

DATA WORKGROUP REPORT

Introduction

This abridged technical report contains the findings and recommendations of the Data and Needs Assessment Workgroup of the Florida Commission on Mental Health and Substance Abuse. The Commission was created by House Bill 2003 for the purpose of conducting a systematic review of the overall management of the state's mental health (MH) and substance abuse (SA) system. Through this review, the Commission will make recommendations to the Governor and Legislature regarding change and improvement in planning, service strategies, funding, accountability, emergency behavioral health services, and the unique needs of older persons.

The Data and Needs Assessment Workgroup was formed with three primary research objectives:

- 1) to review the current information management system for MHSA services and assess its capacity to monitor MHSA services delivery;
- 2) to estimate the annual need for MHSA services in Florida; and
- 3) to assess the intensity, types, costs, and quality of services currently being provided. To this end, the primary focus of the analysis has been on the publicly-supported service delivery system, with supplemental data gathered from the entire MHSA system.

Note: When interpreting the findings herein, the reader should recognize that precise calculations of the number and percent of persons in need for MHSA services, those treated, and the cost of treatment, cannot be enumerated at this time. This is because the present information management system does not track all MHSA need and treatment data in a uniformly-defined, compatible, and integrated manner. Thus, the findings herein represent "best estimates" from available data. When at all possible, estimates are based on Florida-specific data, but in some instances, are extrapolated from national data and from published reports.

Findings

Information

Management System

The MHSA service system in Florida is highly fragmented and complex. As indicated in Table 1, Floridians receive MHSA services in a wide array of sectors (not all inclusive) with funding being provided from local, state, federal, and private sources.

When consumers receive MHSA treatment, most providers within the various service sectors collect a relatively common set of client data including entry diagnosis(es), assessment of functional status, basic demographic information, personal identifying information such as social security number, amount and types of services provided, and either direct or indirect measures of costs of services. With the exception of SA services provided by contractors of the Department of Children and Families (DCF) (and perhaps some MHSA services provided within the private sector), there is generally very limited client follow-up following initial discharge. Thus, for the

most part, the sustained benefit of services received is almost uniformly unknown for clients of MH services, and to a lesser extent, also unknown for many SA clients.

When looking at Florida's MHSA delivery system as a whole, one important question that arises is whether or not the requisite data are being collected, and are reliably accessible, to be able to evaluate the course of treatment and outcome of individual clients. This would include their presenting diagnosis(es), services received, costs of services, and acute and long-term outcome.

Presently, it is ostensibly impractical/impossible to link individual client data across many of the different sectors of the MHSA service system. Theoretically, individual client data can be linked with limited difficulty (notwithstanding confidentiality issues) between DCF providers and Medicare and Medicaid files. However, current linkage of these data with state correctional system data (juvenile justice in particular), private sector data, and Department of Education data is very problematic. A large part of this is due to lack of data accessibility, but the data are also not standardized across the various service sectors.

Thus, for all practice purposes, the treatment strategy(ies), costs, and subsequent outcome of *individual clients* of MHSA services in Florida cannot be tracked over time. This lack of an integrated management information system has several undesirable consequences, including:

- The magnitude of unmet need for MHSA treatment cannot be ascertained.
- Aggregate costs of treatment (across service providers and sectors) by diagnosis and other case mix variables cannot be calculated.
- The relative value of different combinations and sequences of treatment programs across service systems cannot be evaluated.
- "Weak links" in the service delivery system cannot be readily identified.
- Accountability for treatment outcomes cannot be systematically monitored.

Within the DCF-funded system, treatment outcome data are collected in a standardized manner. However, several limitations exist:

First, DCF-client outcome data are not consistently gathered at intake and discharge for given programs, but rather are often required upon admission/discharge to an agency, or at quarterly or 6-month intervals. Thus, the current performance measurement system does not require client evaluation at each segment of treatment. While it is most important to assess treatment outcome at the time of discharge, it is also important to be able to assess interim treatment effectiveness (e.g. program-level evaluation), especially among clients with sub-optimal outcomes. Since clients can cycle in and out of different programs between initial admission and discharge, it is important to have the capacity to identify "weak links" within the entire continuum of care. Second, the current set of DCF-performance outcomes range from "societal indicators" (e.g. days in the community) to clinically-oriented measures (e.g. functional assessment). At present, the balance is inappropriately skewed towards societal indicators than clinical measures. Overall, the societal indicators that are used are uninformative with respect to evaluating individual treatment effectiveness.

Third, district and agency-level performance of DCF-contracted providers tends to be evaluated by societal indicators. This creates a perverse incentive for agencies to shun clients most in need of services. For example, being homeless, having a past history of acute care hospitalization or state hospitalization, having a prior criminal record, etc. all correlate (negatively) with the current performance outcome measures - days in the community, paid work days, employment status at discharge, etc. Thus, in terms of performance targets routinely advocated by the districts, it is to an agency's advantage to discourage service delivery to clients with intensive treatment needs and low-to-modest probability of near-term recovery.

Finally, as mentioned briefly above, SA providers appropriately collect performance outcome data after discharge, including at one and 12 months afterwards. For MH providers, no outcome measurements are made after discharge unless the client re-enters the system. This unrealistically assumes a good outcome for all clients who do not re-enter the system, when, in fact, some clients may be in exceptionally poor MH status.

Need for MH and SA Services

Taking into account the limitations in data accessibility noted above, the following estimates regarding need for MHSA services are presented.

Over the course of a year, about 1 in 3 Floridians (both children and adults) will meet diagnostic criteria for a mental or substance abuse disorder. When distinguishing between mental and substance abuse disorders (among adults), approximately 23% will meet diagnostic criteria for a mental disorder, 12% will meet criteria for substance abuse/dependence, and 5% (1 in 20 Floridians) will meet the criteria for comorbidity (mental illness and substance abuse disorder). (Source: National Comorbidity Survey, Epidemiologic Catchment Area Study, U.S. Census Bureau, etc.).

The above "period prevalence" figures do not, however, mean that 1 in 3 Floridians will need MHSA treatment (whether publicly or privately-funded) since significant impairment does not always accompany a psychiatric diagnosis. In addition, an annual period prevalence figure simply implies the presence of a mental or substance abuse disorder at some time during the year, whether acute or chronic.

From a more practical perspective, the annual rate of serious emotional disturbance (SED) in Florida children and adolescents, which includes substance abuse/dependence as a possible diagnosis, is approximately 8% (Source: *Meta-analysis of published reports*). Thus, about 1 in 12 children and adolescents will have a definite need for MHSA services at some time during the course of a year. Presently, insufficient data exist to individually break out the percent of children and adolescents with SED who have a need for MH services only, SA services only, or both MH and SA services.

Among adults and elders, the annual rate of serious mental illness (SMI), which does not include substance abuse/dependence as a possible diagnosis, is approximately 5.5% (Source: *National Comorbidity Survey, Epidemiologic Catchment Area Study, U.S. Census Bureau, etc.*). These data suggest that about 1 in 20 adults and elders will have a definite need for MH services at some time during the course of a year. In addition, approximately 11.6% of all adults and elders will meet diagnostic criteria for substance abuse/dependence during the year. (Source: *National Comorbidity Survey, Epidemiologic Catchment Area Study, U.S. Census Bureau, etc.*). The proportion of these persons with significant enough impairment to warrant need for SA services

cannot be estimated from available data. Thus, as many as 1 in 9 adults and elders (but probably fewer) may have a need for SA services at some time during the course of a year. The reader should recognize that some of the need for both MH and SA treatment can be met through private insurance and other non-public funding sources.

In addition to these broad Florida population estimates, specific areas and subgroups within Florida with particular need for MHSA services and/or prevention efforts are evidenced from the following findings:

- Among Florida youths ages 11 to 18, about 6% have used alcohol or an illicit drug(s) on 10 or more different occasions in the past 30 days (*Source: Florida Youth Substance Abuse Survey – 2000*). These data suggest heightened need for SA prevention in children and adolescents.
- Approximately 100,000 Florida youths ages 10 to 17 (7% of population) are referred for juvenile delinquency each year. Of these juvenile offenders, about 60% will have emotional or mental problems and about 36% will have substance abuse problems (*Source: Florida Department of Juvenile Justice website*).
- A staggering 335,000 Floridians (2% of total population) are estimated to be detained in a Florida prison or jail at some time over the course of a year. Of these persons, approximately 65% will have a psychiatric and/or substance abuse disorder (40% will meet formal diagnostic criteria for substance abuse/dependence; 60-80% will have substance abuse problems), and 3% will have schizophrenia (*Source: Florida Department of Corrections website, meta-analysis of published reports*). These rates are markedly higher than the rates of mental illness/substance abuse in the general population.
- About 73,000 Baker Act initiations are conducted each year in Florida, consisting of approximately 57,000 individuals. Among individuals with multiple initiations, the average time between initiations is about one month (*Source: ACHA/FMHI 1998 and 1999 Florida Mental Health Act Annual Reports*). More than 50 million dollars are budgeted each year for Baker Act services in Florida.
- Although the definition for being “homeless” is not applied in a standardized fashion, approximately 150,000 Floridians (1% of total population) are homeless at some time during each year. Of these persons, about 60% will have a substance abuse disorder, about 3% will have schizophrenia, and about 12% will have post-traumatic stress disorder (*Source: Florida Coalition for the Homeless, review of published reports, U.S. Census Bureau, Assessment of Need for Alcohol and Drug Treatment Services Among Homeless Adults in the State of Florida, 2000; Florida DCF, Office of Substance Abuse*). Similar to the criminal justice system, these rates are markedly higher than rates in the general population.
- Approximately 138,000 Floridians are residents in nursing homes each year (roughly 5% of the population age 65 and older). More than half of these persons will have a need for MHSA services, the majority of which is not attributed to dementia disorders (*Source: ACHA 1998 Guide to Nursing Homes in Florida, 1997 National Nursing Home Survey*).
- The annual rate of suicide in Florida (14.3 per 100,000 persons), while declining slightly over the past two decades, still remains somewhat higher than the national average (13.3 per

100,000 persons). In Florida in 1997, there were 2,098 recorded suicides (*Source: Centers for Disease Control*).

- About 1 in 10 Floridians rate their mental health as not good for one or more weeks during the past month (Source: Behavioral Risk Factor Surveillance System).

Services Being Provided

According to mandated data supplied by DCF contractors, approximately 250,000 to 270,000 Floridians receive DCF-funded MHSA services each year (>2% of the entire population under the age of 65). About 36% of all recipients are children. Overall, the annual number of clients served is slightly higher in MH programs (about 53%) than in SA programs (about 47%), however, approximately 28% of all DCF clients served receive both MH and SA services within a year. This figure illustrates the considerable short-to-mid-term comorbidity between MHSA disorders, and underscores the need for integrated and coordinated services between the two program areas.

Based on estimates of need for MHSA services (Section 2), the following estimates can be gleaned in relation to the DCF-supported MHSA system:

- Of the estimated 279,881 Florida children and adolescents ages 0 to 17 with SED each year (annual prevalence rate of 7.9%), 76% or more $((279,881 - 64,765) / 279,881)$ do not receive MH services from DCF contract providers. Insufficient data exist to estimate the total percent of unmet need for MH services among children and adolescents.
- Insufficient data exist to estimate the annual prevalence rate of substance abuse/dependence (based on DSM criteria) in children and adolescents ages 0 to 17. Therefore, the percent of treatment need met by DCF contract providers and other providers cannot be estimated at present. This is very problematic; the recent Florida Youth Substance Abuse Survey (2000) indicates that a large percentage of middle school and high school students use alcohol and marijuana.
- Of the estimated 500,880 Florida adults ages 18 to 64 with SMI each year (annual prevalence rate of 5.8%), 79% or more $(500,880 - 105,628) / 500,880$ do not receive MH services from DCF contract providers. Insufficient data exist to estimate the total percent of unmet need for MH services among adults across.
- Of the estimated 964,337 Florida adults ages 18 to 64 with a substance abuse/dependence disorder each year (irrespective of severity), 89% or more $((964,337 - 101,246) / 964,337)$ do not receive SA services from DCF contract providers. Insufficient data exist to estimate the total percent of unmet need for SA services among adults.

Thus, at present, between 1 in 4 to 1 in 10 Floridians with a need for MHSA services each year receive services from DCF contract providers. As previously mentioned, the reader should keep in mind that an unknown percentage of the above apparent unmet need for MHSA services is being met through other funding sources, including private insurance, other governmental agencies, and to a lesser extent, self-help groups. However, given the current information management system (see section 1), and overall lack of accessibility and compatibility with

service utilization across all service sectors, the current proportion of Floridians with unmet need for MHSA services cannot be reliably estimated at present.

Among DCF contract providers, slightly more than \$500 million were allocated for MHSA services in fiscal year 1998-99. The figure does not include treatment in state hospitals, most in-patient healthcare facilities, or facilities operated by the Department of Corrections. Of the total DCF expenditures, 33% were allocated for children's MH services, 39% for adult MH services, 6% for children's SA services, and 22% for adult SA services. The average cost per client served, which does not address intensity or quality of services provided, was about \$2,000, with the following average service costs:

- \$2,557 per child in MH services program
- \$ 633 per child in SA services program
- \$1,835 per adult in MH services program
- \$1,078 per adult in SA services programs

Among clients of DCF-contract providers, the majority of children and adolescents who receive MH services do so for attention deficit/hyperactivity disorder (»23%), adjustment disorders (»20%), and for conduct disorders (»19%). The majority of adults who receive MH services do so for mood disorders (»33%) and psychotic disorders (»25%) (Source: Department of Children and Families IDS System).

Presently, MHSA services are being delivered in at least 13 different primary service sectors (see previous Table 1). There is large variation in the collection and accessibility of service utilization data in these sectors. Listed below are relevant findings on the intensity, types, costs, and quality of services being provided in the various MHSA service sectors:

According to data publicly maintained by the Agency for Health Care Administration (ACHA) regarding MH treatment within in-patient healthcare facilities (excluding state hospitals and facilities operated by the Department of Corrections) in 1998:

- About \$119 million were charged for children and adolescents ages 0 to 17, about \$619 million were charged for adults ages 18 to 64, and about \$242 million were charged for elders ages 65 and older. This sums to nearly one billion dollars annually.
- Among all ages, the leading payer sources were Medicare (»48%), private insurance (»25%), and Medicaid (»13%).
- Among children and adolescents under the age of 18, the leading payer sources were private insurance (»57%) and Medicaid (»25%).
- Among adults between the ages of 18 to 64, the leading payer sources were private insurance (»33%), Medicare (»31%), and Medicaid (»16%). Among elders ages 65 and older, the leading payer sources were Medicare (»84%) and private insurance (»12%).
- The average cost per treatment episode was approximately \$8,600.

Collectively, the approximate \$738 million allocated for in-patient MH treatment for persons under the age of 65 substantially exceeds the annual DCF budget of approximately \$360 million for MH treatment. These data emphasize the need for prevention and early intervention since the average

cost of in-patient treatment exceeds the cost of community-based treatment by a factor of between 3:1 to 6:1.

- Notwithstanding the anticipated closure of G. Pierce Wood Memorial Hospital, there are presently seven state MH treatment facilities with a total capacity of 2,821 beds, and about 4,300 persons served annually. Florida ranks below the national average in the use of state hospital beds. The average cost per bed is approximately \$100,000, with an annual budget of about \$275 million (*Source: Draft DCF State Mental Health Treatment Facilities Bed Reduction Plan*).
- Under Medicaid, MH services are provided somewhat less frequently when needed (81%) compared to other more traditional service needs including medical (96%), special school services (88%), and juvenile justice services (89%). Satisfaction with services is also lower for mental health, alcohol, and drug use services than for traditional medical or dental services (*Source: Florida Health Services Follow-up Survey - Medicaid*).
- There are an estimated 708 licensed SA facilities in Florida serving an estimated 255,000 persons annually. About 1/3rd of all treatment facilities are private-for profit, about 56% of all clients need treatment for both alcohol and drug abuse, about 77% are male, about 37% are court referred, and about 42% have received previous SA treatment (*Source: 1998 Uniform Facility Dataset*).
- About 1 in 4 jail inmates in Florida with mental illness and/or a substance abuse disorder receive MHSA services. Jails of all size report significant problems in dealing with inmates with mental illnesses. However, small jails (capacity < 50) indicate only minimal effectiveness in providing adequate services to inmates with mental illnesses (*Source: Florida Jail Mental Health Service Survey – 1999*).
- The annual Department of Corrections (DOC) budgets for MH and SA services are approximately \$38.6 million and \$14.7 million, respectively (*Source: Kip, personal communications*). The aggregate budget of \$53.3 million corresponds to approximately \$1,050 per prison inmate (excludes jail inmates) with a MHSA disorder.
- From available data, it appears that a very small fraction (< 10%) of homeless persons in Florida with a need for MHSA services actually receive services from a DCF service provider (*Source: Florida Coalition for the Homeless, Department of Children and Families IDS System*).
- According to indirect estimates, approximately 22% of residents in Florida nursing homes with mental illness receive MH services (*Source: 1997 National Nursing Home Survey*).
- Insufficient data were (are) available to estimate the percent of met and unmet need for MHSA services among juvenile offenders detained for delinquency.
- Insufficient data were (are) available to estimate the intensity and effectiveness of MHSA services and prevention efforts being provided for children and adolescents in Florida's public school system.
- Approximately 170,000 Floridians (>1% of total population) attend Alcoholics Anonymous (AA) meetings each year, roughly 19,000 attend Narcotics Anonymous (NA) meetings, and

about 186,000 attend AA and/or NA meetings each year (*Source: AA and NA Florida websites*). Thus, the self-help movement is very active in Florida.

- Finally, Table 2 provides a summary estimate of all payer sources (annual expenditures) for MHSA services in Florida. As seen in the table, approximately \$5 billion are spent each year in the provision of MHSA services across all service sectors. About 86% of all expenditures are for MH services. Also noteworthy is that prescription drugs account for about 15% of all expenditures (*Source: ACHA website, SAMHSA Report - National Estimates of Expenditures for Mental Health and Substance Abuse Treatment, 1997, Kip, personal communications*).

Recommendations

On the basis of the findings and discussions from the workgroup, the following four recommendations have been developed. All of these recommendations center on improving the current information management system, but with somewhat distinct purposes:

1. **Improved Data Integration:** This recommendation refers to maximizing the extent to which MHSA service-related data can be linked across the different service sectors and funding streams.

The Workgroup recommends the development and issuance of a Request for Proposal (RFP) for a contractor to study and develop a plan for maximum data integration of MHSA service delivery data. The RFP should originate from a non-stakeholder office (e.g. Governor's office, FL Commission on MHSA, etc.). Recommended guidelines for contractor development of the Data Integration Plan include:

- A focus on utilizing the current management information systems within the various service sectors (i.e. Medicare, Medicaid, DCF, DOC, etc.) with minimal proposed modifications to these existing systems. In other words, not proposing the development of new data systems.
- Investigating and proposing methods that allow for probabilistic matching of clients across service sectors, while preserving individual client anonymity.
- Investigating approaches that utilize a representative probability sample of Floridians. In other words, the Data Integration Plan need not propose the capacity to be able to link all individual-level data across all service sectors. So long as service use patterns of a representative sample of Floridians can be rigorously evaluated, this should allow for extrapolation to Florida as a whole.
- Compatibility and similarity with management information systems used in the private sector.
- Possible designation of a lead system (e.g. ACHA) in which data from other systems must feed or be compatible.
- Data integration capacity across all government entities in which MHSA services may be provided (i.e., DCF, Medicaid, Medicare, DOC, DOH, DOE, etc).
- Investigate use of "smart card" technology to track service utilization data.

- A reasonably brief yet appropriate contractor performance period, such as not to exceed one year.
- Integration capability of a minimum standard core set of data elements such as:
 - Anonymous matching identifier(s)
 - Presenting diagnosis/condition
 - Description of services provided
 - Costs of services provided, or if not directly tabulated, number of service units provided with average cost per unit
 - Limited set (i.e. 4 to 6) of case-mix (“risk adjustment”) variables that correlate with severity of presenting diagnosis/condition.

2. **Improved Global Needs Assessment:** This recommendation refers to developing processes that monitor current and emerging need for MHSA services that reflect consumer preferences, as well as effective technologies. This may include, but is not limited to:

- Development of targeted and/or universal MHSA screening approaches.
- Methods and procedures to routinely identify individuals at risk of future MHSA problems.
- Methods to identify emerging trends in MHSA service utilization.
- Methods to continuously monitor the range of MHSA services needed by consumers.

The workgroup recommends that this effort be performed in conjunction with the contractor-developed Data Integration Plan (*see recommendation 1*).

A proposed output from this work would be the development of a Global Needs Assessment Strategy that details feasible and appropriate strategies for improving and monitoring public need for MHSA services. There should be special emphasis on needs assessment in non-primary settings (e.g. criminal justice system, primary care system, social services, school system, employment settings, etc.).

3. **Improved Performance Monitoring Systems:** This recommendation refers to the use of outcome measures that are appropriate for the level of the system that is being monitored and the purpose of the monitored program within the overall system of care. In particular, outcome measures must have a clinical focus (rather than political focus) that is appropriate to the particular mix of clients being served.

The workgroup recommends the development of a formal task force with the explicit mission of updating the current set of performance outcomes in use by DCF service providers. The

outcomes developed could also serve as a model for other service sectors. For maximum effectiveness, the task force must have broad representation from key stakeholders and interested parties. Minimally, this should include individual representation from the following:

- DCF program office
- DCF service providers
- Legislative personnel
- Practicing clinicians (without prior DCF involvement) and program-level treatment providers
- Researchers with expertise in MHSA treatment
- Consumers with past and/or current history of MHSA problems.

In addition, recommended guidelines for the task force development of the recommended set of performance outcomes include:

- A relatively brief yet appropriate period of performance for investigation and report development (e.g. not to exceed 6 months).
- Emphasis on clinically-oriented outcome measures, with societal measures being secondary and not the basis for evaluating the performance of district and agency level service providers. However, the recommended set of clinically-oriented performance measures should allow the ability to aggregate upward to measures more commonly desired by the legislature (i.e. societal indicators).
- A sound methodological basis for implementing performance-based budgeting down to the county level. Ideally, this will give local counties incentives to monitor quality of care at the agency level.
- Consistency with the best available scientific evidence for evaluating the effectiveness of MHSA service delivery.
- Emphasis on minimizing the data collection burden on service providers to the extent possible. For example, the task force might recommend the use of “abridged” forms of outcome measures to capture the minimum number of data elements needed for conducting meaningful analyses.
- Consistency with guidelines and efforts of other Government agencies including the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and the Mental Health Statistical Improvement Program (MHSIP).
- A mechanism for post-discharge evaluation of at least a fraction of all MHSA clients served.
- A mechanism that allows for systematic evaluation of individual treatment programs.

- Consideration of measures that assess level of functionality on a continuum, rather than strict dichotomous measures such as complete abstinence of substance use.
 - At least one measure that allows clients to evaluate and provide direct feedback on satisfaction with services received.
4. **Improved Information Accessibility and Dissemination:** This recommendation refers to enhancing the amount and quality of MHSA service-related information that is readily available and disseminated to the public, policymakers, and providers.

The Workgroup recommends that an organization/department be established with the primary responsibility of maintaining and disseminating information to the public and provider community on the locations, types of services, eligibility requirements, past performance and complaints, etc. of providers of MHSA services. In addition, the dissemination mission should have a strong focus on prevention activities. The organization may be formed within the infrastructure of current primary administrators of MHSA services in the state (e.g. DCF, ACHA), or preferably as a cabinet-level entity. Recommended responsibilities of the organization include the following:

- Make use of and coordinate with the network of local and district-level information referral providers.
- Identify and implement strategies for disseminating prevention materials.
- Maintain an up-to-date and comprehensive listing of Florida MHSA providers in the both the public and private sectors, as well as self-help groups.
- Be accessible via an 800 hotline number.
- Disseminate information using multiple media including print-based materials and a dedicated website.
- Facilitate quick and easy identification of appropriate service provision for consumers in need of MHSA services. For example, the website may include a search capacity that identifies relevant service providers by consumer-specified criteria such as location, presenting problem, eligibility requirements, etc.
- Be a resource for patient education on the diagnosis and treatment of MHSA disorders, as well as provider education on current best practice standards.