BROOME COUNTY VISIONING PROJECT FOR CHILDREN AND ADOLESCENTS

AN ASSESSMENT OF WHAT EXISTS AND SERVICE GAPS

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AN ASSESSMENT OF WHAT EXISTS AND SERVICE GAPS

Prepared for:
Broome County Mental Health Department and New York State Office of Mental Health

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July, 2002

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AN ASSESSMENT OF WHAT EXISTS AND SERVICE GAPS

July, 2002

SUMMARY

Recent studies in Broome County have suggested that there are gaps in mental health services for children and adolescents in the county and that, at least in part as a result, growing numbers of children and adolescents in recent years have been referred to hospitals for inpatient psychiatric treatment. This study builds on those earlier efforts to provide a comprehensive, objective assessment of the mental health services currently in place in the county, and of those who are served by those mental health programs. Through extensive analysis of provider and parent surveys and of an extensive emergency services database, and through interviews and focus group discussions with more than 200 parents, service providers and community stakeholders, a clear picture of the strengths, limitations and service gaps of the existing service delivery system emerged. The assessment defined the issues that shaped the development of a vision and plan for the delivery of mental health services for Broome County's children and adolescents, and their families, in the future. That vision and plan are currently being finalized by the Steering Committee for this project.

Primary Conclusions from Analyses

A wide variety of services and programs are currently serving children and adolescents in Broome County. Many programs are well-regarded, and many are operating at or close to full capacity. The county is also unique among counties of its size in having a Comprehensive Psychiatric Emergency Program (CPEP) available to respond to the crisis needs of its Serious Emotionally Disturbed (SED) youth.

Key building blocks of a strong future mental health system for children and adolescents are in place, but some are too small at this point to meet the perceived needs, while others are not

operating at full capacity, despite the perceived needs for expanded services. Finding ways to better match resources with needs is part of the challenge facing the community as a blueprint for a new system is developed.

Rapidly increasing numbers of children and adolescents of all ages, both boys and girls, are being referred to CPEP for crisis assessments, and even more rapid increases have been seen in the last three years in the numbers of youth placed in inpatient psychiatric hospitals (from 101 hospitalizations in 1999 to 247 in 2001), with most of the increases involving hospitalizations outside Broome County. The greatest proportional increases in CPEP presentations/intakes and in hospitalizations involve children under the age of 13 (e.g., annual CPEP presentations among children 8-12 increased from 149 to 270 between 1998 and 2001; hospitalizations in that age group increased from 22 in 1998 to 68 in 2001). Other children and adolescents who are assessed by CPEP but *not* hospitalized are often not connected with follow-up services in the community, and many of those returning from hospital episodes are also not linked effectively with aftercare services. Gaps in services, and ineffective linkages with the services that do exist, help contribute to substantial increases in the numbers of youth who are referred multiple times to CPEP, and even more significant increases in the numbers of multiple hospitalizations for the same child within the same year. Contributing to these increases is the fact that relatively few family-focused support services are in place. Most mental health services for children and adolescents focus their primary attention directly on the youth, with little focus on the family environment in which the young person lives, including the extent to which the family circumstances may be contributing to the youth's behavior.

About one-third of all youth who were assessed at least once at CPEP between 1998 and 2001 accounted for 60% of all CPEP presentations during those four years. The vast majority of all multiple presentations involving the same person occurred within a few months of each other, typically within the same year. For example, within 2001, 83 children and adolescents presented at CPEP three or more times. If it becomes possible to define such small subgroups of multiple users of CPEP, and to develop alternative services for them and their families prior to coming to CPEP in a crisis mode, there could be a substantial future reduction in the burden on CPEP staff, and in the degree of upheaval in the lives of children and families who now end up multiple times at CPEP when crises erupt in their lives.

A Framework for Responding

The Visioning Project's Steering Committee has ultimate responsibility at this point for developing a vision and designing a blueprint for what a future mental health service system for children and adolescents, and their families, should look like, based on the findings from this assessment and the preliminary framework of what such a blueprint might include, which is summarized below. The Steering Committee is currently in the process of addressing these issues as it prepares its companion "vision and action plan/recommended model" document expected to be issued by the Steering Committee later this summer or early fall.

Continuum of Care

The model should be built on a strong continuum of services, ranging from preventive and early intervention services to crisis services and aftercare. The continuum of services should particularly emphasize prevention and early intervention, with strengthened services especially addressed to young children and to total family units. Among the specific types of services that appear to need to be expanded and/or used more effectively are the following:

- Day treatment;
- Flex Team services (Home and Community-Based Waivers);
- Case management;
- CCSI comprehensive services;
- Structured after-school programs, such as the Therapeutic After-School Program;
- Respite care;
- School-based mental health programs;
- Skill-building and other aide services to parents;
- Support groups and various support services for parents dealing with mentally ill children and adolescents;
- Intensive wraparound services and dollars for youth and families;
- Substance abuse services for adolescents in the mental health system;
- Possible expansion of child psychiatrists and/or psychiatric health nurses in the community.

Crisis Intervention Services

A number of issues need to be addressed at the crisis intervention level. Among them are the following:

- Even though it was beyond the scope of this project, the data from all components of the study clearly indicate the need for a small inpatient psychiatric facility in Broome County. The reality is that the current pattern of having 85% of inpatient psychiatric hospitalizations occurring at distant locations appears to have significant negative consequences for the youth and their families.
- There may need to be a pre-CPEP, lower-level assessment process to help prevent situations from escalating to the emergency crisis level, and also to deal with the types of non-mental-health-related behavioral problems that CPEP is not now always able to address.
- Better ways are needed of more fully using the county's limited 72-hour Extended Observation Bed resources for children and adolescents.
- Better use is also needed of the valued but underused Adolescent Crisis Residence beds at Binghamton Psychiatric Center.
- More children and youth specialists may be needed to better meet the needs of youth referred to CPEP who are not hospitalized following the assessment. Likely results of increased specialist staffing would be more appropriate use of CPEP, expanded and more appropriate referrals to community services for those not hospitalized, and more effective follow-through with families and youth to help assure that needed services are actually provided.

Access to Services

Several aspects of access would need to be addressed, including:

- The need for a central intake mechanism which could help provide a single point of entry for youth and families entering the mental health system in the first place, and for those returning to the community following hospitalization and needing to access aftercare services. Such a system, which should be part of the function of a county Single Point of Accountability/Access (SPOA) system required by OMH, should help improve access to services, reduce unnecessary duplication of services, improve the flow and movement of youth between levels of care, and improve communications and direct connections between providers and consumers. This function should also provide the needed research capability to help monitor service gaps, and to enable services to be modified as needed to keep pace with changing demands and needs for services, as monitored by assessments done as part of the intake process.
- Outreach services to outlying areas of the county, provision of services in non-office settings and during non-traditional hours, and the potential for integrating more services into school-based

or other community settings are among the access issues that need to be addressed.

Discharge Planning and Aftercare

This may involve both the need to add or expand services and to provide better access to those services that already exist.

- The most important part of this function may be accomplished via the SPOA operation, in which better communications need to be put in place between hospitals and local service providers and parents, to assure that more effective and realistic discharge plans are put in place, and carried out.
- Parents need to be an integral part of the planning process, and family circumstances need to be factored into discharge plans and aftercare services, such that a child not be returned to an unhealthy environment without supports and alternatives being put in place for the family.

Supports for Parents

Parents need better information to be more effective participants in decisions affecting them and their child, and they need help and support from other parents in similar situations, to help them cope with the issues posed by their child's mental illness.

- More services need to be developed that focus on the provision of holistic, integrated services for the family unit as a whole.
- Better information needs to be made available to parents, on a timely basis in convenient ways and places, concerning the options available to them and their child.
- Strengthened and expanded support groups and other support services, provided in many cases by other parents as peers, are needed to reach a higher proportion of affected parents.

Coordination of Care

More effective cross-training is needed of staff across mental health programs, and better collaboration and partnerships are needed between child/adolescent mental health programs, between child and adult programs, and across mental health and other systems (such as juvenile justice, education, child welfare, MRDD, and substance abuse systems). Better focus is needed on collaborative funding, to make the best use of available resources.

Funding

The development of waivers and other ways of breaking down funding barriers, such that "silo" sources of funds can begin to be merged, both within and across systems, needs to be encouraged. Such blending of funds will be critical to the ability to provide more wraparound and coordinated services to family units as needed.

Accountability

The service system which is designed should have at its core the ability to plan, assess needs, and monitor performance and outcomes across different types of services.

- Such an accountability mechanism should be instrumental in helping reallocate resources, where appropriate, to meet changing needs and opportunities over time.
- The system should enable programs and new approaches to be developed on a prototype basis and pilot tested for a specified period of time, during which the performance of the program is being monitored and evaluated to assess its effectiveness and whether it should continue to be funded in the future, as is or with modifications.

Cross-Systems/ Integrated Services

Although the focus of this project has been primarily on mental health services, it is clear that there are high proportions of overlaps of children and adolescents, and families, involved in the mental health and other service systems (child welfare, juvenile justice, education/special education and disciplinary systems, MRDD, and substance abuse). To address a service system for SED and other mentally ill youth, and youth with behavioral problems, without factoring in the overlapping service networks, would seem foolish and short-sighted. It may be that the SPOA, though focusing primarily on mental health issues, can also be instrumental—at least in the future once it becomes established—in helping to facilitate coordinated services across systems. One of the opportunities that should grow out of increased concentration on cross-systems issues is the potential to develop more cross-funded projects, including joint purchase of service agreements that may make some services possible through expanded joint funding that would not be possible with single sources of funds.

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ACKNOWLEDGMENTS

CGR gratefully acknowledges the vision and leadership of the New York State Office of Mental Health and of the Broome County Mental Health Department and its Commissioner, Arthur R. Johnson, in understanding the need for and value of this study, and in backing that understanding with funding support for the project.

A very active, dedicated project Steering Committee, the members of which are listed in the Appendix to this report, has made innumerable contributions to the project. That Committee is currently in the process of developing a companion document to this report, which will include a recommended vision and blueprint for the children and adolescent mental health service delivery system of the future. The contributions of the members of the Steering Committee have been instrumental to the success of this project, and their dedication will go a long way toward assuring the implementation of their vision for the future.

Special thanks to Dr. Leslie Major of United Health Services for his leadership and support of the CPEP data analyses and the parent surveys that were critical components of the study. Dr. Major went out of his way to help facilitate the process of accessing the key data, and to make it possible to identify and contact the parents who provided such essential information for the project. Thanks also to Dr. Ramiro Guillen and Michelle Kittle of CPEP, and we are especially grateful for the "above and beyond" efforts of George Funnell of the CPEP staff. Without George's enthusiastic efforts, and his rapport with parents, it would have been very difficult, if not impossible, for us to carry out the parent interview component of the project.

Finally, a special note of appreciation for the more than 200 individual parents, service providers, and other community leaders/stakeholders who completed surveys and spent time meeting with us in various interviews and focus group discussions. Their combined knowledge and ideas were critical to defining and shaping the issues throughout the report. We are most especially grateful for and appreciative of the role of all the parents who generously shared with us their emotions, time, insights, and suggestions. The value of their input is noticeable throughout this document.

Staff Team

Kimberly Hood and James Fatula were critical to the success of this effort, and each was involved in key data gathering and analysis components of the project. Each also wrote substantial sections of this report. Susan Lepler was a key contributor in helping us think through many aspects of the project, and was especially helpful in working closely with the project Steering Committee to help guide them toward the development of the vision and blueprint for the future that will be presented in the Steering Committee's companion document to this report.

I. INTRODUCTION

In recent years, the Broome County Mental Health Department has undertaken several studies which have identified weaknesses and service gaps in the delivery of mental health and related services to children and adolescents with Serious Emotional Disturbances (SED children). These studies have helped spark a desire among Broome County officials, service providers and parents to develop a vision for an improved mental health service delivery system for children and adolescents in the county.

Background and Context

In a recent study of Community Reinvestment-funded projects in Broome County, discussions with more than 100 mental health agency staff, policymakers, consumers and other stakeholders knowledgeable about mental health issues yielded a consensus perception that services to children and adolescents remain among the highest priority unmet needs and greatest challenges facing the Broome County mental health system. Nonetheless, the study concluded that—despite gaps in high-priority children's services, and despite a targeted source of funds dedicated to undertaking needed new initiatives—a relatively small proportion of those resources (only 18% of $1.7 million in Community Reinvestment funds spent in 2001 in the county) has been spent on services for children and adolescents (see CGR, "*Evaluation of Broome County's Community Reinvestment Programs,*" July 2001).

At the high-need end of the service spectrum, a study by the County Mental Health Department indicated that growing numbers of children and adolescents have been referred in recent years to hospitals for inpatient psychiatric treatment, mostly in hospitals located substantial distances from Broome County (see "*The Utilization of Inpatient Hospitalization Services by Children and Adolescents in Broome County 1998-2000,*" January 2001).

These studies, among others, reinforce the growing perception that community-based services which might negate the need for hospitalization in individual cases—and preventive and early intervention services which might address the problems at an early age and thereby help limit the incidence of hospitalizations among high-need children—are insufficient within the county. And, at

the other end of the spectrum, studies have suggested that the community is in need of better follow-through with aftercare services needed to assist in the transition from the hospital back into the community and family setting.

Focus of the Project

The identification of the problem has been relatively clear. But what is needed is a comprehensive, objective assessment of what services are currently in place; whom existing programs do and do not serve; the extent to which people are served in multiple agencies and systems; the magnitude of unmet need and potential demand for services; and the potential to build on the existing foundation by expanding and/or better coordinating existing, or adding new, services. An overall assessment is needed to determine the experiences of families with children who have been placed in hospitals, and to learn from them what obstacles they had to face and what would have been helpful in addressing their children's needs, both prior to placement and in helping with the transition back to the community.

This project addresses these issues and responds to the Mental Health Department's request "to assist Broome County officials to develop a vision for the delivery of services to high need children and adolescents" throughout the county (as stated in the County's Request for Proposals, July 1, 2001). CGR (The Center for Governmental Research) was asked to work with State Office of Mental Health and Broome County government officials and other local resources to help the County meet its overall goals of strengthening community-based alternatives to hospitalization, strengthening the community's psychiatric crisis response system, and reducing the number of out-of-county hospitalized children.

The primary focus of the project is on high-need children and adolescents with a serious emotional disturbance (SED) who are in, or considered to be at risk of placement in, a psychiatric inpatient or residential facility. (A more detailed discussion of the definition of an SED child or adolescent can be found in the Appendix to this report.) The project explores, and makes recommendations about, the development of an integrated service delivery system and the full range of programs and services that might ultimately be needed throughout a continuum of care for SED children and adolescents, and their families.

But as important as it is to focus attention on the needs of this high-risk, SED target population, this project would be too narrow in scope, and would fail in its overall mission and vision, if it stopped there. To begin with, most SED children and adolescents do not just arrive in a crisis situation without a context of missed opportunities, services not provided, and individual and/or family needs not met along the way. The needs of high-risk individuals cannot be addressed by only focusing on services needed at the crisis, high end of the service continuum. Unmet needs at earlier stages help contribute to children and adolescents ending up, with needs having been unaddressed at earlier stages, in crisis settings which often wind up leading to hospitalization. *Thus the ultimate focus of this project goes well beyond only the high-risk SED population, and addresses the broader needs of children and adolescents throughout the continuum of the mental health service system, from preventive and early intervention services to crisis-oriented, emergency intervention.*

II. PROJECT METHODOLOGY

In order to stimulate the vision of, and create an action plan for implementing, an improved service delivery system, a multi-component research methodology was designed to collect and analyze the information needed to understand the current system, and to determine where and how it needs to be improved.

The research approach was designed first to summarize the current mental health service system for children and adolescents in Broome County, its strengths and limitations, the numbers and characteristics of those served by the current system, and indications of unmet needs and service gaps. This analysis of "what is," i.e., of what currently exists in the county, was supplemented by an assessment of "best practices" and model approaches used in other communities, to suggest how the experiences of others could potentially be adapted and integrated with Broome's service network.

Research Components

The specific research components undertaken during the project included the following:

- Mental health service provider survey;

- Unduplicated count survey of service recipients;
- Analysis of CPEP/Crisis Center intakes and dispositions;
- Hospitalization follow-up survey;
- CPEP "Prospective" intake survey of 85 parents;
- "Retrospective" interviews with more than 25 parents;
- Provider and community stakeholder interviews and focus groups involving more than 100 participants.

Each of these research components will be explained in more detail when the findings from each are described in the following chapters of the report.

Key Role of Project Steering Committee

From the beginning, it was anticipated that a critical role in this project would be played by a broad-based Steering Committee which was designed to operate in partnership with CGR and the County Mental Health Commissioner to develop a realistic vision and blueprint to improve the system of community-based mental health services for children, adolescents and their families.

The core of the membership of the Steering Committee was the existing Mental Health Management Council, made up primarily of the CEOs of the county's mental health service providers (as well as parent and County Social Services Department representation). For purposes of this project, Management Council membership was supplemented by other key mental health provider staff members with primary responsibility for youth services, as well as by additional parent and consumer representatives and Mental Health/Juvenile Justice program representation. Although not official members of the Steering Committee, representatives from the NYS Office of Mental Health Central Field Office have also met regularly with the Steering Committee, providing where appropriate a state perspective, technical assistance and the experience of other communities. The full Steering Committee membership is included in the Appendix.

CGR's role in this project was to collect, analyze and help interpret the data, and to facilitate extensive Steering Committee discussions of the implications of the findings for the development of a vision and plan for Broome County's future service delivery system. The Steering Committee has spent numerous meetings discussing

perceptions of the strengths of the current service system; perceived limitations of, and issues and concerns about the current system; a vision and the core principles that should guide the development and evolution of the system of the future; and the components that should be part of what the model plan should look like.

Indeed the final recommendations, vision, and blueprint for improving mental health services for the community's children and adolescents, and their families, are being developed by the Steering Committee, in discussions facilitated by CGR. As such, the final vision and plan are not included in this report, but rather will be included in a separate document—the vision and action plan—being developed by the Steering Committee and to be presented by the Committee to the community later this year.

Focus of this Report

As suggested by the previous comment, this project is producing two separate reports. The first product is this CGR report, which summarizes the findings from the separate research components outlined above. This report, along with companion PowerPoint presentations, is designed to present the key findings and to suggest their implications. By design and agreement with the Steering Committee and the Broome County Mental Health Commissioner, this report stops there: *it does not include the specific recommended vision and detailed action plan for the future*. That vision and plan needs to stand on its own, and needs to be presented not as part of a CGR report, but as a related and complementary effort reflecting the broad deliberations and input of the Steering Committee on behalf of the community.

Thus, shortly following the release of this CGR report, the second final product from this project will be released. That report will be produced by the Steering Committee. It will be a report by the Steering Committee to the Broome County community, and it will contain the Committee's subsequent reflections on the findings contained in this first CGR report. *The forthcoming Steering Committee report will outline the Committee's vision and blueprint for the future delivery of mental health and related services for Broome County's children and adolescents, and their families.*

III. WHAT EXISTS: PROVIDER SURVEY RESULTS

In November 2001, the Broome County Mental Health Commissioner and CGR distributed a survey to all known providers of community-based mental health services for children and adolescents in the county. The purpose of the survey was to provide a "snapshot" of the current service delivery system and those it serves. It was designed to develop an overview of services presently available to children and adolescents in the county, to estimate current system capacity, to determine numbers and characteristics of those served by the existing service system, to assess staffing and funding levels, and to determine gaps and unmet needs to help in planning for the future. A copy of the survey and cover letter are included in the Appendix.

Completed survey responses were received from 32 programs identified by the Mental Health Commissioner. These programs offer a variety of mental health services to children and adolescents. The programs are provided under the auspices of the following eight agencies:

- Binghamton Psychiatric Center
- Broome County Mental Health Clinic
- Catholic Charities of Broome County
- Children's Home of Wyoming Conference
- Family and Children's Society
- Lourdes Hospital
- Mental Health Association
- United Health Services

In addition to the core 32 programs, surveys were received from an additional five programs that offer a variety of related, but non-mental health services. Those programs—provided by UHS, the Imaginarium, Samaritan, and the Institute for Child Development—offer such services as drug/alcohol treatment, general counseling, and services for those with developmental disabilities. Most of the analyses presented below focus on the 32 programs specifically designated as mental health programs, but

references are also made to the other five programs where appropriate.

The November 2001 survey was supplemented by a "mini-survey" of the same mental health providers three months later, at the end of February 2002. That survey was designed to obtain an updated count of numbers of children and adolescents served, but more importantly, to also determine how many "unduplicated," unique individuals were served at one time across the entire service system.

Program Types and Use of Program Capacity

The 32 core mental health programs were grouped into five basic categories or types of programs, based on the service descriptions provided by each program. The five program types are listed in the table below, along with the numbers of programs in each, the cumulative capacity within each type of program, and the numbers served within each program type on November 30, 2001 and on February 28, 2002. (The 32 specific programs are listed by program type at the end of the Appendix.)

	# Programs	Capacity	# Served	
Program Type:		**Nov. 2001**	**Nov. 2001**	**Feb. 2002**
Case Management	6	155	134	143
Clinic	2	500	500	456
Counseling/Other	11	775	718	633
Day Treatment	2	34	34	35
Group Home/Residential	11	189	159	168
	32	1,653	1,545	1,435

It should be noted that "Capacity" for Case Management, Day Treatment and Group Home/Residential programs typically refers to licensed official capacity, or specific slots licensed for specific programs. Capacity for Clinic and outpatient Counseling/Other types of programs, on the other hand, does not refer to licensed slots, and is likely to vary somewhat from time to time. These distinctions should be kept in mind in interpreting the discussion which follows.

Proportion of Capacity Used

The 32 programs indicated that they had the capacity to serve 1,653 children and adolescents at a given point in time. As of November 30, 2001, across the system, 1,545 youth were being

actively served ("enrolled in and currently receiving services from this program"), representing 93.5% of the system's total capacity at that time. This total includes some duplicate counts, i.e., individuals served by more than one program at the same time. But from an overall system use perspective, children and adolescents—whether they were being served by a single program or by more than one provider—were filling well over 90% of the capacity estimated by providers to be available for youth countywide.

Three months later, the total numbers using the same services in February were somewhat lower overall, though the numbers using Case Management and Group Home/Residential services (and a few Counseling program services) had increased. Significant reductions in numbers of users of Clinic services, and in two Counseling programs, had the net effect of reducing the total numbers of children and youth served in February by 110 from the November totals. Despite the decline, the total number served in February (1,435) still represents 87% of total system capacity.

During our two sample months, an average of 90% of system capacity was used by existing programs. An average of about 165 "slots" were unused on the two dates analyzed.

Across the two time periods we looked at, an average of 1,490 children and adolescents, 90% of defined system capacity, were served by the 32 programs. An average of about 165 additional children and adolescents could have been served by the programs at those times, based on unused program capacity. An average of about 100 of those 165 were in the Counseling program category.

About 47% of the total system capacity is represented by the 11 programs grouped under the broad Counseling/Other category. About 93% in November and 82% in February of the 775 "slots" available in Counseling programs were being used during the two time periods examined in the study (an average of 87% across the two months). Within Case Management programs, the proportion of slots filled was similar, ranging between 86.5% in November and 92% in February (an average of 89%). Between 84% and 89% of program capacity (an average of 86.5%) was used in the two months by Group Home/Residential programs. Thus, for each of these three types of programs, an average of between 86.5% and 90% of program capacity was used during the two sample months.

Day Treatment programs operate at full capacity. For each other type of program, children and adolescents filled close to 90% or more of capacity during the two sample months.

The two Day Treatment programs were operating at full capacity during both of the survey periods, and the two Clinic programs

ranged between 91% and 100% occupancy during the two sample months.

Number of Programs Operating at Capacity

More than two-thirds (22 of 32) of the programs indicated that they were operating at or above full capacity in November, but at the same time, there is unused capacity within all but one of the program types, as suggested above. Except for the two Day Treatment programs, each program type had at least one program with significant unused capacity (typically 25% or more of capacity unused at a given time): 1 of the 6 Case Management programs, 1 of 2 Clinics (in February only), 4 of 11 Counseling programs (5 in February), and 4 of 11 Group Home/Residential programs (3 in February). Thus there is some room within the existing system to serve more children and adolescents within nearly all types of programs (perhaps by doing such things as modifying admission criteria, providing quicker access and entry to programs, creating better community awareness of programs, etc.).

There is room within all but one of the five types of programs to serve more children. However, most <u>individual</u> programs of all types are currently operating at or very close to capacity.

On the other hand, *in most programs, there is little ability to serve many more children and adolescents than they are currently serving, unless program resources are expanded.* For example, if there is a need to reach more youth through Day Treatment programs, that would not be possible without either expanding the number of slots or moving people in and out of the programs more rapidly, thereby enabling more to be served but for shorter periods of time.

It should be emphasized that information on use of program capacity should be updated periodically, as significant changes can occur in numbers served over a relatively short period of time. Although numbers of children and adolescents served remained relatively similar during November and February in most programs, changes in numbers served of 10% or more occurred between those periods in 13 of the 32 programs. Thus, in the future, *it would probably be wise for the County Mental Health Department to monitor and update data on capacity and numbers served by program on a quarterly basis.*

Children on Waiting Lists

Although almost one-third of the 32 programs reported having unused capacity, half of the programs reported having one or more children on a waiting list. Each of the five categories of programs had at least one program with at least one person on a waiting list, including: 6 of the 11 Group Home/Residential

programs, 6 of the 11 Counseling/Other programs, 2 of 6 Case Management programs, and 1 of the 2 Clinics and 1 of the 2 Day Treatment programs. Moreover, each program type except Day Treatment had one or more programs operating under capacity while, at the same time, having one or more programs with a waiting list. In fact, five individual programs reported having children on a waiting list at the same time that the same program was operating below capacity. Clearly there appear to be problems getting children and adolescents into some programs in a timely fashion, and there appear to be "disconnects" or mismatches within the system, whereby some programs have unused capacity while other similar programs of the same type are having to turn children away and/or place them on waiting lists.

Some programs have unused capacity while similar types of programs are placing children on waiting lists.

Of the 16 programs reporting children on waiting lists, eight said that the average wait was one to two months, two said three or four months, and six said the average wait was five months or longer. Two-thirds of those programs said no other services were provided "while the child/youth is on the waiting list." Five of the programs said they averaged one or two people on the waiting list in a typical month, six programs averaged between three and six, and five programs said 10 or more children were on a waiting list in a typical month. Across the system, a total of 182 children and adolescents were reportedly on a waiting list in a typical month. About 85% of those (154) were on waiting lists in various Counseling/Other programs (the category of programs that also has the most unused capacity). In addition, in a typical month, the programs reported 13 children/adolescents waiting for access to Group Home/Residential programs; six waiting for Clinics; five for a Case Management program; and four for Day Treatment.

Each month an average of 182 children are on waiting lists for services, often for several months. Some of these individuals may be on more than one waiting list at a time.

It is likely that at least some of these figures may understate the numbers of children who cannot be served at any given time, as some programs do not maintain formal waiting lists, but nonetheless are unable to serve individuals upon request. On the other hand, unknown numbers of those totals could be duplicates, i.e., youth referred to more than one program and thus placed on more than one waiting list at a time, in hopes that an opening will occur somewhere. Even after placement in one program, a person's name may stay on other program waiting lists, if they are not informed of the placement. In that sense, some of these

numbers systemwide could be somewhat artificially inflated. The introduction of a monitoring system through a Single Point of Access (SPOA) could help reduce such duplication of numbers (see discussion of SPOA in subsequent chapters of the report).

Numbers of Children Served

As indicated above, in the "snapshots" taken on November 30, 2001 and February 28, 2002, between about 1,435 and 1,545 children and youth were reported as receiving services from mental health programs in the county. Those numbers represent "slots" filled, and include some duplication of individuals who were being served by more than one provider at the same time. In a special component of the February survey update, programs were able to provide sufficient coded information about the children they were serving, without compromising the identity and confidentiality of individuals, that CGR was able to match individuals across programs to determine duplicates and "unduplicated counts" of children served.

Unduplicated Count Served at One Time

The total of 1,435 children and adolescents served across the system in February actually represented 1,196 separate individuals. That is, after accounting for youth who received services from more than one provider, almost 1,200 *separate individuals* were being served within the mental health system at that time. Assuming similar ratios were in effect in November, when 1,545 "slots" were filled across the system, almost 1,300 separate individuals would have been served at that time. Thus, if one assumes that those two dates were reasonably typical of the service system throughout the year, it is estimated that between about 1,200 and 1,300 separate children and adolescents are served at any one time by existing mental health services—out of a total of 46,095 persons under 18 in the county.

An estimated 1,200 to 1,300 separate children and adolescents are served at any one time by mental health programs.

Numbers Served Annually

The numbers of children and adolescents being served in Broome County appears to be increasing, as suggested by the following program data for the past three years:

- New children/youth admissions for the mental health programs in 2000 totaled 2,060, a similar total to 1999. However, in just the first three quarters of 2001, through September (total 2001 data were not available), 1,920 new children and adolescents had been admitted to the same programs.

The number of children and adolescents in mental health programs is increasing. The annual proportion appears similar to national estimates.

- A total of 5,927 children and adolescents were served in one or more programs in 2000, up slightly from 1999. Moreover, in the first nine months of 2001, 5,507 had already been served.

During the course of an entire year, it is assumed that large numbers of these totals represent multiple admissions and duplicates across programs. There is no way to know from the program data how many unique individuals these totals represent, but it is probably not unrealistic to assume that between 3,000 and 3,500 separate children and adolescents were served during the course of 2000—roughly 7% of the Broome County population of 46,095 children and youth under the age of 18. As such, this proportion of children and adolescents receiving services annually is similar to national estimates of youth receiving mental health services.

It should be noted that our data can only measure utilization of services; we do not have measures of *underuse* or inappropriate use of services—that is, who is not being served that should be, and whether children and adolescents are receiving the appropriate level and amount of services.

Characteristics of Children and Adolescents Served

SED Children

As part of the effort to determine the unduplicated number of children and adolescents served at a point in time by mental health providers, the providers identified those individuals who they knew or believed met the definition of the project's primary target population—youth with Serious Emotional Disturbances (SED). At least 70% of the individuals served in February 2002 were considered by the providers to be SED youth. Approximately another 10% were unknown, so that the actual proportions of SED children served may actually have been higher. Applying these numbers to the total numbers of children/youth served in November and February, we conservatively estimate that this represents about 850 to 900 or more SED children and adolescents in the mental health system at any given time.

At least 70% of those served are SED children—850 to 900 or more at any given time.

These unduplicated count proportions of SED children in the system at any one time were somewhat higher than the provider estimates that 62% of new admissions for 2000 were SED children and adolescents. More than 85% of the programs indicated that they served at least some SED youth who they also considered to be at "high risk of placement." In addition, 43% of the programs served SED youth at "low risk of placement." Almost two-thirds of the programs indicated that they served non-SED children and adolescents who were at high risk of placement, and a third of the programs said at least some of those they served were non-SED youth at low placement risk. (Percentages total more than 100% since programs serve children in more than one of those four categories.)

Age and Gender

A significant proportion of those children and youth receiving mental health services are males, compared to their share of the total population. Males account for 51% of Broome County's total population in 2000 under the age of 18, but fully 60% of the individuals served in February 2002 were males.

60% of those served in the mental health system are males, and over half of those served are under 13.

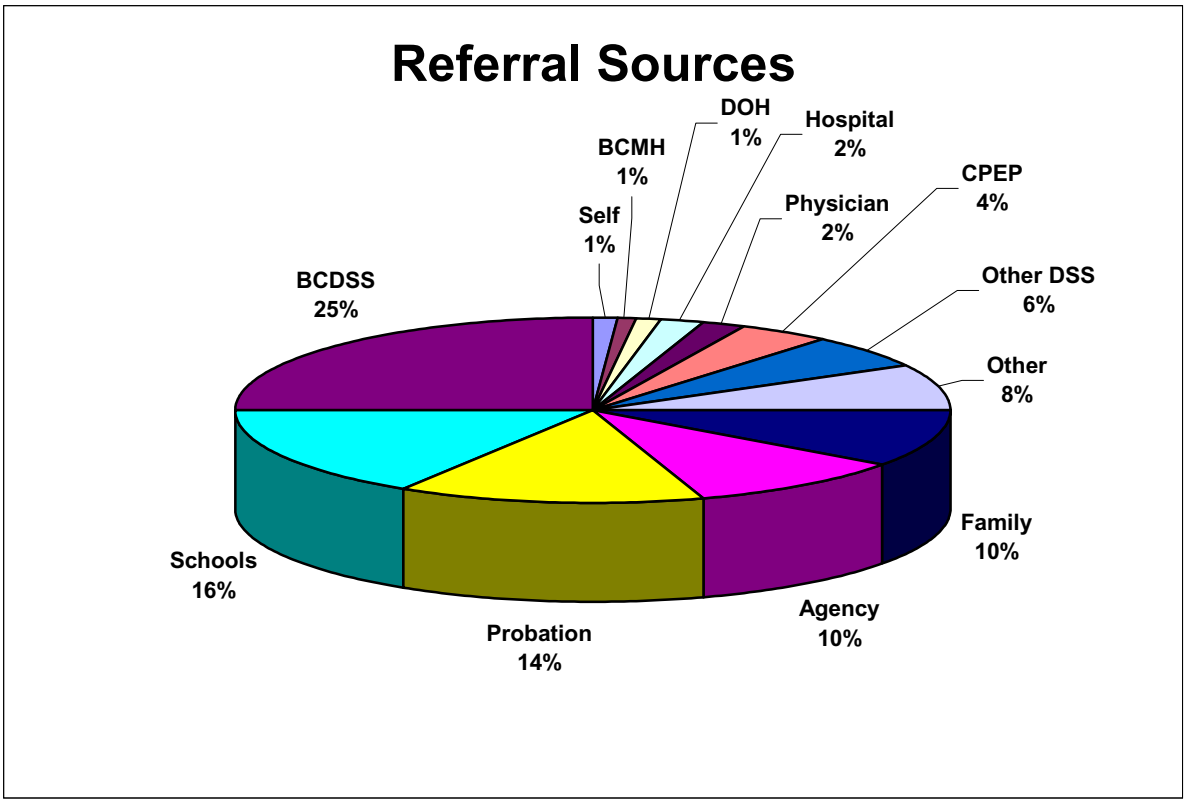
As shown in the table below, almost one-third of those individuals served in February 2002 by mental health programs were 10 years of age or younger, and just over half were under the age of 13.

TOTAL UNDUPLICATED COUNT:	**1,196**	
Unduplicated Count by Age:		
Age (Years)	**#**	**% of total**
0-3	20	1.7
4-6	70	5.9
7-10	279	23.3
11	110	9.2
12	135	11.3
13-17	532	44.5
18-20	42	3.5
Unknown	8	0.7
Total	*1,196*	*100.0*

Sources of Referrals to Programs

As shown in the following graph, children and youth served by mental health programs are referred by a wide variety of sources,

including many from other service systems working with troubled youth and families. A quarter of the referrals in 2001 reportedly came from the Broome County Department of Social Services, supplemented by another 6% from Social Service departments in other counties. Another 16% were referred from schools, 14% from the County Probation Department, and 10% from other service provider agencies. Families accounted for another 10% of the referrals.



Changes in Characteristics of Those Served

Programs were asked to note any significant changes in the population of children and adolescents served over the preceding three years. Nearly all the programs noted that the problems they were seeing were becoming more severe, and that higher proportions of the children, and often their families, come to the programs with more complex, serious emotional and behavioral problems. More often than in the past the cases are perceived to

Providers consistently noted serving more serious cases, more younger children, and more complex family issues in recent years.

involve multiple diagnoses. Several agencies noted the increasing frequency with which they need to address complex family issues, and they frequently noted the need to continue providing services for longer periods of time. Several expressed concerns about the increasing numbers of younger children needing services, and others noted the significant number of children who are involved in multiple service systems.

Selected Characteristics of Mental Health Programs

The survey asked a number of questions about the mental health programs and their operations. Key characteristics of the programs are profiled in the aggregate below:

- Most of the programs currently serving Broome County children and adolescents began serving clients relatively recently. Almost two-thirds of the programs did not exist before 1990, and more than half have been in existence only since 1994, including six programs begun in 2000 or 2001.
- Nineteen of 32 mental health programs (59%) are licensed or certified, including seven by the State Office of Mental Health, nine by the State Office of Children and Family Services, one by both OMH and the State Education Department, and two by the State Department of Health.
- Most of the programs are relatively small—59% typically serve fewer than 25 children and adolescents at one time. About half of those programs are in the Group Home/Residential category, and at least two are in each category of programs except Clinics, which are both much larger. Four of the programs reportedly serve 200 or more at a time, and the remainder typically serve between about 26 and 75 youth.

Most of the programs serve relatively small numbers of children.

- More than half the programs serve at least some children and adolescents who live outside Broome County, although in nearly all of those programs, the proportion of non-county residents is 10% - 20% or less.
- Nearly all the programs say they also provide services to parents of the child they are serving, but in the vast majority of cases, these do not represent extensive, comprehensive family-oriented services.

- About one of every six programs said that their ability to serve children and adolescents is affected by whether the child has health insurance and/or by the type of insurance coverage.
- Three-quarters of the programs reported having 24-hour crisis services available, either through 24-hour coverage or on-call services (10 programs), access to CPEP (11 programs), or a combination of CPEP and on-call services (3).

Program Staffing

The provider survey asked how many full-time-equivalent (FTE) direct care staff (excluding administrative, supervisory or clerical staff) were budgeted for 2001 and, of those, how many were actually on board and working at the time of the late 2001 survey.

Across all 32 programs, about 214 FTE direct care staff had been budgeted for 2001, and about 210 of those budgeted FTE positions (98%) were reported to be filled, with persons currently working in those positions at the end of the year. Several programs also reported that they make use of additional part-time people, on a "purchase of service," as-needed basis. Several of the programs did not include such positions in the above totals. All but six of the 32 programs reported that they were operating with the budgeted number of positions. And the six which had fewer positions filled than budgeted were typically short by only one or a fraction of an FTE position. With the possible exception of an occasional short-term staffing vacancy, programs appear to be consistently staffed at budgeted levels. Thus, it would appear that issues related to any unused program capacity, unserved children on waiting lists or delays in accessing services cannot be directly attributed to any inability of programs to fill budgeted direct care staff positions.

About 98% of 214 budgeted direct care FTE positions in children's mental health programs were filled in 2001.

Eleven programs reported having access to at least a part-time psychiatrist on staff. Three of those programs reported having a full-time psychiatrist, and the other eight shared psychiatric services, with 0.3 FTE or less per program (most of these were either Group Home/Residential or Day Treatment programs).

Program Budgets and Funding Sources

Annual budget information was only available for 28 of the 32 mental health programs. For those programs, the total annual budgets for 2000 exceeded $11.6 million. If we include the five other surveyed programs that offer a combination of drug/alcohol treatment, general counseling and services for those with

developmental disabilities, the total annual budgets exceeded $13.3 million.

At least $11.6 to $13.3 million is spent annually on mental health-related programs for children in the county. Mental health funds leverage other resources to help fund a wide range of services.

The primary sources of funds cited by the programs were the County Department of Social Services, with almost $5.1 million (no breakouts were available of state, federal or local shares); various Broome County funding (mostly unspecified), amounting to just over $3 million; Medicaid (about $2.25 million); and various school districts (about $783,000). Only about $436,000 of the funds were specifically stated as being mental health-related (e.g., OMH, Community Reinvestment, County Mental Health), although it is possible that some of the unspecified Broome County funds may have been mental health-related. Various other sources of funds were also included in lesser amounts, including foundations, private contributions, third party insurers, the United Way, grants, etc. The relatively small amount specifically identified as Mental Health funding suggests the extensive leveraging effect Mental Health dollars can have in accessing a wide range of services primarily funded through other financial resources.

IV. CPEP/CRISIS CENTER INTAKES AND DISPOSITIONS INVOLVING YOUTH

Broome County is the smallest county in New York which has a hospital-based Comprehensive Psychiatric Emergency Program (CPEP) located within the county. Operated by United Health Services (UHS) Hospitals at Binghamton General Hospital, the CPEP offers 24-hour crisis intake, assessment and referral services. As such, it is often thought of as the place of last resort where people experiencing emotional or behavioral crises are referred to seek resolution of the crisis, and hopefully of the issues underlying the onset of the crisis. When all else has failed, and/or when those affected may not know what other services exist in the community or where else to seek assistance, CPEP is typically the place to which they turn for help.

CPEP serves both adults and children, and has a children's unit of full-time specially-trained youth specialists whose efforts are supplemented as needed in the intake and assessment process by nurses who, though not youth specialists, are trained to make assessments of children and adolescents. CPEP also has two full-time children's psychiatrists, who between them provide onsite CPEP coverage 16 hours a day (from 7 am through 11 pm), Monday through Friday. Other psychiatrists are on call during the remaining hours each week night, as well as during the weekend.

Analysis of about two and a half years of CPEP data began to get the attention of mental health officials and other community leaders concerning growing numbers of children and adolescents being referred to out-of-county inpatient psychiatric hospitals (see Broome Mental Health Department, "*The Utilization of Inpatient Hospitalization Services by Children and Adolescents in Broome County 1998-2000,*" January 2001). That study was the primary impetus behind the need for the current project.

Among the key tasks of this project was the need to update the findings of the initial 2001 study, which was only able to track CPEP intakes/presentations and dispositions through part of

2000. A comprehensive analysis of the most current CPEP data was undertaken to determine whether trends identified in the first study held up for an additional year and a half, through 2001 and early 2002, and to undertake additional analyses not possible in the initial study. UHS made available to CGR a comprehensive four-year data base of all CPEP intake visits from 1998 through 2001, and that was subsequently supplemented by additional intake data for the first quarter of 2002. Those data include a variety of information collected at intake for every CPEP visit, including the dispositions of each visit, whether it results in a hospital placement or not, and including various demographic and descriptive information about the child and family.

The detailed analysis of CPEP data was supplemented by a two-month survey of parents of children entering the CPEP assessment process. The parents of about 50% of all child CPEP intakes, during the two months between the first week in February and the first week in April of 2002, completed a brief survey designed to assess their previous experience with the mental health system before coming to CPEP. Findings from that survey are included both in this and the following chapter. A copy of the survey is included in the Appendix.

Pre-Study Perceptions about CPEP and Crisis Intervention

Preceding the initiation of this portion of the study, a number of perceptions existed about the operations of CPEP and the types of decisions made about children and adolescents in that setting. Those perceptions, some based on preliminary data and others on observation of parents, service providers and others in the community, included:

- the perception that increasing numbers of children and adolescents are consistently winding up at CPEP for assessments;
- the perception that increasing numbers of those children are being hospitalized;
- the belief that there are increasing numbers of repeat users of CPEP, and increasing numbers of repeat hospitalizations; and
- the perception that increasing numbers of younger children are experiencing crises and being referred to CPEP.

The analyses presented below were designed in part to determine to what extent these perceptions are or are not accurate.

Trends in CPEP Youth Presentations

Annual presentations to CPEP for assessments increased by 33% from 1998-2001.

As indicated in the table below, the number of presentations/ intakes involving children and adolescents has increased substantially in the last four years. Between 1998 and 2001, the total number of presentations during a year increased by one-third, from 772 to 1,031 last year. And, data from the first quarter of 2002 indicates that the largest-ever volume of presentations last year was continuing at the same pace for the first three months of this year.

CPEP	1998	1999	2000	2001	1998 - 2001
Total Presentations	772	773	871	1,031	+259
% Change Total Presentations		0.13%	12.68%	18.37%	33.5%
Number of Individuals	539	522	605	661	+122
% Change # of Individuals		-3.15%	15.90%	9.26%	22.6%

The 1,031 presentations involved 661 separate individuals in 2001, up from 539 individual children and adolescents who presented at CPEP in 1998 (+23%). Thus it is clear that many of the individuals using CPEP use it more than once a year, as indicated more clearly in the following table showing how many times within each of the last four years youth have presented at CPEP.

Individuals with Repeat Presentations at CPEP				
	1998	1999	2000	2001
# Individuals Presenting 1 Time	386	373	427	454
# Individuals Presenting 2 Times	105	92	118	124
# Individuals Presenting 3 Times	28	30	44	56
# Individuals Presenting 4 Times	11	16	9	6
# Individuals Presenting 5 Times	8	5	4	7
# Individuals Presenting 6+ Times	1	6	3	14
Total # Individuals Presenting	539	522	605	661
Total Presentations	772	773	871	1,031

NOTE: Repeats occur within a calendar year; does not include visits occurring in prior years.

Youth involved in 3+ CPEP intakes increased by 73% to 83 children in 2001.

Each year, about 70% of the total numbers of individual children presenting at CPEP that year were seen at CPEP only one time during the year. The number of individual children and adolescents presenting one time during a year has grown modestly over the four years, by about 18%, to 454 in 2001. During that same time, however, the number of youth presenting more than once in a year has grown by just over 35% (from 153 in 1998 to 207 in 2001). Those with three or more intakes in a year grew by 73%, to a total of 83 different individuals in 2001, including 14 who presented six or more times last year. In each year, half or more of the CPEP intakes/presentations have involved well under one-third of the total number of children who presented during the year. For example, in 2001, 31% of the children and adolescents presented at CPEP more than once, and those 207 individuals accounted for 56% of all 1,031 presentations that year (a total of 577 presentations, an average of 2.8 per youth).

From 1998 – 2001, about 1/3 of all children seen at CPEP accounted for 60.5% of all CPEP intakes during that time. Most repeat presentations occurred within a few months of each other.

These numbers only refer to youth presenting more than once within each individual year; the number of repeat presenters would be higher if visits in previous years had also been included. In fact, in aggregate, across the four years, a total of 2,073 separate children and adolescents were seen at CPEP at least once between 1998 and 2001, of whom 709 (34%) presented more than once during that time, and that relatively small group accounted for 60.5% of all presentations during those four years. Most of those multiple presentations occurred within a few months of each other. Occasionally, multiple CPEP appearances span a more extended period of time, but for the most part, a relatively small proportion of children and adolescents accounts for the majority of presentations, most of which occur within a relatively short period of time. Thus, *if it were possible to address the needs of even a subset of this minority of CPEP users through other means prior to coming to CPEP in a crisis mode, there could be a substantial reduction in the burden on CPEP staff, and in the degree of upheaval in the lives of children and families who end up multiple times at CPEP* (see Chapter V for the family perspective).

Although only speculation, various people throughout the study suggested reasons why the numbers of presentations to CPEP have increased in recent years. Much of the speculation centered around increased numbers of referrals from schools in the "post-

Columbine" era of reduced tolerance for behaviors that might have been ignored in the past or dealt with internally by the schools. Because CPEP's referral source data are not sufficiently clear to draw conclusions, it is not possible to confirm this speculation, but CPEP staff, knowledgeable school officials, and other service providers all independently indicated that this is at least a significant contributing factor to the increase, especially in the last two years, of CPEP intakes. Others noted the increasing numbers and complexity of multi-problem children and families, and insufficient services in place to address those family needs, thus resulting in families and other referral sources having to resort to CPEP when a crisis erupts (see Chapters V and VI).

Characteristics of Children Using CPEP

The large majority (78%) of children and adolescents appearing at CPEP have received at least some services from a variety of community-based service providers before the crisis that precipitated the CPEP visit. As noted above, in many cases, those previous services may have included an earlier CPEP presentation and assessment. Surveyed parents indicated that a wide variety of other services, both within and outside the mental health system, had been used by their child in the three months prior to coming to CPEP. Those services are indicated in the table below, along with a separate indication of whether the services were also being used currently at the time of the crisis that precipitated the CPEP presentation.

Services Received Prior to CPEP Admission:	**Received Service in Past 3 Months**	**Currently Receiving Service**
Child has not received any services during past 3 months	22.4%	NA
School Counselor	42.4%	25.9%
Outpatient Clinic	30.6%	12.9%
Family Physician/Pediatrician	29.4%	15.3%
Other Counseling	23.5%	12.9%
Private Practice Therapist	17.6%	14.1%
Department of Social Services	11.8%	10.6%
Case Management	10.6%	8.2%
Group Home/Residential	10.6%	3.5%
Day Treatment Program	8.2%	5.9%
Private Practice Psychiatrist	7.1%	5.9%
Probation Counselor	7.1%	5.9%
Drug and Alcohol program	2.4%	1.2%

Most CPEP users had recently received services pre-CPEP, but more than one-fifth had not, and many others had not used mental health services.

Although most of the children and adolescents using CPEP had received some type of services during the previous three months, it is significant that more than one in five had had no previous involvement with any services during that time leading up to the crisis, and even many of those who had been receiving services had not been involved with *mental health service providers* prior to accessing crisis services at CPEP.

Age and Gender of CPEP Users

Children and adolescents presenting at CPEP are more likely to be female and 13 and older than among users of other mental health services.

The table below shows the patterns over the past four years in the age and gender makeup of the children presenting at CPEP. The predominant users of CPEP services and those using the rest of the service system differ quite a bit. As shown earlier, about 60% of the users of non-CPEP mental health services are males. By contrast, over the past four years, about half or less of the youth presentations at CPEP have involved males. Even with the increase in 2001, the proportion of males presenting at CPEP (52%) remains considerably lower than the proportion of males among the recipients of other mental health services. Similarly, although just under half of all children and youth receiving non-CPEP mental health services are 13 and over (as shown in the previous chapter), more than 70% of the youth presentations at CPEP during the past four years have involved those 13 and older. (Although the proportions in the table refer to total presentations and not to "unduplicated individuals," separate analyses counting each individual only once yield almost identical proportions.)

CPEP	**1998**		**1999**		**2000**		**2001**	
Total Presentations	772		773		871		1031	
Age < 8 years	28	3.6%	27	3.5%	40	4.6%	36	3.5%
Age 8 - 12 years	149	19.3%	184	23.8%	212	24.3%	270	26.2%
Age 13 - 18 years	595	77.1%	562	72.7%	618	71.0%	722	70.0%
Blank/Missing	0	0.0%	0	0.0%	1	0.1%	3	0.3%
Female	413	53.5%	399	51.6%	449	51.5%	492	47.7%
Male	359	46.5%	374	48.4%	422	48.5%	539	52.3%

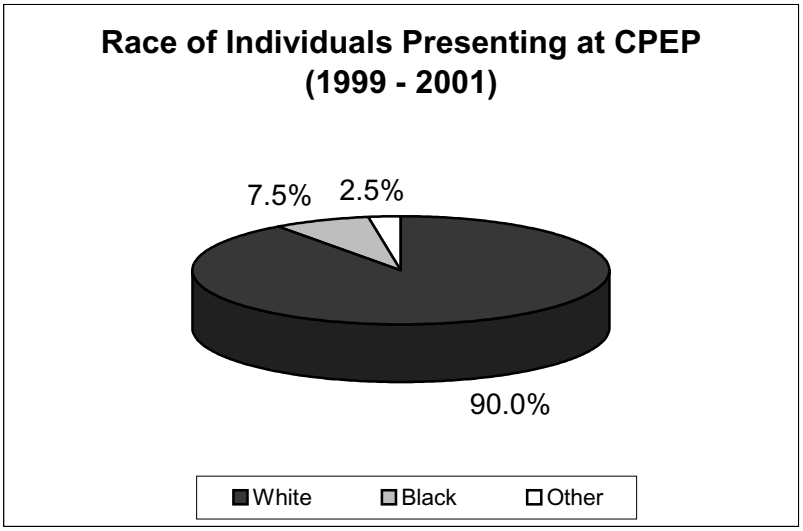
Even though the predominant users of CPEP crisis services have consistently been adolescents over the age of 12, their proportion of all CPEP youth intakes has declined from 77% to 70% since 1998. Most significantly, the number of presentations each year involving younger children between the ages of 8 and 12 has increased dramatically during that time, from 149 to 270 in 2001, an increase of 81%. And, at even younger ages, during just the first three months of 2002, 18 children under the age of 8 presented at CPEP—half the total for all of 2001.

The most dramatic increases in youth presentations at CPEP are among males and children between 8 and 12.

Although the number of presentations at CPEP involving females has continued to increase (by 19% since 1998), the number of males has increased much more rapidly (by 50%), enough to overtake the number of females in total presentations in 2001, as noted above.

Race and Ethnicity

As indicated in the graph below, 90% of all children and adolescents presenting at CPEP during the three years between 1999 and 2001 were Caucasian, and 7.5% were African-American. These proportions are similar to the racial/ethnic breakdowns for youth in the total Broome County population.



Substance Abuse Among Youth Coming to CPEP

Data obtained by CPEP staff at intake indicate that about a third of all individual youth (unduplicated count) appearing at CPEP between 1999 and 2001 had problems serious enough to record that involved the use of alcohol, and similar proportions listed

At least a third, and as many as two-thirds, of all youth presenting at CPEP have alcohol and/or other substance abuse problems.

drug use problems. These are listed separately in the CPEP database, with no indication of how often the problems coexist. Clearly at least a third of all children and adolescents at CPEP are described as having a problem with at least alcohol or other substances, and the proportion could be as high as two-thirds, if the two were each completely independent of the other. It seems most likely that the real proportion using one or both is somewhere in between. Providers suggest anecdotally that substance abuse is a major factor in the presenting problems of many of those at CPEP, especially among older youth.

Marital Status of Parents

More than three-fifths (62%) of the parents of the children and adolescents presenting at CPEP between 1999 and 2001 indicated that they were divorced at the time, 25% were married, and 13% were in some other situation or unknown. Although it cannot be determined from the CPEP data what proportion are single parents and what proportion may have an unmarried parent living with another adult, the large proportion of divorces seems particularly significant in the context of the stresses that are coincident with dealing with crisis situations. As will be seen in more detail in the chapter summarizing the interviews with parents of hospitalized children and adolescents, the degree of family and other types of supports that were or were not present was viewed by many parents as a critical factor in their ability to cope with the behavioral and emotional circumstances associated with their child.

Large proportions of those at CPEP come from divorced families, which may reduce the supports needed to cope with the situation.

Geographic Distribution of CPEP Presentations

Although no consistent data exist on sources of referrals to CPEP, data do exist for about two-thirds of the CPEP children and adolescents on the school district attended. In the absence of other good geographic information, we have used the school district distribution as a rough proxy for geographic distribution of children presenting at CPEP during the years between 1998 and 2001. The table below presents the average number of presentations per year and compares those to the best estimate of average enrollment over the four-year period for each district to generate a rough ratio of number of CPEP presentations per enrolled student. The lower the ratio, the greater the proportion of students presenting at CPEP over the last four years. Thus

Binghamton and Johnson City are the districts which have had the highest proportions of students within their geographic areas presenting at CPEP (one of every 36 and 41 students, respectively, compared with one of every 114 students enrolled in the Chenango Forks area).

Broome County Schools

District	Presentations	Enrollment	Ratio	Poverty Index
Binghamton	174	6204	1:36	21
Johnson City	65	2672	1:41	12
Union Endicott	81	4631	1:57	7
Whitney Point	36	2115	1:59	12
Harpursville	20	1212	1:61	17
Susquehanna Valley	35	2250	1:64	6
Deposit Central	11	737	1:67	24
Maine Endwell	37	2735	1:74	7
Windsor	27	2120	1:79	9
Vestal	47	4284	1:91	5
Chenango Valley	21	2016	1:96	3
Chenango Forks	18	2046	1:114	8
Catholic Schools	13	1644	1:126	NA

With a few exceptions, the geographic areas with the highest poverty indexes tend to be the areas with the highest CPEP presentation rates.

Also shown in the table is a poverty index for each school district geographic area, based on levels of poverty among children, as reflected in US Census data. The higher the poverty index, the higher the proportion of children of any area who are below the poverty level. In general, geographic areas with higher poverty indexes, i.e., lower overall socioeconomic levels, have higher CPEP presentation levels. For example, of the five school districts with the highest poverty indexes (12 or higher), four are among the five districts with the highest proportions of CPEP presentations (Binghamton, Johnson City, Whitney Point, and Harpursville). The primary exceptions to that overall pattern are the Union Endicott area, with the third highest presentation rate but among the lowest poverty index rates; Deposit, with the highest poverty index, but a moderately low CPEP presentation rate; and Chenango Forks, with the lowest presentation rate of all the geographic areas, compared with a moderate poverty index.

Trends in Hospitalizations Resulting from CPEP Intakes

At this point, we shift our attention from the numbers of presentations/intakes at CPEP to the outcomes of those presentations. Of greatest concern to local officials is the proportion of those presentations that result in inpatient psychiatric hospitalizations. The number of children and adolescents who have been hospitalized in a psychiatric inpatient unit has grown at an even more rapid rate than the increased number of CPEP presentations. As indicated in the table below, CPEP assessments resulting in hospitalizations increased by 76% between 1998 and 2001, and the number of hospitalizations through the first quarter of 2002 was on a comparable pace to the first quarter of 2001. The number of separate individuals who were hospitalized in 2001 was 70% higher than it had been in 1998.

CPEP	1998	1999	2000	2001	1998 – 2001
Total Hospitalizations	140	101	163	247	+107
% Change Total Hospitalizations		-27.86%	61.39%	51.53%	76.4%
Number of Individuals Hospitalized	115	93	146	196	+81
% Change Number of Individuals		-19.13%	56.99%	34.25%	70.4%

The number of hospitalizations of youth has increased by 144% in just two years, from 101 to 247.

Given that there was a decline in hospitalizations between 1998 and 1999, there has been an even more rapid growth in the number of youth hospitalized since 1999. In just two years, the number of CPEP intakes leading to hospitalization increased by 144.5%, from 101 youth hospitalizations in 1999 to 247 separate hospitalizations in 2001. Those 247 hospital episodes involved 196 separate individuals in 2001, a 111% increase over the 93 individuals hospitalized just two years earlier.

30% of all youth who appeared at CPEP in 2001 were hospitalized at least once during the year.

The table which follows compares the number of hospitalizations resulting from CPEP intakes to the initial numbers of presentations/intakes for each of the past four years. Following a decline in hospitalizations between 1998 and 1999, as recently as 1999, only 13% of all CPEP presentations resulted in the child or adolescent being hospitalized; just two years later, almost one of every four intakes that year led to the person being placed in a psychiatric hospital setting. When duplicate presentations are factored out, and an individual is counted only once in a year, regardless of the number of times he/she appeared at CPEP or

was hospitalized, 18% of all individuals who presented at least once in 1999 were ultimately hospitalized at least once that year. By 2001, 30% of all individuals who appeared at CPEP during that year were hospitalized one or more times during the year.

CPEP	1998	1999	2000	2001
Total Presentations	772	773	871	1031
Total Hospitalizations	140	101	163	247
% Presentations Hospitalized	18.13%	13.07%	18.71%	23.96%
Individuals Presenting	539	522	605	661
Individuals Hospitalized	115	93	146	196
% Individuals Hospitalized	21.34%	17.82%	24.13%	29.65%

Multiple hospitalizations increased by 400% in two years. One-fifth of youth hospitalized in 2001 were hospitalized more than once, accounting for 37% of all hospitalizations for the year.

As shown further below, in each of the last four years, at least 80% of the individuals hospitalized have only been hospitalized once during the year; a few had also previously been hospitalized in a previous year as well. The number of children and adolescents hospitalized once in a year increased by 83% between 1999 and 2001, from 85 to 156. But the number hospitalized two or more times in a year grew by 400%, from 8 in 1999 to 40 separate youth in 2001. In 2001, fully one-fifth of the individuals placed in a psychiatric hospital setting during the year wound up being hospitalized more than once—up from less than 9% in each of the previous two years. Those 20% of the individual children and adolescents (40 individuals) accounted for 37% of all youth hospitalizations during the year (91 of the 247 hospital episodes).

Individuals with Repeat Hospitalizations				
	1998	1999	2000	2001
# Individuals Hospitalized 1 Time	96	85	134	156
# Individuals Hospitalized 2 Times	13	8	8	32
# Individuals Hospitalized 3 Times	6	0	3	6
# Individuals Hospitalized 4 Times	0	0	1	1
# Individuals Hospitalized 5 Times	0	0	0	1
Total # Individuals Hospitalized	115	93	146	196
Total Hospitalizations	140	101	163	247

NOTE: Hospitalizations within the specified calendar year only; does not include hospitalizations that may have occurred in prior years.

National Perspective

The rate at which children in the county use inpatient psychiatric beds is higher than the national rate.

To put the local data in perspective, we attempted to compare psychiatric hospitalization rates for Broome with comparable rates for other counties throughout the state, but comparable data for all types of youth psychiatric hospital placements were not available county by county. We were able, however, to compare the rates with overall national data. Data reported in the National Institute for Mental Health Blueprint for Change document indicates that nationally 0.2% to 0.3% of all children and adolescents up through the age of 17 use inpatient psychiatric mental health services. It is unclear whether this is at some point during their life or annually, but the context suggests that that proportion is hospitalized each year. By contrast, the comparable proportion in 2001 in Broome County was higher—0.425%. Such comparisons can be misleading without being able to put them in the context of comparing with prevalence of mental illness, demographic factors, supply of hospital beds, availability of other mental health services, etc., but the comparison with national data at least suggests that Broome hospitalization rates are higher than might be expected.

Possible Reasons for Increased Hospitalizations

As with reasons for the increased numbers of presentations to CPEP, reasons for the increased proportions of those presentations resulting in inpatient psychiatric hospitalizations are only speculative at this point, but several possible reasons were offered in various interviews throughout this project. Perhaps most prominent of the reasons suggested is the perception that CPEP is simply seeing more difficult cases, with more serious and complex behavioral problems, that cry out for more extreme and intense resolutions. Some even argue that if anything, probably even more children and adolescents could legitimately be hospitalized than is now the case.

Others argue that this trend is exacerbated by two other trends: More complex family problems and dysfunctional patterns that accompany the child's issues, and increasing desires and demands by school districts for resolution of issues before a student is returned to the classroom. Finally, several of those we interviewed noted that more children and adolescents are referred to hospitals than in the past in part because they are able to receive more thorough in-person assessments by child psychiatrists. In the past, CPEP has always had psychiatrists on call to review cases 24 hours

a day, seven days a week, but more recently, psychiatrists specializing in children and adolescents have been *on site* for 16 of every 24 hours during the weekdays, thereby assuring that more of those presenting at CPEP are actually seen directly by a psychiatrist than was typically the case in the past.

Characteristics of Children Referred to Psychiatric Hospitals

Data showing the distribution of presentations to CPEP by geography, race/ethnicity, client drug/alcohol use, and marital status of parents were presented earlier. Unfortunately, comparable descriptive data were not available for those who were hospitalized. There is no reason to believe that those distributions are any different for the hospitalized versus the non-hospitalized cases, but we have no way of independently confirming that. In partial support of the no-difference argument is the fact that the age and gender profiles of those hospitalized is very similar to the distribution of all presentations to CPEP.

Age and Gender of Hospitalized Youth

The age and gender profile of hospitalized youth is virtually identical to the initial CPEP intake profile.

As indicated in the table that follows, over the past three years, just under 30% of all cases in which a CPEP presentation resulted in a psychiatric inpatient placement involved children under the age of 13; just over 70% involved adolescents between the ages of 13 and 18; and the proportions of males and females have varied from year to year, but over the three years have each hovered close to 50%. These proportions, both by age and gender, differ very little from the CPEP intake proportions shown earlier in the table on page 23, suggesting that there are no differences by age or gender in the proportions of children and adolescents who are assessed at CPEP versus those who wind up being hospitalized as an outcome of the CPEP assessment process.

CPEP	**1998**		**1999**		**2000**		**2001**	
Total Hospitalizations	140		101		163		247	
Age < 8 years	3	2.1%	1	1.0%	9	5.5%	5	2.0%
Age 8 - 12 years	22	15.7%	27	26.7%	38	23.3%	68	27.5%
Age 13 - 18 years	115	82.1%	73	72.3%	116	71.2%	173	70.0%
Blank/Missing	0	0.0%	0	0.0%	0	0.0%	1	0.4%
Female	74	52.9%	52	51.5%	76	46.6%	124	50.2%
Male	66	47.1%	49	48.5%	87	53.4%	123	49.8%

70% of hospitalizations involve youth 13 and older, but hospitalizations of those 8-12 has tripled since 1998. Hospitalizations of both boys and girls are up substantially since 1998.

What has shifted considerably since 1998, as it has for CPEP intakes/presentations overall, is the proportion of young children who are hospitalized. In 1998, only 18% of all hospital admissions involved children under the age of 13. By 2001, that proportion had grown to 29.5%. Indeed, while the number of hospital placements involving 13-18 year-olds was increasing by 50% from 1998 to 2001, the number of children between the ages of 8 and 12 who were hospitalized tripled, from 22 to 68.

By gender, hospitalizations of both boys and girls have increased substantially, but especially among boys: In 2001, female hospitalizations were 68% higher than in 1998, and hospitalizations involving males were up 86% between 1998 and 2001.

Location of Hospital Placements

Several of those interviewed during this study argued that the issue is not so much the numbers of children and adolescents being hospitalized in a psychiatric inpatient facility, but *where* those hospitalizations are occurring. Indeed, some argued that perhaps even more hospitalizations might be justified in some circumstances. The issue, as framed in such arguments, is that the distances involved in sending a child to a hospital outside the county create major hardships for families, create communication and support barriers between child and parent during the hospitalization, compound communications problems between parents and those providing treatment, and increase the problems involved in making the transition back to home and community from the hospital setting. These issues are addressed in more detail from the perspective of parents in the next chapter, and from the perspective of service providers and community stakeholders in the chapter following that.

Regardless of the merits of these arguments, what is undisputable is that the vast majority of referrals to psychiatric hospitals do involve placements in hospitals outside Broome County.

2001 CPEP Hospitalizations (n=247)		
Referrals to:	**#**	**%**
UHS	37	15.0%
Four Winds Syracuse	58	23.5%
Four Winds Saratoga	28	11.3%
St. James (Hornell)	27	10.9%
Stony Lodge (Westchester Co.)	20	8.1%
Fox Adolescent (Oneonta)	13	5.3%
Mohawk Valley Psych. Ctr. (Utica)	12	4.9%
Hutchings Psych. Ctr. (Syracuse)	12	4.9%
Niagara Memorial	12	4.9%
Four Winds (Unspecified location)	11	4.5%
Brylin Hospital (Buffalo)	6	2.4%
Ellis Hospital (Schenectady)	6	2.4%
Jones Memorial (Jamestown)	2	0.8%
Rockland Co. Hospital	1	0.4%
Hillside Hospital (NYC)	1	0.4%
Presbyterian Hospital (NYC)	1	0.4%

85% of youth psychiatric hospitalizations are to sites outside Broome County.

As shown in the table, only 15% of all children and adolescents who were hospitalized in 2001 remained in the county, in wings at Binghamton General Hospital in the UHS system. Only those 16 and 17 years of age can be placed at UHS, so all 37 of the UHS hospitalizations in 2001 involved 16 and 17 year-olds. But even having that local site available for those older adolescents is not sufficient to meet the needs of all hospitalizations involving 16 and 17 year-old youth, as many others in that age range were placed outside the county.

The largest single source of referrals in recent years has been to the Four Winds hospitals in Syracuse and Saratoga County (39% of the 2001 placements). About 10% of the placements have involved the state psychiatric facilities in Syracuse and Utica. Substantial numbers of placements have involved travel to places as distant as Westchester County, Buffalo, Hornell, Niagara Falls and Oneonta.

Youth hospitalizations outside Broome County increased by 180% from 1999 to 2001.

Historically, the number of hospitalizations involving local placements at UHS has been relatively stable—from 26 to 29 to 37 from 1999 to 2001 (a 42% increase), while hospital placements in facilities outside the county have increased from 75 to 134 to 210 during those three years—an increase of 180%.

Data on Hospital Admissions

Through the efforts of the Broome County Mental Health Department, we were able to obtain some additional information from selected hospitals admitting children and adolescents from Broome County. The information included data on some referrals that did not originate through the CPEP process, and enabled us to determine lengths of stay per hospital episode and the type of health insurance coverage of the youth involved.[1]

We were able to obtain useable information concerning hospital admissions in 2000 and 2001 from six hospitals: UHS, Four Winds (both Syracuse and Saratoga), Stony Lodge, St. James, and Hutchings. These six hospitals represent almost 80% of all CPEP admissions from Broome County in 2000 and 2001.

Non-CPEP Referrals

Almost 90% of all psychiatric hospital admissions of county youth come from CPEP. Including non-CPEP referrals, there were 270-275 psychiatric hospital admissions of Broome County youth in 2001.

CPEP is not the only source of referrals of Broome County children and adolescents to psychiatric hospital beds. In the six hospitals for which we had supplemental data, 89% of all admissions of Broome County youth in 2000 and 2001 came directly on referrals from CPEP. Referral sources for the other admissions are not known, but they presumably could include some private practitioners, including ones located in other counties who provide care for some Broome residents. Most of the referrals of county residents that did not come from CPEP involved admissions at Four Winds, plus a few in each year at Hutchings and at UHS. In the two years for which we had additional hospital data, there were between 20 and 25 additional (non-CPEP) hospital admissions involving county children and adolescents. Adding those admissions to the previously-reported admissions referred through CPEP, it appears that in 2001 there

[1] We also attempted to determine the nature of discharge planning that occurred, the referrals made upon discharge, and the degree of follow-through with referral sources. All of the discharge planning-related information received was too vague and unreliable to be of value, so it is not reported.

were a total of between 270 and 275 separate inpatient psychiatric admissions involving Broome County children and adolescents.

Age at Admission

The overall average age at admission was slightly higher at these six hospitals, including both CPEP and non-CPEP referrals, than it was for the CPEP-only admissions for all hospitals. The average age was 14, and 78% of the admissions at the six hospitals involved youth 13 and older—slightly higher than the 70% of all CPEP admissions. This is at least partly, if not entirely, due to the fact that all the UHS admissions involve 16- and 17-year-old youth, and UHS accounts for 21% of the admissions of these six hospitals, compared to only 15% of all CPEP hospital referrals. In addition, it may be that more non-CPEP referrals are made for older youth, although we have no way of knowing that from the data.

Hospital Length of Stay

Average lengths of hospital stays appear to be increasing.

The average length of stay (LOS) in the six hospitals was 17 days in 2000 and 18 in 2001, up from about 14 in 1999, as reported in the earlier Broome County study[2] (data from the two studies are comparable since both included five of the six hospitals included in this study). Stays ranged from as few as two days to as many as 289, with the average lengths of stay typically ranging between 15 and 25 days in the for-profit and non-profit hospitals and considerably longer (one and a half to two months) in the state psychiatric center. The overall median LOS, which was about 9 days in 1999, dropped to 8 in 2000 and increased to 11 in 2001. What appeared to have been "a slight trend toward shorter stays over time," as reported in the earlier study, seems to have been reversed in 2000 and 2001.

Typical hospital lengths of stay are significantly longer for children under 13—the age group with the fastest growth in hospital admissions.

As indicated in the table that follows, the typical hospital LOS is significantly longer for children 12 and under than it is for adolescents 13 and older. Thus the stays are typically shorter for the 70% of the hospitalizations that involve youth 13 and older, but they are considerably longer, and more costly, for the fastest-growing segment of the hospitalized population—those under the age of 13.

[2] *"Utilization of Inpatient Hospitalization Services by Children and Adolescents in Broome County 1998-2000,"* January 2001.

Length of Stay (Days) by Age				
	2000		2001	
Age:	**Mean**	**Median**	**Mean**	**Median**
<8	23	15.5	52	27
8-12	30	16	23	17
13-17	11	7	16	10
18+	19	8	12	9

Type of Health Insurance Coverage

Five of the six hospitals provided data on type of insurance coverage for the youth they were treating. Although the data are somewhat ambiguous as reported, we know the following:

- All of those admitted to these five hospitals in 2000 and 2001 had some level of mental health insurance coverage, i.e., at least some portion of their hospital costs for at least some period of time was covered.
- A minimum of 20% of those in each of the hospitals (and typically much higher proportions) were covered by Medicaid, including all of those admitted at Hutchings. In the aggregate, across all the hospitals, at least half the children and adolescents were covered by Medicaid.
- An additional one-third of the hospitalized youth reportedly had "Private (managed care)" coverage. It is likely that at least some, and possibly all, of this managed care portion is Medicaid managed care, and some might include Child Health Plus coverage, instead of placing it under Medicaid, so that the Medicaid portion may actually exceed 50%, but the data are not clear enough to make any definitive determination.
- About 16% of the youth are covered by "traditional private pay" insurance.

All youth in these hospitals had at least some mental health insurance coverage, and at least half were covered by Medicaid.

While it may be reassuring at some level to realize that all of the youth being treated in these hospitals were covered by at least some level of mental health insurance, the insurance may have had significant limitations on what it would cover, and for how long. As will be seen in more detail in the parent and stakeholder chapters to follow, limitations on types of services, and on lengths of hospital stays that are covered, are perceived by many as placing significant limits on options available to parents and service providers.

Estimated Costs of Purchasing Hospital Coverage

CGR attempted to come up with an admittedly-rough calculation of what it cost to pay for all psychiatric hospital days involving Broome County children and adolescents in 2001. We based our calculations on the following assumptions:

- We used the Medicaid payment rates for specific hospitals, where known. These included rates for hospitals covering about 80% of the Broome County hospitalizations in 2001. For the other hospitals, we applied an average Medicaid rate, based on the average of the known Medicaid hospital rates. As shown above, using Medicaid rates may not be appropriate in every instance, but these were the only reimbursement figures available to us, and we believe they are reasonable to use to determine order-of-magnitude estimated costs.

- For the six hospitals for which we had actual data on lengths of stay, we used those data in our cost calculations.

- For the other hospitals, we used an average LOS based on the experience of the six hospitals for which we had complete data. The average length of stay across those hospitals was 18 days. We used that estimate and applied it to the 54 admissions in 2001 of Broome County youth to hospitals other than the six referenced above.

Based on these assumptions, we estimate that the approximate costs of purchasing inpatient psychiatric hospital coverage for Broome County children and adolescents in 2001 equaled $2,657,500. Most do not appear to involve direct "out of pocket" costs to the individuals involved. But significant proportions represent costs that Broome County or the state must pay through Medicaid. As noted above, the actual proportions of cases covered by Medicaid, and the funding represented by those proportions, cannot be precisely determined. However, based on the data available to CGR, we estimate that at least $1,328,750 and as much as $2,205,725 of the costs are covered by Medicaid. It is probably most reasonable to assume that the actual Medicaid figure is about midway between these estimates, or about $1,765,000 in 2001.

The estimated costs of purchasing inpatient hospital coverage for county youth in 2001 was $2,657,500, 83% of which leaves the county.

Whatever the sources of payments, they represent funds that, for the most part, the public sector and private insurers are paying for services that, as will be seen in the next chapters, are not universally judged to always be effective. And, from a County economic impact perspective, except for the estimated $445,000 going to pay for coverage of treatment at UHS, the remaining $2,212,500 (83% of the total estimated expenditures) are being spent in counties other than Broome.

It should also be noted that these totals do not include what were often perceived to be substantial additional costs involving ambulances to hospitals, transportation-related costs of families traveling to and from hospitals for visits, telephone calls between homes and hospitals, etc.

Non-Hospital Referrals by CPEP

The focus in the preceding pages has been on the growing number and proportions of referrals of children and adolescents to psychiatric inpatient hospitals. But, as noted earlier, despite the growing numbers of hospital placements, three-quarters of the CPEP presentations involving children and adolescents in 2001 did not result in hospitalizations (and more than 80% of all presentations between 1998 and 2001 did not involve hospital placements). Over those four years, that represents about 2,800 presentations in which no hospitalization resulted. In some of those cases, no specific services were provided or referred beyond the intake and assessment at CPEP. Many parents and stakeholders expressed concerns that CPEP officials too often do not make referrals to services following their assessment, and that even when they do, there is typically no effective mechanism for following through to assure that referred or recommended services are actually accessed. Nonetheless, CPEP records indicate that in most cases, some type of referral is made to one of a wide variety of private practitioners and community programs.

In most of the 2,800 non-hospitalized CPEP presentations, at least one referral is made to a community provider.

CPEP records indicate primary referral sources (these same providers may have also been referred additional times as a secondary referral). CPEP records over the past four years indicate that the following community resources have been most frequently listed as the primary non-hospital referral source resulting from the CPEP assessment (out of the approximately 2,800 non-hospitalized presentations to CPEP):

- Broome County and Broome Psychiatric Center clinics – 592 referrals;
- UHS Children and Youth follow-up and interim visits (it is not clear to what extent some of these may also result in subsequent referrals to other providers) – 352;
- Private psychiatric practices and therapists – 256;
- Adolescent Crisis Residence – 225;
- Gateway – 194.

In as many as 20% of the non-hospitalized CPEP presentations, no referrals appear to have been made. It is not clear how often referrals result in actual services being performed.

Numerous other agencies and individual programs are also listed as many as 40 or 50 times, or as few as one or two times. What is not known is how often those referrals result in actual connections being made, and actual services being delivered. Beyond that, it appears from the records as if between 15% and 20% of the non-hospitalized CPEP presentations may result in no formal referrals, although it is possible that in some of these cases, a referral may have been made without being actually recorded in the database.

Accuracy of Pre-Study Perceptions

Early in this chapter, we stated a number of prevailing "conventional wisdom" perceptions about Broome County's crisis intervention process, the numbers of children affected by it, and the outcomes of the crisis intervention assessment process. The data in the preceding pages have essentially confirmed that the initial perceptions have held up as factually accurate, including:

- increasing numbers of children and adolescents are consistently winding up at CPEP for assessments in crisis and perceived crisis situations;
- increasing numbers of those children and adolescents are being hospitalized, increasingly outside Broome County;
- there are increasing numbers of repeat users of CPEP, and increasing numbers of repeat hospitalizations; and
- increasing numbers of younger children are experiencing crises, being referred to CPEP, and being hospitalized.

In addition, data have made clear that over the past four years, about one-third of the children and adolescents who have been seen at least once at CPEP during that time have accounted for 60% of all CPEP presentations.

V. SUMMARY OF PARENT PERSPECTIVES

In this chapter, CGR summarizes what we heard from more than 110 parents. This reflects the voice of parents and their experiences with the mental health system. The chapter presents what parents said, for the most part in their own words (typically noted in italics to call attention to the comments). The comments represent the perceptions of parents, and the comments cannot be independently verified as to their accuracy. However, the perceptions are often quite similar to comments reported in the next chapter from community stakeholders and service providers, and are in many cases verified by data reported in the previous chapters. In any event, the parents' perceptions are important in their own right, and reflect their reality. As such, their voices speak for themselves. As one parent said, "The story needs to be told."

From the perspective of CGR and the Mental Health Department, it was important to include the voice of parents. Too often planning processes incorporate the voices and insights of planners, service providers, policymakers and funders, but overlook the perspectives of those with direct experience with the receipt of services. It was important in this process that those perspectives be shared, including what worked well in parents' experiences, and what changes they would like to see in the future.

Methodology

The study obtained parent perspectives in two ways. Both focused on the experiences of parents who had been involved with CPEP in crisis situations. This emphasis was deliberate, since the primary focus of the project was on the high-risk, SED children and adolescents, many in or at risk of placement. By incorporating the views of parents of these "high-end" youth, we also gained insights about the rest of the mental health system as well, as most of the parents and their children had experienced many aspects of the system prior to, simultaneous with, and/or following their experiences with crisis services.

The first way in which we obtained information from parents was through a written "prospective, mini-survey" which parents completed as their child was undergoing intake at CPEP. That

survey of 85 parents, about half of all CPEP intakes over two months earlier this year, was described in the previous chapter. Some data from that survey were presented in Chapter IV, and the remaining data are presented in this chapter.

The second opportunity to obtain input from parents was via in-depth interviews conducted with a sample of parents of children who had been assessed by CPEP and hospitalized during the first quarter of 2001. In contrast to the "prospective mini-survey" of parents "before the fact," as they entered the crisis center, this survey was designed as a "retrospective" reflection of previous experiences. CGR used CPEP intake data to select a sample of parents representative of all youth intakes that resulted in hospitalization during the first three months of 2001. Letters were sent to the sample inviting them to participate, and follow-up phone calls were made to obtain parents' agreement to be interviewed. No one declined to participate when asked. Parents were offered a $40 stipend to participate. We selected a sample of 25 parents to be interviewed, and 23 of those actually followed through and completed the interviews, representing 12% of all children who were hospitalized as a result of CPEP referrals during 2001. These interviews were supplemented by a group interview with four Parent Partners, including two parents whose children have also had direct experience with CPEP and psychiatric hospitalizations. The interviews typically lasted an hour and a half to two hours. Interviews were confidential and anonymous, and the parent observations which follow are presented in such a way that no one can be identified in any way by the comments. Interviews were semi-structured and conversational, but were designed to elicit certain consistent types of information.

The sample selected appeared to be representative of the range of children and youth who were hospitalized in 2001. The sample was socio-economically and geographically diverse; the children represented in the sample reflected the age, previous CPEP experience and previous hospitalization profiles of the overall hospitalized population; and the parents reflected varying degrees of sophistication and a range of single-parent versus married couple situations. As such, although one should always be cautious about generalizing too much from such a diverse group,

CGR believes that much can be learned from the varied experiences of those in our sample.

Practically all the parents were very much looking forward to the chance to share their experiences, and to help improve the system as a result. Many noted that there is often a sense of isolation, of feeling that no one else knows what a parent and family is going through. As such, it was important and even therapeutic for many to have the opportunity to "tell their story," and they were typically grateful for the opportunity, particularly in the hope that their experiences and insights would help lead to improvements that would reduce the need for other parents to have to go through similar experiences in the future.

Finally, it is worth noting that while parents often had negative experiences with the mental health *system*, many parents expressed their gratitude for the "wonderful" *people* who had been involved in the care of their children. It seems that *systems* issues that parents confront in how they obtain and use mental health services for their children are the overriding issue for parents, even as they find individual people helpful during their episodes of care.

Prospective Survey Findings

In contrast to the "retrospective," after-the-fact in-depth interviews of parents, this brief mini-survey was designed to obtain some summary views of parents as their child was entering the CPEP assessment process. As reported in the previous chapter, most of those entering CPEP had been involved in some services in the previous three months, though more than one-fifth had not, and many others had not been involved with mental health providers immediately prior to the crisis that had precipitated their appearance at CPEP.

Most parents thought services used by their child had been at least somewhat helpful, but half said they had had problems obtaining needed services.

Parents were asked how helpful any previous services their child had experienced had been. Most said they had been at least somewhat helpful: 18% said very helpful, 47% somewhat helpful, and 13% not at all helpful, with 22% not answering the question. When asked if they had had problems obtaining services for their child in the past, half of those responding indicated that they had. Among the major problems or barriers that they believed had prevented them from accessing needed services for their child were the following:

- 14% - parent didn't know what was available;
- 14% - services needed were not available in the county;
- 12% - said their child was uncooperative;
- 11% - child was on a waiting list for services;
- 9% - the program needed had no openings;
- 7% - child wasn't eligible for Medicaid;
- 6% - insurance didn't cover needed services;
- 6% - transportation to services was a problem;
- 5% - services were not offered at convenient times.

In addition, 16.5% of the parents indicated they had tried to manage the problem on their own without professional help.

Although these numbers are not individually overwhelming, they suggest a picture of many parents feeling frustrated at not knowing what resources were available to them, attempting to solve the problems on their own, and not always being able to access services when they were needed.

When asked what services their child, or the parent or family, needed but couldn't obtain, the following were mentioned most often:

Parents noted the need for more counseling and anger management services, a local inpatient facility, and increased parent supports.

- counseling and/or therapist (for the child);
- anger management (mentioned frequently both for the child and for the family);
- a local inpatient psychiatric hospital for children;
- various supports for families to help them cope with the situation, and improved ways to have parental views and needs factored into decisions made about their child.

Retrospective Survey Sample Profile

The average age of the children and adolescents in the retrospective sample of 23 was 13 years, ranging from one child who was 6 at the time of hospital admission, to two adolescents who were 16 at the time of the sample hospitalization. Other characteristics of the sample included:

- About three-quarters had at least some mental health service use prior to the hospitalization.
- Forty percent or more had some PINS/Probation involvement, either before or after the hospitalization.
- Almost half had been involved in special ed/BOCES programs.
- Over a fifth had some kind of DSS involvement.
- About a fifth had some type of developmental disability.
- Sixty percent of the children/adolescents had multiple (2 to 4) hospitalizations (including the sample hospitalization event and others which occurred either before and/or after the sample hospitalization).
- About 60 percent were hospitalized for about a week, although many had longer episodes.
- Almost three-quarters of the parents were dissatisfied with the experience of the hospitalization of their child, at least to some extent.
- More than half of the parents expressed dissatisfaction with the hospital discharge plan, or the lack thereof.

Despite the fact that many parents supported hospitalization for their child, ¾ were dissatisfied with the hospital experience, and more than half were dissatisfied with the discharge planning process.

Parent/Family Experience with the Mental Health System

The experience of parents with the mental health system ranged from a relatively single "episode" of care, related to the current crisis, to fairly life-long issues their children were facing with regard to depression, suicidal behavior, and a variety of behavioral issues, often involving violence.

The experience of using a psychiatric emergency room, followed by an out-of-county hospitalization, was particularly challenging for "first time" parents, although more "veteran" parents—those who had been through a previous hospitalization of their child—did not always fare much better in their subsequent experiences. Parents—especially first time users—understandably are often not sufficiently knowledgeable about mental health issues and services for children—about what these services are, what is available, who is eligible, what is appropriate for them. At the time of a crisis or emergency (particularly first time users), they have to learn a lot very quickly.

For most parents, the experience of a CPEP visit followed by an out-of-county hospitalization was a "long day"—literally and figuratively. It was an exhausting experience for parents, and presumably for their child. As one parent said: "This was the hardest week of my life."

Other parents summarized their overall perspective this way (direct quotes in italics):

- *"It's like a big black hole. If you are not careful, you will be sucked into it."*
- *"We arrived at (hospital) at 1am. We went through intake: sign here, sign here, sign here. We got a guided tour of the pod where he would stay. He was put on a 24-hour suicide watch. It was a hellish 18 hours."*
- *"I've run out of options."*
- *"It is hit or miss with these kids. You feel helpless and the medications may not work."*
- *"When it's your child, you lose it. You're not in charge anymore. God help any other parent who goes through this. It's horrible. Nothing has changed, except he is medicated. He needs so much more. It's day after day with (my child). It's been so difficult. We were let down by the system…. It affects your whole family, but you somehow manage. It affects everything. You do what you have to do."*
- *"We have a good kid and we've had to work too hard to help him out. It's maddening. It's an extraordinarily emotional experience for us."*
- *"There are no lengths a parent will not go to make sure their child gets what they need, but it's frustrating not to have choices."*

Many parents reported feeling out of control during their child's crisis experiences.

- *"You're told to consider yourself lucky if you have a psychiatrist."*
- The experience took a toll on the marriages of some parents. One mother felt she had to basically choose between her husband and her son. *"Maybe if there had been more supports for the family, that wouldn't have been the case."*
- Another parent said *"I can't imagine what it would be like for those without a supportive spouse, kids, job situation and financial stability, good insurance coverage, church support, etc."*

Parents say they need a variety of supportive resources to help get through the situation with their child.

- Some of the parents are single, compounding the burdens they face. As one parent said: *"It's been critical to have two parents who can share the burden and help get through all this. I can't imagine having to do this by myself."*
- *"(My child) is stuck back home, where it wasn't appropriate before, and isn't now either, without a lot more support, which isn't being provided. There needs to be more support for the kid and family when he returns home from the hospital."*
- *"I feel sort of helpless to really know how to deal with the situation."*

There were particular issues with older adolescents. One parent noted:

- *"Now that (my child) is 16 she has a say in what service she will or won't participate in. I would like to see the law changed in this area. I don't believe 16 year olds are always capable of making good choices. I'd like to have the law back the parent and get services for kids. Pursuing help through the legal system is the last opportunity for (my child) to turn around."*
- A few parents mentioned the stigma associated with having a child with mental illness. *"I lost a friendship over this, as the person simply couldn't understand what we were going through, and thought there must be a rational solution that we could control, and that the fact that things were beyond our control must be a sign of bad parenting or weakness on our part and on (my child's) part. This drove a wedge between us, so there's still a lot of misunderstanding about mental illness."*

Experience with CPEP

Overall, parents were generally pleased with their CPEP experience, with the staff, with how they were treated. *Except for the wait.* In saying that, it is important to note that these were parents who had had children hospitalized, in many cases with the agreement of the parents, who recognized the problem needed a drastic solution.

Overall Satisfaction with CPEP

Typical comments from parents about their CPEP experience included:

- *"CPEP does an excellent job. The need is there and they need more staffing. They saved my sanity more than once."*
- *"These people—CPEP—are wonderful; they are really helpful."*
- *"I had older friends who had come to the Crisis Center who were helped and were leading better lives—and this is what I wanted for (my son). The place was great. I would recommend the Crisis Center to anyone. I didn't realize what was going on. I got great help from CPEP."*
- *"Here at CPEP, it was fine. We were treated with respect. Except for the wait."*

But, there were exceptions, particularly with regard to the choices parents felt they did not have.

- *"They really have good staff here at CPEP, but they don't have enough resources in the community to work with."*
- *"The psychiatrist said (my son) would need a psychiatric evaluation but that it couldn't be done here. They called it an evaluation. I asked them if I had any choice in this, they said no. They said that (my son) would have to go for the evaluation at Niagara Falls Hospital, the only one that had the room. When I heard that, I cried. It was so far away. I asked them if I had any say in this, they said no."*
- *"CPEP staff were great and tried so hard to help, and to find an appropriate hospital bed. They made over 50 calls, but either the hospitals said they wouldn't take someone with (my child's) problems or didn't have an available bed. We'd have sent him anywhere at that point, but there was nothing available."*

Parents gave CPEP high marks for their efforts, but often felt CPEP staff didn't have sufficient resources to work with.

Long Wait at CPEP

While parents were generally pleased with CPEP staff, many parents mentioned the long wait at CPEP and the toll it took on them, waiting to find out about the availability of any bed somewhere in the state, and the uncertainty, the not knowing. For a fairly large number of parents in the sample, the "long day"—from initially arriving at CPEP to the subsequent hospitalization—lasted 24 hours or longer, and it was a physically and emotionally exhausting experience.

- *"Here they are helpful, but they are understaffed here. The big issue at CPEP is how long you have to wait when you are here. Usually a 4-5 hour wait. If they don't have good news to tell you, it takes forever to tell you. You are here for 4-5 hours, then they tell you no bed is available and the kid can go back home."*
- *"For me, it would have been a whole lot easier if CPEP, in hunting for a bed, told us that they were doing that, and give us a few hours to come back for him. It turns out to be a long night otherwise, just waiting. "*
- *"It's so hard when you don't have enough sleep."*
- *"When (my child) went to Saratoga, she was taken there late at night. CPEP doesn't have any beds, not even temporary beds for while you wait, so you have to go in the middle of the night if that's when they find a bed. It would be nice if you had a temporary place to stay at CPEP and could leave in the morning particularly if you have to follow in your own car."*

Parents were very frustrated with long waits at CPEP, and not knowing what would happen. They cited a need for better follow-up post-CPEP.

Need Follow-up CPEP Support

Some parents mentioned some other things they felt would be helpful at CPEP.

- *"It would be great if CPEP could provide follow-up, including home visits a couple weeks later, to see how things are going. Or make appointments for the family to return in several weeks, with consequences if they don't. That would hold parents accountable, but also offer follow-up support services. Schedule time to return before we leave CPEP…This could make a difference in how families cope. If not CPEP, could someone else provide such follow-up services?"*

Experience with the Hospital

About three-fourths of the parents expressed significant dissatisfaction with the hospitalization experience—from intake/admission, to the duration of stay, and through discharge.

Admission/Intake

Parents often did not feel well-treated through the hospital admission process, which was not viewed as very friendly to parents. Following are some representative comments:

- *"We were forced to follow an ambulance in the middle of the night to get to the hospital by midnight, and then we were forced to wait for several hours in the lobby before he finally got admitted and into his room about 3 or 4 in the morning."*

- *"At the admission, I didn't talk with anybody. I did not know what to expect at the hospital. When (my child) was being put under observation, I was not told anything. I didn't know how long I would be waiting for (my child), and I didn't know what to expect."*
- Another parent said: *"This place was not parent friendly, especially for a first time parent. I had to wait three hours before someone spoke to me."*

During the Stay

Parents expressed a genuine appreciation when the admitting hospital was in contact with them to let them know what was going on, but most indicated that that didn't happen often enough, and they expressed frustration when that didn't routinely happen:

- *"Hospitals are not real parent friendly. Parents are not thought of a real lot in these hospitals. They don't think about you at all, until they want to discharge."*
- *"As stressful as hospitalization is for the child, it is also for the parent. I didn't know what to expect—it makes a big difference. For the first visit, more could be done."*

Length of Stay

Length of stay ranged widely for admissions, although for many parents, a week seemed to be typical, certainly for private hospitals. And, these fairly short admissions often seemed geared exclusively to "stabilizing" the child, and establishing them on a medication regime. Parents talked about "failed discharges" when their child was discharged in a week or so, prematurely and unnecessarily from the parents' point of view.

Generally, and there were exceptions, parents reported having had better experiences when their child was hospitalized for a longer period of time (which seemed more common with admissions to state psychiatric centers than with private hospitals, at least among our sample group—this was also confirmed by our data from hospitals).

There was considerable frustration that underlying issues often didn't get addressed in the hospital.

- As one parent put it: *"Some hospitals will just stabilize the child for a few days, and then release the child. They will tell you this upfront—that they will hold the child up to seven days, then discharge. (Hospital) is a good example. The discharge plan is just medications. The pharmacy may not have the prescription locally. Some prescriptions are heavily used and the pharmacies run out."*

It also seemed, at least from our sample, that children/adolescents with repeated hospitalizations tended to be ones with fairly short (one week or so) hospital stays.

Discharge, Discharge Plan, and Supports for Parents

Parents often felt that got a short shrift for the discharge. A number of parents were called a day or two in advance, sometimes on the same day, and told to pick up their child because the child was being discharged. In several cases, parents complained that the only discharge plan was to take prescribed medications. Typically little guidance was given to parents to ease the transition back to home and the community.

- *"They gave me enough pills for 24 hours. They didn't tell me anything else, who to see, whether to see the Crisis Center."*

If the child had an existing relationship with a provider, that was generally re-instituted. Hospitals varied regarding setting up post discharge mental health. Some hospitals initiated the contact and the follow up appointment (typically with the Broome County Mental Health Clinic). This follow up was important if for no other reason than to have medications monitored and re-prescribed. But if there was no previous or ongoing provider connection, the post-hospital arrangements and discharge plans were likely to be much more tenuous.

Several parents experienced what might be called "failed discharges," discharges where their child was apparently discharged prematurely and had to be re-hospitalized within another day or two. In these cases, parents recognized fairly quickly that their child needed continued hospitalization.

- *"They basically said to us, 'just live with it, there's nothing we can do.' They basically offered no help at all. They essentially took no responsibility for working out a post-discharge alternative plan. The hospital basically said with changed medications, a new plan was in effect, so that was the best they could do. But the problem was that the only thing that had changed was the medication (my child) was taking, and the core problem of his violent behavior was unresolved. He would still attack others, or himself if no one else was around."*
- *"The hospital had very little contact with me while my child was there, or with his service providers back here the whole time he was in the hospital. They didn't help at all when he returned home."*

- *"Three days in the first hospital were not nearly enough to really know what was going on. (My child) was discharged too soon from (hospital), with no help for us. (My child) needed more time to be observed, but they sent (my child) home with no resolution of problems, because they couldn't justify to the insurance company that (my child) should stay there. As part of discharge process, they need to pay more attention to safety within the home, and how that will be protected, but it wasn't considered….They just gave me medications, and sent my child away without really dealing with any of the underlying issues."*
- *"If child doesn't directly indicate that (he) wants to hurt himself or others, the hospital discharges for non-payment/non-coverage."*
- Another parent described it this way: *"The hospital said they needed to have a plan in place for a psychiatrist to monitor medications, and had to verify that there was an appointment before they would release (my son). Also, they wanted (my son) to continue to see the same therapist he'd been seeing, which he would do. Hospital was very helpful and gave good advice. However, the burden was strictly on me as the parent to make any arrangements and find a psychiatrist who would see (my son). My husband and I had to call 26 psychiatrists, including at local county clinics, before we could find one who was accepting new patients and was willing to see (my son). It was frightening that no one would take him, and distressing that no one from the hospital would help us in the process."*

  Many parents said they did not know what to expect when their child was hospitalized (particularly for the first experience), at least they did not know what to expect at the time of the admission. But parents did have expectations at discharge, expectations that were often not met.

- *"It would have been nice to have CPEP stay in touch while (my child) was gone, but even more, there needs to be someone working with me and other parents to help prepare for when kids return from the hospital. Someone needs to be checking to make sure that things will work well when he returns, but there is never any follow-up."*
- As one parent was told by hospital staff: *"We are acute care only, our job is to stabilize the child."*

Parents expressed numerous frustrations with the lack of support they received in the hospital and during and following the discharge process. Most felt unprepared to follow-up with the child and service providers post-hospital discharge.

- One parent described the hospitalization of her son this way: *"There were no discharge instructions. I was given a prescription which I could not fill (while out of town)… It sucked. I was relieved (my son) would be alive. I thought he was getting intensive therapy and skills, that they would teach these kids self esteem, to be honest with themselves. Nobody taught me how to deal with him. There was no behavior modification. I could not leave him alone. I had to take vacation time from work. There was no phone call between the hospital and the psychologist. I arranged to see the psychologist the next day. At (hospital), you just get medicated. I found out that it cost $2000/day to stay there. There was no preparation for discharge. No follow up for aftercare. What should I do about schooling, attendance? This was never discussed with me. How do I deal with a suicidal child? Nobody taught me. He didn't learn any skills (at the hospital) to carry him through; he just took medication (while hospitalized)."*

- *"More parent support would be very helpful, as I never knew what to expect. There hasn't been a lot of help or support while (my child) was gone, or since he's returned. It's not easy managing all this and trying to know what to do as a single working parent. There is a real need for more parent support. It would have been very helpful to have known more about what to expect, and to prepare for (my child's) return from the hospital, and to know what I should be doing differently."*

- *"We were told that (our child) was only acting out because he wanted attention, so the doctor increased the medications. I said yes, I realized he wanted attention, but I wanted to know WHY. I felt the hospital should have done more evaluation and found out why the child was so angry, then worked with him on controlling the anger rather than just giving him more medications. Looking back, I wish that while the child was hospitalized we could have had help understanding the child's problem—both the diagnosis and what it means, as well as how to deal with it—how to act at home and respond when he does different things."*

For a number of parents, a big problem post-discharge was finding a psychiatrist in Broome County who would be able to prescribe and monitor medications for their child. And this could be complicated by whether the psychiatrist was part of the panel covered by the particular insurance the parents had.

Hardships with Out-of-County Hospitalization

All of the parents mentioned a number of hardships they experienced in having their child hospitalized in an out-of-county facility. They complained about having to travel so far to have their child receive the needed care. It was a real burden for almost all parents, not only for the admission but during the admission, in taking off time from work to visit, not being able to participate in possible activities with their child while hospitalized, etc. They all said some version of: *"Why can't we get the care we need locally?"*

Parents pointed out some of the effects of having to travel, sometimes at quite some distances, for psychiatric hospitalization for their children:

- Taking off time from work, putting them at risk for their jobs;
- Inability to regularly attend advised counseling sessions;
- Some did not have their own car, and had to rely on others to get to the hospital, for visiting, and for discharge;
- Long distance phone calls—very expensive. One parent mentioned running up a phone bill of over a thousand dollars during the hospitalization.

Some representative comments from our interviews follow:

- *"I would like to see (inpatient) services closer by. Rockland was ridiculous—five and a half hour drive. If you have to do any kind of family involvement, it could not have happened. You can't come down to Rockland and stay in a hotel for 3 days."*
- *"This is all scary. (My child) had made a suicidal gesture, we are waiting for an ambulance, we are being told there are no local beds."*
- *"You take whatever (facility) you can get."*
- Another parent explained her experience this way: *"I filled out forms. They interviewed (my son), they interviewed me. It went fairly well. We waited, waited, waited—it seemed endless. The psychiatrist said he needed to be hospitalized. I had no problem with that. It was a very difficult day. They found a bed in Albany… I got upset—it was so far away. Albany? Albany? I don't even know how to get to Albany. We haven't eaten. It was a very difficult situation. It took forever for the ambulance to arrive."*

Hospitalizations outside the county created numerous hardships and inconveniences for most parents.

- *"Traveling out of town [to Syracuse] in the winter during snowstorms was too much for us to deal with."*
- *"It was distressing to be so far away. I couldn't get there. I had to work. Distance was a real hindrance. I couldn't participate as much as I wanted to."*
- *"It was emotionally hard for both of us to be so distant."*
- *"It was a real hardship to travel to see my son. This is where the problem came in—it's a real hardship on me and my husband, who had to drive me there. I didn't want my husband to lose his job over this."*
- *"We could use better directions to the hospitals."*
- *"It's extremely difficult having children sent so far away."*
- *"Parents like us who don't own a vehicle, on a fixed income, have a hard time traveling; plus, sky high telephone bills for her being there."*

A number of parents mentioned the hardship of finding an affordable hotel room nearby, in an area they were not familiar with.

- *"I spent two days there, spent two nights at the hotel—that's all I could afford."*
- *"While at the hospital—I had no idea of places to stay; plus cab fares back and forth from the hospital to the hotel. Even the Salvation Army at $5 a night would have been helpful. It took 4-5 people to let me know about where to stay."*

Parents were concerned about the financial costs of out-of-county placements, and worried about the money going to other communities.

One parent put it bluntly:

- *"Why should Hornell get my insurance money, and any other expenses related to my visiting my son while hospitalized there? That's money going out of the county that is lost to this community. Multiply our experience by 200 or 250 kids a year, times the days spent in out of county facilities, and that's a lot of money going elsewhere."*

Another parent had another point of view:

- *"(Hospital) was good, the doctors were good, but the hospitals make you come up for family counseling. Why can't that be done over the phone?"*

Overall Hospital Experience

In summary, parents experienced both "excellent" and "horrible" hospital stays for their child. Some representative comments follow:

- *"It was an excellent experience."*
- *"When the doctor talks with you, when the staff talk with you about medications, when the staff want to meet with you on a weekly basis, this is a good hospital."*
- *"(Hospital 1) is much closer, better counseling. I am very impressed with (hospital)—it's meant for children and teens—excellent. The group counseling was excellent. (My son) had the support he needed. It was hard on me, but it was very good. I really benefited from it. I think he was there two months. They are very caring there. They cared about the individual; at (hospital 2), all they cared about was the insurance. I am still paying the $2000 bill for the ambulance, at $25/month. There was a gap in coverage between Child Health Plus and our coverage. Another great thing at (hospital 1)— When he was discharged, they set him up with a month's supply of medication, and they made an appointment with Broome County MH Clinic….Thank God for (hospital 1). We learned a lot there. They were wonderful. Wish they were here in Broome."*

But these experiences were generally the exception, at least for the parents we interviewed.

- *"(My child) spent 9 days at (hospital). It was horrible. We weren't allowed to see where he was staying. We would call during the hours we'd been told we were allowed to call and talk with (my child), but then we'd be told we weren't allowed to speak to him. We pushed and pushed and put pressure on the staff to get him out of there. We may have taken him out before he was really ready to go home, but it was just that bad, and we didn't want him staying in there."*
- *"The hospital wasn't at all helpful in terms of providing any information on(my son's) diagnosis. Nor were we able to get the staff to talk to us when we would call. We were not even allowed to see where our child was staying!"*
- *"They treated him as a caged animal, and kept him locked in a room most of the time. The hospital originally wanted to release him after 3 days, saying he wasn't the type of person they served. They said his problem was being autistic and they didn't consider it a mental health problem, so we can't help you. Basically the hospital officials were asking me what they should do from the beginning, rather than offering suggestions for me. No help at all! After 18 days in the hospital, we had nothing to show for it. The psychiatrist there was dismissive of us, and neither the case manager nor the psychiatrist was sympathetic or helpful. They were arrogant and basically said they were doing us a favor by taking him in the first place, but they never really tried to treat him. They made us feel like dirt."*

- *"Unfortunately that's where he learned to smoke, and started doing cocaine, and we heard about drugs being brought into the hospital for the kids, so we pulled him out of there. Our overall experience as a result was horrible. The only good thing about it was two and a half weeks of quiet at home. We could give needed attention to the other 3 kids."*
- *"We made daily phone calls to stay in touch and to be updated. (Hospital #1) was much more family oriented than (Hospital#2), which took the position that 'the child is a mental monster and had to be treated that way.' (Hospital #1) instead wanted to work with us and tried to help our child improve. They tried to get (our child) to think about things differently. It was not just an issue of medicating to solve the problem. (Hospital #2) used more strait jackets, medications, ….(Hospital #1) used such approaches only as a last resort."*
- *"I can't believe they are allowed to practice medicine there. They are going to kill someone some day….I was devastated by what I saw. He was barely a zombie. They had overmedicated him. They would not listen to me. I told them I wanted him transferred to (another hospital). They said they couldn't do that. They started a transfer to (another hospital). I was so upset with them. My son will never go there again. I am not the only parent who has experienced this problem with the hospital. I really can't believe they are still in business. I was furious about this hospital."*

Many parents had frustrating experiences with distant hospitals, and felt they had little control over what happened, with no good way to monitor care on a regular basis.

Behavioral vs. Psychiatric Issues

It appears that relatively straightforward "psychiatric" issues (e. g., severe depression, suicide) are more cleanly and clearly dealt with by the mental health and hospital system. When there are "behavioral" issues—including kids with developmental disabilities—it is a much more cloudy picture for kids and their parents.

Parents facing a severe depression or suicidal threat from their child face extraordinary challenges in understanding and coping with what to do. Parents whose child is experiencing "behavioral" issues (behavior out of control, aggressive or assaultive) appear to experience even greater challenges.

Parents whose child was "behavioral" tended to have more dissatisfaction with the mental health system (and hospitalization in particular). Here are some of their experiences:

- *"The most frustrating discharge was from (hospital). My son was there for three months. Even though they kept telling me, you can't handle him, they said he was more behavioral than psychiatric, so they discharged him."*
- *"We're basically prisoners in our home, as we can't really take him out to a restaurant or any thing like that, because we don't know what would happen. Anything could set him off."*
- Another parent said: *"Maybe if the boy had been "psychotic," we would have been able to get services quicker. This kid was all-consuming for me. When I was finally out from under, I felt like a cloud was removed, like Rip Van Winkle waking up to a new life."*

Insurance Issues

"Insurance issues" were experienced by some, although not all parents. These issues ranged from having to spend extensive time "negotiating" with the insurance companies; limitations in coverage (admissions, number of days in the hospital); out of pocket costs; and a limited panel of (child) psychiatrists. Issues were described as follows:

- *"Basically too much of the decisions are determined by insurance."*
- *"Kids shouldn't have to suffer because their parents don't have health insurance."*

Several parents mentioned things such as:

- *"I had to make a lot of phone calls…to follow up, and with the insurance company….I was constantly having to follow up."*

A number of parents complained about the limited coverage under their health insurance plans.

Parents felt that too many decisions were made based on insurance, especially with private insurance providers. This was less the case with publicly-funded insurance.

- *"Blue Cross was only allowing so much. BC set a length of time. I think she could have used a little more time."*
- *"It's horrible—the insurance companies are saying you have to release him to outpatient treatment, but there are no child/adolescent psychiatrists [available in Broome County]."*
- *"(My child) was only in (hospital) for about 5 days this time, as our 30-day yearly allocation of hospital days was about to expire. Actually it may have been exceeded by a couple days, and I think the hospital may have picked up the costs of the last two days; they were really wonderful. He needed to be there longer, but again, this was insurance-driven, rather than needs-driven. He*

received very good services at (hospital), and continuity, and Dr. ( ) was great, but their hands were tied by length of time they could work with him."

- *"The doctors can't justify to insurance companies to keep my child hospitalized unless they can absolutely justify that services are needed and that child is in immediate danger…They're going by criteria that are inappropriate. In effect, they're denying needed service…The true colors or true picture may not emerge in a short evaluation period, or even in a 2 or 3 day hospitalization, so too often the kid is sent back home too soon without solving the problems….The people doing the assessment need to listen more carefully to the parents, so they really understand the background and not just the immediate situation as they observe it. They need to factor in the home safety situation as they make their decisions."*

Other parents experienced significant out-of-pocket costs for the services. Often, insurance will cover only half of the outpatient bills. The insurance may not have covered ambulance bills.

- *"(My child) no longer sees his therapist, since we can no longer afford him. 50% of his costs are covered by insurance, but with co-pays, we owed about $6000 and that was adding up as (my child) continued to see him, so we've had to cut that off while we pay the back bills. (My child) needs to see him, and values his opinions, but for now, that's cut off, because of insurance and cost limitations."*

Parents with Medicaid coverage for their child generally had no issues. Child Health Plus was used by a number of families for their coverage. Practically all of the issues mentioned by parents regarding health insurance coverage had to do with private insurance restrictions (although several parents had what might be called "very generous" private insurance coverage).

School Involvement

How helpful were schools when the parents had problems with their child? The picture again is mixed and uneven. Schools (and school districts) vary widely in how supportive parents perceived them to be. Some were described as very helpful, while others were described as not helpful at all.

Parents' experience with schools ranged from very positive to very negative when it came to the extent to which schools were helpful in identifying and helping secure access to appropriate mental health services for kids. Parents also referred to the difficulties

they had with Committees on Special Education. Here are some representative comments from parents:

- *"School has done an outstanding job" (Spec Ed involvement)*
- *"School is wonderful at ….. They came to my house after (my child's) discharge—it was wonderful."*
- *"School district ( ) was not very helpful. (My child) should have been referred to CSE but was never referred."*
- *"Why couldn't the schools see something early and address them?"*
- *"The (school district) is lacking in the knowledge of children with psychiatric needs—and they don't even try to understand….. My biggest complaint or worry is school placements. This is the biggest problem—they don't take into account psychiatric needs, and they don't understand them. I am worried that (my son) will be illiterate. Schools don't have the right education programs for kids with psychiatric needs."*
- *'Some of the BOCES are good, it's just the behavioral ones that are bad, and they treat kids like they're stupid."*

PINS/Probation Involvement

At least 40% of the families had experience with PINS/Probation, and it was generally positive:

- *"The court system was really good. Law Guardians were excellent. Probation was excellent. Family Court: would have been helpful if someone had given us a "handbook" about what happens when your child goes into DSS custody (through PINS?)"*
- *"….the court was involved, and intense supervision from Probation was ordered. Probation officer came over to the house. This was excellent—the officer was a man, which he needed. But this was only for a year. There was a little bit of follow up, but once the year is over, that's it."*

Police/Sheriff

A number of parents called the police (or sheriff, or state police) when they faced a crisis with their child. Consistently, parents found that police/sheriff/state police acted conscientiously and prudently with regard to acts by adolescents which could easily be interpreted as criminal in nature rather than as psychiatric.

- "The police have been wonderful and very understanding and helpful, both to [child] and to us as parents. They are specially trained officers to address such mental health issues, and they were

very non-confrontational, explained what was going on and what would happen, what would happen if there was another episode, etc., and did it all in a kind, helpful way, for both us and [child]."

System Not Parent Friendly

For "first time" parents experiencing a psychiatric hospitalization of their child, it was not uncommon to hear how "parent-unfriendly" the experience was for them. As stressful as hospitalization is for the child, it is also for the parent. Parents don't know what to expect. And often they do not feel that they are being involved in the decision-making. They do not feel that they have any choices. Several parents felt they had no say in the events unfolding.

- *"Hospitals are not real parent friendly. Parents are not thought of a real lot in these hospitals. They don't think about you at all, until they want to discharge. Some hospitals have meetings every two weeks, but it is very hard for me to get there. There is a lot of miscommunication. It happens a lot, but it's never their fault."*
- *"Providers don't know what to do with kids who don't fit neatly into one little 'box,' or who fit it multiple 'boxes.'"*
- *"Providers are treating the child and NOT the family. There needs to be more of a family focus, e.g., support groups for siblings and support groups for parents…The support groups need to be appropriate based on the child's diagnosis and behavior, and perhaps providers could help refer parents to appropriate services."*
- *"When I was at the hospital I felt like I was being pushed away, like I had nothing to do with my child."*
- *"The psychiatrist said (my son) would need a psychiatric evaluation but that it couldn't be done here. They called it an evaluation. I asked them if I had any choice in this, they said no. They said that (my son) would have to go for the evaluation at Niagara Falls Hospital, the only one that had the room. When I heard that, I cried. It was so far away. I asked them if I had any say in this, they said no…..I don't feel I was heard. They were going to do what they were going to do. This should not have happened….If I felt I needed help in the future, I would call (mental health provider). I felt comfortable at (mental health provider), I felt I had choices there.*
- *"I would be afraid to bring him back here (CPEP). We sat in the room for hours crying, holding each other, I am gun shy about bringing him back here.*

As a parent, I should have had the choice. It was a rough two days. I have never been through anything like this before."

- *"It was an experience I don't care to relive. It was very frustrating, very sad. I never cried so much in my life here. I felt totally helpless. Why couldn't we do here what they did in Niagara Falls? We were here over 8 hours. Parents should have some say—it's their child. It was wrong what we went through. If I told my story, I hope it would help others not to have to go through this. It's been kind of relieving to get out what I wanted to say. It took me time to get over this. When I got home from the hospital, it was like a bad nightmare. I was angry when they did this. 'Don't I have a say in this?' They said, no, he has to go there. I won't bring him back here, I won't put him through that again. He's a good kid. We're glad it's over."*

Many parents felt that their needs were not considered adequately throughout the process, and that their input was not valued. The family's needs as a unit were rarely addressed.

A number of parents (including fairly knowledgeable persons) mentioned how much time they spent making phone calls, following up, contacting various folks at the facility, calling insurance companies, etc. They wondered how other parents were able to cope with these kinds of challenges.

A number of parents mentioned how helpful and instrumental their pediatrician was throughout the episodes of care.

Communication and Information Sharing

Communication with various staff during the CPEP/ hospitalization experience was a big issue for many parents.

- *"Ultimately, the decision [to hospitalize] was a good one, but we needed to be taken care of also. We were scared to death, but no doctor talked with us."*
- *"Problem I saw: CPEP saw what they needed to do, and they did it. Something breaks down between CPEP and the hospital."*

In particular, communication between the hospital and the parents tended to be quite spotty, quite uneven. While there were some notable exceptions, parents tended to be displeased with the lack of communication between the admitting hospital and themselves.

- *"I was surprised that no one [from the hospital] called me. I had to call them. Then I got a call—they are ready to discharge him; pick him up tomorrow. But, you are welcome to meet the doctor. I met the doctor. He says, you can file a PINS. The doctor kept using the wrong name!"*
- *"I would have liked better communication with the hospital—wasn't getting a lot of information from them."*

It is scary enough facing the prospect of an emergency room visit, and the prospect of a psychiatric hospitalization. It became scarier when parents learn for the first time that there are no beds locally, and that may have to travel 2, 3, 4, 5 hours to get to the hospital where their child is being hospitalized. No parent is ever prepared for that—the first time around, and perhaps not the second or third time around either.

One parent talked about going to the hospital every day and paying the expenses herself, and she was allowed two hours for visiting. The doctor was never available, and to this day, the parent said she doesn't know who her daughter saw. Nor was there a nurse or social worker who would speak with her. She asked for the doctor's phone number so she could call, but the hospital wouldn't give it to her. She then asked that the doctor call her, but he never did.

Parents felt they rarely had access to information they needed to make informed choices or give consent, during and following the child's hospitalization.

A number of parents mentioned how difficult it was to obtain information. Some families said they had difficulty obtaining information that was important to them, whether from the hospital, or the psychiatrist, or the nurse or social worker. Communication (and its lack) was a big issue for a number of families.

Here are some representative comments we heard:

- *"Parents rarely get the information they need. You shouldn't have to go through 20 people to get the information you need. There should be one number to call for information, instead of being bounced around."*
- *"You often feel like you have to settle for the best option presented to you without knowing the full array available. I wish I had seen the menu and known what my choices were."*
- *"Providers need to tell parents what's going on so 1) parents and the family understand what to expect in terms of understanding the mental illness and what the road to recovery might look like; and 2) providers need to develop a plan and involve the parent in that plan, then ask for parent feedback—ask 'how are things going?'—no one ever asked."*
- *"Information was difficult to obtain. A lot of research we did on our own: What is a RTF? You just don't know. There is the stigma."*

- One parent said she still doesn't know a lot about what services are available, and commented *"If you're coming in to CPEP, you must need that kind of information."*

  One parent said she believes that there were times between two hospitalizations when it would have been helpful to have had services available, maybe something like a counselor. She didn't know what was available. She suggested a nurse hotline (similar to what health plans have) where you can call up with questions, find out what doctors take what insurance, etc.

  Some parents turned to the Internet to find out, and indeed, to join chat rooms with other parents in similar circumstances.

Parent Support

The ability to talk to other parents was a key theme of many of the experiences of these parents:

- *"It would be helpful to have other parents to talk to."*
- *"We need to find a way to use parents and our experiences to help other parents, just as we wish the resources of other parents had been available to us. Parents need lots of support, and I'd be willing to respond to requests from other parents. I'd be glad to provide times when I could be available, and would be happy to offer any support possible, to help either the child or the parent or both. I think 30% or more of parents with problem kids would be willing to provide support to other similar parents if asked. It would be great if we could be paid to provide such supports, but many would do it even without that, just to help share their experiences and maybe help some others avoid problems they've had to face. For example, we could help provide respite if the child was being sent home from CPEP, or when returning from the hospital, to allow some time to help with the transition. Take the kid bowling, for example, to provide time away from parents, or do something with parents. It could help provide a different perspective. Just give us some limited money to cover expenses and let us help. We could help provide some space, some perspective, time for parents to hug, space for the kid, etc. to help with the transition."*

Parents expressed the need for support from other parents with similar experiences.

One parent mentioned the Finger Lakes Parent Network and praised its support.

Perceived Lack of Services

A number of parents commented on the lack of available services. Typical comments from parents included:

- *"The hardest thing was waiting to get into BPC clinic. This was the most difficult time overall. At least when he was hospitalized he was safe. We needed something to kick in sooner and not have to send him so far when he has to be admitted. For six weeks (after the discharge from……, and waiting for intake at the clinic), it was like trying to keep a lid on a boiling pot. We hung out for six weeks with no service."*
- *"He is on a waiting list for day treatment. What do you do with kids coming out of RTF? There is a gap for these kids. What do I do, while on the waiting list for day treatment?"*
- *"The whole system for teens really sucks."*
- *"He needs the help. I am not ashamed my son tried suicide. I am appalled at the [lack of] resources in the community for this. There is still a lot of work to be done with him, and it's fallen in my lap alone."*
- *"Problem is that now the system essentially forces you to fail at lower levels before you can access higher level services, even if that's what's needed."*
- *"The community is lacking male social workers."*
- *"What is most frustrating: we don't have all the programs we need. We've been to almost every hospital in the state. Overall, there need to be more programs and better programs for children and adolescents. There are far too many kids who need services."*
- *"Our family seems overwhelming to providers. We have been referred to every agency in the community. We are a whole lot to handle. We have been referred; then, we are either denied as not appropriate or we are put on a waiting list because they are full. They all say: you're not appropriate. The staff would not have time to give what is needed."*

What Parents Are Grateful For

- *"We have had some wonderful people. We have been very impressed with the social workers and the people who handle the patients."*
- *"(My child) has gotten a lot of services and we appreciate it."*

A number of parents expressed gratitude for the respite provided by the Adolescent Crisis Residence.

Parents' Recommendations

Practically every parent mentioned the need for local inpatient beds. A variety of other issues were also mentioned:

- *"We need inpatient beds locally. It would not be so hard on us as parents. As a parent, children need to be closer to us."*

- *"Why isn't there something here in Broome County for these kids? When we had a crisis, we were sent to Niagara Falls!"*
- *"I think they need to get more child psychiatrists around here. That scares me that kids have to travel so far. I see kids who could use the help."*
- *"It would have made a huge difference if he had been able to stay in an extended observation bed for a couple days to allow time to seek other solutions."*
- *"Support as a parent: you want to know what is going on. They need to better communicate with parents. Schools need to be better at identifying problems."*
- *"Four things need to be done through this process:*
  - *More care needs to be taken with parents in the decision making process—there were too many things we had to work to find out.*
  - *Insurance companies have too much clout.*
  - *There are too few beds (inpatient in particular).*
  - *The availability of child psychiatrists is a big issue."*
- *"Somehow we have to beef up the system for the benefit of our kids. It is criminal to have to send our children hours away for treatment. It is completely unacceptable."*
- *"We need local facilities. And a nice cluster of adolescent psychiatrists and psychologists for continuity of care—for the same person to see him through. If there could be one place, the same group of therapists to see the children both in and out of the hospital—and a resource place for parents. And a resource place for kids—for someone to call, who would be familiar with them."*
- *"Here are the improvements I'd like to see:*
  - *better planning and helping parents know how to deal with my child;*
  - *put an actual treatment plan in place—something so that parents understand what the road ahead might look like and what some different options might be—to better help parents understand not only what can be done for your child, but also so that they might experience some sense of 'a light at the end of the tunnel';*
  - *the whole family needs help, not just the child, and we need to include the family because the family doesn't know what to do to help the child;*
  - *parents would like to hear more recommendations and options from providers who have worked with your child;*

- *could be helpful to be more informed; for instance, linking up with other parents who have gone through the same thing."*

❖ Parents mentioned the need for "step down services." *"Once Flex Team drops you, you're dropped."*

Other services identified by parents as needed:

❖ Support programs for families getting back together.

❖ Activities for child: after school or weekend.

❖ Need programming for younger kids.

❖ Need more Big Brother type programs that can provide relief/respite for parents and also good connection/role model for kids.

❖ Need earlier intervention. *"Don't wait for a major problem before trying to fix. Schools, for example, had warnings but basically ignored them and didn't respond to signs until too late. Should develop list of warning signs and make available to parents along with suggested actions."*

Numerous suggestions were made by parents to improve the service system. Many involved expansion of local services, more cross-systems coordination, and focusing more on the total family.

❖ Pay more attention to both kids and parents. Would be very helpful if there could be more family-oriented services throughout the system. CPEP tries to be, but need other support services for families at all levels.

❖ Need more schools like Adolescent Day Treatment.

❖ Kids should be able to access someone to talk to without the parent having to be involved (provide opportunity for kids to seek help, but allow for confidentiality and require parent notification).

❖ *"Treat the family and not just the child."*

❖ Need beds in Broome County for younger kids.

❖ *"It would be helpful if there was one entry point into the system, one person to help you find your way through it and someone who could explain different options to you."*

❖ *"Not all kids may need intensive services when they're coming back into the community, but they may need something."*

❖ *"Could you set up something on the computer for these kids to be able to meet others who have had similar experiences? What about other groups, some type of support group so kids don't think they're the only one with problems?"*

- There needs to be a method so families of mentally ill children can get "the menu" of options available to them. There is no such thing as coordination of services.
- There are no cross-systems connections; services are limited – *"DD is focused on DD and MH focuses on MH." "At my son's CSE meeting last week there were 14 people there. It was good because they were all finally in one place and could share information, but it's rare that sharing of information happens between providers."*
- There needs to be support for families and the other children in them.
- *"Services need to be connected across systems rather than just built up within a particular system."*
- *"It would be wonderful to have a library of resources."* One parent described several videotapes she'd been able to borrow from a provider and also said she spent a lot of time selecting and reading books about her son's mental health issues. *"It would be great to have these things available from a resources library."*
- More therapy programs (both group and individual).

VI. Perceptions of Mental Health Providers and Community Stakeholders

CGR conducted a series of individual and small group discussions with a wide range of providers of mental health services and community leaders/stakeholders knowledgeable about the way in which services are provided to children and families in Broome County. The interviews and small group discussions involved more than 100 people in the following categories of individuals:

- Key Mental Health Service Providers
- CPEP Leadership and Staff
- Discussions with Visioning Project Steering Committee
- Community Services Board and Mental Health Subcommittee
- Psychiatrists in Private Practice and Local Mental Health Clinics
- Representatives of Local School Districts Who Provide Services to Students
- Representatives of Department of Social Services/Child Welfare System
- Representatives of Juvenile Justice/Probation System
- Representatives of the Mental Retardation/Developmental Disabilities (MRDD) Service System
- Representatives of Alcohol/Substance Abuse Service System
- Parent Partners/Representatives of Parents with Children Involved in Mental Health Service System
- Youth Representatives Involved in Free Radicals Group

These discussions were wide-ranging, and covered numerous aspects of the ways in which mental health and related services are perceived, by those being interviewed, as being provided to children and adolescents, and their families, in Broome County. Although each set of interviews and focus group discussions yielded observations and insights unique to the person or group being interviewed, there were many common themes and issues

that surfaced consistently across the various provider and stakeholder discussions. The primary observations are summarized below in various categories under three overall categories of findings: Perceived Strengths of Existing Services, Perceived Concerns and Service Gaps, and Recommendations for Change.

It should be emphasized that what follows are *perceptions* as expressed by those who were interviewed. CGR has reported and paraphrased the observations as the statements were made and clarified in the various discussions, without adding any editorial observations. These perceptions could not always be independently verified through empirical data, although in many cases what is reported below is at least consistent with data reported in other chapters of this report, and is often consistent with the reported experiences of parents of children involved in the mental health service system, as summarized in the previous chapter. Furthermore, although the perceptions reported below cannot in each case be independently verified as to accuracy, the fact that these reported perceptions were typically stated frequently, across a wide range of individuals and groups, suggests that they are at least rather widely-held "conventional wisdom" upon which judgments are made and decisions are based concerning how the current children's mental health system is used, and concerning changes that should be considered for the future. It is in that context that the perceptions and observations reported below should be considered.

The perceptions as reported are presented in no particular order, and should imply absolutely no ordering of priority or perceived order of importance, either by the stakeholders who were interviewed, or by CGR.

Perceived Strengths of Existing Services

Those interviewed noted a number of individual services or components of the mental health system as it currently exists in Broome County which they considered to be strengths and/or building blocks upon which a future improved service delivery system for children and families could be built. Despite service gaps, Broome is perceived to have a wide range of services for a relatively small county. Those reported perceived strengths include the following:

Service Mix/System Capacity/Continuum of Services

- A perceived effort to support non-clinical, non-traditional mental health programs, and to be sensitive to cultural diversity within the service delivery system.
- Programs such as the Day Treatment Program at Wyoming Conference and Adolescent Day Treatment at BPC, though they need to be expanded.
- Strong programs such as the Flex Team/Children's Home and Community Based Waiver model; the CCSI model; Binghamton Psychiatric Center Mobile Mental Health (MH) Team; Families First; local clinic services; Adolescent Crisis Residence; and Therapeutic After-School Program (TASP). In addition, some school-based services have been established. Several of these program strengths are also viewed as being underused, having insufficient resources, or needing streamlined access, but they are nonetheless viewed as being strong building blocks for a service system of the future.
- The fact that the community has a local CPEP, with caring staff who do the best they can without all the community and state resources they need.
- The ability to have State shared staff at CPEP, to make this resource feasible.

Management of System/Planning

- A strong provider network, with considerable sharing of ideas among providers and MH leadership in Broome County.
- A very strong collaborative process and history, good communication among providers, and not many "turf issues."
- Key decision makers are accessible and involved. The Broome County area is viewed as innovative.
- The community places a high priority on looking at barriers and attempting to develop solutions to effect continual quality improvement.

Family Support/Parent Involvement

- The county has a strong Parent Partners organization, and also a strong parent support group through CCSI and the Wyoming Conference.

- Strong efforts to promote consumer involvement and participation.

Perceived Concerns and Service Gaps

Those interviewed noted a number of perceived gaps in services, concerns about how services are or are not provided within the current system, and issues that need to be addressed if services are to be improved in the future. Those reported concerns, gaps and issues include the following:

Service Mix/System Capacity/Continuum of Services

- There's a widespread perception that problems being seen within the MH system are more severe than in the past, with a lot of serious behavioral problems with kids who "are out of control," and that often these are accompanied by serious related dysfunctional family problems as well.
- The county is generally perceived to be lacking sufficient services for younger children (e.g., 12 and under). Better early recognition is needed of the problems of young children, especially by parents and teachers.
- More slots are needed in programs/services such as Flex and ICM, especially for children not on Medicaid. Slots are primarily allocated for MA children, so kids, especially those not on MA, are often turned away and/or placed on a waiting list.
- Too often children and adolescents are pushed to a higher level of care than ideal, because they can't access lower levels of care (they often go to CPEP as a result).
- More step-down services are needed at lower levels of care throughout the system to free up higher levels of care for those needing it, and to make more appropriate levels of care more available throughout the continuum.
- Both day treatment programs in the county are full, and need a combination of more slots available and/or more turnover of cases, with transitions to other programs, so more children can be served during a year. However, New York State doesn't want to expand Medicaid-funded programs, even though this could help reduce RTF placements, inpatient hospitalizations, and foster care placements.

Many of the strong programs in the county appear to have insufficient slots or resources, or too many restrictions, to meet the perceived needs.

- Respite services are limited to children in certain programs, and even there, the hours are severely limited. Both individual and group respite (which help improve social skills) are too restricted. Some think respite is particularly in short supply for younger children and is less of a gap for adolescents. The perceived result is that there are more referrals to CPEP, when parents say they "can't deal with this kid anymore." (A particular need is perceived by some for respite care for parents of dual MRDD/MH kids.)
- Gaps exist in family-based services such as skill building, family supports, 24-hour respite, etc.
- We have to send some of the sickest kids in the community too far from Broome County to get the care they need. More local psychiatric inpatient beds are needed.
- Poor discharge planning for children leaving hospital placements affects all aspects of the system, as providers try to compensate, and some people don't get services they need, others get duplicate services, others get delayed and put on waiting lists, some get sent back to CPEP, etc.
- There is a perception that the use of psychotropic drugs/ medications to treat children and adolescents is growing and "too frequent," and that in too many of these cases, medications are being prescribed and monitored by physicians who are not trained to address psychiatric issues of children.
- There are insufficient psychiatrists in the community who specialize in working with children and adolescents, and some who do are not accepting new patients, or not taking those on Medicaid, or not taking dual MRDD/MH cases, etc., so there are significant gaps in needed services. Too many children and adolescents wind up seeing "adult psychiatrists," or just getting medication monitoring from primary care physicians, even though they are not trained to prescribe or monitor such medications for children/adolescents. Some estimate a shortfall of at least 2 or 3 FTE child psychiatrists in the county.
- In addition to limits on inpatient beds, the State has placed a moratorium on RTF beds as well; this limits community flexibility to respond to needs at appropriate levels. It creates a bottleneck in services. Placements average about two years length of stay; the State wants to limit the LOS to about nine months. Some believe

that these restrictions on community residential beds force more children to be placed within the DSS foster care system.

- Sexually abused children are viewed as a growing issue.
- Too many services are categorical in nature, which limits the ability to provide holistic, comprehensive services. There is a perceived need for better integration of services, and for a more holistic focus on the broad needs of children and their families.

The county appears to need more integrated, comprehensive services for both children and families.

- It is perceived that opportunities are not being fully explored to link MH services and schools, to reach children and adolescents where they are a "captive audience," and also as a way of reaching out to their families.
- There are insufficient structured after-school activities for most young children in most areas of the county.
- Some perceive that the MH system is largely a medical model driven more by insurance and Medicaid than by needs.
- Often children and families need structured settings and services within the community that can be accessed while living at home, such as day treatment, after-school programs, family support services, etc. Such services do not appear to be sufficiently available in the county to meet the needs.
- Adolescent Crisis Residence beds are underused, though highly valued, due to staffing issues and overly restrictive admission criteria. This is a tough population to work with, but the ACR should be used more as an alternative to costly hospitalizations. Some perceive that CPEP should refer more behavioral problem cases to ACR.
- There is too much service duplication, including multiple case managers whose roles are not always clearly defined.
- The county does not have an intensive wraparound services model in place. What exists is not sufficient, and the intensity of services is not great enough to meet the needs.
- In general, the county does not have sufficient aftercare services to help with the transition of a child from more to less intensive services throughout the continuum of care.

Crisis Services/ Hospitalization

- Even those who view CPEP as a positive community resource are concerned about the amount of time it takes to get assessments done, and decisions made about case resolution. The time it takes to arrange for a hospital placement is often inordinately long.
- Some are concerned that CPEP is too oriented to medicating kids too quickly, without exploring other options, but that may partly be a function of the fact that they don't have as many options available to them in the community as they need.
- CPEP is too often the only option available in a crisis, given the absence of other services. Often children are brought to CPEP just to get medications or stabilization, but some avoid using CPEP because of the fear of inappropriate hospitalization. Others fear that needed hospitalization won't be recommended. Another pre-CPEP level of crisis care may be needed.
- There is a strong perception that many parents go to CPEP expecting hospitalization for their child, but then when that doesn't occur, they're left on their own pretty much to fend for themselves, without any treatment plan or suggestions or support mechanism from CPEP to help guide the parents re how to respond as the child returns home.
- Need better use of Extended Observation Beds (EOBs). We need a better way of isolating and accessing these beds more often for younger children to minimize long CPEP waits of child and parent for other hospital beds; it may be possible to avert some hospitalizations if EOBs are used more often while multiple options are fully explored.
- CPEP needs a separate children and youth area away from the adult CPEP area.
- CPEP appears not to have enough dedicated children and youth specialists on staff. Even though the nurses at CPEP who do many of the assessments of children are cross-trained to assess kids and their needs, there is the perception that they do not always know as much about resources available in the community as the specialized children and youth services CPEP team, so appropriate community referrals aren't as likely to be made as would be the case if there were more children and youth specialists. There is a need to have sufficient staff to make better referrals, do better follow-through, have effective liaisons with

CPEP is viewed as a crucial community resource, but may need more specialized children and youth staff to meet the needs.

schools and other community agencies, and do more training for referral sources to help them make the most appropriate use of CPEP.

CPEP needs more resources in place to provide needed follow-through to assure that needed services are in place.

- CPEP used to be able to provide at least some follow-through after CPEP assessment, but with the added number of cases, and no more staff, this is rarely possible now, except for some "interim cases," and some survey follow-up contacts. But many expressed the need for more resources to be available to provide follow-through on cases, both those returned by CPEP directly to home/community and those resulting in hospitalization (and ultimately those returned home from hospital settings). Some mechanism is needed to incorporate such follow-through with child and family.
- The community needs more local inpatient psychiatric beds. It also need more "partial hospitalization" and day treatment slots to provide structured services during the day, with the child continuing to live at home.
- There may need to be a step below CPEP, especially to deal with what appears to be an increasing number of referrals to CPEP of behavioral problems that CPEP considers inappropriate because they are not psychiatric in nature. Whether appropriate for CPEP or not, they are often crisis behavioral issues that need to be assessed, but we need to decide at what level and by whom such issues should be addressed, and who should follow-up on those issues to be sure they were resolved.

There is a concern that too often CPEP does not adequately consider the home situation and returns children and adolescents home with no resolution and no effective alternatives or supports in place.

- Too often CPEP does not identify or attempt to address larger family issues, and focuses only on the child's problems. Similarly, too often CPEP won't consider how safe the home/community environment is to which the child is being returned, if hospitalization is not recommended. These factors often result in the child being returned to the same unchanged home situation with no resolution and no alternatives in place, so even if the child has been "treated," it's not reasonable to assume any real lasting behavioral changes will result.
- There is a concern that if CPEP or other local resources are not adequately addressing behavioral issues, and that many hospitals would not accept kids with behavioral (but not diagnosed MH) problems, these problems will simply continue to escalate and wind up back at CPEP or other service providers. We need to

find a way to address these behavioral issues earlier rather than later.

- Concerns were expressed that CPEP's future may be in doubt, unless the State continues to make shared staff positions available. Despite concerns about what CPEP is able to do, there is a consensus that the community would be much worse off without its services.
- Some perceive that the State Office of Mental Health has not lived up to its commitment to use OMH facilities as a "last placement resort" or safety net when all else fails. The perception is that State psychiatric centers are least willing to accept patients, and that often they won't accept a child even when all other options have been explored without success.
- CPEP is the gatekeeper for Adolescent Crisis Residence beds in crisis settings, but often it sends a child home or elsewhere instead of to the ACR, because the issue is viewed as a behavior problem. No follow-through is provided to see what happened as a result. The community should be making better use of this important ACR resource.

Post-Hospitalization/ Discharge Planning/ Aftercare Services

- There is a strong perception that there are insufficient resources/ services in the community to address aftercare/transition issues as the child returns to the community from hospital settings.
- Information is rarely exchanged between hospitals if a child is placed over time in more than one hospital. Records are rarely shared, so often services at one facility do not build on previous services. Much key information is typically not shared with local providers either.
- Discharge plans from hospitals are too often vague concerning the transition back to the community, and are not communicated effectively with either parents or local providers. Too often it's left up to the parent to make arrangements, often with little guidance or support from anyone. Hospitals need to be more directly connected to local officials and parents before a discharge decision is made.

Post-hospital discharge planning and follow-through on services is a major service gap in the community.

- Too often children and family don't get linked up with appropriate services when a child is discharged from the hospital, so even if

progress was made while in the hospital, often it's undermined by the lack of appropriate follow-up back in the community, and often parents get no support to try to complement any gains made in the hospital.

- There is a perception of some that discharge planning and appropriate lengths of stay are handled better within State hospitals than among private (for-profit and non-profit) hospitals, which are more likely to discharge a child prematurely when insurance runs out. State hospitals are more likely to keep a child as long as needed. But relatively few kids in the county are sent initially to State hospitals, as they are generally harder to get into.
- Those connected to community-based MH services before being hospitalized are perceived to have a better shot at success upon discharge, as there's at least a place to receive continuing services upon return to the community. But those not previously connected are perceived to be most likely to "fall through the cracks" at discharge. There needs to be a way of assuring better follow-through on any post-discharge services; otherwise the child and parent may not follow up, even if a treatment plan was established.

Coordination of MH Services

- There is not enough cross-training of people within the MH system, let alone across systems, of what is available and when it is appropriate to make referrals to certain types of services. Staff at CPEP, school social workers, and other service providers need better awareness of "what's out there."
- With MH issues, a child (and family) need to be working with someone who knows their case, their needs, what medications they're on, etc., and who can help assure that appropriate decisions are made that factor all this into consideration. There is the perception that there is less case management now than in the past, even as the need may be increasing (e.g., less actual case management in Flex, CCSI, etc.).
- There needs to be some type of case management in effect to help stay with the child and family throughout a "step down" process as the case moves from one level of services to another.

- There needs to be better coordination and communications between the adult and children's sides of the MH system, as well as across systems.
- The perception exists that there are limits by some providers concerning from whom they will accept referrals. This limits collaboration and may limit the ability to get kids to the level of services they need.

Access to Services

- It is difficult to access services, other than crisis services, on a 24-hour basis. If a person needs to get advice at night or during weekends, about all that's available is CPEP. What does a parent do if a child is discharged from a hospital late Friday, and needs access to services during the weekend?
- There are perceived long waits to get into local services such as clinics, psychiatrists, Flex, etc. This is perceived as limiting options at CPEP. Need quicker access to services and/or better ways of triaging to get people into appropriate levels of care when needed. This is perceived to be part of the reason why some parents give up on services and fail to follow through.

Delays in accessing services, lack of services in rural areas, and inconvenient hours all limit access to MH services.

- Strong perception that most MH services are concentrated within the Binghamton area, and that satellite services and/or school-based services, and/or other forms of outreach, would be needed in the future as a way of reaching more rural areas more effectively. As it is now, the perception is that in many cases, kids and families in outlying areas "wait for a crisis before accessing services," and then it's a higher level of services as a result.
- Also there is a sense among many that in order to reach more families, in particular, there would need to be more services provided during late afternoon, early evening and weekend hours.
- There is little transportation to outlying areas, and no Medicaid cabs to help access services.

Management of System/Accountability

- There is generally the sense that within the MH system, there are few objective criteria currently used to monitor how well the system and individual providers are doing in serving kids and helping to effect positive outcomes.

- Some concerns were expressed that there is too much emphasis on turf protection, and not enough on what's best for the future services needed by children and families, even if that means some shifts in how resources are allocated in the future. Some resources may need to be reallocated to reflect changing needs in the community.
- Needs to be better coordination within agencies and within the overall mental health system of adult and childrens services. Needs to be better planning and resource allocation, and better coordination of services involving entire families, than is now the case.
- We need to be careful not to make reduced inpatient use the sole measure of the impact of a new system and what it should look like. For some who are not now hospitalized, hospitalization may be the most appropriate level of care. The key is to determine what is most needed, and assure we can access the levels of care that are appropriate to the need, and evaluate how we're doing in that context. Would probably lead to reduced hospital days overall, but some will need more, so factor that into any assessment of outcomes and accountability.
- Providers need to be held accountable for seeing patients within a reasonable period of time, which some say is not now happening, because no one is tracking cases.

Family Support/Parent Involvement

- Parent support group opportunities offered in conjunction with CCSI and the Wyoming Conference need to be expanded to other parents in different parts of the system.
- Some hospitals have support groups for families, but that plus may be negated if parents can't easily access the supports because of being so far away. Hospitals need to find ways to be more supportive of parents and keep them informed, even if they can't be frequently present because of the distances involved.
- Far too often, parents of children in the MH system also have MH issues which are not addressed. Often the issue may be more a family issue than a child issue, but the system too often only deals with the child, and ignores the parent/family issues that could help resolve the problems if they were identified and addressed.

The community has strong parent support resources, but they need to be expanded to reach more families.

- Parents need to be better educated to know what's available, and need to be helped to access the most appropriate services for their child and/or family. Too often they don't know what's available and appropriate, what to access under what circumstances, what types of questions to ask, and what their expectations should be of different types of services.
- Support systems for parents are perceived as insufficient, including training and oversight in providing parenting skills; but these skills must be wanted by the parents, as often there is no way, except through a court order or Child Protective referral, of getting parent attention and follow-through.

Funding/Insurance Coverage

- Although Medicaid is a major source of funding of MH services, it does not always support many of the non-clinical services needed by children.
- Too often children who have private insurance (not Medicaid) don't qualify for certain MH services and/or receive only partial coverage. Community-based services are particular problems; e.g., non-MA insurance often does not cover case management, though MA does, so case management programs may have open slots, which can't always be filled if a non-MA kid needed the services. Also, hospital stays beyond a certain length, if there is no immediate evidence of potential harm to self or others, are limited.
- Insurers won't always pay for a psychologist, who may be more available than a psychiatrist. In the meantime, there are gaps in child psychiatrists, and some psychiatrists are not accepting Medicaid patients.
- There is the perception that insurance companies will force children into lower levels of care than are needed before they will agree to a "needed" higher level of care. "Kids are placed into lower levels of care and forced to fail there before they can access the care they needed initially."
- There is a perception that some providers limit whom they will serve, based on level of reimbursability.
- Children's MH services are a stated priority, but the money doesn't always follow; new sources of revenues, or reallocation of resources, will be needed. Some agencies now often continue to

provide some services to children, even after reimbursement has ended.

Integrated Services/ Cross-Systems Issues

- There are many cross-systems kids with mental health issues not being adequately addressed (their own or, in many cases, their family's). Substantial proportions of kids in other systems have mental health and/or behavioral issues that should be addressed within the MH service network, or on a collaborative cross-systems basis, but too often they are not addressed (and often not even identified or formally referred by the different systems).
- There is a strong perception that growing numbers of kids in MH and other systems also have alcohol/substance abuse problems (kids as well as families).
- The perception is that domestic violence and sexual abuse are also significant issues among those seen by MH providers.

Many children and adolescents in the mental health system are also involved in one or more other systems as well. These services need better coordination.

- There is no single point of entry or core assessment process to identify kids or families with cross-systems issues and needs (though Probation has an instrument they use to attempt to identify MH and other cross-systems issues).
- In general, we don't do a good job of serving kids with dual diagnoses, such as MH and MRDD, MH and substance abuse, etc. Too many MH programs place limits on serving children/ adolescents who have problems other than just MH diagnoses. Perceived example: Limits on who's willing to accept conduct disorders.
- We need more case management of cases in which a child and/or family is involved in more than one system. "All systems benefit from better mental health care that is coordinated with other services."

Cross-Systems: Schools

- Schools report that they are seeing a substantial increase in the number of students with MH issues in the past 3-5 years, and that the problems are more severe, and are occurring at a younger age.
- There is a perception within the MH community that too many schools are making too many inappropriate referrals to CPEP for cases best addressed in school or through other resources. Too often teachers and other school personnel are not adequately

educated or trained in appropriate developmental behavior, and in what issues and behaviors should be referred to CPEP or other resources, vs. which should be addressed in-house.

- CPEP tries to send staff to help school personnel determine the best use of CPEP, but there isn't enough time to do this routinely.
- Schools and CPEP seem to agree that it would be helpful to have a school person call ahead before sending a case to CPEP, but this doesn't seem to happen often, as there is no designated liaison at CPEP who schools know and trust to provide good advice.
- There currently are some community-based services located in some schools, but they may need to be expanded in the future. Some suggest that the best location for services such as CCSI and others would be directly in the schools, where there is a captive audience and where the needy kids can be targeted easily.

Schools appear to be making more referrals than in the past to CPEP, and more effective coordination is needed between the schools and the MH system.

- On the other hand, schools are concerned that any school-based services not interfere with the learning/academic priorities of the school, so that any services should be provided without interrupting classroom time. However, this creates a dilemma in that many kids won't stay after school for services, whereas they can be reached during the school day; study hall/free periods sometimes offer options for providing services.
- Schools perceive that information flow between them and MH providers is one-way; that they provide information but rarely receive information back in terms of what services are being provided, what schools should be doing, how schools and service providers should be collaborating, etc.

Cross-Systems: Child Welfare/DSS

- An informal review of the DSS foster/institutional care caseload indicated that about 25% of those children and adolescents were SED kids, and that many of their MH-related needs were not being met. Overall, DSS estimates that about 1/3 of all the children in their services system have MH needs.
- Kids in the DSS/Child Welfare system (and their families) do not receive MH assessments; DSS does not do the types of assessments that Probation provides for kids in the juvenile justice system. There is the sense that such assessments would be helpful, but who has the resources to provide such assessments, and who would provide needed follow-up services?

- Some perceive that many CPS reports are triggered less because of an underlying abuse and neglect issue, and more because mental health needs of kids and/or families are not being addressed. DSS perceives that many children become DSS cases when the MH system can't serve them, or isn't sure what to do with a case. They are convinced that there are many kids in the DSS system whose issues are more MH than protective or preventive. DSS suggests that it may be the behavior that triggers the entry of a child or family into the DSS system, but the underlying cause of that behavior is often an unresolved mental health issue.
- On the other hand, some believe that DSS often lets go of a case too soon; if a child is identified as a problem and referred to a psychiatrist, DSS may close the case when they need to keep it open longer for services. Need better case management between the systems.
- MH and DSS staff believe that there are misperceptions on each side as to what each system can and cannot do, and what constraints each is operating under. They should be able to work more effectively together, with greater understanding of the needs of each, so that the needs of the kids and their families can be met more effectively.
- Some suggest that the MH system is more comfortable dealing with single adults traditionally served by the system, and that services haven't kept pace with a growing population of children and their families which have many unaddressed needs.

There is a substantial overlap in MH and DSS caseloads, but little coordination of cases between systems, especially at the holistic family service level.

- More and more, it seems as if issues that need to be addressed jointly by DSS and MH involve families and providing appropriate services that address issues more holistically. DSS currently purchases some services from MH providers, and more services may need to be jointly purchased in the future.
- DSS perceives that MH often needs to use the DSS out-of-home placement system to place children who should be placed within MH facilities, except that the MH system has too few community residential options available.

Cross-Systems: OMRDD

- Some MRDD officials estimate that 25-30% of the children and adolescents in their system also have MH issues; often developmental delays lead to MH and/or behavioral problems.

Plus there are many family-related problems caused by the stresses that often don't get addressed. Some estimate that perhaps a couple hundred MRDD children and adolescents need crisis care and support during a year, but don't receive MH services. Relatively few referrals are reportedly made to CPEP, since staff there have few options available to them for MRDD/MH children.

- However, of those that are referred to CPEP, many are viewed as inappropriate referrals, but it's because there are no other options for outpatient services. However, CPEP has few options to place these kids, as few hospitals will take them.

- The perception is that most agencies in the MH system don't want to address children and adolescents with developmental delays/ MRDD kids. If the primary diagnosis is MRDD, OMH basically says "hands off, we won't cover costs of any MH-related services for MRDD kids." Similarly, the MRDD system doesn't have resources or trained staff to deal with behavioral/emotional/MH problems that often grow out of the child's DD (e.g., psychiatrist at Broome DDSO is not a child psychiatrist and focuses heavily on adults within the MRDD system, with few child referrals). So dual kids get caught in the middle. MRDD kids get referred to MH system, and no one wants to address the needs, and CPEP often finds resistance of hospitals throughout the system to accepting such dual-diagnosis kids (or MRDD kids with a behavioral problem but no formal MH diagnosis). So a number of kids fall through the cracks or wind up being served in both systems, without much coordination of services between the systems.

Many dual MRDD and MH children and adolescents get caught in the middle between the two systems, with neither completely meeting their needs.

- MRDD officials don't understand why the MH system should be unwilling to provide appropriate MH services, even if a child's primary diagnosis is DD, or why resources shouldn't be shared between the two systems. Both local and state officials need to be part of the solution to these problems.

- Apparently only one child psychiatrist in the county has been seeing any significant number of MRDD kids with MH or behavioral issues, and now restrictions are being placed on that person taking on new cases. The perception is that there are many children with a primary MRDD classification who also need MH services. Now, some cases have to be referred to primary care

physicians to prescribe and monitor medications, but they often are not trained to meet the special needs of MRDD/MH kids. Some believe that the MRDD system needs its own child psychiatrist. Ideally there should be integrated solutions, rather than having to address issues within the separate systems.

- MRDD kids are perceived to be in all systems in increasing numbers, yet the MRDD perspective is typically not perceived to be represented at the table discussing solutions.
- There is a perceived lack of sufficient respite care for parents of MRDD kids with emotional/MH issues.

Cross-Systems: Probation/ Juvenile Justice

- An informal survey of Probation Officers with the Youth Diversion/PINS/JD unit tracked 275 children and adolescents between the ages of 7 and 17. Of those 275, as many as 124 (45%) either had formal MH diagnoses, suspected MH issues needing services, and/or MICA issues. Another 20% had diagnosed or suspected substance abuse issues not related to MH.
- A separate survey of PINS last year indicated that one-third had actual MH diagnoses, and about 30% had substance abuse issues, including 5-10% MICA cases. About 70% of JDs had MH issues.
- Estimates of Probation Officers were that at least half of PINS cases also have parents with MH problems, plus others with various abuse and parenting skills problems.
- Similar to the child welfare system, there is the perception that many behavioral problems that wind up in courts and the juvenile justice system (e.g., PINS and JDs) are often the direct outgrowth of MH problems not adequately addressed within the MH system. Some perceive that too often, the juvenile justice system becomes the primary provider unless and until the child gets into appropriate MH services. The perception is that a number of PINS and JD cases could be avoided with appropriate earlier intervention by MH services. Some of this is perceived to be due to lack of follow-through of MH clients, and once they get dropped from services by MH providers, they often wind up as PINS or JD cases.
- There is the perception that Probation Officers often are attempting to provide clinical supervision in many cases, in lieu of

MH providers, because they cannot get the frontline MH providers to provide the needed services. They are attempting to fill a void, but are not trained to provide such services; this is clearly not the preferred solution. Sometimes the courts and the juvenile justice system become the enforcer and the follow-through for the MH system, as the only way at times to get compliance.

There is substantial overlap between juvenile justice and MH youth, and many Probation Officers believe they act in lieu of MH providers in many cases. They assess clients for MH issues, though they are not trained to do so.

- Too often Probation and/or Family Court believe they pick up the responsibility for monitoring cases that grow in part out of poor post-discharge follow-through in the MH system, where no one at either the hospital or local levels is typically held accountable for assuring that services were delivered to the child or family following hospital discharge.
- Probation does a full psychosocial assessment, but Probation Officers may not be the most appropriate people to do so, as they are not trained to spot MH issues. Who should be doing such assessments in the future, and what training is needed?
- Even as Probation Officers are perceived as filling gaps in MH services, they are not perceived as being sufficiently "at the table" in designing solutions for the future. There is a perceived need to get MH providers, Probation, court and other juvenile justice officials together to discuss appropriate roles and accountability.

Cross-Systems: Substance Abuse

- Despite reported substantial numbers of children and adolescents in all service systems with substance abuse problems, currently there are only two core programs focusing on substance abuse issues for children and adolescents in the community. One focuses primarily on prevention and the other on treatment (treatment is provided to only about 30-35 kids at a time). "We're only addressing a fraction of the needs for treatment." There is currently relatively little coordination between these programs, or between them and the MH system. The two systems have very different philosophies. Need to address the full family's needs, and not just the youth.

There is little effective coordination at this point between MH, substance abuse treatment, and substance abuse prevention programs.

- There is also insufficient focus by current MH services on dually diagnosed mentally ill/chemically abusing (MICA) youth. One program offers case management and intensive in-home services to about 10-15 MICA youth at a time. There is a perceived need

for more joint services for kids with both MH and substance abuse issues.

- Most of those served by the substance abuse treatment program are those with private insurance and parent involvement. Need to do a better job of "connecting with the more disenfranchised group of substance abusing adolescents."

Stakeholder Suggested Recommendations for Change

Based on the perceived service gaps, concerns about service delivery, and issues that need to be addressed in the future, the service providers and community stakeholders who were interviewed offered a number of suggestions and recommended improvements that *they believe* are needed to strengthen mental health and related services for Broome County's children and families in the future. The suggestions outlined below represent composites of the many discussions CGR had with various providers and stakeholders, and each of the reported suggestions/recommendations was made, directly or indirectly, in at least two or three (typically more) of the interviews/focus group discussions we conducted. As such, the composite recommendations, summarized under the same broad categories as used in the perceived service gaps/concerns sections above, should be thought of as potential components of a model children's/family mental health system of the future for Broome County, as envisioned by those interviewed by CGR. These suggestions represent the thinking of those interviewed, in their words, and do not imply any endorsement, or specific recommendations, by CGR staff. For CGR's perspective, see the concluding chapter.

It is important to emphasize that although these represent what many stakeholders perceive to be desirable model components, there has been no attempt at this point to determine which of these potential components would receive the highest priorities for ultimate inclusion in the actual model to be developed. Presumably, not all of these "desirable" components would ultimately be a part of a working model, as choices will need to be made as to what is most feasible, what can be afforded, what is most likely to lead to desired outcomes, etc. Those choices are in the process of being made by the project's Steering Committee, and ultimately the larger community, in the ongoing phase of this visioning project. But in the meantime, these composite suggestions and recommendations should provide the basis for

Steering Committee members to begin to think about their own priorities as they consider the list below.

Service Mix, System Capacity/Continuum of Services

- A full continuum of care/services needs to be developed, ranging from preventive services to aftercare, with increased focus on prevention and early intervention, and strengthening services for younger children, to avert as many as possible of the "high-end" and crisis interventions.

The community needs a fully-developed continuum of care from prevention to aftercare services, designed to meet holistic needs of families as well as kids.

- Services should be designed and provided to meet the comprehensive, holistic needs of the child and the entire family unit. The client should be defined more as the family and not just the child.
- Families should have access to a comprehensive assessment process to determine their strengths and needs, and should be involved in the process of selecting the services that best address their strengths and needs.
- Any new system needs to provide quicker access to services, more timely intervention, and a better intake and triage system for children and families. This should facilitate easier access, with a central point of entry to services, perhaps building on the Catholic Charities Single Point of Entry case management approach for adults, and expanding that. The model should use central intake as the basis of the state-required Single Point of Accountability/ Access (SPOA) system to minimize duplication of services and better manage services, with better coordination and better information systems to track cases. It should also provide a better means of assessing treatment needs in a consistent fashion, and helping to assess gaps in services in the future. The modified single-access/SPOA system should also be used as the point of entry for cases returning to the community from hospitalizations or other placements, so that appropriate transition services can be put in place as needed, for both child and family.

The system needs a strong means of improving access to core services through a single point of entry, which also coordinates return to the community from hospital settings.

- The model should incorporate more step-down services at lower levels of care throughout the system.
- More Flex Team (HCBW) slots are needed for children.
- More structured after-school programs should be developed throughout the county. Expansion of the Therapeutic After-

School Program model would serve more children with mental health issues, and the broader expansion of other non-therapeutic after-school programs—even though not considered specific mental health services—should help address MH-related and behavioral issues in the community.

- More slots are needed to supplement the two (younger and older) day treatment programs in the county. To the extent possible, increased turnover of cases should be encouraged within the day treatment programs, to the extent that children can be transitioned to other appropriate programs, so that more children and adolescents can be served by these programs.
- The community needs more respite slots, and the respite hours which a parent can access during specific periods of time should be expanded as much as possible.
- Ideally, the community should recruit and maintain additional child psychiatrists (some estimates suggest as many as two or three in addition to those currently in the county).
- More direct services are needed for families to help engage them and provide the supports they need to address child and family issues (see further discussion of family issues below).
- The county needs a more intensive wraparound services model to address the needs of more families and children. The model would need to increase available wraparound dollars to provide supports for children and families, increase the intensity of services, and increase the numbers who could be served through wraparound services.

Stakeholders recommend expanded respite care, day treatment, structured after-school programs, intensive wraparound services, flex team, and family support services.

Crisis Services/ Hospitalization

- There may need to be more inpatient psychiatric beds for children within the county, to prevent many out-of-county hospitalizations. If such beds are needed, it should be possible to create a wing making use of unused beds in a local hospital, without major construction or renovation costs.
- If local beds are needed, it may be that what should be considered is a crisis unit less intensive than an inpatient hospital, sort of a cross between a psychiatric hospital and respite services. It could serve a child perhaps up to 10 days, with the advantage that he/she would be staying in the community, and getting intensive

There may need to be more inpatient psychiatric hospital beds in the county, to reduce the negative effects of out-of-county placements.

services and psychiatric support and medications if needed. Providers would also be working with the family during this period. This could also be used as step-down service transitioning from a hospital setting, for a period of restabilization in the community before the child goes home. A model along these lines has been tested in Maine, and apparently is working well.

- Another alternative to a local psychiatric unit that has also been developed in Maine would involve a small number of children in a cottage setting with therapists working with both kids and families for a 6-week period, to help the family become more empowered to work with the child—again, either to keep him/her out of a hospital setting, or as a return from such a setting. In this approach, family members learn direct skills to help address underlying issues. The child lives in the cottage, develops group social skills and gets counseling, and goes home on weekends. Families visit during the week, and they work together with the child on issues. The approach holds everyone accountable, but provides skills to make success possible.

- Many parents coming to CPEP are not familiar with the mental health system, and/or what they will need to do in working with providers, especially if their child is hospitalized. More attention needs to be given by staff involved in the crisis intake process (whether at CPEP and/or through other "sub-CPEP" mechanisms suggested below) to providing information and supports to parents attempting to negotiate the service system. This happens to some extent now, but not as consistently as needed, given the crisis nature of the CPEP operation.

Parents dealing with crises involving their children need better information on which to base decisions, and more supports to negotiate the service system. Additional specialized children and youth staff are needed to assist in that process, including follow-through with parents and providers.

- Ideally, CPEP should have additional staff with specialized training in children and youth mental health issues. Such specialized staff would provide more focused attention on youth and families, provide support and information to families throughout the intake process, work with and make referrals to appropriate community-based providers of services to children and families, provide needed follow-through with families and providers, provide training to various referral sources in the appropriate use of crisis services, etc.

- Whether through CPEP or a sub-CPEP assessment process, there needs to be an assessment process for addressing the types of behavioral problems that CPEP is reluctant to address but which,

left unaddressed, can escalate and lead to subsequent crisis situations and the need for repeat crisis interventions. Some have suggested that there needs to be an assessment process a step below CPEP to handle such behavioral, non-MH crisis situations.

- There needs to be more extensive use of Extended Observation Beds, which should be re-configured in conjunction with CPEP and the Binghamton General Hospital facility such that they are more available for more widespread use for short-term stays to help stabilize children, to provide more time to find the most appropriate hospital setting, and potentially to act on occasion as a transition bed when returning from a hospital stay.

In crisis situations, the home environment should be an increasing factor in determining best solutions.

- CPEP (and/or any sub-CPEP process that may be established) should more consciously focus on family issues and the home environment in making its assessments and recommendations. The focus has historically primarily been on the child's problems, but more attention should be given in the future to the context in which the child lives, and what services may be needed to address that context. Such a focus may become more practical if the CPEP process and staffing are expanded, and if broader family support services are in place in the community, as recommended, thereby giving CPEP staff more to work with as they consider family needs.

Better use is needed of Extended Observation Beds and Adolescent Crisis Residence beds.

- Attention should be given to making State psychiatric hospital facilities more accessible to CPEP as CPEP staff attempt to place children in the network of hospitals within reasonable driving range of the Broome County area.
- CPEP, as the gatekeeper for Adolescent Crisis Residence beds in crisis settings, should be making fuller use of this community resource, which now goes unused about 2/3 of the available days.

Post-Hospitalization/ Discharge Planning/ Aftercare Services

- There is a need for more aftercare/continuing care services for children and adolescents as they return from hospitalization to the community, and in general to ease the transition from more to less intensive levels of care. This would include the availability of more step-down services throughout the continuum of care. Additional sources of funds may be needed to expand the array of such services.

Better aftercare services, and improved discharge planning, with more parental involvement and better links to local services, must be critical components of an improved service system.

- Parents should be more directly involved routinely in the process of making discharge decisions about their child. Too often in the past they have not been.
- Better liaison is needed, while a child is in a hospital, between the hospital (especially the treating hospital psychiatrist) and the local psychiatrist or other local services providers. Too often decisions get made in the hospital which may be harmful or delay problem resolution because of no contact with providers who've being treating the child.
- There must be a direct point of access through which hospitals can maintain connections to parents and to local service providers for children while they are in the hospital setting, and through which discharge plans and follow-up services can be coordinated. Such a linkage does not now exist. The proposed SPOA mechanism should be considered as the locus through which such linkages should be facilitated. The SPOA should also be responsible for tracking actual service delivery, beyond a simple referral being made.

Coordination of Mental Health Services

- There should be incentives under the new system for MH and cross-systems agencies (in both public and private sectors) to develop collaborative approaches to service delivery, and to test such approaches on a prototype/pilot project basis. Such collaborative efforts are not always needed or desirable, but there should be significant opportunities—as we think of new approaches to change the focus of services to more holistic, family-focused approaches—to utilize our agency resources differently. Some opportunities are likely to only be possible through partnerships.

Increased emphasis should be placed on partnerships within the MH system and across systems, with reallocation of resources as needed to integrate resources.

- We should be talking about making better use of existing resources, and thinking of how we can develop partnerships, collaborative funding across systems, and reallocation of existing funds where appropriate, to develop our model. This doesn't all need to involve new dollars to create an improved service delivery system. We need to be thinking of how to better coordinate children's and traditional adult mental health services into a more integrated, seamless system focused on family needs and services, and make sure we are not setting up adult and children's services as competing priorities.

- There should be more cross-training of staff within the MH service system, as well as across systems, concerning what services are available and how and when to access them.
- Effective case management needs to be in place to assure that needs are met and carefully coordinated as a child and family move across services and from one level of services to another. Highly effective coordinated care needs to be promoted within the model, rather than rationed care.

Access to Services

- Expanded satellite offices of mental health providers would be helpful, particularly into more rural areas of the county. The service system should become less office- or clinic-based in its orientation. Where feasible, services linked to schools would be desirable. Access to late afternoon, evening, and Saturday appointments would be especially helpful in order to involve families.
- Establishing formal linkages between CPEP and schools (and perhaps other primary sources of referrals to CPEP) could help assure that more appropriate referrals are made on a consistent basis, and that other options are explored where appropriate without involving CPEP.

Access to services should be improved by expanding services in rural areas, in non-traditional hours, by linkages with schools, and through a central intake/SPOA function.

- A central intake/SPOA function, building on existing resources such as the Catholic Charities Single Point of Entry mechanism, could help improve access to services, and reduce unnecessary duplication, while helping improve direct connections between parent/child and service provider, thus reducing the number of cases where no linkages are made between client and provider. The SPOA would be responsible in part for follow-through to assure that services are provided as intended and scheduled.
- Services should emphasize cultural competency and access to all segments of the community.

Management of System/Accountability

- Any new model service delivery system should be planning-, outcome- and performance-driven and limit as much as possible the extent to which it is revenue-driven.
- Services should be evidence-based; model or service approaches should be predicated on proven methods as much as possible, but

we should also allow for creativity and pilot testing of new approaches.

- The system should have needs assessment and accountability mechanisms, including data systems, to monitor performance. We should allocate adequate resources to assure that these functions are carried out.
- Service design should lend itself to evaluation and revision of services as needed. Indicators should be in line with desired outcomes.
- Resources may need to be reallocated within and between service providers in the future to reflect evaluations and changing assessments of needs and to address service gaps.
- The new system should be a proponent of selecting and funding prototype/pilot test proposals, and evaluating them over a reasonable period of time to assess how well they accomplish their goals and expected outcomes. Future funding would be based on the success of the prototype/pilot test implementation, thereby enhancing the probability that future funding will lead to desirable outcomes and restrict any unsuccessful trial programs to a limited period of funding. Under such a system, rather than viewing any pilot program that doesn't meet performance measures as a "failure," each prototype program becomes the basis for learning about what works and what doesn't under what circumstances, thereby enhancing the likelihood that programs funded in the future are meeting specified goals and outcomes.

Any new service delivery model should be planning-, outcome- and performance-driven, and should pilot-test and evaluate new prototype approaches.

Family Support/Parent Involvement

- Comprehensive, holistic services should be available for families, with assessments of family needs and strengths central to the process of developing core services, rather than limiting the focus to the child or adolescent.
- As much as possible, families should have access to needed services regardless of ability to pay.
- Families need help in understanding the mental health system and how to access the services they need. Expanded use of Parent Partners, the expansion of existing parent support groups, and other ways of using parents with experience in the MH system should all be explored as ways of helping parents understand the

MH system and cope with issues they are facing with their child and family. Such resources can help parents know what to expect, and hopefully the support services can become involved with parents *before* they are placed in a crisis context.

Parent Partners and other family support groups should be expanded to help more parents understand the MH system and cope with issues affecting their family.

- Expanded use of MH Family Aide positions should be considered as a means of providing direct supports and practical parenting guidance for families in need, as well as helping them learn new skills for the future. Rather than putting all the burden on the child, parents need to be part of the solution, and to be held accountable for making progress, but they also need to be assisted in developing needed skills to make progress realistically possible.
- A better system is needed of follow-through with parents, calling and reminding them of appointments. A crisis can overwhelm many of them, so many need constant reminders and support to help get them to services, follow-through on referrals, etc. Reminder calls and ongoing follow-through and support not only can help those families, but also enable the system to work more efficiently and serve more people, because they help limit the provider "no-shows" and wasted time, and should as a result help reduce waiting time for services.

Funding/Insurance Coverage

Cross-systems funding approaches, expanded waiver options, and use of psychiatric nurse practitioners should be explored as cost-effective alternatives to the status quo.

- Given the difficulties in recruiting and retaining child psychiatrist specialists, some have suggested making increased use of psychiatric nurse practitioners, for a fraction of the cost, and having them work under the supervision of psychiatrists. Having such an arrangement—as some state agencies in particular, as well as at least two local provider agencies, have done—may be far more cost effective while also enabling a high level of care to be maintained for the large numbers of children needing access to psychiatric services.
- Discussions will need to occur with the State and other potential sources of funding to access new resources to cover the costs of community-based services not covered by Medicaid or private insurance. For example, further opportunities should be explored to expand waiver options as a means of accessing expanded sources of funding.
- There should be opportunities to develop collaborative cross-systems funding approaches, and to reallocate some existing funds

to modified services that better meet the needs of families, so that significant components of a new model system should be able to be funded without the need for new financial resources. Certainly some additional resources are likely to be needed, at least for some up-front changes, but if we are creative, the community should be able to do much more than it has been doing with more focused use of existing resources in the future.

Integrated Services/ Cross-Systems Issues

- A Single Point of Access/Accountability System (SPOA) as outlined above could be helpful, once fully implemented, in integrating services on a holistic, cross-systems basis.

Improved cross-systems linkages of services, including case management, are needed, given the involvement of many youth in multiple service systems.

- Although the focus of this project was designed to be on developing an improved mental health service system for children and families, it should also consider opportunities for improving cross-systems linkages between MH and other systems, given that so many children and adolescents are involved in multiple systems. Barriers between systems should be addressed and reduced or eliminated wherever possible.
- Cross-systems case management should be in place wherever possible and appropriate. The need for specific case management and other cross-systems services should become more apparent through careful analysis of SPOA data, once it is operational.

Cross-Systems: Schools

- With many referrals to CPEP originating in schools, including through BOCES, there is the need for better training/orientation of teachers and other school staff concerning how they should handle various situations, and what types of cases should be considered crisis cases in need of referral to CPEP and which can be handled in other ways.

Staff from MH agencies should be decentralized, where feasible, into targeted schools.

- CPEP and the schools should establish liaisons to facilitate communications and trust relationships between these resources, so that advice about particular cases can be provided by phone where appropriate, thereby avoiding some unnecessary referrals to CPEP.
- School and MH officials need to discuss ways in which they can communicate more effectively on an ongoing basis around specific cases, so that information that can be mutually helpful can be shared judiciously in ways that improve both systems' ability to

serve children and families, but without violating appropriate confidentiality limitations.

- Consideration should be given to adding more on-site MH services based in schools, including structured after-school programs. Where possible, staff from appropriate MH agencies should be decentralized to targeted schools to provide direct services, ideally focused on both children and families.

Cross-Systems: Child Welfare/DSS

- Ideally, children and families in the DSS/Child Welfare system should receive a mental health assessment, as part of an overall assessment of child/family needs and resources, much as now happens within the Probation assessment system. Such an assessment process would have resource and training implications, but may help link services more appropriately between families involved in both systems.
- MH and DSS leadership should build on existing efforts to communicate each other's respective needs and develop cross-systems service approaches that address the mutual needs and regulations of each system, while addressing family needs holistically and minimizing the need for families to be receiving services from two different systems.

Mental Health and DSS should develop more joint purchase of service agreements to access appropriate services for their dual-service families.

- DSS and the MH system should build on previous efforts and jointly purchase services that meet the needs of mutual clients. Programs that provide family supports and practical parenting training, Families First, family case management, day treatment programs, various types of aftercare services, etc. may be examples of types of services that would be mutually beneficial and lend themselves to joint purchase of services agreements whereby DSS and MH would agree to share costs of purchasing services from appropriate community agencies. Such purchase of services efforts should be linked to performance-based contractual agreements with the community providers.

Cross-Systems: OMRDD

- Local county MH officials, and representatives from the regional State DDSO, should begin to formally discuss ways in which their two systems and sets of services can collaborate more effectively, rather than maintaining the current "silo" approach to service

delivery. Ways should be explored of sharing MRDD and MH resources for children and adolescents who cross both systems.

MH and MRDD officials should be exploring a structured program designed to serve MRDD youth with behavioral problems, as well as possible sharing of state staff between MRDD and CPEP.

- Consideration should be given, presumably in discussions involving state officials, to the possibility of creating a small residential unit, or a structured day treatment unit of some sort, which would serve MRDD children/adolescents who manifest out-of-control behaviors. A cross-systems solution is needed that recognizes legitimate needs and limitations of each system, while acknowledging that MRDD kids with MH and/or behavioral problems, and their families, have needs that are not now being adequately addressed by either system.
- Consideration should be given to having shared staff allocated between the State MRDD system to CPEP or other local MH resources, to help address dual MRDD/MH needs, just as CPEP has been able to do through the OMH system. This might become a way to increase local resources while also breaking down barriers between the two systems.

Cross-Systems: Probation/Juvenile Justice

- There are many children involved in both the mental health and juvenile justice systems, and others that should be involved in both—or that could be prevented from involvement in one if more effectively involved in the other. In order to develop better working relationships and consider how the systems can better work together to complement each other, key MH officials and Probation/juvenile justice/Family Court officials should develop a strategic planning approach to discuss appropriate roles, services, possible partnerships, and accountability for the future.

Probation Officers should be trained to carefully identify mental health issues in their assessment process.

- Probation Officers provide psychosocial assessments of those in the juvenile justice system, including informal mental health assessments, but they are not trained to identify MH issues. If they are to continue doing such assessments, they need more formal training to make sure that the assessments are as accurate and helpful as possible.

Cross-Systems: Substance Abuse

- There needs to be a more effective way of reengineering substance abuse services for youth. Within the Substance Abuse system, consolidation of existing youth-related substance abuse services should be considered, as well as better working relationships

MH and Substance Abuse services and financial resources should be linked as much as possible, given the considerable overlap in clients across the systems.

between the preventive and treatment services, to assure continuity of services and that as many youth as possible can be served.

- Within Mental Health services, there should be more joint services for kids with both substance abuse and MH issues (in effect, expanded MICA services for youth). The Substance Abuse and Mental Health service systems and financial resources should be linked as much as possible to assure maximum impact on the substantial number of youth estimated to be in both systems.

VII. Best-Practice Models

The project Steering Committee has focused its primary "best practice model" attention on selected models and evidence-based practices advocated by the state Office of Mental Health. At its May 30 meeting, the Steering Committee received a detailed presentation from OMH Central Office staff on best practices and evidence-based models, based on OMH's *Winds of Change* document. That presentation focused on the following:

What Does the Evidence Tell Us?

For children and their families, OMH suggests the following:

- The research evidence linking services to positive outcomes is strongest in the following areas: home-based services, therapeutic foster care, case management, and pharmacotherapy for some disorders.
- Evidence is accumulating documenting the efficacy of specific family educational interventions.

Evidence-Based Practices for Children

OMH lists the following "best practices" in the *Winds of Change* report:

- Functional family therapy;
- School-based mental health services;
- Home-based crisis intervention;
- Evidence-based prescribing practices;
- Home and community-based waiver and intensive case management with wrap-around funds;
- Family education and support.

The Steering Committee and County officials should keep these practices—and their potential implications for Broome County—in mind, along with the issues and recommendations suggested throughout this report, as they develop the final vision and action plan for the future.

VIII. CONCLUSIONS AND POTENTIAL COMPONENTS OF MODEL

This concluding chapter attempts to outline the primary findings from the research and to suggest a framework of key components that might need to be part of an improved model of mental health and related services for children and families in Broome County. The project Steering Committee is currently in the process of addressing these issues as it prepares its companion "vision and action plan/recommended model" document to accompany this CGR report. It is currently anticipated that that document will be issued by the Steering Committee later this summer or early fall.

Primary Conclusions from Analyses

A wide variety of services and programs are currently serving children and adolescents in Broome County. Many programs are well-regarded, and many are operating at or close to full capacity. The county is also unique among counties of its size in having a psychiatric crisis center (CPEP) available to respond to the crisis needs of its Serious Emotionally Disturbed (SED) youth.

Key building blocks of a strong future mental health system for children and adolescents are in place, but some are too small at this point to meet the perceived needs, while others are not operating at full capacity, despite the perceived needs for expanded services. Finding ways to better match resources with needs is part of the challenge facing the community as a blueprint for a new system is developed.

Rapidly increasing numbers of children and adolescents of all ages, both boys and girls, are being referred to CPEP for crisis assessments, and even more rapid increases have been seen in the last three years in the numbers of youth being hospitalized, with most of the increases involving placements in psychiatric hospitals outside Broome County. The greatest proportional increases in CPEP presentations/intakes and in hospitalizations involve children under the age of 13. Other children and adolescents who are assessed by CPEP but *not* hospitalized are often not connected with follow-up services in the community, and many of those returning from hospital episodes are also not linked effectively with aftercare services. Gaps in services, and ineffective linkages

with the services that do exist, help contribute to substantial increases in the numbers of youth who are referred multiple times to CPEP, and even more significant increases in the numbers of multiple hospitalizations for the same child within the same year. Contributing to these increases is the fact that relatively few family-focused support services are in place. Most mental health services for children and adolescents focus their primary attention directly on the youth, with little focus on the family environment in which the young person lives, including the extent to which the family circumstances may be contributing to the youth's behavior.

About one-third of all youth who were assessed at least once at CPEP between 1998 and 2001 accounted for 60% of all CPEP presentations during those four years. The vast majority of those multiple presentations involving the same person occurred within a few months of each other, typically within the same year. For example, within 2001, 83 individuals presented at CPEP three or more times. If it becomes possible to define such small subgroups of multiple users of CPEP, and to develop alternative services for them and their families prior to coming to CPEP in a crisis mode, there could be a substantial reduction over time in the burden on CPEP staff, and in the degree of upheaval in the lives of children and families who now end up multiple times at CPEP when crises erupt in their lives.

A Framework for Responding

The Visioning Project's Steering Committee has ultimate responsibility at this point for developing a vision and designing a blueprint for what a future mental health service system for children and adolescents, and their families, should look like. A preliminary framework of what such a blueprint might include is outlined below, focusing on a number of the key building blocks that are likely to be the foundation of the ultimate model. This framework is based on study findings and suggestions growing out of those findings, and recommendations by parents and stakeholders throughout the study process. The framework is offered as a point of departure for the ongoing deliberations by the Steering Committee, which, as noted, is currently modifying and amplifying on this framework and is finalizing its priorities for short-term and longer-term action.

Continuum of Care

The model should be built on a strong continuum of services, ranging from preventive and early intervention services to crisis services and aftercare. The continuum of services should particularly emphasize prevention and early intervention, with strengthened services especially addressed to young children and to total family units. Among the specific types of services that appear to need to be expanded and/or used more effectively are the following:

- Day treatment;
- Flex Team services (Home and Community-Based Waivers);
- Case management;
- CCSI comprehensive services;
- Structured after-school programs, such as the Therapeutic After-School Program;
- Respite care;
- School-based mental health programs;
- Skill-building and other aide services to parents;
- Support groups and various support services for parents dealing with mentally ill children and adolescents;
- Intensive wraparound services and dollars for youth and families;
- Substance abuse services for adolescents in the mental health system;
- Possible expansion of child psychiatrists and/or psychiatric health nurses in the community.

Crisis Intervention Services

A number of issues need to be addressed at the crisis intervention level. Among them are the following:

- Even though it was beyond the scope of this project, the data from all components of the study clearly indicate the need for a small inpatient psychiatric facility in Broome County. The reality is that the current pattern of having 85% of inpatient psychiatric hospitalizations occurring at distant locations appears to have significant negative consequences for the youth and their families.

- There may need to be a pre-CPEP, lower-level assessment process to help prevent situations from escalating to the emergency crisis level, and also to deal with the types of non-mental-health-related behavioral problems that CPEP is not now always able to address.
- Better ways are needed of more fully using the county's limited 72-hour Extended Observation Bed resources for children and adolescents.
- Better use is also needed of the valued but underused Adolescent Crisis Residence beds at Binghamton Psychiatric Center.
- More children and youth specialists may be needed to better meet the needs of youth referred to CPEP who are not hospitalized following the assessment. Likely results of increased specialist staffing would be more appropriate use of CPEP, expanded and more appropriate referrals to community services for those not hospitalized, and more effective follow-through with families and youth to help assure that needed services are actually provided.

Access to Services

Several aspects of access would need to be addressed, including:

- The need for a central intake mechanism which could help provide a single point of entry for youth and families entering the mental health system in the first place, and for those returning to the community following hospitalization and needing to access aftercare services. Such a system, which should be part of the function of a county Single Point of Accountability/Access (SPOA) system required by OMH, should help improve access to services, reduce unnecessary duplication of services, improve the flow and movement of youth between levels of care, and improve communications and direct connections between providers and consumers. This function should also provide the needed research capability to help monitor service gaps, and to enable services to be modified as needed to keep pace with changing demands and needs for services, as monitored by assessments done as part of the intake process.
- The SPOA function should also monitor waiting times and delays in accessing services, and work with providers to help address such issues affecting timely delivery of services to children and families.

- Outreach services to outlying areas of the county, provision of services in non-office settings and during non-traditional hours, and the potential for integrating more services into school-based or other community settings are among the access issues that need to be addressed.

Discharge Planning and Aftercare

This may involve both the need to add or expand services and to provide better access to those services that already exist.

- The most important part of this function may be accomplished via the SPOA operation, in which better communications need to be put in place between hospitals and local service providers and parents, to assure that more effective and realistic discharge plans are put in place, and carried out.
- Parents need to be an integral part of the planning process, and family circumstances need to be factored into discharge plans and aftercare services, such that a child not be returned to an unhealthy environment without supports and alternatives being put in place for the family. Where such supports are not possible, discharge planners need to factor that in, and develop other options while the home situation is being resolved.
- More effective aftercare services and discharge planning should ultimately lead to reduced hospital inpatient days overall, through the reduction of repeat hospital episodes involving the same child.

Supports for Parents

Parents need better information to be more effective participants in decisions affecting them and their child, and they need help and support from other parents in similar situations, to help them cope with the issues posed by their child's mental illness.

- More services need to be developed that focus on the provision of holistic, integrated services for the family unit as a whole.
- Better information needs to be made available to parents, on a timely basis in convenient ways and places, concerning the options available to them and their child.
- Strengthened and expanded support groups and other support services, provided in many cases by other parents as peers, are needed to reach a higher proportion of affected parents.

Coordination of Care

More effective cross-training is needed of staff across mental health programs, and better collaboration and partnerships are needed between child/adolescent mental health programs, between child and adult programs, and across mental health and other systems (such as juvenile justice, education, child welfare, MRDD, and substance abuse systems).

- Better case management of children and families is needed to help people access coordinated, non-duplicative services.
- Better focus is needed on collaborative funding, to make the best use of available resources.

Funding

The development of waivers and other ways of breaking down funding barriers, such that "silo" sources of funds can begin to be merged, both within and across systems, needs to be encouraged. Such blending of funds will be critical to the ability to provide more wraparound and coordinated services to family units as needed.

Accountability

The service system which is designed should have at its core the ability to plan, assess needs, and monitor performance and outcomes across different types of services.

- The system should enable programs and new approaches to be developed on a prototype basis and pilot tested for a specified period of time, during which the performance of the program is being monitored and evaluated to assess its effectiveness and whether it should continue to be funded in the future, as is or with modifications.
- Such an accountability mechanism should also be instrumental in helping reallocate resources, where appropriate, to meet changing needs and opportunities over time.

Cross-Systems/ Integrated Services

Although the focus of this project has been primarily on mental health services, it has become clear that there are high proportions of overlaps of children and adolescents, and families, involved in the mental health and other service systems (child welfare, juvenile justice, education/special education and disciplinary systems, MRDD, and substance abuse). To address a service system for

SED and other mentally ill youth, and youth with behavioral problems, without factoring in the overlapping service networks, would seem foolish and short-sighted. It may be that the SPOA, though focusing primarily on mental health issues, can also be instrumental—at least in the future once it becomes established—in helping to facilitate coordinated services across systems. One of the opportunities that should grow out of increased concentration on cross-systems issues is the potential to develop more cross-funded projects, including joint purchase of service agreements that may make some services possible through expanded joint funding that would not be possible with single sources of funds.