

***Connecting Need and Capacity:***  
***A Study of Mental Health Services for Milwaukee County Youth***

Thomas E. Lengyel, MSW, Ph.D.  
Jamie Harris, M.A.  
Department of Research & Evaluation Services  
Alliance for Children and Families

Martina Graves  
Social Work Intern, The Counseling Center of Milwaukee

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## *Executive Summary*

### *Connecting Need and Capacity:*

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Many providers of mental health services in Milwaukee report shortages of key personnel and programs that interfere with the delivery of needed treatment to youth with serious disorders. Treatment options appear especially limited for children from low-income families. Their experience questions whether the mental health delivery system contains sufficient capacity to address the quantity and nature of these disorders among Milwaukee County's youth. In fact, there are very few sources of information that bear directly on this issue. No community-wide mental health needs assessment or capacity assessment has been conducted previously. This study attempts to fill that void by approaching need and capacity through prevalence research, via a quantitative survey of youth mental health service providers, and by in-depth interviews with key persons in the field.

The 2000 U.S. Census establishes that 247,707 children live in Milwaukee County. Children as a group are slightly concentrated in the City of Milwaukee, where 171,131 (69%) of them live. Importantly, almost all of the county's low-income children and almost all of the county's children of color also live in the city. Prevalence research shows that 15% of youth suffer from a mental disorder accompanied by impairment. That rate predicts that about 37,000 of Milwaukee County children currently experience such a condition and have a need for treatment. About 26,000 of them live within the city, and about 8,500 live in low-income households.

The survey of youth mental health providers, conducted in February and March 2005, elicited a wide variety of data on services offered, staffing, caseload, hours of service, waiting lists, fees, and revenue sources from 18 non-profit and public organizations in Milwaukee who together appear to constitute about one-quarter of the youth mental health system capacity. These data, compared to the expected numbers of youth with mental disorders, show a service delivery system that is roughly in balance with need at the most general level. The data also demonstrate that need overwhelms capacity at particular points of service delivery, including especially psychiatric assessment and consultation, and outpatient therapy.

Interviews with leaders of mental health agencies complemented the survey data by identifying how mental health services have evolved at the agency level, where there are gaps in services for youth, what interferes with service delivery, and how agencies relate to each other. In the absence of guidance from prior needs assessments or community-wide information resources that capture the youth mental health scene, providers have applied eclectic criteria in service planning, yielding a set of capacities that only partly articulate with recognized needs. Interviewees identified significant service gaps at the prevention end of the service continuum, and in services for youth who cross seams in the system, especially at the youth-adult boundary.

They describe real shortages in personnel, particularly therapists, that share the ethnic and cultural background and life experiences of the youth they are trying to help. They also lack a forum that would bring them into connection with each other for service coordination or common action.

The study addresses several fundamental issues about service delivery in Milwaukee County. It affirms that the surveyed agencies are making a concerted effort to serve low-income youth and minorities, though more comprehensive data from a broader set of providers are needed to draw firm conclusions. Youth mental health providers have focused their service delivery on treatment methods, mostly at the deep end that manages serious disorders, crises, and high risk cases. The network of providers is loosely connected and has not yet developed common definitions, conventions, and understandings that are the hallmarks of mature systems. The network lacks institutions and functions that would cause it to behave like an organized system, including central information resources and centralized direction or oversight. This nature appears related to the reported overloading of service capacity at particular points and in particular circuits.

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Introduction

The genesis of this study lies in the perception of several major players in the Milwaukee youth mental health (YMH) arena that youth, and particularly low-income youth were being underserved in terms of mental health. Further, that the mental health needs of youth were not a focus of public concern or investment. At the same time these professionals acknowledged that they lacked an empirical foundation for these conclusions that might focus public attention or justify action. No community-wide study of YMH needs or system capacity currently exists.

In the summer of 2004 a group of seven human service providers linked through their membership in the Alliance for Children and Families<sup>1</sup> and their interest in the mental health of Milwaukee youth formed a coalition to study and bring public attention to this issue.<sup>2</sup> Applying funds granted by the Annie E. Casey Foundation and channeled through the Alliance to promote National Family Week, the Milwaukee National Family Week Partnership resolved to fund a study of need and capacity as the foundation for a summit meeting on the mental health of youth. The fundamental goal of this study is to understand the relationship between current service system capacity and underlying need as the basis for coordinated, concerted public action.

The Milwaukee Scene

In the 2000 census<sup>3</sup>, Milwaukee County had a total population of 940,164. The City of Milwaukee's population was 596,956 or 63% of the County's total population. There were 247,707 children and youth living in Milwaukee County with a somewhat larger share of children and youth living within the city of Milwaukee (69.1% of the county total or 171,131 children and youth).

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<sup>1</sup> The Alliance for Children and Families is a national association of 303 private, non-profit human service agencies throughout the United States and Canada. Its headquarters are in Milwaukee.

<sup>2</sup> The members of the Milwaukee National Family Week Partnership are: Aurora Family Service, The Counseling Center of Milwaukee, Milwaukee Women's Center, St. Aemilian-Lakeside, St. Charles Youth & Family Services, The Salvation Army-Milwaukee Social Services, and the Social Development Commission.

<sup>3</sup> 2000 census data are used in this report because the annual American Community Survey (ACS) does not break down age groupings by gender, racial and ethnic categories and poverty status combined. In addition, because the ACS is conducted as a sample versus a census, smaller geographic units and subgroupings produce greater error in their population estimates. 2004 population estimates of the city and county differ little from the 2000 census indicating 2000 census data should be considered the most reliable.

Table 1 depicts how children and youth are represented in the county and city population by race/ethnicity and poverty status.

**Table1. -- Racial/Ethnic Groups by Poverty Status in Milwaukee**

Youth by Race/ethnicity and Poverty Status	County			City			City share of county's total children
	Total # of Youth* (247,707)	% of total youth	Poverty rate by group	Total # of Youth* (171,131)	% of total youth	Poverty rate by group	
African American, poor	37,246	15.04%	43.15%	36,812	21.51%	43.70%	98.83%
African American, non-poor	49,069	19.81%		47,425	27.71%		96.65%
Totals	86,315			84,237			
American Indian, poor	867	0.35%	30.21%	742	0.43%	33.65%	85.58%
American Indian, non-poor	2,003	0.81%		1,463	0.85%		73.04%
Totals	2,870			2,205			
Hispanic, poor	9,637	3.89%	30.76%	8,991	5.25%	33.24%	93.30%
Hispanic, non-poor	21,696	8.76%		18,054	10.55%		83.21%
Totals	31,333			27,045			
Asian, poor	1,725	0.70%	22.71%	1,619	0.95%	27.91%	93.86%
Asian, non-poor	5,872	2.37%		4,182	2.44%		71.22%
Totals	7,597			5,801			
Caucasian , poor	6,740	2.72%	6.27%	4,048	2.37%	9.65%	60.06%
Caucasian, non-poor (not Hispanic)	100,783	40.69%		37,900	22.15%		37.61%
Totals	107,523			41,948			

Source: 2000 census data

\*Note: Columns do not sum to the county and city population totals because some demographic categories were not included.

In terms of social and economic characteristics, the county and city diverge considerably. Due to the concentration of poverty and hypersegregation that exists within the county, the bulk of child poverty falls among city residents. For example, while 69% of all children and youth in Milwaukee County live within the City of Milwaukee, 93% of the poor children in Milwaukee County reside within the city limits. Similarly, of the 86,315 African American children in the county, 98% live within the city's boundaries. The same is true for other groups: 86.3% of all Hispanic children reside in the City of Milwaukee, 76.3% of all Asian children, and 77.8% of American Indian children. The situation is reversed for Caucasian children; only 39% of all white children in the county live in the City of Milwaukee. However, among poor Caucasian children, 60% of the county total lived in the city.

## Study Design

We approach the understanding of the mental health needs of youth and the capacity of the service system to meet those needs from three angles. The first perspective is that provided by the literature on the prevalence of mental health disorders among youth populations coupled with census information about the Milwaukee community. Our second approach is through a quantitative survey of service providers who primarily address the mental health needs of youth, and low-income youth in particular. The third leg of the stool is the views of key players in the local mental health scene, including service providers, advocates, educators, and consumers gathered through comprehensive interviews. This report integrates findings from these three components of the study.

### The Survey

To lay the foundation for our quantitative survey of service providers we attempted to identify the universe of mental health providers who directed their services at youth, and particularly at low-income youth. This presented challenges. No single list was readily at hand nor was it easy to assemble one. This fact, in itself, foreshadows one of the findings of this study. Ultimately, a list of 64 agencies was elicited from the Non-Profit Center of Milwaukee, augmented with information from the 211-IMPACT telephone referral system.<sup>4</sup> A letter and email inviting agencies to participate in the Youth Mental Health Survey were sent to the list of non-profit mental health service providers so derived.<sup>5</sup>

Agencies had six weeks to complete and submit this comprehensive on-line survey. Over this period several additional agencies were identified and invited to participate yielding a net universe of 66 invited providers. A total of 18 agencies ultimately completed the survey. We discovered through direct phone contact with the invited agencies that 36 of them did not in fact provide YMH services, and we therefore revised our effective pool down to 30, producing a 60% response rate. Responding and non-responding agencies are presented in Appendix 1.

### Representation of System Capacity in the Survey

It is worth considering carefully what portion of YMH system capacity is represented by the 18 responding agencies in order to assess the validity of our results, even if we can do so only in

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<sup>4</sup> This list was derived from the Center's category "youth serving agencies", which was then narrowed to "mental health providers". The manner of assembly of this list of youth mental health providers proved far more fateful to the validity of the survey than anticipated. We discovered in the course of the survey that the majority of agencies on the list did not consider themselves providers of mental health services to youth. Furthermore, in examining IMPACT data on youth referred for "adolescent/youth counseling" and "child sexual assault counseling" we learned that a number of agencies who received significant numbers of youth mental health referrals had been omitted from our survey list. Interviews with youth mental health professionals confirmed that these omitted agencies were in fact important providers of mental health services for youth. We attempt to characterize and quantify this bias below.

<sup>5</sup> Private practice clinicians were not considered for participation in this survey because the study's focus pertains to the availability of mental health services for low income youth. It is generally understood that few if any private clinicians provide mental health services to poor children.

very approximate terms. The issue devolves into one of identifying a metric that represents the universe of study (i.e., the YMH delivery system). None existed prior to this study, so we use surrogate indicators.

We developed profiles of the extent of the YMH service system (i.e., the universe of agencies who provide these services) using United Way service data, and IMPACT referral data. United Way provided us 2004 data on the numbers of youth served by funded agencies in the program areas of disabilities, emergency shelters-runaways, individual/family counseling, and mental health/mental illness.<sup>6</sup> Of the 3,055 youths served in these program areas in Milwaukee County in 2004, 2,724 (89%) were served by agencies responding to our survey. At first blush, this suggests that the 18 respondents do represent a significant portion of system capacity.<sup>7</sup>

A more sobering assessment emerges from inspection of IMPACT referral data. Of 475 referrals made during 2004 for adolescent/youth counseling and child sexual assault counseling 101 (21.3%) went to responding agencies.<sup>8</sup> 64 referrals (13.5%) went to the 12 non-responding agencies on our original list of invitees. And, 311 referrals (65.5%) went to other providers.<sup>9</sup> This finding suggests that our strategy for identifying providers of YMH services in Milwaukee County failed to identify the major part of that capacity. Our difficulty itself signals that this delivery system is not well organized, at least in terms of having tools or central information sources that allow the easy identification of system capacity. To the degree that IMPACT referral data constitute a satisfactory metric -- and it's the only comprehensive one we currently have -- they imply that about one-fifth of system capacity is represented in our survey data. Shaded by the United Way service statistics we might generously guess that our survey tapped one-quarter to one-third of system capacity in the area of YMH services. Our conclusion will be significantly affected by the review of caseload statistics and hours per case data, presented below.

### Uncharted YMH system capacity

In order to better identify the YMH service provider universe in the aftermath of the quantitative survey we recovered other databases of providers that offer some context for the effort. The 211-IMPACT system maintains lists of providers for each referral category. Their "adolescent/youth counseling" list contains 60 county-based providers, and their "child sexual assault counseling" list has 16 (B. Waite, 2005). The service provider list for Wraparound

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<sup>6</sup> These program areas were the closest analogs to youth mental health services in terms of United Way program categories. United Way requires all funded programs to report annually the number of individuals served in each program by age and by zip code of residence.

<sup>7</sup> We must bear in mind that United Way of Greater Milwaukee funds only 130 area programs, a relatively small part of a rich service universe. Youth mental health is not currently one of their funding priorities. The group of YMH agencies they fund is therefore far from comprehensive.

<sup>8</sup> Adolescent/youth counseling and child sexual assault counseling were the closest analogs to youth mental health services in IMPACT's repertoire of categories.

<sup>9</sup> 62 of these agencies received a single referral during the year, and 16 others received but two, implying relatively marginal involvement in youth mental health. Some apparently major players who were not surveyed received anywhere from 9 to 30 IMPACT referrals of youth for counseling services, and together handled 102 (21.5%) of these calls. These agencies include ARO Counseling Centers, Aurora Sinai Medical Center – Sexual Assault Treatment Center, Children's Hospital – Child and Adolescent Center, Family Intervention and Support Services, and The Parenting Network. They are clearly candidates for inclusion in future studies.

Milwaukee has a grand total of about 200 providers of all types, of whom 90 offer specifically youth mental health and AODA services in Milwaukee County (J. Maher, 2005). The Program Certification Unit of the state Bureau of Quality Assurance lists 189 certified mental health clinics in Milwaukee County, with 123 in the city proper. Inspection of address and zip code data for these various providers reveals broad dispersion of the agencies geographically, with some inner city zip codes (e.g., 53202, 53204, and 53205) very heavily resourced. This indicates a rich provider network in Milwaukee, a conclusion reinforced by the spontaneous comments of a colleague positioned to have such an overview. However, these lists do not speak to the issue of access by low-income youth to the services the providers offer. Mental health colleagues suggest that at least some of them do not accept Medicaid and other forms of partial reimbursement and there may be other barriers as well.

### Profile of Survey Respondents

Of the 18 agencies that responded, 16 were private, non-profit organizations and two were public entities. Eight respondents classified themselves as a mental health provider/clinic. One agency was a school. Half the respondents (9) distinguished themselves from these closed-ended options, providing self-descriptions including community education facility, multi-service child welfare provider, public health department, youth shelter, and Indian health center.

In terms of type of service provider, the majority were outpatient, mental health providers. A few agencies provided only information/referral services. Residential treatment and educational agencies were rare.

### Key Person Interviews

The Steering Committee of the Milwaukee NFW Partnership consisted of the leaders of the seven collaborating organizations, in addition to several of their staff members. In order to develop the set of key person interviews this group initially generated a list of 25 organizations who were significantly involved either in youth development or directly in the provision of YMH services. The list was intended to represent the full diversity of agencies involved with youth, including those primarily serving minorities, and the school system. Subsequently the list was winnowed to 12 organizations whose primary focus was mental health, plus the Milwaukee Public School system. Two-hour interviews with officials at these 13 organizations were conducted between February 11 and April 4, 2005. The list of organizations and interviewees appears as Appendix 2 and the interview format appears as Appendix 3.

### Defining Terms: Need as a Concept

The definition of need is critical to any community mental health needs assessment. Defining need, however, is not a straight forward matter. It is fundamentally a value based endeavor. (For a review see Robinson and Elkan (1996).) In practice, measuring need typically involves collecting information about the prevalence of disease and about the amount of service delivery. Both approaches have certain drawbacks as measures of need within a community.

Prevalence research which considers the epidemiologic basis of disease and disorder makes certain assumptions about need. First, it defines need by examining mental health in the negative. Thus, individuals without a disease or disorder lack a mental health need, and those with a disorder have a need. However, it can be argued that those without a disorder, so called healthy individuals, have mental health needs, whether that means access to information, prevention programs, or certain kinds of emotional support in one's life. In general, the health care field has been organized around this deficit understanding of need.

Secondly, prevalence rates are not absolute measures of need, but change over time as diagnostic methods and professional and cultural attitudes about behavior change. And prevalence rates also do not necessarily tap what sociologists refer to as "expressed need" or need that is put into action by seeking out the assistance of a mental health professional. Some individuals diagnosed with a disorder may not feel compelled to seek treatment. Thus, instead of tapping expressed need prevalence rates apply the "normative need" of health care professionals which may or may not be shared by individuals with a given disorder.

Given these drawbacks with prevalence, service use might appear a better approach. However service use, although manifesting expressed need, cannot be interpreted as directly reflecting underlying need. Essentially, service use is more a reflection of the structure of the mental health delivery system than an expression of need. Such things as the structure of referral systems, information about the services, the availability of services, financial limitations, or social and cultural impediments such as stigma all conspire to limit and suppress the extent of need from being expressed in the uptake of service. In addition, service use in and of itself should not be taken to mean a need has been met since some treatments may not be effective.

For the purposes of this study, we consider elements of both approaches, recognizing these limitations. For example, we apply prevalence rates to produce estimates of the pool of potential need in Milwaukee County. We also use evidence from service delivery such as waiting lists and trend data on caseloads to consider questions about need.

### Estimates of Need Using Prevalence Research

There are few rigorous epidemiologic studies that identify prevalence rates for a variety of mental health disorders in youth (for a review see Waddell and Shepherd (2002)). Over the last 25 years, six studies have been conducted that employ a rigorous design, use samples that are nationally representative, and employ standardized assessment protocols for both symptoms and impairment. It is from this core group of studies that general prevalence rates are derived for

seven mental health disorders.<sup>10</sup> These rates are then combined with 2000 census data for youth in Milwaukee County and the City of Milwaukee to estimate the number of youth with mental disorders.

Note that the prevalence rates we cite from the Waddell and Shepherd study incorporate impairment into the thresholds for defining clinically important mental disorders. This results in a somewhat lower overall prevalence rate than the 20% figure for youth experiencing mental disorders at any given time cited in a number of studies over the past 20 years.

We acknowledge some limitations to this method of determining prevalence rates<sup>11</sup> and to our manner of applying these prevalence rates to the Milwaukee County youth population.<sup>12</sup> These limitations uniformly operate to render the counts we generate conservative rather than generous. In other words, our estimates of the number of Milwaukee County youth with particular mental disorders are on the low side, and we have reason to believe the actual numbers, were we able to determine them through a comprehensive assessment, would be higher.

In order to characterize need for treatment across a diverse youth population, we provide separate estimates for different racial/ethnic groups in Milwaukee County, recognizing that there is some error in applying a general rate to each group. The rationale for breaking down estimates in this way is that they can serve as a baseline for community-wide coordination of mental health programming and client profiles, and help to assess potential gaps in mental health service provision to certain groups.

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<sup>10</sup> The prevalence rates are derived from a distillation of six studies that were selected and analyzed by researchers at the University of British Columbia (Waddell and Shepherd 2002). The six studies cover populations in Canada, the U.S., and England and examined diverse populations of youth. The rates refer to significant symptoms and impairment derived from standardized assessment protocols. Because these rates reflect six studies, they should be viewed as providing balanced estimates of prevalence rates in the population. The six studies are the following: The Ontario Child Health Study (Offord et al., 1987); the National Institute of Mental Health Methods for the Epidemiology of Child and Adolescent Mental Disorders Study (Shaffer et al., 1996); the Great Smoky Mountains Study (Costello et al., 1996); the Virginia Twin Study of Adolescent Behavioral Development (Simonoff et al., 1997); the Quebec Child Mental Health Survey (Breton et al., 1999); and the British Child Mental Health Survey (Meltzer et al., 2000).

<sup>11</sup> Most studies define mental illness within a three month time frame and often target a select set of ages. Thus, prevalence rates cover only one part of the year for certain ages of youth and the actual prevalence in a given year or over a child's entire period of youth would be somewhat higher. In addition, epidemiologic research often comes from community surveys that exclude certain persons living in institutional settings. It is well established that individuals in institutional settings such as juvenile detention or group homes have higher rates of mental illness than the general population

<sup>12</sup> An overall rate will be applied to give a general estimate for different age, race, ethnicity, and poverty status categories of youth. Because the literature on prevalence rates for different subgroups of the population is quite limited and conditioned by numerous other factors that we do not examine here, it is not possible to apply individual group rates. In general we consider these estimates to be conservative for several reasons. The prevalence rates are compiled from six studies, balancing out some of the sampling error that might produce artificially high or low rates. Also, the research literature indicates that rates increase with urbanization and certain risk factors that coincide with poverty. Thus it is likely that these rates would actually be higher for Milwaukee County than for the nation as a whole.

To estimate the extent of child and youth mental disorders, we multiplied prevalence rates for the seven most frequent mental disorders by the relative size of the city and county youth populations. We provide the rates and city-wide and county-wide estimates in table 2.

**Table 2.--Estimated Youth Mental Health Disorders in Milwaukee County:  
All Youth**

Prevalence Rates		City Youth with Disorder	County Youth with Disorder
Any disorder <sup>13</sup>	15.0%	25,670	37,156
Anxiety	6.5%	11,124	16,101
Conduct Disorder	3.3%	5,647	8,174
ADD/ADHD	3.3%	5,647	8,174
Depressive	2.1%	3,594	5,202
AODA	0.8%	1,369	1,982
PDD	0.3%	513	743
OCD	0.2%	342	495

We provide estimates of mental disorders among youth in Milwaukee County for five major racial/ethnic groups in an appendix (see Appendix 4). Applying the prevalence rates for “any disorder” (15%), we would expect 37,156 youth to suffer from a disorder in the county as a whole, and 25,670 from the City of Milwaukee. If we consider only low-income youth in the entire county summing for the five defined racial/ethnic groups, we estimate 8,432 individuals.<sup>14</sup> The highest prevalence is for anxiety disorders with 6.5% of youth affected, and the lowest we cite here is obsessive-compulsive disorder, at 0.2%. Other disorders occur at prevalence rates of 0.01% or less. We discuss this subject in more detail in our gap analysis (below).

#### Empirical Indicators of Need

Several quantitative measures included in the survey of mental health providers can be used to provide some assessment of need in the population. Although many of these measures are imperfect, they provide a starting point for gauging the extent of need among low-income youth.

The types of mental health diagnoses and services provided to youth are listed below, ranked highest to lowest (table 3). These are disorders that agencies reported being able to treat and not actual treatments delivered. We cannot ascertain what the actual mix of treatment was relative to need. However, we can assess the availability of treatments relative to need.

Two-thirds of agencies provided treatment for anxiety disorders which is consistent with the fact that these disorders have the highest prevalence in youth populations (6.5%). The same applied

<sup>13</sup> Any disorder includes all disorders listed plus other disorders for which we did not provide rates such as Tourette’s, bipolar disorder, schizophrenia, and eating disorders. All the latter occur at prevalence rates of 0.01% or less in youth populations.

<sup>14</sup> This estimate is from Appendix 4. It amounts to a slight undercount since there are two racial/ethnic categories (“other race” and “two or more races”) that are omitted in our tally.

to conduct disorders and depression which were next highest in prevalence, though at about half the level of anxiety disorders. ADD/ADHD was equal to anxiety disorders in service availability despite its much lower prevalence. 30 to 40% of our sample of agencies report providing treatment for PDD, PTSD, ATODA, and RAD, which together may affect about 3,500 children county-wide. This might suggest a higher number of referrals for these disorders, a more robust supply of professionals trained in these specialties, more funding targeting these conditions, or a combination of these factors. To the degree our sample of respondents represents the service delivery community the availability of service for particular disorders imperfectly tracks their frequency in the youth population.

**Table 3.--Mental Health Disorders Treated**

	Agencies with Service	Prevalence of disorder
ADD/ADHD	67%	3.3%
Anxiety Disorder	67%	6.5%
Depression	61%	2.1%
Conduct Disorder	56%	3.3%
Pervasive Development Disorder	39%	0.3%
PTSD	39%	--
ATODA	33%	0.8%
Reactive Attachment Disorder	28%	--
Other	11%	--

This profile of treatment availability becomes entirely understandable in light of the comments of the key person interviewees. They were asked to describe how the particular array of services at their agencies came to be. They explained the origin of the repertoire of services at their agencies in very distinct ways. Various, the current service array was attributed to the history of the agency, to a theoretical perspective (e.g., providing services across the life span), to the need to economize on spending public funds, to the political climate in the state, to the content of court orders, to the particular research and clinical interests of the managing clinician. One colleague offered that his agency's services were formed by "triaging what's coming in the door." Not mentioned were external needs assessments, the use of prevalence rate research to shape service array, or coordination (e.g., complementarity) with other service providers. Also notable, none of the providers believed that the availability of funding was a basic determinant of the shape of services.

The interviewees viewed the adequacy of services as considerably more complex than the availability of treatment for particular disorders. They were particularly sensitive to the life cycle of youth served in their agencies and how the paths that youth follow require them to cross over between service systems and institutions. A significant group of interviewees noted that transitions across these seams in the service delivery system were problematic. One executive pointed out the lack of transitional services for youth returning home from out of home placement and two others cited the same problem for kids returning from placement in the juvenile justice system. An educator decried the absence of transition planning for students

returning to mainstream programming after receiving services in Wraparound. An even larger problem noted by another interviewee is the transition to adulthood for children with mental health issues. For example, there were no group homes for youth aged 16 to 24 years. Kids transitioning out of Wraparound at age 18 “don’t translate well into the adult world. ... Some of these kids become your homeless population.” Services that follow or assist youth who are crossing major boundaries and divisions appear to have significant potential for improvement in the Milwaukee YMH system.

Need may be compared to capacity via the extent of waiting lists and referrals. Forty-one percent of agencies ( $n = 7$ ) did not maintain waiting lists while 24% ( $n = 4$ ) did keep them for some programs. Thirty-five percent of agencies reported that the question did not apply to them. For those agencies that kept waiting lists, the highest number of individuals on a list at any given time ranged from 15-40 in the last fiscal year, indicating a substantial degree of unmet need at these agencies.

Interviews confirmed that service providers are troubled by waiting lists and are seeking ways to avoid them. Some providers have shifted to very short term (e.g., two-week) waiting lists, which are recreated at the end of each cycle. Those with waiting lists typically have a means to promote priority cases to the head of the list, though the basis for priority may be either the youth’s pressing need, or something else entirely (e.g., being referred by an in-house, rather than external physician). Psychiatric and psychological assessment and outpatient clinical counseling were services characterized by waiting lists, with some waits as long as five months.

In terms of the referral to service ratio, agencies received an average of 272 referrals in 2004 (median 105). Out of that total number of referrals, 69% of those referrals on average received actual services (median 75%) and 31% of referrals did not receive services for a variety of reasons. That suggests that referrals are broadly appropriate (i.e., clients are generally being sent to the proper service providers), though clearly not optimal. We can assume that a certain share of the 31% of referrals that did not receive service represents unmet need in the population for mental health services. A certain share also likely reflects changed diagnoses, or a withdrawal by the client.

Need may also find expression through caseload size and change over time. On average agencies provided mental health services to 571 youths in 2003 and 604 youths in 2004, a 5.8% increase. Agencies projected an even larger increase in 2005, expecting average caseload size to grow from 604 to 679, a 12.4% increase. Caseload counts, then, point to an increase in need against a backdrop of slight decreases in the overall county and city population. Our time perspective is shallow, however, and evidence of a trend should be treated cautiously.

The key person interviews sought to explore possible explanations of the expansion and contraction of need for treatment over time. There was no agreement either about the basic factual issue of whether need for services changed over time, or, assuming it had, what the driving forces might be. A few professionals noted an upward drift in expressed need, but others believed it had remained relatively steady. A sizable group of the interviewees attributed changes, primarily increases, in the need for YMH services to long-term changes in family structure (e.g., the increasing engagement of women in the work force) and broad economic

shifts (e.g., the loss of manufacturing jobs in Milwaukee). Increasing rates of substance abuse were also cited as a cause of increased service need, as was the social policy of deinstitutionalization and favoring of community-based placement and treatment. Since most of these forces are barely detectable over the short run they are not likely causes of the apparent rise in caseloads from 2003 to 2004, or of the expectation for a sharp rise from 2004 to 2005. One interviewee argued that the increase in need for services resulted from the lamentable state of the mental health system after years of disinvestment in services, especially in the inner city. In particular, he argued that the lack of investment in upstream prevention and early intervention in the 1990s was resulting in a flood of need downstream today. More comparable caseload data (i.e., for the same types of cases) over a longer span would help to clarify patterns of change in need for treatment.

To place these comments in perspective, national survey data reveal an increase in the rate of outpatient mental health service use since the 1980's (National Advisory Mental Health Council 2001, 35). The surveys showed that 5% to 7% of youth use any mental health specialty services in a year. Applied to the local youth population these rates suggest that the YMH system needs the capacity to provide services to between 12,400 and 17,300 county youth over a one-year period.

Because agencies reported both number of cases and total hours of service, it is possible to measure hour to case ratios (see table 4). For agencies that reported both hours and caseload information, 15.3 hours of service were provided per case on average in 2003 (median 3.7). In 2004, 13.1 hours of service were provided per case on average (median 3.3), a decline of 14.4%. Projected information for 2005 shows an increase to 14.8 hours of service per case on average, (median 4.4) which is still slightly less than 2003 figures.<sup>15</sup> The disparity between average and median indicates that a few agencies had particularly high values, in which case the median represents a better indicator.

**Table 4.--Caseload and Hours of Service: All Respondents**

	FY 2003		FY 2004		Projected FY 2005	
	Caseload	Hours of Service	Caseload	Hours of Service	Caseload	Hours of Service
<i>Agencies reporting</i>	<i>n = 15</i>	<i>n = 8</i>	<i>n = 14</i>	<i>n = 9</i>	<i>n = 13</i>	<i>n = 10</i>
Total Volume	8,562	67,163	8,459	74,044	8,825	81,094
Average Value	571	12,067	604	8,227	679	8,109
Median Value	225	2,232	233	2,117	300	1,850

The trend data indicate two developments moving in somewhat opposite directions. Caseloads are increasing while the number of hours devoted to each case is declining somewhat. This may be due to the fact that the pool of referrals is expanding while the number of staff to

<sup>15</sup> Note: these ratios cannot be calculated from the table because not all agencies provided both caseload and hour information.

accommodate this increase has not kept pace, a question we will address in the capacity section. A reduction in hours per case may mean a certain degree of unmet need in the quality of treatments, it may reflect greater efficiency in treatments due to a reliance on other resources, on pharmacological regimens, or a move to greater use of short-term interventions.

Interviewees' assessments of caseload pressure were more dramatic than the quantitative data imply. In line with earlier cited comments about waiting lists, various professionals involved in both service delivery and advocacy report being pressed to the wall by demand for the services their agencies provide.

Interviewees were asked to identify unmet needs for YMH services in Milwaukee County. Virtually every aspect of the mental health delivery system was cited as overburdened. Services characterized as being in short supply included gender specific services for youth, after school services, day treatment, case management, residential beds, in-patient beds, anger management, services for children with sexual problems, services for prematurely independent youth, prevention programs, as well as job opportunities. A significant group of interviewees observed that crisis services were overtaxed and several mentioned a shortage of adequate housing. There was broad agreement only about the dearth of child psychiatrists, particularly in the inner city. These comments fell into two camps. Those who stressed individual-level treatment noted the absence or scarcity of highly specialized services or personnel. Those who adhered to a community mental health orientation focused on the lack of general supports for families.

Patterns of program expansion or contraction also speak to need. Only 5.9% of agencies reported experiencing program discontinuation while 31.3% of agencies added new programs. Although there are many reasons a new program may be developed, at a very basic level it indicates some level of need since a new program will presumably be filled by clients. Notably the two programs that were discontinued were both shut down due to lack of funding, a possible indication that funding availability plays a larger role in service structure than was acknowledged in the interviews.

### Gap Analysis

The total number and diversity of youth served in agencies can be aligned with what would be expected based on the prevalence of disorders and census data for different demographic groups. This amounts to a so-called gap analysis. Discrepancies between our estimates and clients receiving actual services can be taken as reflecting a gap between service provision and need across different socioeconomic and racial/ethnic groups, at least in principle.

In the mental health survey, agencies provided information on the economic status and racial/ethnic background of their clients. Among those youth clients seen, 33% came from households with incomes less than \$12,000, and 46% had incomes between \$12,000 and \$24,999. All families are poor in the first income category, and depending on family size (about

which we lacked data), families with household incomes that fall within the second category are also likely to be poor by Census Bureau standards.<sup>16</sup>

**Table 5.--Youth Clients by Income Category**

Income level	% of youth clients
\$0-11,999	33%
\$12,000-24,999	46%
\$25,000-49,999	14%
\$50,000 or more	7%

In order to assess any gap, we can examine total caseloads against our estimates of need. Based on our table of estimates, we would expect a total of 37,156 county youth with mental disorders. Total caseloads in 2003 and 2004 were about 8,500 for the full sample of responding agencies. Since the focus of these agencies is addressing the needs of low income youth, it may be instructive to compare this approximate capacity with the total estimated treatment needs of low-income youth.

Applying prevalence rates to the demographic profiles of the five defined racial/ethnic groups (Appendix 4) we would expect 8,432 low-income youth with mental disorders county-wide. Agencies reported that 33% of youth served had family incomes less than \$12,000, or about 2,800 cases (33% x total caseload of 8,500). These children are patently from low-income households. An additional 46% of youth were from families with incomes between \$12,000 and \$25,000. In the absence of knowledge of the structure of these families (i.e., the number of children and adults in each) we will assume that half of this number—23%—were poor by Census Bureau standards. Applying this percentage to the total caseload yields about 1,950 cases. Combining, we provisionally estimate that the surveyed agencies may be serving about 4,750 low-income youth with mental disorders, or 56% of the projected pool of 8,432.

There are many ambiguities in our survey results that weaken comparisons between current caseload size and prevalence of mental health disorders. Among these ambiguities is the fact that some of the survey respondents are not mental health treatment providers, but are instead engaged in youth development, education, health promotion, and mental health education. Their caseload capacity, folded into the overall figure of 8,500 yearly cases, cannot be said to properly address the need for mental health treatment. Also, the level of service that a “case” receives calls into question whether these cases ought to be summed (see below).

Focusing on the eight respondents that checked the category “mental health clinic” might offer a more defensible portrayal of YMH treatment caseloads and overall system capacity. Separating out one crisis services provider that offered extremely high caseload numbers and one AODA treatment provider, average youth caseloads for mental health clinics in the survey are represented in table 6.

<sup>16</sup> 2004 Census Bureau poverty thresholds consider a family of one adult and one child to be poor if their household income falls below \$13,020. And a family consisting of two adults and four children is considered poor if their household income falls below \$25,241.

**Table 6.--Mental Health Clinic Caseloads**

	2003		2004		2005 (Projected)	
	Total	Mean	Total	Mean	Total	Mean
Mental Health Clinics ( <i>n</i> = 7)	2818	402.6	2843	406.1	3140	448.6
AODA Provider ( <i>n</i> = 1)	140	--	169	--	180	--
Crisis Services ( <i>n</i> = 1)	3500	--	4000	--	4500	--

Recalculating family income levels reported by this subset of seven agencies we find that 45% of the youth they served fall into the lowest income category of \$0 to \$11,999. 33% are in the next income block. Adopting the assumptions applied above, about 62% of the youth served by these clinics live in low-income families. Taken together these clinics may be providing services to about 1860 low-income youth with mental health disorders, or a little more than 20% of the predicted frequency for this group county-wide. This projection is more or less in line with our very rough estimate of the respondents' share of system capacity (i.e., 25% to 33%). The preliminary indication of these data is that the capacity of current service providers to offer treatment is of the same order of magnitude as the inferred frequency of these disorders in the population they serve. The question remains as to whether all of these cases are receiving services of the same kind.

Caseload is admittedly only a very gross measure of system capacity and offers little direct testimony about whether the need for treatment is satisfied. Other details from the quantitative survey provide some evidence on this score. The median hour to case ratios discussed previously for 2003 and 2004 (3.3 hours and 3.7 hours, respectively), indicate that most clients receive a small amount of service (as measured in hours).

As we might expect given the diversity of agencies swept up in the survey, we found great variation in average hour to case ratios for mental health clinics, ranging from 2 hours per case to 66 hours per case. Clearly, these agencies are not providing the same intensity of services, and follow-up interviews with key person interviewees confirm this. For example, one of the responding clinics provides crisis intervention services that average about two hours per case (= an instance of crisis intervention). Another clinic variously provides outpatient, residential services, and intensive treatment for youth sex offenders that averages above 60 hours per case (= a youth).<sup>17</sup> The conclusion is inescapable that responding clinics are not providing the same service in treating youth mental disorders in terms of type or quantity.

In its fine detail, then, hours of service per case harbors complexities that render impossible any firm judgments about the relationship of capacity and need. It does seem reasonably certain that only part of the capacity for 1,860 YMH treatment cases that we attributed to the seven mental health clinics is actually applied to treating the mental health disorders of low-income youth.

<sup>17</sup> While crisis intervention serves to diminish the average hours per case, in virtue of its brevity and means (e.g., telephone interaction), other types of services greatly expand the average. A clinic that includes residential services in its repertoire will count 24 hours of a day as service hours, for all days in care, whether this is residential treatment or shelter services for runaway youth.

This reasoning implies that the stable of providers captured in our quantitative survey probably meets considerably less of the need than we estimated for them from IMPACT referrals, United Way data, and caseload statistics. A much more conservative estimation of respondents' capacity also brings our findings into line with the majority of key person interviewees, who characterized their agencies as overwhelmed by demand for services.

Responding agencies were asked to report the ethnicity of the youth they served (table 7). However, the survey did not require a breakdown of youth by income categories, so there is no basis for knowing whether the numbers of youth served in the various ethnic groups approximate the estimates of low-income youth with mental health disorders derived from prevalence rates.

The geographic dispersion of clients across the county may also be treated as a window on expressed need. We would assume that mental health need in the larger population is fairly evenly dispersed with some exceptions.<sup>18</sup> Because low-income youth are a focus of the efforts of the surveyed agencies, we would expect poorer zip codes to have a higher concentration of their clients.

**Table 7.--Racial/Ethnic Group As a Percent of Agency Caseload**

Youth Race/Ethnicity	Percent of Clientele (average across agencies)	Percent of Clientele (median across agencies)
African American	50%	54%
Caucasian	28%	25%
Hispanic	11%	9%
American Indian	7%	1%
Asian	3%	1%
Hmong	0.5%	0%
Other	0.7%	0%

Agencies were asked to report the top five zip codes by number of youth served in each. The survey results showed a considerable range of zip codes. By combining all zip codes reported in any of the five ranks, there was some overlap, reflecting geographic concentration in certain areas of the city. Those zip codes that overlapped across agencies were in neighborhoods with generally high levels of poverty and the concentration of specific racial/ethnic minorities (table 8).

<sup>18</sup> The report of the National Advisory Mental Health Council noted: "Mental disorders appear to have equivalent incidence and prevalence across majority and minority populations." (National Advisory Mental Health Council 2001, 21).

**Table 8.--Top Zip Codes Served by Responding Agencies**

Zip codes reported as one of top 5	Number of agencies	Poverty Rate for zip code	Largest Racial/Ethnic Group
53215	6	19.60%	Hispanic (38.4%)
53210	5	24.80%	African American (70.4%)
53208	5	32.70%	African American (50.8%)
53206	5	18.20%	African American (62.8%)
53209	4	39.20%	African American (96.1%)
53216	4	19.60%	African American (75.7%)

## Capacity

In addition to assessing need, this study represents an effort to map the capacity of the YMH delivery system. The means to this end was a series of survey questions regarding type of agency, type of services offered, staffing types, and staffing levels.

### Agency Focus and Specialization

The agencies in our sample were overwhelmingly private, non-profit organizations. The largest block of agencies were those offering outpatient counseling and treatment, often in conjunction with other specialized services (e.g., treatment foster care, adolescent day treatment). Also represented were several organizations whose mission is mental health education and screening, in addition to a school, and an AODA treatment provider. This profile of agencies reflects an emphasis on treatment strategies, as distinct from prevention and early intervention, and within treatment on the deep end of services for serious disorders.

Half of the interviewees spontaneously commented on this imbalance of services along the continuum from prevention to institutionalization. Several interviewees offered the conclusion that prevention services are non-existent in Milwaukee or nearly so, though several agencies who answered the survey documented their own prevention and education efforts. Those who analyzed this state of affairs attributed weakness on the prevention side to absence of sustained funding streams. In fact, one colleague whose agency provides treatment made channeling money into prevention his number one recommendation to policy makers and legislators.

The emphasis on youth services varied somewhat across agencies. Fifty-three percent ( $n = 9$ ) of agencies who supplied answers identified youth as their primary focus, while 18% ( $n = 3$ ) considered adults their primary focus. Twenty-nine percent ( $n = 5$ ) considered their focus divided equally between youth and adults. Judging from our pool, the mental health delivery system for youth is not distinct from the mental health delivery system generally. The youth and adult mental health delivery systems are intertwined.

Among YMH providers, two-thirds of agencies considered teens/adolescents their specialization. Fifty percent considered children/preteens (6-11) their specialization, and one third of respondents identified infants/preschoolers (0-5) as a specialization.<sup>19</sup> The progressively greater emphasis on older youth matches the nationally documented increase in rate of use of services with age. National surveys have shown that the youngest children use the least amount of services, and older cohorts use progressively more (National Advisory Mental Health Council 2001, 34).

In addition to the variety of disorders agencies treat such as ADD or depression, discussed in an earlier section, we also asked agencies to report the type of programs and services they offered (table 9). Family therapy was the most frequently cited.

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<sup>19</sup> Note: percentages don't sum to 100 because agencies could have more than one age group specialization.

**Table 9.--Programs Provided to Youth<sup>20</sup>**

Program Type	% of Agencies
Family Therapy	67%
Other	50%
Behavior modification	
Crisis intervention	
Education	
Group therapy	
Advocacy	
Health counseling	
Sex offender treatment	
Special education	
Recreation leagues	
Support Groups	39%
Youth Development	33%
Play Therapy	28%
Youth Recreation	17%

### Staffing

Table 10 summarizes staffing levels reported in the survey. Among these providers, mental health staff size ranged from 1 to 133 with an average of 21 FTE staff (median 9 FTE) per agency. “Other” was the most reported category and consisted primarily of support staff. It accounted the largest share of staffing (48.1%) and an average of 17.3 FTE staff per agency.<sup>21</sup> This category included such positions as public health nurse, educators, youth and family advocates, house managers, LPN, direct service workers, graduate students, and interns.

Therapists were the second most common staff position, representing 20% of all staffing, with an average 6.5 FTE per agency. They were followed in frequency by social workers (16.3%), counselors (10%), psychologists (3.6%), and psychiatrists (2.0%).

These quantitative results provide a firm grounding for the most frequently voiced complaint by the interviewees: namely, the shortage of child psychologists and child psychiatrists. Psychiatrists, in particular, are a genuine choke point in staffing in the YMH delivery system. Virtually all interviewees cited difficulties in accessing psychiatric services for kids, and most also reported a decline in the availability of these specialists to low-income youth. The

<sup>20</sup> Note: percentages do not sum to 100 because agencies could offer more than one program.

<sup>21</sup> 152 FTE of the total 173 FTE reported as “other” derived from two agencies and the mean is therefore unrepresentative of our pool of respondents. For this category one agency reported 110 FTE as “direct service workers” and a second agency reported 42 FTE as “trainees, plus 19 youth and family advocates.”

bottleneck was attributed most often to inadequate reimbursement rates by Medicaid, but also to the withdrawal from the inner city scene of several significant YMH providers.

It was not just the type of specialists available that concerned the interviewees, however. They directed considerable commentary at a broader human resource issue. As a body, these colleagues noted a serious shortage of adequately trained therapists. In particular, most interviewees recounted stories of their frustrated efforts to hire Latino therapists, African American therapists, African American mentors, Hmong therapists, bilingual therapists, or even just male therapists. Beyond ethnic and cultural identity these colleagues found that many professionally trained therapists lacked other vital qualities, including clinical skills, knowledge of community mental health, or “front line” experience. Several laid responsibility for these shortcomings at the doors of the local educational institutions that graduate social workers and therapists.

**Table 10.--Staffing Levels of Responding Agencies**

	<i>n</i>	Total Staff Reported	% of all staff	Mean FTE	Median FTE
Other	10	173	48.0%	17.3	1.5
Therapists	11	71.8	20.1%	6.5	3
Social workers	14	53.5	16.3%	4.2	3
Counselors	11	36.0	10.0%	3.3	1
Psychologists	11	13.2	3.6%	1.2	1
Psychiatrists	8	7.03	2.0%	0.9	1

Applying several assumptions about the capabilities of therapists and the average term of outpatient treatment to the staffing level documented in the survey provides a gross estimate of maximum outpatient capacity at the reporting agencies. A standard that is widely accepted at outpatient clinics holds that therapists are able to provide 20 to 25 hours of treatment per week. A second benchmark commonly used is that a typical term of outpatient treatment is 5 to 7 sessions. Assuming that this level of work could be sustained for 45 weeks per year, the 72 therapists employed at the 11 agencies that provided data would generate about 64,600 hours of outpatient therapy (71.8 therapists x 20 hours/week x 45 weeks = 64,620). This level of productivity would provide typical terms of outpatient treatment to between 9,200 and 12,900 youth, thereby serving about 25% of the predicted number of youth with mental disorders in Milwaukee County. This aligns with our earlier estimates of the respondents’ share of system capacity.

## Funding

### Hourly rate

Sixty-five dollars was the *actual average* hourly rate for provided mental health services (median \$58). The range ran from \$41 to \$110.

The *lowest* fee actually charged was \$22 on average (median \$15), and ranged from \$2 to \$64). The *highest* fee actually charged was \$118 on average (median \$120).

Fifty percent of agencies reported using a sliding scale. Among those agencies that reported using a sliding scale, 36% (median 26%) of all clients (youth and adult) on average received a sliding scale fee.

The manner in which mental health services are funded came in for sharp criticism from most interviewees. Medicaid reimbursement for outpatient counseling runs in the range of \$40 to \$60 per hour for outpatient services, about half of the current market rate in Milwaukee of \$120 per hour. Mental health carve outs within health insurance plans also starve the reimbursement process. Together this means that mental health providers often take a loss on outpatient services for youth, and undoubtedly contributes to the paucity of child psychiatrists on the Milwaukee scene.

### Funding sources

Other governmental funding represented the highest percentage of funding for agencies, accounting for 33% of total funding on average. Fee-for-service was a distant second representing 17% of all funding on average, followed by Medicaid, United Way, foundations, other funding, TANF, and Medicare. Other streams of funding consisted of such varied sources as grants, endowments, membership fees, special events, and individual donations.

**Table 11.—Sources of Funding for Responding Agencies**

<b>Funding Source</b>	<b>Percent Agency Received (average across agencies)</b>	<b>Percent Agency Received (median across agencies)</b>
Other Government Funding	33	30
Fee-for-Service (private insurance, etc.)	17	3
Title 19/Medicaid	14	1
United Way	12	5
Foundations	11	5
Other Funding	9	1
TANF	3	0
Title 18/Medicare	1	0

## Small versus Large Agencies

In order to examine differences in capacity that might derive from agency size, we divided organizations by caseload size<sup>22</sup> to provide a rough measure of organization size. Within that frame we review the break down for agency specialization, staffing, and funding sources.

There are some notable differences among agencies in these two groups. In general, smaller organizations are more likely to focus disjunctively on youth or adults (youth emphasis 43% of agencies; adult emphasis 43%; youth and adults equally 14%). Larger organizations are more likely to emphasize youth and adults equally (youth emphasis 43%; youth and adults equally 57%). Small agencies generally reported that they concentrated on serving younger children, whereas their larger peers concentrate their services on older cohorts.

In terms of treating different disorders, several distinctions emerge. Smaller agencies appeared more restricted in the availability of different treatments. Fifty-seven percent of smaller agencies provided ADD/ADHD treatment compared to 100% of larger organizations. None of the smaller agencies reported treating reactive attachment disorder while 71.4% of larger agencies did so. AODA and pervasive developmental disorders differences were not as great, but still higher for larger organizations (28.6% vs. 42.9% for AODA and 28.6% vs. 57.1% for pervasive developmental disorders). Treating conduct disorders was also less common for smaller organizations (42.9% vs. 85.7%), as were anxiety (57% vs. 100%), depression (57% vs. 85.7%), and PTSD (14.3% vs. 85.7%). Simply put, smaller agencies were less likely to provide treatment for the less common mental disorders of youth.

If we consider staffing differences, here too there are some notable differences. Overall staffing size for the smaller agencies was 6.5 FTE (median 5) compared to 43 FTE (median 13) for larger agencies, not surprising given differences in caseload size between the two groups. However, there are some notable differences in terms of how staffing was distributed across positions. Social workers were utilized similarly (4.3 FTE vs. 5.1 FTE on average for small and larger organizations, respectively). However, larger organizations made much more use of therapists (2.5 FTE vs. 10.3 for large organizations), support staff contained in the “other” category (1 FTE vs. 32 FTE for larger organizations), and counselors (1.5 FTE vs. 5 FTE for larger organizations). Somewhat surprisingly, smaller organizations had higher FTE averages for psychiatrist (1.5 FTE vs. 0.8 FTE for larger organizations).

Finally, if we look at funding sources, there is a similar pattern in many cases, but there are also a few differences to note. For example, larger organizations tended to have a higher share of United Way funding in their total amount of funding (16.8% vs. 9.1%), and also a larger share of Medicaid fee-for-service payments (25% vs. 6.3%). Smaller agencies on the other hand, tended to receive a much larger share of government grants (46.4% vs. 19.7%).

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<sup>22</sup> We divided agencies into two equal groups based on median caseload size: agencies with a 2004 youth caseload above the median of 233, and agencies with a caseload below.

## Findings: What We Learned

The learning that took place from this study occurred in all phases of the work including conceptualizing, planning and design of the work, the process of carrying out the research design, and of course analyzing the formal results. We take up these phases of learning in their natural order.

### Planning

Need has multiple meanings within the arena of mental health. It is most commonly interpreted from a deficits orientation, inherited from the health care field. But need can also refer to the prerequisites of mental wellness such as knowledge, access to preventive measures, and emotional support, or as the Mental Health Association felicitously phrases it to “the overall way people meet the demands of life” (Mental Health Association 2005, 14). The choice between these paradigms lands one squarely in two related debates: Whether resources should be preferentially invested in the prevention or the treatment end of the continuum, and whether mental health should be pursued as an individual-focused or a community-focused enterprise. A decision at this level commits one to a frame of reference, an ideology, and a technology. We ultimately found ourselves committed, but not out of a conscious decision grounded in theory.

It follows that there is equal indeterminacy about how to count need. In our early deliberations over design of the study we engaged in a debate about how to operationalize need. We considered as options counting diagnoses, referrals for services, “cries for help”, and cases served. Each had some benefit, but each also had important weaknesses (see Appendix 5). Further, whatever measures we finally adopted had to survive the test of practical retrieval. Our measures had to be information that practitioners recorded and were willing to give us. The variables we ultimately chose to collect embodied a series of compromises between the needs of the research and the tolerance and practices of our subjects. Knowledge of local level practices at YMH providers (e.g., their informational technology) is therefore critical to the success of future research on need and capacity. This might have to be acquired through field methods such as participant observation at YMH agencies if this exercise is repeated.

There is no central source of information on youth mental health providers, nor, it seems, on adult mental health providers. Existing guides, such as those produced by the Mental Health Association in Milwaukee, list only a fraction of the universe. One must rely on compilations developed for other purposes, such as the IMPACT referral list, the Wraparound list of service providers, the Non-Profit Center’s list of youth serving agencies, or the state directory of certified mental health providers. The lists, of course, only partly overlap and, as we discovered, they are not necessarily accurate. The consequence is that the pool of YMH agencies cannot be accessed, for example, for research, nor can it be activated, for example, for advocacy or planning.

We discovered that there was no template to follow in designing and implementing a study of mental health needs in Milwaukee County. Not only had there been no recent study, there had never been a needs assessment in this field. The current work thus represents a pioneer effort.

Technology and resources directed the study of YMH need and capacity as much as the concept and underlying theory. Prevalence rates and most available data all derive from a deficits model. Deficits technology, for example in epidemiology, is highly developed. But, there are very few resources that assist in measuring need defined from a resources or strengths perspective. This imbalance in conceptual and informational technology compounded by limited resources for conducting the study constrained the direction we could take. A more comprehensive understanding of need will have to discover or create the tools for measuring mental health wellness.

### Process

The prevailing mental health paradigm is limiting, focusing attention on youth who have been diagnosed, and deemphasizing those with “lower” levels of need and those who have wellness needs. Further, those who are not diagnosed, or perhaps have no deficit at all, are exceptionally difficult to locate and measure in a targeted way. Most are not noticed or registered in the service delivery system, and are therefore almost invisible to research, except through a broad, expensive census or perhaps through creative outreach strategies.<sup>23</sup> Because of these considerations, it is expedient to design and implement research targeting individuals registered in the service delivery system. The overall context thus favors studies of expressed need.

We learned through conversation with and questioning of many providers, including the key person interviewees and the members of the Partnership Steering Committee, that mental health providers have relatively little knowledge of each other. They generally do not know the services that other providers offer, nor do they know who the other providers are serving. This state of knowledge suggests that they do not interact with each other frequently.

Related to this “thinness” of inter-provider knowledge is the fact that no forum or common ground appears to draw YMH providers together, even coincidentally. The hunger for this kind of connection may be one reason for the overwhelming turnout at the mental health crisis summit in 2004, and certainly fueled the creation of the Youth Mental Health Connection group last year.

### Results

#### Method and implementation

The barriers and problems we encountered in conducting the research embodied significant features of the system we set out to study. We were initially unable to identify the major share of organizations that purvey mental health services to youth in Milwaukee County. Our difficulties pointed to a defining characteristic of the Milwaukee mental health “system” that was reaffirmed

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<sup>23</sup> In 1995 the Planning Council for Health and Human Services undertook a study of older adults with developmental disabilities in Milwaukee County for the County Department on Aging. The Planning Council found that the number of such adults expected from prevalence rates far exceeded the number identified from the collation of service provider client lists. Despite considerable effort, it proved extremely difficult to contact those who were “living outside the system” (see Lengyel 1996).

in all phases of the research: there exists no central information resource or clearinghouse, nor any effective centralized administration and coordination.

The survey was the vehicle intended to capture features of the delivery system as a whole. Our failure to include some significant players in the quantitative survey, on the one hand, and our inclusion of some providers who apparently do not provide YMH services, on the other, injected uncertainty into the interpretation of results, and made extrapolation of partial findings to the whole universe conditional. Our struggle to estimate what portion of system capacity was represented by respondents ultimately led to the discovery of rich sources of provider information (i.e., annotated lists) that can be integrated in future studies and will provide much improved coverage of the provider universe.

Within the partial universe that we selected for survey we recovered responses from 18 agencies, a numerically small but significant subset of the 66 who were originally invited to participate. That result grew from persistent efforts by Steering Committee members to personally contact non-respondents to encourage their participation. We therefore confronted very small samples in some comparisons. Such circumstances limit interpretation. The experience underscores the necessity of recruiting YMH providers to the research mission in future iterations.

This effort should be understood as a first try at assessment of need and capacity. It revealed what improvements are needed to facilitate future replications. Since the ability to gather systematic and reliable information about conditions, interventions, and results manifests the capacity of the system, that capacity has increased though the lessons learned here.

### Service and system issues

The study documents that at least some YMH service providers are serving youth from low-income families as well as youth of color. Seventy-nine percent of the youth served by the respondents live in families with incomes below \$25,000 per year. Moreover, the clients of the mental health clinics in the survey were balanced toward the low end of this range. We know that YMH providers are extending services to some neighborhoods with high levels of poverty and high concentrations of youth of color. Youth of color comprise about two-thirds of the combined caseloads of the 18 responding agencies. That distribution might be an artifact of selective recruitment to the survey and the fact that these agencies stress services to low-income youth, a demographic that concentrates youth of color. Despite these patterns, the data are not broad enough to conclude that low-income kids and minorities are adequately served. The question deserves a closer look and especially more comprehensive data.

Appropriate human resources are a big issue for the youth mental health system in Milwaukee. Youth mental health agency leaders want a culturally and racially more diverse, more broadminded, and seasoned workforce of clinicians. They are not finding them. Evidently, educational institutions are not producing therapists with the qualifications that youth mental health agencies value, or, if they are, those who are qualified are seeking employment elsewhere. This shortage cannot be remedied without community-wide coordination and action.

The manner in which agencies responded to the survey questions, supported by comments from key person interviews, signals that the local mental health scene has not yet developed conventional, broadly shared understandings of key concepts. Among these are the definition of a “case”, what are appropriate treatments and interventions, who is a mental health provider, or even the definition of mental health. Generally, the development and maintenance of such conventions and norms requires intense, frequent communication among the members of a network. The lack of common understandings has its roots in the tenuous nature of the network.

The development of services at the agency level has come about for reasons unique to each agency. Youth mental health providers do not report using research, needs assessments, or joint planning with other agencies to determine what services to offer. The availability of funding appears to play a significant role in setting services, to a degree that is uncomfortable for most providers to acknowledge. Services at the community level are the aggregate sum of these agency level decisions. Surprisingly, in some limited respects the resulting array of services and capacity approximates the frequency and patterning of the disorders it seeks to address. In other important respects need and capacity are not aligned.

The study identified places in the YMH system where no services exist or where they are, by consensus, clearly inadequate. The prevention end of the continuum lacks infrastructure, financial resources, and human capacity that is remotely comparable to deep end treatment. Services are absent to help kids cross boundaries between major divisions in the YMH system and between that system and the adult system.

Generally, the qualitative and quantitative data regarding the relative balance of treatment need and capacity are contradictory. Analysis of agency caseload and staffing information suggests that capacity to deliver treatment is more or less proportional to the frequency of mental health disorders among Milwaukee youth and among low-income youth in particular. Waiting lists and waiting periods for services, supported by almost unanimous interviewee comments, argue that need greatly exceeds capacity. The truth seems to be that need is very unevenly felt or experienced. Particular nodes and circuits in the youth mental health service delivery network seem to be overloaded. These pressure points include particular agencies (e.g., Children’s Service Society), particular types of interventions (e.g., crisis services), particular treatment specialties (e.g., treatment of RAD), and types of personnel (e.g., clinicians of diverse cultural and ethnic backgrounds, child psychiatrists). This apparent overloading of capacity at particular nodes of a diverse, resourced delivery system refines our earlier conclusion that no administrative mechanism functions to distribute load. The delivery system is not regulated, nor is it self-regulating. Fortunately, awareness of this basic fact is the first step toward adapting capacity to need.

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## Appendices

### Appendix 1: Surveyed Youth Mental Health Providers

Names of responding agencies	Provides YMH
Aurora Family Service	Yes
Catholic Charities	Yes
Children's Service Society of Wisconsin	Yes
City Milwaukee Health Department - Site 1	--
City of Milwaukee Health Department - Site 2	--
Gerald L. Ignace Indian Health Center	No
InHealth Wisconsin	--
Jewish Family Service	Yes
Lutheran Social Services of WI & Upper MI	Yes
Mobile Urgent Treatment Team	Yes
New Concept Self Development Center, Inc.	No
Penfield Children's Center	No
Social Development Commission-Youth Development Program	Yes
Southeastern Youth & Family Services, Inc	Yes
St. Aemilian-Lakeside, Inc.	Yes
St. Francis Children's Center	Yes
The Counseling Center of Milwaukee, Inc.	Yes
Walker's Point Youth and Family Center	No
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Names of non-responding agencies	Provides YMH
ASHA Family Services	Yes
Cedar Creek Counseling Centers	Yes
Child & Adolescent Treatment Center	Yes
Childynamics	Yes
Department of Health & Human Services	Yes
Islamic Family and Social Services	Yes
Lad Lake	Yes
Lutheran Counseling and Family Services	Yes
Meta House, Inc.	Yes
St. Charles Youth & Family Services	Yes
St. Rose Youth & Family Center	Yes
Wisconsin Community Mental health Counseling Centers	Yes
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## Appendix 2: Key Person Interviewees

### Final List of Interviewees

Interview date	Person	Title	Agency Name
3/21/05	Margaret Jefferson	Executive Director	Families United
3/8/05	Frank Gaunt	Director, Child Welfare Services	La Causa, Inc.
3/4/05	Sheri Johnson	Behavioral Health Services Clinic Director	Milwaukee Health Services, Inc.
3/3/05	Chris Morano	Clinical Program Director	Mobile Urgent Treatment Team
3/10/05	Ada Rivera	Chief	Milwaukee Public Schools Office of Pupil Services
3/11/05	Jan Stenlund	Program Services Director	Social Development Commission
Reply 4/6/05	Sharon Dossett	Acting Pres. & CEO	Children's Family & Community Partnership
3/9/05	Bruce Kamradt	Executive Director	Milwaukee County Child & Adolescent Treatment Center
3/11/05	Ron Pupp	Clinical Director	Children's Service Society
4/6/05	Undraye Howard	Executive Director	My Home Your Home, Inc.
3/11/05	Martha Rasmus	Executive Director	Mental Health Association in Milwaukee
2/11/05	Jane Pirsig	Executive Director	Aurora Family Service
3/18/05	Russell Scheffer	Division Director	Child Psychiatry, Children's Hospital

Appendix 3  
Youth Mental Health Interview Format

Interviewee:

Agency:

Date and start time:

1. In your opinion, what factors drive the need for youth mental health services in Milwaukee County?

2. What led to the specific array of youth mental health services that your organization currently offers? I.e., how did they come to be?

What's working and what's not?

3. What has led to the current state of youth mental health services currently available in Milwaukee County?

What's working and what's not?

4. Do you believe there is significant unmet need for mental health services among youth in Milwaukee County? If so, what are the particular needs that remain unmet?

5. What mental health services(s) would you provide to low-income youth if the funding was available? Why?

What mental health service(s) should the Milwaukee community provide if funding were available?

6. Are the mental health *needs* of low-income youth different from those of youth from more affluent backgrounds? How?

Are the mental health *services* for low-income youth different from those for youth from more affluent backgrounds? How?

7. What three things would you like policy makers and funders to do with respect to youth mental health services in Milwaukee?

End time:

Appendix 4: Mental Disorders in Milwaukee County Youth for Five Racial/Ethnic Groups

**Mental Disorders in Milwaukee County Youth: Five Ethnic Groups**

Youth by Race/ethnicity and Poverty Status		Total # of Youth		Any Disorder		Anxiety		Depressive Disorder		Conduct Disorder		ADD/ADHD		AODA	
		County	City	County	City	County	City	County	City	County	City	County	City	County	City
African American	Poor	37,246	36,812	5,587	5,522	2,421	2,393	782	773	1,229	1,215	1,229	1,215	2,980	2,945
	Non-poor	49,069	47,425	7,360	7,114	3,189	3,083	1,030	996	1,619	1,565	1,619	1,565	3,926	3,794
	Totals	86,315	84,237	12,947	12,636	5,610	5,475	1,813	1,769	2,848	2,780	2,848	2,780	6,905	6,739
Hispanic	Poor	9,637	8,991	1,446	1,349	626	584	202	189	318	297	318	297	771	719
	Non-poor	21,696	18,054	3,254	2,708	1,410	1,174	456	379	716	596	716	596	1,736	1,444
	Totals	31,333	27,045	4,700	4,057	2,037	1,758	658	568	1,034	892	1,034	892	2,507	2,164
White	Poor	6,740	4,048	1,011	607	438	263	142	85	222	134	222	134	539	324
	Non-poor	100,783	37,900	15,117	5,685	6,551	2,464	2,116	796	3,326	1,251	3,326	1,251	8,063	3,032
	Totals	107,523	41,948	16,128	6,292	6,989	2,727	2,258	881	3,548	1,384	3,548	1,384	8,602	3,356
Asian	Poor	1,725	1,619	259	243	112	105	36	34	57	53	57	53	138	130
	Non-poor	5,872	4,182	881	627	382	272	123	88	194	138	194	138	470	335
	Totals	7,597	5,801	1,140	870	494	377	160	122	251	191	251	191	608	464
American Indian	Poor	867	742	130	111	56	48	18	16	29	24	29	24	69	59
	Non-poor	2,003	1,463	300	219	130	95	42	31	66	48	66	48	160	117
	Totals	2,870	2,205	431	331	187	143	60	46	95	73	95	73	230	176
Column total	Poor	56,215	52,212	8,432	7,832	3,654	3,394	1,181	1,096	1,855	1,723	1,855	1,723	4,497	4,177
	Non-poor	179,423	109,024	26,913	16,354	11,662	7,087	3,768	2,290	5,921	3,598	5,921	3,598	14,354	8,722
	Sum	235,638	161,236	35,346	24,185	15,316	10,480	4,948	3,386	7,776	5,321	7,776	5,321	18,851	12,899

Important Note: Column totals are less than the total number of youth measured by the 2000 Census because some groups of youth are not counted in the five above named ethnic/racial categories.

## Appendix 5

**Operationalizing Need**

(Meeting of the NFW Partnership Research Committee 12/1/04)

<b><u>Operationalizing Need</u></b>		
<b><u>Method</u></b>	<b><u>Positive</u></b>	<b><u>Negative</u></b>
a) Count diagnoses	Clear cut, measurable	Undiagnosed not counted; reflects structure and capacity of system
b) Count referrals for services	Counted, clear	Reflects structure and capacity of system; cultural/demographic factors may distort picture of need
c) Count “cries for help”	Captures undiagnosed	Stable individuals not counted; hidden population; may not apply to each illness
d) Count those receiving services (“cases”)	Counted, clear	Reflects structure and capacity of system; cultural/demographic factors may distort picture of need
e) Extrapolation from previous studies	Reflects actual prevalence of illness	Projections are from other studies; may not include all categories of interest; may not describe functioning