow-up. Need to test interventions and develop best practices. (Note: few interventions tested in primary care; little information on evidence-based practice.)**
- **Other opportunities for early identification/intervention should be fostered/expanded, especially schools, wellness centers, school based health clinics. Other avenues for early identification/intervention include: Schools (including school nurses as screeners), PCPs, faith-based programs, child care providers, early intervention/Head Start. (Strategy should look outside of the current systems to identify kids.)**
- **Mental health screening needs to become routine/normalized for all children. Education for parents/community should be made available that focus on the importance of mental health screening (cf. vision, hearing, etc.)**
- **Special, court-appointed advocates should be made available for kids under age 6.**
- **Models for early intervention prior to diagnosis should be developed to involve families. Successful models should institute services that would preclude intense services being needed later.**
- **For children aged 0-3: identification by physicians, medical community, early childhood community there needs to be:**
 - **Training for providers in skill-based approaches, developmental aspects.**
 - **Training on how to meet behavioral needs of kids (building social-emotional screening into pediatric services).**
 - **Screening needs to start at the earliest possible age.**
- **3-5: Identification in Preschool, Physicians and medical community.**

Service Options and Flexibility

Summary: The services that are offered do not cover the broad spectrum of needs and are not matched to the populations they are intended to serve.

- Alternative services are not Medicaid eligible.
- Our systems are not culturally competent—there are insufficient minority providers and providers who are bilingual.

- There is no well-developed continuum of care; for example, there are no services available between acute, inpatient hospitalization and residential care; step-downs are not available.
- Mental health is a long-term need; there is often no “cure”. Mental health needs are treated with short-term, system-oriented services which are not comprehensive. There is no long term support available for the children/family.
- Lack of emergency services when hospitalization is not appropriate or available.
- Service options need to include: dual diagnosis services, respite, more mobile crisis, skill builders, supervised programs before/after school and during vacations, recreation activities, support groups for children, sibling groups and friends/family groups.
- No level of care between acute inpatient and residential care.
- Systems do not teach self-advocacy skills to children/youth.
- Children are placed into existing services rather than having options of which services might be the most appropriate/accessible. Money needs to follow the child.
- Services are designed to meet the convenience of providers, agencies, adults, etc., rather than considering the needs of parents/children. For example, there are few providers available evenings or weekends.
- Systems are not flexible enough to provide intervention/support services/preventive services. There is a need to be able to identify “the lost kids”, who are impacted by various issues and are sometimes victims, but not always acting out.
- It is not possible to provide comprehensive services in schools (and other settings).
- Need shift in paradigm of how treatment providers perceive their roles, e.g., as case manager or “consultant” rather than as therapist for the different types of families and challenges that are presented. Children being seen in outpatient settings are more frequently in need of a higher level of care. This does not mean outpatient cannot serve them, but rather that they will be served differently.
- Children cannot be enrolled on the OMR and OMH waiver at the same time.

STRATEGIES

- **Develop flexibility in services offered within the county to avoid out-of-county placements whenever possible. If placement is necessary, ISP (individualized service planning must be done early, including a discharge plan).**
- **All Individualized service planning should include a comprehensive plan.**
- **Map what currently exists and what is missing. Define what elements the system needs to include.**
- **Develop a central point of entry with 24 hour answering capability, including either a telephone number or walk-in. A variety of settings should be available within the community (e.g., health centers, schools, community agencies). In this system, there would be the ability to get referral to any service at this point of contact. There would be triage capability with knowledgeable responders about what is available, how it can be paid for, etc.**
- **The system should take services to kids, rather than kids to services. Options need to include flexibility in scheduling (location, time), and tolerance (flexibility) in applying regulations.**
- **Schools: Need to expand what is currently in place in schools and develop a better way of connecting kids to mental health services and to community agencies. Increase access to Mental Health services through school-based clinics. Mental health services must be part of all school-based health clinics. Access to mental health services should also occur through student support centers. Access to all school-based services should be less difficult than is currently the case.**
- **Before and after school programming should be available (and during vacations). (Note: Services should**

- **reduce the time that a child spends out of the classroom on suspension.)**
- **Services/programs should be developed that are “open” vs “closed” due to diagnostic or funding constraints.**
- **Service philosophy should be strength based.**
- **Crisis intervention must be provided immediately (regardless of whether there is a mental health “diagnosis”). Families should be communicated with as soon as possible once crisis intervention has been instituted. Social/emotional support for the family should be available before/during/after crisis.**
- **Establish in-home residential care (intensive) to be in place immediately upon discharge from inpatient care (cf. visiting nurse services).**

Accessing Services

Summary: Currently, the system is complex and difficult to navigate, requires restrictive criteria for entry and does not necessarily have the ability or resources to meet needs.

- Insurance coverage is lacking and inadequate (e.g., there are limits on amount of care that can be provided). Co-pays are high. There is no parity with physical health.
- There is a limited number of providers (especially child psychiatrists). There is a limited number of minority, bilingual and culturally competent providers.
- Difficult to navigate system(s).
- The system of care is complicated; there is a lack of understanding about available options. Very few people have a real understanding of all the options across all the different funding streams.
- Diagnosis or label is required to access many services. It is not possible to get services until behavior has become “bad”, or until the child is acting out. Therefore, there are a number of children who are not identified as needing mental health services despite needing them desperately.
- Transportation, especially to alternative care, is not adequate/available.
- There is a lack of ownership over the permanency issue in mental health system: mental health should have a role in getting child a secure, permanent place to live.

STRATEGIES

- **System is complex and will probably remain that way. However, a goal of developing a “new” system of care is to enable services to be accessed easily, and for families not to have to experience the complexities of navigating the system. Strategies need to be developed for smooth transitions, both within the system and between systems.**
- **Develop a single point of entry with 24 hour response which would include:**
 - **1-800.....telephone number**
 - **assessment centers (diagnostic, including psychosocial) with linkages**
 - **standard/consistent assessments (which will include environment, family issues)**
 - **common tools**
 - **user-friendly (this must include attending to the needs of minority populations so that they will be able to secure appropriate services.)**
 - **triage point**
 - **knowledgeable personnel about services, funding requirements, and ability to “match” child/family to appropriate services, etc.**
 - **culturally competent**
 - **publicized information**
 - **cross system understanding/training.**
- **If intake is done at “a physical site”, it should be at a place where families/child(ren) feel comfortable going. In some cases, schools, in others, community agencies (including faith-based), physician’s offices, etc.**

- **Assess wellness centers (in schools): what programs work? Why? Why do some wellness centers “work” better than others?**
- **Need to educate many constituencies.**
- **Need to do community outreach and identify children with possible mental health issues.**

Note: Issue of stigma which prevents services from being used.

Navigating Services/ Continuity of Care

Summary: Continuity of care is lacking; the system is complicated and difficult to navigate. This is particularly true for those whose needs cross systems and/or are transitioning between systems.

- Consistent, one-person to connect child/family with services is generally lacking.
- Complicated system. It is difficult to navigate the system without assistance.
- There is very little continuity. When client moves from one service/system to another, it is necessary to “start again from the beginning”.
- Services are not designed for the convenience of the child/family. There are few services available at times/locations that are convenient to the child/family.
- For children placed out of county (across the state), there is a lack of continuity of care. There is a lack of communication with families, and sometimes families are neither involved in the care plan for the returning child nor are they adequately prepared for the child’s return. This also holds true with regard to communication between systems when one system is discharging to another system.
- There is no advocate available for the child in an out-of-county placement as his/her parents (or care provider) are often not available.

STRATEGIES

- **There should be a consistent/continuing person as the point of contact with systems who would act as manager, advocate. The person should be knowledgeable, and be able to cross systems/address needs that change over time.**
- **Development of natural support systems (community based) that support the child/family over time and during transitions. Planning for use of natural supports should begin as soon as individual service planning starts.**
- **Regarding children who receive services out of home/county: challenge is to develop linkages back to the community/family.**

Data Needs/Evaluation

Summary: There is a lack of comprehensive information regarding how the current systems work and how effective they are.

- There is a lack of analysis of current services.
- There is a lack of information regarding how the current system(s) works and what its effectiveness is; there is a lack of sharing of best practices.
- There needs to be community-wide performance measures.
- The children’s system is not focused on recovery or living with a mental illness.

- Strength based outcomes are not emphasized
- Based on national experience/data, what level of mental health problems can be “expected” in Monroe County?
- Extent of involvement of child/family in more than one system (Note: data systems/data bases don’t talk to each other)

STRATEGIES

Note: Data Needs/Evaluation was not discussed as a separate category

Training

Summary: Training of personnel from all child serving systems lacks a comprehensive focus as each system trains according to its own needs and requirements. Parents/youth/community are not offered training opportunities.

- For cross-system children, service providers need to be trained regarding each disability, system needs/issues, and provision of services across systems.
- Training needs to be provided for multiple categories of workers: CPS staff, case workers, legal guardians, police, EMTs, community workers, etc.
- Destigmatization training for children, families and staff is lacking.
- Primary care physicians do not have adequate time/training/reimbursement to provide mental health care
- Education system does not understand “mental health” issues.

STRATEGIES

Training needs to be provided at multiple levels:

Community
Family
Children
Health/mental health staff
Schools

Note: Training was not discussed as a separate category. Training proposals are included in other areas.

Specific Population Groups

Summary: The current systems do not adequately address the needs of certain distinct population groups.

- Older youth not connected to other systems—e.g., health, education, etc. they cannot obtain the services they need.
- It is difficult to meet the needs of children who are diagnosed with conditions that would put them in any 2 or more systems (e.g., mental health and substance abuse; mental health and developmental disabilities; etc.).
- When to define a “child” as an “adult” varies by service and by system; they are not consistent.

- 0-3; 3-5 and 5+ all represent major developmental transitions, as well as transitions between different systems in which the child is receiving services. Transition from one stage to another is abrupt; there is a disconnect between the system and a need to start over each time. From 0-3, the emphasis is on the medical model; 3-5 is preschool; 5+ is school age.
- In transitioning to adult services, confidentiality issues become barriers when the client is not longer considered a child, but remains living at home (parents cannot provide/access information)
- Many kids are not equipped to go out on their own after high school; school transition planning services are poor; and there is a lack of services available for kids who don't continue education after high school.

STRATEGIES

- **Older adolescent work group recommendations will be included here.**
- **Other groups are included in other sections.**
- **There is a need to better understand the issues presented by cross-system children/families.**

Appendix C - System of Care Family Task Force Meeting Notes-6/12/04

(Note: The comments made by the Family Advisory Group are noted in “bold”. The Family Advisory Group used the Issues and Barriers and Strategies that were originally generated by the full System of Care Task Force.)

System Issues

Summary: There is a lack of vision and driving philosophy for the current systems that result in barriers and difficulties that prevent addressing the needs of children. This is especially true for children who cross multiple systems.

- Mental illness is a chronic condition, like a chronic physical illness (e.g., diabetes), and requires long-term personal management. However, mental illness is not treated in a similar manner. **Important Issue**
- Reimbursement issues drive how services are delivered. There is a need to train/educate re: how to obtain payment for various aspects of services **Who is to be trained? If trained, will it lead to improved access to services?**
- Inadequate community consensus to change the way things are being done.
- There is no “image” of what the system should look like.
- Mental Health services are not an entitlement (like DSS, education); even when a child/family is identified as needing services, the services may be unavailable, and so the client may have a long wait to gain access, etc. **Important Issue-Agree with statement.**
- Parents do not see primary care providers as appropriate sources of support around mental health issues. **Group questioned the wording of this statement particularly noting that on page 3, second bullet, comments that "Primary care providers generally do not do MH screening, nor do they necessarily have the skills to do MH". Group agreed this is true and asked "why then would parents see primary care providers as appropriate sources of support around MH issues?"**

See strategy suggestion below.

- For “cross-system” children—there are issues of who pays for services and what service options are available to them. **Important Issue.**
- For “cross-system” children, coordination and communication is very difficult and inconsistent. **Agree.**
- Staff burnout and inadequate compensation are significant contributory factors to turnover and the lack of consistency in relationships between youth/families and providers. **Important Issue-critical need for best qualified and consistent staffing. Frequent change in staff significantly reduces quality of services.**

STRATEGIES:

- **Eliminate insurance discrimination for MH treatment: Promote parity.**
- **Educate and train primary care providers to recognize MH issues and use referrals to specialists earlier and more efficiently.**
- **Promote anti-stigma work.**

Families

Summary: The current systems do not adequately address the multiple needs of families or empower them to engage meaningfully in dialogue about their own needs, the needs of their family members, and the larger systems needs.

- From the probation standpoint, it is difficult to convince/engage parents to get mental health services for their children. **Group took issue with this statement and questioned whose issue is this? Family engagement practices seen as Important Issue. See strategy suggestion below.**
- Parents fear losing child to CPS. **Agreed.**
- Siblings (not the designated client) often “victim” of mental health issues in the family, but cannot receive care. (Often care is only provided to designated patient/client and not to the entire family.) **Important Issue. See Strategy suggestion below.**
- Care should involve the active participation of the child in developing his/her treatment plan. This includes young children. **See Strategy suggestion below-**
- Children may have parents with psychiatric disabilities; however, children may not receive any care/attention because he/she is not the identified “patient”.
- Families/parent may need to place kids in foster care when parent has need for inpatient or residential treatment.
- Treatment is usually directed towards one member of the family.
- Parents/child(ren) should be involved in evaluation of programs/services. **Agreed Strongly. See Strategy suggestion below.**
- Treatment plans should include parent/youth involvement. Families should receive written copies of treatment plans. **Agreed Strongly. Especially inpatient settings (seen as current gap in practice).**
- Confidentiality—in terms of what information must be shared vs. what information cannot be shared with parents.

STRATEGIES

- **Fund, offer and evaluate family-centered approach training to providers to improve engagement and family partnering practices-all systems including child welfare and juvenile justice.**
- **Family members should be active participants in the evaluation of programs.**
- **Promote Community Development approach to helping families: improve capacity of natural community supports to include families experiencing MH challenges.**
- **Build competencies among providers working with our families.**

Prevention/Early Identification/Early Intervention

Summary: The child serving systems are focused on providing treatment rather than prevention/early identification/early intervention.

- Prevention, to keep kids out of the system—is difficult. There is no funding attached to it—we tend to prevent placement vs. preventing mental health issues. **Important issue- See Strategy suggestion below.**
- Screening is inadequate. Primary care providers generally do not do mental health screening, nor do they necessarily have the skills to do mental health screening. There are significant constraints on PCP time. **Important Issue- See Strategy suggestion below.**
- Many parents do not understand what “mental health” issues are, what mental health services are, and what services will benefit their child(ren). Diagnosis or label required for early intervention/care. Many parents are resistant to having child labeled. **Group took strong issue with word "resistant"-suggested promoting strength based "attitudes" in SOC work. E.g. group suggested this be re-framed as "parents are appropriately cautious" in having their child labeled.**
- Earlier intervention than is currently available is needed. People need to learn when bad behavior becomes a mental health issue.

STRATEGIES

- **Develop/promote supports for more "normal" opportunities for children/families experiencing MH challenges at day care settings, recreation, pre-school, school, etc.**
- **Develop/promote the use of MH screenings at schools, pediatricians offices, CPS, etc.**
- **Develop a community education strategy to increase awareness of MH/behavioral issues, to include anti-stigma campaign.**
- **Develop strategies/opportunities for parent education: teach parents/family members how to best use their expertise in their knowledge of their own child to get appropriate help; and to expect providers to use such expertise in the treatment of the child/family.**

Service Options and Flexibility

Summary: The services that are offered do not cover the broad spectrum of needs and are not matched to the populations they are intended to serve.

- Alternative services are not Medicaid eligible.
- Our systems are not culturally competent—there are insufficient minority providers and providers who are bilingual. **See Strategy suggestion below.**
- There is no well-developed continuum of care; for example, there are no services available between acute, inpatient hospitalization and residential care; step-downs are not available.
- Mental health is a long-term need; there is often no “cure”. Mental health needs are treated with short-term, system-oriented services which are not comprehensive. There is no long term support available for the children/family.
- Lack of emergency services when hospitalization is not appropriate or available. **Big Issue with lack of immediate access to mobile crisis services.**

- Service options need to include: dual diagnosis services, respite, more mobile crisis, skill builders, supervised programs before/after school and during vacations, recreation activities, support groups for children, sibling groups and friends/family groups. **Add/emphasize peer to peer supports and psycho-social supports.**
- No level of care between acute inpatient and residential care. **Group liked the concept of the PASS program and suggested such practices be more infused into other programs/interventions.**
- Systems do not teach self-advocacy skills to children/youth.
- Children are placed into existing services rather than having options of which services might be the most appropriate/accessible. Money needs to follow the child. **Important Issue.**
- Services are designed to meet the convenience of providers, agencies, adults, etc., rather than considering the needs of parents/children. For example, there are few providers available evenings or weekends. **Important issue- See Strategy suggestion below.**
- Systems are not flexible enough to provide intervention/support services/preventive services. There is a need to be able to identify “the lost kids”, who are impacted by various issues and are sometimes victims, but not always acting out.
- It is not possible to provide comprehensive services in schools (and other settings). Suggestion: provide comprehensive services in schools! **See Strategy suggestion below.**
- Need a shift in paradigm of how treatment providers perceive their roles, e.g., as case manager or “consultant” rather than as therapist for the different types of families and challenges that are presented. Children being seen in outpatient settings are more frequently in need of a higher level of care. This does not mean outpatient cannot serve them, but rather that they will be served differently.
- Children cannot be enrolled on the OMR and OMH waiver at the same time.

STRATEGIES

- **Promote better use of wraparound/empowerment approaches that use natural supports to help families-would address some of the cultural competency gaps.**
- **Make crisis services immediately available and relevant to individual need**
- **Develop/promote peer to peer opportunities for youth that are peer run and that promote self-advocacy**
- **Services need to be available when families are available-working families frequently cannot attend meetings during day working hours**

Accessing Services

Summary: Currently, the system is complex and difficult to navigate. There are restrictive criteria applied to services. The systems do not necessarily have the ability or resources to meet needs.

- Insurance coverage is lacking and inadequate (e.g., there are limits on amount of care that can be provided). Co-pays are high. There is no parity with physical health. **Important Issue**
- There is a limited number of providers (especially child psychiatrists). There is a limited number of minority, bilingual and culturally competent providers.
- Difficult to navigate system(s) because of their complexity.

- The system of care is complicated; there is lack of understanding about available options. Very few people have a real understanding of all the options across all the different funding streams.
- Diagnosis or label is required to access many services. It is not possible to get services until behavior has become “bad”, or until the child is acting out. Therefore, there are a number of children who are not identified as needing mental health services despite needing them desperately. **See Strategy suggestion below.**
- Transportation, especially to alternative care, is not adequate/available. **Important issue**-seen as a chronic problem- See Strategy suggestion below
- There is a lack of ownership over the permanency issue in mental health system: -mental health should have a role in getting child a secure, permanent place to live. **Group expressed concern over this statement: do we really want our systems to "own" kids? If so, for whom? Agreed that MH system should improve long term living options for youth- See Strategy suggestion below.**

STRATEGIES

- **Promote community development approaches to increase access to community/neighborhood-based preventive supports before problems get severe enough that youth are eligible for intensive services.**
- **Improve access to transportation options for families. Make better use of transportation options currently existing; share resources, including those of community/neighborhood organizations that have vehicles and volunteers (churches, CBOs, etc.)**
- **Improve transition supports-especially for older youth to address some of the permanency issues**
- **Address waiting list issues, especially access to psychiatrists, respite and SPOA services**
- **Develop alternative intervention models for youth refusing treatment**

Navigating Services/ Continuity of Care

Summary: Continuity of care is lacking; the system is complicated and difficult to navigate. This is particularly true for those whose needs cross systems and/or are transitioning between systems.

- Consistent, one-person to connect child/family with services is generally lacking.
- Complicated system. It is difficult to navigate the system without assistance.
- There is very little continuity. When client moves from one service/system to another, it is necessary to “start again from the beginning”. **Important Issue.**
- Services are not designed for the convenience of the child/family. There are few services available at times/locations that are convenient to the child/family. **Important Issue- See previous Strategy suggestion.**
- For children placed out of county (across the state), there is a lack of continuity of care. There is a lack of communication with families, and sometimes families are neither involved in the care plan for the returning child nor are they adequately prepared for the child’s return. This also holds true with regard to communication between systems when one system is discharging to another system. **Important Issue- Communication with families is routinely poor with many residential providers no matter where located. See Strategy suggestion below.**
- There is no advocate available for the child in an out-of-county placement as his/her parents (or care provider) are often not available. **See Strategy suggestion below.**

STRATEGIES

- **Promote training for residential providers in family centered/empowerment approaches.**
- **Provide/promote transportation and support to families with children in placement out of their communities to allow for more involvement in their child's treatment.**
- **Offer family support services to families of children in residential care-whether issues directly affect/involve the child in care or not-to help improve positive discharge home.**

Data Needs/Evaluation

Summary: There is a lack of comprehensive information regarding how the current systems work and how effective they are.

- There is a lack of analysis of current services.
- There is a lack of information regarding how the current system(s) works and what its effectiveness is; there is a lack of sharing of best practices.
- There needs to be community-wide performance measures.
- The children's system is not focused on recovery or living with a mental illness.
- Strength based outcomes are not emphasized.
- Based on national experience/data, what level of mental health problems can be "expected" in Monroe County?
- Extent of involvement of child/family in more than one system. (Note: data systems/data bases don't talk to each other.)

STRATEGIES

The group did not review the rest of issue lists due to a lack of time. But a number of issues overlap with previous issues and comments below reflect the group's discussions

Training

Summary: Training of personnel from all child serving systems lacks a comprehensive focus as each system trains according to its own needs and requirements. Parents/youth/community are not offered training opportunities.

- For cross-system children, service providers need to be trained regarding each disability, system needs/issues, and provision of services across systems.
- Training needs to be provided for multiple categories of workers: CPS staff, case workers, legal guardians, police, EMTs, community workers, etc.
- Destigmatization training for children, families and staff is lacking. **See Previous Strategy suggestion.**
- Primary Care physicians do not have adequate time/training/reimbursement to provide mental health care. **See Previous Strategy suggestion.**
- Education system does not understand "mental health" issues. **Huge issue- See Strategy suggestions below.**

STRATEGIES

Develop comprehensive strategy to collaborate with local education system to improve school staffs' understanding of behavioral and MH issues and to develop school settings that are youth and family friendly to students experiencing behavioral and/or MH challenges. School based MH, school-community collaboration practices, implementation of Positive Behavior Interventions and Supports (PBIS) systems, school-based family support (parent to parent/youth to youth) opportunities, training in family centered/empowerment approaches for school personnel are all needed.

Specific Population Groups

Summary: The current systems do not adequately address the needs of certain distinct population groups.

- Older youth not connected to other systems—e.g., health, education, etc. cannot obtain the services they need. See Previous Strategy suggestion re: improved transition supports.
- It is difficult to meet the needs of children who are diagnosed with conditions that would put them in any 2 or more systems (e.g., mental health and substance abuse; mental health and developmental disabilities; etc.).
- When to define a “child” as an “adult” varies by service and by system; they are not consistent.
- 0-3; 3-5 and 5+ all represent major developmental transitions, as well as transitions between different systems in which the child is receiving services. Transition from one stage to another is abrupt; there is a disconnect between system and a need to start over each time. From 0-3, the emphasis is on the medical model; 3-5 is preschool; 5+ is school age. **See Previous Strategy suggestion re: improved transition supports.**
- In transitioning to adult services, confidentiality issues become barriers when the client is not longer considered a child, but remains living at home (parents cannot provide/access information).
- Many kids are not equipped to go out on their own after high school; school transition planning services are poor; and there is a lack of services available for kids who don't continue education after high school.