CHILDREN IN BROOME COUNTY WITH CO-OCCURRING MENTAL HEALTH AND DEVELOPMENTAL DISABILITY CONDITIONS

NUMBERS AND SERVICE GAPS

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October, 2005
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CHILDREN IN BROOME COUNTY WITH CO-OCCURRING MENTAL HEALTH AND DEVELOPMENTAL DISABILITY CONDITIONS

NUMBERS AND SERVICE GAPS

Prepared for:
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SUMMARY

The Broome County Children's Mental Health Task Force is a coalition of local agencies and individuals concerned about the lack of adequate mental health services for children and adolescents with mental health needs who also have or are considered likely to have developmental disabilities. The Task Force requested CGR (Center for Governmental Research Inc.) to conduct a needs assessment to determine the numbers of such children with co-occurring mental health and developmental disability conditions and the extent of gaps in services for this population.

The study's primary findings, conclusions and implications are:

❖ Based on imprecise national estimates, there may be between about 3,600 and as many as about 13,500 children and adolescents in Broome County with some level of mental health needs/ emotional disturbances, and between about 1,400 and as many as about 10,400 with a developmental disability. More than 5,350 children have been classified as having special educational needs and/or disabilities within the county's 12 school districts.

❖ During 2004, almost 3,000 children with mental health needs and almost 900 with developmental disabilities were reportedly

served by the county's Mental Health and Mental Retardation/ Developmental Disability community-based service providers.

❖ Of those children and adolescents, about 500 county children with co-occurring MH and DD conditions have reportedly been identified and are currently being served by the MH and MRDD service providers in the county.

❖ Of those, approximately 300 county children with co-occurring MH and DD conditions reportedly had service needs which could not be met by MH and MRDD providers during 2004 and early 2005. This includes:

- an estimated 122 children with developmental disabilities who required MH services that could not be provided;
- an estimated 151 children with mental health needs who required DD services that could not be provided; and
- an estimated 41 children with co-occurring conditions who were on waiting lists to access services (mostly within MH agencies).

❖ It is significant that despite different independent approaches to identification of needs, both community-based service providers and special education school officials are consistent in estimating that about 300 county children with co-occurring MH and DD conditions have unmet needs due to service gaps and difficulty accessing needed services.

❖ These approximately 300 children, while a relatively small and manageable number to engage and serve, represent a substantial concern and challenge in the context of the current and historical inability of the MH and MRDD service systems to be able to come together to develop service plans, practices and policies to meet the needs of these children with co-occurring conditions.

❖ Consensus among major service provider groups in the county suggests the following major Highest Priority unmet service needs for children and adolescents with co-occurring MH and DD conditions:

- Child and adolescent psychiatric evaluations;
- Counseling for children and family members;

- Emergency and ongoing respite care;
- Crisis intervention; and
- Medication management.

❖ Most consistently cited as the major barriers to providing needed services for children with co-occurring conditions were:

- Poor coordination between agencies and particularly between the MH and MRDD service systems;
- Insufficient availability of psychiatric services;
- Problems with Medicaid and other insurance coverage; and
- Lack of sufficient providers and access to needed services.

❖ Too often, children with co-occurring MH/DD conditions do not receive the services they need, get bounced between systems or "fall through the cracks," and are placed in higher levels of care than is appropriate. Often they cannot obtain needed services, or even evaluations, because of specific mental health or developmental disability conditions.

❖ Broome County is in one sense no different from counties throughout New York regarding difficulties in addressing the needs of children and adolescents with co-occurring MH and DD conditions. The main difference is that Broome has begun to address the issue by beginning to define the problem and the scope of the needs. There are actions that local officials and service providers can begin to take, and indeed seem willing to consider, as suggested in recommendations that conclude the report. Comprehensive, full-scale solutions, including adequate funding, will require actions not only by the county, but also by the state at the OMH and OMRDD levels.

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ACKNOWLEDGMENTS

To be added

Staff Team

I. INTRODUCTION

Background and Context

The Broome County Children's Mental Health Task Force is a coalition of local agencies and individuals concerned about the lack of adequate mental health services for children and adolescents with mental health needs (including in particular Serious Emotional Disturbances) who also have or are considered likely to have developmental disabilities. The Task Force requested CGR (Center for Governmental Research Inc.) to conduct a needs assessment to determine the numbers of such children and the extent of gaps in services for this population.

In a July 2002 "Visioning Project" report for the Broome County Mental Health Department, CGR concluded that "There are many cross-systems children with mental health issues not being adequately addressed (their own or, in many cases, their family's)." More specifically, the report noted rough estimates from some mental health (MH) and mental retardation/developmental disabilities (MRDD) officials that 25-30% of the children and adolescents in the MRDD system may also have mental health issues, and "some estimate that perhaps a couple hundred MRDD children and adolescents need crisis care and support during a year, but don't receive mental health services." Moreover, the report added that many family-related problems caused by the stresses often don't get addressed. However, beyond those broad estimates, no one at that time had reliable data on the true magnitude of the numbers of co-occurring MH/MRDD children and families affected, or the gaps in services for this population.[1]

The Broome Visioning report went on to discuss various disconnects between the mental health and MRDD systems, with the MRDD system often perceived as unwilling or unable to serve a child or adolescent with a primary mental health diagnosis, and

[1] See CGR, *Broome County Visioning Project for Children and Adolescents: An Assessment of What Exists and Service Gaps*, July 2002. See especially pp. 82-84.

vice versa for the Mental Health system. Officially dually-diagnosed youth, and those considered likely to have co-occurring MH and MRDD conditions, often are caught in the middle, receiving inadequate services, and many "fall through the cracks or wind up being served in both systems, without much coordination of services between the systems." [2]

The subsequent priority recommendations and action plan developed by the Broome County Visioning Project's Steering Committee listed the need for expanding services for various specialized populations, including dually-diagnosed MH and MRDD youth, as the group's top priority. As stated in the 2002 action plan, "A key first step in this process would be to obtain better empirical estimates of the numbers" of dually-diagnosed cross-systems youth.[3]

Thus, in mid-2004, the Children's Mental Health Task Force put this issue of youth with co-occurring mental health and developmental disability conditions squarely on the table for consideration. In order to move the issue forward, the Task Force requested CGR to quantify the numbers of affected youth and any service gaps more precisely than anyone had been able to do previously. This report presents CGR's findings and suggested implications.

Methodology

Most of the data-gathering for this project was done via a series of surveys, supplemented by analyses of various existing databases. The overall study methodology was developed in consultation with the Children's Mental Health Task Force, which also reviewed and approved drafts of the various survey instruments (the drafts were developed in consultation with small survey steering committees established by the overall Task Force).

Research Components

This report is based on findings from the following key research components:

[2] CGR, *Broome County Visioning Project*, p.83.

[3] See *Broome County Visioning Project: Steering Committee's Vision, Priorities and Recommendations to Strengthen Services for Children and Families*, October 2002.

Surveys

❖ Five separate surveys provided most of the data presented in this report. They, along with an "Information Sheet and Definitions" explaining terms used in the surveys, are included in Appendix A, and each is briefly described below:

- A survey of all known providers of children's mental health and mental retardation/developmental disability services in Broome County. The programs/service providers from which surveys were received are listed in Appendix B.
- A survey of Service Coordinators who provide case management support to many of the children and adolescents served by the MRDD service system.
- Two separate surveys of the chairpersons of special education services in each of the county's 12 school districts—Chairpersons of Special Education (CSEs) and of Preschool Special Education (CPSEs).
- A survey was designed for completion by parents of children with developmental disabilities and/or with mental health needs.

Completed surveys were received from the following:

Type of Survey	Surveys Distributed*	Surveys Completed
Providers	59	58
Svc. Coordinators	32	31
CSE Chairpersons	12	12
CPSE Chairpersons	12	12
Parents	na	20

* Note that some additional surveys were distributed to providers who subsequently informed us that they did not serve the study's target population. They are not included in the totals. Surveys were distributed to Service Coordinators who serve at least some children. Service Coordinators were responsible for distributing surveys to parents. It is not known how many were actually distributed; 20 were completed and returned. Other than the parent surveys, 98% of the distributed surveys were completed and analyzed.

Additional Analyses

❖ A special analysis was undertaken by Coordinated Care Services Inc. (CCSI) of Medicaid recipients 21 and under with dual

MH and MRDD diagnoses who accessed services over a two-year period.

❖ A special analysis was undertaken by the Broome Developmental Disabilities Service Office (DDSO) of all children receiving services in the MRDD service system during the summer of 2005.

❖ Data were obtained from the 12 school districts and from NYS Education Department indicating the numbers of children classified in each district with various classifications of special educational needs.

❖ Selected data were reviewed from the Broome County SPOA (Single Point of Accountability/Access).

❖ A literature/internet survey was undertaken of best practices in place throughout the country for addressing the needs of children and adolescents with co-occurring MH and MRDD conditions.

❖ Estimates were obtained from national research of numbers of children in the country with mental health needs/illness and developmental disabilities.

The research components are explained in more detail as needed in the various chapters of the report.

Key Definitions

Several terms are used frequently throughout the report, and were key to the completion of the project's various surveys and data analyses. Among the study's key definitions are the following (for a more complete list, see the "Information Sheet and Definitions" as part of the surveys in Appendix A):

Children: Children, adolescents, young adults from birth through age 21.

Diagnosed: An official diagnosis of a specific mental health need or developmental disability.

Dually-Diagnosed: A child age 0-21 who has been officially diagnosed with both a mental health need and a developmental disability.

Co-occurring Developmental Disability/Mental Health Conditions: A child has some combination of either officially-diagnosed or program/agency judgment of likely developmental disability plus mental health need(s).

Developmental Disability (DD): A condition that qualifies (or if diagnosed would qualify) a child 0-21 for access to developmental disability services. More specifically, a disability that originates before age 22, has continued or is likely to continue indefinitely, and constitutes a substantial handicap to a person's ability to function normally in society. A developmental disability is attributable to:

> (a) mental retardation, cerebral palsy, epilepsy, neurological impairment or autism; or
>
> (b) any other condition closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior or requires treatment of services similar to those required for mentally retarded persons.

Mental Health (MH) Need/Emotional Disturbance: A condition that qualifies (or if diagnosed would qualify) a child 0-21 for access to mental health services. Such conditions are often, but not necessarily, defined in the DSM-IV as Axis I or Axis II mental health disorders.

> **SED (Serious Emotional Disturbance):** This is a subset within the overall Mental Health Need definition. To be considered SED, a child 0-21 must meet certain criteria (see Appendix A "Information Sheet and Definitions").

Mental Retardation/Developmental Disability (MRDD): Refers to the broad MRDD service system, as well as to a condition that qualifies a person for access to developmental disability services. For purposes of this study, CGR and the Children's Mental Health Task Force chose to use the broader term Developmental Disability (DD), including mental retardation as a subset within the DD classification.

Professional Judgment of Likely Mental Health Need and/or Developmental Disability: No official diagnosis, but professional's best judgment is that a child has a mental health need and/or developmental disability.

Survey Limitations

The project sponsors were aware from the beginning of the research that most of the key data would be obtained from surveys, and that some of the information obtained would be based on the perceptions and judgments of those responding to the questions. Some of the numbers presented in the report were based on estimates involving the best judgments of those completing the surveys, and not necessarily always on careful professional assessments of mental health or developmental disability conditions.

So some of the data presented in the report are subject to inherent limitations of surveys, which cannot always provide definitive data. In some cases the data are more suggestive than providing definitive, final answers. But surveys can be useful in providing data, even if only best estimates, where no other reliable sources of the data of interest exist, and that was the case in this project. In such cases, survey data can be useful in pointing to potential issues where further exploration is needed, even if "absolute truth" is not possible from the survey findings.

These limitations having been noted, it is also important to state that there were many similarities and consistencies in the findings across the various data components that lend strength to the validity and value of the survey data. These will be noted where appropriate throughout the report. Perhaps of greatest importance to the major conclusions of the study is the fact that both mental health/MRDD providers and school-based special education officials—approaching data questions from different classification perspectives—wound up with very similar estimates of the numbers of children with co-occurring mental health and developmental disability conditions. Thus we believe it is fair to conclude that, limitations notwithstanding, the data presented in the report meet the test of being sufficiently consistent and accurate to provide a reasonable basis for making recommendations to guide future planning and decision-making, as addressed in the final chapter of the report.

II. THE SERVICE PROVIDERS: WHO PROVIDES MH AND MRDD SERVICES

The survey process identified 41 Mental Health (MH) programs and 17 Mental Retardation/Developmental Disability (MRDD) programs which provide services to children and adolescents living in Broome County. The programs are summarized briefly below, with some additional information provided in Appendix C.

MH Providers

Eleven agencies identified 41 separate mental health programs serving Broome County children and adolescents. They are listed in Appendix B. These represent three more agencies and nine more programs than were identified in the 2002 Visioning project referenced in Chapter I. *Some of these additional programs have been added as new providers/services in response to that study*; some were described as separate and distinct programs by providers in this study that were listed as combined programs in 2002; and at least three programs surfaced in this project that may or may not have existed in 2002.

For a grouping of the 2002 programs by types of services provided, see the Visioning report, page 7.[4] The programs identified in this 2005 survey could be classified broadly within the same five project types determined in the earlier study: case management services, clinics, treatment, group home/residential, and counseling/other.

Cumulatively, the MH programs have the following characteristics:

❖ In addition to providing services to children and adolescents with mental health needs, 29 of the 41 MH programs (71%) indicated that they also provide services to DD children. Only four MH service providers indicated that their programs specifically exclude serving children with developmental disabilities.

[4] *Broome County Visioning Project*, p. 7 plus Appendix listing.

❖ All MH programs serve at least some children between the ages of 11 and 18; only 15 serve adolescents older than 18.

❖ Overall, an estimated 87% of the children served by the 41 programs live in Broome County. More than half of the providers (21) reported that their services are provided exclusively to Broome County children, while the others serve at least some youth from other counties as well.

MRDD Providers

The survey identified 17 separate MRDD programs, provided by 15 different agencies, as listed in Appendix B. Technically, only 16 provide direct DD services, as the Department of Social Services is listed even though it does not provide specific services, because it completed a survey indicating a number of DD children who receive regular DSS services. The Southern Tier Independence Center (STIC) is not listed, because most of its services are provided through Service Coordinators. Data reflecting Service Coordinator services are described in a section later in the report.

Cumulatively, the MRDD programs have the following characteristics:

❖ None of the MRDD providers specifically exclude serving children who have mental health needs, although fewer than half (7) indicated that they actually provide mental health services to children between the ages of 0 and 21.

❖ Most of the MRDD providers serve at least some children and adolescents in all age ranges, with the age group 11-18 the most commonly served.

❖ Overall, an estimated 84% of the children served by the programs live in Broome County. Six of the providers reported that their services are provided exclusively to Broome County children, and another six reported that at least 90% of the children receiving their services live in the county.

III. NUMBERS OF CHILDREN SERVED BY MH AND MRDD SERVICE PROVIDERS

Providers were asked to report the capacity of their programs—with capacity defined as the number of children ages 0-21 that a program could serve at one time—and the numbers of children with various characteristics who were being served at the time of the survey.

MH Providers

Respondents were asked to report the number of children with different types of needs who were being served by their programs as of April 15, 2005. Table 1 on the next page summarizes the total numbers of children reportedly served by the providers in each category of service needs, as well as estimates of the total numbers of children from each category who were living in Broome County. (See Appendix Table D-1 for more detailed data, reflecting minimum, maximum and median numbers of children served by various programs in each category.)

As of April 15, the MH programs were providing services to the following children:

❖ More than 1,500 children were officially diagnosed with or judged by their programs as likely to have a mental health need/emotional disturbance. This number is within the range of 1,435-1,545 who were served at two points in time during the 2002 Visioning Project. This represents about 91% of the system's program capacity of 1,663, as reported by the programs. It should also be noted that the stated capacity of the MH providers as of 2005 is virtually identical to the 1,653 capacity documented in the 2002 visioning project,[5] not counting seven programs for which no capacity numbers were reported and which typically indicated that they simply respond to needs as they arise, with no specified number of designated program slots (e.g., programs such as

[5] *Broome County Visioning Project*, p.7.

SPOA, Children and Youth Mobile Mental Health Team, CPEP, etc.)

❖ Of the total of 1,514 children estimated to have mental health needs, an estimated 1,390 were Broome County residents.

Table 1.

Numbers of children with various characteristics being served by MH providers as of April 15, 2005		
	Total # of children	**Estimated number living in Broome County**
# diagnosed with or likely to have a mental health need of any type	1514	1390
# diagnosed with or likely to have a serious emotional disturbance	1051	956
# diagnosed with or likely to have a developmental disability	244	225
# dually-diagnosed with both an MH need and DD	177	162
# with a mental health need who are likely to have a DD	48	45
# with a DD who are likely to have a mental health need	2	2
# with a DD who are likely to have SED	151	137
# with both MH and DD conditions but w/o official diagnosis for either	15	15

N = 38 programs providing data, not including SPOA, CPEP and Our Lady of Lourdes Hospital Student Assistant Program, which do not maintain active cases.

❖ Of those with mental health needs, 69% were identified by providers as being diagnosed with, or likely to have, a serious emotional disturbance—956 Broome County children. This proportion is comparable to the estimate of 70% or more in 2002.[6]

[6] *Ibid.*, p12.

Almost 1,400 Broome County children with mental health needs were collectively served by all the MH providers on April 15. Factoring out those served by more than one program at a time, an estimated 1,158 separate children with MH needs were served at that time.

❖ It should be noted that the previous CGR report found that a number of children were served by more than one program at the same time, and that the unduplicated count of individual children receiving services was about 83% of the total number of children who reportedly received services from individual programs.[7] Applying this ratio to the present data would mean that the 41 MH providers were serving a total of 1,262 unique, unduplicated children as of April 15th, 2005—approximately 1,158 of whom would have been Broome County residents, including about 800 defined as SED.

❖ Mental Health service providers were also providing services to 225 Broome County children with developmental disabilities, over 60% of whom (137) were identified as having a Serious Emotional Disturbance.

❖ Table 1 also indicates that 162 Broome County children were identified as having dually-diagnosed mental health and developmental disability conditions—11.65% of all children with MH needs reportedly being served and 72% of those identified with developmental disabilities.

At least 187, and as many as 224 children with co-occurring MH and DD conditions, were served by MH providers in April 2005.

❖ Factoring in those 162 officially diagnosed children with DD and MH conditions—plus 45 children with mental health needs who were reported by the programs as being likely to have (but not diagnosed with) a developmental disability, two DD children who were likely to have (but not diagnosed with) mental health needs, and 15 children who were considered to have co-occurring MH and DD conditions (but without an official diagnosis for either)— *the total estimated number of children with co-occurring MH and DD conditions receiving services from MH providers equaled 224 on April 15.* Factoring in an unduplicated count estimate of about 83% of that total, the actual number of individual children with co-occurring MH and DD conditions served by the MH programs was likely to be between 187 and 224.

MRDD Providers

Table 2 summarizes the responses of 16 MRDD service providers to questions regarding the numbers of children from each category

[7] *Ibid.*, p.11.

receiving services as of April 15th, 2005. (A more detailed version of this table appears as Table D-2 in Appendix D.)

Table 2.

Numbers of children with various characteristics being served by MRDD providers as of April 15, 2005		
	Total # of children	**Estimated number living in Broome County**
# diagnosed with or likely to have a mental health need of any type	298	225
# diagnosed with or likely to have a serious emotional disturbance	90	63
# diagnosed with or likely to have a developmental disability	741	567
# dually-diagnosed with both an MH need and DD	140	108
# with a mental health need who are likely to have a DD	39	39
# with a DD who are likely to have a mental health need	173	132
# with a DD who are likely to have SED	56	43
# with both MH and DD conditions but w/o official diagnosis for either	13	13

N = 16 programs providing data.

Table 2 shows that:

❖ The MRDD programs were serving 741 children officially diagnosed with, or judged by their programs as likely to have, a developmental disability of some type Eight programs did not provide a numerical capacity, indicating either that their programs do not have limits on the number of children they serve or that their program's capacity depends on staffing levels. If numbers

served are compared with capacity for only those programs that provided precise numbers both for program capacity and for numbers served, the numbers served represented 91% of program capacity—identical to the proportion within the MH programs.

❖ Of the 741 DD children served by the MRDD providers, an estimated 567 live in Broome County. This may be a conservative estimate of the number of children with disabilities served in the county, as an independent analysis of children in the Developmental Disabilities Service Organization (DDSO) data base indicates an unduplicated count of 667 children.

Between 567 and 667 Broome County children with developmental disabilities were reportedly being served in the spring of 2005 by MRDD service providers.

❖ As of April 15th, 2005, MRDD programs were also reportedly providing services to 225 Broome County children with mental health needs, including 63 SED children (28% of those with MH needs receiving services through MRDD providers were estimated to be SED, compared with 69% of those receiving services through MH providers).

❖ MRDD programs reported 108 Broome County residents officially diagnosed with both mental health needs and developmental disabilities whom they were serving as of April 15th, 2005—48% of all children with MH needs reportedly being served and 19% of those with DDs.

❖ *A total of 292 Broome County children with co-occurring mental health and developmental disability conditions were estimated to be receiving services from MRDD providers on April 15*: the 108 officially dually-diagnosed children, plus 39 children with mental health needs who were reported by the providers as also likely to have (but not diagnosed with) a developmental disability, 132 developmentally disabled children who were likely to have (but not diagnosed with) mental health needs, and 13 children considered to have co-occurring mental health and developmental disability service needs, but without a diagnosis for either condition.

Almost 300 Broome County children with co-occurring DD and MH conditions were reportedly served by MRDD providers in the spring of 2005. This represents a higher proportion of children served in the MRDD system with co-occurring conditions than is true among MH service providers.

❖ In short, a higher proportion of children served in the MRDD service system are identified as having co-occurring MH and DD conditions than is true of children served by MH service providers.

Combined MH and MRDD Provider Totals

Table 3.
Numbers of children with various characteristics being served by MH and MRDD providers as of April 15, 2005

	# of MH and MRDD provider responses	Combined Total # of children	Estimated number living in Broome County
# diagnosed with or likely to have a mental health need of any type	54	1812	1615
# diagnosed with or likely to have a serious emotional disturbance	53	1141	1019
# diagnosed with or likely to have a developmental disability	54	985	792
# dually-diagnosed with both an MH need and DD	54	317	270
# with a mental health need who are likely to have a DD	53	87	84
# with a DD diagnosis who are likely to have a mental health need	53	175	134
# with a DD who are likely to have SED	53	207	180
# with both MH and DD conditions but w/o official diagnosis for either	52	28	28

Based on the above discussions of data in Tables 1 and 2, Table 3 summarizes the combined totals for MH and MRDD service providers regarding the number of children with different needs who were receiving services within the two service systems as of April 15th, 2005.

N = 54 programs providing data.

About 500 Broome County children with co-occurring mental health and developmental disability conditions were reportedly being served by MH and MRDD service providers this spring. Roughly 20% of those were receiving services paid for by Medicaid.

❖ Service providers were serving more than 1,600 Broome County children with mental health needs (including more than 1,000 with an SED), and nearly 800 children with developmental disabilities. Of these, an estimated 516 were either officially dually-diagnosed with both mental health and developmental disability conditions or were thought likely by service providers to have co-occurring MH and DD conditions. Factoring in both MH unduplicated count estimates and higher indications from DDSO data of numbers served, estimates of numbers of children with co-occurring conditions could fall within ranges slightly lower or slightly higher than the 516 total. However, it seems reasonable to conclude that these upper and lower estimates may cancel each other out, so that for planning purposes, *we believe it is reasonable to use an estimate of about 500 children with co-occurring MH/DD conditions currently living in the county and being served by MH and/or MRDD programs*.

❖ Analyses by Coordinated Care Services Inc. (CCSI) of Broome County data indicate that during 2002 and 2003, 99 county children and adolescents made at least one Medicaid claim with a mental health diagnosis and at least one Medicaid claim with an MRDD diagnosis. Although the cases may not be identical to those identified in the 2005 survey, *it seems reasonable from these data to conclude that roughly 20% of children with co-occurring conditions use services paid for by Medicaid*. (See further analyses of these Medicaid cases in Chapter VIII.)

IV. NUMBERS OF CHILDREN NOT RECEIVING SERVICES AND NUMBERS ON WAITING LISTS

Another set of survey questions was intended to obtain an estimate of the numbers of children with co-occurring MH and DD conditions who were not able to receive all of the services they required during the year 2004. Furthermore, respondents were asked about the number of children on waiting lists for their programs as of April 15, 2005 and the number of children on those waiting lists who were likely to have co-occurring MH and DD conditions.

MH Providers

The responses of the MH service providers to these questions are summarized in Table 4 below, with more detailed information included in Appendix Table D-3.

Table 4.

Numbers of children with various characteristics served by MH providers in 2004 and on waiting lists as of April 15, 2005		
	Total # of children	**Estimated number**

		living in Broome County
# with a DD served in 2004	306	278
# with a DD who had unmet MH service needs	27	26
# with MH needs served in 2004	3074	2744
# with MH needs who had unmet DD service needs	147	136
As of April 15, # of children 0-21 on waiting list	303	286
Of those on waiting list, # with both DD & MH conditions	35	34

N = 35 programs providing data, except N = 37 for waiting list data. See text for indication of relative lack of significance of missing program data.

❖ The table shows that during 2004, the 35 MH programs providing this information served an estimated 278 Broome County children with developmental disabilities. An estimated 26 of those (9.4%) were in need of mental health services that could not be provided. (These and other numbers in the table might have been slightly higher had all 41 programs responded to these questions, but it is not likely that the numbers would have been significantly different because providers not answering these questions were those without regular caseloads such as SPOA and CPEP and those serving relatively few children.)

At least 162 Broome County children served in 2004 by MH service providers reportedly had some co-occurring MH and DD needs that could not be met. In addition, an estimated 34 children with co-occurring conditions were on MH waiting lists in April 2005.

❖ Of an estimated 2,744 Broome County children with mental health needs served by MH programs in 2004, an estimated 136 (5.0%) were in need of developmental disability services that could not be provided.

❖ An estimated 286 Broome County children were on program waiting lists for MH service providers as of April 15th, 2005. Of those, based on preliminary evaluations by program officials, an estimated 34 (11.9%) were children with co-occurring mental

health and developmental disability conditions.[8] These waits were typically for two months or more.

MRDD Providers

Table 5 below summarizes the responses of MRDD service providers to similar questions, with more detailed information provided in Appendix Table D-4.

Table 5.

Numbers of children with various characteristics served by MRDD providers in 2004 and on waiting lists as of April 15, 2005		
	Total # of children	**Estimated number living in Broome County**
# with a DD served in 2004	822	607
# with a DD who had unmet MH service needs	103	96
# with MH needs served in 2004	249	218
# with MH needs who had unmet DD service needs	15	15
As of April 15, # of children 0-21 on waiting list	44	41

[8] Questions can be raised concerning how program officials can know if a child has co-occurring conditions when only on a waiting list for services and therefore not fully evaluated. However, many of the children had received preliminary evaluations. Based on those evaluations, the numbers of children on waiting lists to access program services who were estimated by program officials to have co-occurring conditions is generally consistent with the numbers of children case managed by Service Coordinators and identified as needing to be wait-listed for a wide range of services (see Chapter VIII). This footnote also applies to children wait-listed by MRDD programs, as described below.

Of those on waiting list, # with both DD & MH conditions	7	7

N = 16 programs providing data.

An estimated 111 Broome County children served in 2004 by MRDD providers reportedly had some co-occurring DD and MH needs that could not be met. In addition, an estimated 7 children with co-occurring conditions were on MRDD waiting lists in April 2005.

❖ During 2004, MRDD providers reportedly served 607 Broome County children with developmental disabilities. Of those, an estimated 96 (15.8%) had mental health service needs that could not be provided.

❖ During 2004, the MRDD providers also served 218 Broome County children with mental health needs, of whom 15 (6.9%) reportedly had developmental disability service needs that could not be met.

❖ In addition, there were 41 Broome County children on program waiting lists for MRDD agencies as of April 15th, 2005, of whom an estimated 7 (17.1%) had co-occurring mental health and developmental disability conditions, based on preliminary evaluations by program officials. These waits were typically for four to five months or more.

Combined MH and MRDD Provider Totals

Based on the discussions above of data in Tables 4 and 5, Table 6 summarizes the combined totals for MH and MRDD providers regarding the total reported numbers of children served during 2004, the numbers of those children who had unmet service needs, and the number of children estimated to have co-occurring conditions on waiting lists as of April 15th, 2005.

Table 6.

Numbers of children with various characteristics served by MH and MRDD providers in 2004 and on waiting lists as of April 15, 2005		
	Combined Total # of Children	**Estimated # Living in Broome County**
# with DD served in 2004	1128	885
# with DD who had unmet MH service needs	130	122
# with MH needs served in 2004	3323	2962
# with MH needs who had unmet DD service needs	162	151
As of April 15, # of children 0-21 on waiting list	347	327
Of those on list, # with both DD & MH conditions	42	41

N = 51 programs providing data, except N = 53 providing waiting list data.

In 2004, an estimated 122 children with developmental disabilities, mostly served in MRDD programs, required MH services that could not be provided.

❖ All MH and MRDD service providers together reportedly served nearly 900 Broome County children with developmental disabilities at some point during 2004. Of those, an estimated 122, or 13.8%, had mental health needs that were not being met during 2004. It should be noted that 79% of the 122 DD children with unmet mental health needs were being served by MRDD service providers.

❖ In 2004, all MH and MRDD service providers together reportedly served just under 3,000 Broome County children with mental health needs. Of those 2,962 children, 151 (5.1%) were reported to have developmental disability service needs that were not met in 2004. Most of the children with mental health needs/emotional disturbances who also had unmet developmental disability needs were served by MH providers (90%).

An estimated 151 children with mental health needs, mostly served by MH providers, required DD services that could not be provided in 2004.

❖ Although a higher proportion of DD children being served in 2004 had unmet MH service needs (13.8%) than was true of MH children who had unmet DD service needs (5.1%), *in terms of absolute numbers*—given that more children have defined mental health needs than developmental disabilities—higher numbers of children with MH needs also had unmet DD service needs (151 to 122).

More than 300 county children with co-occurring MH and DD conditions reportedly had service needs which could not be met by MH and MRDD providers during 2004 and early 2005.

❖ In addition to the reported 273 children with co-occurring mental health and developmental disability conditions who had identified unmet service needs in 2004, an estimated 41 Broome County children who were wait-listed by programs had co-occurring mental health and developmental disability service needs, based on preliminary evaluations by program officials (83% of those were on waiting lists in the MH service system). Adding these totals together suggests that *there were more than 300 children in the county during 2004 and early 2005 with co-occurring MH and DD conditions who were unable during that time to access needed services*.[9]

[9] Adjusting for unduplicated counts, the total numbers may be somewhat smaller than the total of 314. On the other hand, six providers didn't respond to these questions, so that their numbers would likely have increased the totals somewhat. Taking all factors into consideration, CGR believes that for planning purposes it is reasonable to conclude that about 300 or more children exist in Broome County with co-occurring DD and MH conditions who have unmet service needs in one or both service systems. These numbers are also consistent with school data presented later in Chapter VII.

V. Significance of Numbers of County Children with Co-occurring Conditions with Unmet Needs

Out of an estimated 500 Broome County children with co-occurring MH/DD conditions, about 300 (60%) have unmet service needs. These in turn represent about one-third of all DD children served by the service system in 2004 and about 10% of those with MH needs who were served.

The number of children and adolescents in Broome County with co-occurring MH and DD conditions who have unmet service needs in one or both service systems represents the top of a pyramid—the proportion of a much larger number of children with various types of mental health disorders or developmental disabilities who are and are not known to their respective service systems.

Based on the data presented in the earlier chapters, it is estimated that there are about 500 children and adolescent residents of Broome County with co-occurring MH and DD conditions. Of those 500, about 60% are estimated to have unmet service needs in one or both of the MH and MRDD service systems. This total of about 300 children with unmet service needs represents about one-third of the total number of DD children estimated to have been served by these service systems in 2004, and about 10% of those served with MH needs.

To put these service system numbers into further perspective, ranges of estimates are provided below of the numbers of total children in the overall county youth population, whether served by programs or not, with mental health disorders and developmental disabilities.

Potential Prevalence of Children with Mental Illness in County

Unfortunately, although a number of national studies have been done concerning the prevalence of mental health/emotional disturbances among children in the United States, the reported data and conclusions are inconsistent and ambiguous. Different definitions of mental disorders, different measurement standards and different age ranges have been used in various studies, thus making it almost impossible to settle on a definitive proportion to use even for population estimation purposes. What appear to be the most comprehensive and most-frequently-cited studies on the prevalence of mental health/emotional disorders within the youth

Using imperfect national prevalence figures to estimate Broome County numbers, between about 3,500 and as many as roughly 13,500 children and adolescents may be experiencing some level of mental health/emotional disturbances within the county at any given time.

population report ranges of between 5.9% and 22% of the population with some degree of mental health needs within a given period of time (typically within a year). Roughly 20% of the youth population, at least within school ages, seems to be the most-quoted proportion. (For further discussion, see a broader discussion of prevalence rates in Appendix E.)

As imperfect as these estimates are, they provide the basis for a rough range of estimates of the numbers of children and adolescents experiencing mental health/emotional disorders in Broome County. Based on the 2000 Census, Broome County had 61,121 residents 21 and younger. Applying the 5.9% to 22% estimates to that number would suggest an estimated range of between 3,606 and 13,446 children and adolescents with some level of mental health disorders.

Potential Prevalence of Children with Developmental Disabilities in County

Depending on definitions, there could be between about 1,400 and as many as about 10,400 developmentally disabled children and adolescents in Broome County.

A national study in 1994 estimated that as many as 17% of the youth population may be developmentally disabled, though it appears as if that estimate may have also included some emotional and behavioral problems not necessarily connected to DD as defined in this study (see Appendix E). As a lower range, two standard deviations below the average standard IQ score (persons with an IQ of 70 or lower) is often used to define the onset of Mental Retardation. This would include an estimated 2.275% of the population.

Using these imperfect and imprecise markers as a rough range of estimates, there could be between about 1,400 and as many as about 10,400 developmentally disabled children and adolescents in Broome County at this time.

School Estimates

National estimates suggest that relatively small proportions of those with mental health disorders actually seek or receive treatment at any given time from a mental health professional. On the other hand, those with developmental disabilities may be more likely to surface in the service system, particularly in schools. Thus school data on numbers of students classified with special educational needs may be as close as we can get to determining the "prevalence" of DD children in the county at any given time.

Using school data to estimate the "prevalence" of students with disabilities, almost 4,800 students 5-21 were classified as having special educational needs, plus 563 preschool students ages 3-5.

Using 13 classifications of students with disabilities, as defined by Section 4401(1) of the State Education Law, the 12 school districts based in Broome County identified 4,798 students between the ages of 5 and 21 as requiring special education services during the 2004-05 school year.[10] In addition, 563 preschool children (ages 3-5) were identified by school districts with disabilities in 2003-04.[11]

The Broome County Early Intervention Program also reported serving 662 children between birth and age 2 last year. These children should be considered as being developmentally delayed, though historically only about 17% transition into preschool programs for children with disabilities.

Summary

The chart on the next page summarizes the "funneling" of children and adolescents in the county, from the potential overall population prevalence of youth with various mental health or developmental disability conditions to the numbers known to the service system, and of those, how many have co-occurring MH/DD conditions and how many of those have unmet service needs. Out of several thousand youth estimated to have some type of mental health disorder or developmental disability, about 500 have been diagnosed with, or have been judged by programs as likely to have, co-occurring MH and DD conditions, with about 300 of those estimated to have unmet service needs in one or both service systems.

[10] The 13 special education classifications include: autism, deafness, deaf-blindness, emotional disturbance, hearing impairment, learning disability, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, speech or language impairment, traumatic brain injury, and visual impairment including blindness. Districts are not necessarily consistent in how students are classified. For example, in the 15 school districts in the Broome-Tioga BOCES, the proportion of district enrollments classified as special education students (i.e., into one of these 13 classes) ranged from 7% to 19%.

[11] Numbers for the Broome County preschool (3-5) program are higher (891 instead of 563), but those higher numbers include those who receive evaluations as well as direct services. The more conservative number of 563 represents those receiving direct services from school districts.

Categories of Children	Numbers of Broome County Children Birth-21 in Each Category	
Estimated Children with Co-Occurring Conditions with Unmet Service Needs	300	
Estimated Children with Co-Occurring Conditions	500	
Estimated Children with DD and MH Needs Served by MH/MRDD Programs in 2004	2,962 MH	885 DD
Estimated Ranges of Children with DD and MH Conditions in County Population	Between 3,606 and 13,466 MH	Between 1,390 and 10,390 DD Schools: about 5,400 special needs children

A relatively small proportion of children in the county have co-occurring MH and DD conditions. However, they represent a significant challenge for the MH and MRDD service systems.

These approximately 300 children at the top of the pyramid can be viewed as representing a relatively small proportion of the MH/DD population in the county and appear to be a small enough, manageable number for the service providers to be able to engage and ensure that their needs are met. On the other hand, it is a sufficiently large number to significantly challenge the MH and MRDD service systems to come together to develop service plans, practices and policies to meet the unmet service needs of these children with co-occurring conditions.

VI. SERVICE COORDINATOR DATA

In addition to the surveys completed by Mental Retardation/ Developmental Disability service providers, 31 surveys were filled out by Service Coordinators who serve mentally retarded and developmentally disabled children and adults. All but one of the known Service Coordinators who serve children completed the survey. Table 7 on the next page summarizes information regarding the number of children on the caseloads of Service Coordinators in 2004 and on the ability of DD children who also had co-occurring mental health needs to receive mental health evaluations and access the MH services they needed. (See also Appendix Table D-5 for more detailed data.)

Services Provided

Service Coordinators provided coordination/case management services for about half of all children reportedly served by the MRDD system in 2004.

Service Coordinators are part of the MRDD service system, coordinating service provision for children who qualify for services within the MRDD/DDSO service system. In 2004, they coordinated services for 311 Broome County mentally retarded and developmentally disabled children—representing 51% of the 607 developmentally disabled Broome County children MRDD providers said they served that year. The Service Coordinators had as few as two and as many as 23 children on their respective caseloads, in addition to any adults for whom they were also responsible.

Table 7.

Numbers of children served by Service Coordinators in 2004 who had Mental Health diagnoses, needs and services	
Types of Children	**Total # of Children**
# of children ages 0-21 on caseloads in 2004	311
Of those on caseloads, # with suspected MH needs	107
Of those suspected, # for whom MH diagnosis was sought	71
# unable to obtain MH evaluations or diagnosis	25
Of those evaluated, # diagnosed with an MH need	46
Of those diagnosed with an MH need, # able to access MH service	41
Of those with suspected MH needs, # told they could not access MH services due to their DD	21
Of those on caseloads, # with an official dual diagnosis	58

Based on data from 31 Service Coordinators.

❖ Service Coordinators indicated that, in their opinions, just over one-third (107) of the 311 children on their caseloads in 2004 had co-occurring mental health needs.

❖ Formal mental health diagnoses were sought for two-thirds (71) of those 107 children.

❖ *Twenty-five (35%) of the children for whom mental health evaluations were sought were unable to obtain an evaluation or diagnosis*, while 46 were formally diagnosed with a mental health need/illness. (Service Coordinators identified a total of 58 children on their 2004 caseloads with official dual diagnoses; this total presumably includes the 46 children who were diagnosed with mental health needs during 2004 as well as any children who had previously been diagnosed and therefore did not need to seek a diagnosis during 2004.)

Service Coordinators were able to access MH services for most children officially diagnosed with co-occurring MH and DD conditions. However, many other children could not obtain needed MH services, or even receive MH evaluations, because they had a developmental disability.

❖ Once diagnosed with mental health needs, most children with co-occurring mental health and developmental disability conditions were able to obtain mental health services: 41 of the 46 diagnosed with a mental health need during 2004 (89%). For those unable to obtain access to mental health services, and the 25 children unable to even receive an evaluation, *the primary obstacle to receiving mental health services appears to have been the simple fact that they had a developmental disability or were mentally retarded.* For at least 21 of the children who Service Coordinators identified as having mental health needs, they were explicitly told that they could not receive services because of their developmental disability.

Characteristics of Those Served

Table 8 below summarizes additional characteristics of the children on the caseloads of Service Coordinators during 2004. Of the 107 children suspected of having mental health needs, the Service Coordinators considered that 33 had a Serious Emotional Disturbance. Furthermore, 90 of the 311 children on their caseloads (29%) were on psychotropic medications. Four-fifths of the children had individual education plans (IEPs) in school, and just over 90% were on Medicaid.

Table 8.

Numbers of children with various characteristics being served by Service Coordinators in 2004	
Characteristics	**Total # of Children**
Of those on caseload, how many were considered to be SED?	33
Of those on caseload, how many were on psychotropic medications?	90
Of those on caseload, how many had an IEP in school?	249
Of those on caseload, how many were on Medicaid?	281

Based on data from 31 Service Coordinators.

Those Denied Services

Table 9 below depicts the number of children referred by Service Coordinators to OMRDD during 2004 and denied eligibility for various reasons. A total of 93 children were referred during the year, an average of three children per Coordinator. Ten Coordinators did not refer any children to OMRDD during 2004.

Table 9.

Numbers of children referred by Service Coordinators to OMRDD and denied eligibility for various reasons	
	Total # of children
In 2004, # of children referred to OMRDD to determine their eligibility for services	93
Of those referred, # denied because their IQ was too high	3
Of those referred, # denied because their physical disability was not serious enough	2
Of those referred, # denied because their adaptive skills were too high	5
Of those referred, how many were denied for an unknown reason	2

Based on data from 30 Service Coordinators.

12 of 93 children referred by Service Coordinators to OMRDD for services were denied eligibility for various reasons.

Relatively few children were referred and denied services: All told, 12 children (13%) who were referred to OMRDD during 2004 were denied eligibility for various reasons.

VII. SCHOOL SURVEY RESPONSES

As part of this project, Committee on Special Education (CSE) and Committee on Preschool Special Education (CPSE) chairpersons from each of the 12 Broome County school districts completed surveys.

CSE Surveys (School-Aged Children)

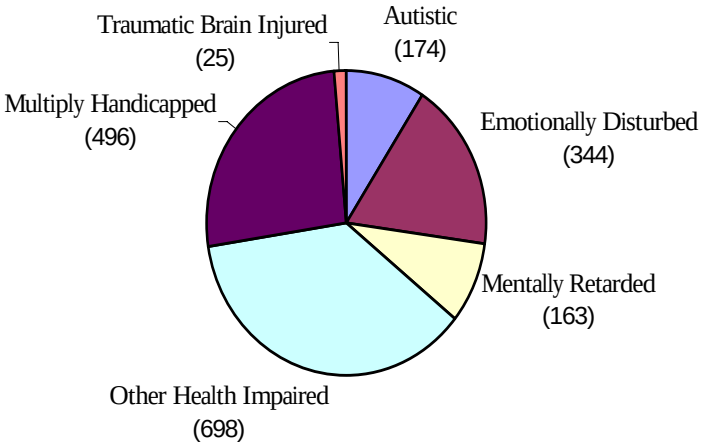
CSE chairpersons provided information on the number of children ages 5-21 identified by their districts with various disabilities, and the numbers with co-occurring MH needs and unmet service gaps, during the .2004-05 school year.

Students by Disability Category

Of the 13 official classifications used by NY school districts to define students with special educational needs, six were deemed by local educational experts, consulted as part of this study, to be most comparable to the developmental disability definition used in the service provider surveys. Chart 1 below summarizes the number of children ages 5-21 with each of the six different classifications of disabilities across the county's 12 school districts. (For more information, see Appendix Table D-6.)

The total number of children officially classified by the 12 districts

Chart 1: Numbers of Children within Key Disability Categories for School Children Ages 5-21 in Broome County



with the six disabilities was 1,900 during the 2004-05 school year. Each student can only be counted once. The largest category of disability was "Other Health Impaired," which included 698 children, or 37% of the 1,900 with the designated disabilities. The next largest category was "Multiply Handicapped," which included 496 children.

It should be noted that these categories are not as "neat and distinct" as they may appear to be. School districts may differ in the categories to which students with similar disabilities may be classified. For example, some students who are mentally retarded may be included in other categories by some districts, depending on other characteristics of the individual. Some of the children in certain classifications may have more mental health needs than DD conditions. Thus these numbers should be treated with some caution. However, the process identified below for determining students with co-occurring conditions and unmet needs was designed to correct for such deficiencies in the category numbers.

Students with Co-Occurring Conditions and Service Needs

Table 10 on the next page (and Appendix Table D-7) summarizes the information provided by CSE chairpersons concerning the numbers of children with co-occurring mental health and developmental disability conditions in the 2004-05 school year, as well as the numbers of those identified with unmet service needs.

❖ Of the 1,900 students in the six disability classifications, 972, or 51%, met the survey definition of having a developmental disability, in the opinion of the CSE chairpersons and those with whom they consulted in their respective districts (e.g., school psychologists, social workers, etc.).

❖ More relevant for purposes of this study, 408 of the classified students were deemed by their districts to have co-occurring mental health and developmental disability conditions. Beyond those, CSE chairpersons and those with whom they consulted estimated that there were an additional 335 children in Broome County school districts with co-occurring MH and DD conditions, who were included in the other seven special education classification categories. *Thus the districts estimated the total number of children with co-occurring conditions to be 743*. Of these 743 children,

131 (18%) were considered to have a Serious Emotional Disturbance.

743 students were identified in the 12 school districts with co-occurring MH and DD conditions. Of those, an estimated 295 had unmet needs due to service gaps in the community.

❖ CSE chairpersons estimated that 295 children, 40% of the 743 students estimated to have co-occurring mental health and developmental disability conditions, had unmet needs due to service gaps in the community. In addition, CSE chairpersons identified 109 children (15% of those children with co-occurring needs), as being in need of additional educational programs that would better meet their emotional and educational needs.

Table 10.

Numbers of children in need of services for Developmental Disabilities and Mental Health conditions in 12 Broome County school districts – CSE Chairpersons	
	Total
Total All Six Categories of Disabilities	1900
# that met the definition for DD	972
# of those with DD that also had MH needs	408
Estimated # of additional children with both DD and MH conditions	335
Total estimated # of children with both DD and MH conditions	743
Of those with co-occurring needs, # with unmet needs due to service gaps	295
Of those with co-occurring needs, # in need of educational programs that would better meet emotional/educational needs	109
Of those with co-occurring needs, # with SED	131

Based on data from all 12 CSE Chairs.

CPSE Surveys (Pre-School Children)

To supplement the data provided for children ages 5-21 by CSE chairpersons, CPSE chairpersons from each district (often the same person as the CSE chairperson) provided data for children ages 3-5 who received Special Education programs and services within their districts during the 2003-2004 school year.

Table 11.

Number of pre-school children in need of services for Developmental Disabilities and Mental Health conditions in 12 Broome County school districts – CPSE Chairpersons	
	Total
# of children ages 3-5 in Special Education programs	563
# that met the definition for DD	111
# of those with DD that also had MH needs	37
Of those with co-occurring needs, # with unmet needs due to service gaps	15
Of those with co-occurring needs, # in need of educational programs that would better meet emotional/educational needs	16
Of those with co-occurring needs, # with SED	11

Based on data from all 12 CPSE Chairs.

Table 11 above shows that there were a total of 563 children aged 3-5 who were officially reported to NYS as receiving Special Education programs and services in the county's 12 school districts during the 2003-2004 school year.[12] One district served as many as 110 pre-school aged children, while another district served as few as 16. Of the 563 total preschool children served in Special Education programs, 111 (20%) met the survey definition

[12] These students all received services from school districts. Additional children ages 3-5 received services, and received evaluations/assessments, from the county's Preschool (3-5) Program.

of having a developmental disability, in the opinion of the CPSE chairpersons.

❖ Fewer than 7% (37 children) of the 563 children in Special Education preschool programs were identified as having co-occurring mental health needs. Of these 37, 11 (30%) were identified as having a Serious Emotional Disturbance.

There are relatively small numbers of preschool children with co-occurring conditions and unmet service needs.

❖ CPSE chairpersons reported that 15 of the 37 children with co-occurring conditions had unmet needs due to service gaps in the community—2.7% of those in the Special Education preschool programs.

❖ In addition, CPSE chairpersons identified 16 children (43% of those with co-occurring conditions) who were in need of additional educational programs that would better meet their emotional and educational needs.

Comparing School District and Service Provider Data

The CSE and CPSE chairperson data on children with developmental disabilities and co-occurring mental health problems can be compared with the information provided by MH and MRDD service providers to see how well the data from these two sources fits together.

Both community-based service providers and school data are consistent in estimating that about 300 county children with co-occurring MH and DD conditions have unmet needs due to service gaps.

MH and MRDD providers reported that during 2004, there were an estimated 273 children with co-occurring MH and DD conditions who had unmet service needs. In addition, 41 county children estimated to have co-occurring conditions were on waiting lists for services, often for lengthy periods of time, in early 2005. By comparison, CSE and CPSE chairpersons reported that there were 310 children in Broome County school districts who had unmet mental health or developmental disability needs due to service gaps in the community. *Thus the data from the community-based service providers and from school officials are rather consistent: both independently suggest that approximately 300 children in the county with co-occurring MH and DD conditions have needs that are not being met due to service gaps.*

VIII. TYPES OF SERVICES OFFERED AND SPECIFIC SERVICE GAPS

In order to identify the extent to which various services are offered in Broome County, Mental Health and Mental Retardation/Developmental Disability service providers were asked to indicate whether or not they offered a given service to (a) children with mental health needs; (b) Seriously Emotionally Disturbed children; and (c) children with developmental disabilities.

Not surprisingly, MH providers typically offer fewer services to DD children than to those with MH needs. Conversely, MRDD providers typically offer fewer services to children with MH needs than to DD children.

To supplement these service provider data, Service Coordinator and Medicaid data are presented later in this chapter to provide additional insights into services available to children with co-occurring mental health and developmental disability conditions.

Services Offered by MH Providers

Table 12 on the next page summarizes the number of MH service providers offering a variety of services (school-based services are not included).

Table 12.

Number of MH programs offering service to each population			
Services	**Children with MH needs**	**SED Children**	**DD Children**
Psychological testing *	12	12	10
Child and adolescent psychiatric evaluations *	13	13	10
Medication management	15	15	11
Developmental pediatrician/assessment*	7	7	7
Behavior management	28	27	20
Counseling services for children	27	26	20
Counseling services for family members	27	26	20
Neuropsychological evaluations	0	0	0
Residential treatment	8	8	6
Ongoing respite care	8	8	7
Emergency respite care	8	8	7
Case management	25	25	18
Day treatment	4	4	1
Parent support	31	30	23
Advocacy services	24	24	18
Crisis intervention	23	23	17
Other	8	8	6

Data in this table are based on 38 programs. * The numbers of programs offering these services can be misleading. Even though participants in those programs have access to such testing and evaluation services, these programs are all located in a small handful of agencies offering the services, so access to such services is much more restricted than the numbers suggest, as indicated in more detail in the text.

Listed below are the six services offered by the fewest MH programs to children with mental health needs:

- Neuropsychological evaluations – 0 programs
- Day treatment – 4
- Developmental pediatrician/assessment – 7
- Residential treatment – 8 [13]
- Ongoing respite care – 8
- Emergency respite care – 8

Outside of schools, few opportunities exist for psychological testing and for child and adolescent psychiatric evaluations in the county.

It should also be noted that even though psychological testing and child and adolescent psychiatric evaluations appear to be offered by a dozen or so total programs, and developmental pediatrician/assessment by seven, these data are misleading: *The practical effect is that these services are actually offered by only about three different agencies that provide the services to those children served in their various multiple programs*. Data in Table 12 should therefore be interpreted with caution—to assume, for example, not that 12 different opportunities exist for accessing psychological testing, but that only a handful of psychologists exist in the county. Aside from school psychologists, few opportunities exist for psychological testing and for child and adolescent psychiatric evaluations in the county.

Seven different services are each offered to children with MH needs and not to those with developmental disabilities by at least six MH service providers.

It is also clear from Table 12 that the number of MH providers offering a service to children with mental health needs is often greater than the number offering the same service to children they serve with developmental disabilities. In many cases, services offered by the most programs to those with mental health needs are offered less frequently to those with DD conditions. For instance, 28 MH programs offer *Behavior management* services to children with mental health needs, but only 20 programs offer such services to children with developmental disabilities. *Parent*

[13] The term residential treatment may have been understood differently by different people responding to the surveys. Some may have interpreted this possible response as a group home, while others may have thought in terms of a residential psychiatric facility. Thus data in the report concerning residential treatment services and potential service gaps should be treated with caution.

support, *Counseling services for children*, *Counseling services for family members*, *Case management*, *Advocacy services* and *Crisis intervention* are other services for which the number of programs offering the service to children with mental health needs is at least 6 more than the number of programs offering the same service to children with developmental disabilities.

Services Offered by MRDD Providers

Table 13 below summarizes the number of MRDD service providers offering a variety of services.

Four different services are each offered to children with developmental disabilities and not to those with MH needs by at least four MRDD providers.

Just as a greater number of MH providers offer certain services to children with mental health needs than to children in their agencies with developmental disabilities, a number of MRDD providers offer certain services to children with developmental disabilities more often than to children they serve with mental health needs. For instance, *Case management* services are offered to children with developmental disabilities by nine MRDD providers, but offered to children with mental health needs and serious emotional disturbances by only three of these providers. *Parent support*, *Advocacy services*, and *Ongoing respite care* are other services for which the number of providers offering the service to children with developmental disabilities is at least four more than the number of providers offering the service to children with mental health needs.

Table 13.

Number of MRDD providers offering service to each population			
Services	**Children with MH**	**SED Children**	**DD Children**
Psychological testing *	4	3	7
Child and adolescent psychiatric evaluations *	1	1	1
Medication management	1	1	2
Developmental pediatrician/assessment*	1	1	1
Behavior management	4	3	6
Counseling services for children	2	2	4
Counseling services for family members	1	1	4
Neuropsychological evaluations	1	1	2
Residential treatment	2	1	3
Ongoing respite care	2	1	6
Emergency respite care	2	1	5
Case management	3	3	9
Day treatment	2	2	4
Parent support	4	3	9
Advocacy services	1	1	6
Crisis intervention	2	1	1
Other	3	2	6

Note that data are based on 17 programs.

* For these services, the number of actual programs in which the services are available is misleading, as the number of actual agencies offering the services is much smaller, as noted in the text.

As with MH providers, *the number of MRDD programs offering psychological testing is deceptive: seven programs, but only three or four separate agencies. Accessing testing services is especially difficult for older children outside the school setting.*

Listed below are the six services offered least often by MRDD programs to children with developmental disabilities:

- Child and adolescent psychiatric evaluations – 1 program
- Developmental pediatrician/assessment – 1
- Crisis intervention – 1 (2 programs for children with mental health needs)
- Medication management – 2
- Neuropsychological evaluations – 2
- Residential treatment – 3

Comparison of MH and MRDD Service Availability

Four services appear among the most frequently offered services for both MH and MRDD providers:

- Behavior management
- Case management
- Parent support
- Advocacy services

MH and MRDD providers also share three of the least commonly offered services:

- Developmental pediatrician/assessment
- Neuropsychological evaluations
- Residential treatment

The service *Crisis intervention* is among the most frequently offered by MH providers, but among the least frequently offered by MRDD providers. *Ongoing respite care* and *Emergency respite care* are among the most frequently offered services by MRDD providers, but proportionately among the least frequently offered by MH providers. All three of these services show up later in Chapter IX among the perceived highest priority unmet service needs, based on ratings from five groups of service providers.

24-Hour Crisis Services

MH and MRDD service providers were also asked whether or not their programs provide 24-hour crisis services. Not surprisingly, a higher percentage of MH service providers offer 24-hour crisis service than do MRDD providers. Only two (12%) of the 17 MRDD providers offer 24-hour crisis service, compared to 13 (32%) of the 41 MH providers. This finding is in line with the fact that *Crisis intervention* was among the least-frequently-provided services by MRDD providers and a relatively frequently-provided service among MH providers.

Numbers of DD Children Receiving Various Services on Service Coordinator Caseloads

In order to identify the numbers of developmentally disabled children on Service Coordinator caseloads who were receiving or waiting to receive various services, Service Coordinators were asked to indicate how many children on their caseloads in 2004 (a) received a service; (b) were on a waitlist for the service; or (c) needed the service, but found it was unavailable.

Table 14 below summarizes the numbers of children receiving (or not receiving) various services, out of the total of the 311 children on the Coordinator caseloads. As such, *the numbers refer to all children with developmental disabilities on their caseloads, and not just those with co-occurring MH and DD conditions.*

Table 14.

Number of DD children served by Service Coordinators receiving and not receiving various services in 2004			
Services	**Number receiving service**	**Number wait listed**	**Needed but unavailable**
Psychological testing in schools	101	2	1
Psychological testing in the community	22	9	24
Child and adolescent psychiatric evaluations	32	7	21
Medication management	89	6	12
Developmental pediatrician/assessment	21	4	17
Behavior management	56	3	31
Counseling services for children	38	1	24
Counseling services for family members	23	0	24
Neuropsychological evaluations	11	1	21
Residential treatment	21	12	2
Ongoing respite care	79	16	21
Emergency respite care	5	1	7
Case management	157	0	0
Day treatment	3	1	0
Parent support	98	0	9
Advocacy services	203	0	0
Crisis intervention	11	0	18
Other	10	7	9

Based on total number served by Service Coordinators = 311.

Services Received

In addition to the data in the table showing numbers of children on Service Coordinator caseloads receiving services, using different ways of categorizing services to persons with disabilities, the Broome DDSO indicated the following use of services in the MRDD system by program type:

- Home and Community-Based Services Waiver (304 children 21 and under)
- Medicaid Service Coordination (MSC) services (296, including all of those in Waiver services)
- Family Support Services (FSS) (211)
- Clinic (204)
- Residential (not including Developmental Center) (32)

Services Requiring Waiting Lists

The five services with the highest number of children served by Service Coordinators who were on waiting lists are listed below. Only *Ongoing respite care* and *Residential treatment* had more than 10 children on waiting lists during 2004.

- Ongoing respite care (16 children)
- Residential treatment (12)
- Psychological testing in the community (9)
- Child and adolescent psychiatric evaluations (7)
- Medication management (6)

The five services listed below had *no DD children served by Service Coordinators on waiting lists:*

- Counseling services for family members
- Case management
- Parent support
- Advocacy services
- Crisis intervention

Services Not Available

The four services with the highest number of DD children needing them but finding them unavailable are listed below:

- Behavior management (31 children, even though it is also among the most frequently-offered services)

- Psychological testing in the community (24)
- Counseling services for children (24)
- Counseling services for family members (24)

There are five services for which the number of children who needed the service but found it unavailable during 2004 was greater than the number of children who actually received the service. These services are listed below in descending order based on the difference between the number of children receiving the service during 2004 and the number of children who could not access the service during 2004.

- Neuropsychological evaluations
- Crisis intervention
- Psychological testing in the community
- Emergency respite care
- Counseling services for family members

Conversely, the following services had the highest ratio of children receiving the service compared with the number of children who needed but couldn't access the service:

- Advocacy services
- Case management
- Psychological testing in schools
- Parent support
- Medication management

Types of Services Accessed by Children with Co-Occurring Conditions on Medicaid

One additional way to determine what services are provided to children specifically diagnosed with both MH and DD conditions is to examine Medicaid claims for such children 21 and under. As noted earlier, CCSI, which tracks Medicaid claims for Broome County, was able to supply such information for those for whom at least one claim with an MH diagnosis and at least one with an MRDD diagnosis were filed during 2002 and 2003. A total of 99 such children and adolescents with co-occurring conditions surfaced during that period—about 20% of the number of

children identified by service providers as having co-occurring conditions. Even though the Medicaid data preceded our survey data by two years, it is worth noting that the 99 Medicaid children with co-occurring conditions accessing services is very similar to the 107 children on Service Coordinator caseloads (nearly all of whom are on Medicaid) judged to have co-occurring conditions.

Table 15 summarizes the numbers of the 99 children receiving various types of services, and the costs of their claims for those services.

Table 15.

Children with Co-occurring MH and DD Conditions Using Various Services Paid for by Medicaid		
Services	**# Using Services**	**Costs of Claims**
Mental Health	35	$122,534
Psychiatric Inpatient	5	61,997
CPEP Emergency	14	8,962
Alcohol/Substance Abuse	12	4,639
MRDD Services	73	2,595,483

Note: Numbers refer to children using various services out of total of 99 with co-occurring conditions who used both MH and MRDD services during two-year period.

99 Broome County children with co-occurring MH and DD conditions accessed services via Medicaid in 2002 and 2003. About $123,000 was spent for MH services for 35 of those children, while nearly $2.6 million was spent to access MRDD services for 73 children.

Recognizing that *the data apply only to the subset of children with co-occurring conditions who were receiving Medicaid, and therefore cannot necessarily be generalized beyond that subgroup,* the following statements can be made about services received by the Medicaid children:

- A total of 35 of the 99 children and adolescents with co-occurring conditions accessed Medicaid-covered mental health services (including inpatient, emergency, outpatient and case management). The total MH-related claims accounted for $122,534—2.9% of the total of $4,248,719 in Medicaid claims processed for this co-occurring population during the two-year period.

- Five of the 99 (including one between the ages of 19 and 21) used psychiatric inpatient care at Article 28 or 31 facilities, including none from state facilities.

- Fourteen received emergency evaluation services from CPEP (by way of context, 661 youth accessed CPEP intake services during 2001).

- Twelve accessed alcohol/substance abuse services in clinic or other outpatient settings.

- A total of 73 of the 99 accessed various types of MRDD services, mostly in various clinic rehabilitation and residential treatment settings. Together, the claims for these 73 amounted to $2,595,483—61.1% of all claims for the 99 individuals.

Difficulty Obtaining Services for Different Age Groups

As part of the effort to identify those children for whom mental health and developmental disability services are most difficult to obtain, CPSE chairpersons, CSE chairpersons, and Service Coordinators were asked whether services were particularly difficult to obtain for certain age groups.

Generally, 75% or more of all groups agreed that services for children with co-occurring conditions are difficult to access across all age groups.

IX. SERVICE GAP PRIORITY RATINGS

All respondents—MH and MRDD service providers, Service Coordinators, CSE and CPSE chairpersons—were asked to rate services based on the level of unmet needs and service gaps for children with co-occurring mental health and developmental disability conditions. A rating of "Highest Priority" indicates that the service is perceived to be among the highest unmet needs for children with co-occurring MH and DD conditions, compared to "Moderate Priority," and a rating of "Low Priority," which indicates that a service is not an urgent unmet need at this time. Respondents were asked to assign one of the three rating categories for each of a wide variety of services. Thus each rating was used multiple times by each survey respondent.

Overall Priority Ratings

Table 16 below summarizes the average ratings for each service across each of the five survey groups. There was typically a relatively high level of agreement in ratings across groups, particularly in terms of the highest priority unmet needs, and those

services least in need of immediate attention for children with co-occurring MH and DD conditions.

Appendix Tables D-8 through D-12 provide more detailed analyses of the proportions of respondents in each of the five survey groups who rated each service as Highest, Moderate or Low Priority.

It should be noted that these ratings of service gaps may not always agree with unmet needs outlined by Service Coordinators in previous Chapter VIII. That discussion was focused on DD children in general, whereas the unmet priority need focus in the ratings below was on the more specific subset of children with co-occurring MH and DD conditions. Thus, *although some of the specified service gaps can be found in both lists, for purposes of assessing perceived service gaps for the co-occurring population, what follows is more pertinent.*

Table 16.

Respondents groups' average priority ratings of unmet service needs among children with co-occurring MH and DD conditions (in rank order by weighted average)						
Service	**Wtd.Avg. (N=113)**	**MH (N=41)**	**MRDD (N=17)**	**Svc.Cdrs. (N=31)**	**CPSE (N=12)**	**CSE (N=12)**
Child/adol. psychiatric eval'ns.	2.58	2.5	2.2	2.8	2.5	2.6
Cnslg. svcs/children	2.26	2.0	2.0	2.8	2.0	2.4
Emergency respite	2.24	2.0	2.2	2.6	1.9	2.4
Ongoing respite	2.24	2.1	2.0	2.6	1.7	2.3
Crisis intervention	2.21	2.0	1.9	2.5	2.0	2.8
Medication mgmt.	2.19	2.1	1.9	2.5	1.9	2.6
Cnslg. svcs/family	2.18	2.0	1.8	2.4	2.2	2.5
Behavior mgmt.	2.11	1.8	1.9	2.6	1.9	2.4
Neuropsychol. evals.	2.07	2.1	1.9	2.2	1.7	2.0
Developmental pediatrician/ass'mt.	2.04	1.7	2.0	2.5	2.1	1.9
Parent support	2.01	2.0	2.1	1.9	1.9	2.2

Psychological testing / community	2.01	2.0	2.0	2.6	1.1	1.4
Residential trtment.	1.91	2.0	1.6	2.0	1.4	2.2
Day treatment	1.72	1.8	1.5	1.4	1.6	2.7
Case management	1.69	1.8	1.8	1.5	1.7	1.8
Advocacy services	1.68	1.7	2.0	1.5	1.3	1.9
Psychological testing / schools	1.47	1.6	1.5	1.7	0.8	1.0
Educational services	1.08	-	-	-	0.7	1.2

Note: Averages based on average priority rating for each service for each respondent group (3 points assigned for each Highest Priority rating, 2 for each Moderate Priority, 1 for each Low Priority). Weighted average = average rating for each service across all 113 respondents. For detailed ratings, see Appendix Tables D-8 through D-12.

❖ The priority ratings of all groups make it clear that *Child and adolescent psychiatric evaluations* is the service with the greatest perceived unmet demand to address the needs of children with co-occurring mental health and developmental disability conditions: As shown in the Appendix tables, 65% or more of all five groups listed this within the Highest Priority unmet needs. In fact, in four of the five groups, it was the single service that received the greatest number of Highest Priority votes.

❖ Six other services each received average overall ratings of 2.2 or higher across all five groups, and received Highest Priority ratings from one-third or more of the respondents in at least four of the five survey groups: *Counseling services for children*, *Emergency respite care*, *Ongoing respite care*, *Crisis intervention*, *Medication management*, and *Counseling services for family members* (only MRDD providers viewed the latter as a lower priority, with only 12% rating it among the Highest Priority service gaps).

Consensus among the five survey groups suggests the following major unmet service needs for children with co-occurring MH and DD conditions: child and adolescent psychiatric evaluations, emergency and crisis respite care, crisis intervention, medication management, and counseling for children and family members.

❖ General consensus was that the following are not among the most urgent needs for immediate attention: *General educational services*, *Psychological testing in schools*, *Advocacy services*, *Case management*, and *Day treatment* (except for CSE chairs, who saw the latter as the Highest Priority need).

More detailed findings for each survey group are briefly summarized below.

MH Providers

As shown in more detail in Appendix Table D-8, *Child and adolescent psychiatric evaluations* was by far the service most frequently identified as Highest Priority unmet need for children with co-occurring mental health and developmental disability conditions. Nearly three-quarters (73%) of MH providers identified this service as Highest Priority. No other service was rated as Highest Priority by more than 50% of the MH respondents. For the most part, the services seen as the lowest priority gaps were typically the same as those in the consensus overall survey findings shown in Table 16.

MRDD Providers

Child and adolescent psychiatric evaluations was most frequently identified as the Highest Priority service gap, with 65% of MRDD providers considering it an urgent unmet service need. *Emergency respite care* and *Ongoing respite care* were both rated Highest Priority by more than half of the respondents. *Parent support* was also among the services receiving strong support at both Highest and Moderate priority levels. As noted above, MRDD providers were the only group indicating little support for *Counseling services for family members* as a Highest Priority service gap. (See Appendix Table D-9 for more details.)

Service Coordinators

As shown in Appendix Table D-10, Service Coordinators gave more ratings of Highest Priority to more services than did any other surveyed group. Ten services were rated as Highest Priority by at least 50% of Service Coordinators, compared to just one service for MH providers, three services for MRDD providers, three for CPSE and six for CSE coordinators. Service Coordinators also identified *Child and adolescent psychiatric evaluations* as the most important service gap for children with co-occurring

mental health and developmental disability needs. This service was rated as Highest Priority by 84% of all Service Coordinators. *Counseling services for children* was also rated Highest Priority by 81% of all Service Coordinators. In addition, several services—*Ongoing and emergency respite care, behavior management, psychological testing in the community, and crisis intervention*—each received Highest Priority ratings from about two-thirds of all Service Coordinators.

Service Coordinators gave the lowest priority ratings to *Case management, Advocacy services,* and *Day treatment,* all of which received more than 50% Low Priority ratings.

CPSE Chairpersons

CPSE chairpersons agreed with MH and MRDD service providers and Service Coordinators that *Child and adolescent psychiatric evaluations* represents the greatest unmet need for children with co-occurring mental health and developmental disability conditions. Three-quarters of CPSE chairpersons rated this service gap as Highest Priority, while 50% considered *Counseling services for family members* and *Crisis intervention* also to be Highest Priority.

No CPSE chairpersons indicated that *Psychological testing in schools* or *Advocacy services* are Highest Priority service gaps, and only 8% indicated that *Psychological testing in the community* is an urgent unmet need. In fact, half or more of this group specifically gave each of those three services a Low Priority rating. (See Appendix Table D-11 for more details.)

CSE Chairpersons

As shown in Appendix Table D-12, CSE chairpersons are the only group that did not select *Child and adolescent psychiatric evaluations* as the highest priority service gap. Instead, *Crisis intervention* was a Highest Priority need in the opinion of 83% of CSE chairpersons, while *Day treatment* and *Child and adolescent psychiatric evaluations* were each rated as Highest Priority by 75%. This was also the only survey group in which *Day treatment* received Highest Priority ratings from more than 25% of group respondents.

All of the CSE chairs considered *Psychological testing in schools* to be the lowest priority service, and two-thirds also rated *Psychological testing in the community* as a Low Priority.

X. MAJOR BARRIERS AND UNMET NEEDS

In addition to the priority service gaps/unmet needs identified in the previous chapter, all groups of respondents were asked to identify up to five major barriers or unmet needs in Broome County's efforts to provide service to children with co-occurring mental health and developmental disability conditions. In addition, Service Coordinators were asked to identify the three most important unmet needs for families of children with co-occurring conditions.

Barriers to Serving Children with Co-Occurring Conditions

Almost 60% of all MH service providers, and significant proportions of all survey groups, noted poor coordination with and between agencies, and typically between the MH and MRDD service systems, as the greatest barrier to improved services to children with co-occurring conditions.

The written comments of the respondents were coded in order to identify common themes touched upon by service providers, Service Coordinators, and CSE-CPSE chairpersons. Other than the perceived priority service gaps summarized in Table 16 in the previous chapter, the following major themes emerged as the major barriers to meeting the service needs of the county's children with co-occurring MH and DD conditions:

❖ The barriers identified most frequently across the survey groups could be classified under the overall category of *Coordination with or between agencies.* Almost 60% of all Mental Health providers, 45% of the Service Coordinators, and between a quarter and a third of MRDD providers and SCE and CPSE chairs all referenced problems and frustrations with the lack of adequate coordination between the OMH and OMRDD service systems.

Coordination with or between agencies includes responses that refer to the systematic problems faced by children with co-occurring conditions as they try to obtain an array of services to meet their needs. For instance, one respondent wrote: "OMRDD passes the buck – if any mental health issues – not their problem." This response argues that the Office of Mental Retardation and Developmental Disabilities is unwilling or unable to confront mental health issues faced by children with developmental disabilities, indicating that a comprehensive set of services is difficult to coordinate with this organization. A number of similar comments were offered by both MH and MRDD respondents about problems with both systems.

Insufficient availability of psychiatric services was consistently noted as the second most significant barrier to serving children with co-occurring conditions.

❖ *Availability of psychiatric services* was consistently the second most frequently-identified barrier. Between a quarter and a half of the respondents in each of the survey groups referenced lack of sufficient psychiatric services as a major barrier to serving children with co-occurring conditions. This finding is consistent with the earlier finding that *Child and adolescent psychiatric evaluations* was the service most often rated as a Highest Priority service gap. Given the opportunity to enter written responses, many service providers expressed a desire not only for psychiatric evaluations but also for expanded psychiatric treatment in general for children in the county.

Problems with Medicaid and other insurance coverage, including doctors and other providers who will not accept Medicaid, was identified as a major barrier to needed services.

❖ A third frequently-selected barrier was a series of frustrations grouped under the category of *Insurance coverage/Medicaid*, which was identified as a major barrier by 48% of the Service Coordinators, and by about one-fourth of the MH and MRDD providers. Written comments in this category focused around the difficulty of finding local service providers who accept children with Medicaid insurance. Given the fact that 281 of the 311 children (90%) on the caseloads of Service Coordinators during 2004 were on Medicaid, the dearth of providers accepting Medicaid insurance is a problem that potentially affects a very high percentage of children with co-occurring mental health and developmental disability conditions. Survey respondents also frequently mentioned related issues of lack of sufficient financial resources to pay for or develop needed services.

❖ A fourth major category of barriers referenced services that were not sufficiently available or accessible: grouped into a *Lack of providers or access to services* category. A third of the Service Coordinators and CPSE chairs, and two-thirds of CSE chairs, noted broad concerns with lack of providers or access to services—which was often related to the larger issue of coordination between agencies and service systems.

Barriers to Meeting Needs of Families

Service Coordinators also identified what they considered to be the three most important barriers to meeting needs of families with children with co-occurring conditions. The issues selected by the greatest percentage were: *Respite care* (selected by about a third of the Coordinators) and *Lack of providers or access to services* (identified by 29%). The next most common responses were *Availability of psychiatric services* and *Insurance coverage/Medicaid* (each selected by about a fifth of all Coordinators), and *Coordination with or between agencies* and *Knowledge of available services* (between 15% and 20% each).

XI. WHAT HAPPENS TO CHILDREN WHO CAN'T ACCESS SERVICES?

MH and MRDD providers were asked to provide written responses to the following question: What typically occurs with any children with co-occurring mental health and developmental disability conditions whom you were unable to serve in the past year?

Children are often placed in higher levels of care than needed due to lack of appropriate services for children with co-occurring conditions.

Mental Health service providers frequently reported that such children are referred to other programs so that at least some of the service needs of the child can be met. However, as a result of these referrals, children are often placed in programs that are inappropriate for their conditions. For instance, several MH providers indicated that children with co-occurring mental health and developmental disability conditions are often hospitalized in mental health centers until more appropriate levels of care become available. Others may be placed in juvenile detention centers. Thus, children are often placed in higher levels of care than necessary due to the lack of services available for children with co-occurring conditions. A number of MH service providers wrote that they had difficulty in accessing OMRDD services for such children.

Children with co-occurring conditions often do not receive the services they need, receive higher levels of care than needed, or may be bounced between systems.

The responses of MRDD service providers echo the MH provider responses. Children are referred to different agencies, but face the potential of being bounced around between mental health and developmental disability systems, with some eventually winding up in higher levels of care than necessary.

What Happens to Children Denied OMRDD Eligibility?

Service Coordinators were asked to provide written responses to a related question: What typically happens with children who are denied OMRDD eligibility?

Children denied MRDD eligibility often do not receive needed services from either the MRDD or the MH service system.

The responses centered around three common outcomes. The first is that children go through Second Step Review, an additional layer of review that involves one additional psychologist and the director of DDSO. The second common outcome is that children are referred to other organizations, such as the Office of Mental Health, in hopes of finding services that can manage at least some of the child's service needs. The third common outcome described by Service Coordinators is that children denied OMRDD eligibility simply "fall through the cracks" of both systems and can go months or years before receiving appropriate services.

XII. PARENT SURVEYS

In order to ascertain the experiences of the parents of children in need of developmental disability services, surveys were distributed to families through Service Coordinators. It could not be determined how many families were asked to complete the survey, but in all, 20 surveys were completed by the parents of children with developmental disability and/or mental health conditions concerning the services their children had received and what services they believe their children may still need. Fifteen of these surveys were returned by parents working with Service Coordinators affiliated with the Southern Tier Independence Center, four through the Handicapped Children's Association, and one through Catholic Charities. Since only three service coordinating agencies are represented among the parent surveys,

and since we do not know how many parents were asked to complete a survey, it cannot be determined how representative the comments of these parents are of the experiences of all parents who receive service coordination in Broome County. Thus the parental responses should be reviewed with caution, in light of these caveats.

Services Received

Parents were first asked to list the services that their child with a developmental disability received during 2004. Services identified by multiple respondents include:

- Medicaid service coordination – at least 10 families
- Special Education/BOCES (including Speech therapy, Physical therapy, and Occupational therapy) – 10
- Counseling – 8
- Respite – 8
- Residential treatment – 6
- Medication management – 5
- Financial assistance/Waivers – 5
- Miscellaneous medical care – 4

Services Wanted but Unavailable

When parents were asked which services they wanted their children to receive but found unavailable, the following services were identified most often:

- Psychiatric treatment/evaluations – 4
- Respite – 3
- Mental health services – 3
- Behavior management – 3
- Music/Art therapy – 3
- More accessible local doctor or developmental pediatrician – 3

Services with Waiting Lists

Parents were also asked to identify the services for which their children had been on waiting lists. The services on the list below each appeared in the responses of at least three parents:

- Respite – 5
- Mental health/Psychiatric services – 4

Additional Services Needed

The following services appeared in the responses of at least three parents when parents were asked what additional services their children needed. Many of these services were previously identified in the question regarding services that were wanted, but not available.

- Psychiatric services – 4
- Counseling – 4
- Behavior management – 3
- Respite – 3
- Social skills training – 3
- Occupational/speech/physical therapy – 3

Services Needed by Family Members

Finally, parents were asked to identify services that were needed by the members of their family as a result of their child's developmental disability and/or mental health needs. Most frequently-mentioned were:

- Parent support/training in specific ways of helping child with disabilities – 7
- Respite – 5
- Family Counseling/therapy – 4
- Assistance/Behavior management in home – 3

Summary

Parents expressed a need for various types of support respite and counseling services for both children and their parents and siblings.

From the responses of those parents who completed surveys, it is clear that various types of parent support and training, respite and counseling services are in demand both for children with developmental disabilities and/or mental health needs and for their parents and siblings. The surveyed parents also expressed a desire for greater access to psychiatric and behavior management services for their children. Whether these surveys reflected a representative sample of parents or not, the responses were generally consistent with those of the various provider groups.

XIII. BEST PRACTICES WORKING WITH CHILDREN WITH CO-OCCURRING MENTAL HEALTH AND DEVELOPMENTAL DISABILITY CONDITIONS

(Written by Robert Russell, Ed.D., Licensed Psychologist, Broome County Mental Health Department)

This psychologist was asked to write a summary of Best Practice methods for assessment and treatment of youth with co-occurring mental health and developmental disability conditions. As noted in a discussion of best practice literature in Appendix F, because this topic is so diverse—with significant variability across diagnoses, settings and treatment providers—trying to paraphrase the Best Practice literature in a brief review has its limitations. In light of this, the following is based upon the Best Practice and Expert Consensus literature that I have read along with my own personal experience of many years working in the field.

Assessment

Basic Evaluation

Every child with a suspected developmental disability should receive a psychological workup including intelligence testing. A complete assessment should include a thorough psychosocial evaluation involving the gathering of information from multiple sources. Looking at the entire child—including family, developmental, educational, medical, and social history—is important. A focus should be placed on documenting behavioral deficits and excesses, sources of stress and availability of supports and resources and personal strengths.

An assessment of the child's achievement level and adaptive functioning is highly desirable depending upon the purpose of the evaluation. Achievement testing is used to assess the nature of a learning disorder while adaptive functioning is used to look at strengths and weaknesses in the child's overall maturity and level of independence. Other tests are available to assess for certain clinical syndromes. Speech, occupational and physical therapy evaluations are also very useful when examining the nature and extent of developmental impairment. One needs to weigh the costs and benefits of doing a more comprehensive neuropsychological battery. Although recommended in cases of Traumatic Brain Injury, the additional information gathered in such lengthy evaluations does not always justify the cost involved. Finally, keep in mind that behavior, motivation, language or motor difficulties can sometimes make test interpretation more difficult in the developmentally disabled child.

Problems in Diagnosing Mental Illness

The literature suggests that there is a higher co-morbidity of mental illness among those with developmental disabilities then among the general population. There are difficulties, however, in assessing mental illness with the developmentally disabled. The lower one's intellectual level is, the harder it is to reliably diagnose the presence of a mental illness. Communication difficulties or poor comprehension can all interfere with gathering reliable information. For instance, someone with low intellect may answer in the affirmative when asked if they "hear voices" and be falsely perceived as psychotic. Also symptoms which might be consistent with a specific clinical syndrome may be explained better by the disability rather than the syndrome. For example, it is not uncommon for developmentally disabled youth to be perceived as having Attention Deficit Hyperactivity Disorder. Their inattention and distraction might be better understood, however, by their developmental disability rather than ADHD. When there is a co-occurring mental illness and a developmental disability, the evaluator looks for and tries to explain how a child's developmental disability can sometimes influence or exacerbate his/her mental illness.

Functional Analysis

Just as important as arriving at a diagnostic classification, a "functional analysis" can be very helpful when examining specific problematic behaviors. This type of evaluation focuses on assessing the antecedents, behavior and consequences (ABCs) that define the problem and lead directly to effective interventions targeting the variables which trigger and reinforce, or maintain a problem behavior.

Ongoing Assessment

Ongoing assessment is helpful to assess the effectiveness of a treatment intervention, whether pharmacological or behavioral. Too often treatment interventions are implemented with little or no evidence of their efficacy other than anecdotal reports, which can be biased. Target symptoms are identified and daily monitoring of these symptoms is conducted. Baseline data is compared with data collected as an intervention begins or changes. Daily monitoring of symptoms, and the contexts in which they arise, can also be useful in better understanding the nature of the problem and arriving at suitable interventions.

Eligibility Determinations

A common use of evaluations is for documentation of eligibility for certain services such as Special Education services, Social Security Disability or Office of Mental Retardation Developmental Disabilities services. Unfortunately, information needs are often different for each of these and an evaluation which is used in one context is not always sufficient or helpful in another context. Still, obtaining these evaluations is important since it has long term consequences for services and benefits.

Therapies

General Principles

There is a range of clinical interventions which can be used when working with MH/DD youth, with some being more effective than others depending upon the child or adolescent's developmental level as well as the specific nature of the problems being targeted. It would be beyond the scope of this section to list all of the possible treatment interventions or techniques used with children. Instead a few general principles and some of the more common modalities will be discussed.

Usually, there are multiple presenting problems that need to be addressed with the MH/DD child. These can generally be classed into behavioral "excesses" and "deficits". One example of a behavioral excess might be a child's tantrum and a corresponding behavioral deficit might include the child's lack of self calming or coping strategies. One goal of treatment is to discourage or inhibit these maladaptive behavior excesses and a second goal is to replace behavior deficits in adaptive functioning with age appropriate skills. In fact, the long term goal of raising a developmentally disabled child, whether with a mental illness or not, is to expose him/her to learning opportunities which will teach the daily living skills needed for maturation and independence.

Low adaptive functioning contributes to stress and hardship in these children's lives which, in turn, exacerbates any mental illness. As a group, they are more vulnerable to stress and challenges they face on a daily basis. Much can be done by identifying and reducing stresses in their environment, especially ones that trigger problem behaviors. These stressors can vary and can range from too much commotion to excessive hostility in the home or school

environment. In addition to reducing stress, one needs to find ways to increase social supports and resources in the child's life. This is where Service Coordinators play such a vital role. Also, one should not underestimate the importance of arranging for and facilitating friendships in the child's life. This is a good example of how to create a naturally occurring support system. Healthy peer relationships allow the child to improve on their social skills while it inoculates them against depression.

Verbal Therapies

Many children with developmental disabilities can benefit from verbal therapies. Motivating, educating and supporting the child are just some of the many tasks which are commonly done in the office setting. However, those children who are young or who have low intelligence sometimes lack the cognitive ability for retrospection and prospection needed for insight oriented therapies. Limited expressive or receptive language ability can also interfere with verbal therapies. Thus verbal therapies should only be one part of the clinical intervention.

Parental Consultation

Parents and guardians are a critical part of any treatment program since they are the ones who can have the greatest influence over a child's environment and who can alter many of the antecedents and consequences which control daily behavior. Because the demands of raising an MH/DD child are high, parents need to be clever and they need to have a range of skills and supports in place to assist them. Providing them with information about special education or community services is important. Some parents will seek guidance on what should be realistic expectations for their child, and the best ways to help their child toward short and long term goals.

Behavior Modification

Whether or not one considers themselves a "behaviorist", one can not deny the role that classical and operant conditioning plays in one's daily life. This psychologist would argue that most strategies used to raise or teach children, good and bad, can be explained by the Learning Theory or Behavioral model. Appropriate application of behavioral methods can have positive impact on the child, and these methods have been repeatedly touted as the intervention of choice in best practice and expert consensus

literature. Likewise, the misapplication of behavioral principles can have inadvertent or deleterious consequences.

In some homes or classrooms there are methods in place which may have the trappings of a behavior modification plan but these methods are either ineffectual or counter therapeutic. Most of these plans or programs have one element in common: the over-reliance on punishment. For instance, a common strategy used in some special education classrooms includes the removal of points for misbehavior or inattention with the ultimate consequence being the loss of privileges. This is like a token economy or point system in reverse[14]. The problem is that punishment does not teach or shape appropriate behavior and may have the unintended consequence of raising the child's stress and anger level. This, in turn, creates additional problems for the teacher and the student. More emphasis should be placed on the prevention of problem behaviors by addressing the antecedents of the behavior. Likewise, the use of positive reinforcement is vital to the shaping and acquisition of new behaviors and skills which are alternatives to these dysfunctional behaviors. Just because something resembles a behavior modification plan does not ensure that it is a good one.

Organizational structures can be in place to prevent the misuse of treatment methods. For instance, the NYS Office of Mental Retardation and Developmental Disability has a Human Rights Committee at each Developmental Disability Services Office (DDSO). At the Broome DDSO there is a Human Rights Committee which, among other duties, will review behavioral treatment plans to ensure that positive reinforcement and non-punitive methods are used. The focus is on protecting the consumers' rights and to ensure that they receive the most effective, non-harmful treatment in the least restrictive environment.

Psychopharmacology

Although medication can sometimes provide rapid, significant and positive results in children with mental health needs, medications are not without risk. The potential for iatrogenic disorders is

[14] Usually the token or points are awarded for appropriate behavior to be redeemed for tangible rewards at a later time.

always present and needs to be closely monitored. We know that the use of "off label" medications (medications not approved for children or for the purpose intended) are being used with greater frequency with children. Some of these medications, and even those approved for children, can have serious side effects and their influence on the developing child is not always clearly understood. Movement disorders, weight gain, tics and disturbance in mood and behavior are just some of the side effects that can result. There is evidence that children with developmental disabilities may be at higher risk for side effects from their medication. Also, children with developmental disorders are more likely to have other medical or neurological conditions requiring medication. Being on more than one medication increases the chance of drug interactions with this population.

In response to recent warnings by the U.S. Food and Drug Administration (FDA) regarding the use of antidepressant medication (prozac, paxil, zoloft, etc.) with children and adolescents, the NYS Office of Mental Health is implementing new standard of care procedures including the use of informed consent, better information about side effects and much more frequent monitoring for side effects[15]. It seems likely that such procedures will become common when using other off label psychotropic medications with children and adolescents.

In addition to such procedures, best practice for placing children on medication should include the ongoing assessment of the target symptoms (preferably conducted by a "blind" rater). If the medication does not have the desired effect, ongoing assessment provides the physician with feedback to modify or stop the medication regimen. Regarding the dosing of medication, expert consensus agrees that the physician should start the child "low and go slow" when titrating up and use a lower than maximum level dose. Finally, literature suggests using dose reduction and/or extended periods of medication cessation to assess the continued effectiveness and need for the medication.

Conclusion

[15] Initially weekly for the first month, bi-weekly the second month and then no less than once a month after this.

Whether it involves assessment or treatment, one can not separate mental health difficulties from the developmental disability. Promoting maturation and independence in the developmentally disabled child will go a long way towards reducing vulnerability to mental illness. Various treatment options are available, some of which are more effective or suitable than others. Treatment approaches should be monitored for their effectiveness, and parents and providers need to be alert that no harm is done to the child as a result of treatment. Long term goals should focus on helping children maximize their fullest potential and assisting them to grow into adulthood with the greatest level of autonomy and best quality of life possible.

XIV. CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

CGR offers a series of suggestions and recommendations, based on the following summary conclusions and implications from the study:

Conclusions

❖ Based on national estimates, there may be between about 3,600 and as many as about 13,500 children and adolescents in Broome County with some level of mental disorders, and between about 1,400 and as many as about 10,400 with a developmental disability. More than 5,350 children have been classified as having special educational needs and/or disabilities within the county's 12 school districts.

❖ Services to MH and DD children in the county are provided by at least 58 separate programs operated by 26 different agencies, in addition to services provided by 12 separate school districts located in the county.

❖ During 2004, almost 3,000 children with mental health needs and almost 900 with developmental disabilities were reportedly served by the county's MH and MRDD community-based service providers.

❖ Of those children and adolescents, about 500 county children with co-occurring MH and DD conditions have reportedly been identified and are currently being served by the MH and MRDD service providers in the county.

❖ Of those, approximately 300 county children with co-occurring MH and DD conditions reportedly had service needs which could not be met by MH and MRDD providers during 2004 and early 2005. This includes:

- an estimated 122 children with developmental disabilities who required MH services that could not be provided;
- an estimated 151 children with mental health needs who required DD services that could not be provided; and
- an estimated 41 children with co-occurring conditions who were on waiting lists to access services (mostly within MH agencies).

❖ It is significant to note that despite different approaches to identification of needs, both community-based service providers and special education school officials are consistent is estimating that about 300 county children with co-occurring MH and DD

conditions have unmet needs due to service gaps and difficulty accessing needed services.

❖ These approximately 300 children on one level represent a relatively small enough, manageable number for the service providers in the county to engage and ensure that their needs are met. On the other hand, this number is substantial in the context of the current and historical inability of the MH and MRDD service systems to be able to come together to develop service plans, practices and policies to meet the needs of these children with co-occurring conditions.

❖ Consensus among major service provider groups in the county suggests the following major Highest Priority unmet service needs for children and adolescents with co-occurring MH and DD conditions:

- Child and adolescent psychiatric evaluations;
- Counseling for children and family members;
- Emergency and ongoing respite care;
- Crisis intervention; and
- Medication management.

❖ Most consistently cited as the major barriers to providing needed services for children with co-occurring conditions were:

- Poor coordination between agencies and particularly between the MH and MRDD service systems;
- Insufficient availability of psychiatric services;
- Problems with Medicaid and other insurance coverage; and
- Lack of sufficient providers and access to needed services.

❖ Too often, children with co-occurring MH/DD conditions do not receive the services they need, get bounced between systems or "fall through the cracks," and are placed in higher levels of care than is appropriate. Often they cannot obtain needed services, or even evaluations, because of specific mental health or developmental disability conditions.

❖ Broome County is in one sense no different from counties throughout New York regarding difficulties in addressing the needs of children and adolescents with co-occurring MH and DD conditions. The main difference is that Broome has begun to address the issue by beginning to define the problem and the scope of the needs. There are actions which local officials and service providers can begin to take, and indeed seem willing to consider, as suggested in the recommendations which follow. Comprehensive, full-scale solutions, including adequate funding, will require actions by the state at the OMH and OMRDD levels.

Recommendations

Based on the findings and conclusions of this study, CGR offers the following suggestions and recommendations for state and local consideration and action:

❖ This report should be forwarded to the Commissioners and other key state and regional officials in OHM and OMRDD, and Broome County officials, service providers and advocates should follow-up with meetings with those officials to present suggestions and action plans to be developed locally in response to the report.

❖ An action planning process should be convened by the Broome County Mental Health Commissioner, including representatives from the County Children's Mental Health Task Force and high level officials from the county's MH and MRDD service providers and advocacy groups, to develop specific short-term and longer-term action and implementation plans in response to the report.

❖ Concentrated efforts should be undertaken to formally identify the roughly 300 children and adolescents with co-occurring MH and DD conditions who have unmet needs in one or more service system—and begin to determine how to best address their short-term and longer-term needs. There is currently no central register of these individuals, and no way of carefully defining their needs or even evaluating and diagnosing them on a consistent, professional basis. Once a formal process can be established for the identification of such individuals, beyond a one-shot survey process such as used in this study, it becomes possible to begin to more carefully define their needs and processes for addressing them.

❖ The initial step in defining this group of children and adolescents more precisely is to establish a consistent process based on access to licensed trained professionals (e.g., psychologists, MSWs, etc.) conducting comprehensive diagnoses and needs assessments of youth identified by service providers as likely to have co-occurring MH and DD conditions. Such assessments should be focused on determining diagnoses and establishing service and treatment needs.

❖ Consistent with the previous recommendation, emphasis should be placed in the community on expanding the capacity for conducting psychological assessments of troubled youth in the community as a realistic alternative to expanding the number of child psychiatrists. More focus is needed on obtaining sound psychological testing and assessments of children considered as likely to have co-occurring MH and DD conditions. To supplement the efforts of psychologists and social workers, clinical trainees with Masters degrees at SUNY Binghamton could perhaps be used to help in the diagnostic process.

❖ Once such a diagnosis process is in place, individuals with co-occurring conditions should be able to access services through a single point of entry. This could either mean making revisions in the existing county SPOA to incorporate children with co-occurring conditions, creating a new but similar process to expedite the review and service access process for such persons, or potentially building on the existing processes involved with the county's Coordinated Children's Services Initiative (CCSI).

❖ In the meantime, MRDD representatives should be explicitly invited to, and expected to become active participants in, the SPOA process in order to begin to ensure that broad cross-systems perspectives are represented in the discussion of individuals who have, or may have, co-occurring conditions. Eligibility for services across systems needs to be explicitly addressed.

❖ Ultimately an effective database and management system should be established to record the characteristics, diagnoses and service needs of children with co-occurring conditions; to track

services they are receiving; and to monitor their progress and outcomes across service systems over time.

❖ Task forces should be established to determine what can and should be done to respond to the following needs and service gaps identified in the study for children with co-occurring conditions: (a) child and adolescent psychiatric and psychological evaluations and testing, including the need in particular for more comprehensive professional psychological diagnoses and assessments prior to, and perhaps even avoiding in many cases the need for, any involvement with a psychiatrist; (b) counseling services for children and parents; (c) emergency and ongoing respite care for children and families; (d) crisis intervention (including the potential for an MRDD expert at CPEP); and (e) medication management. Any expansion of services should be done consistent with the "best practices" recommendations in the report.

❖ More effective linkages should be explored between community-based service providers and school district special education programs. Such linkages should include representation on SPOA or related processes for accessing services, and should include discussions of the extent of need for cross-referrals between school, MH and MRDD systems to ensure that information is shared across systems where appropriate, and that service and treatment needs are met appropriately, efficiently and cost-effectively.

❖ Consideration should be given to exploring ways of putting together cross-agency, cross-systems recruiting packages to help share the costs of bringing needed specialists to Broome County who may not otherwise be attracted to the community without more financial resources than individual agencies could afford. Combined funding packages, and sharing of staff time across agencies, may create options for attracting high-caliber professionals not otherwise likely to consider coming to the area.

❖ The State should be approached for cross-systems funding to establish a pilot project in the county to develop implementation plans, strategies and staffing to address specific actions that are developed by the action planning team recommended above.

Ideally state funding should be available to help with such a comprehensive pilot approach, including contributing to the afore-mentioned recruit-funding package. The State should be a willing contributor to Broome's efforts, as those efforts could become a model for other areas across the state.

APPENDIX A: SURVEYS USED IN STUDY

APPENDIX B: MENTAL HEALTH AND MRDD PROGRAMS AND AGENCIES WITH COMPLETED SURVEYS

[need to insert Appendix A and B with surveys and program names; to be added in final report]

APPENDIX C: ADDITIONAL DESCRIPTION OF MH AND MRDD SERVICE PROVIDERS

This Appendix provides additional information about the providers of mental health and developmental disability services to children and adolescents living in Broome County. The information in the Appendix supplements data summarized in Chapter II of the report.

Mental Health Providers

As noted in the text, the survey identified 41 separate programs which identified themselves as mental health providers serving Broome County children and adolescents.

Services Provided and Groups Excluded

In addition to providing services to children and adolescents with mental health needs, 29 of the 41 MH programs (71%) indicated that they also provide services to DD children. Only four MH service providers indicated that their programs specifically exclude serving children with developmental disabilities, although 17 (41%) indicated that their programs do specifically exclude serving children who are mentally retarded. None exclude serving children who are seriously emotionally disturbed. About 90% of the MH providers (37 of 41) indicated that they exclude at least some ages between 0 and 21 years old.

The table below depicts the number of MH providers that exclude anyone from the age groups listed below. A program that excludes any of the ages from a certain age group is counted as excluding children from that age group. For instance, a program that does not serve children ages 0-3 is counted as excluding at least some children in the age group 0-5, even if it serves children ages 4-5.

Number of MH organizations excluding ANYONE from each age group		
Age Group	**Providers excluding any within each age group**	**Percent of Total (N = 41)**
Age 0 to 5	29	70.7%
Age 6 to 10	16	39.0%
Age 11 to 18	15	36.6%
Age 19 to 21	23	56.1%

Over 70% of MH service providers do not provide service to at least some children between the ages of 0-5. In addition, 56% of MH providers exclude some children between the ages of 19-21, while less than 40% of MH providers exclude any school-age children between 6-10 and 11-18.

At the direction of the project steering committee, specific age breakdowns were not requested in the survey, to reduce the burden on survey respondents. But the survey was able to ascertain that nine of the 41 programs serve children from the time of birth, while one program serves children only above the age of 18. The average minimum age served by all the MH programs is 6.0 years, and the average maximum age is 18.6 years. Four of the MH service providers serve children from birth all the way through age 21.

All 41 programs provide services to at least some children between 11 and 18 years old. It should be noted that a program does not have to serve all ages within an age group to be counted as serving someone in that age group. For instance, a program that serves children ages 11-16 is counted as serving the age group 11-18 even if it does not serve children ages 17-18.

All MH programs serve at least some children between the ages of 11 and 18; only 15 serve adolescents older than 18.

The next most frequently-served age group is 6-10, served by 78% of MH service providers, and 61% serve at least some children 0-5. Only 15 MH providers (37%) serve children between the ages of 19-21. (It should be noted that the 2002 Visioning project indicated that 44.5% of the children served at that time were between the ages of 13 and 17, with another 23% between the ages of 7 and 10, and only 3.5% 18 and older.)[16]

Broome County Residents Served

For the 41 MH service providers, an estimated 87% of the children served were living in Broome County. More than half of the providers (21) reported that their services are provided exclusively to Broome County children, while the others serve at least some youth from other counties as well.

MRDD Providers

[16] *Broome County Visioning Project*, p.13.

As noted in the text, the survey identified 16 separate programs which identified themselves as developmental disability providers serving Broome County children and adolescents.

Services Provided and Groups Excluded

In contrast to MH service providers, 71% of whom provide services to DD children, fewer than half (7) of MRDD providers indicated that they provide mental health services to children between the ages of 0 and 21.

Although no MRDD providers specifically exclude serving children with MH needs, only about 40% actually provide MH services to children.

On the other hand, none of the MRDD providers specifically exclude children who have mental health needs, although one provider did report specifically excluding children with serious emotional disturbances from receiving their services. Most MRDD providers (12) indicated that they do not serve all ages between 0 and 21 years old.

As with MH providers, the age group that is most frequently excluded from receiving services is the group aged 0-5. However, only 53% of MRDD providers exclude children from this group, compared with over 70% of MH providers. Only about a third of the MRDD providers exclude children in each of the age groups 6 and older.

Seven of the programs serve children from the time of birth, and one program only serves children above the age of 16. The average minimum age served is 4.4 years, and the average maximum age is 18.9. Eleven of the programs serve children through the age of 21. One program serves children only through age 8. As with MH providers, four MRDD programs serve children from birth all the way through age 21.

MRDD providers typically serve at least some children and adolescents in all age ranges.

As with MH providers, the age group 11-18 is the most commonly served by MRDD providers, with 94% of the 17 providers serving at least some children in that age range. The next most commonly served age group is 6-10 (82% of the MRDD providers). The age groups 0-5 and 19-21 were both served by 71% of MRDD providers. Note, however, that in terms of actual numbers of children served, according to DDSO data, the following proportions were true among those served in mid-2005:

- 0-5: 25%;

- 6-10: 30.3%;
- 11-14: 18.7%;
- 15-17: 14.5%;
- 18-21: 11.4%.

Broome County Residents Served

Overall for MRDD providers, an estimated 84% of the children served live in Broome County. As with MH providers, most MRDD providers (12) reported that at least 90% of the children receiving their services live in Broome County, including six providers which serve exclusively county residents.

APPENDIX D: DATA TABLES

Table D-1.

Numbers of children with various characteristics being served by MH providers as of April 15, 2005 (N=38 programs providing data)					
MH Providers	**Minimum**	**Maximum**	**Median**	**Total # of children**	**Estimated number living in Broome County**
# diagnosed or likely to have a mental health need of any type	0 (1)	280	17	1514	1390
# diagnosed or likely to have a serious emotional disturbance	0 (4)	224	11	1051	956
# diagnosed or likely to have a developmental disability	0 (10)	90	1.5	244	225
# dually-diagnosed with both a MH and DD	0 (16)	75	1	177	162
# with a mental health need who are likely to have DD	0 (21)	15	0	48	45
# with a DD who are likely to have a mental health need	0 (36)	2	0	2	2
# with a DD who are likely to have SED	0 (19)	80	0	151	137
# with both MH and DD needs but w/o official diagnosis for either	0 (33)	10	0	15	15

* Number in parentheses equals the number of providers at the minimum levels for each category.

Table D-2.

Numbers of children with various characteristics being served by MRDD providers as of April 15, 2005 (N=16 programs providing data)

MRDD Providers	Minimum	Maximum	Median	Total # of children	Estimated number living in Broome County
# diagnosed or likely to have a mental health need of any type	0 (3)	57	9	298	225
# diagnosed or likely to have a serious emotional disturbance	0 (9)	59	4	306	278
# with a DD who are likely to have a developmental disability	0 (28)	10	0	27	26
# dually diagnosed with both a MH and DD	0 (17)	50	0	147	136
# with a mental health need diagnosis who are likely to have DD	0 (18)	145	1	303	286
# with a DD diagnosis who are likely to have a mental health need	0 (8)	50	1	173	132
# with a DD who are likely to have SED	0 (6)	25	1.5	56	43
# with both MH and DD needs but w/o official diagnosis for either	0 (12)	8	0	13	13

* Number in parentheses equals the number of providers at the minimum levels for each category.

Table D-3.

Numbers of children with various characteristics served by MH providers in 2004 and on waiting lists as of April 15, 2005 (N=35 programs providing data as of 2004 and 37 for waiting list data)

MH Providers	Minimum	Maximum	Median	Total # of children	Estimated number living in Broome County
# with DD served in 2004	0 (8)	42	2	90	63
# from 6a with unmet MH needs	0 (1)	230	32	741	567
# with MH needs served in 2004	5	450	39	3074	2744
# from 7a with unmet DD needs	0 (5)	39	3.5	140	108
As of April 15, children 0-21 on waiting list?	0 (14)	23	0	39	39
Of these, # with both DD & MH conditions?	6	274	55	1832	N/A
Average time on waiting list (days)					

* Number in parentheses equals the number of providers at the minimum levels for each category.

Table D-5.

Numbers of children served by Service Coordinators in 2004 who had Mental Health diagnoses, needs and services (N=31 Service Coordinators providing data)				
Service Coordinators	**Minimum**	**Maximum**	**Median**	**Total # of Children**
How many children ages 0-21 were on your caseload in 2004?	2	23	9.0	311
Of those on your caseload, how many had MH needs?	0 (3)	10	3.0	107
Of those in Q2, for how many did you or someone else seek an MH diagnosis?	0 (6)	6	2.0	71
How many were unable to obtain MH evaluations or diagnosis?	0 (16)	5	0.0	25
For those evaluated, how many were diagnosed with an MH need?	0 (7)	6	1.0	47
Of those in Q2c, how many were able to access MH service?	0 (10)	4	1.0	41
Of those in Q2, how many were told they could not access MH services due to their DD?	0 (13)	4	0.5	21
Of those on caseload, how many had an official dual diagnosis?	0 (6)	6	2.0	58

Table D-4.

Numbers of children with various characteristics served by MRDD providers in 2004 and on waiting lists as of April 15, 2005 (N=16 programs providing data)					
MRDD Providers	**Minimum**	**Maximum**	**Median**	**Total # of children**	**Estimated number living in Broome County**
# with DD served in 2004	5	230	30.5	822	607
# from 6a with unmet MH needs	0 (8)	50	0	103	96
# with MH needs served in 2004	0 (2)	50	9	249	218
# from 7a with unmet DD needs	0 (9)	12	0	15	15
As of April 15, children 0-21 on waiting list?	0 (11)	18	0	44	41
Of those, # with both DD & MH conditions?	0 (12)	4	0	7	7
Average time on waiting list (days)	11	365	144.5	1091	N/A

* Number in parentheses equals the number of providers at the minimum levels for each category.

* Number in parentheses equals the number of providers at the minimum levels for each category

Table D-6.

Numbers of children in each category of disability in 12 Broome County school districts: Classifications during 2004-05 school year				
	Total	**Avg. per District**	**Minimum**	**Maximum**
Autistic	174	14.5	4 (2 districts)	40
Emotionally Disturbed	344	28.67	9 (3 districts)	130
Mentally Retarded	163	13.58	1	62
Other Health Impaired	698	58.17	7	130
Multiply Handicapped	496	41.33	10 (2 districts)	116
Traumatic Brain Injured	25	2.08	0 (5 districts)	8
Total All Six Categories	1900	158.33	41	475

Table D-7.

Numbers of children in need of services for Developmental Disabilities and Mental Health needs in Broome County school districts – CSE Chairpersons: 2004-05 school				
	Total	**Avg. per District**	**Minimum**	**Maximum**
Total All Six Categories of Disabilities	1900	158.33	41	475
How many of total meet definition for DD?	972	81	16	230
How many in also have MH needs?	408	34	2	82
Estimate of # of additional children with both DD and MH needs	335	27.92	0	100
What is the total # with both DD & MH conditions?	743	61.92	6	130
How many had unmet needs due to service gaps?	295	24.58	0 (2 districts)	125
How many are in need of education programs that better meet emotional/educ. needs?	109	9.08	0 (2 districts)	35
How many are SED?	131	11.91	0	65

* Average is based on the sum of ratings for each service (with 3 points for each Highest Priority rating, 2 points for Moderate, 1 point for Low) divided by Total Respondents.

Table D-8.

Table D-9.

Ratings of priority for service areas with unmet needs for children with co-occurring MH and DD conditions – MH providers (Based on 17 responses)

Service	Service	Highest Priority		High Priority		Moderate Priority		Low Priority		No Response		Average
Child/adolescent psychiatric evaluations	Child/adolescent psychiatric evaluations	30		11	5	1	3	2	3	3	2.5	2.2
Medication management	Emergency respite care	19		10	12	4	5	0	5	3	2.1	2.2
Ongoing respite care	Parent support	17		7	17	7	3	0	4	3	2.1	2.1
	Ongoing respite care			9		3		1		4		2
Neuropsychological	Developmental pediatrician/assessment	17		8	16	3	5	4	3	2	2.1	2
Counseling services for family members	Advocacy services	18			11		7		5		2	2
Emergency respite care	Psychological testing in	16		7	15	6	5	1	5	3	2	2
Parent support	Counseling services for	16		6	14	8	7	0	4	3	2	2
Counseling services for children	Neuropsychological	15		6	16	8	5	0	5	3	2	2
Psychological testing in the community	Crisis intervention	15		8		2		5		2		1.9
Residential treatment	Medication management	15		7	15	5	8	1	3	4	2	1.9
Crisis intervention		13		7	15	4	7	3	4	3	2	1.9
Behavior management	Behavior management	11			19		4		5		2	
Day treatment	Case management	7		6	16	6	8	3	6	2	1.8	1.9
	Counseling services for			5	23	5	7	5	4	2	1.8	1.8
Case management	Residential treatment	7		2		12		0		3		1.8
Developmental	Day treatment	11		6	22	3	8	4	4	4	1.8	1.6
Advocacy services		8		4	13	4	12	5	5	4	1.7	1.5
Psychological testing in schools	Psychological testing in schools	6		3	20	5	7	6	6	3	1.7	1.5
					17		13		5		1.6	

* Average is based on the sum of ratings for each service (with 3 points for each Highest Priority rating, 2 points for Moderate, 1 point for Low) divided by Total Respondents.

Table D-10.

Ratings of priority for service areas with unmet needs for children with co-occurring MH and DD conditions – Service Coordinators (Based on 31 respondents)

Service	Highest Priority	Moderate Priority	Low Priority	No Response	Average
Child/adolescent psychiatric evaluations	26	4	1	0	2.8
Counseling services for children	25	5	1	0	2.8
Ongoing respite care	22	7	2	0	2.6
Emergency respite care	21	8	1	1	2.6
Behavior management	21	7	3	0	2.6
Psychological testing in the community	20	9	2	0	2.6
Crisis intervention	20	8	3	0	2.5
Developmental pediatrician/assessment	18	10	3	0	2.5
Medication management	18	10	2	1	2.5
Counseling services for family members	17	11	3	0	2.4
Neuropsychological	10	18	3	0	2.2
Residential treatment	11	9	11	0	2
Parent support	8	12	11	0	1.9
Psychological testing in schools	5	13	13	0	1.7
Case management	5	5	21	0	1.5
Advocacy services	3	10	17	1	1.5
Day treatment	1	12	17	1	1.4

* Average is based on the sum of ratings for each service (with 3 points for each Highest Priority rating, 2 points for Moderate, 1 point for Low) divided by Total Respondents.

Table D-12.

Ratings of priority for service areas with unmet needs for children with co-occurring MH and DD conditions – CSE Chairpersons (Based on 12 responses).

Table D-11.

Ratings of priority for service areas with unmet needs for children with co-occurring MH and DD conditions – CSE Chairpersons (Based on 12 responses)

Service	Highest Priority	Moderate Priority	Low Priority	No Response	Average
Crisis intervention	10	2	0	0	2.8
Day treatment	9	2	1	0	2.7
Child/adolescent psychiatric evaluations	9	1	2	0	2.6
Medication management	7	5	0	0	2.6
Counseling services for family members	8	2	2	0	2.5
Counseling services for children	8	1	3	0	2.4
Behavior management	5	7	0	0	2.4
Emergency respite care	5	7	0	0	2.4
Ongoing respite care	4	8	0	0	2.3
Residential treatment	5	5	2	0	2.25
Parent support	5	5	2	0	2.25
Neuropsychological evaluations	4	4	4	0	2
Developmental pediatrician/assessment	4	4	3	1	1.9
Advocacy services	4	3	5	0	1.9
Case management	3	4	5	0	1.8
Psychological testing in the community	1	3	8	0	1.4
Educational services	3	1	5	3	1.2

Service	Highest Priority	Moderate Priority	Low Priority	No Response	Average
Child/adolescent psychiatric evaluations	6	4	1	1	2.25
Developmental pediatrician/assessment	5	4	2	1	2.1
Crisis intervention	6	2	2	2	2
Counseling services for children	5	4	1	2	2
Emergency respite care	5	4	0	3	1.9
Medication management	5	3	2	2	1.9
Behavior management	4	5	1	2	1.9
Parent support	3	6	2	1	1.9
Ongoing respite care	3	6	0	3	1.75
Neuropsychological evaluations	3	4	3	2	1.7
Case management	2	6	2	2	1.7
Day treatment	3	3	4	2	1.6
Residential treatment	3	4	2	4	1.4
Advocacy services	0	3	6	1	1.3
Psychological testing in the community	1	1	8	2	1.1
Educational services	2	0	2	8	0.7

* Average is based on the sum of ratings for each service (with 3 points for each Highest Priority rating, 2 points for Moderate, 1 point for Low) divided by Total Respondents

* Average is based on the sum of ratings for each service (with 3 points for each Highest Priority rating, 2 points for Moderate, 1 point for Low) divided by Total Respondents

APPENDIX E: MENTAL HEALTH / DEVELOPMENTAL DISABILITIES PREVALENCE RATES

Mental Health / Developmental Disabilities Prevalence Rates

Oliver Fassler, MA, SUNY Binghamton

Mental Illness Prevalence

It is difficult to determine the prevalence of behavioral and emotional problems among children because researchers utilize differing, nonstandardized criteria to identify the presence of a mental illness, and the labels and definitions of problem behaviors also vary (Schroeder and Gordon, 2002). The difficulties are further complicated by developmental variability from infancy to adolescence (Schroeder and Gordon, 2002). For example, fear of separation from caretakers is normal for children under three years of age, but can be considered a disorder in older children.

Bird (1996) reviewed epidemiological studies conducted in various countries after 1980, and found wide variability in the percentages of children with a diagnosable disorder, between 12.4% and 51.3% of children 6-18 years of age. Estimates decrease to between 5.9% and 19.4% when only clinically significant or severe disorders are included. Nottelmann and Jensen (1995) also reviewed prevalence of mental illness in children and adolescents. The authors found prevalence rates of child and adolescent mental disorders based on DSM-III criteria ranged from 5% to 26% (Offord et al., 1987; Costello, 1990; Brandenburg, Friedman, and Silver, 1990; and Fleming, Offord, and Boyle, 1989). Again, this wide range is consistent with the difficulties mentioned above in gathering reliable and valid data. The authors' conclusion: "Larger, more methodologically rigorous general population studies, however, suggest prevalence rates in a narrower range, 17.6 to 22% (Nottelmann & Jensen)." This range seems consistent with widely-cited work by Friedman, Katz-Leavy, Manderscheid et al (1996), which suggests that 20% of youth between the ages of 9 and 17 have a diagnosable disorder in a given year (see also Shaffer, Fisher, Dulcan et al, 1996; Healthy People 2010, Chapter 18; Substance Abuse and Mental Health Services Administration, Surgeon General report, Chapter 2, 1999).

It is even more difficult to determine prevalence rates for preschool children. Prevalence rates for infants, toddlers, and preschool children have only recently received attention from the research community, most likely because few reliable and valid methods for assessment are available for this age group (Schroeder and Gordon, 2002). In general, prevalence rates for DSM diagnoses of preschool children tend to be similar with those for older children, although the types of disorders evidenced may vary. Arend et al. (1996) reported that 21.4% of preschool children from pediatric primary care settings had "probable" DSM-III-R diagnoses while 9.1% had "severe" DSM disorders. It is unclear what is meant by "probable" and "severe." The most common disorder was Oppositional Defiant Disorder. A recent survey of a representative sample of healthy births indicated that about 11.8% of parents of 2 year olds reported clinical or subclinical levels of problems as measured by the CBCL/2-3 (Briggs-Gowan, Carter, Skuban, & Horitz, 2001). Approximately 6% of parents of 1 to 2 year olds reported clinically significant problems on the Parenting Stress Index Difficult Child scale.

Prevalence rates for childhood problems are much higher among low-socioeconomic status samples than in the general population (Lavigne et al., 1996). Higher rates of psychiatric disorders have been associated with low intelligence.

Important in understanding estimates of prevalence is determining how one defines need as well as the severity level. Largely because of the rise of managed care, it is no longer feasible to equate need with a diagnosis of mental illness. As a result, "epidemiologists have begun to focus more carefully on the level of psychopathological impairment associated with these disorders" (Regier et al, 2000, pp. 47). In addition, it is also acknowledged that in most epidemiological studies the prevalence of mental illness exceeds the perceived need for, demand for, and availability of professional services (Regier et al., 2000). The Senate Appropriations Committee determined specific disorders that it considered were within the scope of severe disorder. Using these criteria, approximately 2.8% of the US adult population has a severe mental disorder (Regier et al., 2000). It is also important to know the course of illnesses—e.g., which disorders are relatively brief and self-limiting, and which become chronic and disabling.

Serious Emotional Disturbance (SED)

In the 1980s the U.S Department of Education estimated the prevalence of SED among school-aged children to be 1.2-2%. Some estimates report that children with SED represent approximately 5% of youth diagnosed with mental disorders (Oswald & Coutinho, 1995). Among disabled children who received special education related services under IDEA, approximately 9% were SED (Friedman & Kutash, 1986). In the MECA study of children between the ages of 9-17, approximately 2.5% of children met the Senate definition of severe mental illness. Using broader definitions, most recent reports suggest annual SED prevalence rates ranging between 9% and 13% of the youth population (Friedman, Katz-Leavy, Manderscheid, et al, 1996, and Surgeon General report, 1999, both citing 9% to 13% SED "with substantial functional impairment" and 5% to 9% "with extreme functional impairment"; National Mental Health Association, citing one in ten children with SED).

Developmental Disabilities

As mentioned above, determining prevalence rates for mental illnesses is difficult for a number of reasons. The problem becomes even more complex when one tries to determine the prevalence of developmental disabilities. The first and probably the most problematic issue is defining developmental disabilities. The definitions and the criteria used to determine if a child has a developmental disability vary widely. As was the case with mental illness, severity is an important concern in determining who is identified as having a "developmental disability." The definition from the OMRDD web site is as follows:

> Developmental disabilities are a variety of conditions that become apparent during childhood and cause mental or physical limitation. These conditions include autism, cerebral palsy, epilepsy, mental retardation, and other neurological impairments.

This is a narrow definition because of its inclusion of disorders that are more severe. The definition appears unambiguous until one tries to determine what is meant by "other neurological impairments." Given the narrowness of this definition, one is likely to find low prevalence rates when this definition is used.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines "developmental disability" as a "severe, chronic disability of an individual that

is attributable to mental or physical impairment or combination of mental and physical impairments;
is manifested before the individual attains the age of 22;
is likely to continue indefinitely;
results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive living, and economic self-sufficiency; and;
reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."

Other definitions are broader. A study by Boyle and Yeargin-Allsopp (1994) labeled children as developmentally disabled if they had deafness or trouble hearing, blindness, epilepsy or seizures, stammering and stuttering, other speech defects, cerebral palsy, delay in growth or development, learning disabilities, and emotional or behavioral problems. The authors found that 17% of children were reported to have ever had a developmental disability. The prevalence of the individual disabilities ranged from .2% (cerebral palsy) to 6.5% for learning disabilities. This definition is much more inclusive. A difficulty with the broader definition is that it makes it harder to tease apart the groups of children with mental illness and developmental disabilities. There can be some overlap between disorders included in developmental disabilities and mental illness. For instance, mental retardation and pervasive developmental disabilities are DSM-IV disorders. The high numbers are for children who meet criteria for a DSM disorder.

According to the Association for Retarded Citizens (ARC) between one and three percent of Americans have mental retardation. The estimates for rates of co-occurrence of mental illness within the developmentally disabled population range from 30-70% in adults (Ddhealthinfo.org).

Mental Illness	Prevalence	Source
Clinically significant disorders (6-18 years old)	5.9-19.4%	Bird (1996)
DSM-III disorder (6-18)	17.6-22%	Nottelmann & Jensen (1995)
Preschool children with "severe" disorder	9.1%	Arend et al. (1996)
1 to 2 year olds with "clinically significant problems"	6%	Briggs-Gowan et al. (2001)
Youth 9 – 17 with a diagnosable disorder within a year	20%	Friedman, Katz-Leavy, Manderscheid et al (1996)
Serious Emotional Disturbance		
School-aged children	1.2-2%	U.S. Department of Education
Of children diagnosed with mental disorder	5%	(Oswald & Couthino, 1995)
Of children 9 – 17: SED with substantial functional impairment	9-13%	Friedman, Katz-Leavy, Manderscheid et al (1996)
Developmental Disabilities		
Developmental disability as defined by Boyle	17%	Boyle and Yeargin-Allsopp (1994)
Learning Disability (school-aged)	4% - 6.5%	Boyle and Yeargin-Allsopp (1994); U.S. Department of Education
Cerebral Palsy	.2%	Boyle and Yeargin-Allsopp (1994)
Mental Retardation	1-3%	Association for Retarded Citizens
Autistic disorder	.02 to .05%	APA, 1994
Co-occurrence of mental illness and developmental disability	30-70% of adult DD population	Ddhealthinfo.org

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APPENDIX F: THE PROBLEM OF DEFINING SPECIFIC "BEST PRACTICES" IN MH/DD

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The notion of a list of best practices is an intuitively appealing one, but it can be very difficult in a field as complex as this one. The population of children with co-occurring mental health and developmental disability conditions (MH/DD) is extremely diverse. Children with developmental disabilities include those with mental retardation, cerebral palsy, epilepsy, neurological impairment, or autism/pervasive developmental disorder. Those with mental health needs include all who have one of a long list of psychiatric diagnoses. Any combination of developmental disability and mental health need will qualify a child, but not guarantee that they are similar to other children who also qualify as MH/DD. To further complicate matters, these children must be treated in various settings (e.g., school, home, community) which entail different treatment goals and approaches. Similarly, a wide range of helping professionals are involved in the care of MH/DD children, including, but not limited to, nurses, occupational therapists, physical therapists, physicians, psychiatrists, psychologists, social workers, speech therapists, and teachers. Thus, the variability across diagnosis, setting, and treatment provider complicates the adoption of integrated treatment policies and practices.

There is not a universally agreed upon "best practice" for treating dually diagnosed children. There is not a large amount of research on what actually works in treating children with co-occurring conditions. The following resources do not constitute an exhaustive list of pertinent resources. Rather, it is a sample of some of the best examples of practice guidelines and expert opinion about the treatment of co-morbid mental health and developmental disorders. The psychological and psychiatric literature provided the bulk of the material contained in this review, although research in other areas may contain valuable information as well. None of these resources replaces the sound judgment of the clinician, based on careful consideration of all factors specific to each individual. These resources simply provide

information about what approaches have been shown to be most helpful generally.

Helpful Resources for Providers and Families

Expert Consensus Guidelines Update: Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation (MR).

There are many practical questions about how to treat psychiatric and behavioral disorders in MR populations that cannot be answered by the existing research literature. To address these concerns the Expert Consensus Guidelines were developed. In 2000 the American Journal of Mental Retardation devoted an issue to compile the opinions of experts in psychosocial treatment and in psychopharmacology. Their recommendations about the appropriateness of many different aspects of assessment and treatment for a MH/MR population were listed for both general and specific issues. Data were analyzed to establish what experts considered first-line, second-line and third-line options. This report was summarized and updated in 2004 to provide a resource for members of all disciplines involved in the treatment of this population including physicians, psychologists, social workers, nurses, teachers, rehabilitation and speech therapists, as well as family members and caregivers. This report provides a resource that can be used in conjunction with information specific to each individual being treated.

Ordering information

To request a copy of the 2004 publication, send your name and mailing address to eks@ls.net. There is no charge.

Or contact

Jobson Education
367 Inverness Parkway, Suite 225
Englewood, CO 80112
Phone: (720) 895-5300
Fax: (303) 858-8842
http://www.psychguides.com/index.php

Clinical Practice Guidelines for Autism and Pervasive Developmental Disorders: Assessment and Intervention for Children (age 0-3 years)

In 1999, The New York State Department of Health Early Intervention Program created a list of "best practices" for children with Autism and PDD. This report reviews the evidence for many common treatments for autism and makes recommendations.

Ordering Information

Single copies of the guideline publications are available free of charge to residents of New York State. Multiple copies are available free of charge to New York State Early Intervention providers and municipal officials for use with parents and staff.

To order, contact:

Publications
New York State Department of Health
P.O. Box2000
Albany, New York 12220
or visit
http://www.health.state.ny.us/nysdoh/eip/index.htm

Practice Parameters for Children, Adolescents, & Adults with Mental Retardation and Co-morbid Mental Disorders.

The American Academy of Child and Adolescent Psychiatry published these general practice parameters that focus on treatment of co-morbid MH and MR in children aged 0-21. The report states that while mental disorders appear more frequently among persons with MR, there is no essential difference in the expression of the disorders. However the clinical presentation may be modified by language difficulties, so a greater emphasis on behavioral symptoms is often appropriate. The AACAP recommends a comprehensive assessment and treatment process

that synthesizes a bio-psycho-social approach with multiple intervention techniques.

The Parameters were published in the AACAP journal volume 38 supplement in December, 1999.

Ordering Information

AACAP Communications Dept.
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016

New York State Guidelines

In January 2005 the New York State Assembly Committee on Mental Health, Mental Retardation, and Developmental Disabilities published a report by their Mental Hygiene Task force; An Evaluation of the Delivery of Mental Hygiene Services in New York State. This report outlines the mental health delivery system and focuses on four issues.

- Planning and interagency cooperation
- Continuum of services
- Underserved populations
- Resources

The Report also makes several recommendations for improved delivery of mental health services in NYS.

Other State Guidelines

Several states have published dual diagnosis treatment guidelines including Tennessee, Ohio, and Mississippi. These guidelines generally emphasize informed consent, comprehensive assessment, and treatment based on the principals of normalization and community based care. The state guidelines are available online:

Tennessee:
http://www.state.tn.us/mental/BestPractice/bpg.pdf pages 38-44

Ohio: http://www.nasddds.org/pdf/Ohio-MIMR-Report.pdf

Mississippi: http://www.dmh.state.ms.us/resources.htm

A great deal of useful information is located on the website for The National Association of State Directors of Developmental Disabilities Services (NASDDDS), including Technical Resources: State Strategies for Supporting Individuals with Co-Existing Conditions:http://www.nasddds.org/NASDDDS_Technical_Resources.shtml