



THE GEORGIA PERFORMANCE INDICATOR PROJECT:

Measuring The Progress Of Reform

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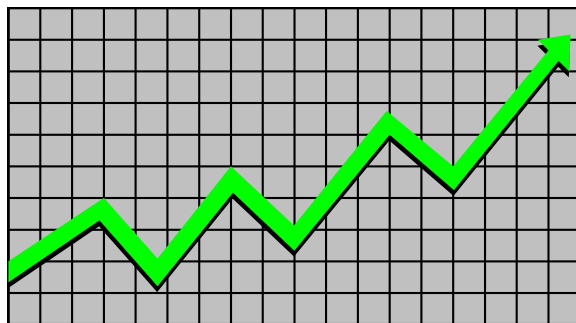
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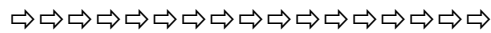
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CHAPTER 1



Overview of Performance Indicator Project and Activities

Background

The State of Georgia has taken a pioneering step toward systematic oversight of services and supports to people with mental illness, mental retardation, and substance abuse problems -- the development of performance indicators to assess trends, to chart the course of reform and to detect problems and potential obstacles to continued progress. Once implemented, Georgia will be the first state in the country to augment its quality assurance apparatus with a set of indicators reflective of the aspirations of people with disabilities and their families, providers of services and supports, and program administrators.

The State of Georgia, by embracing the course charted in *A Call for Change* (1992) and the provisions of House Bill 100 (H.B. 100), embarked on a course of action that significantly altered the way services and supports are provided to people with mental retardation, mental illness and substance use disorders. The changes that the system is undergoing reflect major shifts in service provision occurring around the country including decentralization of decision-making to a local level; the inclusion of consumers and family members in decision-making regarding planning and resource allocation; the adoption of the values of choice, self-determination and inclusion as valued outcomes, the encouragement of competition and choice among providers, and the adoption of a system of continuous quality improvement.

As noted above, the State's commitment to system change, however, goes beyond one-time system restructuring and reorganization. Georgia policy makers are also concerned about the ongoing performance of the reform. This concern springs from a desire to ensure the continuing viability of the changes, to generate the information necessary to make mid-course corrections, and to ensure the well-being of people supported by the system. To respond to these issues, the State of Georgia, in 1995, issued a Request for Proposal to develop a performance indicator system to assess the performance of the service system for people with mental illness, mental retardation, and substance abuse problems.

The following report, prepared by the Human Services Research Institute with assistance from the Institute for Health Policy at Brandeis University, outlines proposals for the creation of a performance indicator system to assist the State of Georgia to safeguard the important reforms currently taking root in the service system for people with mental illness, mental retardation and substance abuse problems.

Project Objectives and Working Assumptions

Project Purposes

The purposes of the quality indicator project were as follows:

- To develop a consensus among the various constituencies in the state regarding the major objectives of the system and those events, trends, and milestones most likely to capture progress toward the aims of the HB 100 reform;
- To create a series of proposed performance indicators that capture the major sentinel achievements of the reform;
- To assess the ability of the state's current management information system to generate data to assess performance on specific indicators and to develop baseline information;
- To develop instruments for the collection of data not currently available in the information system;
- To pilot test the instruments to determine their viability and applicability;
- To address the relevance of the indicators to proposed plans for managed care and to suggest additional indicators where necessary;
- To provide the State with recommendations regarding the implementation of a performance indicator system;
- To explore the application of performance indicators in a continuous quality improvement system.

Introduction to Performance Indicators

Major changes in the way services and supports for adults and children with disabilities are funded and organized require the creation of thoughtful and

innovative mechanisms to safeguard the well-being of people who rely on such supports. One of the methods currently being discussed in many states and at the federal level is the installation of “performance indicators” to monitor important individual and systemic outcomes.

In addition to system changes, such as those embodied in H.B. 100, a cost containment strategy like managed care requires the development of indicators that measure progress but that also provide information about quality compromises and other potential problems -- problems that may be linked to excessive cost cutting, inappropriate care criteria, inadequate practice guidelines, unanticipated economic effects on providers, the shifting of costs, and other negative events. There are a number of areas where such problems can be detected, such as health and safety, and changes in patterns of utilization. The continual monitoring of indicators in these areas should provide states with an “early warning” system regarding potential problems. Such a system will also necessitate the development of a continuous quality improvement process to ensure the appropriate corrective actions.

In addition to the need to protect against the negative impacts of cost-cutting, performance systems should also capture positive events. In surveying the 50 states regarding their quality assurance practices, HSRI found that 22 states were either in transition to an outcome-focused quality assurance system or had already taken significant strides in that direction. Half of the states surveyed have identified as key outcomes such characteristics as individualization, integration/inclusion, relationships/social connections, health and safety, personal growth, and self determination. Further, states will need indicators to monitor performance in a decentralized system of services. As in Georgia, decentralization is happening independently from the adoption of managed care.

Planners in the health, mental health, and nursing home/home health fields are well down the road to developing the national norms/standards needed for payers, consumers and families to assess the relative quality of the services provided by one agency compared to others. There are *the Health Plan Employer Data and Information Set (HEDIS and Medicaid HEDIS)* developed by the National Committee on Quality Assurance, performance indicators developed by the Foundation for Accountability, the *Nursing Care Report Card* developed by the American Nurses Association, and numerous other report cards developed by different health purchasing coalitions (e.g. Pacific Business Group on Health, Digital Equipment Corporation). In mental health, there are the *Performance Measures for Managed Behavioral Healthcare Programs* (AMBHA), disseminated by the American Managed Behavioral Healthcare Association, the *Mental Health Performance Indicators and Consumer Report Card* being framed by the Mental

Health Statistics Improvement Program (HSRI supported), and the *Mental Health Performance Indicators* developed by the Institute of Medicine.

In addition, the National Association of State Mental Health Program Directors is developing a set of mental health performance indicators; HSRI is doing the same in conjunction with county behavioral health care directors as well as with the National Association of State Directors of Developmental Disabilities Services. The Health Care Financing Administration has been supporting the development of performance indicators for home health care and for nursing homes for some time now. There are also a number of private organizations that collect and market HMO performance data to the field.

Increasingly, funding agencies (executive and legislative budget offices) are demanding that public managers furnish basic information that justifies the use of public dollars in performance and outcome terms. Moreover, state managers need better information in order to improve system performance through contract management. Requests for new dollars should emphasize community support strategies that hold the greatest promise in achieving system goals in the most economical fashion. System managers also need to know how their service delivery system stacks up against other systems across the country. If state human services officials are to manage effectively, they must have vastly more powerful and comprehensive performance/outcome indicator systems in place.

What is a Performance Indicator?

In order to select candidate indicators, project staff developed a profile of the desirable features of any performance outcome or indicator including the following:

- *Reflect major organizational or system goals:* Outcomes must be directly relevant to the central mission of the organization.
- *Address issues that can be influenced by the organization/system:* Outcomes should reflect activities that are to some extent within the control of the monitoring organization
- *Face validity:* The outcomes chosen should be relevant to the major concerns of the constituencies served by the monitoring organization.
- *Directional:* Another quality of outcomes or indicators is that they represent change over time. For instance, the numbers of consumers in segregated settings or who are at risk of abuse, neglect and exploitation decreases.

- *Rates or sentinel events:* An indicator or an outcome is usually expressed as a rate or a proportion. Using the above example, the rate would be the number of people represented in segregated settings compared to all service consumers.
- *Associated standards:* Many outcome/indicator systems include a standard or a goal for the attainment level of each element. These standards will grow out of applications in particular states.

There were also several other considerations that dictated the initial selection process:

- *Whose Voice?* As noted above, it is important to determine who will make the judgment about whether a particular outcome has been achieved.
- *Sound psychometric properties:* Any outcome measure should be a valid and reliable reflection of the target activity.
- *Clarity and objectivity:* Outcome measures should be clear, objective and quantifiable.
- *Simple implementation:* Collection of information regarding outcomes must be relatively easy and straightforward.
- *Low cost:* The development of any outcome system must weigh the costs of administration as well as the burden on administrative staff and respondents.
- *Utility to service functions:* Outcomes selected should have direct relevance to the specific functions of the service system.
- *Easily interpretable:* Each potential outcome measure should be assessed in terms of the ease of interpretation of the resulting data. If the outcome measure is too complex or includes more than one idea, then it may be difficult to determine what the data mean.
- *Culturally competent:* Outcomes should reflect a broad range of minority and cultural concerns.

Project Approach and Methodology

To complete the project eight activities were undertaken: a) assessing the context; b) developing proposed indicators; c) canvassing existing data sources;

d) developing data collection instruments; e) conducting a pilot test; f) assessing the applicability to managed care; g) exploring the application of performance indicators in Georgia; and h) preparing final recommendations for implementation and analysis.

Assessing the Context

The first step in the process of developing performance indicators for the State of Georgia was to develop an understanding of the policy context in the state through interviews with key informants in the system, and to review policy documents, reports and legislation. Specifically, staff carried out the following activities:

- Meetings were held with a range of individuals and organizations including Regional Directors and Regional Chairs, representatives of the Coalition for Change, 811 Commission members, DHR management team, private providers, community service board directors, and other advocates, providers and administrators.
- A review of regional plans and contracts was carried out in order to determine the types of outcome expectations that were being developed by regional boards.
- The HB 100 legislation, 811 Commission reports, and plans for specific disability groups in the state were reviewed to determine the central features of the reform and the key aspects of the vision for the next several years.

Developing Proposed Indicators

Because of an expressed need on the part of regional directors regarding the immediate need for information on outcomes, project staff developed a compilation of indicators that had been developed nationally and in other states as a preliminary technical assistance resource.

Based on the values and principles in the HB 100 legislation and the priorities for system enhancement that grew out of the key informant interviews, staff prepared a preliminary exhaustive list of indicators using the criteria (e.g., directionality, measurability, etc.) noted above. This preliminary document was shared with the DHR management committee and with the 811 Commission. After their review, the list of indicators was significantly reduced and organized into three general areas: Quality of Life, Accountability and Responsibility, and Resource Utilization. The choice of these three areas was based on the major

themes of H.B. 100 legislation. The areas were then divided into specific domains as noted below:



QUALITY OF LIFE ISSUES

- | | |
|-----------------------|--------------------------|
| 1) Jobs and Education | 4) Health and safety |
| 2) Housing | 5) Community connections |
| 3) Independence | 6) Choice |

ACCOUNTABILITY/RESPONSIBILITY: ISSUES

- | | |
|--|-------------------------------------|
| 1) Consumer and family grievances | 4) Consumer and family empowerment |
| 2) Provider accountability | 5) Responsiveness to local concerns |
| 3) Decentralization of decision-making | 6) Service Coordination |

RESOURCE UTILIZATION: ISSUES

- | | |
|--|--|
| 1) Reallocation of funds to community services | 3) Interagency collaboration |
| 2) Maximization of resources | 4) Access to Services |
| | 5) Resource allocation for state-of-the-art services |



This outline was further fleshed out to include specific areas of concern under each domain, one or more indicators for each concern, and measures and sources for information for each indicator. After a review by the management committee and the 811 Commission, additional revisions were made.

The draft of indicators was then made available to all regions and regional boards in anticipation of the conduct of 15 workshops around the state. Approximately 604 persons attended the workshops including consumers and families; regional directors and board members; CSB directors, staff and board members; private providers; representatives of advocacy organizations; and members of the general public. Each participant at the workshops was asked to rank the indicators in terms of their importance and relevance to the reform (See the Appendix A for materials available at the workshops as well as the ranking sheets). Copies of the indicators and ranking sheets were also sent to key advocacy and provider organizations in the State.

Rankings by workshop participants were tabulated and tables indicating the relative priorities were prepared. Total tallies were generated in addition to tallies by region, by affiliation, and area of interest. The results of the workshop and ranking were presented to the 811 Commission in April, 1996.

In addition to the selection of indicators, the Commission determined that, given feedback from major advocacy organizations, that there was a need to conduct some limited focus groups to ensure that the specific interests of people with substance abuse problems, children and families, and people with severe physical disabilities were covered in the final indicator set. As a result, the HSRI scheduled focus groups for early May. A fourth focus group, concerns of providers, was also added in response to concerns from a member of the DHR Board.

In determining criteria for selection, it was decided that the top five indicators in each category would be chosen in addition to: 1) one additional indicator in those domains where an indicator was not voted a top priority (e.g., health and safety); 2) indicators of obvious interest where the state was already collecting -- or was proposing to collect -- data (e.g., emphasis on the consumer and minority representation on regional boards and CSB boards); 3) an indicator reflecting the performance of service coordination; and 4) indicators that affect a particular

constituency where the constituency gave them a high priority (e.g., regional board members are satisfied with regional planning).

Commission members also reinforced the importance of the consumer survey as a means of ascertaining the satisfaction of people receiving services and their families. The Commission agreed that the only way to determine whether the quality of the lives of service recipients is improved is to ask them directly; there are no other proxy measures that are as direct and powerful.

Following the conduct of the four focus groups, final revisions were made to the indicators in preparation for the pilot tests. Under Quality of Life, six domains, twelve concerns and fourteen indicators. Examples of draft indicators are:



- **Jobs and Education**

Concern: The system supports people to find and maintain employment that is commensurate with their skills and that is in integrated settings.

Indicator 1: (For MH and DD) The proportion of consumers working in integrated employment settings increases.

Measure: Analysis of trends in the distribution of consumers, by disability and age, working: 1) in full-time employment; 2) part-time employment; 3) full time in supported employment; 4) part-time in supported employment.

Source of Information: Consumer and Family Survey.

Indicator 2: The proportion of consumers in recovery from alcohol and drug dependence who report that their employment is consistent with their skills.

Measure: The number of consumers in recovery who report that their employment is consistent with their skills compared to all people in recovery reporting.

Source of Information: Consumer and Family Survey

Concern: The system supports children to remain in school.

Indicator: The number of school days lost related to disability decreases.

Measure: The number school days lost during the preceding semester by age and disability.

Source of Information: Consumer and Family Survey.

With respect to Accountability and Responsibility issues, six domains, eight concerns and ten indicators were developed including the following: examples:



- **Decentralization of Decision-Making**

Concern: The regional boards set policy and direction for the regional service system.

Indicator: Regional board members express satisfaction with their ability to influence policies and set directions for the regional service system.

Measure: The number of regional board members expressing satisfaction with their ability to set policy and influence direction compared to the total number of regional board members reporting.

Source of Information: Regional board member survey.

Concern: The composition of the regional and community service boards meets or exceeds the requirement for consumer and family participation.

Indicator 1: The proportion of the regional board members who are primary consumers and family members by type of disability. (18)

Measure: The number of people on the regional board who are consumers and family members compared to all people on the regional board, by disability .

Source of Information: State database being developed.

Finally, in the resource utilization area, five domains, eight concerns and eight indicators were developed, including:



- **Access to Services**

Concern: Consumers and families are able to secure services when and where needed.

Indicator: The proportion of consumers reporting that they are able to secure quality services when and where needed.

Measure: The number of consumers reporting that they are able to secure services when and where needed by age and disability compared to all consumers reporting.

Source of Information: Consumer and Family Survey.

Concern: Services are available to consumers who meet the definition of most in need.

Indicator: The proportion of consumers who meet the definition of Most in Need.

Measure: The numbers of consumers who meet the definition of Most in Need compared to the number of consumers served by age and disability.

Source of Information: MIS.

Concern: Children under 18 and their families have ready access to services when needed.

Indicator: The number of children under 18 receiving services increases.

Measure: The number of children under 18 receiving services by disability and age.

Source of Information: State management information system.

Canvassing Existing Data Sources

Once a final draft of indicators was developed, a major task was to assess whether there was sufficient data in the existing management information system to serve as a baseline for some of the performance benchmarks. Through a series of conference calls and in person meetings, HSRI staff worked with DHR MIS staff to assess the viability of existing sources and to think collaboratively about the ways in which protocols could be altered and data could be analyzed and portrayed. The results of this process are included in Chapter 2 of this report.

Developing Data Collection Instruments

For many of the indicators in the draft set, there were no existing data (e.g., The number of consumers reporting that they are able to secure services when and where needed by age and disability compared to all consumers reporting). To provide the state with the tools necessary to collect performance data, HSRI developed three draft instruments: 1) a consumer and family survey (described in Chapter 3); 2) a stakeholder survey (described in Chapter 4); and 3) a regional board survey (described in Chapter 5).

Conducting a Pilot Test

In order to assess the viability of the draft instruments, a pilot region, the Northeast Georgia Region, was selected. The participation of the regional director, regional board, and community service board was critical to the success of the pilot process and their feedback and assistance were invaluable. Participants from the pilot site assisted in reviewing the draft indicators and made suggested revisions, worked with HSRI to select a small consumer and family sample to test the utility of the consumer survey, reviewed the content of all three surveys, and provided information on continuous quality improvement and outcome monitoring activities going on in the Northeast Georgia Region. The pilot lasted approximately six months beginning in June 1996 and ending in November 1996.

Assessing the Applicability to Managed Care

Like many states, policy makers in Georgia are also considering ways of reorganizing the way that services to people with mental illness, mental retardation and substance abuse problems are financed through Medicaid and are exploring possible managed care options in mental health and substance abuse through an 1115 waiver as well as increased flexibility in mental

retardation through a 1915 (b) waiver. During the course of this project, these plans became more concrete and performance indicators geared specifically to managed care were also developed. In work with the Behavioral Health Planning Unit (BHPU), HSRI staff carried out the following activities:

- BHPU staff were provided with a compilation of existing indicators used at the federal level and other states to oversee managed behavioral health care.
- A meeting was held with representatives of BHPU, the Division of MH/MR/SA, and the Medicaid agency to explore additional indicators for a managed care system.
- A concept paper was prepared for BHPU laying out the major concerns in the development of performance indicators in a managed care setting (see Appendix B).
- A series of meetings was held with BHPU to develop indicators for managed care in addition to those outlined in the draft H.B. 100 indicators.
- A final report addressing the specific concerns of BHPU was prepared.

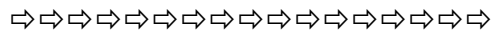
Exploring the Application of Performance Indicators

The development of a performance indicator system must be accompanied by a process for applying the information in a quality enhancement structure. Unlike typical quality assurance systems that rely on compliance and plans of correction, the use of performance indicators is an integral part of a continuous quality improvement system. Recommendations for such a process are included in Chapter 6.

Preparing Final Recommendations for Implementation and Analysis

The final task in the development of performance indicators for Georgia is the preparation of a final report and the submission of final recommendations for technical implementation as well as the use of the indicators in ongoing policy analysis and program evaluation. Chapter 7 of this report includes recommendations for the creation of a performance indicator system and the maintenance of the system over time.

CHAPTER 2



Analysis of Existing Data Sources Available to Assess Performance

Introduction

This chapter provides information regarding the viability of using existing sources of data collected by the State of Georgia to assess the performance based on specific HB 100 indicators. In order to prepare this analysis, project staff worked closely with the management information staff of the Division of Mental Health, Mental Retardation, and Substance Abuse at the Georgia Department of Human Resources, as well as with staff in other agencies including the Departments of Education and Corrections and the University of Georgia. The names of those individuals who assisted in the analysis are included in the Appendix.

As part of this analysis, a pre-test was conducted during the summer and early fall of 1996. The pre-test involved generating data from the potential data bases based on specifications keyed to the content of each relevant performance indicator. Data was then assessed to determine whether the information was in fact consistent with the specifications and whether changes in the manner of data collection and/or analysis would be required.

As noted in Chapter 1, each of the final indicators selected for inclusion in the final set of HB 100 performance measures was initially assessed to determine the most appropriate source of performance data. Based on a review of existing data collection instruments and interviews with management information staff, it was determined that 18 of the indicators across the three domains could be assessed using existing data. The following discussion describes the suggested data sources for each indicator, a description of the data set, analytic and substantive concerns, results of the pre-test, timing of data collection where relevant, and recommendations for implementation. The concluding sections notes other data sources consulted.

Part 1. Quality Of Life Issues

4. Health and Safety

Indicator 2: The proportion of youth reporting decreased access to alcohol and tobacco during the reporting period.

Measure: The number of adolescents aged 12-17 who report that it is more difficult to obtain alcohol and tobacco from retail outlets by region.

Recommended Data Sources:

Short-Term: University of Georgia Alcohol and Other Drug School Survey

Long-Term: Georgia Department of Education's Safe and Drug Free School Program (See "Other Data Sources Examined" for description of this data source)

Description of Recommended Data Sources:

University of Georgia Alcohol and Other Drug School Survey:

Under the auspices of the Department of Human Resources, Division of Mental Health, Mental Retardation and Substance Abuse, the University of Georgia is conducting a statewide survey of students in Georgia's public schools this Fall. The survey is targeting approximately 32,544 randomly chosen students from five grades: 4, 6, 8, 10 and 12. The sample is comprised of one elementary, middle and high school from each school system in Georgia. The sample includes forty students from each of the five grades surveyed in each school system. The number of school systems in each town/city vary. For example, Atlanta has approximately 25 school systems.

The survey will employ two instruments: one for fourth and sixth graders; and the other for adolescents ages 12- 19 plus. (See Appendix A for survey instruments) The instruments include the following questions which are a good "data match" for measuring this indicator. For fourth and six graders, there is one question- number 9 " Tobacco products are easy for me to buy". Answer: true/false; for the adolescents, there are two questions :

- Number 38 -- "How do you usually get the cigarettes or tobacco products that you use? " Mark all that apply. Answers: 1) I don't smoke; 2) I buy them myself from a store; 3) I buy them myself from a vending machine; 4) I get them from a friend or relative my age; 5) I get them from an older friend or relative; 6) I get them from a parent or adult; and 7) Other source.
- Number 39 --" How do you usually get the alcohol that you use?" Answers: 1) I don't drink alcohol; 2) I buy it myself from a store; 3) I get it from a friend or relative my age; 4) I get it from an older friend or relative; 5) I get it from a parent or adult; and 6) Other Source.

There are no plans to conduct the University of Georgia's Alcohol and Other Drug School Survey on an annual basis.

Georgia Department of Education's Safe and Drug Free School System Survey.

The Department of Education's Drug Free School Program has recently been required to conduct an annual survey of students. The first survey was conducted in April 1996. (See Appendix for survey) The first survey did not include questions on accessibility of alcohol and tobacco. All future surveys will be conducted in January of each year beginning in 1997. The sample targets all 180 public school systems in Georgia and focuses on students in grades 5, 8 and 10. It is expected that approximately 150 out of the 180 school systems will participate on an annual basis. Students will need to have parental consent to participate. For future surveys, total sample size is expected to exceed 32,000.

The coordinator of this survey and the individuals involved with the University of Georgia survey including DMHM RSA staff have been working collaboratively on school survey issues. Given the close working relationship between these prevention professionals and the fact the federal grant already requires some collaboration between the Department of Education and the Department of Human Resources, it is recommended that the DMHM RSA collaborate with the Georgia Department of Education to collect the data needed for this indicator on an ongoing basis. Specifically, we recommend that the two questions from the University of Georgia Survey being used to measure this indicator be incorporated into the annual Safe and Drug Free School Program during the next survey period.

Analytical & Substantive Considerations:

The samples from both the University of Georgia Alcohol and Other Drug School Survey and the Department of Education's Safe and Drug Free School Survey are large enough to conduct regional analyses for this indicator. Because of the sample's composition, the findings on accessibility of alcohol and tobacco from both surveys can only be generalized to youth in school. However, as the majority of prevention efforts for youth target adolescents in school (before drop out occurs), data from school surveys provide useful information for both planning prevention services and for measuring the impact of prevention and intervention services.

The University of Georgia's survey includes additional questions that appear to be relevant to this indicator which should not be used unless changes are made to these questions. Currently on the survey for the 4th and 6th graders # 11 asks students who reported they had never tried alcohol, tobacco, and other drugs to check a series of reasons they had not used drugs including "I do not know where to get drugs" Number 35 on the survey for adolescents asks students who similarly reported that they had not used alcohol, tobacco, or other drugs to check a series of reasons they had not used drugs including: " I do not know where to get drugs". In addition, this survey also asks students who reported using alcohol, tobacco, or other drugs to check all the reasons they do use drugs including " Drugs are Easy to Get."

These questions on how easy it is to get drugs are limited in interpretation as it is clear the survey lumps alcohol, tobacco and other drugs under one category -- drugs. A separate question on access is really needed for each substance in order to understand from what perspective the student answered. For example, does the answer mean the student does not know where to get all three substances or does not know where to get one or two of the substances. The University of Georgia Survey staff are working on resolving the problems with these questions which already appear on the printed surveys.

Timing of Data Collection:

The University of Georgia Alcohol and Other Drug School Survey was conducted in September 1996. The preliminary results are therefore available and can be used as baseline information for the indicators.

The Georgia Department of Education's Safe and Drug Free School Program is being conducted annually in January. Survey results are available the following May.

Pretest Findings:

Because the University of Georgia Alcohol and Other Drug School Survey was only conducted in September 1996, data were not available for this pretest. However, the specific data needed to measure this indicator have been delineated and are described in the previous section of this report. These data will be available in late October.

Recommendations:

1. DMHM RSA request that the University of Georgia provide the specific data needed as a baseline for measuring this indicator. It is further recommended that DMHM RSA request assistance in interpreting the data from survey staff. This assistance should include recommendations, if any, for improving the survey questions used for collecting the data.
2. The Department of Education's most recent Drug Free School System Survey was scheduled for January 1997. As soon as possible DMHM RSA should begin negotiating with the Georgia Department of Education to have the data needed for this indicator collected on the annual Safe and Drug Free School System Survey. It is further recommended that the DMHM RSA prevention staff and the Department of Education staff, who are already working collaboratively, develop and implement this agreement.
3. If the wording of the questions used to collect the data for this indicator are changed for the January 1997 survey, the impact on the baseline needs to be considered. For example, if more adolescents report either an increase or a decrease in access to either alcohol or tobacco, is the change due to the change in the wording of the question or to a change in accessibility of the substances?

Part 2: Accountability/Responsibility Issues

1. Consumer and Family Grievances

Indicator 1: Providers respond to grievances within time limits established through contracts with the regional board.

Measure: The number of grievances resolved within the specified period of time compared to all grievances filed, by type of grievances, and by age and disability.

Recommended Data Source:

Short-Term: Regional Board Records. Recommendations for implementing data collection efforts for this indicator are described under "Analytical & Substantive Considerations."

Long-Term: SOARS (Statewide Operational and Administrative Regional System) which is the new computerized Regional Database.

Description of Recommended Data Source:

Each Regional Board would implement language in provider contracts specifying the time limits for the resolution of grievances.

Analytical & Substantive Considerations:

The procedures for submitting and resolving a grievance are fairly straightforward. They are described in the three attachments: 1) Rules and Regulations for Patient's Rights (for hospital consumers); 2) Rules and Regulations for Client's Rights (for community consumers), and 3) Memorandum on Interim Patient/Client Rights Procedures from Carl E. Roland dated November 1, 1995.

These procedures, however, do not require reporting all grievances, which are filed or resolved, to a central or regional data bank. Consequently, at this point in time it is almost impossible to get accurate data on the number of grievances that occur in each Region or the number that occur statewide.

In order to collect accurate data on the number of grievances that are resolved within a specific period of time, regional boards will need to develop contract language that stipulates policies and practices for addressing grievances at the provider level. To collect accurate data for this indicator on a long-term basis, it is recommended that Regional Boards report statistics from providers regarding resolutions to the SOARS, the new computerized regional database.

In addition to holding providers accountable for the resolution of grievances during a specified period of time, Boards should also develop procedures regarding those grievances -- either because of their gravity or because of a failure to resolution the grievance in a satisfactory fashion -- that should be brought to the Regional Board for discussion and recommendations.

2. Provider Accountability

Indicator 1: The Regional Board carries out a review of the attainment of goals by each provider at the conclusion of each contract year and takes appropriate action.

Measure: The number of contracts reviewed by the Regional Board each year compared to all regional contracts.

Recommended Data Source

Regional Board records and minutes, and Regional Board survey.

Analytical and Substantive Considerations

The initial indicator in this section addressed the Regional Boards response to contract exceptions and failures of compliance. Discussions with staff at the pilot site in Athens strongly suggested that this indicator was both unwieldy and unlikely to generate relevant information. The above language was suggested in order to encourage Regional Boards to conduct systematic reviews of contract performance on a yearly basis exploring levels of accomplishment with specified outcomes, potential constraints, and necessary revisions of the subsequent year's expectations. This process, which should be part of any regional continuous quality improvement procedure, would involve regional board members in program oversight and would ensure state funders that the accomplishment of outcomes for people were reviewed on a systematic basis.

In preparation of its annual plan, each regional board should report on the contract performance review process. In addition, the regional board survey should request feedback from regional board members regarding the effectiveness of the contract review process and the extent to which members of the boards were provided with sufficient information and background to make substantive observations that in turn led to enhance of provider performance.

Pre-Test Findings

Discussions with staff in the Athens pilot indicated that such reviews were in fact carried out and that a more systematic process would be productive and would contribute to enhancement of system performance.

3. Decentralization of Decision-Making

Indicator 1: The proportion of the Regional Board members who are primary consumers and family members by type and disability (compared to all people on the regional board, by disability).

Measure: The number of people on the Regional Board who are consumers and family members compared to all people on the Regional Board, by disability .

Indicator 2: The proportion of Community Service Board members who are primary consumers and family members by type of disability (compared to the all people on the CSB, by disability).

Measure: The number of people on Community Service Boards who are consumers and family members compared to all people on the Community Service Board, by disability.

Indicator 1: The proportion of Regional Board members who are representative of the cultural and social composition of the region (compared to the cultural and social composition of the region).

Measure: The proportion of Regional Board members who are representative of cultural and social composition of the region compared to the cultural and social composition of the region.

Indicator 2: The proportion of Community Service Boards members who are representative of the cultural and social composition of the region (compared to the cultural and social composition of the service area).

Measure: The proportion of Community Service board members who are representative of the cultural and social composition of the service area compared to the cultural and social composition of the region

Recommended Data Source:

- Short-Term: a. Database developed by Regional Operations Support Services Staff
b. Census Data

- Long-Term: a. SOARS (Statewide Operational and Administrative Regional System)
b. Census Data

Description of Recommended Data Source:

Regional Operations Support Services Database:

George Johnson collected some of the data needed to measure this indicator and developed a database for storing and retrieving the data. In order to facilitate data collection for these indicators on Regional and CSB membership, four data collection instruments were developed by HSRI staff for use in the pretest in the Athens' Region: 1) Community Service Board Membership by Consumer/Family Status and Disability Orientation; 2) Community Service Board Membership by Race/Ethnicity; 3) Regional Board Membership by Consumer/Family Status and Disability Orientation; and 4) Regional Board Membership by Race/Ethnicity. The instruments on race/ethnicity employ the same race/ethnic categories used on the DMHM RSA MIS data collection forms. (See Appendix)

Census Data:

Census data are available at the Central Office on the following six racial/ethnic categories by region and CSB catchment area: 1) White; 2) Black; 3) Native American/Alaskan; 4) Asian; 5) Other and 6) Hispanic.

More detailed racial/ethnic categories, which more closely match the race/ethnic categories used in the DMHM RSA's Management Information data collection forms, are available through the State of Georgia Office of Planning and Budget. These categories are: 1) Chinese; 2) Japanese; 3) Korean; 4) Vietnamese; 5) Other Asian; 6) Black; 7) Cuban; 8) Mexican American; 9) Puerto Rican; 10) Other Hispanic; 11) American Indian; 12) Alaskan Native; 13) White; 14) Multi-Racial; and 15) Unknown.

SOARS Data on Board Memberships

SOARS includes a platform for storing and retrieving data on Regional Board membership including all the data needed to measure the four indicators on Board Membership. To date the platform is incomplete as data related to Regional Board membership are still in the process of being collected and loaded into SOARS. Although the SOARS does not currently include a platform for CSB Board membership, plans have been developed for the inclusion of this platform in the SOARS.

Analytical & Substantive Considerations:

Due to the relatively small numbers of certain racial/ethnic groups in Georgia combined with the lack of resources for accessing detailed Census data, it will be necessary to compare Board Memberships with census data according to six major race/ethnic categories as opposed to 15 categories (The categories are listed above under Recommended Data Sources). However, it is advisable to collect the data on the boards' race/ethnic composition according to the 15 categories that are comparable to the categories collected by DMHM RSA's MIS. This will allow for comparisons between the population served by DMHM RSA and Board Membership. In addition, when Census data is more accessible, it allows for more detailed comparisons between the racial/ethnic compositions of Boards and the populations represented by the Boards.

The data on number of Hispanics served in DMHM RSA funded programs need to be interpreted carefully. In the data collected by DMHM RSA, the category of Hispanic is not mutually exclusive meaning that an individual with Hispanic

ancestry is coded as belonging to both a particular racial group as well as belonging to the Hispanic ethnic group. Moreover, it is not possible to determine how many individuals reported as having Hispanic ancestry are reported as being White, Black, or as any other racial category.

Timing of Data Collection:

Until the SOARS collects these data, the data needed for measuring the four indicators on Boards should be updated at least annually because of on-going turnover in membership. While the data are being collected by survey as opposed to by the SOARS, it is recommended that the data be collected between mid-June and mid- July. The majority of Board changes occur over the summer months, and by mid-June the Regional and CSB Offices know the names and characteristics of new Board members.

When the SOARS module on Board membership is complete and operational, Boards will be able to update their membership on an on-going basis as changes in membership occur, thus eliminating the need for updating by survey.

Indicator 1: The proportion of the Regional Board Members who are primary consumers and family members by type and disability (compared to all people on the regional board, by disability).

Source of Pretest Information:

Regional Board Records/Regional Executive Director

Pretest Findings:

The pretest data for this indicator appear in Table A. As shown in Table A, the Northeast Regional Board has 11 members. The overwhelming majority (72%) of Board members are either family members or consumers. Almost half (45%) are family members and slightly over one quarter (27%) are consumers. The remaining Board members (27%) are neither family or consumers.

An analysis of consumer/family status by disability orientation reveals that the largest proportion of consumers/family members have a Mental Health

disability orientation. Four of the 11 members represent consumer/family members with a Mental Health orientation. In comparison, 2 out of 11 members represent family members with mental retardation and 2 out of 11 members represent consumers with a substance abuse orientation.

Implications/Discussion:

This indicator is useful for monitoring compliance with HB 100's goal which requires a high level of consumer and family involvement in planning, implementing and monitoring comprehensive services. The data establish that consumers and family members are well represented on the Athen's Regional Board. These data provide a baseline for monitoring continued compliance and assessing relative participation among the different disability groups. When representation is disproportionate, Boards should prioritize underrepresented groups for vacancies.

Recommendations:

The following recommendations recognize that Regional Boards and their Executive Directors can not dictate but can influence Board membership. (Board membership is based on at least one representative from each county within the Board's catchment area and the appointment is made by the County.)

1. The Regional Board should develop a long-term plan for Board membership that includes objectives (i.e. specific targets) according to projected vacancies for proportional representation by: consumers and family member status; disability orientation and race/ethnicity.
2. This year's data should be used as a baseline to measure progress in both achieving and then maintaining the goals established in the long-term plan in subsequent years.
3. Lack of progress in achieving targets should be assessed in terms of documented efforts made to influence appointments to the Board. For example, if the Board was unsuccessful in achieving its objective to increase substance abuse representation, but had formally requested a county with a vacancy to appoint a recovered substance abuser to the Board (and even provided the County with the name of a good candidate) then the Board's efforts to implement the target should be interpreted positively.

4. The data collection form developed for this indicator needs to be revised to include a row for vacancies. A designated space for reporting the date the form was completed also needs to be added.
5. The issue of non voting members needs consideration. It is recommended that non voting members not be included in the assessment of how well Boards are doing in accomplishing goals for participation. The data collection form needs to be revised to reflect this recommendation. This could be accomplished by adding a note on the form about not including non voting members.
6. It is recommended that as long as information on Board composition is collected by use of a paper form, either: a) the Board name and identification number should be completed (filled in) before giving the form to the regional office to complete; or b) the regional office should be provided a master list of identification numbers along with the request to complete the form.

Indicator 2: The proportion of Community Service Board Members who are primary consumers and family members by type of disability (compared to the all people on the CSB, by disability).

Source of Pretest Data Information:

Community Service Board Records and CSB Executive Director by means of George Johnson.

Pretest Findings:

The pretest data for this indicator appear in Table B. As shown in Table B, at the time of data collection, there had been three vacancies on the CSB resulting in a total of 11 as opposed to 14 members for this analysis. Among the 11 members, the overwhelming majority (72%) of the CSB members are either family members or consumers. Similar to the Regional Board, almost half (45%) are family members and slightly over one quarter (27%) are consumers. The remaining (27%) members are neither family or consumers.

An analysis of consumer/family status by disability orientation shows that there is a relatively even balance in representation by disability with Mental Health, Mental Retardation and Substance Abuse respectively represented by 3 out of 11, 3 out of 11, and 2 out of 11 members.

Implications/Discussion:

As noted in the discussion of the previous indicator, this indicator is useful for monitoring compliance with HB 100's goal for high levels of consumer and family involvement in planning and implementing consumer oriented services. While the data establish that: 1) consumers and family members are well represented on the CSB and 2) there is a relatively even balance in disability representation on the CSB, the new appointments for the three vacancies could alter both of these findings.

Recommendations:

- 1-6. The six recommendations made for the previous indicator (on consumer/family representation on the regional board) apply to this indicator.
7. In addition, the pretest revealed the need to consider the impact of vacancies on the measurement of all indicators focusing on Board memberships. The data collection form should be revised to indicate that if it is known who will fill a vacancy within the next two months, the data on the new member should be reported on the form.
8. The form should also be revised to include a few questions about the vacancies that warrant consideration in assessing Board membership including:
 - a. How long has the particular Board position/s been vacant?
 - b. If any position has been vacant for more than two months, why has the position remained vacant?
 - c. What specific steps have been taken to fill the position/s vacant for more than two months ?
 - d. Is the vacancy targeted for an individual with specific characteristics, e.g. gender, consumer/family status, race/ethnicity? If yes, describe.
 - e. What are the biggest barriers to filling positions vacant more than two months ?

Indicator 1: The proportion of Regional Board members who are representative of the cultural and social composition of the region (compared to the social and cultural composition of the region).

Source of Pretest Information:

Regional Board Records/Regional Executive Director

Pretest Findings:

The pretest data for this indicator appear in Table C. As shown in Table C, approximately one in five (21%) residents in the region are African American. One percent of the residents are of Hispanic origin and approximately another 1 % are of Asian/Pacific Islander ancestry. Thus, collectively Whites and African Americans account for 98% of the Region's population. This fact is reflected in the composition of the Board.

Nine of the 11 (82%) Regional Board members are White which is somewhat higher than the proportion (77%) of Whites residing in the Regional catchment area. In comparison, African Americans which comprise the largest group (21%) of racial minorities in the Region, are somewhat under represented on the Board with 2 of the 11 (18%) members.

Implications/Discussion:

Although the Region's racial/ethnic diversity is primarily limited to African Americans, the Regional Board data indicate a slight under representation of this group. The data also suggest that the Board should consider increasing its diversity by including a member with either Hispanic or Asian/Pacific Islander ancestry.

Recommendations:

The recommendations outlined above for the previous indicator apply to this indicator.

Indicator 2 The proportion of Community Service Boards members who are representative of the social and cultural composition of the service area (compared to the social and cultural composition of the community service area).

Source of Pretest Information:

Community Service Board Records and CSB Executive Director by means of George Johnson.

Pretest Findings:

The pretest data for this indicator appear in Table D. As noted previously, at the time of data collection, there had been three vacancies on the CSB resulting in a total of 11 as opposed to 14 members for this analysis.

The catchment area for this CSB is the same as the catchment area for the region. As described previously, African Americans comprise the largest group (21%) of racial minorities residing in the region, and collectively Whites and African Americans account for 98% of the regional population.

The data on CSB membership reveal that slightly over one-third (36%) of the members are Black which is higher than the proportion (21%) of this group in the catchment area. In comparison, Whites comprise nearly two-thirds (64%) of the Board which is lower than the proportion (77%) of this group in the catchment area.

Implications/Discussion:

Although the data establish that Blacks are currently well represented on the Board, the three new appointments to the Board for the three vacancies could affect their level of representation. This finding again highlights the need to collect more information on the nature of vacancies as well as the Board's long-term plan for the composition of the Board. The adequacy of any particular group's representation on the Board can only truly be assessed by comparing levels of representation to established targets for representation. The Board should consider establishing targets that increase its diversity which in this case could be achieved by including a member with either Asian/Pacific Islander or Hispanic ancestry.

Recommendations:

The recommendations outlined above for the other indicators on Boards apply to this indicator.

5. Responsiveness to Local Concern:

Indicator 2: Regional Boards fund community prevention initiatives, in partnership with schools, churches, civic groups, law enforcement, and business, and use multiple prevention strategies to address at-risk populations.

Measure: Number of prevention grantees and dollars allocated to prevention per region with counts of programs by a) population risk category, b) age/race category, and c) prevention strategy.

Recommended Data Sources:

Prevention Provider Reporting Forms developed by the Division of Mental Health, Mental Retardation, and Substance Abuse Services

Regional Board Contract Records.

Description of Recommended Data Source:

This reporting form is a new data collection tool being implemented by DMHM RSA's prevention unit. The form provides information on each prevention grantee and identifies the at-risk populations addressed in the program, the number of individuals served by age and race categories, and the prevention strategies used in the program (see Appendix D). The number of forms received provides a count of the prevention grantees and Regional Board contract records will provide detail on the amount of awards.

This data collection tool focuses on the 11 high risk groups defined by CSAP and the seven prevention strategies required by CSAP. The high risk groups are: 1) children of substance abusers; 2) pregnant women/teens; 3) drop-outs; 4) violent and delinquent behavior; 5) mental health problems; 6) economically disadvantaged; 7) physically disabled; 8) abuse victims; 9) already using substances; 10) homeless and/or runaway youth; and 11) Other, specify. The strategies are: 1) information disseminating; education; alternatives; 4) problem identification and referral; 5) community-based process; 6 environmental and 7 other strategies.

Eight race categories are collected: 1) White; 2) African American; 3) Hispanic; 4) Native American/Alaska Native; 5) Asian/Pacific Islander; 6) Multiracial (including White); 7) Multiracial (excluding White); and 8) Unknown. The following six age categories are also collected: 1) 5 years old or less; 2) between 6-

12 years old; 3) between 13-19 years old; 4) between 20-34 years old; 5) between 35-55 years old; and 6) 56 years old or older.

Analytical & Substantive Considerations:

This form is designed to reflect federal regulations on expenditures of funds from the Substance Abuse Prevention and Treatment Block Grant for prevention services. Thus, it monitors the areas designated by the Center for Substance Abuse Prevention and may not capture evolving approaches to prevention.

Approximately \$1,000,000 are currently allocated to community prevention efforts. Much of the prevention set-aside currently is used to support other types of services.

Source of Pretest Information:

Prevention Provider Reporting Forms developed by the Division of Mental Health, Mental Retardation, and Substance Abuse Services to monitor prevention programs in each region. Supplemented with information on contract awards.

Pretest Findings:

Information from the pretest analysis is summarized in Table E and Table F. The count of programs and funds for each program indicates that seven prevention services were funded for a total commitment of \$75,698. All of the funds were from federal resources; two-thirds of the funds were from the prevention set-aside in the Substance Abuse Prevention and Treatment Block Grant (\$50,196); the remainder was allocated from the federal award for Safe and Drug Free Schools. Funding varied between \$4,000 and \$15,000; the mean funding per contract was about \$11,000.

Prevention Provider Reporting Forms were obtained for five of the seven contracts. (Note that one of the five contracts provided four reports - one for each county where it provided services; the four reports from the same contract were aggregated for this analysis). The five contracts for which reports were available indicated that 592 individuals received services. Three of the programs identified their main priority population as economically disadvantaged individuals; children of substance abusers and students with academic failure were prioritized by the two remaining programs. All five of the services

Prevention Participants by Age and Race Categories

Race	Age Category				Total	Percent
	0-5	6-12	13-19	20-24		
White	1	18	98		117	19.8
African - American	5	301	140	5	451	76.2
Hispanic		8	4		12	2.0
Native American						
Asian		1			1	0.2
Multi-Racial	1	8	2		11	1.8
Total	7	336	244	5	592	
Percent	1.2	56.8	41.2	0.8		100.0

Table

Prevention Programs for the Athens Region: Funding, Number Served, Priority, and CSAP Strategies

Program	Block Grant	Drug Free Schools	Number	Main Priority	Prevention Strategies						
					Information	Education	Alternatives	Problem ID	Community	Environment	Other
ACTION	14,796		58	Econ Dis		12, 17					
Alcove	10,000		94	Child of SA		12, 13, 17	26		43		
Attention Home		15,206	96	Econ Dis	4, 9	13, 17	23-27		43		
Athens Tutorial	8,400		277	Failing Stds	4, 9	11, 14, 15, 17	22, 24, 26	34	42, 43		
Boys & Girls		10,296	62	Econ Dis	1, 2, 7	12, 14	21, 24, 26	32	43		62
Social Circle	13,000		NA	NA	NA						
Strong Day	4,000		NA	NA	NA						
Total	50,196	25,502	592								

Note: Econ Dis = Economically Disadvantaged; Child of SA = Children of Substance Abusers; Failing Stds = Students with academic failure; NA = Not Available

indicated that they served more than one population. The programs reported using 22 different service strategies (identified as the numbers circled on the Prevention Provider Reporting Form,) but emphasized interventions using educational and alternative activities. None of the programs reported using environmental strategies, and only one “other” strategy was noted.

The analysis of participant age and race suggests that 76 percent of the individuals were African-American and 20 percent were white. Small numbers of Hispanic, multi-racial, and Asian children were also served. Most of the participants (57 percent) were between the ages of 6 and 12 years. In addition, two of five individuals (41 percent) were between the ages of 13 to 19 years. Small portions of the participants were less than five years of age (1 percent) or over 20 (1 percent). Data on the number of participants suggests that four of the five programs with reports served between 60 and 100 children and young adults. The program with the second to the lowest funding (\$8,400), however, reported serving 277 individuals (47 percent of the total participants).

Implications/Discussion

The Prevention Provider Reporting Forms, in combination with information on contract awards, appear to provide data that permit a reasonable summary of the prevention activities in a region. The lack of data from two of the seven contracts may limit the current analysis but does not alter the conclusion that useful data are readily available and can be easily summarized. Regional Boards and consumers can easily monitor changes in annual funding levels, assess the priority populations and track the populations being served and the prevention strategies being utilized.

The form did not provide clear data on the allocation of effort between the priorities, and some programs provided ambiguous responses or responses that were not clear. In addition, multiple reports from one contract complicated the analysis of the data. For the pretest, the responses in each area were generally similar so that the four reports of participants were added and the normative response were used to identify priority populations and prevention strategies.

Over time it should be easy to discern changes in funding levels, numbers served, and contracts awarded. Comparisons between regions also appear to be feasible although they should be conducted carefully to assure that size and urbanicity do not bias the comparisons. The analysis of prevention strategies suggests that even though programs have relatively limited funds they report

using multiple strategies. Finally, the analysis suggests that the cost per participant varies substantially between contracts. It is not clear, however, that each program uses the same definition of a participant.

Recommendations:

1. Regional service plans should include specific goals for total funds allocated to community-based prevention programs. The goals should reflect federal requirements and could identify priority populations and preferred prevention strategies.
2. Because programs serve multiple populations, specification of priority groups can be difficult and the data may be ambiguous. A modest reworking of the instructions on the Prevention Provider Reporting Form may be necessary to help providers indicate priorities among the populations they serve.
3. An algorithm may be necessary to combine data from contracts operating in more than one location. Alternatively, programs could be instructed to combine data from multiple locations into one report.
4. Standardized definitions could be developed for participants, populations, and strategies in order to facilitate comparisons among contracts and across regions. Representatives from Regional Boards and prevention providers could work together to develop common understandings and definitions.
5. Regional Boards may wish to encourage a focus on specific populations and specific strategies to maximize the value of small awards.
6. Clear requirements should be established to ensure completion of the forms by all eligible providers.

Part 3 Resource Utilization

1. Reallocation of Hospital System Resources to Community Services

Indicator 1: Regional utilization (DACE) for all cost centers associated with the Hospital Resources Allocation Formula are within the fair share allocation for each Region.

Measure: The number of Regions that achieve utilization targets agreed upon between Region and the Division.

Recommended Data Source:

Annual Report on Cost Centers Produced by Deputy Director for the Regions and Hospitals

Description of Recommended Data Source:

This report provides data that measure this indicator precisely. The report includes tables describing regional utilization by hospital cost center for a complete fiscal year. There is one table for each region as well as one table summarizing statewide utilization by hospital cost center. (See Appendix E for complete report.)

Analytical & Substantive Considerations:

The cost center data are produced quarterly. Consequently, it is possible to assess how well regions are doing on this indicator several times a year. However, because utilization generally varies throughout the year (e.g. less admissions during certain holidays and summer) and resources are also limited, it is recommended that this indicator be assessed once a year. It is further recommended that the assessment be based on data for a complete fiscal year.

Timing of Data Collection:

The cost center report which includes data for a complete fiscal year is available about 4-6 weeks after the close of a fiscal year which is sometime between August 1-15. Therefore, mid-August is recommended as the time to begin analyzing how well Regions are doing on this indicator.

Source of Pretest Findings:

Annual Report on Cost Centers Produced by Deputy Director for the Regions and Hospitals

Pretest Findings:

The pretest data for this indicator appear in Table G. As shown there are four cost centers that contribute to the total utilization. Based on the minimal threshold of purchasing at least 90% of the previous Fiscal Year's days of care, Region 9 could have purchased a total of 19,241 days of care in Fiscal Year 1996. The data reveal that Region 9 actually purchased 18,760 days of care, which resulted in an overall decrease of 12.3 % in the Region's days of care between Fiscal Year 1995 to Fiscal Year 1996.

Implications/Discussion:

Although utilization goals were established in Fiscal Year 1996 using Fiscal Year 1995 as the baseline year, these goals did not have to be implemented until Fiscal Year 1997. By the end of Fiscal Year 1997, all regions are required to meet these initial utilization goals.

The pretest data indicate that in Fiscal Year 1996 Region 9 actually met and exceeded the reduction in days of care required for Fiscal Year 1997. The pretest data, however, are based on how well a Region is doing in terms of meeting the minimal threshold of purchasing 90% of the Region's days of care from the baseline year (which is Fiscal Year 1995) as opposed to the actual percentage of days of care agreed upon between the Region and the Division. If the Region agreed to purchase a different percentage of care, it is not possible to determine precisely how well the Region was doing using these pretest data. However, the new report format being used for these data on days of care in Fiscal Year 1997 rectifies this problem as it includes a column that specifies the precise number of days of care the Region agreed to purchase.

Recommendations:

1. Develop a plan for monitoring the on-going maintenance of the utilization targets.
2. Develop criteria for determining when a region has achieved the maximum allowable reduction in days of care.

Indicator 2: Regions' purchase agreements demonstrate that an increasing number of community services are developed for people with severe and persistent mental illness, mental retardation and people with substance abuse problems.

Measure: For each Region, the amount of program resources expended for community services for people with severe and persistent mental illness, people with mental retardation and people with substance abuse problems as a proportion of resources allocated for community services in the previous fiscal year.

Recommended Data Source/s

Regional Board

Description of Recommended Source:

It is recommended that Regional Boards use a standard format for reporting these data.

Analytical & Substantive Considerations:

Analyses focusing on variation in the amount of funds expended according to disability need to be interpreted carefully. The amount of funds categorized as expended on MH, MR and SA can be misleading as such categorization does not take into account individuals served with dual problems.

CSBs use a small portion of money targeted for community services to purchase local hospital beds. However, Regional and CSB staff have reported that these services are really just one component of comprehensive community services. In other words, community services include emergency and/or short term inpatient care for MH, MR, or SA. Additionally, it was reported that these episodes of short-term inpatient care were paid for by either Medicaid or private insurance. In a small proportion of cases the CSB reimburses some physicians for services rendered during the short-term hospitalization.

However, this issue may be a little bit more complicated in a few regions where the community service board is located in the same geographic location as the regional hospital. In these cases, it is possible that the CSB may use the regional hospital for short-term emergency hospitalizations. In such cases, they should be

able to distinguish the cost between short-term emergency inpatient treatment and long-term hospitalization. Moreover, the regional budget should account for the short-term costs.

Timing of Data Collection:

Proposed funds are not reported in the Regional Budgets until after the funds have been allocated, and funds may also be reallocated during the fiscal year. Therefore, it is recommended that the fiscal information needed for this indicator be collected after all expenditures for a fiscal year have been completed and processed which is between 4 to 6 weeks after the end of a fiscal year. Annual efforts to measure this indicator should begin in Mid-August.

Source of Pretest Information:

Regional Records/Executive Director

Pretest Findings:

The data for this indicator appear in Table H. As shown, in Fiscal Year 96 this region's Community Service Board received the greatest proportion (94% or \$9,331,857 out of \$9,980,128) of regional funds targeted for community services. The distribution of these CSB funds among the disabilities was uneven with more of the funds allocated on mental health services (\$4,131,494) and mental retardation services (\$3,705,094) as opposed to substance abuse services (\$1,495,269). Only slightly over 6% of the regional funds for community services were expended on private programs (i.e. non CSB) and these funds were targeted for three programs providing mental retardation services.

Implications/Discussion:

The Fiscal Year 1996 data provide a baseline for measuring shifts in the distribution of funds targeted for community services. The differences in the distribution of funds across disabilities suggest that change should be examined according to: 1) the total amount expended on Community Services; 2) the amount expended on CSBs as opposed to private programs; and 3) the distribution of funds according to disability.

Recommendations:

1. The Regional Board should develop a long-term plan for the distribution of funds targeted for community services that includes goals for funding: a) Community Service Boards; b) private programs; and c) equity/non equity in the distribution of funds across disabilities.
2. Fiscal Year 1996 data should be used as the baseline for assessing progress in achieving and then maintaining goals.
3. Lack of progress in achieving goals should be assessed in terms of both: a) documented barriers affecting goal achievement; and b) alternative goals adapted. For example, if the Regional Board had planned to increase the amount of funds expended on private programs for mental retardation by 50% over two years but new federal regulations subsequently prohibited use of funds for these programs, the resulting failure to achieve the target should be interpreted in light of that barrier as well as the alternative goal adapted for increasing community MR service.
4. The data collection form used to collect data for this indicator needs to be revised to include questions that need consideration in assessing goal achievement for increasing and/or redistributing funds for community services such as:
 - a. If a goal was not achieved (meaning less than 66% was achieved), what were the biggest barriers to achieving the goal?
 - b. What, if any, changes in the original goal have been proposed and/or what alternative goal has been developed?

4. Access to Services

Indicator: The proportion of consumers who meet the definition of Most-in-Need

Measure: The numbers of consumers who meet the definition of Most-in- Need compared to the number of consumers served by age and disability.

Recommended Data Source/s:

MHMRMIS and HMIS

Description of Recommended Data Source:

The two Management Information Systems administered by DMHM RSA each include a data item which requires reporting whether a client meets the criteria for most-in-need. Both MISs also include client's birth date. These items provide the basic data necessary to analyze this indicator.

The specific data employed for assessing this indicator are: For Fiscal Year 1996 the number and percent of consumers by disability (meaning mental health, mental retardation, and substance abuse) according to their most-in-need status by the following seven age categories:

- 1) 0-2 years; 2) 3-12 years; 3) 13-17 years; 4) 18-24 years; 5) 25-44 years; 6) 45-64 years; and 7) 65 years and older.

Appendix F includes a sample format for requesting these data from the MIS unit

Analytical & Substantive Considerations:

Measurement for this indicator should be based on data for a complete fiscal year. The MIS has the capability to generate both duplicated and unduplicated counts of clients served. Because this indicator focuses on the number of individuals who meet the definition of most-in-need as opposed to focusing on levels of utilization, it is recommended that an unduplicated count be used for this indicator.

The current definition of most-in-need used by DMHM RSA will probably change in the near future. When the definition changes, it will be necessary to make an assessment of how the change impacts the baseline established with Fiscal Year 1996 data.

Timing of Data Collection:

The end of the year file for MIS data is made 2 to 3 weeks after the close of a fiscal year, sometime between July 15 - July 23. Once the end of the year file is made, the MIS unit develops several end year reports. Therefore, it is recommended that the annual assessment of this indicator begin in mid-August.

Source of Pretest Information:

MHMRMIS and HMIS

Pretest Findings:

The pretest data for this indicator appear in Tables I-K. As shown in these tables, the overwhelming majority (90%) of individuals served in state-funded programs in the Athens region during Fiscal Year 1996 met the definition of most-in-need, and there was no difference in the proportions meeting this definition by disability. The data also reveal that there was very little variation in the proportions meeting the most-in-need definition when controlling for age. Nearly three-quarters (74%) of the 19 age groups examined have at least 85% who met the most-in-need definition. The few variations in the most-in-need status by age category that appear on Tables I-K are due to the small number in the particular age category.

There is interesting variation, however, in the proportions reported as not meeting the most-in-need definition according to disability. Whereas, 9% with mental retardation are reported as not meeting this definition, only 3 % and 1% of those with mental health and substance abuse diagnoses respectively do not meet the definition of most-in-need. These differences are related to the higher proportion reported as having an "unknown" status among consumers with substance abuse problems (8.5%) and among those with mental illness (6.3%) as opposed to only 1% among consumers with mental retardation.

Implications/Discussion:

The data establish that the overwhelming majority of individuals served across categorical programs do meet the definition of most-in-need. While this appears as a very positive finding, the interpretation of these data are dependent on the reliability and validity (hence the adequacy) of the operational definition of "most-in-need". The relatively high proportion of substance abuse and mental health clients reported with an unknown most-in-need status also raises questions that warrant addressing including: 1) Why is the percent in the unknown category so high among the individuals served with those disabilities (i.e. is it systematic reporting error among programs serving those consumers?); 2) Would increased training on how to complete the most-in-need question reduce these percentages reported as unknown?; and 3) Who do those categorized as "unknown" really represent in terms of need status?

In addition, the pretest findings are based on unduplicated counts of individuals served in both community programs and hospitals. Although other data suggest that currently there is little difference between community programs and hospitals in terms of the proportion served who meet the most-in-need definition, it is conceivable that such differences may increase in the future.

Recommendations:

1. Long-Term Regional service plans should include specific goals (meaning targets) for most-in-need based on age and disability. In developing these targets, the need for implementing different targets for hospitals and community programs should be considered.
2. The targets should be used to assess how well the Region is doing in serving individuals who meet the most-in-need definition.
3. If the definition for most-in-need changes considerably, it is recommended that the first complete year of data using the new definition be used as the baseline for this indicator.
4. It is recommended that future analyses of the most-in-need status examine community programs and regional hospitals separately.
5. Finally, the basis for any notable differences in the percent reporting unknown for most-in-need status by disability as well as any notable differences in the percent reported as not meeting the most-in-need status by disability need to be addressed in future assessments of this indicator.

<p>Indicator: The number of children under 18 receiving services increases.</p> <p>Measure: The number of children under 18 receiving services by disability and age.</p>

Recommended Data Source/s:

MHMRMIS and HMIS

Description of Recommended Data Source:

Both the MHMRMIS and the HMIS collect client birth date which is the basic data needed for analyzing this indicator.

The specific data employed for assessing this indicator are: For Fiscal Year 1996, the number and percent of consumers by disability (mental health, mental retardation, and substance abuse) according to their Child/Adult Status. Children are defined as those between 0-17 years and adults as 18 years old or older.

Appendix F includes a sample format for requesting these data from the MIS unit.

Analytical & Substantive Considerations:

Measurement for this indicator should be based on MIS data for a complete fiscal year. It is also recommended that an unduplicated count of clients served (as opposed to a duplicated count) be used for measuring this indicator because this indicator focuses on the number of individuals served.

Timing of Data Collection:

The end of the year file for MIS data is made 2 to 3 weeks after the close of a fiscal year, sometime between July 15 - July 23. Once the end of the year file is made, the MIS unit develops several end year reports. Therefore, it is recommended that the annual assessment of this indicator begin in mid-August.

Source of Pretest Information:

MHMRMIS and HMIS

Pretest Findings:

The pretest data for this indicator appear in Tables L-M. As shown in Table L, the majority of individuals served in each of the three disability categories in DMHM RSA funded programs in Region 9 during Fiscal Year 1996 were adults. There were, however, notable differences in the proportions of children served by disability. Nearly a quarter (24%) of the clients diagnosed with mental health problems and 17% of the those with mental retardation were under 18 years of age as opposed to slightly less than one percent (.8%) of the substance abuse clients.

There were also notable differences in the distribution of adult clients by age and disability. Three-fourths (74.5%) of the substance abuse clients were between 25-

44 years at admission as opposed to 39.6% of those with mental health problems and 46.5% of those with mental retardation. Moreover, in the age category of 45 years or older, there were fewer substance abuse clients (14.2%) than clients with either a mental health (26.4%) or mental retardation (24.2%) disability.

Implications/Discussion:

While the pretest findings show that the majority of consumers served by the DMHM RSA funded programs in Region 9 are adults, the data also reveal anticipated differences in the distribution of consumers by age and disability. Substance abuse treatment programs generally serve adults not children, and substance abuse prevention programs generally serve adolescents. Consequently, it would be expected that there would be relatively fewer children reported as substance abuse clients in these pretest data which are based on data collected from treatment programs.

The greater distribution of consumers in mental health and mental retardation programs across age categories is also an expected outcome. Services for both of these disability groups are designed to include consumers from childhood through late adulthood.

Finally, the same concerns raised previously about combining data for hospitals and community programs apply to the analysis of data for this indicator.

Recommendations:

1. Long-term Regional service plans should include specific goals (meaning targets) for increasing the proportion of children served by disability. In developing these targets, the need for implementing different targets for hospitals and community programs should be considered.
2. The targets should be used to assess how well the Region is doing in serving children using Fiscal Year 1996 data as a baseline.
3. Adequacy of services should be determined, in part, by information of levels of need among different age groups.
4. The number of children served in state-funded substance abuse prevention programs should be considered in assessing how well a region is doing in meeting its targets for serving children.

5. It is recommended that future analyses of this indicator examine community programs and regional hospitals separately.

5. Resource Allocation for State-of-the Art Services

Indicator: The proportion of consumers receiving the following state-of-the-art services or interventions by disability and age:

Supported employment;
Court diversion programs;
Family support, respite and in-home crisis support (including wrap around services);
Medication management and education;
Self-help programs and support groups;
Clozaril, Risperidone, and other

psychoactive medication trials;
Supported housing;
Therapeutic foster care;
Group homes for recovering youth;
Family treatment for substance abuse;
Flexible funding
Ambulatory detox
Mobile crisis services

Measure: The number of consumers receiving each of the above services compared to all people receiving services, by disability and age.

Recommended Data Source/s:

MHMRMIS and HMIS

Consumer Survey

Description of Recommended Data Sources:

Both MISs include birth date and data on 7 types of state- of-the art services. These elements will provide some of the data needed for measuring this indicator. Additional data on state-of the-art services will be collected on the consumer survey.

The specific MIS data employed for this indicator are: For Fiscal Year 1996, the number and percent of consumers by disability (mental health, mental retardation, and substance abuse) according to the following seven age categories and status on eleven services.

age categories: 1) 0-2 years; 2) 3-12 years; 3) 13-17 years; 4) 18-24 years; 5) 25-44 years; 6) 45-64 years; and 7) 65 years and older.

services: 1) supported employment; 2) court diversion program; 3) family services; 4) respite services; 5) in -home crisis support; 6) therapeutic foster care; and 7) family treatment.

Appendix F includes a sample format for requesting these data from the MIS unit.

Analytical & Substantive Considerations:

Assessment of this indicator should be based on a complete fiscal year and an unduplicated count of clients served according to each of the seven services listed above. It needs to be noted that an unduplicated count for this measure refers to an unduplicated count within each of the seven services as opposed to an unduplicated count of individuals across these seven services. For example, an individual who received respite services and supported employment services would be counted once on the data table for respite services and once on the data table for supported employment services.

Timing of Data Collection:

The end of the year file for MIS data is made 2 to 3 weeks after the close of a fiscal year, sometime between July 15 - July 23. Once the end of the year file is made, the MIS unit needs to develop several end year reports. Therefore, it is recommended that the annual assessment of this indicator begin in mid-August.

Source of Pretest Findings:

Division of Mental Health, Mental Retardation, and Substance Abuse management information system data on unduplicated counts of consumers by age and disability for each service type.

Pretest Findings:

Data were provided on seven services specified as state-of-the-art: court diversion, family support, in-home crisis, respite care, supported employment, family treatment services, and therapeutic foster care. The number of consumers receiving each service is summarized by disability group in Table N. Three services (family treatment, in home crisis, and therapeutic foster care) are not currently available in Region 9 (Athens area). The four remaining services appear to be used infrequently. Although data were available on over 7,600 individuals, only 252 individuals received any of the services (3.2 percent). One service (family support) accounted for most of the utilization ($n = 217$), primarily among consumers with mental retardation. The remaining two services (court diversion and respite care) were used by 20 or fewer individuals. Although the numbers are small, utilization appears to be dependent on the consumer's

disability category. For example 32 percent of all mental retardation consumers received family support services. Finally, there were no obvious differences related to age (again because the numbers were small) so the age variable is not included in the summary table. See Table N.

Table 14

Number of Region 9 Consumers Receiving State-of-the-Art Services by Disability for Fiscal Year 1996

Service	Consumers	Mental Health	Mental Retardation	Substance Abuse	Total
Court Diversion	7,627	11	0	1	12
Family Support	7,627	18	198	1	217
Respite Care	7,933	1	19	0	20
Supported Employment	7,627	0	3	0	3
Family Treatment	7,627	na	na	na	na
In Home Crisis	7,627	na	na	na	na
Therapeutic Foster Care	7,627	na	na	na	na

na = not available in Region 9

Statewide data were examined for the services not available in Region 9 and are summarized in the second portion of table N. Service utilization reflects the historical development of services and tends to be targeted toward specific groups of consumers. Supported employment was used primarily by individuals with mental retardation. Family treatment was used most often in conjunction with consumers with mental illness or problems related to substance abuse. In home crisis was used most frequently by individuals with serious mental illness. Therapeutic foster care was used only with individuals with serious mental illness. Overall, 1,508 consumers and families utilized one or more of these services statewide, and represented less than one per cent of all consumers.

Number of Consumers Statewide Receiving State-of-the-Art Services by
Disability
For the Services Not Available in Region 9 for Fiscal Year 1996

Service	Consumers	Mental Health	Mental Retardation	Substance Abuse	Total
Supported Employment	165,289	45	724	13	782
Family Treatment	165,289	200	8	178	386
In home crisis	165,289	276	5	7	288
Therapeutic care	165,289	52	0	0	52

Implications/Discussion:

The pretest suggests that the use of state-of-the-art services can be tracked using MIS data. Comparisons among Regions should be instructive and year to year comparisons will reveal changes in the utilization of each service. Because many of services are used infrequently, statewide information may also be useful in tracking utilization. The small frequencies suggest that either there is a potential to promote dramatic increases in the use of these services or that service utilization is carefully managed to limit access. Services that are age specific or targeted toward specific age groups can be monitored using age categories but it may not be necessary to monitor age for each service.

Recommendations:

1. Regional Boards may wish to establish specific goals and promote increased utilization of some of the state-of-the-art services.
2. Expectations should be developed for age and disability categories so that provider performance can be monitored easily.
3. State-of-the-art services are not static. The list of emerging services should be reviewed and updated annually.

Other Data Sources Examined

Part 1. Quality Of Life Issues

4. Health and Safety

Indicator 2: The proportion of youth reporting decreased access to alcohol and tobacco during the reporting period.

1. *The PRIDE Survey:*

This is an annual survey of adolescents in Georgia. This survey is not random and the sample consists of students in school. Annual survey size has varied from 20,00 to over 400,000. The sample size varies as schools who want to participate in the survey contract with PRIDE. However, the sample should be large enough for regional analyses.

The survey includes a question that asks students to rate "how easy it is get the following three substances" 1) beer; 2) wine cooler; and 3) liquor. The rating are: 1) cannot get; 2) fairly difficult; 3) fairly easy; 4) very easy; and 5) don't know. Note this question does not measure access by location i.e. retail store or home. The survey does not ask how easy it is to get tobacco.

Accessing the PRIDE data: If it is determined that the PRIDE Survey is a better long-term source of data for this measure, the DMHM RSA will need to develop a contract with the PRIDE office to pay for special analyses. Currently, the relevant data have not been analyzed by region. The Director of the Survey reported that the cost would be moderate. In addition, if the Pride Survey is used for this indicator, a question on how easy it is to access tobacco will need to be added to the survey, and the impact of using a non random sample will need to be considered in reporting the results.

2. *Tobacco Surveillance Data:*

The legislative requirements attached to the Federal Substance Abuse Prevention and Treatment Block Grant require all States to develop methods of conducting surveillance on the sale of tobacco to minors. Georgia has recently initiated its surveillance effort. Small sample size, however, precludes using these data for examining adolescent's access to tobacco by regions.

Part 2: Accountability/Responsibility Issues

1. Consumer and Family Grievances

Indicator 1: The proportion of grievances that are resolved at the regional level within a specified period of time, by category of grievance(i.e., rights issues, services issues, physical plant issues, and ancillary support issues).

1. SOARS Module on Grievances

As part of the SOARS, DMHM RSA has had plans to develop a computerized module on grievance/ complaints. The feasibility of using this new module was explored. However, the Division has put its plans to develop this computerized module for grievance/complaints on hold.

Part 3 Resource Utilization

1. Reallocation of Hospital System Resources to Community Services

Indicator 1: Regional utilization (DACE) for all cost centers associated with the Hospital Resources Allocation Formula are within the fair share allocation for each Region.

Measure: The number of Regions that achieve utilization targets agreed upon between Region and the Division.

Other cost data provided by the fiscal unit were examined before it became known that the cost center report was available through the Deputy Director's Office.

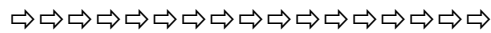
Summary and Conclusions

The main themes that emerge from this analysis, in addition to specific recommendations for data collection and analysis, center around the need for long-term planning and goal setting in order to develop “targets” or standards for these indicators. By monitoring the accomplishments of such targets, barriers can be identified and alternative goals developed. Recommended examples of such goal-setting from the above discussion include:

- Set targets for consumer/family, minority, and disability representation, then compare actual level of representation to these targets. if there are vacancies in membership, what is the nature of the vacancies, what is the impact, and what steps are being taken to fill the positions?
- Set goals for allocating funds to community-based prevention programs. Specify and define priority populations and prevention strategies
- Develop utilization targets and criteria
- Set targets for distribution of funds to community services
- Set targets for serving MIN consumers, based on age and disability. different targets for hospital and community programs
- Set targets for utilization of state of the art services

In general, this analysis also suggests that for the above performance indicators, the State of Georgia already has or is developing data that can be used as a baseline for annual review. Without significant additional investment, these indicators can form the nucleus or an HB 100 performance measurement system. The next step should be the identification of an individual in the Division of Mental Health, Mental Retardation and Substance with sole responsibility for coordinating the project on an ongoing basis and the development of an implementation schedule that specifies, among other things, a schedule by which each measurement should be collected on an annual basis.

CHAPTER 3



Analysis of the Feasibility of Data Generated from a Consumer Survey

Introduction

This chapter explores the use of a consumer survey to gather data for indicators and corresponding measures developed in response to the HB 100 legislation by the Georgia Department of Mental Health, Mental Retardation, and Substance Abuse. Data that were not available through already existing sources in the state, as described in Chapter 3 above, were sought through a variety of methods including the consumer survey (the Stakeholder and Regional Board surveys are discussed in Chapters 4 and 5 respectively)

The chapter is divided into three content areas: (1.) Methodological and Implementation Concerns, (2.) Survey Pretest results, and (3.) Recommendations. A revised Consumer Survey, incorporating the recommendations in this chapter, can be found in the Appendix. Under Methodological and Implementation Concerns issues of sampling, interview method, and paid interviewers are addressed. The Survey Pretest section presents findings from the pilot administration of the Consumer Survey in the Athens region. The reader should note that the pilot was intended to test the applicability of the consumer survey among the three populations -- people with mental illness, mental retardation, and substance abuse problems -- and to test whether certain data could or should be gathered through this method. Findings presented in the Consumer Survey *should not* be construed to represent normative rates and cannot be used to describe the characteristics of the population of service users. Finally, recommendations for the revision and implementation throughout Georgia of the Consumer Survey are interspersed throughout the chapter and summarized in the Recommendations section.

Methodological and Implementation Concerns

Sampling for the pilot:

John Baio at the Northeast Georgia Center randomly selected 400 consumers of services for the pilot of the Consumer Survey. Letters requesting consumer participation and offering nominal compensation for their time (\$5) were sent, with consent forms, to prospective pilot participants. Consumers using subacute detoxification day services and consumer residing at the Georgia Regional Hospital were offered the opportunity to participate on-site. Table 15 shows the number of request letters mailed to consumers by service population.

Table 15
Mail Sampling

SERVICE POPULATION	ESTIMATED POPULATION SIZE	NUMBER OF REQUESTS MAILED
MR Org. Employment	350	40
MR Community Empl.	40	32
MR Comm. Support (Adult)	250	48
MR Comm. Support (<Age 21)	50	40
MH Outpt. (Adult)	2300	40
MH Outpt. (Elderly)	125	40
MH Outpt. (Child)	700	40
MH Multiple Agencies	525	40
Alcohol & Drug Svcs. open > 1 year	66	40
Alcohol & Drug Svcs. open <1 year	66	40

At the close of data collection in November 1996, the sample for the pilot consisted of 52 valid cases (completed surveys.) The number of respondents by disability and age category are listed in Table 16. Because of the small number of responses, reporting by service type may compromise respondent confidentiality and is not included here.

**Table 16
Respondents**

POPULATION	NUMBER OF RESPONSES
DISABILITY: Mental Health	23
Mental Retardation	12
Substance Abuse	16
Missing	1
AGE: 0 -- 12	4
13 -- 22	9
23 and older	37
Missing	2

Sampling for implementation:

In order to meet the analysis demands for the HB 100 indicators, 12 data cells need to be filled: 3 populations (Mental Health, Mental Retardation, and Substance Abuse), 2 settings (community and hospital/center), and 2 ages (adult and child.) Ideally there should be 250 respondents in each cell to allow for meaningful analyses. A statewide survey, therefore, necessitates a sample size of 3000 respondents to yield meaningful results. If Regional or provider level analysis is desired, the number of respondents (sample size) must increase accordingly. We recommend implementing the consumer survey on the statewide level, and then moving to Regional level in subsequent years of implementation (e.g. adding 3 Regions each year.) This strategy will allow data managers and data collectors the opportunity to continue refinement of the survey and the survey process if necessary, and will allow for thoughtful planned training and development of data collectors within the state.

Further, while it is important to assess the effects of service and satisfaction with services among current users, it is also vitally important to understand the perceptions and needs of those who do not use services. Therefore, we recommend sampling cases that were active three months prior to the date that sampling begins. By this approach, the resultant sample should include both individuals who are receiving services and individuals who have stopped receiving services. Additionally, we recommend selecting a small sub-sample of new admissions to service.

Interview Method:

The survey instrument was administered to consumers over the telephone or in-person. Although the method was ostensibly decided by the consumer, interviewers' policy of not meeting individuals in unfamiliar locations in the

evening, as well as the convenience of the telephone for consumers, may have contributed to a disproportionate number of telephone interviews. 31 telephone interviews and 18 face to face interviews were conducted for the pilot of the Consumer Survey (3 cases did not indicate type of interview).

The majority of interviews with consumers of mental health services (16 of 23) were conducted over the telephone, as were the majority of the interviews with consumers of mental retardation services (10 of 12 interviews were conducted by telephone.) For consumers of substance abuse services, only 6 of 16 interviews were conducted by telephone. Presumably the remaining 10 substance abuse service users were among those contacted at the day treatment site for interviews.

One curious finding related to the interview type is the assistance used to answer the survey. Interviewers are asked to report who (if anyone) assisted the consumer to answer and what level of assistance s/he provided the consumer (e.g. answering on behalf of the consumer, providing explanations or translations, or other.) Of 22 individuals receiving assistance to answer the survey, only 1 of those interviews was conducted in-person. Further, 18 of those receiving assistance had total help (that is, usually a family member answered for the consumer.)

Another notable difference between the two interview methods is the length of time required to complete the instrument. Telephone interviews took on average 37 minutes to complete, whereas in-person interviews averaged 31 minutes for completion. Further, the majority of telephone interviews (17 of 31 interviews) required more than 30 minutes to complete, but the majority of in-person interviews required less than 30 minutes to complete (13 of 18 interviews.) These completion times do not include the travel time required of the interviewer.

Although travel time should not impact the burden on the responding consumer, it can significantly impact the cost of data collection to the state. We recommend continuing with both methods of interviewing while simultaneously analyzing the costs of each. Cost estimates for in-person interviews must include the total time for which the interviewer is reimbursed as well as the time required to complete the instrument.

Additional considerations about interview method:

Administration of the survey via telephone was the preferred method of some interviewers, despite the increased amount of time required to complete the instrument. Presumably, the telephone, with decreased intrusion in the consumer's home and the possible heightened sense of anonymity, may have been preferred by consumer respondents. Future considerations for telephone and remote interviewing might include:

1. As an incentive to respondents, sending out calling cards that are activated for free calls or minutes after the consumer calls in for the interview;
2. On-line/interactive interviews (using computers at service sites where possible) using touch screens. (Florida is presently exploring this method.)

Interviewers:

GEST, Inc., a consumer run survey firm, conducted the interviews in the Athens Region for the pilot. There are extensive benefits of using present and former service consumers as interviewers. These include (but are not limited to) the level of comfort experienced by respondents, the fostering of professional development and growth within the consumer community, lower costs for data collection than when using a professional survey company, and the coherency achieved within the system where the stated concern is consumer input and consumer professionalism and employment are fostered.

Some challenges are also presented when consumer organizations, rather than professional survey companies, collect data. These include the expectation of intensive training and support by the state for the data collection process, external monitoring of quality of data collection and reporting, and managing the effects on data collection when leadership changes within the consumer run organization.

In short the primary benefits of consumer interviewers are that by employing consumer interviewers the department demonstrates its customer service orientation and reduces the costs of large data collection efforts. The primary challenges of this approach are the need for quality control as interviewers are being trained and the need for fast capacity building for a large data collection

effort (recall that the recommended sample size for state level analysis is 3000 respondents).

The department has three options in selecting interviewers:

1. *Hire a professional survey firm.* In doing so, there will be higher levels of predictability and quality control. The costs incurred will likely be higher as well.
2. *Hire a consumer run survey firm.* In doing so, relations with consumers will be positive, costs will likely be lower. However, training and quality oversight needs will be greater.
3. *Contract with a professional survey firm to hire and train consumer data collectors.* Training and capacity building will occur within the consumer community; costs for data collection may be greater; oversight by the department will be lessened.

Consumer Survey Pilot

The purpose of the pilot/pretest is to explore whether expected variations appear when using the consumer survey, to test whether data can be collected through the consumer survey, and to explore whether persons with disabilities can answer the questions as presented in the survey. All *findings* presented below should be viewed in this context and should not be misconstrued as representative of whole populations nor as establishing normative rates of any kind.

This section is organized by **Indicator, Measure** and corresponding **Survey Question**. The **Source of the Survey Question(s)** follows the question(s) when possible. The subsections titled **Analytical and Substantive Considerations** address concerns raised through the implementation of the pilot test of the survey and broader content and methodological issues specific to each indicator or survey question. **Pretest Findings** are presented primarily to demonstrate that the data needed for the measure can and have been collected through the pilot administration. Recommendations are found in both the **Analytical and Substantive Considerations** subsection and in the **Recommendations** subsection for each indicator.

Part 1. Quality Of Life: Performance Indicators

1. Jobs and Education

Indicator 1: (For MH and DD) The proportion of consumers working in integrated employment settings increases. (1)

Measure: Analysis of trends in the distribution of consumers, by disability and age, working: 1) in full-time employment; 2) part-time employment; 3) full time in supported employment; 4) part-time in supported employment.

Survey Question(s):

5. Do you work for pay?

Yes

No (please go to question 11)

6. Is this job in a sheltered workshop?

Yes

No

7. Do you have a special supervisor or job coach?

Yes

No

Don't know

8. How many hours do you usually work each week? (check one) [1]

less than 8 hours

8 -- 16 hours

17 -- 24 hours

25 -- 32 hours

33 -- 40 hours

over 40 hours)

don't know

9. Do you work closely with any people without disabilities? [1]

Yes

No

11. What is the highest level of education and/or training you completed? [1]
[2]

- less than 8th grade
- 8th grade
- Some high school
- High School degree
- Technical/Vocational degree
- some college
- Associate degree
- Bachelor degree
- Graduate degree
- Don't know

15. Are there other students without disabilities in most of your classes (at least half of the school day)? [1]

- Yes
- No

Source(s) of Survey Question(s): Questions 5 and 8 were adapted from CDIHOS. Question 9 was adapted from COPAR (Question 9). Lehman Quality of Life (Questions 4-8), was also consulted in selecting these questions.

Analytical and Substantive Considerations:

Exceptionally small *Ns* in the regional pretest limit the amount and type of analyses that can be performed. As the sample size increases, cross disability and cross age comparisons should be fairly simple. Within group trends (such as the proportion of persons with mental retardation in supported employment, the proportion of children in segregated classes) will likely yield straightforward indications of resource allocation, service design, and policy concerns.

Interviewers reported no problems with the interview questions for these measures.

Pretest Findings:

Only 12 respondents reported that they work for pay, findings by age and disability should be considered in the context of the small *N* for the survey and for the exceptionally small *N* for those reporting working for pay.

Work for pay by target group: 81% of persons using substance abuse services report that they do not presently work for pay. Persons using mental retardation services report the highest employment rate (n=5, 42%), yet 4 of those individuals work in sheltered workshops. Persons using mental health services report the lowest employment rate at 17% (n=4), however 26% of the mental health consumers did not respond to the question.

Work for pay by age: One person under age 23 reports working for pay. All others, save two that did not report age, are over the age of 23.

Supported employment: Four persons who work for pay report having a special supervisor or job coach. Three who report having a job coach also report working in a sheltered workshop, thus indicating special supervision but not supported employment. Of the four reporting having a job coach, three work 32 hours or fewer each week. One is in full-time supported employment. Given the exceptionally small n, analysis by target group would not be meaningful at this time and might compromise respondent confidentiality.

Full and part-time employment by target group: Five persons report working full time (defined as 33 or more hours/week.) Because of the small N, analysis by disability would not yield meaningful results here.

Integrated work and school by target group: Persons with mental retardation were the only respondents to report working in sheltered workshops (and consequently the only ones to report not working closely with people without disabilities.) Ten individuals report attending school, and two of those report that there are no students without disabilities in most of their classes.

Recommendations:

We recommend adding a skip instruction to question 6 of the survey so that those who work in sheltered workshops do not mistakenly answer questions about supported employment. Additionally, question 9 ("Do you work closely with any people without disabilities?") should precede question 7 ("Do you have a special supervisor or job coach?")

Indicator 2: The proportion of consumers in recovery from alcohol and drug dependence who report that their employment is consistent with their skills. (2)

Measure: The number of consumers in recovery who report that their employment is consistent with their skills compared to all people in recovery reporting.

Survey Question(s):

10. Do you feel the work you do is consistent with your skills and qualifications? [2]

- Yes
- No, I am overqualified for the work I do
- No, I am underqualified for the work I do
- I don't know

11. What is the highest level of education and/or training you completed? [1]
[2]

- less than 8th grade
- 8th grade
- Some high school
- High School degree
- Technical/Vocational degree
- some college
- Associate degree
- Bachelor degree
- Graduate degree
- Don't know

Source(s) of Survey Question(s):

These demographic questions were developed by HSRI staff.

Analytical and Substantive Considerations:

In addition to its value as demographic data about the consumers of services, highest level of education may also be useful for interpreting reports of over- or under-qualification for work.

Although the indicator above applies only to persons in recovery from alcohol and drug dependence, all consumers who reported working for pay responded to this question.

No problems were associated with these questions.

Pretest Findings:

Consistency by target group: All respondents who reported working for pay were asked whether the work they do is consistent with their skills and qualifications. 2 of 3 working respondents in recovery report they are over-qualified for the work they do. The majority (n= 9; 56%) of persons in recovery responding to the survey hold high school degrees or higher, yet only 3 are employed.

Additionally, 2 of 5 persons with mental retardation report they are over-qualified, while none of the consumers of mental health services report feeling over-qualified for their jobs.

Recommendations:

For adults, we recommend adding a question about the number of work days lost due to disability. This cursory measure of major functional limitation is included in several standardized tests, and provides the state with the opportunity to compare Georgia’s results with norms established by those tests. The revised consumer survey should include the following question:

During the last six months, how many days did you miss work because of your disability?

- _____ 0 days (none)
- _____ 1 -- 5 days
- _____ 6 -- 10 days
- _____ 16 -- 20 days
- _____ more than 20 days

Indicator: The number of school days lost related to disability decreases. (3)

Measure: The number school days lost during the preceding semester by age and disability.

Survey Question(s):

13. Are you 22 years old or older? [3]

_____ Yes (skip to question 17)

_____ No

14. Do you go to school? [3]

_____ Yes

_____ No (skip to question 17)

16. During the last complete semester (half school year), how many days of school did you miss because of your disability? [3]

_____ 0 -- 5 days

_____ 6 -- 10 days

_____ 11 -- 15 days

_____ 16 -- 20 days

_____ more than 20 days

Source(s) of Survey Question(s):

These questions were developed by HSRI.

Analytical and Substantive Considerations:

The structure of survey question 16 does not allow for a distinction between students who have missed *no* school due to their disability and students who have missed *up to 5 days* in the previous semester. We recommend revising this question to allow for this distinction. The new question would read:

During the last complete semester (half school year), how many days of school did you miss because of your disability?

_____ 0 (none)

_____ 1 -- 5 days

_____ 6 -- 10 days

_____ 11 -- 15 days

_____ 16 -- 20 days

_____ more than 20 days

Pretest Findings:

The majority of students (7 of 10 responding, 70%) who report missing school because of their disability report missing five or fewer days in the previous semester. Only 2 (20%) missed 11 -- 15 days, and none reported missing more than 15 days of the previous semester. Because of the small n, analysis by disability would not yield meaningful results at this time.

School days missed by target group: No persons using substance abuse services report missing school. 7 of 10 respondents using mental health or mental retardation services report missing between 0 and 5 days of school (4 mental health consumers; 3 mental retardation consumers.)

Recommendations:

We recommend revising question 16 to include a response option for 0 days of school missed.

2. Housing

Indicator: Proportion of consumers who are able to choose their housing. (4)

Measure: Number of people reporting they had the opportunity to make choices about their housing compared to all people reporting.

Survey Question(s):

17. Who chose the home where you live? (check one) [4]

- I chose it
- I chose it with help from:
 - My spouse, housemates, or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say in where I would live
- I don't know
- I live with my parents
- Other (please describe _____)

18. If you don't live with your family, who chose your roommates/housemates?
[4]

- I chose
- I chose with help from:
 - My spouse or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say about who I live with
- I live with my family
- I don't know
- Other (please describe _____)

Source(s) of Survey Question: Question 17 was adapted from COPAR.

Analytical and Substantive Considerations:

Presumably, the state values the family home as the most preferable, least restrictive environment for children. As least restrictive environment is addressed under a different indicator, the issue of choice in housing applies to adult consumers. Analysis of responses for this measure should be based on adult respondents only.

Although not requested, when responses are broken out by target group, people using mental retardation services were the only ones that do not report choosing their home without assistance. These results do not imply no choice, as no respondent, regardless of target group, reports having no say in where to live. Rather, given the complexity of such a decision, people with mental retardation are receiving support to make informed decisions.

Pretest Findings:

Of 52 respondents, none report having no say about where to live or with whom. 20 of these respondents report living in the parental home, another 20 report living on their own in some fashion (not the parental home). Of those living on their own, 8 of 20 report choosing their home and 4 report choosing the people with whom they live. 12 respondents received assistance choosing their home, and the majority of them (10 of 12) were assisted by a family member (including spouse.)

12 consumers responded "other" to the question "Who chose the home where you live?" The hospital (n=7) and various family members (n=3) are the most frequently cited explanations recorded on the survey form. However, it is not clear whether respondents mean to indicate that they had no say in where to live or whether they mean to identify who/what contributed to the decision. Finally, as only one respondent reports living at a hospital, the responses to this

question may indicate that the hospital (through its staff) chose the home. A prompt of “who chose it? _____” should follow the “I had no say” response.

Similarly, 3 of 7 respondents selecting “other” in response to “who chose your housemates cite the hospital. Another 2 state that they live alone. “I live alone” and the prompt “who chose them? _____” (following “I had no say”) should be added to the list of possible responses.

Recommendations:

The measure for this indicator should be revised to reflect the presumption that choice in housing primarily applies to adult consumers of services. We suggest the following:

Measure: Number of adults reporting they had the opportunity to make choices about their housing compared to all adults reporting.

We recommend that the survey questions be revised for clarity to read:

17. Who chose the home where you live? (check one)

- I chose it
- I chose it with help from:
 - My spouse, housemates, or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say in where I would live
(who did choose it _____)
- I don't know
- I live with my parents
- Other (please describe _____)

18. If you don't live with your family, who chose your roommates/housemates?

[4]

- I live alone
- I chose
- I chose with help from:
 - My spouse or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say about who I live with
(Who did choose who you live with _____)
- I live with my family

I don't know
 Other (please describe _____)

Indicator: The number of consumers in recovery living in alcohol and drug free housing. (5)

Measure: The number of units of alcohol and drug free housing in each region.

Survey Question(s):

53. Is your place of residence alcohol and drug free? [5]

Yes

No

Source(s) of Survey Question(s):

Analytical and Substantive Considerations:

Ostensibly, this indicator and its corresponding measure will show whether people using substance abuse services have drug and alcohol free housing. As currently phrased, the indicator implies a level of inquiry (around the term "recovery") that is neither necessary for the measure nor appropriate for the consumer survey. We recommend revising the indicator and its measure to read:

Indicator: The number of substance abuse service consumers living in alcohol and drug free housing.

Measure: The number of substance abuse service consumers reporting living in alcohol and drug free housing compared to all substance abuse service consumers reporting.

Finally, this question appears at the end of the survey in a section exclusively focusing on people using substance abuse services. Although specific to people using substance abuse services, this question pertains to housing concerns and should follow question 18 in the consumer survey.

Pretest Findings:

No problems were reported with this question. Of 16 respondents who use substance abuse services, 13 report that their place of residence is alcohol and drug free.

Some consumers of mental health and mental retardation services also answered this question. Although substance abuse services are not commonly accessed by persons with mental retardation, all five who were mistakenly asked this question report living in alcohol and drug free housing. Six persons using mental health services also answered this question. Although they did not

identify as primary consumers of substance abuse services, these respondents may be receiving both mental health and substance abuse services. Five of the six consumers of mental health services report living in alcohol and drug free housing.

Recommendations:

We recommend revising the indicator and measure as noted in the **Analytical and Substantive Considerations** section. Additionally, interviewers should be reminded during training that only consumers of substance abuse services should be asked the question relating to this indicator.

3. Independence

Indicator: The proportion of people living in restrictive living environments decreases. (6)

Measure: Analysis of the trends in the distribution of people, by disability and age, living in 1) own home or apartment with or without support; 2) board and care facility or SRO; 3) supervised group living arrangement (4 residents or less); 4) supervised group living arrangement (5 or more residents); 5) children’s residential facility; 6) skilled nursing facility; 7) public institution; 8) homeless shelter; 9) jail or prison; 10) homeless.

Survey Question(s):

19. What type of place do you live in? (check one) [6]
- My own home or apartment
 - Boarding/rooming house
 - Community Living Arrangement (CLA), group home or apartment
30 hours or more of staff time per week
 - Community Living Arrangement (CLA), group home or apartment
less than 30 hours of staff time per week
 - Substance abuse halfway house
 - Residential substance abuse treatment
 - Children’s residential facility
 - Skilled nursing facility
 - Criminal justice halfway house
 - State hospital/state school
 - Jail/prison/detention center
 - I am homeless/live in a homeless shelter
 - Other (please describe _____)

Source(s) of Survey Question: Question 19 was adapted from CDIHOS.

Analytical and Substantive Considerations:

Lay persons and consumers of services may have difficulty making distinctions between living environments on the basis of restrictiveness. Pretest findings (below) suggest that although these distinctions are important in terms of the experienced quality of life of the consumer and in terms of service system design, many consumers do not view their living arrangements in terms of categorical program labels. Data for this indicator may be obtained more reliably from state management information systems than from self-reports of individuals not familiar with the terminology.

Pretest Findings:

The majority of respondents (37 of 52) report living in their own home, however these own homes may also be program models that the respondents did not identify. One respondent reports that s/he is homeless, and one other reports living in a state hospital. Analysis by age and disability does not yield meaningful results at this time and may compromise consumer confidentiality.

8 respondents selected the response “other,” and 6 of those 8 indicate they live with other family members. If this question remains in the consumer survey, the first response option “My own home or apartment” should be revised to “My own home/apartment (including the family home).”

Recommendations:

We recommend trends in living environments be addressed through the management information system rather than by consumer self report, as reporting on program models may be more reliable there.

Indicator: The proportion of people who report no major functional limitations compared to everyone reporting. (7)

Measure: The number of people reporting no functional limitations compared to all people reporting by disability and age.
(Data note: Implies different scales for different disabilities)

Survey Question(s):

	A. How much help did you need?	B. How often did you need help?
Taking care of your personal needs (go to the bathroom, groom, dress, eat by yourself)	5 4 3 2 1	4 3 2 1
Community living skills (cook, clean, grocery shop, use public transportation, or manage money.)	5 4 3 2 1	4 3 2 1

Dealing with everyday things that change or go wrong, such as a change in schedule, arguments or being on time for appointments.	5 4 3 2 1	4 3 2 1
Making friends, having fun, or doing things that are important to you.	5 4 3 2 1	4 3 2 1

Source(s) of Survey Question: Question 20 was adapted from CDIHOS.

Analytical and Substantive Considerations:

The measurement of change in functional level across three different target populations using the same measure for those populations presents significant difficulties. While consumer function is a paramount concern of any service system, the aggregation of data and individual variation required for the measurement of *performance indicators* diminishes the meaning of broad function measures. Meaningful inclusion of *level of function* in the consumer survey would require considerable additions in terms of length and content thereby creating greater burden for respondents, and it would likely require different measures for the three target populations. We propose that the consumer survey seek to identify *major functional limitation* rather than level of function.

Pretest Findings:

Interviewers reported difficulty completing these questions.

Recommendations:

We recommend that measures of level of consumer function be examined in a different context, such as contracting procedures with providers, provider and system CQI practices, and separate survey methods. The inclusion of survey questions from the SF-12 and measures of work and school days lost due to disability should yield cursory indications of major limitations of function without requiring extensive surveying and testing for level of function in the interview.

We recommend the substitution of the following questions from the SF-12 in the consumer survey:

During the past week, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Accomplished less than you would like

- Yes
- No

Didn't do work or other activities as carefully as usual

_____ Yes

_____ No

During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

Indicator: The proportion of consumers and families that report support to make the transition from school to work and independent living increases. (8)

Measure: The number of families and consumers that report support to make the transition from school to work and independent living compared to all people reporting by age and disability.

Survey Question(s):

21. Are you graduating from high school this year or have you graduated from high school within the last 2 years? [8]

- Yes
- No (skip to 24)

22. Have you received the support or services you needed to get a job after finishing school? [8]

- Yes
- No

23. Have you received the support or services you needed to live where you want to live? [8]

- Yes
- No

Source(s) of Survey Question:

Analytical and Substantive Considerations:

The transition from school to work is typically a young adult experience. For accuracy's sake the indicator and its corresponding measure should explicitly define the target population. We recommend editing both to read:

Indicator: The proportion of consumers and families *in the designated age range* that report support to make the transition from school to work and independent living increases.

Measure: The number of consumers and families *in the designated age range* that report support to make the transition from school to work and independent living compared to all people in the designated age range reporting.

The designated age range should reflect the transition practices of the state. Support for transition might begin two years prior to high school graduation. As special education is available to eligible students until the age of twenty-two, the designated age range for this indicator should reflect the beginning and end limits of transition support: ages 16 through 24. The survey question should be changed to:

Are you between the ages of 16 and 24 years old?

Yes

No (skip to 24)

Pretest Findings:

Six individuals responded to the question about transition support for work following high school. Of those six respondents, four were 23 years of age or older. 10 individuals responded to the question about the transition support they received for their living situation; 6 were 23 years of age or older.

Because of the small n, analysis of response by age and disability at this time might compromise consumer confidentiality.

Recommendations:

Modification of the indicator, measure, and consumer survey question are discussed above in the Analytical and Substantive Considerations section.

4. Health and Safety

Indicator 1: The proportion of consumers reporting that they were the victim of a crime during the past 6 months. (9)

Measure: The number of people reporting that they were the victim of a crime by disability and age compared to all people reporting.

Survey Question(s):

24. In the past year, were you a victim of any violent crimes (crimes that you were a victim of and occurred in your presence), such as assault, rape, mugging or robbery? [9]

_____ Yes

_____ No

25. In the past year were you a victim of any non-violent crimes (crimes that you were a victim of but not present when they occurred), such as burglary, theft of your property or money or being cheated? [9]

_____ Yes

_____ No

Source(s) of Survey Question(s): Questions 24 and 25 were adapted from Lehman Quality of Life Toolkit and CDIHOS.

Analytical and Substantive Considerations:

Normative rates should be available from other states using the Lehman Quality of Life scale and the CDIHOS, as well as from nationwide statistics.

Sampling issues may confound the findings of the pretest, as the many of the substance abuse service consumers were interviewed on-site at a day treatment program. If these respondents are in the early stages of recovery, they may have been exposed to unsafe conditions more recently than the general population and the population of substance abusers further along in recovery. The issue also may be true of mental health service consumers who are just entering services.

Pretest Findings:

Victimization by disability group: 52 individuals responded to questions about their safety. All consumers of mental retardation services (n=12) report that they were not victims of crime (either violent or non-violent.) Consumers of mental health and substance abuse services reported greater incidence of victimization. 5 of 23 (22%) mental health consumers report they were victims of violent crimes in the past year, and 5 of 23 (22%) mental health service consumers report they were victims of non-violent crimes in the past year. 3 of 16 (19%) people using substance abuse services report they were victims of violent crime in the past year, and 4 of 16 (25%) report they were victims of non-violent crime.

Victimization by age group: 7 of 9 individuals reporting they were victims of violent crime were 23 years of age or older. No respondent between the ages of 0 and 12 reports being a victim of a violent crime in the past year. Likewise, all respondents who report being victims of non-violent crimes are 23 years of age or older.

Recommendations:

We recommend retaining the indicator, measure and survey questions as stated.

Indicator: The proportion of consumers and families that report support in securing health services, medication or equipment necessary to sustain their health and independence. (11)

Measure: The number of people reporting that they received support to secure needed health services, medication or equipment, by age and disability, compared to all people reporting.

Survey Question(s):

26. During the past year, have you been able to obtain the health services you needed? (including medication, equipment, medical specialties, Physical Therapy, Occupational Therapy, etc.) [11]

- I didn't need any health services
- Yes, I obtained all the health services I needed
- Yes, I obtained some but not all of the health services I needed
- No, I haven't been able to obtain any health services I needed

27. Did your staff try to help you get the health services you needed? [11]

- Yes
- No
- Don't know

32. Have you used HIV/ AIDS services in the past year? [11]

- Yes
- No (skip to 34)

33. Please check which HIV/ AIDS services you have used in the past year? [11]

- HIV/ AIDS testing
- HIV/ AIDS counseling
- HIV/ AIDS medication
- HIV/ AIDS Education
- Physician services
- Support groups
- Service Coordination/ Case management
- Other (please describe: _____)

34. Were there HIV/ AIDS services you would have used but were unable to obtain in the past year? [11]

_____ Yes

_____ No (skip to question 36)

35. What were the HIV/ AIDS services you were unable to obtain? (Please list them below.) [11]

Source(s) of Survey Question(s): Question 26 was adapted from NYS Task Force and MHSIP. Question 27 was adapted from NYS Task Force.

Analytical and Substantive Considerations:

Questions 26 and 27 address two concerns of the indicator: (1) whether needed health services are available and (2) whether consumers have the support necessary to acquire needed health services.

Questions 32 through 35 were added to the consumer survey after consultation with substance abuse service users.

Pretest Findings:

51 individuals responded to the question about their ability to obtain needed health services. 35 of 51 respondents report that they had no need for health services (n=4) or that they were able to obtain all the health services they needed (n=31.) 8 respondents report that they were unable to obtain any health services in the past year, and another 8 report that not all of their health needs were met in the past year.

Needed health services by target group: Although the majority of respondents report they were able to obtain needed health services in the past year, persons using substance abuse services report the greatest difficulty in securing health services. 8 of 16 respondents using substance abuse services report that they were not able to meet some (n=5) or all (n=3) of their health service needs. Only 5 of 22 mental health service user and 2 of 12 mental retardation service users report similar difficulties.

Needed health services by age: Of the 16 respondents reporting limited or no accesses to needed health services, only 1 is under age 23.

Staff assistance by target group: 28 of 48 respondents report that their staff assisted them in obtaining needed health services. Persons using mental health services most frequently report staff assistance (15 of 22,) whereas consumers of mental retardation and substance abuse services report lower use of staff assistance. 5 of 10 mental retardation service consumers report that their staff assisted them, and 8 of 15 substance abuse service consumers report assistance by staff in acquiring needed health services.

Staff assistance by age: Only 3 persons under the age of 23 report that they did not receive staff assistance to obtain needed health services; one respondent that did not receive assistance is 12 years old or younger.

HIV/AIDS services unavailable by target group: 49 individuals responded to the question of whether there were HIV/AIDS services they were unable to obtain. Consumers of mental retardation services report that there were no HIV/AIDS services that they would have used but were unable to get (n=12). 3 of 21 consumers of mental health services report that there were unable to obtain HIV/AIDS services they wanted, and 5 of 15 substance abuse service users were unable to obtain wanted HIV/AIDS services.

HIV/AIDS services unavailable by age: 2 respondents between the ages of 13 and 22 report they were not able to obtain HIV/AIDS services they would have used.

Types of wanted services that were unavailable: 4 individuals listed the HIV/AIDS services that were unavailable to them. They are education/information and testing.

Recommendations:

Because HIV/AIDS represent a major public health risk and because vulnerable populations often have limited access to health care, we recommend that HIV/AIDS services be treated as a special category within this indicator. Further, although originally suggested by substance abuse service consumers, we recommend that all service consumers are asked about the availability of HIV/AIDS services.

Question 26 should include a skip direction to those respondents who did not need health services or who received all the services they needed. Only those respondents that report difficulty obtaining health services should respond to whether the staff assisted them in acquiring health services (question 27.)

5. Community Connections

Indicator: Proportion of people that report that adequate transportation is available to them. (12)

Measure: Number of people reporting that transportation is available by age and by disability compared to all people reporting.

Survey Question(s):

28. Do you have any problems with transportation (trouble getting around town, to the grocery store, to your doctor's appointments, to meetings)? [12]

- _____ Yes
- _____ No (skip to question 30)

29. If you don't have adequate transportation, why? (check all that apply) [12]

- _____ I can't afford it
- _____ Public transportation is not available where I live/work
- _____ Accessible public transportation is not available where I live/work
- _____ I don't have a license
- _____ I don't know how to get transportation
- _____ Other (please describe _____)

Source(s) of Survey Question: Question 28 was adapted from COPAR.

Analytical and Substantive Considerations:

Pretest Findings:

Transportation problems by target group: 19 of 45 respondents report having problems with transportation. People using mental retardation most frequently report difficulty with transportation (8 of 12 respondents.) 7 of 17 respondents who use mental health services report problems with transportation, as do 4 of 16 substance abuse service consumers.

Transportation problems by age: 14 of 19 respondents having difficulty with transportation are 23 years of age or older. 4 respondents having difficulty with transportation are between the ages of 13 and 22.

Reasons for transportation problems by age: Respondents between the ages of 13 and 22 report they do not have adequate transportation because they cannot afford it (n=4). Respondents 23 years of age and older report problems with transportation due to the unavailability of public transportation (n=2), their lack of a driver's license (n=3) and other reasons (n=9). Of those 9 responding "other," 4 report that the vehicles they own or use require repair, presumably repairs that the consumer does not have the funds to make. 4 respondents report that they rely on family members for transportation, and 2 report they are scared to drive themselves.

Recommendations:

We recommend instructing interviewers to probe "other" responses and to record vehicle maintenance problems related to insufficient funds as "I can't afford it." Further we recommend adding a response option for persons who rely on friends or family for their transportation. Question 29 should read:

29. If you don't have adequate transportation, why? (check all that apply) [12]

- _____ I can't afford it (including I can't afford to maintain my transportation)
- _____ Public transportation is not available where I live/work

- _____ Accessible public transportation is not available where I live/work
- _____ I don't have a license
- _____ I rely on friends or family to provide transportation for me
- _____ I don't know how to get transportation
- _____ Other (please describe _____)

Indicator: Proportion of people reporting that they receive sufficient support to participate in age appropriate social, volunteer and recreational activities. (13)

Measure: The number of people reporting that they receive sufficient support to participate in age appropriate social and recreational activities by disability and age compared to all people responding.

Survey Question(s):

30. Did you need help with any of the following activities in the last month and did you receive the help you needed? [13]

	I needed help (Circle Yes or No)		I got the help I needed (Circle Yes or No)	
Making friends	Yes	No	Yes	No
Attending social functions	Yes	No	Yes	No
Arranging for transportation	Yes	No	Yes	No
Meeting with people to discuss problems we share	Yes	No	Yes	No
Going to religious institutions	Yes	No	Yes	No
Finding or keeping a job	Yes	No	Yes	No
Joining clubs or sports teams	Yes	No	Yes	No
Enrolling or staying in school	Yes	No	Yes	No

Source(s) of Survey Question: Question 30 was adapted from CDIHOS.

Analytical and Substantive Considerations:

Analysis of responses requires the development of a simple scale from the survey question. The activities included in the survey question are derived from

the CDIHOS survey and appear to represent typical social and recreational activities. However, the DMHM RSA may wish to revise these categories over time and as more data are available.

The measure sought for this indicator is the amount of help received for social and recreational activity divided by the amount of help needed. Respondents who omitted whether they needed help or who indicated they did not need help were excluded for the calculation for each activity. Likewise, respondents indicating a need for help but omitting answers to whether they received the help were excluded from calculation.

As more data are collected, proportions can be calculated for each social/recreational activity listed, if desired.

Pretest Findings:

Interviewers report some difficulty completing the matrix. Instructions should precede the question that direct the interviewer to (1) ask whether the respondent received help only if the respondent reports s/he needed help and (2) to skip to the next activity if the respondent reports s/he did not need help.

The data exclusions discussed above created a sample size of 37 valid cases. 22 of 37 respondents report they received the help they needed in the areas they indicated. 7 of 37 report they did not receive any of the help they needed. The rest (n=8) report receiving support for 25% of their needs to receiving support for 88% of their stated needs. For ease of interpretation, the results of the pretest are characterized as the frequencies of (1) those who received none of the help they needed, (2) those who received some, but not all of the help they needed, and (3) those who received all the help they needed. As the sample size increases, greater distinction can be made among those who are receiving some, but incomplete, support. (For example, those who received 25% of the help they needed, those who received 50% of the help they needed, etc.)

Received needed help for social life by target group: The three populations of service users appear very similar in the distribution of receiving needed help. The majority of service users in each group report receiving all the help they needed: 9 of 15 mental health service consumers, 5 of 10 mental retardation service users, and 8 of 12 substance abuse service consumers.

Received need help for social life by age: All respondents who report that they did not receive any of the help they needed are 23 years of age or older.

Recommendations

We recommend retaining the indicator and survey questions.

6. Choice

Indicator: The proportion of consumers reporting that their preferences were sought and acted upon in the preparation of their service plans. (14)

Measure: The number of consumers reporting that their preferences were sought and acted upon in their service plans compared to all consumers reporting, by disability and age.

Survey Question(s):

31. Please indicate how much you agree with the following statements (on a scale of 5= strongly agree to 1= strongly disagree; 0= does not apply):

A.) I feel comfortable requesting particular services.

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

B.) My requests are incorporated in my treatment/service plan.

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

C.) I feel comfortable refusing services I don't want (including refusing a treatment/service plan or meeting).

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

D.) I participate actively in decisions about the services and treatment I receive.

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

E.) Staff take my concerns seriously.

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

F.) Staff take the concerns of my family members seriously.

Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

Source(s) of Survey Question:

Analytical and Substantive Considerations:

Focus groups with consumers of mental health and mental retardation services lead to the development of the six questions above. These questions are meant to show differences in degree of consumer empowerment in service planning and provision (for example, consumer comfort would presumably influence whether they made requests or stated preferences for their service plans.) However, the indicator and its measure concern only two aspects of

consumer involvement: that preferences are sought and acted upon in service planning. A more efficient attempt to measure this indicator would be two survey questions computed into a simple ratio as in the previous indicator.

For this indicator, we recommend deleting questions 31C through 31F. Further we recommend the following modifications to questions 31A and 31B:

A.) My preferences are sought in preparation of my treatment/service plan.

Strongly agree	Agree	Neither Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3	2	1	0

B.) My preferences are acted upon in my treatment/service plan.

Strongly agree	Agree	Neither Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3	2	1	0

Pretest Findings:

On each of the survey questions, the majority of service consumers indicate that they feel they are influencing the development of their treatment/service plans.

Comfort requesting services by target group: 6 of 23 mental health service consumers disagree (circled 2 or 1 on the survey) with the statement “I feel comfortable requesting particular services;” 16 of 23 indicate comfort requesting services (5 or 4 on the survey.). 3 of 12 mental retardation service users are not comfortable requesting services, and 9 are. 3 substance abuse service users indicate they are not comfortable requesting services, whereas the remaining 13 of 16 substance abuse service users note they are comfortable making such requests.

Comfort requesting services by age: Of 12 respondents citing discomfort in requesting services, 10 reported their age. 8 of 10 of these consumers are 23 years of age or older.

Requests are incorporated by target group: 35 of 52 respondents report that their requests are incorporated in their treatment/service plans. 9 respondents indicating disagreement with the statement in the survey are evenly distributed among the three populations.

Requests are incorporated by age: 5 of those 9 indicating that their requests are not incorporated in their treatment/service plans are 22 years old or younger.

Comfort refusing services by target group: Persons using mental retardation services report near universal comfort refusing services (11 of 11 respondents for whom the question applies.) Persons using mental health services also indicate a high degree of comfort refusing services -- 20 of 23 respondents report feeling comfortable refusing services. However, 6 of 16 substance abuse service users are not comfortable refusing services. It should be noted, though, that data on

court mandated treatment for substance abuse is not available for the consumer survey, and that the discomfort indicated on the survey may be explained by the unique ways in which services are delivered to persons with substance abuse issues.

Comfort refusing services by age: 8 of 10 respondents over who state that they are not comfortable refusing services are 23 years old or older.

Participation in decisions by target group: 39 of 50 respondent participate actively in decisions about the services and treatment they receive. 9 respondents do not. Those 9 are evenly distributed among the 3 consumer groups.

Participation in decisions by age: 3 of the 9 reporting they do not actively participate in decisions about their services are between the ages of 13 and 22 years old.

Staff take consumer's concerns seriously by target group: 43 of 52 respondents indicate that their staff take their concerns seriously. The 6 who disagree with the statement on the survey are distributed evenly among the three populations.

Staff take consumer's concerns seriously by age: 4 of the 6 respondents who report that their staff do not take their concerns seriously are 23 years of age or older.

Staff take family's concerns seriously: 42 of 46 respondents report their staff take their family members' concerns seriously. Only two individuals indicate disagreement with the statement on the survey. Analysis by disability or age would not yield meaningful results at this time.

Recommendations:

We recommend retaining questions 31A and 31B as modified under Analytical and Substantive Considerations.

PART 2. ACCOUNTABILITY/RESPONSIBILITY TO ACHIEVE OUTCOMES: PERFORMANCE INDICATORS

4. Consumer and Family Empowerment

Indicator 1: The proportion of consumers and families who report that they know how to make recommendations to the regional board. (22)

Measure: The number of consumers and families who report that they know how to make recommendations to the regional board by age and disability compared to all people responding.

37. Do you know how to contact the Regional Board for your service area if you have a problem or a suggestion about services you would like to share? [22]

- Yes
- No
- Not sure

Source(s) of Survey Question:

Analytical and Substantive Considerations:

Pretest Findings:

Know how to contact Regional Board by target group: Of 52 respondents, the majority do not know how to contact their Regional Board (n=36) or are not sure how they might contact the Regional Board (n=6). The remaining 10 respondents who do know how to contact their Regional Board with a suggestion or problem are fairly evenly distributed among the 3 populations.

Know how to contact Regional Board by age: 9 of 10 respondents who report they know how to contact their Regional Board are 23 years of age or older.

Recommendations:

We recommend retaining the indicator and survey question.

Indicator 2: The number of consumers and families who report that their recommendations regarding changes in the service system were acted upon. (23)

Measure: The number of consumers and families reporting that their recommendations regarding changes in the services were acted upon by age and disability compared to all consumers and families reporting.

Survey Question(s):

38. In the past year, have you made a suggestion(s) to the Regional Board? [23]

- Yes
- No (skip to question 40)

39. If you made a suggestion(s) to the Regional Board, what happened: (check one, then skip to question 41) [23]

- They listened and changed things
- They listened but nothing changed
- They listened, but they are still thinking or talking about the issue I raised
- They didn't listen to me
- Other: _____

- Y N advocate for me with my service providers/help stick up for me
- Y N get housing or advocate for housing
- Y N change my supports/services when I ask
- Y N meet with me to discuss my wishes and services (please check how often you would like to meet):
- _____ once a year
- _____ once every 3 months
- _____ once every month
- _____ Don't know
- Y N Other (please describe _____)

42. Do you have a service coordinator/case manager? [26]

- _____ Yes
- _____ No (skip to question 44)
- _____ Don't know (skip to question 44)

Source(s) of Survey Question:

Analytical and Substantive Considerations:

Interviewers report that the repetition of question 41 was bothersome to some respondents. Although the extent of assistance and support service coordinators provide to their consumers is valuable information for CQI activities, as an indicator, the availability of service coordination is the primary concern (e.g. the quality of the coordination should be addressed through other methods.) Question 42, which initially served as the screen for question 43, is the question which more efficiently addresses the measure as stated. However, we recommend data on the availability of service coordination be gathered from the MIS system, as the terminology (e.g. some direct support workers are called case managers.) may be confusing to some consumers

Pretest Findings:

Service coordination by target group: 17 of 23 consumers of mental health services report that they have a service coordinator. 9 of 11 consumers of mental retardation services report they have a service coordinator, and 11 of 16 substance abuse service consumers report they have a service coordinator/case manager. The high ratio of substance abuse service consumers with service coordinators may be misleading, as many of those consumers were interviewed on-site at a day treatment facility. The sustainability of service coordination may be better addressed with a more diverse sample (for example, assuring that persons using substance abuse services over the long term are included in the sample.)

Service coordination by age: 9 of 13 respondents between the ages of 0 and 22 have a service coordinator, and 28 of 36 respondents 23 years of age and older have a service coordinator.

Recommendations:

We recommend removing questions 41 and 43 from the consumer survey. Further, although question 42 remains in the consumer survey, the primary source of data regarding the availability of service coordination should be the state MIS system.

PART 3. RESOURCE UTILIZATION: PERFORMANCE INDICATORS

4. Access to Services

Indicator: The proportion of consumers reporting that they are able to secure quality services when and where needed. (31)

Measure: The number of consumers reporting that they are able to secure services when and where needed by age and disability compared to all consumers reporting.

Survey Question(s):

44. Have you asked for services and not gotten them? [31]

- Yes
- No (skip to question 46)

45. What were the service(s) you did not get? (please list them below) [31]

46. Are most of your services provided at locations that you prefer? [31]

- Yes
- Somewhat
- No

47. Are most of your services available at a time that is good for you? [31]

- Yes
- Somewhat
- No

48. When you call with a serious problem, how soon does someone usually speak with you? [31]

- _____ I can speak with someone right then and there
- _____ They call back less than 24 hours after I call them
- _____ They call back one to two days after I call
- _____ They take more than 2 days but less than 1 week to call back after I call
- _____ They call back one week or longer after I call
- _____ I have to call again
- _____ I've never called with a problem
- _____ Other (please describe _____)
- _____ Don't know

51. Were there substance abuse services you would have used but were unable to obtain in the past year? [31]

- _____ Yes
- _____ No (skip to question 53)

Source(s) of Survey Question(s): Questions 46-48 were adapted from the MHSIP Report Card.

Analytical and Substantive Considerations:

Question 44 of the Consumer Survey addresses whether consumers are able to secure services. Question 46 addresses whether services are provided where consumers prefer, and questions 47 addresses whether services are provided when the consumer needs them. Although question 48 addresses one dimension of convenience of service (e.g. timeliness of response), this dimension may be addressed through other means (for example, provider CQI practices, in the function surveys, ad hoc studies.)

Although questions 51 and 52 address specific services, these can and should be included in responses to questions 44 and 45. Therefore we recommend deleting questions 51 and 52. Further, as questions 49 and 50 address issues of function, we recommend removing them from the consumer survey and addressing them in other surveys.

Pretest Findings:

Service access by target group: 9 of 52 respondents report they asked for and did not receive services. 4 of 23 mental health service consumers report they did not receive services; 2 of 12 mental retardation service consumers and 2 of 16 substance abuse service users report they did not receive requested services.

Service access by age: 8 of the 9 respondents not receiving requested services are 23 years old or older. 1 is between the ages of 13 and 22.

Services not received: SEE DATA

Convenience of location of services: Only 3 of 52 respondents report that services are not provided in locations they prefer. Analysis by age and disability would not yield meaningful results at this time and might compromise respondent confidentiality.

Convenience of time of services by age: 34 of 45 respondents report that services are provided at a time that is convenient for them. 5 report that the time of services is somewhat convenient, and 6 report inconvenience. Of those 6 reporting that services are not provided at a time convenient for them, 4 are 23 years of age or older.

Timeliness of response: 35 of 46 respondents report that their calls for assistance are responded to within 2 days. 29 of them report that they are responded to in less than 24 hours.

Recommendations:

We recommend deleting questions 51 and 52 from the consumer survey. Question 48 may also be deleted if timeliness of response is addressed in another survey or assessment process.

5. Resource Allocation for State-of-the-Art Services

Indicator: The proportion of consumers receiving the following state of the art services or interventions by disability and age: (34)

Supported employment;
Court diversion programs;
Family support, respite and in-home crisis support (including wrap around services);
Medication management and education;
Self-help programs;
Clozaril, Risperidone, and other psychoactive medication trials;
Supported housing;
Therapeutic foster care;
Group homes for recovering youth;
Family treatment for substance abuse;
Flexible funding.

Measure: The number of consumers receiving each of the above services compared to all people receiving services, by disability and age.

Survey Question(s):

4. What specific services are you receiving? (check all that apply):

- Residential services
- Work or vocational services
- Respite/family support
- In-home support
- Early Intervention
- Transportation
- Day activity/treatment
- Hospital/ inpatient treatment
- Clubhouse
- Crisis Intervention
- Medication management
- Medication education
- Clozaril, Risperidone, or
other psychoactive
medication trials
- Detoxification
- Methadone treatment
- Self-help groups
- Counseling/Therapy/
behavioral specialist
- Service coordination/case
management
- Supported employment
- Court diversion program
- Supported housing
- Therapeutic foster care
- Group home for recovering
youth
- Family treatment for
substance abuse
- Other (please list below)

Source(s) of Survey Question:

Analytical and Substantive Considerations:

These data are more accurately collected through the state MIS. Although as sample size increases, data on state of the art services collected through the consumer survey may be more easily accessed for analysis. (That is, service data and survey data may be contained in the same database and analysis by specific service may be accomplished quickly.) Therefore, we recommend continuing to collect data on state of the art services in the consumer survey.

Data on “flexible funding” as a service should be collected through the state MIS.

Pretest Findings:

The small sample size and small N’s for each of the services preclude analysis by age and disability at this time. However, frequencies of each service for the total sample of 52 respondents are reported below.

SERVICE	NUMBER OF CONSUMERS USING THE SERVICE
Supported employment	4
Court Diversion Programs	9
Family support, respite and in-home crisis support (incl. wrap around)	5
Medication Management and Education	Management = 20 Education = 12
Self-help programs	16
Clozaril, Risperidone and other psychoactive medication trials	6
Supported Housing	1
Therapeutic Foster Care	0
Group Homes for Recovering Youth	0
Family Treatment for Substance Abuse	10

Recommendations:

These data can be collected in the consumer survey as well as maintained in state MIS systems.

Recommendations

This section summarizes the substantive recommendations of the Methodological and Implementation and Survey Pretest sections. Editorial recommendations for the Consumer Survey are not repeated in this section; a revised survey with recommended edits is included in the Appendix.

We recommend continued use of the consumer survey as a means to measure the HB 100 indicators identified in the table and in this chapter. With adequate survey and data management procedures, the survey should yield meaningful data for analysis for these indicators.

Sampling:

1. We recommend that, initially, the Consumer Survey is implemented for statewide level of analysis. After the first year of implementation, Region level comparisons can begin through the incremental additional of regional cells for data collection (likely 2 -- 3 Regions added in Year 2 of implementation.) A sample of 3000 respondents, 250 in each of 12 data cells (3 populations by 2 age groups by two locations) should be sought in Year 1.
2. We recommend sample selection include consumers who are/were receiving services 3 months prior to the date the sample is drawn. With this approach, current consumers and those who have left services are included in the sample. Additionally, 3 months appears sufficient time to assess attrition while hopefully not so long a time that individuals addresses change or they are lost to the providers.

Interview Method:

1. We recommend continuation of both the telephone and in-person interview methods.
2. We recommend the state track proxy responses by disability (e.g. the rates at which family members and other answer for the consumer.) In subsequent years of implementation, the type of interview may be targeted to accommodate or correct trends, if any, in proxy responses.
3. We recommend careful monitoring of the total costs of both interview methods. Costs of in-person interviews must include the costs of travel and travel time for the interviewer.

Instrument:

1. We recommend substitution of major functional limitation questions for the level of function questions in the consumer survey
2. Editorial and structural changes in the consumer survey are address in the pretest section. Those recommendations are incorporated in the revised consumer survey found in the Appendix.

APPENDIX _____

Analysis of Existing Data Source: Individuals Contacted

PART 1. QUALITY OF LIFE ISSUES

4. Health and Safety

Indicator 2: The proportion of youth reporting decreased access to alcohol and tobacco during the reporting period.

- a. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- b. Margaret Cone, former coordinator of Regional Substance Abuse activities at DMHM RSA.
- c. Jim Granade, Ph.D., Prevention Consultant for the Research, Development Training and Redeployment Support Services, DMHM RSA. Telephone: 404 657-2136
- d. Doug Hall, Director of PRIDE Survey . Telephone: 404 577-4500
- e. Dr. Laura Kahn, Center for Disease Control
- f. John Roddy, Georgia Department of Education, (CDC's contact for Georgia Youth Risk Behavioral Study)
- g. Sandy Demin, The Director/Coordinator of the Georgia Department of Education's Safe and Drug Free School System. Telephone: 404 651-9406
- h. Doug Bachtel, Ph.D., Senior Author of the Georgia Country and Director of the University of Georgia Alcohol and Other Drug School Survey. Telephone: 706 542-4894
- i. Susan Paul, Coordinator of University of Georgia Alcohol and Other Drug School Survey. Telephone: 706 542-4936
- k. Peter Gillespie, Director of Metropolitan Atlanta Council on Alcohol and Drugs

PART 2: ACCOUNTABILITY/RESPONSIBILITY ISSUES

1. Consumer and Family Grievances

Indicator 1: The proportion of grievances that are resolved at the regional level within a specified period of time, by category of grievance(i.e., rights issues, services issues, physical plant issues, and ancillary support issues).

- a. Phyllis Lloyd, Project Manager, MIS Unit.
- b. Jeanie McCuin, Director of Constituent Services.
- c. Marta Fernandez, Rights and Advocacy Coordinator.
- d. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- e. Andy McCollum, Executive Director, Athens Regional Board.

2. Provider Accountability

Indicator 1: The number of contract outcome indicators that were not achieved but were remedied with a year.

Measure:

The number of contract violations in the previous reporting period that were remedied by the current reporting year compared to the total number of contract violations in the prior reporting year.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. George Johnson
- c. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- d. Andy McCollum, Executive Director, Athens Regional Board
- e. John Biao, Director, Quality Improvement.

3. Decentralization of Decision-Making

Indicator 1: The proportion of the Regional Board Members who are primary consumers and family members by type and disability (compared to all people on the regional board, by disability).

Indicator 2: The proportion of Community Service Board Members who are primary consumers and family members by type of disability (compared to the all people on the CSB, by disability).

Indicator 1: The proportion of Regional Board Members who are minorities (compared to the proportion of minorities in the region's population).

Indicator 2 The proportion of Community ServiceBoards Members who are minorities (compared to the proportion of minorities in the community service area).

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- c. George Johnson
- d. Andy McCollum, Executive Director, Athens Region

5. Responsiveness to Local Concern:

Indicator 2: Regional Boards fund community prevention initiatives, in partnership with schools, churches, civic groups, law enforcement, and business, and use multiple prevention strategies to address at risk populations.

Measure:

Number of prevention grantees and dollars allocated to prevention per region with counts of programs by a) population risk category, b) age/race category, and c) prevention strategy.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- c. Margaret Cone, former coordinator of Regional Substance Abuse activities at DMHM RSA
- d. Jim Granade Prevention Consultant for the Research, Development Training and Redeployment Support Services Telephone: 404 657-2136

e. Peter Gillespie, Director of Metropolitan Atlanta Council on Alcohol and Drugs

PART 3 RESOURCE UTILIZATION

1. Reallocation of Hospital System Resources to Community Services

Indicator 1: Regional utilization (DACE) for all cost centers associated with the Hospital Resources Allocation Formula are within the fair share allocation for each Region.

Measure:

The number of Regions that achieve utilization targets agreed upon between Region and the Division.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.
- c. John Baio, Director, Quality Assurance
- d. Andy McCollum, Executive Director, Athens Regional Board
- e. Lynne Wright, Special Assistant to the Deputy Director

Indicator 2: Regions purchase agreements demonstrate that an increasing number of community services are developed for people with severe and persistent mental illness, mental retardation and people with substance abuse problems.

Measure:

For each Region, the amount of program resources expended for community services for people with severe and persistent mental illness, mental retardation and people with substance abuse problems compared to the program resources for these persons in the previous fiscal year.

- a. Phyllis Lloyd, Project Manager, MIS Unit

b. Darlene Meador, Ph.D., Acting Director, Research, Development, Training and Redeployment Support Services Section, DMHM RSA.

c. John Baio, Director, Quality Assurance

d. Andy McCollum, Executive Director, Athens Regional Board

4. Access to Services

Indicator: The proportion of consumers who meet the definition of Most-in-Need

Measure:

The numbers of consumers who meet the definition of Most-in- Need compared to the number of consumers served by age and disability.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Bruce Bailey, Coordinator of MHMRMIS
- c. Charles Beard, Senior Programmer MIS Unit

Indicator: The number of children under 18 receiving services increases.

Measure:

The number of children under 18 receiving services by disability and age.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Bruce Bailey, Coordinator of MHMRMIS
- c. Charles Beard, Senior Programmer MIS Unit

5. Resource Allocation for State-of-the Art Services

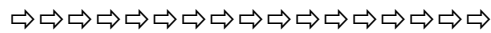
Indicator: The proportion of consumers receiving the following state-of-the-art services or interventions by disability and age:

Measure:

The number of consumers receiving each of the above services compared to all people receiving services, by disability and age.

- a. Phyllis Lloyd, Project Manager, MIS Unit
- b. Bruce Bailey, Coordinator of MHMRMIS
- c. Charles Beard, Senior Programmer MIS Unit

CHAPTER 3



Analysis of the Feasibility of Data Generated from a Consumer and Family Survey

Introduction

This chapter discusses a pilot test of a Consumer and Family Survey to gather data for indicators and corresponding measures developed in response to the H.B. 100 legislation by the Georgia Department of Human Resources, Division of Mental Health, Mental Retardation, and Substance Abuse. Data that were not available through already existing sources in the state, as described in Chapter 2 above, were sought through a variety of methods including the Consumer and Family Survey (the Stakeholder and Regional Board Surveys are discussed in Chapters 4 and 5 respectively).

The pilot Consumer and Family Survey collects data for 17 of the original 33 proposed HB 100 performance indicators. Under Part 1. Quality of Life Indicators, the Consumer and Family Survey collects data for several indicators in each of the six domains: (1) Jobs and Education, (2) Housing, (3) Independence, (4) Health and Safety, (5) Community Connections, and (6) Choice (total 12 indicators). For Part 2. Accountability Indicators, the pilot Consumer and Family Survey addresses the domains of Consumer and Family Empowerment and Service Coordination (a total of 3 indicators). The domains of Access to Services and Allocation for State-of-the-Art Service under Part 3. Resource Utilization Indicators are addressed in the pilot Consumer and Family Survey (a total of 2 indicators.).

The chapter is divided into three content areas: (1) Methodological and Implementation Concerns, (2) a question by question Review of the Pilot Survey, and (3) Recommendations for application in Georgia. A revised Consumer and Family Survey, incorporating the recommendations in this chapter, can be found in Appendix J. Under Methodological and Implementation Concerns, issues of sampling, interview method, and alternative interviewers are addressed. The Survey Pretest section presents findings from the pilot administration of the Consumer and Family Survey in the Northeast Georgia Region. The reader should note that the pilot was intended to test the applicability of the Consumer

and Family Survey among the three populations -- people with mental illness, mental retardation, and substance abuse problems -- and to test whether certain data could or should be gathered through this method. Data collected in the Consumer and Family Survey *should not* be construed to represent normative rates and cannot be used to describe the characteristics of the population of service users in the Northeast Georgia Region area. Finally, recommendations for the revision of the Consumer and Family Survey and for implementation throughout Georgia are addressed in the Methodological and Pretest sections and summarized in the Recommendations section.

Methodological and Implementation Concerns

This section explores the methodology and implementation of the pilot Consumer and Family Survey in the Northeast Georgia Region. The section is organized around four primary concerns for implementation: (1) instrument development; (2) sampling; (3) conducting interviews; and (4) the feasibility of the Consumer and Family Survey. The question by question review of the pilot survey follows this section.

Instrument Development:

A variety of instruments employed by states and stakeholder groups were examined for their application to the Georgia Consumer and Family Survey. For each instrument, the following three concerns guided this examination:

1. The instrument makes direct inquiries of or about the service consumer and/or the family;
2. The instrument questions have relevance to the indicators or measures developed for Georgia;
3. The instrument questions may be taken verbatim or may be adapted to measures for Georgia for ease of direct comparisons.

No single instrument addressed all the concerns of the Georgia indicators, however several instruments addressed some or many. Selection of survey instrument questions for inclusion in the Georgia Consumer and Family Survey was based on how closely the question under examination directly answered the concerns articulated by Georgia. For ease of comparison to Georgia's data, questions and response options were taken verbatim whenever possible from examined instruments. Minor adaptations also were made to some survey questions or response options when necessary. The sources of survey questions for Georgia's Consumer and Family Survey are noted in the Survey Pretest section of this chapter.

Some indicators and measures could not be located in other instruments (for example, transportation issues and contact with the regional board.) In those cases, HSRI developed the questions for the Consumer and Family Survey. Five instruments figured prominently in the development of the Consumer and Family survey for Georgia. Phrases and acronyms in parentheses below denote

how the instruments are identified within the Pretest section. The instruments cited in the Consumer and Family Survey are:

1. The Colorado Progress Assessment Review (COPAR).
2. The Cross-Disability Integrated Health Outcomes Survey (CDIHOS).
3. The (Lehman) Quality of Life Interview for Persons with Severe Mental Illness
4. The Draft Report to the NY Mental Health Task Force Subcommittee of the New York State Medicaid Managed Care Advisory Committee, Performance Measurement Section. (NYS Task Force)
5. The Mental Health Statistics Improvement Program (MHSIP) Consumer-Oriented Mental Health Report Card

A complete listing of instruments examined for the Georgia Consumer and Family Survey is included in the Appendix K.

A draft version of the Consumer and Family Survey was reviewed by members of the Northeast Georgia Regional Board and the Northeast Georgia Center. Reviewers were invited to comment on the survey construction and content. Additionally, focus groups were conducted in Massachusetts with each of the three target populations: mental health service consumers, mental retardation service consumers, and substance abuse service consumers. Participants were asked to comment on survey length, content, and clarity. Some modifications to survey questions and response options resulted from focus group observations. Each group reported that they understood the questions on the survey and that they could respond to those questions. Focus group participants were paid \$5.00 for their participation in a one hour meeting.

Sampling:

Pilot:

Four hundred consumers from the Northeast Georgia Center were randomly selected for the pilot test of the Consumer and Family Survey. Letters requesting consumer participation and offering nominal compensation for their time (\$5) were sent, with consent forms, to prospective pilot participants. Consumers using subacute detoxification day services and consumers residing at the Georgia Regional Hospital in Augusta were offered the opportunity to participate on-site.

Table 15 shows the number of request letters mailed to consumers by service population.

Table 15
Mail Sampling

SERVICE POPULATION	ESTIMATED POPULATION SIZE	NUMBER OF REQUESTS MAILED
MR Org. Employment	350	40
MR Community Empl.	40	32
MR Comm. Support (Adult)	250	48
MR Comm. Support (<Age 21)	50	40
MH Outpt. (Adult)	2300	40
MH Outpt. (Elderly)	125	40
MH Outpt. (Child)	700	40
MH Multiple Agencies	525	40
Alcohol & Drug Svcs. open > 1 year	66	40
Alcohol & Drug Svcs. open <1 year	66	40

Approximately one fourth of those contacted by the Northeast Regional Center agreed to participate in the pilot test of the survey. Because of time and other constraints, fifty-two individuals (13%) were surveyed. The number of respondents by disability and age category are listed in Table 16. Data are presented in aggregate form due to the small sample size.

Table 16
Respondents

POPULATION	NUMBER OF RESPONSES
DISABILITY: Mental Health	23
Mental Retardation	12
Substance Abuse	16
Missing	1
AGE: 0 -- 12	4
13 -- 22	9
23 and older	37
Missing	2

Response Rate:

As noted above, 13% of the original sample of 400 were surveyed. In order to control for selection bias and to achieve a sample of the magnitude suggested in the Statewide Sampling section below, sampling in the future should occur in a rigorous and strategic manner. Prior to and as sample selection occurs, regions should make efforts to inform consumers of the survey process. These efforts might include discussion of the survey at regional and community service board meetings, press releases, mail notices to and postings notices at service sites, announcements at staff meetings and presentations to self-advocacy organizations. As an incentive to respondents, calling cards that are activated for free calls or minutes might be mailed to consumers after they call in for the interview. Pilot staff in the Northeast Georgia Region also suggest that the initial sample (400 in this case) should be significantly larger given the proportion of individuals who ultimately consented.

A further problem in the pilot test had to do with the accuracy of addresses and phone numbers for consumers. Of the initial mailing, a substantial number of letters were returned "addressee unknown." The returned mail slowed the process and required drawing additional consumers for the sample. Based on the experience in the pilot test, staff at the Northeast Georgia Region have made changes to their computerized data base as well as tightening procedures for updating identifying data. Clearly, updating provider databases will be a prerequisite for efficient administration of the consumer survey.

Additionally, systematic follow-up for consenting participants is required (In the pilot, over 100 individuals indicated consent to be interviewed, however only 52 could be contacted and interviewed). Finally, point-of-service interviewing (interviewers ask consumers to participate in the survey while the consumer is at a service) is one method that should be considered to enlarge sampling size although only when other avenues have been exhausted.

Statewide Sampling:

In order to meet the analysis demands for the H.B. 100 indicators, respondents will have to be sampled from a minimum of 12 sub-populations: 3 groups of service users (Mental Health, Mental Retardation, and Substance Abuse), 2 settings (community and hospital/center), and 2 ages (adult and child.) There should be at least 250 respondents in each cell to allow for meaningful analyses. A statewide survey, therefore, necessitates a minimum sample size of 3000 respondents to yield meaningful results. If regional or provider level analyses

are desired, the number of respondents required (sample size) will increase accordingly.

A survey of 3,000+ respondents is a very large undertaking for any state. Because the sample required to represent numerous smaller sub-state levels would be considerably larger, we recommend implementing the Consumer and Family Survey on the statewide level, and then moving to the regional level in subsequent years of implementation (i.e., adding 3 regions each year.) This strategy will allow data managers and data collectors the opportunity to continue refinement of the survey instrument and survey process if necessary, and will allow for thoughtful planned training and development of data collectors within the state. :

Targeted Samples:

Sampling consumers randomly may yield an adequate picture of consumer and family member perceptions of how the service system is operating for most people. However, policy concerns may arise that will require oversampling of certain specific sub-populations. For example, the state might wish to learn more about the perceptions of individuals who drop out of the service system before treatment is completed or about individuals with specific combinations of problems (e.g. persons with both mental health and substance abuse concerns, or children with developmental and mental health issues). These concerns can only be addressed through targeted special purpose studies that oversample people with particular characteristics.

Conducting the Interviews:

Interviewer Training:

Interviewers were identified and hired by GEST, Inc., a consumer run quality enhancement organization. Celia Feinstein of Temple University's Institute on Disability/UAP conducted a half-day training on the survey instrument and interview technique. Ms. Feinstein is viewed as the ideal interviewer trainer for this pilot as Ms. Feinstein has trained scores of data collectors throughout the country, including interviewers with developmental, psychiatric and physical disabilities.

The half-day training included an item-by-item review of the instrument and instructions for correctly completing the forms. In response to observations

made by Ms. Feinstein and the interviewers at the training, some minor changes (such as wording and order of items) were made to the pilot instrument.

Phone and In-person:

In order to test alternative methods of administration, the survey instrument was administered to consumers over the telephone or in-person. Thirty-one telephone interviews and 18 face-to-face interviews were conducted for the pilot of the Consumer and Family Survey (3 cases did not indicate type of interview).

The majority of interviews with consumers of mental health services (16 of 23) were conducted over the telephone, as were the majority of the interviews with consumers of mental retardation services (10 of 12 interviews were conducted by telephone.) For consumers of substance abuse services, only 6 of 16 interviews were conducted by telephone. Presumably the remaining 10 substance abuse service users were among those contacted at the day treatment site for interviews.

No substantial differences by interview method were noted. Telephone interviews took on average 37 minutes to complete: in-person interviews averaged 31 minutes for completion. However, these completion times for the face to face interviews do not include the travel time required of the interviewer. Rates of missing responses did not vary by interview method either.

The use of telephone interviewing has precedent in other parts of the country. Administration of consumer surveys in the Colorado developmental disability system is done by phone as are systemwide interviews of mental health consumers in Indiana.

Of course limiting a consumer and family survey to people who have access to telephones will limit the sample and will skew the results. Therefore, we recommend that the state ensure that those without access to phones have the opportunity to participate in the survey either through face-to-face interviews or at the point of service. When point-of-service interviews are held, they should be conducted in a fashion that will ensure the confidentiality of the results.

Conducting the Interviews:

Assistance with response

Interviewers are asked to report who (if anyone) assisted the consumer to answer and what level of assistance s/he provided the consumer (e.g., answering on behalf of the consumer, providing explanations or translations, or other.) Of 22 individuals receiving assistance to answer the survey, 18 had total help (that is, usually a family member answered for the consumer.) Nine of 23 mental health service consumers, 11 of 12 mental retardation service consumers, and 2 of 16 substance abuse service consumers received assistance in responding.

The level and frequency of assistance provided to respondents in this pilot are somewhat surprising. In Colorado, for example, 40% of respondents with mental retardation are able to respond to the COPAR. Although the consistency of responses among actual and proxy respondents may vary, the benefits of consumer and family input and evaluation of services far outweigh the limitations of proxy responses.

We have no clear indications of why high levels of assistance were used in the pilot test of the Consumer and Family Survey. As a safeguard, we recommend that interviewer training emphasize the preference for primary consumer responses and encourage interviewers to survey respondents directly.

Conducting the Interviews:

Interviewers:

GEST, Inc., a consumer-run quality enhancement organization, conducted the interviews in the Northeast Georgia Region for the pilot. There are extensive benefits of using present and former service consumers as interviewers. These include (but are not limited to) the level of comfort experienced by respondents, the fostering of professional development and growth within the consumer community, and the coherency achieved within the system where the stated concern is consumer input and consumer professionalism and employment are fostered. Additionally, there may be cost savings to the state as well, since some of these organizations have considerably lower overhead costs than the typical professional survey company.

Most of the consumer organizations that states have used for data collection are multi-purpose advocacy and support operations. They have available to them

numbers of individuals with highly relevant experiences who can be trained to collect data. However, they may not have the highly developed infrastructure of professional survey companies. As a result, the state may have to play a more active role in assisting these organizations to develop procedures related to sampling, interviewer training, mechanisms for assessing data quality, and procedures for data handling.

The department has three options in selecting interviewers:

1. *Contract with a professional survey firm.* In doing so, there will be higher levels of predictability and quality control. The costs incurred will likely be higher as well.
2. *Hire a consumer organization.* In doing so, the state gains the advantage of having interviewers who understand the experience of other consumers and may be able to put respondents at greater ease during the interview. Due to lower overhead costs, the cost to the state may be lower. However, training and quality oversight needs may be greater.
3. *Contract with a professional survey firm to hire and train consumer data collectors.* Training and capacity building will occur within the consumer community; costs for data collection may be greater; the need for oversight by the Department may decrease.

Feasibility of Consumer and Family Survey

The purpose of the pilot/pretest was to: (1) explore whether the questions can be understood by persons with disabilities and whether they can be answered in an unambiguous fashion, (2) explore whether data relevant to the selected performance indicators can be collected through the Consumer and Family Survey, and (3) explore whether there is any variation in consumers' responses. All findings presented below should be viewed in this context and should not be misconstrued as representative of whole populations nor as establishing normative rates of any kind.

Data Can Be Collected

The Consumer and Family Survey can be used efficiently in Georgia. The findings of the pilot indicate that data can be collected in this manner. Few questions or sections yielded high rates of missing responses. For some questions, a high number of respondents chose the least likely response option

(usually “other”). Those responses can be attributed to unclear questions in the pilot Consumer and Family Survey. For example, questions about consumers’ choice in housing yielded ambiguous results. Twenty-three percent of pilot respondents selected “other” in response to “who chose your home?” Analysis of write-in responses indicated that the response options and directions to interviewers were unclear. Those individuals selecting “other” were likely indicating they had no choice in their housing, and in the “other” response they identified who in fact did choose their home. The survey question has been edited to allow respondents to first respond whether they chose their homes and then to identify who, if anyone other than themselves, chose their home. Similarly, 19% of pilot respondents selected “other” in response to the question about what trouble they were having with their transportation. In this instance, write-in responses indicated that the response option “I rely on others for my transportation” is needed on the survey form.

Consumers were able to answer most survey questions. Where ambiguity in responses was found, editing (in the form of greater clarity or choice of response options) of the Consumer and Family Survey is hoped to remedy this problem.

Survey Items Vary Predictably:

The Consumer and Family Survey yielded expected variations in response by population. For example, rates of victimization of crime varied by population and age. In the pilot sample, persons with mental illness and persons with substance abuse problems report they were victims of both violent and non-violent crime, while no persons with mental retardation report being victims of crime . This variation by population is expected, given the unique needs and circumstances of the different populations. Similarly, the only respondents in the pilot to report they work in sheltered workshops are persons with mental retardation, thus reflecting the variations in service design among the three populations. The Consumer and Family Survey pilot further found that persons using substance abuse services reported in greater proportion that they needed, but were unable to obtain HIV/AIDS services. This variation, as well, is expected due to the unique needs and circumstances of the populations responding.

Where variation was expected but not found with the Consumer and Family Survey, the survey question and interviewer technique were examined for clarity and changes are recommended. Some survey questions did not yield expected variations. In some cases, this may be remedied through adjustments to the instrument (such as adding response options or clarifying directions to the interviewer). Other times, the data may be more accurately gathered through

another method. For example, 71% of pilot respondents reported that they live in their own homes, and almost none reported living in any program model presented. One may reasonably assume that even when a consumer lives in a boarding house or a community living arrangement, the consumer would identify that residence as his/her own home or apartment, thus the lack of variation in responses. Data about residential services and program models should be available through regional and community service board records, therefore we have recommended removing this question from the Consumer and Family Survey.

Multiple Populations Can Respond:

Difficulties in responding or the presence of missing responses does not vary by population. In general, each population was able to respond to the survey questions except where the survey question itself was problematic (recommendations for correction of problematic questions are presented item by item in the following section). Additionally, availability and legitimacy of assistance in responding to the survey, allows children and persons with cognitive impairments to respond to the survey.

Question by Question Review

The rest of this section is organized by indicator, measure and corresponding survey question. The source of the survey question(s) follows the question(s) and full citations for the source material are included in Appendix K. The subsections titled implementation and application considerations address concerns raised through the implementation of the pilot test, methodological issues specific to each indicator or survey question, and findings regarding the clarity of the question(s) and variations in consumers' responses. Recommendations regarding changes in the survey instrument and/or its implementation follow. Calculations of the raw data to answer the measure and recommendations are provided where necessary. At the conclusion of this question by question review, we provide examples of how some of the data may be analyzed and graphically displayed.

Part 1. Quality Of Life: Performance Indicators

1. Jobs and Education

Indicator 1: (For MH and DD) The proportion of consumers working in integrated employment settings increases.

Measure: Analysis of trends in the distribution of consumers, by disability and age, working: 1) in full-time employment; 2) part-time employment; 3) full time in supported employment; 4) part-time in supported employment.

Survey Question(s):

5. Do you work for pay?

Yes

No (please go to question 11)

6. Is this job in a sheltered workshop?

Yes

No

7. Do you have a special supervisor or job coach?

Yes

No

Don't know

8. How many hours do you usually work each week? (check one) [1]

less than 8 hours

8 -- 16 hours

17 -- 24 hours

25 -- 32 hours

33 -- 40 hours

over 40 hours)

don't know

9. Do you work closely with any people without disabilities? [1]

Yes

No

11. What is the highest level of education and/or training you completed? [1]

[2]

less than 8th grade

- 8th grade
- Some high school
- High School degree
- Technical/Vocational degree
- some college
- Associate degree
- Bachelor degree
- Graduate degree
- Don't know

15. Are there other students without disabilities in most of your classes (at least half of the school day)? [1]

- Yes
- No

Source(s) of Survey Question(s): Questions 5 and 8 were adapted from CDIHOS. Question 9 was adapted from COPAR (Question 9). Lehman Quality of Life (Questions 4-8), was also consulted in selecting these questions.

Implementation and Application Considerations:

Interviewers reported no problems with the interview questions for these measures.

Employment rates (work for pay) varied by disability in the pilot, as did the location of work (sheltered workshop v. integrated settings).

Recommendations:

We recommend adding a skip instruction to question 6 of the survey so that those who work in sheltered workshops do not mistakenly answer questions about supported employment. Additionally, question 9 ("Do you work closely with any people without disabilities?") should precede question 7 ("Do you have a special supervisor or job coach?").

Indicator 2: The proportion of consumers in recovery from alcohol and drug dependence who report that their employment is consistent with their skills.

Measure: The number of consumers in recovery who report that their employment is consistent with their skills compared to all people in recovery reporting.

Survey Question(s):

10. Do you feel the work you do is consistent with your skills and qualifications?

[2]

- Yes
- No, I am overqualified for the work I do
- No, I am underqualified for the work I do
- I don't know

11. What is the highest level of education and/or training you completed? [1]

[2]

- less than 8th grade
- 8th grade
- Some high school
- High School degree
- Technical/Vocational degree
- some college
- Associate degree
- Bachelor degree
- Graduate degree
- Don't know

Source(s) of Survey Question(s): These questions were developed by HSRI staff.

Implementation and Application Considerations:

In addition to its value as demographic data about the consumers of services, highest level of education may also be useful for interpreting reports of over- or under-qualification for work.

Although the indicator above applies only to persons in recovery from alcohol and drug dependence, all consumers who reported working for pay responded to this question. Variation within and among groups can be found with this question.

No problems were associated with these questions.

Recommendations:

For adults, we recommend adding a question about the number of work days lost due to disability. This measure of major functional limitation is included in several standardized tests, and provides the state with the opportunity to compare Georgia’s results with norms established by those tests. The revised Consumer and Family Survey should include the following question:

During the last six months, how many days did you miss work because of your disability?

- 0 days (none)
- 1 -- 5 days
- 6 -- 10 days
- 16 -- 20 days
- more than 20 days

Indicator: The number of school days lost related to disability decreases.

Measure: The number school days lost during the preceding semester by age and disability.

Survey Question(s):

13. Are you 22 years old or older? [3]
 Yes (skip to question 17)
 No

14. Do you go to school? [3]
 Yes
 No (skip to question 17)

16. During the last complete semester (half school year), how many days of school did you miss because of your disability? [3]
 0 -- 5 days
 6 -- 10 days
 11 -- 15 days
 16 -- 20 days
 more than 20 days

Source(s) of Survey Question(s): These questions were developed by HSRI.

Implementation and Application Considerations:

The structure of survey question 16 does not allow for a distinction between students who have missed *no* school due to their disability and students who have missed *up to 5 days* in the previous semester.

Students were able to answer these questions.

Recommendations:

We recommend revising this question to allow for this distinction. The new question would read:

During the last complete semester (half school year), how many days of school did you miss because of your disability?

- 0 (none)
- 1 -- 5 days
- 6 -- 10 days
- 11 -- 15 days
- 16 -- 20 days
- more than 20 days

2. Housing

Indicator: Proportion of consumers who are able to choose their housing.

Measure: Number of people reporting they had the opportunity to make choices about their housing compared to all people reporting.

Survey Question(s):

17. Who chose the home where you live? (check one) [4]

- I chose it
- I chose it with help from:
 - My spouse, housemates, or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say in where I would live
- I don't know
- I live with my parents
- Other (please describe _____)

18. If you don't live with your family, who chose your roommates/housemates?
[4]

- I chose
- I chose with help from:
 - My spouse or friends
 - My parents
 - Other relatives
 - My staff or case manager
- I had no say about who I live with
- I live with my family
- I don't know
- Other (please describe _____)

Source(s) of Survey Question:

Question 17 was adapted from COPAR.

Implementation and Application Considerations:

As least restrictive environment is addressed under a different indicator, the issue of choice in housing applies to adult consumers. Analysis of responses for this measure should be based on adult respondents only.

When pilot responses are examined by target group, no one using mental retardation services reported choosing their home independently. These results do not imply no choice, as no respondent, regardless of target group, reports having no say in where to live. Rather, given the complexity of such a decision, people with mental retardation are receiving support to make informed decisions. Such results suggest that the Consumer and Family Survey is sensitive to variations in populations and choice making.

Twenty-three percent of respondents in the pilot selected "Other" as a response to "Who chose the home where you live?" This selection suggests that the response options of the pilot survey are not complete or are confusing to the respondent. Next to the "other" response, interviewers frequently wrote "hospital," indicating that they had overlooked the "I had no say" response option.

Recommendations:

The measure for this indicator should be revised to reflect the presumption that choice in housing primarily applies to adult consumers of services. Additionally, interviewer training should include instructions to select “I had no say” when respondents name the person or institution that did choose. We recommend that the survey questions be revised to include response options that indicate who chose the home where the consumer resides, and recommend that the measure reflect choice of housing as an adult concern. We suggest the following edits:

Measure: Number of adults by disability reporting they had the opportunity to make choices about their housing compared to all adults reporting.

17. *Who chose the home where you live? (check one)*

- I chose it*
- I chose it with help from:*
 - My spouse, housemates, or friends*
 - My parents*
 - Other relatives*
 - My staff or case manager*
- I had no say in where I would live*
(who did choose it _____)
- I don't know*
- I live with my parents*
- Other (please describe _____)*

18. *If you don't live with your family, who chose your roommates/housemates? [4]*

- I live alone*
- I chose*
- I chose with help from:*
 - My spouse or friends*
 - My parents*
 - Other relatives*
 - My staff or case manager*
- I had no say about who I live with*
(Who did choose who you live with _____)
- I live with my family*
- I don't know*
- Other (please describe _____)*

Calculations:

Data can be calculated as the percent of respondents choosing each response option by disability group. The response options “I chose it” and “I chose it with help from...” are positive indications of consumer choice. All other response options do not indicate choice or indicate choice is denied to the consumer.

Indicator: The number of consumers in recovery living in alcohol and drug free housing.

Measure: The number of units of alcohol and drug free housing in each region.

Survey Question(s):

53. Is your place of residence alcohol and drug free? [5]

Yes

No

Source(s) of Survey Question(s): This question was developed by HSRI.

Implementation and Application Considerations:

No problems with consumers' *ability to respond* to this question were noted.

This indicator and its corresponding measure are intended to show whether people using substance abuse services have drug and alcohol free housing. As currently phrased, the indicator implies a level of inquiry (around the term “recovery”) that is neither necessary for the measure nor appropriate for the Consumer and Family Survey. Further, the primary concern for policy makers is the number of units of alcohol and drug free housing available to persons using substance abuse services and not the number of persons living in such housing. The Consumer and Family Survey represents a relatively inefficient method of measuring the number of drug and alcohol free housing units.

Recommendations:

More reliable data can and should be gathered through regional board records. We recommend removing this indicator from the Consumer and Family Survey. Further, we recommend revising the indicator and its measure to read:

Indicator: The number of alcohol and drug free housing units available in the state and by region.

Measure: The number of alcohol and drug free housing units reported by region.

3. Independence

Indicator: The proportion of people living in restrictive living environments decreases.

Measure: Analysis of the trends in the distribution of people, by disability and age, living in 1) own home or apartment with or without support; 2) board and care facility or SRO; 3) supervised group living arrangement (4 residents or less); 4) supervised group living arrangement (5 or more residents); 5) children's residential facility; 6) skilled nursing facility; 7) public institution; 8) homeless shelter; 9) jail or prison; 10) homeless.

Survey Question(s):

19. What type of place do you live in? (check one) [6]

- My own home or apartment
- Boarding/rooming house
- Community Living Arrangement (CLA), group home or apartment
30 hours or more of staff time per week
- Community Living Arrangement (CLA), group home or apartment
less than 30 hours of staff time per week
- Substance abuse halfway house
- Residential substance abuse treatment
- Children's residential facility
- Skilled nursing facility
- Criminal justice halfway house
- State hospital/state school
- Jail/prison/detention center
- I am homeless/live in a homeless shelter
- Other (please describe _____)

Source(s) of Survey Question: Question 19 was adapted from CDIHOS.

Implementation and Application Considerations:

Lay persons and consumers of services may have difficulty making distinctions between living environments on the basis of restrictiveness. Pretest findings suggest that although these distinctions are important in terms of the experienced quality of life of the consumer and in terms of service system design, many consumers do not view their living arrangements in terms of categorical program labels. Little variation was found for this question.

Data for this indicator may be obtained more reliably from state management information systems than from self-reports of individuals not familiar with the terminology.

Recommendations:

We recommend that trends in living environments be addressed through the management information system rather than by consumer self report, as reporting on program models will be more reliable there.

Indicator: The proportion of people who report no major functional limitations compared to everyone reporting.

Measure: The number of people reporting no functional limitations compared to all people reporting by disability and age.

Survey Question(s):

	A. How much help did you need?	B. How often did you need help?
Taking care of your personal needs (go to the bathroom, groom, dress, eat by yourself)	5 4 3 2 1	4 3 2 1
Community living skills (cook, clean, grocery shop, use public transportation, or manage money.)	5 4 3 2 1	4 3 2 1
Dealing with everyday things that change or go wrong, such as a change in schedule, arguments or being on time for appointments.	5 4 3 2 1	4 3 2 1

Making friends, having fun, or doing things that are important to you.	5 4 3 2 1	4 3 2 1
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Source(s) of Survey Question: Question 20 was adapted from CDIHOS.

Implementation and Application Considerations:

Interviewers reported difficulty with this matrix in the pilot of the Consumer and Family Survey.

The substitution of items from the SF-12, developed by Ware, Kisinski, and Keller (1995) for these questions about major functional limitation may prove a more efficient way to obtain a brief measure of functional limitation. The SF-12 items offer the state the possibility of comparisons with other areas, as the SF-12 is a widely used instrument.

Recommendations:

We recommend inclusion of survey questions from the SF-12 and measures of work and school days lost due to disability. Taken together, these items should yield general indications of major functional limitations.

We recommend the substitution of the following questions from the SF-12 in the Consumer and Family Survey:

During the past week, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Accomplished less than you would like

Yes

No

Didn't do work or other activities as carefully as usual

Yes

No

During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time

Most of the time

Some of the time

- A little of the time*
 None of the time

Indicator: The proportion of consumers and families that report support to make the transition from school to work and independent living increases. (8)

Measure: The number of families and consumers that report support to make the transition from school to work and independent living compared to all people reporting by age and disability.

Survey Question(s):

21. Are you graduating from high school this year or have you graduated from high school within the last 2 years? [8]

- Yes
 No (skip to 24)

22. Have you received the support or services you needed to get a job after finishing school? [8]

- Yes
 No

23. Have you received the support or services you needed to live where you want to live? [8]

- Yes
 No

Source(s) of Survey Question: These questions were developed by HSRI.

Implementation and Application Considerations:

The transition from school to work and independent living is typically a young adult experience. For accuracy's sake the indicator and its corresponding measure should explicitly define the target population. No other problems during the pilot were associated with these survey questions.

Recommendations:

We recommend editing the indicator and measure to read:

Indicator: The proportion of consumers and families in the designated age range that report support to make the transition from school to work and independent living increases.

Measure: The number of consumers and families in the designated age range that report support to make the transition from school to work and independent living compared to all people in the designated age range reporting.

The designated age range should reflect the transition practices of the state. Support for transition might begin two years prior to high school graduation. As special education is available to eligible students until the age of twenty-two, the designated age range for this indicator should reflect the beginning and end limits of transition support: ages 16 through 24. The survey question should be changed to:

Are you between the ages of 16 and 24 years old?

- Yes
 No (skip to 24)

4. Health and Safety

Indicator 1: The proportion of consumers reporting that they were the victim of a crime during the past 6 months.

Measure: The number of people reporting that they were the victim of a crime by disability and age compared to all people reporting.

Survey Question(s):

24. In the past year, were you a victim of any violent crimes (crimes that you were a victim of and occurred in your presence), such as assault, rape, mugging or robbery? [9]

- Yes
 No

25. In the past year were you a victim of any non-violent crimes (crimes that you were a victim of but not present when they occurred), such as burglary, theft of your property or money or being cheated? [9]

- Yes
 No

Source(s) of Survey Question(s): Questions 24 and 25 were adapted from Lehman Quality of Life Toolkit and CDIHOS.

Implementation and Application Considerations:

Normative rates should be available from other states using the Lehman Quality of Life scale and the CDIHOS, as well as from nationwide statistics.

Sampling issues may confound the findings of the pretest, since many of the substance abuse service consumers were interviewed on-site at a day treatment program. If these respondents are in the early stages of recovery, they may have been exposed to unsafe conditions more recently than the general population and the population of substance abusers further along in recovery. The issue also may be true of mental health service consumers who are just entering services.

Recommendations:

We recommend retaining the indicator, measure and survey questions as stated.

Indicator: The proportion of consumers and families that report support in securing health services, medication or equipment necessary to sustain their health and independence. (11)

Measure: The number of people reporting that they received support to secure needed health services, medication or equipment, by age and disability, compared to all people reporting.

Survey Question(s):

26. During the past year, have you been able to obtain the health services you needed? (including medication, equipment, medical specialties, Physical Therapy, Occupational Therapy, etc.) [11]

- I didn't need any health services
- Yes, I obtained all the health services I needed
- Yes, I obtained some but not all of the health services I needed
- No, I haven't been able to obtain any health services I needed

27. Did your staff try to help you get the health services you needed? [11]

- Yes
- No
- Don't know

32. Have you used HIV/AIDS services in the past year? [11]

Yes

No (skip to 34)

33. Please check which HIV/AIDS services you have used in the past year? [11]

HIV/AIDS testing

HIV/AIDS counseling

HIV/AIDS medication

HIV/AIDS Education

Physician services

Support groups

Service Coordination/Case management

Other (please describe: _____)

34. Were there HIV/AIDS services you would have used but were unable to obtain in the past year? [11]

Yes

No (skip to question 36)

35. What were the HIV/AIDS services you were unable to obtain? (Please list them below.) [11]

Source(s) of Survey Question(s): Question 26 was adapted from NYS Task Force and MHSIP. Question 27 was adapted from NYS Task Force.

Implementation and Application Considerations:

Questions 26 and 27 address two concerns of the indicator: (1) whether needed health services are available and (2) whether consumers have the support necessary to acquire needed health services.

Questions 32 through 35 were added to the Consumer and Family Survey following the focus group consultation with substance abuse service users.

Recommendations:

Because HIV/AIDS represent a major public health risk and because vulnerable populations often have limited access to health care, we recommend that HIV/AIDS services be treated as a special category within this indicator. Further, although originally suggested by substance abuse service consumers, we

recommend that all service consumers are asked about the availability of HIV/AIDS services.

Question 26 should include a skip direction to those respondents who did not need health services or who received all the services they needed. Only those respondents that report difficulty obtaining health services should respond to whether the staff assisted them in acquiring health services (question 27.)

5. Community Connections

Indicator: Proportion of people that report that adequate transportation is available to them. (12)

Measure: Number of people reporting that transportation is available by age and by disability compared to all people reporting.

Survey Question(s):

28. Do you have any problems with transportation (trouble getting around town, to the grocery store, to your doctor's appointments, to meetings)? [12]

- Yes
 No (skip to question 30)

29. If you don't have adequate transportation, why? (check all that apply) [12]

- I can't afford it
 Public transportation is not available where I live/work
 Accessible public transportation is not available where I live/work
 I don't have a license
 I don't know how to get transportation
 Other (please describe _____)

Source(s) of Survey Question: Question 28 was adapted from COPAR.

Implementation and Application Considerations:

Minor difficulties were associated with this question. In particular, the selection of the response option "other" suggests that the list of possible responses is not sufficient. If the response was available, several pilot respondents would have selected "I rely on friends or family to provide transportation for me." Additionally, interviewers recorded responses that implied, but did not

explicitly state, financial difficulty under “other” (for example, “Need new alternator”). Thus the response options and interviewer training require some minor modifications.

Recommendations:

We recommend instructing interviewers to probe “other” responses and to record vehicle maintenance problems related to insufficient funds as “I can’t afford it.” Further we recommend adding a response option for persons who rely on friends or family for their transportation. Question 29 should read:

29. *If you don't have adequate transportation, why? (check all that apply) [12]*
- I can't afford it (including I can't afford to maintain my transportation)*
 - Public transportation is not available where I live/work*
 - Accessible public transportation is not available where I live/work*
 - I don't have a license*
 - I rely on friends or family to provide transportation for me*
 - I don't know how to get transportation*
 - Other (please describe _____)*

Indicator: Proportion of people reporting that they receive sufficient support to participate in age appropriate social, volunteer and recreational activities.

Measure: The number of people reporting that they receive sufficient support to participate in age appropriate social and recreational activities by disability and age compared to all people responding.

Survey Question(s):

30. Did you need help with any of the following activities in the last month and did you receive the help you needed? [13]

	I needed help (Circle Yes or No)		I got the help I needed (Circle Yes or No)	
Making friends	Yes	No	Yes	No
Attending social functions	Yes	No	Yes	No
Arranging for transportation	Yes	No	Yes	No
Meeting with people to discuss problems we share	Yes	No	Yes	No
Going to religious institutions	Yes	No	Yes	No
Finding or keeping a job	Yes	No	Yes	No
Joining clubs or sports teams	Yes	No	Yes	No
Enrolling or staying in school	Yes	No	Yes	No

Source(s) of Survey Question: Question 30 was adapted from CDIHOS.

Implementation and Application Considerations:

In a few cases, interviewers proceeded to the third column (“I got the help I needed”) when respondents did not indicate they needed help. During training, interviewers should be reminded to proceed to the third column for each item only when the respondent indicates that s/he needed help with the item in question.

Analysis of responses requires the development of a simple scale from the survey question. The activities included in the survey question are derived from the CDIHOS survey and appear to represent typical social and recreational activities. However, the DMHMRSAs may wish to revise these categories over time and as more data are available.

The measure sought for this indicator is the amount of help received for social and recreational activity divided by the amount of help needed. Respondents who omitted whether they needed help or who indicated they did not need help were excluded for the calculation for each activity. Likewise, respondents indicating a need for help but omitting answers to whether they received the help were excluded from calculation. As more data are collected, proportions can be calculated for each social/recreational activity listed, if desired.

Recommendations:

We recommend retaining the indicator and survey questions.

Calculations:

The percent of needed assistance received is calculated as: (Sum of Yes responses in Column 3)/(Sum of Yes responses in Column 2) * 100.

6. Choice

Indicator: The proportion of consumers reporting that their preferences were sought and acted upon in the preparation of their service plans.

Measure: The number of consumers reporting that their preferences were sought and acted upon in their service plans compared to all consumers reporting, by disability and age.

Survey Question(s):

31. Please indicate how much you agree with the following statements (on a scale of 5= strongly agree to 1= strongly disagree; 0= does not apply):

A.) I feel comfortable requesting particular services.

Strongly agree	Agree	Neither Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3	2	1	0

B.) My requests are incorporated in my treatment/service plan.

Strongly agree	Agree	Neither Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3	2	1	0

C.) I feel comfortable refusing services I don't want (including refusing a treatment/service plan or meeting).

Strongly agree	Agree	Neither Agree nor disagree	Disagree	Strongly Disagree	N/A
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5	4	3		2	1	0
D.) I participate actively in decisions about the services and treatment I receive.						
Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0
E.) Staff take my concerns seriously.						
Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0
F.) Staff take the concerns of my family members seriously.						
Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

Source(s) of Survey Question: HSRI staff prepared these questions.

Implementation and Application Considerations:

Focus groups with consumers of mental health and mental retardation services lead to the development of the six questions above. These questions are meant to show differences in degree of consumer empowerment in service planning and provision (for example, consumer comfort would presumably influence whether they made requests or stated preferences for their service plans). However, the indicator and its measure concern only two aspects of consumer involvement: that preferences are sought and acted upon in service planning. A more efficient attempt to measure this indicator would be two survey questions computed into a simple ratio as in the previous indicator.

Recommendations:

For this indicator, we recommend deleting questions 31C through 31F. Further we recommend the following modifications to questions 31A and 31B:

A.) <i>My preferences are sought in preparation of my treatment/service plan.</i>						
Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0
B.) <i>My preferences are acted upon in my treatment/service plan.</i>						
Strongly agree	Agree	Neither	Agree nor disagree	Disagree	Strongly Disagree	N/A
5	4	3		2	1	0

Part 2. Accountability/Responsibility To Achieve Outcomes: Performance Indicators

4. Consumer and Family Empowerment

Indicator 1: The proportion of consumers and families who report that they know how to make recommendations to the regional board.

Measure: The number of consumers and families who report that they know how to make recommendations to the regional board by age and disability compared to all people responding.

Survey Question(s)

37. Do you know how to contact the regional board for your service area if you have a problem or a suggestion about services you would like to share? [22]

- Yes
- No
- Not sure

Source(s) of Survey Question: HSRI prepared this question.

Implementation and Application Considerations:

Very few pilot respondents indicated that they know how to contact their regional board.

Recommendations:

We recommend retaining the indicator and survey question.

Indicator 2: The number of consumers and families who report that their recommendations regarding changes in the service system were acted upon. (23)

Measure: The number of consumers and families reporting that their recommendations regarding changes in the services were acted upon by age and disability compared to all consumers and families reporting.

Survey Question(s):

38. In the past year, have you made a suggestion(s) to the regional board? [23]

- Yes
- No (skip to question 40)

39. If you made a suggestion(s) to the regional board, what happened: (check one, then skip to question 41) [23]

- They listened and changed things
- They listened but nothing changed
- They listened, but they are still thinking or talking about the issue I raised
- They didn't listen to me
- Other: _____

40. Why haven't you made a suggestion to your regional board? (check one)
[23]

- I don't have a problem
- The problem I had resolved itself
- I didn't know who to contact
- I was afraid to make waves
- Other _____

Source(s) of Survey Question: These questions were developed by HSRI.

Implementation and Application Considerations:

Because few pilot respondents report that they know how to contact their regional board, few could respond to these survey questions. Nonetheless, as awareness of the regional board grows, the implications of its responsiveness to consumer concerns should be measured.

Recommendations:

We recommend retaining the indicator and survey question. We also recommend that a specific question regarding consumer and family input to regional boards be included in the Stakeholder Survey as well as in the Regional Board Survey.

6. Service Coordination

Indicator: Consumers and families report that they have access to service coordination when needed.

Measure: The number of consumers and families in a region that report access to service coordination compared to all consumers and families reporting, by disability and age.

Survey Question(s):

41. Do you need someone to help you with any of the following? (Please circle Y for Yes or N for No for each of the items listed) [26]

43. In the past year, has your service coordinator done, or helped you do, the following?

- Y N provide information that I need
- Y N facilitate service planning or team meetings
- Y N get or maintain benefits (e.g. SSI, SSDI, Medicaid, Section 8, VA Benefits, etc.)
- Y N obtain medical services I needed (including adaptive equipment)
- Y N obtain other services I needed (e.g. residential services, transportation, therapy)
- Y N advocate for me with my service providers/help stick up for me
- Y N get housing or advocate for housing
- Y N change my supports/services when I ask
- Y N meet with me to discuss my wishes and services (please check how often you would like to meet):
 - _____ once a year
 - _____ once every 3 months
 - _____ once every month
 - _____ Don't know
- Y N Other (please describe _____)

42. Do you have a service coordinator/case manager? [26]

- _____ Yes
- _____ No (skip to question 44)
- _____ Don't know (skip to question 44)

Source(s) of Survey Question: These questions were developed by HSRI.

Implementation and Application Considerations:

Interviewers report that the repetition of question 41 was bothersome to some respondents. Although the extent of assistance and support service coordinators provide to their consumers is valuable information for CQI activities, as an indicator, the availability of service coordination is the primary concern (e.g., the quality of the coordination should be addressed through other methods). Question 42, which initially served as the screen for question 43, is the question

which more efficiently addresses the measure as stated. However, we recommend data on the availability of service coordination be gathered from the MIS system, as the terminology (e.g. some direct support workers are called case managers) may be confusing to some consumers

Recommendations:

We recommend removing questions 41 and 43 from the Consumer and Family Survey. Further, although question 42 remains in the Consumer and Family Survey, the primary source of data regarding the availability of service coordination should be the state MIS system.

Part 3. Resource Utilization: Performance Indicators

4. Access to Services

Indicator: The proportion of consumers reporting that they are able to secure quality services when and where needed.

Measure: The number of consumers reporting that they are able to secure services when and where needed by age and disability compared to all consumers reporting.

Survey Question(s):

44. Have you asked for services and not gotten them? [31]

_____ Yes

_____ No (skip to question 46)

45. What were the service(s) you did not get? (please list them below) [31]

46. Are most of your services provided at locations that you prefer? [31]

_____ Yes

_____ Somewhat

_____ No

47. Are most of your services available at a time that is good for you? [31]

- _____ Yes
- _____ Somewhat
- _____ No

48. When you call with a serious problem, how soon does someone usually speak with you? [31]

- I can speak with someone right then and there
- They call back less than 24 hours after I call them
- They call back one to two days after I call
- They take more than 2 days but less than 1 week to call back after I call
- They call back one week or longer after I call
- I have to call again
- I've never called with a problem
- Other (please describe _____)
- Don't know

51. Were there substance abuse services you would have used but were unable to obtain in the past year? [31]

- Yes
- No (skip to question 53)

Source(s) of Survey Question(s): Questions 46-48 were adapted from the MHSIP Report Card.

Implementation and Application Considerations:

Question 44 of the Consumer and Family Survey addresses whether consumers are able to secure services. Question 46 addresses whether services are provided where consumers prefer, and questions 47 addresses whether services are provided when the consumer needs them. Although question 48 addresses one dimension of convenience of service (e.g., timeliness of response), this dimension may be addressed through other means (for example, provider CQI practices, ad hoc studies, etc.)

Recommendations:

Although questions 51 and 52 address specific services, these can and should be included in responses to questions 44 and 45. Therefore we recommend deleting questions 51 and 52. Question 48 may also be deleted if timeliness of response is addressed in another survey or assessment process.

5. Resource Allocation for State-of-the-Art Services

Indicator: The proportion of consumers receiving the following state of the art services or interventions by disability and age: (34)

Supported employment;
 Court diversion programs;
 Family support, respite and in-home crisis support (including wrap around services);
 Medication management and education;
 Self-help programs;
 Clozaril, Risperidone, and other psychoactive medication trials;
 Supported housing;
 Therapeutic foster care;
 Group homes for recovering youth;
 Family treatment for substance abuse;
 Flexible funding;
 Mobile crisis services;
 Ambulatory detoxification.

Measure: The number of consumers receiving each of the above services compared to all people receiving services, by disability and age.

Survey Question(s):

4. What specific services are you receiving? (check all that apply):
- | | |
|---|---|
| <input type="checkbox"/> Residential services | <input type="checkbox"/> Methadone treatment |
| <input type="checkbox"/> Work or vocational services | <input type="checkbox"/> Self-help groups |
| <input type="checkbox"/> Respite/family support | <input type="checkbox"/> Counseling/Therapy/
behavioral specialist |
| <input type="checkbox"/> In-home support | <input type="checkbox"/> Service coordination/case
management |
| <input type="checkbox"/> Early Intervention | <input type="checkbox"/> Supported employment |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Court diversion program |
| <input type="checkbox"/> Day activity/treatment | <input type="checkbox"/> Supported housing |
| <input type="checkbox"/> Hospital/ inpatient treatment | <input type="checkbox"/> Therapeutic foster care |
| <input type="checkbox"/> Clubhouse | <input type="checkbox"/> Group home for recovering
youth |
| <input type="checkbox"/> Crisis Intervention | <input type="checkbox"/> Family treatment for
substance abuse |
| <input type="checkbox"/> Medication management | <input type="checkbox"/> Other (please list below) |
| <input type="checkbox"/> Medication education | |
| <input type="checkbox"/> Clozaril, Risperidone, or
other psychoactive
medication trials | |
| <input type="checkbox"/> Detoxification | |

Source(s) of Survey Question: HSRI staff developed these questions.

Implementation and Application Considerations:

These data are more accurately collected through the state MIS. Although as sample size increases, data on state of the art services collected through the Consumer and Family Survey may be more easily accessed for analysis. (That is, service data and survey data may be contained in the same database and analysis by specific service may be accomplished quickly). Therefore, we recommend continuing to collect data on state of the art services in the Consumer and Family Survey. Data on “flexible funding” as a service should be collected through the state MIS.

Recommendations:

These data can be collected in the Consumer and Family Survey as well as maintained in state MIS systems.

Examples of Uses and Presentation of Data

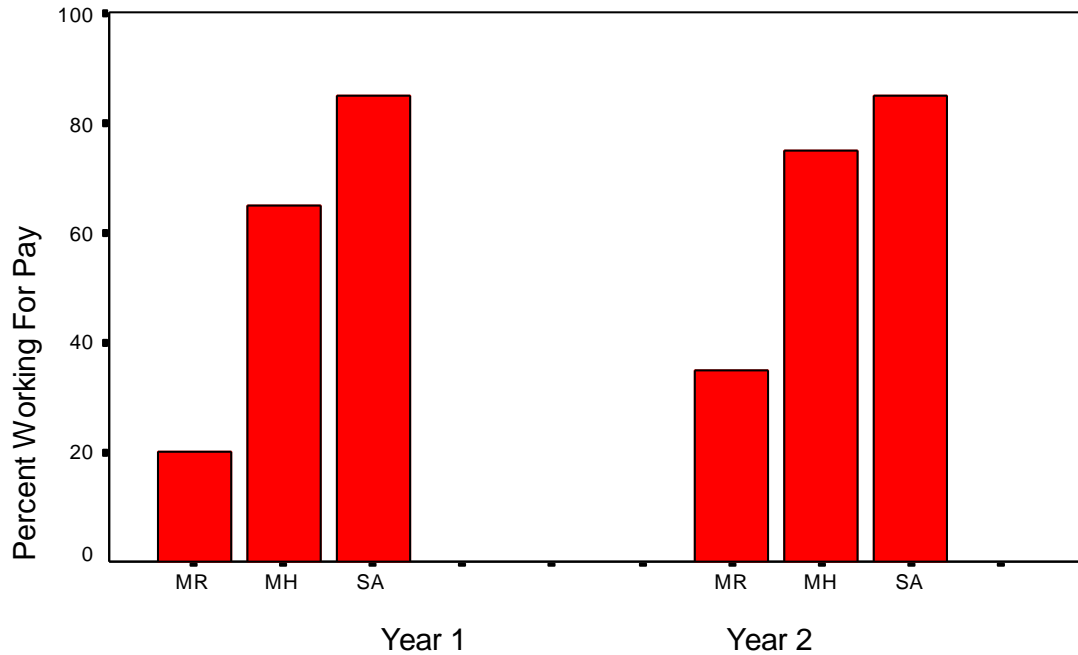
Data gathered through the Consumer and Family Survey may be used to answer specific policy questions (e.g., “What percentage of persons with mental retardation work in integrated setting?”) and to show changes and trends in the system (e.g., “Are consumers living in less restrictive environments than they have in previous years?”). Below we illustrate some ways in which data may be presented graphically to answer questions about the policies and practices of the service system. Bar charts, tables, and pie charts are simple graphic representations and can be created in common PC software programs (here, we used Microsoft Word and SPSS).

The reader should note that these examples are not taken from the pilot data. The numbers, percentages, ratios, etc. are fictitious and supplied here only to illustrate what may be done with data.

Data gathered through survey questions about employment should yield simple, yet powerful results. Specific policy questions, such as differences in the use of supported employment by disability group, can be answered with basic percentages. Within group and longitudinal variations can also be explored

through these data (For example, whether the percent of persons with mental retardation working in integrated settings increases over years).

The bar chart below demonstrates how data gathered in this section of the survey may be graphically displayed to show changes within groups and over time.



The extent of over- and under-qualification may be easily understood as a cross tabulation of education level and sense of qualification. The table below demonstrates how such data may be presented.

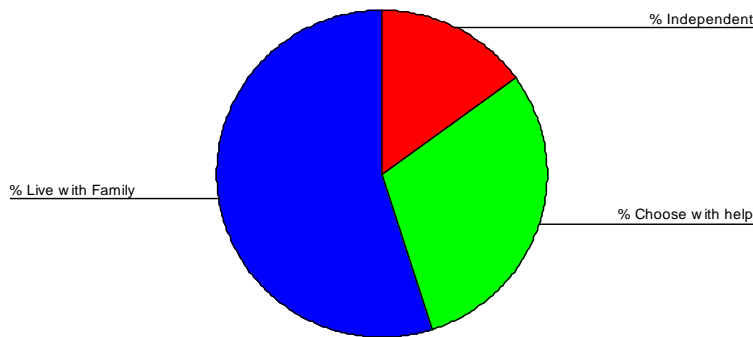
Consistency of Qualifications with Work

Educ. Level	<High School	High School	< Bachelors	Bachelors & >
Consistent	%	%	%	%
Overqual.	%	%	%	%
Underqual.	%	%	%	%

Although living in one's own home is in absolute terms the least restrictive environment, service users often need assistance and support in living. Non-community based, e.g., institutional environments are more restrictive than community based living situations even when those community based situations have some restrictive characteristics. Decreases in restrictive environments is indicated by an increase in less restrictive ones. Therefore, appropriate presentation of the data for the independence indicator should show decreased use of restrictive environments and increased use of less restrictive environments over time. One table showing change over time by disability and one by age are adequate for presenting these data. A blank example of the disability table is presented below.

	MH			MR			SA		
Living Environ.	YR 1	YR 2	% Δ	YR 1	YR 2	% Δ	YR 1	YR 2	% Δ
A	%	%	+/-	%	%	+/-	%	%	+/-
B	%	%	+/-	%	%	+/-	%	%	+/-
C	%	%	+/-	%	%	+/-	%	%	+/-
D,	%	%	+/-	%	%	+/-	%	%	+/-

Pie charts offer a simple, yet powerful way to view data. The pie chart below might be used to represent the amount of choice in housing a particular population report.



Summary and Recommendations

This section summarizes the substantive recommendations of the Methodological and Implementation and Survey Pretest sections. Editorial recommendations for the Consumer and Family Survey are not repeated in this section; a revised survey with recommended edits is included in the Appendix J.

We recommend continued use of the Consumer and Family Survey as a means to measure the HB 100 indicators identified in the table and in this chapter. With adequate survey and data management procedures, the survey should yield meaningful data for analysis for these indicators.

Sampling:

1. We recommend that, initially, the Consumer and Family Survey is implemented for statewide level of analysis. After the first year of implementation, region level comparisons can begin through the incremental addition of regional cells for data collection (likely 2 -- 3 Regions added in Year 2 of implementation). A sample of 3000 respondents, 250 in each of 12 data cells (3 populations by 2 age groups by two locations) should be sought in Year 1.
2. We recommend a variety of methods to increase the response rate including the use of a range of incentives for consumer participation, the development of strategies to publicize the consumer survey, and the use of point-of-service interviewing (in person) as a means to gather an adequate sample size.

3. We recommend conducting targeted studies for unique service users or policy concerns. Such studies will require over-sampling of some populations.

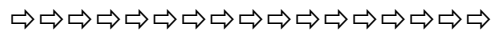
Interview Method:

1. We recommend continuation of the telephone interview method. In addition, we recommend other targeted approaches, including face-to-face surveys and point-of-service surveys, to ensure the inclusion of people without phones, who have communication problems, move frequently, or for other reasons are not able to participate in phone interviews.

Instrument:

1. We recommend substitution of the SF-12 questions for functioning questions in the pilot Consumer and Family Survey.
2. Editorial and structural changes in the Consumer and Family Survey are addressed in the pretest section. Those recommendations are incorporated in the revised Consumer and Family Survey found in Appendix J.

CHAPTER 4



Measures of Performance from Stakeholder Survey

Background

The decentralization of decision-making implied in the H.B. 100 legislation entails a planning and priority-setting process that involves the range of interests in the community who are potential customers of and collaborators with the Regional Board. Such stakeholders include generic human services agencies, schools, law enforcement, the courts, advocacy organizations, and other public agencies.

Such involvement and collaboration -- while always important to coordinated service delivery -- becomes increasingly important in an era of cost consciousness and devolution. As more people with disabilities live in communities and fewer people are relegated to institutions, the ability of the mental health, mental retardation and substance abuse system to meet all of the needs of people with disabilities is greatly compromised. Further, more progressive conceptions of best practice suggest that individuals with disabilities should be participants in the range of generic services in the community, not merely those that offer specialized supports. As more and more consumers aspire to jobs, housing, and a full life in the community, the involvement of a range of organizations and informal networks will be necessary.

Further, the presence of people with disabilities in communities also means that some may come into contact with the criminal justice and law enforcement system. These stakeholders will require information and education in order to make informed judgments and dispositions and to ensure that the particular needs of each disability group are accommodated.

Children with disabilities, a relatively recent but growing group of consumers for the public mental health, mental retardation, and substance abuse system, also require services that cross a number of boundaries including those with the education system, the child welfare system, and the health system. Connections

with these stakeholder groups are critical to the realization of family-centered coordinated services.

The H.B. 100 legislation recognized the importance of such community collaboration and this aspiration was translated into a concern area and performance indicator:

- **Responsiveness to Local Concerns**

Concern: The Regional Board develops plans that are responsive to community needs.

Indicator 1: Key stakeholders (e.g., courts, employers, providers, social services agencies, juvenile court, juvenile justice organizations, child serving agencies, etc.) in the region are satisfied that the Regional Board is informed and responsive.

Measure: The number of stakeholders in a region that report satisfaction with the service system's performance compared to all stakeholders reporting.

Source: Stakeholder Survey.

The following chapter describes the pilot test of the Stakeholder Survey (a copy of the full survey is included in the Appendix L).

Method and Findings

Development of the Survey

In order to provide useful information to decision-makers at the regional level, project staff designed a survey that addressed the specific indicator and that also solicited information on related issues surrounding regional coordination, referrals, services responsiveness and other interagency issues. To ensure responsiveness to local concerns, the draft survey of stakeholders was reviewed by the director of the Northeast Georgia Region, the Northeast Georgia Region quality enhancement consultant, the director of the Northeast Georgia Center, and the head of quality assurance for the Northeast Georgia Center. The areas covered in the survey include the following:

- The nature of the stakeholder organization;

- Extent of collaboration with the regional board;
- Whether input was sought into regional priorities;
- Familiarity with regional board activities;
- Level of knowledge on the part of the board and staff of particular stakeholder needs;
- Level of satisfaction regarding board services to stakeholder clientele;
- Impact of regional board on referrals from stakeholder organization.

In addition to the specific questions for stakeholders, a separate section of the survey was devoted to inquiries aimed at providers of services to mental health, mental retardation and substance abuse service consumers in the region. The inclusion of questions to providers was stimulated by feedback received from participants in the focus group for providers held prior to the finalization of the draft indicators. Areas canvassed included:

- Types of services provided and whether or not respondent had a contract;
- Specific ratings on the timeliness of payments, timeliness of contract awards, adequacy of technical assistance and support, the quality of the RFP process, accessibility of staff, and the nature of service quality oversight;
- Suggested areas where collaboration could be improved.

Administration of the Survey

The survey was mailed to stakeholders in the Northeast Georgia Region in late summer, 1996. Out of over 300 surveys mailed, 57 surveys were returned for a response rate of approximately 20%. Those responding fell into the following categories:

Table 17
Stakeholder Survey Respondents by
Organizational Auspices

Organization	Frequency	Percent of Respondents
Adult Welfare/Social	1	1.8
Child Welfare Service	1	1.8
Other Law Enforcement	2	3.5
Public School	9	33.3
Substance Abuse Service	1	1.8
Mental Health Service	2	3.5
Mental Retardation	9	15.8
Advocacy	1	1.8
Other	9	15.8
Adult & Child Welfare	3	5.3
Advocacy & Other	1	1.8
Other Law Enforcement	1	1.8
Sub Abuse, MH Service	1	1.8
Sub Abuse, MH & Hosp	1	1.8
Child Welfare & Public	1	1.8
Adult & Child Welfare	1	1.8
Sub Abuse, MH, MR	2	3.5
MR & Advocacy	1	1.8
Total	57	100.0

Valid cases 57 Missing cases 0

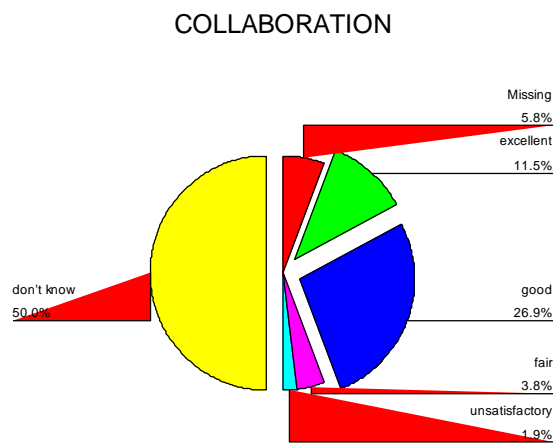
As indicated from the table, responses were received from a wide range of stakeholders with many responses concentrated in education, mental retardation, and adult and child welfare. For a presentation of the data from each question, please see the Appendix M.

Pre-Test Findings

As a general matter, the response rate was minimally satisfactory but certainly not optimum. Further, many of the respondents to the survey were not familiar with regional board activities. Thus, many of the inquiries received a “don’t know” response. According to Northeast Georgia staff, one reason for the lack of clarity regarding regional board activities may stem from the fact that the

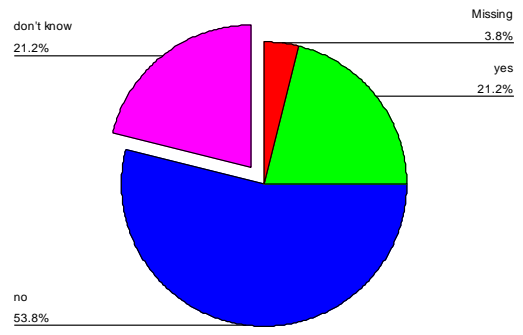
surveys were sent to individuals who were the directors of heads of private and public agencies. In many instances, such as in the public schools, the superintendent may not have any reason to be familiar with the work of the board whereas specific special education teachers would have had direct contact. Another speculation is that those who received the survey did not pass it on to those in the agency who may have had contact -- a fact that suggests more specific instructions regarding who should fill out the survey are needed. Recommendations regarding improvement of response rates and the potential application of the information at the regional level are included in the final section of this chapter.

Collaboration: Figure 1 shows the responses to the inquiry regarding satisfaction with the level of collaboration with the Regional Board experienced by stakeholders. These responses strongly suggest that among those respondents who were familiar with the regional board, the majority rated collaboration as excellent or good.



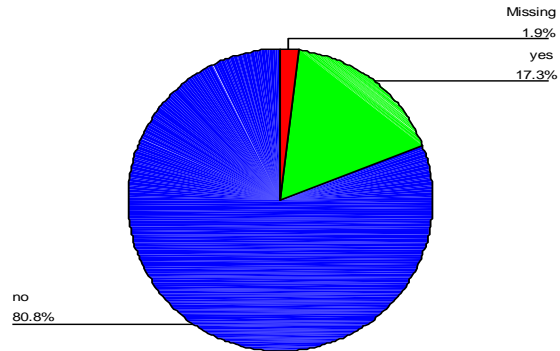
Input on Regional Plan Figure 2 indicates responses to the question regarding the solicitation for input into the regional plan. Again, a substantial number of respondents (almost a fourth) answered “don’t know” and only 21.2% answered yes. Given the fact that the regional system is still somewhat new, it is not surprising that more organizations have not made input, however, one would hope to see the number of affirmative responses to increase over time.

INPUT SOUGHT IN REGIONAL PLAN



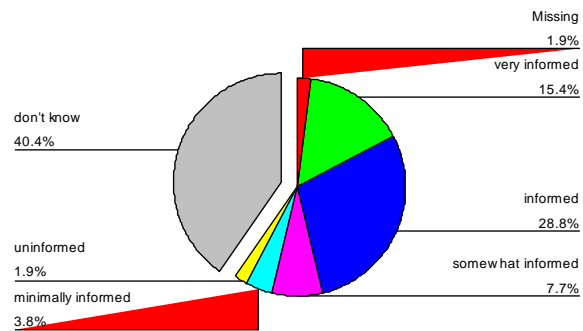
Attendance at Regional Board Meetings Response to this question indicated that approximately 17% of respondents had attended a regional board meeting. Again, given the lack of familiarity among respondents with the regional board, this finding is not surprising. As in the indicator above, one would expect that this percentage would increase over time as the regional board is identified as an important forum for the discussion of needs and priorities for mental health, mental retardation and substance abuse services in the community.

Attendance at Regional Board Meetings



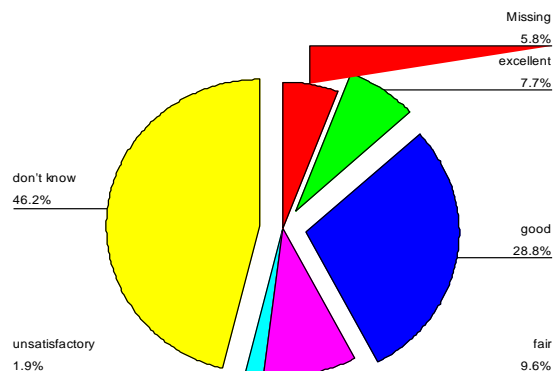
Extent to which regional board is informed about constituency: The response to this question shows an overall level of satisfaction among those stakeholders who are familiar with the activities of the regional board regarding the level of insight that the regional board and staff have regarding particular stakeholder needs. Again, the large number of “don’t knows” (40%) makes the results of this question somewhat inconclusive and indeterminate regarding action implications.

EXTENT BOARD INFORMED ABOUT SERVICE CONSTITUENCY

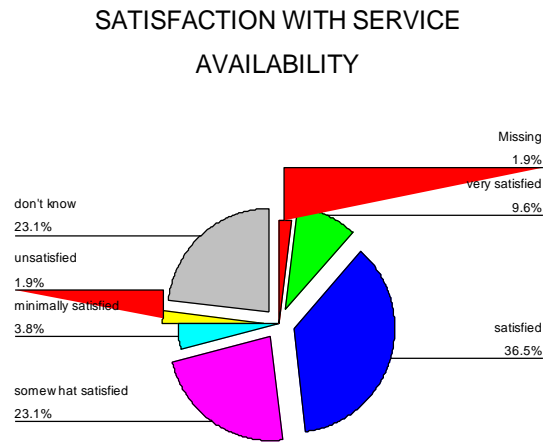


Responsiveness to requests Factoring out the “don’t know” responses to this question, those who had made requests were satisfied with the responsiveness of the Board. Certainly, as the work of the Board becomes more publicized in the community, the extent of interaction and requests for technical assistance should increase.

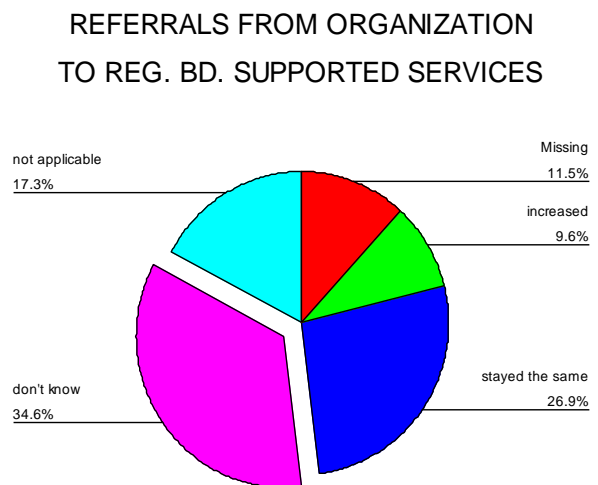
RESPONSIVENESS



Satisfaction with services: This question indicates that respondents are more familiar with the services offered by the Board than with the Board itself and its role in the determination of regional priorities. Of those commenting on their satisfaction with services to their constituents of consumers, about 46% said they were satisfied or very satisfied with services. Only about 5% were unsatisfied or minimally satisfied. Further analysis of the results at the regional level would allow Board members and staff to determine which stakeholders were less than satisfied and to explore the reasons as they relate to particular groups of stakeholders.



Experience with referral from the regional service system: The responses to this question suggests that the presence of the regional system has not had a significant impact on the volume of referrals accepted by stakeholders responding to the survey. Again, there is a substantial group of respondents who don't know whether the number of referrals has changed and another group, 17%, for whom this question is not applicable.



Additional responses: Additional responses suggested that almost 30% of respondents reported having the opportunity to make input into regional priorities since the Board was established in 1994. The remaining questions, which related to the experience of providers of mental health, mental retardation and substance abuse services indicate that half of those responding were currently contracting with the Regional Board. Because of the small number of providers responding, data is not presented in chart form.

Additional Findings

In another portion of the pre-test, the administration of the consumer and family survey, the responsiveness of the Regional Board to input from consumers and families was explored. The responses to the survey suggest that most consumers and families are not familiar with the Board and questions about “input” or “influence” are highly abstract and difficult for people to grasp. It was therefore recommended that this issue would be better treated in the Stakeholder Survey. The specific indicator is:

Indicator: The number of stakeholders in each region who report that their recommendations regarding changes in the service system were acted upon.

Measure: The number of stakeholders in each region reporting that their recommendations regarding changes in the services were acted upon compared to all consumers and families reporting, by age and disability.

Source: Stakeholder Survey.

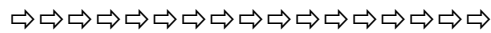
Recommendations

In consultation with staff from the Northeast Georgia Region, the following recommendations regarding future administration of the survey were developed:

- The construction of the survey and the content proved satisfactory;
- The response rate was disappointing and could be enhanced by: 1) targeting the survey only to those individuals among community stakeholders most likely to have had contact with the Board and the services that it supports; 2) changing the instructions in the survey to request that it be given to the individual or individuals within the organization with relevant experience; and/or 3) expanding the reach of the survey to include the heads of agencies (e.g., the superintendent) as well as directly relevant personnel (e.g., special education teachers).
- Include those who have attended Regional Board meetings on the mailing list for the survey;

- Include a question directed at consumers and families and representatives of consumer and family advocacy organizations regarding their specific experience in making input to the regional priority-setting process.

CHAPTER 5



Measures of Performance from Regional Board Survey

Background

The creation of the regional boards was key to the aims of the H.B. 100 reform. It crystallized the intent of policy makers to decentralize decision-making, to increase the participation of consumers and families in decision-making and priority-setting in their communities and to increase the diversity and range of services and supports offered. The regional boards were also given responsibilities to monitor the quality of services and to assist the regional directors in setting expectations for providers. The creation of the boards is consistent with a decentralization trend around the country. For instance, Colorado is taking steps to devolve increased decision-making to its community services boards; Pennsylvania is devising plans in both mental health and mental retardation to capitate its systems and place power in the hands of county programs, and a range of states have established family support councils whose missions are to make decisions about the allocation of resources in their communities.

There are a number of indicators in the proposed set that address the functions of the regional boards including the perceptions of community stakeholders regarding the responsiveness of the boards and the familiarity of consumers and families with the role played by the boards.

It is also important to assess whether the members of the regional board are satisfied with their levels of participation and the extent to which they feel prepared to take on the tasks they have been assigned. To assess this component of the system, the Regional Board Survey was developed. The specific indicator linked to the survey is:

- **Decentralization of Decision-Making**

Concern: The Regional Boards set policy and direction for the regional service system.

Indicator: Regional board members express satisfaction with their ability to influence policies and set directions for the regional service system.

Measure: The number of Regional Board members expressing satisfaction with their ability to set policy and influence direction compared to the total number of Regional Board members reporting.

Source: Regional Board Survey.

Method and Findings

The Regional Board Survey (included in Appendix N) was developed in collaboration with staff in the Northeast Georgia Region. It included inquiries in the following areas:

- Description of affiliation and interests;
- Satisfaction with input into the priorities and direction of the service system in this region;
- Level of satisfaction with support for consumer participation, training, availability and clarity of materials, convenience and conduct of meetings, opportunities to interact with other community stakeholders, information about best practices;
- Impact of the regional board on the service system;
- Perception of priorities in the region (e.g., waiting list, consumer and family empowerment, expansion of services, etc.);
- Suggestions for improvement.

The survey was mailed to all 10 members of the Northeast Georgia Regional Board; eight board members responded. The results of the survey are included in Appendix O.

The findings of the survey suggest a general level of satisfaction and offer particular areas of possible improvement including support for consumers on the Board and the improvement of materials made available prior to meetings. In discussions with Northeast Georgia Regional staff, it was determined that the survey would have been more productive if the Board had not already been the subject of two other surveys. The Regional Director, however, felt that the content of the survey questions reflected valid concerns.

Recommendations

It is strongly recommended that the survey of regional board members be adopted system-wide. The staff at the pilot site suggested that consideration should be given to administering the survey on at least a quarterly basis in order to ensure an accurate reading over the year. A point in time survey, it was noted, may be skewed by particular events in the region at the time of the survey. It was also noted that the results of the Regional Board survey are difficult to reduce to a rate or a norm and that the survey should instead be used as an organizational development tool. For this reason, the Division should consider changing the indicator to read:

Regional boards should conduct a periodic survey to determine whether members are satisfied with their level of input to planning and priority setting.

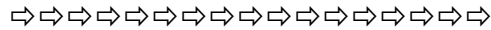
It is also recommended that the Regional Board Survey be used as a source of information for the following indicator which is part of the final proposed set:

Concern: The Regional Board monitors the achievement of goals by providers in a year.

Indicator: The Regional Board carries out a review of the attainment of goals by each provider at the conclusion of each contract year and takes appropriate action.

Measure: The number of contracts reviewed by the Regional Board each year compared to all regional contracts.

CHAPTER 6



Performance Indicators and Continuous Quality Improvement

Quality Improvement for Behavioral Health

The Georgia Department of Human Resources, Division of Mental Health, Mental Retardation, and Substance Abuse (DMHM RSA) in collaboration with the 811 Commission, regional boards and community service boards have selected a set of performance indicators to assess systemic improvements related to the H.B. 100 reforms. The performance measures monitor the quality of life for consumers (6 domains with 14 indicators), regional and provider accountability (6 domains with 12 indicators), and resource utilization (5 domains with 8 indicators). The final recommended domains, concerns, and indicators are summarized in Table 18.

Specification of these indicators can facilitate the implementation of comprehensive quality improvement initiatives within the Division and in each regional system. Quality improvement methods can be used to promote a system-wide commitment to continual improvement of services. The following guidelines for quality improvement can provide an initial structure for regional boards, community service boards and the Division and support their efforts to implement and monitor improvement processes. The first section provides a brief overview of key developments and concepts in the field of quality improvement efforts in health care. The second section outlines a strategy for the introduction and initiation of quality improvement programs within Georgia's publicly-funded systems for mental health, substance abuse, and mental retardation services.

Table 18 Issues, Domains, and Concerns for Georgia's Performance Indicators

Issues	Domain	Concern	Indicators
Quality of Life			
	Jobs & Education	consumers locate/maintain jobs	% working in integrated settings (MH/MR) % employment consistent with skills (SA)
	Housing	children remain in school	number of school days lost by disability
		adults receive voc. support	number of work days lost by disability
	Independence	consumers have choice in housing	% satisfied with ability to choose housing
		alcohol and drug free housing	number of consumers living in AOD free housing
	Health & Safety	use of restrictive living reduced	% living in restrictive settings declines
		skills of daily living are acquired	number reporting no major functional limitations
		transition to independent living	% reporting school to independent living support
		consumers are safe in community	% reporting criminal victimization
	Community	support for accessing healthcare	% youth reporting decreased alcohol & tobacco access % reporting support accessing health and medical care
		access to transportation	% reporting adequate transportation
		social and recreation activity	% reporting support to participate in activities
	Choice	choice of services	number reporting they influenced program plan individualization of plan is acceptable by CARF and ACD standards
		provider networks expand	increase in number of providers in network
Accountability			
	Grievances	grievances are resolved quickly	% grievances resolved within specific time limits
	Provider Account.	achievement of goals	number of contract goals reviewed each year

Table 18. Issues, Domains, and Concerns for Georgia's Performance Indicators Continued

Issues	Domain	Concern	Indicators
	Decentralization	regional boards set direction boards meet requirements for consumer representation	member satisfaction with ability to set policy % of RB members who are consumers/family % of CSB members who are consumers/family
		boards are representative of cultural/social comp of region	% minorities on regional boards % minorities on community service boards
	Empowerment	consumers have influence	% knowing how to make recommendations to RB % reporting recommendations changed system
	Local responsiveness	reg. plans respond to community	% of stakeholders satisfied with regional system
	Service coordination	facilitated access to services	plans fund a range of prevention initiatives consumers report access to service coordination
Resource Utilization			
	Reallocation	reduced use of state hospitals region specifies core services	DACE within fair share allocation increase services for priority populations by disability
	Resources maximized	collaboration expands funding	total funding based on interagency collaboration
	System collaboration	intersystem referrals	% served by more than one agency
	Access to services	services available when needed services available to most in need services available for children	% reporting ability to secure services when needed % meeting most in need definition increased service to children
	State-of-Art services	access to state-of-the-art services	% receiving specific services by disability

Overview of Quality Improvement

Donabedian's pioneering efforts (1980; 1982; 1985) to define and measure the quality of health care recognized that consumer sentiments and desires were essential components and that analysis of cost could not be divorced from the assessment of quality. In many ways, his discussions anticipated contemporary debate about the need to balance quality and cost within public service systems generally and managed care environments in particular. Donabedian's categorization of variables into "process" (the delivery of care), "outcome" (the results of care), and "structure" (staff and facility resources and standard procedures) continues to provide a useful conceptual framework for analysis of the variables that can affect the quality of human and health care services.

During the 1980s, however, improvements in the quality of care were slow, in part, because tools to measure and monitor quality had not been developed and human services and health care practitioners and administrators were unaware of or reluctant to implement the quality improvement tools developed for industrial environments (Berwick, Godfrey & Roessner, 1991). It is perhaps ironic that Donabedian's approaches and values are very consistent with the concepts of total quality management and continuous improvement that evolved from efforts of Japanese manufacturers to improve products, increase productivity, and reduce costs (e.g., Deming, 1986; Imai, 1986; Juran, 1988).

Quality Improvement and Quality Assurance

Quality improvement represents an evolution and enhancement of the traditional quality control and assurance. Quality was originally managed through inspection -- service delivery was examined to detect flaws and, if not satisfactory, the service provider was required to produce a plan of correction. The approach, therefore, was inherently reactive; errors were corrected after they occurred. Short-term goals were emphasized and production quotas were used to monitor productivity. There was also an adversarial element -- an inspector or supervisor would review the product and judge the quality of the product and, implicitly, the quality of the worker responsible for the product. Systems based on this model (results oriented management) do not encourage innovation, do not empower workers to assume greater responsibility, and encourage games that inhibit identification and correction of problems (Imai, 1986; Scholtes, 1988). Quality improvement strategies, on the other hand, attempt to prevent problems from occurring so that corrective efforts are not required. Management and supervision become proactive and emphasize processes (process oriented management): individuals are not blamed, processes are reviewed and critiqued, barriers that inhibit quality are eliminated, workers are encouraged and

empowered to participate and assume responsibility, and products are designed to meet the needs and desires of both internal and external customers (Imai, 1986; Scholtes, 1988).

An Institute of Medicine (IOM, 1990), panel that examined quality review and assurance for Medicare compared quality assurance and quality improvement models. They found that, while both emphasize outcomes and stress the linkages between processes, the models differed on five dimensions. First, quality improvement models require continuous efforts at improvement even when high levels have been achieved; quality assurance efforts, in contrast, would be directed at another issue once specific problems were resolved. Second, a consumer perspective is essential to quality improvement efforts and identifies communication and interorganizational relationships that may be overlooked in quality assurance reviews. The third difference between the two approaches is a quality improvement interest in patient needs, experiences, and satisfaction that is usually not part of quality assurance. Fourth, quality improvement efforts attempt to improve mean performance levels while quality assurance reviews focus on identification and removal of outliers. The last difference is the role of leadership; quality improvement programs require the organizational leadership to assume overall responsibility for persistent improvements in quality and to empower individual workers to participate in and contribute to the transformation of the organization.

The IOM (1990) review also cautioned that there were few demonstrations of the application of quality improvement techniques to clinical care issues and the usefulness of these tools to health care was unknown. Nonetheless, by 1992 an Institute of Medicine (1992) panel examined clinical guidelines and found growing interest in quality improvement models within health care settings. The National Demonstration Project was an early effort to begin a transformation of health care and increase the use of quality improvement techniques.

In 1987 and 1988, the National Demonstration Project on Quality Improvement in Health Care worked with 21 American health care organizations and examined the application of the quality management technology developed for manufacturing processes to the delivery of health care (Berwick, et al., 1991). Ten management principles guided efforts in the National Demonstration Project (Berwick, et al., 1991) work requires processes -- individuals and departments are both consumers and suppliers and medical care relies on increasingly complex and interdependent processes; 2) relationships and communication between consumers and suppliers must be sound -- organizations that meet customer needs better will be more effective and more successful; 3) defects in quality are usually related to problems in process -- systems are more influential than

individuals and changing or berating individuals will not improve processes; 4) poor quality is costly -- defective processes and products are a significant expense and prevention of defects and problems reduces expenses; 5) quality improvement requires an understanding of the causes of variability -- failure to control variation leads to quality problems and variation must be controlled to enhance quality; 6) select the most critical processes for attention -- it is impossible to control and measure everything so clearly define goals and identify the most important sources of problems; 7) use scientific and statistical thinking - - measurement helps workers understand processes, facilitates hypothesis testing about the causes of problems, and provides prompt feedback on results; 8) All employees must be involved -- senior management provides leadership and eliminates barriers while line staff provide ideas and expertise; 9) new organizational structures are often required to achieve improvements -- quality teams and councils cross organizational levels and facilitate integration of efforts; and 10) management must plan for quality, control for quality, and improve quality.

Participants in the National Demonstration Program began with modest efforts and applied the tools of quality improvement to administrative systems and service systems similar to those found in industries -- billing, inventory control, services; clinical processes were not addressed and improvements in patient health status were not assessed (Berwick, et al., 1991). Analysis of the demonstrations suggested 10 lessons that are consistent with experiences in more industrialized environments (e.g., Imai, 1986): 1) health care systems can benefit from the use of quality improvement tools, 2) teams that cross disciplines and functions facilitate improvement efforts, 3) there is an abundance of potential data that can be used for improvement initiatives, 4) participants enjoy using quality improvement tools, 5) quality improvement initiatives can reduce expenses, 6) it is challenging to motivate physicians to participate -- time donated for quality improvement activities is not billable and many are displeased with the punitive aspects of typical approaches to quality assurance, 7) training is essential for all levels of the organization, 8) it is easier to apply quality improvement to nonclinical processes, 9) health care environments may need to broaden their definitions of quality because consumer needs and desires are usually not a factor in their analyses of quality, and 10) leadership is the key to successful implementation of quality improvement -- chief executives and heads of departments must share and support the commitment to quality (Berwick, et al., 1991).

The key to quality improvement is a change in perspective. Instead of assessing quality through inspection of people and products, processes and systems are created and monitored to prevent flaws and problems and, because quality is

determined by the customer, products and services are designed to meet consumer needs and expectations (Berwick, et al., 1991; Imai, 1986). Quality improvement also requires the application of scientific methods to the analysis and monitoring of processes -- "statistical thinking." Decisions are based on data rather than intuition so information systems are built and graphical tools used to monitor critical processes and track the effects of alterations in the delivery of a service or production of a product. Using these tools, workers are empowered to continually adjust the process and make consistent and persistent improvements in both process and outcomes. Persistent, gradual improvement in all aspects of life but particularly the quality of the environment, process, and products of work is embodied in the Japanese word "kaizen" (ky ' zen) (Imai, 1986). A commitment to kaizen requires a careful understanding of processes, systems, and consumers and the application of strategies and tools to the production and delivery of high quality products and services. The focus on long term gradual improvement using scientific methods and attention to consumer needs characterizes true quality improvement orientations.

Application of quality improvement methods has expanded substantially in health care settings. An annual review of American health care reported that 94% of hospital Chief Executive Officers expected quality improvement programs to increase efficiency and reduce expenses (Business & Health, 1993). Increasingly, accreditation agencies and purchasers expect organizations to have formal quality improvement programs and assess the quality improvement processes as part of their review of a health care organizations (e.g., American Managed Behavioral Healthcare Association, 1995; CARF, 1996; Digital Equipment Corporation, 1995; National Committee for Quality Assurance, 1996; Utilization Review Accreditation Commission, 1996). Similarly, the federal Health Care Financing Administration (HCFA) is responsible for monitoring the quality of services for Medicare recipients and is supporting a quality improvement initiative that emphasizes continuous quality improvement methods, makes information available to the public, is consistent with state and private certification and accreditation programs, and employs multiple measures of quality and performance (U. S. General Accounting Office, 1996).

Improvements in patient care and outcomes are the ultimate test for quality improvement technology within health care settings. Applications are inhibited, however, because of the variable presentation of illnesses, variations in practice patterns, the hierarchical structure of patient care, and the complexity of hospitals and managed care programs. It is note worthy, therefore, that the Northern New England Cardiovascular Disease Study Group applied quality improvement techniques and documented a significant reduction in hospital mortality associated with coronary artery bypass graft surgery in a multi-

institutional regional environment (O'Connor et al., 1996). Clinicians, administrators, and researchers from the five hospitals in Vermont, New Hampshire, and Maine where coronary artery bypass graft surgery is performed created a patient registry in 1987 and began a quality improvement initiative in 1990. Data from 1993 suggest a cumulative reduction of 74 deaths from expected mortality levels prior to the intervention -- a 24% reduction. There were multiple changes in procedures and techniques across five institutions so there is no single cause for the decline in mortality; the observed improvements are due to the net effect of their efforts to learn and improve (Berwick, 1996). Berwick (1996), in commenting on the Study Group's report, suggests that this type of discovery may be more valuable than randomized clinical trials for cumulative improvement and for the identification of techniques that enhance health care and reduce costs. It is also critical, he argues, that such information be reported to and published in peer reviewed journals and not be guarded as proprietary information. The techniques and outcomes will be most useful if they become public information.

There do not appear to be comparable demonstrations of the successful application of quality improvement methods to improved patient outcomes for mental health and substance abuse treatment services. Both public and private treatment systems, however, have begun to adapt and apply quality improvement technologies. In Massachusetts, for example, the Quality Improvement Collaborative (QIC) is a peer review total quality management initiative designed to foster the introduction and use of continuous improvement protocols within all of the substance abuse treatment programs under contract with the Massachusetts Department of Public Health, Bureau of Substance Abuse Services (Fishbein & McCarty, in press). Detoxification centers adopted and implemented a model clinical record and methadone services standardized evaluations of client progress and linked progress to phases of care; evidence of improvements in patient care, however, are not yet available. Massachusetts Medicaid has also applied quality improvement methods to the management of relationships with its suppliers (managed care organizations and health care providers) and reports improved responsiveness among the suppliers of health care (Friedman, Bailit & Michel, 1995). As a result of this initiative, the managed behavioral health care organization responsible for management of mental health and substance abuse services for Massachusetts Medicaid developed its own quality improvement program (Nelson, Hartman, Ojemann & Wilcox, 1995).

In mental retardation and developmental disabilities, there are some emerging efforts to link information about quality to a continuous quality improvement and organizational development process. The Accreditation Council, which has recently adopted quality outcomes as part of its standards, and offers training

and technical assistance on a range of quality improvement and enhancement methodologies linked to the collection of outcomes.

Guidelines for Quality Improvement

Quality improvement is challenging because most participants must learn new skills and many must alter their perspective from changing persons to changing processes. This section outlines some of the steps a group may work through but is not a comprehensive handbook. Many guidebooks provide much more detail for participants and we encourage individuals to obtain more complete frameworks. One book frequently recommended is *The Team Handbook* (Peter R. Scholtes and other collaborators, 1988. *The Team Handbook: How to Use Teams to Improve Quality*. Madison, WI: Joiner Associates, Inc.). It provides some of the structure for this section.

Leadership

A successful quality improvement program requires a commitment from the organizational leadership to fully participate. Responsibility for quality begins at the top and cannot be delegated. Senior management in the agency must understand the principles of quality improvement and support staff efforts to develop and implement changes in work processes that improve the quality of services and products.

Training and Coaching

Agencies that make a commitment to quality improvement must anticipate a substantial investment in training for both management and staff. Effective quality improvement requires a change in perspective and the development of new skills and knowledge. Team members must have a basic understanding of quality improvement strategies, the scientific approach to problem resolution, quality improvement tools and charts, and team member roles and responsibilities in a quality improvement program. Without appropriate ongoing training the initiative will not succeed. In addition, participants may benefit from a quality advisor -- an individual with quality improvement experience who can function as a coach and help the group through difficult aspects of problem identification and resolutions.

Select a Project

Begin with a focus on one goal that team members feel is important. Georgia has identified 36 performance indicators and each indicator is associated with a service concern or goal. Each region should select one of those concerns (see Table 18 for a summary) and within the concern focus on one population. Although ambitious groups may wish to articulate multiple goals and work with multiple service populations, development of a quality improvement strategy is hard work and it seems advisable to gain experience working through all aspects of one problem before attempting to generalize the skills and approaches to additional problems. It also seems wise to select a problem where the team has some ability to control and anticipates a capacity to improve services and outcomes.

As currently articulated the performance concern may be stated too broadly for a particular region. Effective quality improvement requires a well-defined mission statement. Work as a group to narrow the focus of your mission to one facet or element of the concern and frame a mission statement in terms of a process. For example, the general concern may be prompt resolution of grievances. A more specific mission statement might be expressed as "Development of a process to resolve consumer dissatisfaction with a medication protocol within 24 hours." The grievance is specified as related to dissatisfaction with medication and a time period for response is set. The specificity will facilitate development of measures and description of variation in the resolution of grievances related to medication. Finally, frame the issue in a way that retains a sense of importance. Few team members will maintain their motivation if the issue is perceived as trivial.

Develop an Improvement Plan

Improvement plans include at least five stages (Scholtes, 1988): 1) understand the process, 2) eliminate errors, 3) streamline the process, 4) reduce variation, and 5) continue improvement.

To understand a process, it must first be described and the customers identified. An understanding will help to specify problems and to propose an improved standard process. Flow charts are often used to help articulate all of the facets of a process from beginning to end. As the process is described, some problems, inefficiencies, and inconsistencies will become apparent -- the obvious problems are the starting point for improvements. It is also critical to describe the customers. Customers may include consumers, staff, and other programs. Know each of the potential customers and recognize that their needs and expectations may sometimes conflict. Points of conflict provide additional opportunities for

improvement. Once the process and customers are outlined, a standardized process can be proposed -- how it should be done as opposed to the current problematic process.

Error elimination is a second facet of the improvement strategy. Review your ideal standard process and anticipate errors and problems -- what can go wrong. Consider how to reduce the potential for problems and modify your process as necessary to eliminate opportunities for problems. Keep in mind that the environment often exerts a powerful influence on individuals and their work processes. Often changes in the organization, structure, or location of work can be an effective strategy for error reduction and prevention.

Review the proposed process again to eliminate redundancy and minimize steps in the process. Simple, streamlined processes will be less error prone and more conducive to quality care. Can the number of required steps and staff be reduced? Does each have an essential responsibility that cannot be done in other ways?

Variation inhibits improvement. If the process is different time each time it is used, there will be little cumulative improvement. As processes are tested and implemented, look for sources of variation and begin to understand the causes of variation -- different people, different types of customers, different points in the week, month, or year. Eliminate the variations that can be controlled. Measurement of the process will help identify the nature and sources of variation. Data collection will facilitate detection of variation and provide evidence of improvements.

The final stage of the improvement plan is to continue improvement. Obvious problems can often be eliminated quickly. More subtle problems, however, may appear infrequently. Continued monitoring and attention to sources of variation are required to achieve consistently high standards of care. Ultimately, quality improvement programs rely on a cycle of planning change, doing the change, checking on the change, acting to refine and standardize, and starting the cycle again. This is the "Plan-Do-Check-Act" cycle (Scholtes, 1988) and it summarizes the basic iterative nature of quality improvement. Planning requires thoughtful analysis and development of a strategy for change. Change ("do") is an action step but skilled implementers will usually test the change on a small scale before attempting to implement a major change. Checking is critical. Gather data to be confident that the change is an improvement and that there are no unanticipated deleterious effects. Act to refine and improve. The final step in the process is also the start of a new cycle. Action requires planning.

Data Collection and Analysis

Collection and analysis of data are integral components of all quality improvement plans. The data must be meaningful and reflect the goals and processes that are being improved. A first step is to clarify the purpose of data collection -- what will the data reveal and how will the analysis contribute to quality improvement? A key to the collection of useful data is operationalization -- a definition that translates a value construct into a specific variable. The proposed analysis of consumer complaints about medication, for example, requires specification of the type of medications of interest and formalization of a consumer complaint or grievance. Grumbling about side-effects may not be counted as a grievance but a telephone call to a counselor or a clinician that includes a request for change might be defined as a measurable grievance. Thus, the development of operational definitions also helps specify data collection procedures. Often training becomes important because staff must use new procedures and complete data collection records to facilitate the monitoring of processes. Once the procedures are in place, data can be collected and used to assess the effects of system changes.

Data must be summarized so that teams can interpret the information and apply it to the improvement initiative. The most useful analyses are usually the simplest. Control charts are one simple analysis tool. Data are plotted against time to create a time series chart. The time series will reveal increasing and decreasing trends, but if the process is variable, improvements may be difficult to interpret. Control charts add information about variation to the picture. Upper and lower expected limits help observers know when a substantive change occurs -- either positive or negative. Careful monitoring will help reduce variation and give the team more confidence that the strategies for improvement are having desired or undesired effects. Teams may need training to fully understand and use different graphical tools to foster their improvement efforts.

Conclusion

If each region plans its own quality improvement initiative, Georgia will begin a transformation to management for quality and become more proactive. Ongoing quality improvement protocols at all levels of the service system will help focus on consumer needs and enhance the effectiveness and efficiency of care. The concerns and indicators listed in the current set of performance indicators are only starting points. The data associated with the performance indicators will help regions begin to identify the most important processes to review and monitor. Ultimately, however, each region is likely to develop its own much

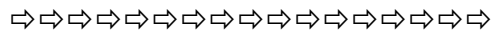
more detailed and sophisticated set of measures that intimately reflect a commitment to quality improvement and effective and accountable services.

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CHAPTER 7



Recommendations for the Implementation of a Performance Indicator System in Georgia

Overview and Rationale

Historical Context

The increasing emphasis on outcomes as a mode for monitoring the quality of services to people with disabilities is more than merely a change in measurement approaches. It represents a change in the expectations regarding what is a “quality” service and, as such, is part of a much larger shift in the field; specifically from program-oriented, formulaic models of care to individually tailored supports based on individual choices and preferences. As a result, the infusion of outcome-oriented quality monitoring techniques is both the result of the change in expectations as well as a method for expediting the shift at the provider level. There are a variety of reasons why this shift has taken place:

- The expectations of people with disabilities and their families regarding the quality of services has changed as fewer people have been placed in institutions, as more people are included in their local service systems, and as policies regarding empowerment of people with disabilities and their families have become more widespread (e.g., expansion of family support, the adoption of person-centered planning, etc.)
- Performance monitoring mechanisms have evolved as systems have evolved and become more competent: input approaches were needed when the major goal of public policy was provide for people’s basic need; process measures were needed when the emerging technologies and interventions needed to be codified and expanded; and outcome measures are needed now to ensure that those technologies are in fact resulting in an improved quality of life for those being served and supported.
- In order to provide individually tailored supports, it is necessary to allow a certain amount of flexibility for innovation and creativity.

Certain process requirements are seen by some providers and policy makers as constraining innovation whereas outcome measurements allow for more flexibility.

- Quality assurance systems that rely on punishment and sanctions were probably suited to a period when the state of the art was not broadly understood and when the basic concerns had to do with people's physical well-being. They are also more consistent with periods of time when there is a shared orthodoxy, a standardization of service models, and a more hierarchical administrative structure for providing services. The emergence of the more individually tailored models of service, treatment and support moves away from standardized methods of and requires a less standardized and therefore less sanction oriented method for assessing performance.
- Finally, and linked to the point above, the growth of continuous quality improvement and total quality management initiatives has strongly influenced the tenor of quality assurance and has shifted the focus of program oversight from process oriented measures to customer satisfaction, and from deficit spotting to performance enhancement.

This final chapter of the report outlines the ways in which other states have begun to make the transition from process to outcomes and enhancement and the specific steps that Georgia should take to install a performance indicator system.

Public Context

As a purchaser of services, the Division of Mental Health, Mental Retardation and Substance Abuse of the Georgia Department of Human Resources is interested in developing performance indicators, that will serve as a catalyst to encourage further enhancement of services at the state, regional and provider levels and to energize internal quality management processes. The latter expectation is based on the assumption that a provider's own internal quality management system is the key to good performance and that performance can be encouraged from the outside, but cannot be compelled. The expectation is that the regions and providers will welcome information on performance norms and will use the information to motivate staff and management.

This approach is quite evident now in the health and mental health care fields as managed care and health maintenance organizations are increasingly being profiled using different sets of performance indicators (Quality Improvement

Review Committee, 1996; Digital Equipment Corporation, 1995; MHSIP Phase II Task Force, 1995; National Committee for Quality Assurance, 1995; and National Leadership Council Task Force, 1995). The results are used by payers, consumers as well as the organizations themselves in making decisions designed to obtain improved performance.

In large part, performance indicators reflect a person's quality of life. In a competitive, demand-driven market, consumers (or their representatives) would promote their own life quality by exercising the power of the purse. They would choose those providers and services that they feel would most contribute to their life quality. The indicators are essentially proxies for the consumer feedback and for the buy/no-buy decisions that come naturally in market-based systems.

Second, as a regulator in the public interest, DMHM RSA is obliged to enforce health and safety standards. The limited availability of staff for on-site surveys has caused many states to consider the use of quality indicators to spot those areas of the system where consumer health and safety is of particular concern and where surveyor time is best concentrated. A critical task is identifying those indicators that can serve as reliable signals or warnings of worsening or untenable situations where consumers are likely to be exposed to an unacceptable level of risk unless action is taken.

Third, DMHM RSA is responsible for ensuring that the major elements of public policy and public vision for the system are in fact being carried out. Issues such as decentralization of decision-making, increased competition, and movement to least restrictive and individualized services are all areas of performance that require monitoring in order to ensure that aspirations for the system are in fact realized.

As noted in Chapter 1 of this report, however, the application of performance indicators -- especially across populations -- is still in an embryonic state in many areas around the country. There are some activities that have been identified in other states that are comparable if not parallel to the initiative being developed in Georgia.

Related Experiences in Other States

Based on surveys conducted by the Human Services Research Institute, nearly all state level databases are limited to socio-demographic information, fiscal information and information about services rendered. They are used for

administrative, fiscal and planning purposes. Though quality assurance and enhancement processes operate in all states, few include a “quality” database as an integral component. The following are descriptions of some exemplary efforts at the collection of performance data and the development of related CQI processes.

Alabama: Mental Retardation Quality Indicators

The Alabama Department of Mental Health and Mental Retardation, Bureau of MR Facility Services operates this system. It is one of a number of quality assurance and continuous quality improvement (CQI) systems managed by the state. The other systems include an incident reporting system, peer review programs, and standards compliance mechanisms. Statewide and regional CQI steering panels oversee the quality improvement processes insuring that the information gained from the CQI activities is used to initiate improvements in system performance. The IPMS system has been in operation for several years.

The Mental Retardation Continuous Quality Improvement Committee, with the support of the Bureau of Mental Retardation Facility Services, had developed a set of thirty-seven quality indicators as of May 1995. The indicators are used to monitor and evaluate the appropriateness and effectiveness of the services being provided by the State Developmental Centers. The indicators are concentrated in the health and safety domains. There are related indicators pertaining to qualified mental retardation professional (QMRP) efforts, disciplinary actions, employee grievances and complaints, client census and staffing levels. There is one indicator pertaining to personal growth (development of adaptive skills).

The indicators are evolving. They are reported out quarterly, always with an accompanying narrative completed by “experienced professionals” in order to guard against misinterpretation and misuse. These reports are used to inform the Centers, external monitors and state administrators about the performance of the organizations and staff as they work to improve outcomes. Trends, patterns and performance problems are identified. This information is fed back to all levels of the system in the interest of promoting quality improvement. Technical assistance may be provided to resolve identified problems and promote better performance.

Indiana: Hoosier Assurance Plan Provider Profile Report Card

As part of The Hoosier Assurance Plan Provider Profile Report Card (Newman, DeLiberty, Hodges, & McGrew, 1996), data is collected on consumers of mental

health and substance abuse services from 30 providers in the State of Indiana. The Provider Profile includes data from consumers regarding levels of distress, ability to manage activities of daily living, decrease in dependency on the service system, promotion of involvement in educational/vocational activities, development of positive support networks, and maintenance of good health and sobriety. Each month, people who were in services the same month during the previous year are called. Each person is asked question related to events before entering services as well as questions regarding their current circumstances.

Data collection is carried out by phone and results are included in a simple report card format that lists results for each provider. In addition, the preparation of the report card is based on a provider survey requesting information about staffing, organization, and services as well as data collected as part of Indiana's existing management information system. The report card, which began as a pilot project, will be issued on a yearly basis beginning in 1997.

Colorado: Colorado Progress Assessment Review (COPAR)

Developmental Disabilities Services (DDS) of the Colorado Department of Human Services operates the system along with other quality assurance approaches including surveys, accreditation and a growing emphasis upon technical assistance. COPAR was developed in 1986 in response to the legislature's request for an assessment of progress in accomplishing the Division's mandate. The system is utilized for assessment and planning purposes regarding the state's two public ICFs/MR, as the tool for pre-admission screening for persons seeking admission to nursing facilities, as the annual resident review for persons living in nursing facilities and as a planning tool for supported living services.

External surveyors on contract to DDS conduct the interviews, consumer surveys and record reviews annually. The Office for Program Evaluation and Information Services analyses the surveys and prepares a written report for internal dissemination; community-centered planning boards (area administration and service agencies) and other providers do not receive the reports; though DDS has identified dissemination to the community-centered boards as a goal.

COPAR reports are utilized to inform the legislature and to identify systemic patterns as the basis for program planning and policy development. An additional benefit is described as raising the awareness of agencies who participate in the COPAR process about consumer perceptions and concerns.

Connecticut: Mortality Review

Beginning in 1994, the Division of Quality Assurance of the Department of Mental Retardation began loading post-mortem diagnoses into CAMRIS. The information is input from the reviews of the Department's Medical Quality Assurance Board. The data are to be utilized for future tracking and research.

Oklahoma Longitudinal Assessment Of Consumer Outcomes

The Division of Developmental Disabilities Services administers the system within its Quality Assurance Unit. The Quality Assurance Unit developed the Longitudinal Assessment of Consumer Outcomes process in 1990 in response to the Homeward Bound V Hissom consent decree. The focus of the tool is on adaptive and challenging behaviors and quality of life outcomes. It is complemented by other QA processes that focus on health and safety, including an annual Provider Performance Survey.

The Division contracts with Oklahoma State University to conduct the surveys and prepare an annual report. Direct care staff are interviewed as well as consumers. The database currently includes 4451 consumers in every service setting, large public ICFs/MR, large and small private ICFs/MR, group homes, supported living and nursing facilities. The only group excluded are people residing in private ICFs/MR who are not Hissom class members or who are ineligible under OBRA-87.

The consumer surveys are based on the Pennhurst (Temple University) consumer tool and focus on measuring annual changes in independence, integration, productivity and consumer satisfaction. The instrument includes adaptive behaviors, challenging behaviors, consumer satisfaction and the physical quality of the environment, all measured on 100 point scales. Information is also obtained on the type and frequency of social interactions, and scored in terms of the number of "outside events" that a person experiences per week. Written reports of findings are disseminated to the service agencies, area offices and case management agencies. They are available to consumers. Case managers are responsible for following-up with technical assistance in problem areas identified in the report.

Initially, for purposes of assessing the effects of outplacement on Hissom residents, the Quality Assurance Unit controlled for the mitigating effects of adaptive behavior, challenging behavior, age and gender by matching the test group of people who moved out of Hissom with the control group of people who

remained at the Hissom Center on these bases. A paired t-test is used to identify the progress or regression of the movers relative to the stayers. The strategy to control for the mitigating effects of individual differences on scale achievement for the broader universe of consumers now being surveyed is to use the individuals as their own controls through a longitudinal study design.

Oregon: CQI in Vocational Rehabilitation

The Oregon Department of Vocational Rehabilitation collects a range of data regarding the local and statewide performance of its job training and placement activities. Performance indicators are constantly reviewed to ensure their continuing relevance to enhancement of services as well as to the expressed needs of consumers. The data, which are collected on varying schedules depending on the frequency of the phenomenon, are part of a data base that is continually up-dated. Each year, the Department develops “benchmarks” or standards for specific activities based on its analysis of past performance. Action plans are then developed to enhance the possibility of achieving goals. The review and assessment of performance is carried out by CQI teams at the local and state level. The teams include vocational rehabilitation staff, employers, and consumers.

Major Implementation Milestones

The following section describes a series of recommended steps to ensure the implementation of an effective and efficient performance indicator system. Several issues are addressed including: appointment of a performance oversight committee; identification of internal responsibility, development of standards and benchmarks; conduct of training for a range of stakeholders; stimulation of continuous quality improvement activities; determine procedure for application of Consumer and Family Survey; issue preliminary report; and ongoing dissemination.

Appoint a Performance Oversight Committee

An important first step in ensuring that the performance indicators enjoy broad support is the appointment of a permanent Performance Oversight Committee at the state level. The membership of the Committee should include consumers, family members, providers, regional administrators, regional board members, and state officials. The function of the Oversight Committee should be:

- To formally adopt the performance indicators;

- To assist the Division to develop standards or benchmarks for each indicator;
- To advise on the formats that should be developed to display the information collected to a variety of audiences;
- To review the indicators on a yearly or more frequent basis and provide the Division with recommendations regarding the implications of the findings;
- To assist in targeting particular problems highlighted by the indicator data and to develop action plans and benchmarks for succeeding years;
- To assess the set of indicators on a periodic basis to ensure their ongoing viability and responsiveness to changing circumstances.

Identify An Individual(s) Within the Division Responsible for Implementation

The process of implementing a performance indicator system will require the identification of an individual or individuals within the Division for whom such implementation is their sole responsibility. It is recommended that the position be at a fairly senior level given the necessity of interacting with multiple entities within the Division as well as the Department as a whole. Specific examples of the tasks for which this individual would be responsible include:

- Working with the MIS staff to ensure that recommended changes in data collection protocols take place and that data collection schedules are developed;
- Assisting the Division Director and the Performance Oversight Committee regarding the implementation and ongoing maintenance of the performance indicator system;
- Providing liaison with regional directors and board members as well as providers regarding the implication of the performance indicator system and assisting them to build on the work of the state by enhancing internal quality assurance mechanisms;
- Working with local CQI teams;
- Working with advocacy and consumer organizations to ensure their input to the process and to communicate the results of data collection;

- Preparing yearly reports regarding the status of performance indicators;
- Overseeing the preparation of action plans.

Development of Standards/Benchmarks

In conjunction with the Performance Oversight Committee, the Division should review the performance indicators and set specific standards for those that can be ascertained without the collection of additional baseline data (e.g., through the Consumer and Family Survey). For instance, it would seem reasonable that the standard for the presence of families and consumers on regional boards should be 100%. Further rates for the movement of people and costs from institutions to communities can also be assigned to the relevant indicators.

There are a range of indicators that could be “benchmarked” by reviewing national data or data from other states. For instance, in the area of supported employment for people with developmental disabilities, a national data base on the numbers of individuals receiving such services is maintained by the Institute on Disabilities at Children’s Hospital in Massachusetts and the University Affiliated Program at Virginia Commonwealth University. Further, the National Association of State Mental Health Program Directors Research Institute is currently compiling information about state trends expenditure and utilization trends. The information is published periodically in the *State Mental Health Agency Profile System Highlights*. This could be a vehicle to assessing national norms and extrapolating such norms to state circumstances.

Many of the indicators, however, will not lend themselves to benchmarking until an initial round of information is collected. Such indicators include issues like access to service coordination, extent of victimization, access to services, and extent of community involvement.

Initiate Training

As noted throughout this report, the use of performance indicator systems is still a relatively recent phenomenon. In order to ensure that the Georgia indicators are implemented in a productive fashion, it will be important to introduce people in all aspects of the system to the uses of performance indicators, the contrast between such systems and traditional sanction-oriented systems, and the attendant CQI process that should be linked to performance measurement. In sum, the intention of the training should be to create a “learning culture” at all levels of the system and to enhance trust among participants in the system.

Stimulate Continuous Quality Improvement

One major aim of the new performance indicator system should be to encourage and energize CQI activities statewide. Clearly, there are already examples of such processes in the state including activities in the Northeast Georgia Region that served as the pilot site. To move the CQI agenda, each region should appoint a CQI committee made up of providers, consumers, families and representatives of other human services agencies and civic organizations. These committees should, based on the recommendations made in Chapter 6, focus on specific issues of relevance to the particular area of the state. Working in conjunction with regional boards, CQI committees can assist in interpreting results of the performance indicators for the region, can encourage the development of internal quality assurance mechanisms among providers, and assist in community outreach and the enhancement of interagency collaboration.

In line with the training described above, the Division should also sponsor workshops “showcasing” the internal quality assurance efforts of exemplary providers in Georgia in such areas as assessment of functioning, consumer satisfaction, and enhancement of staff capabilities.

Determine Process for Administering Consumer and Family Survey

In conjunction with the Performance Oversight Committee, the Division should move quickly to administer the Consumer and Family Survey statewide in order to establish a baseline on the quality of life and other relevant indicators. Decisions and action steps regarding implementation include:

- Whether or not to proceed with a professional survey organization, a consumer controlled organization, or a hybrid of the two;
- How to improve provider data collection systems in order to ensure more accurate addresses and phone numbers;
- When to schedule the statewide survey and which regions should be selected for more intensive data gathering;
- Whether or not to conduct targeted surveys of consumers of priority interest and/or among those most difficult to reach.

Issue a Preliminary Report

To signal the Division's commitment to the performance indicator initiative, it is advised that a report be issued and disseminated throughout the State. The report should include:

- The final version of the performance indicators;
- A preliminary display of information from existing sources linked to specific performance indicators;
- A description of the Division's plans for implementation of the indicators including the Consumer and Family Survey, the Performance Oversight Committee, local CQI committees, and the potential uses of the information gained on a yearly basis for planning, priority setting, and system enhancement;
- The connection between the performance indicator project and aims of the H.B. 100 reform and other Division initiatives.

Ongoing Dissemination

An important element of the implementation of the performance indicator initiative over time will be the nature of dissemination and the ways in which the data are displayed. Since the use of performance indicator information should be available to all stakeholders in the system, especially consumers and families, care should be taken to ensure the data are portrayed in a readily accessible fashion and described in ways that are accessible to a range of individuals. The use of graphs and charts, such as those suggested in Chapter 3, will prove invaluable to increasing the understanding and the utility of the indicators to many audiences.

Once the initial baseline data has been collected, the Division should also consider employing the data to develop provider profiles. This can be accomplished in the following ways:

- Selecting subsets of questions from the Consumer and Family Survey to be administered by all providers in the state in such areas as jobs, housing, service access, health status, and improvement of functioning (see the discussion of the Indiana report card);

- Developing a subset of questions of particular relevance to people with mental retardation, mental illness and substance abuse problems that can be incorporated into ongoing consumer satisfaction surveys;
- Developing provider surveys that request information regarding organizational mission, staffing, and state-of-the art service offerings.

The development of potential provider profiles should be carried out in conjunction with the Performance Oversight Committee.

Conclusion

The State of Georgia has taken a bold step by making the commitment to measure system progress through a set of indicators aimed at the key values and goals of the H.B. 100 reform and the Division's public mission. This commitment ensures that the system will undergo ongoing scrutiny and that W. Edward Deming's admonition -- "Beware continuous improvement of things not worth improving" -- will be heeded.