Human Services Research Institute

Valerie J. Bradley, Project Director
Sarah Taub
Deepika Chawla

Boston University School of Social Work

Ruth Freedman, Ph.D., Project Director
Deborah Chassler, MSW
Faith Little, MSW

Evaluation of Services and Supports to People with Mental Retardation and Their Families in Massachusetts

Final Report

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I. Overview

The following report presents data collected over the past year that illuminates various aspects of the system of services and supports to people with mental retardation in the State of Massachusetts. It includes the experiences of adults with mental retardation and their families who are receiving services from the Massachusetts Department of Mental Retardation (DMR) as well as the perceptions of other stakeholders. It also describes a variety of other performance benchmarks including those related to health and safety, staff turnover, consumer and family participation on provider boards, and access to services.

The purpose of the study, conducted by the Human Services Research Institute (HSRI) and the Boston University School of Social Work (BUSSW) was to provide the Department of Mental Retardation with information necessary to gauge system performance, to identify emerging priority areas in order to develop strategic responses, and to create a baseline or benchmark that will allow the Commonwealth of Massachusetts to track performance over time and to compare performance in the state with other states around the country.

The latter purpose, cross-state comparisons, is facilitated by DMR's participation in the national Core Indicators Project (CIP). CIP, which began in January 1997, is a joint effort of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute. The project's aim is to develop nationally recognized performance and outcome indicators that will enable developmental disabilities policy makers to benchmark the performance of their states against the against the performance levels achieved in other states. CIP performance indicators also enable each state developmental disabilities agency to track system performance and outcomes from year to year on a consistent basis.

Through the project, participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results. This multi-state collaborative effort to improve performance is unprecedented.   The activity currently includes 17 state Mental Retardation/Developmental Disabilities agencies, each collecting performance data on approximately 60 indicators. At the time of the evaluation in Massachusetts, a total of 12 states were participating.

The commitment of the Massachusetts Department of Mental Retardation to examine system performance is particularly timely given the shifts taking place in the ways in which services and supports are provided and the increasingly important role of consumers and families in shaping the content and direction of services. The inclusion of people with disabilities and their families as the primary respondents in this evaluation indicates recognition on the part of DMR of the importance of consumer input for future planning.

The chapters (II-IV) that include a detailed report of the findings of the external evaluation all follow a similar format: Introduction, Method, Results, and Conclusions. The specific content of each chapter follows.

Chapter II – Consumer Survey

Conducted by Boston University School of Social Work
Ruth Freedman, Deborah Chassler, and Faith Little

> This chapter of the report describes the results of over 600 in-person interviews with adults receiving services and supports from DMR. Individuals responded to questions regarding their community participation, choice and decision-making, and satisfaction with services and supports, among other issues.

Chapter III – Family Survey

Conducted by Boston University School of Social Work
Ruth Freedman, Faith Little, and Deborah Chassler

> This chapter of the report presents findings from a mail survey assessing family satisfaction with DMR services and supports. Over 600 family respondents commented on the quality of services received by consumers and their families, involvement in service planning, and satisfaction with individual and family supports.

Chapter IV – Family Focus Groups

Conducted by Human Services Research Institute
Sarah Taub and Deepika Chawla

> This chapter describes the results of focus groups conducted with family members around the state. The total number of individual family members that participated was 79. The results include their perceptions of the quality of DMR services, their unmet needs, and cultural competence, among other issues.

Chapter V – System Data and the Provider Survey

> This chapter summarizes the method and results of system data collection by the Department of Mental Retardation for the national Core Indicators Project.

Chapter VI – Recommendations and Implications of Findings

> This final chapter summarizes recommendations for further action by the Department of Mental Retardation.

II. Consumer Survey

INTRODUCTION

The purpose of the Consumer Survey was to assess consumer outcomes and satisfaction with DMR services and supports. Boston University School of Social Work conducted this survey of over 600 DMR consumers and/or their proxies as part of the External Evaluation of DMR. The Consumer Survey questionnaire was developed by HSRI and the National Association of State Directors of Developmental Disabilities Services for use in the national Core Indicators Project (CIP). The Survey asked questions about various consumer outcomes: community inclusion, choice and decision-making, respect and rights, relationships, satisfaction, service coordination, access, service acceptability, safety and health. The guiding principle of the Consumer Survey was the importance of obtaining consumer input to the maximum extent possible.

METHODOLOGY

Sampling

The Department of Mental Retardation drew a stratified random sample of 1597 consumers who met all of the following criteria: 18 years or older; receiving "service coordination plus one other service/support" (but excluding consumers receiving only service coordination and transportation), and receiving services for at least one year. The sample was stratified to reflect the proportion of consumers in each of the five DMR regions in the Commonwealth.

All 1597 consumers in the Consumer Survey Sample received letters of introduction from DMR that explained the survey and invited them to participate. A first wave of letters was mailed to 997 consumers in late May 1999, followed by a second wave of letters to 600 consumers in October 1999. Forty percent (40.1%) of the 1597 consumers in the sample had full guardians, guardians of the person, or limited guardians (DMR Consumer Registry System codes 01, 02, and 07). Guardians were sent introduction letters that explained the survey and requested permission to interview wards.

Introduction letters to consumers and guardians were followed by recruitment phone calls from Boston University School of Social Work interview staff. Recruitment calls were made to 1431 of the 1597 consumers, leaving 166 consumers who interviewers did not attempt to contact due to time constraints. (See Appendix B, Table B-1.) Of the 1431 consumers that were called, 207 consumers were ineligible, and 17 were deceased, leaving 1207 eligible consumers. The survey response rate was 51.1%, calculated by dividing the number of completed Consumer Surveys (n = 617) by the number of eligible consumers (n =1207). The number of completed Consumer Surveys is based upon phone calls to both consumers and guardians, while the number of eligible consumers is based solely on phone calls to consumers.

Section I of the Consumer Survey was completed by 433 consumers. Section II was completed by 617 consumers and/or their proxies. Of the Section II completed interviews, 179 (29.0%) were completed by consumers only, 221 (35.8%) were completed by consumers and proxies together, and 217 (35.2%) were completed by proxies without consumer participation, as shown in Appendix B, Table B-1.

In order to ensure that the respondent sample was representative of the original randomly drawn DMR sample, statistical comparisons of the background consumer characteristics of the respondents (n = 617) and the non-respondents (n = 980) were conducted. As shown in Appendix B, Table B-2, there were no statistically significant differences between the respondents and the non-respondents in terms of the consumers' gender, race, age, and level of mental retardation, guardianship status, and DMR region. The only background variable for which there was statistically significant variation between the respondents and non-respondents was type of residence: consumer respondents living in nursing homes and specialized facilities were slightly underrepresented and consumers living independently slightly over-represented, compared to the residential settings of the non-respondents.

Survey staff had greater difficulties contacting consumers living in specialized facilities than in other types of residences. This difference could account for some variation in the sample by type of residence. Phone calls to consumers in specialized facilities were more often not returned, and the rate of non-guardian proxy refusal (i.e., staff refusing on behalf of the consumer) for consumers in specialized facilities was higher than for consumers in other living situations.

Measurement Tool

The external evaluation of consumer outcomes and satisfaction was conducted using the Core Indicators Project (CIP) Consumer Survey, developed by HSRI and the National Association of State Directors of Developmental Disabilities Services. The Consumer Survey was designed by the CIP and has been tested for reliability and validity. It is based on the premise that "it is absolutely essential that people with developmental disabilities tell us whether the services and supports they are receiving meet their needs and preferences," as stated in the CIP Draft Guidelines.

In Massachusetts the survey included the two-part Consumer Survey and two additional sections for gathering background information. (See Appendix A.) Questions in Section I of the Consumer Survey were asked only of consumers during face-to-face interviews. Section II questions could be answered by consumers, proxies, or by consumers and proxies together. Proxy-only interviews could take place over the telephone. Section I of the Consumer Survey consisted of short satisfaction questions about day activities, staff, and living situation; questions about relationships; safety; rights; access to services; and service coordination and planning. Section II contained more detailed questions about these same domains, and also included questions about whether and to what extent consumers used integrated community services and participated in everyday community activities (community inclusion), and whether and to what extent consumers made life choices and participated actively in planning their services and supports.

Survey questions were semi- open-ended: the consumer was not given a set of answer choices, but the questions required only a short answer. The interviewer coded the response based on the answer provided by the consumer and/or proxy, choosing from among the survey answer choices (usually "yes", "no", or "in-between"). Each Section II question had a sub-question for the interviewer to indicate who answered the question, the consumer or the proxy. Section I had several "consistency" questions to check for acquiescent response set bias, using negatively and positively worded items that tapped the same dimension. The last item in Section I asked the interviewer to rate the consumer's comprehension of the questions in Section I: the consumer "understood most questions (even if prompted) and could give an opinion, " "not sure," or "No, very little understanding or no comprehension."

Much of the required background information about consumers, including information about service utilization, waitlist status, basic demographics including level of mental retardation, type of residence, as well as age, race, gender, and guardianship status, was provided by DMR's Consumer Registry System (CRS). Additional background information not available in the CRS was collected by proxy interview, either in-person or by telephone. These background data included health and healthcare status, medication and medical needs, and other background information including marital status, information about consumer's living situation and use of services.

On the recommendation of the Core Indicators Project and HSRI, the survey included questions about the behavioral functioning of the consumers who participated in the survey. Phase I project results indicated that the frequency of certain problematic behaviors was significantly related to many of the questions in the survey. Because Massachusetts is participating in the CIP that will compare the survey results across states, it was necessary to factor out, or take into account, differences in these functional characteristics. As part of the data collection, interviewers asked proxies to complete the "Frequency of Behavior" section which asked about the presence and frequency of the four identified behaviors to be used for outcome adjustment: self-injury, property destruction, disruptive behavior, and uncooperative behavior. These questions were never asked in the presence of the consumer.

Data Collection

Twenty-two interviewers conducted in-person interviews during eight months of data collection. Nearly all of the interviewers were women, most had at least some graduate training in the human services, and all had experience either with the population and/or doing in-person surveys. All interviewers were given extensive training in general survey interview technique, received written information abut survey research with persons with disabilities, and on the use of this particular survey instrument. In addition, the first training included a workshop hosted by two consumer advocates. Each interviewer was provided with a Question-by-Question Manual that contained specific and detailed instructions on the intent of each question in the survey and solutions to potential problems with questions. Each interviewer also received scripts for recruiting consumers and guardians by telephone. Role-plays of the recruitment phone calls and the in-person consumer interviewers were required of all interviewers.

Interviews were conducted in-person where the consumer lived, at day program or job locations, or at another setting in which the consumers felt comfortable, (e.g., a coffee shop or library). Two interviewers who were fluent in both Spanish and English conducted ten interviews in Spanish, translating during the interview. Several other interviewers used translators to conduct another eight cases in Spanish and other languages. One interviewer conducted an interview in sign language.

Data collection was complicated by the need to obtain written permission from the consumer's guardian, prior to the consumer interview, for nearly forty percent of the sample. Interviewers had to be persistent in finding and obtaining consent from guardians, by calling service coordinators and/or staff where the consumer lived to obtain correct contact information. Interviewers also had to be persistent when helping guardians, families and staff to assess the capacity of the consumer to participate in the survey.

Families, staff, and other intermediaries often were the first people with whom interviewers spoke. Interviewers were trained to emphasize that it was up to the consumer to decide whether or not to participate in the survey. Some families had a tendency to assume that the consumer did not have the capacity to participate. The interviewers encouraged

everyone -- families, guardians, and staff -- to ask the consumer if s/he wanted to participate, before moving forward with the interview. Copies of the interview were sent to reluctant or hesitant families (and consumers) and guardians, and even staff, to give them an opportunity to review the questions that would be asked of the consumer.

Obtaining informed consent was an integral part of data collection activities. Section I of the survey was completed by the consumer only after the consumer had signed, by signature or mark, or in a few cases indicated verbally, that s/he had understood the Consumer Informed Consent, which was read aloud to each consumer. In cases where the consumer had a legal guardian, the guardian was required to sign a Guardian Informed Consent prior to the consumer interview. In those cases the interviewer also asked the consumer to assent to the interview. Consent forms were written in concrete, non-technical language and approved by the Boston University's Institutional Review Board (IRB).

Data Management

The goal of data management was to establish a data file that would provide all the necessary information in the form required for the data analysis. Data management was designed to facilitate the merging of the two independent data sets: the DMR CRS data and the data generated by data collection activities. In order to make the CRS data compatible with the survey data, CRS data were reorganized into a data file that contained all the information about a given consumer on one line.

Data collection forms enabled staff to monitor and track survey activities. Each survey section tracked who completed that section (consumer or proxy and if proxy, was the person family, guardian, staff and so on), and the mode of completion (in-person, telephone, or in the case of the background information, self-administered). Every survey was given a "final disposition" for Section I (completed or not completed) and Section II (consumer completed, consumer and proxy completed, proxy only completed). Nearly all surveys were also given a telephone call disposition which tracked the results of the recruitment calls and included consumer agreement to participate, consumer refusal, no contact despite repeated phone calls, ineligible/unavailable/phone problems, deceased, proxy agreement for a consumer judged not to have the capacity to participate and who did not have a legal guardian, and proxy/gatekeeper refusal for a consumer without a legal guardian.

Survey data were coded onto computer readable scan sheets. Interviewers were trained in the use of these scan sheets, and were given a detailed manual that explained, step by step, the coding scheme for the responses to every question on the survey. Office staff rigorously edited scan sheets, and questionable responses were referred back to the interviewer for clarification. Edited scan sheets were collected, counted, and ultimately scanned by the Boston University Office of Information Technology, resulting in an electronic data file later used for the data analysis. Ultimately, one data file was created that contained all the information, CRS and survey data, about each sample consumer (n = 1597).

Data Analysis

Data for the analysis were drawn from several sources: the DMR Consumer Registry System (CRS); the two sections of the Consumer Survey; the Health, Residence, and Other Supports background information section; and the Frequency of Behavior section which gathered information on problem behaviors. The CRS data provided information on each respondent in the sample although there were instances where the CRS data were incomplete or outdated.

A data file consisting of over 300 variables was created that included all the information gathered in the field and all of the CRS information provided by DMR. Data cleaning activities included checking for coding errors, scanning problems (e.g., poorly "bubbled" scan sheets), incomplete responses, duplicates, and other data problems.

The next step in data cleaning was to determine if there were any surveys that should not be counted as completed interviews. To be counted as completed, a consumer and/or proxy had to have answered at least half of the questions in either Section I or Section II. There were several cases where over half the questions were not answered in Section I. Those Section I interviews were not included in the analysis of survey results. In addition, if the consumer completing Section I was scored as having had very little understanding of the questions, or no comprehension, the survey was not included in the analysis, even if the questions had been answered. Of the original 508 Section I consumer interviews, 73 consumers, or 14.4%, were coded as not having understood the questions. These 73 interviews were not included in the analysis of survey results. The background information sections did not have to be completed for the survey to be considered complete.

The exact number of responses on any given item varied depending on a number of factors. The questions in Section I have fewer respondents because they were answered by consumers only, while Section II questions were answered by consumers and/or their proxies, resulting in a larger number of respondents. The number of respondents to questions also varied when a question was coded "not applicable" because the question was applicable only to certain subgroups (for example, questions pertaining to day programs were answered only by those consumers participating in day programs). The number of respondents also varied when answers to questions were coded as "no response, unclear response" because the consumer or proxy refused to answer or the interviewer could not understand the consumer or proxy response. Each of these types of responses was not counted in the analysis.

There were multiple steps in the analysis of the consumer outcome data. First, the frequencies of each consumer outcome were examined, question-by-question. The CIP outcomes were then analyzed by key subgroups that had been identified by DMR, by HSRI, or by BUSSW, as having potential impact on outcomes. These subgroup variables included type of residence, DMR region, level of mental retardation, age, current service utilization, current service configuration, waitlist status, and frequency of problem behavior. Chi-square analyses were conducted by subgroup for each outcome variable. The purpose of the chi-square analysis was to identify subgroup variables that were significantly related to specific consumer outcomes and to identify compelling trends by subgroups. (See the Results Section below for a full explanation of the subgroup analysis.)

RESULTS

Consumer Characteristics

Who are they?

As shown in Appendix B, Table B-3, consumers in the survey ranged in age from 19 to 86 years, with a mean age of 41.5 years. They were primarily Caucasian (88.5%) and slightly more than half were male (53.8%). Most were classified as having mild or moderate retardation (70.8%). About one-fourth of the consumers had severe or profound retardation (24.1%).

- 59.8% of the consumers had at least one other disability, most frequently mental illness (21.3%) or brain injury/neurological problems (20.4%).

- 54.5% exhibited one or more of the following problematic behaviors (based upon ratings by staff or family): uncooperative behavior; disruptive behavior; self-injury; and, property destruction.

- Consumers with severe or profound retardation were most likely to have another disability or to have a problematic behavior. (See Figures B-2 and B-3 in Appendix B.)

Where do consumers live?

The number of respondents in each of the five DMR regions reflects the regional distribution of consumers in the overall DMR population. As explained in the Sampling section above, the respondent sample was quite close to the overall sample in terms of distribution among types of residence. Regional and residential distributions are given below, along with highlights of the subgroup analysis. Complete details are contained in Appendix B, Table B-4 and Appendix B, Figures B-1 through B-4.

Region:

% 1 (Western)	*14.1*
% 2 (Central)	*15.7*
% 3 (Northeast)	*18.5*
% 5 (Southeast)	*19.6*
% 6 (Metro)	*32.1*

Residential Setting:

% parent/relative home	*52.4*
% living independently	*2.3*
% in community residence/apartment	*37.6*
% in nursing home	*4.2*
% in specialized facility	*3.2*

Source: DMR Consumer Registry System
June-September 1999

Residential Setting and Region:

In all regions, consumers were most likely to live in parent/relative homes or community residences.

- *Regions 1,3, and 6 had no respondents living independently*
- *Region1 had no respondents in nursing homes*

Residential Setting and Level of Mental Retardation:

- *Consumers living in specialized facilities were most likely to have severe or profound mental retardation*
- *Persons living in community residences were approximately evenly distributed across three levels of mental retardation (mild/above mild, moderate, severe/profound)*

Residential Setting and Presence of Disabilities and Problem Behaviors:

- *50% of the consumers living in specialized facilities, and 26.0% of persons in community residences, had a diagnosis of mental illness (compared to less than 20% of persons in other types of settings)*

- *Persons in specialized facilities or in community residences were most likely to exhibit self-injurious behaviors, property destruction and uncooperative behavior*

What services do consumers use?

Services received by consumers depended, in part, on the type of residence in which they lived, and in part, in what region they lived. Level of mental retardation also played a role in service receipt. Details are contained in Appendix B, Table B-5 and Appendix B, Figures B-5 through B-7.

Services Used:

- *75.7% received day services*
- *45.2% received residential services*
- *65.6% received support services: most frequently family or individual supports and/or transportation*
- *25.9% received a combination of day, residential and support services*

Residential Setting and Service Utilization:

- *Consumers living in community residence or in parent/relative homes were most likely to receive day services*
- *71.4% of persons living in family homes received supports, 100% of consumers living independently, but only 19.2% of nursing home residents received supports*

Region and Service Utilization:

- *Consumers living in Regions 1, 2, and 3 were most likely to receive supports*
- *The proportion of consumers receiving residential services was highest in Region 6 and lowest in Regions 2 and 3*

Level of Mental Retardation and Service Utilization:

- *Residential services were most frequently utilized by persons with severe/profound mental retardation*

Source: DMR Consumer Registry System, June-September 1999.

What services are consumers waiting for?

Consumers in the respondent sample were on waitlists for day services, residential services and support services. Complete details are contained in Appendix B, Table B-6 and Appendix B, Figures B-8 and B-9.

Waitlisted Services:

- *9.1% on waitlist for day services*
- *19.9% on waitlist for residential services*
- *10.4% on waitlist for support services, primarily family or individual supports*

Residential Setting and Waitlist:

- *Nursing home residents were most likely to be waiting for residential services*
- *Consumers living with parents or relatives were most likely to be waiting for support services*
- *Consumers waitlisted for day services were most likely to be living in nursing homes or specialized facilities*

Region and Waitlist:

- *Region 3 had the highest proportion of consumers on a waitlist for residential services*
- *Region 3 had the highest proportion of consumers on a waitlist for support services*
- *Consumers in Region 5, Region 3 and Region 6 were most likely to be on a waitlist for day services*

Source: DMR Consumer Registry System, June-September 1999.

Outcome Results

Results for the Core Indicator Project Consumer Outcomes are listed below. Highlights of the descriptive statistics for survey questions are provided. Complete details of findings are contained in Appendix C, Tables C-1 through C-10. Many outcomes had significant variation by type of residence and by region. Highlights of the significant findings are described below, identifying compelling trends. Bar charts detailing the significant differences by type of residence are found in Appendix D, Figures D-1 through D-8, and by DMR region in Appendix E, Figures E-1 through E-17.

Community Inclusion

Section II of the Consumer Survey contained six questions designed to assess whether consumers used integrated community services and participated in everyday community activities.

- Nearly all respondents reported that they went on errands or appointments (94.1%) went shopping (89.9%) and out to eat (89.6%), or out for entertainment (80.9%).

  - Persons living in community residences, persons living independently, and consumers living with parents or relatives were the most likely to go out on errands or appointments, shopping, or out to eat.

  - Persons living in community residences, specialized facilities, or with parents and relatives were the most likely to go out for entertainment.

- Overall, fewer consumers participated in exercise or sports (67.9%), or religious services or events (52.0%), than went on errands, shopping or out to eat.

Choice and Decision-Making

Twelve items in the Consumer Survey were designed to assess how many and to what extent consumers made life choices and participated actively in planning their services and supports. Most consumers had some control or decision-making power about daily aspects of their lives (with or without assistance); fewer had control over important life decisions.

- About three-quarters or more of all consumers made choices about their daily schedules (75.3%), fun things to do (90.9%), what to buy (85.4%), and access to money for buying things (77.4%).

  - Consumers living independently, at home with parents or relatives or in community residences were the most likely to have decision-making power over these daily aspects of their lives.

- Most consumers did **not** choose home (52.4%), roommates (66.0%), home staff (59.2%), job staff (75.1%), or day program (66.4%). Consumers working in jobs were the exception; 70% of consumers with jobs reported that they chose their jobs.

  - Consumers living in parent/relative homes or living independently were the most likely to have chosen the home they were living in or their roommates.

- Consumers living independently or living in community residences were the most likely to have chosen their home staff.

- Nearly all consumers did **not** choose their service coordinators (91.8%).

    - Consumers living independently or in community residences were the most likely to have chosen their service coordinators.

Rights and Respect

Section II of the Consumer Survey contained eight questions designed to assess whether consumers received the same respect and protections as others in the community. Overall, most consumers reported that their rights were respected. Few consumers participated in self-advocacy activities.

- Most consumers could have privacy with guests (76.7%), could use the phone when they wanted to (84.6%), and could spend as much time alone as they wished (85.3%).

- About 88% of consumers said that no one enters their homes or their bedrooms without permission.

    - Consumers living in nursing homes or specialized facilities were the most likely to have someone enter their home or bedroom without permission.

- About two-thirds of consumers **never** have their mail opened **without** their permission (64.0%).

- About two-thirds of consumers reported that they had an advocate or guardian to help them (68.4%).

- About one-quarter of all consumers had participated in self-advocacy activities (26.7%).

    - Consumers living independently and those living in community residences were the most likely to have participated in self-advocacy activities.

Service Coordination

Five questions in Section I of the Survey were designed to assess consumer perception of service coordinators and the service planning process. Overall, consumers who were actively involved with their service coordinators and had service plans seemed to be satisfied.

- About three-quarters of consumers reported that they received help from their service coordinator (77.3%) and could talk to their service coordinator when they wanted to (74.3%).

    - Consumers living in community residences, specialized facilities, or living with a parent or relative, were the most likely to report that they received help from their service coordinators when they needed it.

Only some consumers had service plans that required annual ISP meetings. The results indicated below refer to the group of consumers whose service plans required an annual ISP.

- Of consumers whose service plans required an annual ISP meeting (and who answered this question), 78.4% reported that they had a planning meeting this year.

    - Consumers living in specialized facilities, in community residences, or living with a parent or relative, were the most likely to have reported that they had an ISP meeting.

- Of consumers whose plans required an ISP meeting, 94.7% reported that people listened to them at the meeting, and 74.1% reported that they chose what was in the plan.

Service Access

Three questions in the Consumer Survey assessed consumer access to services.

- Seventy percent (70.2%) of all consumers said that they had received help this year to learn new things.

    - Nearly eighty percent (78.3%) of all consumers reported that they almost always had transportation when needed.

- Consumers living in community residences and nursing homes were the most likely to have reported almost always having transportation.

- About one-third (37.0%) of all consumers said they had asked for services or supports and did not get them.

- The service they asked for most was transportation.

Service Acceptability

Service acceptability was assessed by asking consumers about the staff who worked with them. The overwhelming majority of consumers reported that the staff that worked with them were nice.

- Over ninety percent of consumers felt that their day staff were nice (91.1%), work staff were nice (91.6%), and home staff were nice (90.6%).

Health

Four health indicators provided data about healthcare for consumers. Health outcomes for consumers were obtained from proxy respondents, including parents and guardians, staff, and service coordinators and other helpers. Consumers did not complete this section of the survey.

- Most consumers reportedly had a recent physical exam (94.0%) and a recent dental exam (73.9%).

    - Consumers living independently, in community residences, or in nursing homes were the most likely to have had a recent physical exam.

    - Consumers living in community residences or specialized facilities were the most likely to have had a recent dental visit.

- About two-thirds of female consumers had an OB/GYN exam during the last year (62.8%).

  - Female consumers living in specialized facilities, independently, or in community residences, were the most likely to have an OB/GYN exam.

- About one-fifth of female consumers were reported to have never had an OB/GYN examination.

  - Over one-third of female consumers living at home with parents or relatives had never had an OB/GYN exam.

- Over forty percent (42.8%) of the consumer sample reportedly were taking medication for "mood, anxiety, sleep or behavior problems."

  - Consumers living in specialized facilities, nursing homes, and community residences were the most likely to be taking these medications.

- Forty percent of consumers were reportedly taking medications for "other health problems."

  - Consumers living independently and those living in nursing homes were the most likely to be taking medications for other health problems.

Safety

Section I of the Consumer Survey contained two questions to determine the proportion of consumers who feel safe at home and in their neighborhood.

- The overwhelming majority (92.0%) of consumers reported that they felt safe at home.

  - Consumers living independently were the least likely to feel safe.

- Three-quarters (74.8%) of consumers reported that they felt safe in neighborhoods.

Satisfaction

Consumers were asked a few satisfaction questions about their daily lives.

- Nearly all consumers said that they liked their homes (86.5%), their day programs (87.4%), and their jobs (87.4%).

  - Consumers living independently were the least likely to report that they liked their homes.

- Over half of the consumers who had jobs reported that they would like to work more hours (56.7%).

Relationships

Section I of the Consumer Survey contained five questions that were designed to assess consumers' relationships with family and friends.

- Most consumers reported that they have friends (80.0%), family (81.5%), and best friends (80.1%).

- Almost three-quarters of consumers reported that they could see family when they wanted to (72.9%), and best friends when they wanted to (73.1%).

- About half of all consumers reported that they "sometimes" feel lonely (48.1%).

  - Consumers living in the homes of parents or relatives, or in nursing homes, were the most likely to say they "never" feel lonely.

CONCLUSIONS

The Consumer Survey findings point to many positive outcomes for DMR consumers. Most consumers participated in community activities and had relationships with family and friends. They liked where they live, liked their day activities, and felt safe at home and in the neighborhood. They felt that staff treated them well and that their rights were generally respected. In short, the vast majority of consumers appeared satisfied with many aspects of their lives and with the staff who supported them.

In addition to these generally positive outcomes, there are also some outcomes for which the findings were more mixed – where some consumers appeared to do well in terms of certain indicators, but many others did not fare so well. Some outcomes with mixed findings relate to basic components of service coordination, access, and health. In addition, consumers fared unevenly in terms of choice and decision-making. These mixed indicators require further examination and attention by DMR in order to develop policies to address areas of need. The implications of the Consumer Survey findings and recommendations for improving consumer outcomes follow.

Ensuring the basics of service provision

Annual ISP meetings constitute a basic provision of the DMR service delivery system. Planning meetings enable consumers and families/advocates to access needed services and to exercise choice about the services and supports they receive or need. Among DMR consumers for whom annual Individual Service Plans were mandated by regulations, 78.4% reported that they had an ISP meeting this year. Most consumers who had an annual ISP meeting were pleased with the planning process – they chose what was in their plans and felt that their concerns were heard.

However, about one-fifth of consumers did not have annual ISP meeting as required and about one-fourth felt that they did not get help from their service coordinator and could not talk to the service coordinator when they wanted to. It is important to investigate why required ISP meetings did not occur for these consumers and why some consumers did not feel well served by their service coordinators. Service coordinators play a critical role in helping consumers and families plan for and obtain access to services and supports. DMR needs to eliminate barriers that may prevent some consumers and families from participating in the planning process, and to develop ways for service coordinators to better respond to consumers' needs.

In future stages of data collection, DMR should consider including additional questions in the Consumer Survey about reasons for lack of ISP planning meetings and perceived barriers to obtaining assistance. The findings of the DMR Family

Survey and the Family Focus Groups provide some additional insights about family and consumer interactions with and concerns about the DMR service system.

Providing health care to women

While most consumers had recent physical and dental exams, recent OB/GYN exams for female consumers were less frequent. About one-fifth of female respondents had never had an OB/GYN exam. Women living at home with parents/relatives were least likely to have ever had an OB/GYN exam (one-third had never had an exam).

Lack of adequate gynecological care poses serious public health risks for this population, particularly given the mean age (42 years) of women in the sample. Older women are at higher risk of breast, ovarian, and other types of cancer that require early detection and timely treatment. At menopause, women may face mid-life changes that may require medical, psychological, nutritional, or social support. Regardless of whether women are sexually active, gynecological care is a critical component of their overall health.

DMR needs to investigate why women consumers did not receive annual OB/GYN exams and what barriers (health provider, insurance coverage, financial, attitudinal) may prevent them from receiving proper care. More detailed information about these issues might be obtained through additional Consumer Survey questions in future data collection efforts and/or through convening focus groups with female consumers, caregivers, and staff about women's health care needs.

DMR should consider implementing a statewide initiative to address women's health care issues through targeted public education and preventive health measures. Physicians and other health care professionals need to be educated about the health care needs of women with mental retardation and how best to serve them. Consumers and their families also need information about the importance of seeking help for women's health issues and linkages to health care resources.

Monitoring mood medications

Another survey finding with important health care implications is the large proportion of consumers who received medications for mood, anxiety, sleep, or behavior problems. Over two-thirds of consumers living in specialized facilities and over half of persons living in community residences were taking these types of medications. It is unclear whether these medications were used to treat consumers' psychiatric/behavioral symptoms and/or to restrain problematic behaviors of consumers. Survey findings indicate that one-fifth of the consumers had psychiatric conditions in addition to mental retardation and about half had one or more behavioral problems.

DMR needs to monitor the high rates of medication use for consumers with mood, anxiety, sleep, or behavior problems, particularly in specialized facilities and community residences. It is important to examine:

- What specific drugs are used and for what reasons?

- To what extent are these medications used to treat co-morbidity of this population?

- To what extent are medications used as a chemical restraint in residential and day settings?

Based on this information, DMR should provide staff training and consultation regarding appropriate (and inappropriate) uses of medications with this population and the relative effectiveness of non-pharmacological behavioral interventions.

Promoting choice, decision-making, and self-advocacy

As services for persons with mental retardation shift to a more consumer-driven model in Massachusetts and nationwide, DMR needs to develop policies and practices that provide opportunities for all consumers to make decisions about their lives to the maximum extent possible. It should be presumed that all consumers have some capacity to make choices about their daily lives (either with or without assistance) and to communicate their preferences and values (either verbally or non-verbally).

DMR Consumer Survey findings indicate that most consumers exercised some choice about their daily activities, but that far fewer people had control over the choices about where they live, their staff, or their roommates. Persons living in nursing homes and in specialized facilities had the most limited opportunities to exercise choice. Decision-making by consumers represents a significant shift from the traditional service model in which professionals and caregivers typically make decisions on behalf of consumers. In order to implement a consumer-driven support model, DMR must provide training and supports to prepare staff for their new roles and relationships with consumers and families. Staff, guardians, and other caregivers need training in ways to facilitate consumer choice and to support consumers in making their own decisions to the fullest extent. Training and support is especially needed in institutional settings where opportunities for consumer choice are generally more restricted and where consumers may have more significant disabilities.

Consumers also need support and training regarding how to make informed choices, since many have traditionally been excluded from the decision-making process. Self-advocacy organizations provide valuable opportunities for consumers to learn and exercise their right of self-determination. Consumer Survey findings, however, indicate that most consumers did not participate in self-advocacy activities. Persons living independently or in community residences were most likely to participate in self-advocacy groups. DMR should provide information to consumers about self-advocacy groups and promote consumer participation, as well as educate staff about the importance of supporting consumer involvement in self-advocacy. Opportunities for self-advocacy should be available for consumers living in all types of residential settings and across DMR regions.

Ensuring positive outcomes across residential settings

Consumer outcomes were highly dependent upon where the consumer lived. In terms of service coordination and health care outcomes, persons living in community residences or in specialized facilities seemed to fare best. Perhaps this is because the residential settings in which they live are a critical and major component of the DMR service system. In contrast, consumers living in settings external to the formal DMR service system (those living with family or independently) were less likely to access basic services and health care. DMR needs to forge new connections to consumers living outside of the formal DMR residential service system and to

eliminate barriers (e.g., service delivery, financial, insurance, or other) that may prevent these consumers from obtaining basic services and health care. As more consumers choose to live in their own homes, or in flexible, supported living arrangements that may not be part of the formal service system, DMR needs to develop new ways to link these individuals to services and supports as needed.

Consumer inclusion, choice and rights outcomes also varied significantly by type of residence. Persons living independently and in community residences were most likely to participate in community activities and self-advocacy and to exercise choice in several domains. Persons living in specialized facilities and in nursing homes were least likely to fare well in terms of these outcomes. These differences may be due, in part, to differences in consumers' functional levels, given that persons in institutional settings tend to have more severe limitations. Training and supports should be provided to consumers with severe disabilities to enable them to participate to the maximum extent possible in community activities and in decision-making. Consumers living in all residential settings should have opportunities for community inclusion and self-determination.

Future data collection

The DMR Consumer Survey process was successful in obtaining consumer outcome data from a large representative sample of DMR consumers. The effectiveness of this data gathering effort can be measured by the wealth of information obtained about a broad set of consumer outcomes, the important policy implications of these findings, and the identification of issues that require further investigation by DMR. These data can assist DMR in evaluating the effectiveness of the services and supports it provides and in identifying areas in need of improvement.

The survey data can also be used to probe key policy questions or information needs identified by DMR. Based upon further analysis of the Consumer Survey data (in conjunction with DMR Family Survey data), policy briefs can be prepared to investigate specific issues of interest or pressing concern to DMR. For example, consumer outcome data could be further analyzed regarding the following issues:

- Consumers living at home with families

- Older clients of DMR and their aging caregivers

- Consumers with multiple disabilities/behavioral problems

- Consumers on waitlists for services

- Legal guardian involvement

- Medication usage

- Women's health care

We support the intention of DMR to continue implementing the Consumer Survey on an annual basis, in order to reach a broad cross-section of consumers, and to assess changes in outcomes over time.   Based on the successes and challenges encountered in Year 1 of data collection, the following recommendations are made to enhance the effectiveness of future consumer survey efforts. For Year 2 of Consumer Survey data collection, we suggest that DMR:

- Draw a stratified random sample of DMR consumers (who were not included in Year 1 sample).

- Draw an additional sample of DMR consumers who completed the Year 1 Consumer Survey, in order to conduct a longitudinal analysis of consumer outcomes.

- Utilize a rolling data collection methodology so that interviewers can contact potential respondents immediately after they receive a recruitment letter from DMR.

- Update the CRS data re: sample members to ensure accuracy of telephone numbers, addresses, guardian status, residential setting, service coordinator, and other information.

- Do thorough "advance work" with DMR staff and with providers throughout the state to inform them of the Consumer Survey and its importance, and to educate them about survey protocol regarding outreach, informed consent, and interview procedures. Conduct specific "advance work" with gatekeeper staff in specialized facilities and nursing homes that may have specific institutional protocol which prevent interviewer access. The more information staff receives in advance, the easier it will be for interviewers to gain access to consumers and guardians.

- Educate staff, family members, guardians, and other caregivers about the importance of obtaining the consumer's opinions in the interview process, to the maximum extent possible. Encourage the use of alternative communication methods in interviews with consumers who have limited or no verbal skills.

- Provide guidelines to proxies about their involvement in consumer interviews, including when it is appropriate (or not appropriate) for proxies to answer questions on behalf of consumers.

- Ask family members who are involved at the Consumer Survey interview to complete the DMR Family Survey, in order to provide supplementary data from the family's perspective and to serve as an additional source of respondents for the DMR Family Survey analysis.

- Incorporate additional questions in Year 2 Consumer Survey, based upon issues/questions that emerged from the analysis of Year 1 data.

DMR has undertaken a major effort to obtain consumer feedback about services. The agency should be commended for its commitment to collecting data about consumer outcomes that will be compared to national benchmarks. The findings of the Consumer Survey, Family Survey, and other Core Indicator data will help inform DMR as the agency moves increasingly toward providing consumer-directed and family-directed supports.

III. Family Survey

INTRODUCTION

The goal of the Family Survey was to assess family satisfaction with supports and services received from DMR – both supports received by the person with a disability (the "consumer") or received by the family. This mail survey, conducted by Boston University School of Social Work, utilized a questionnaire adapted from the national Core Indicators Project (CIP). Massachusetts is one of 14 states participating in CIP that seeks to develop nationally recognized performance and outcome indicators for services provided by state mental retardation agencies to consumers with mental retardation and their families. The Family Survey results will help policy-makers understand families' preferences, and compare family ratings of DMR supports and services to national benchmarks.

METHOD

Sample

The overall sample consisted of 2,000 families who had a family member at least 20 years of age currently receiving services from DMR. Two versions of the survey were created, one for families in which the consumer lived at home ("in-home families"), and one for families in which the consumer lived in an out-of-home placement ("out-of-home families") (See Appendix F). To ensure enough respondents from both types of families, a random sample of 1,000 families was drawn separately for the in-home and out-of-home families. The samples for both versions were stratified by DMR region in order to ensure geographic representation of families in each of the five regions.

The two versions of the survey were mailed out to the samples of in-home families and out-of-home families in October 1999, along with a pre-addressed, stamped return envelope to Boston University School of Social Work. In order to more easily track which version of the survey (in-home or out-of-home) was returned, and to track from which region each came, the surveys were color-coded. Two weeks after the original mailing, a reminder postcard was sent to each family asking them to complete the survey if they had not already done so.

A total of 610 completed surveys were returned, with an overall response rate of 32%. The response rate for the in-home family survey was 30%, with 275 completed surveys returned. It is notable that 53 out of the 1,000 families in the in-home sample returned the survey without completing it, because their family member did <u>not</u> live at home with them, and consequently, they had received the wrong version of the survey. In a few cases, families provided identifying information in the returned survey, so the correct survey version was then mailed to them. An additional seven in-home family surveys were returned with incorrect addresses. Sixteen in-home family respondents who returned surveys with incomplete data were also excluded from the analysis.

The response rate for out-of-home families was 35%, with 335 completed surveys returned. Only nine of the out-of-home families received the incorrect version of the survey; there were 16 returned surveys with incorrect addresses. Eight out-of-home family respondents with incomplete survey data were likewise excluded from the analysis.

Data Collection

The Family Survey was a self-administered questionnaire. (See Appendix F.) Both the in-home and out-of-home versions included questions on consumer and family respondent background characteristics, family satisfaction with services provided to the consumer, and a final open-ended comments page in which respondents were asked to offer additional comments if they wanted. The survey was anonymous; no identifying information about the respondent was present on the surveys. However, families were given the option of waiving anonymity by providing their names, addresses, and telephone numbers if they wanted DMR to contact them about the concerns that they expressed in the survey.

In addition to the questions described above, the Family Survey (for out-of-home families) asked families to rate their involvement in and satisfaction with the supports provided to the consumer (e.g., "Did you help develop this person's plan?" "Overall, are you satisfied with the services and supports this person currently receives from DMR?"). Each question was rated on a three-point scale (yes or mostly; somewhat; no or not at all).

The Family Support Survey (for in-home families) asked the same background questions as the out-of-home version of the survey, with some additional questions about the primary caregiver of the consumer. As in the Family Survey, the Family Support Survey also asked about family involvement in and satisfaction with services provided to the consumer. In addition, the Family Support Survey asked about the types of services the family received from DMR and posed 15 questions about five areas of support the family may have been receiving: information; choices and planning; access; and, links to community. These questions used the same three-point rating scale as described above regarding the Family Survey.

Data Analysis

The objectives of the data analysis were twofold: 1) to describe in-home and out-of-home families' characteristics, service utilization, and satisfaction with DMR services; and 2) to compare these characteristics and outcomes across the two groups of families.

Data first were analyzed separately for the in-home and out-of-home family groups, using descriptive statistics to summarize information on background characteristics of the consumers, family respondents, and primary caregivers (for in-home families only). Descriptive statistics were also used to analyze responses of in-home families and out-of-home families on types of services received by families and consumers as well as families' involvement and satisfaction with these services. In order to compare the responses of in-home and out-of-home families across these outcomes, cross tabulations were conducted and the chi-square statistic used to determine whether significant differences existed between the two groups of families.

In addition to these quantitative analyses, families' responses to the open-ended question about additional comments were analyzed qualitatively by coding for content and then organizing the comments into key themes.

RESULTS

Background Characteristics

Consumer Characteristics

Table G-1 (Appendix G) presents information about the background characteristics of consumers living at home or out-of-home. The mean age of consumers living at home with families was 34.1 years. Out-of-home consumers were about 10 years older on average (mean age 43.8 years). For both groups, most consumers were between the ages of 20 – 55 years. However, about one-fifth of the out-of-home consumers were older than 55 years.

Level of mental retardation of the consumer was significantly different between the in- and out-of-home family groups. For in-home consumers, more than three-quarters (79.1%) had mild/moderate mental retardation, and about one-fifth (20.8%) severe/profound retardation. This differed significantly from consumers living out-of-home, where slightly over half (51.5%) had mental retardation at the mild/moderate level, and nearly half (48.5%) at severe/profound levels. More than twice as many persons in the out-of-home families had severe/profound mental retardation than in-home consumers (48.5% and 20.8%, respectively).

Consumers living out-of-home were also significantly more likely than in-home consumers to have disabilities in addition to mental retardation (52.9% in-home and 65.3% out-of-home). Mental illness/psychiatric diagnosis and autism were the additional disabilities that occurred significantly more often in the out-of-home family group.

Living situations for out-of-home consumers varied. Well over half (58.0%) lived in group homes and about one-fifth of the consumers lived in an institutional setting (15.7% in specialized facility and 5.4% in nursing home). The proportion of respondents in each DMR region for both the in-home and out-of-home families are generally representative of DMR's sample, and are also not significantly different from each other.

Family Survey Respondent Characteristics

Table G-2 (Appendix G) presents background data on the characteristics of the Family Survey respondents. The majority of respondents for both in- and out-of-home families were parents of the consumer (85.7% of in-home families and 63.9% of out-of-home families). However, many respondents were siblings (11.2% for in-home families and 28.8% for out-of-home families). Frequently, the survey respondent was also the consumer's legal guardian (68.1% of in-home families and 77.8% of out-of-home families).

In-home family survey respondents were slightly younger than out-of-home respondents (mean age of 59.6 and 62.9 years, respectively). For both groups, over half of the respondents were 60 years or older. There were 36 family respondents (across both groups) who were 80 years of age or older.

For both in-home families and out-of-home families, the majority of survey respondents were women (80.1% of the in-home families and 67.2% of the out-of-home families.) Across both groups, the vast majority of survey respondents were white (89.2% of in-home families and 94.1% of out-of-home families).

Out-of-home family respondents reported significantly higher incomes than in-home families, with 27.8% of in-home families reporting annual household income greater than $40,000, compared to 37.9% of out-of-home families. For both groups, however, the proportion of families with annual household income under $25,000 was striking: 54.1% for in-home families and 38.4% for out-of-home families.

Characteristics of Primary Caregiver among In-Home Families

As shown in Table G-3 (Appendix G), over 90% of in-home survey respondents were the primary caregivers of consumers, most often the consumer's mother. The mean age of the primary caregiver respondents was 61.0 years, with a range of 23 to 95 years. Over half (56%) of the primary caregivers were age 60 or over and fully 25% of the caregivers were age 70 or older. Most respondents (73.6%) reported they were in excellent or good health. Slightly more than one-fourth of the caregivers (26.4%) reported they were in fair or poor health.

Supports And Services Received By Consumer

Types of Supports and Services Received by Consumer

- Consumers living at home with their families received significantly fewer supports and services than consumers living out-of-home. (See Appendix G, Table G-4.) For example:

    - Seventy-two percent of in-home consumers received case management/service coordination, compared to 95.5% of out-of-home consumers.

    - About two-thirds (67.1%) of consumers living at home with family received transportation services, compared to 90.7% of out-of-home consumers.

Family Involvement in Service Planning for Consumer

Family respondents were asked to rate their involvement in various aspects of service planning for the consumer. (See Appendix G, Table G-5.)

- More than three-quarters of in-home and out-of-home families felt they were able to contact the case manager when necessary (77.4% and 88.2% respectively).

- About half of the in-home and out-of-home families reported that they helped develop the service plan (55.9% and 49.4% respectively).

- Out-of-home families were significantly more involved than in-home families in four of the six areas of family involvement surveyed. Out-of-home families were more likely to report that:

    - they received enough information to participate in the service plan

    - the service plan included important things to the family

- the family could contact the service coordinator when needed

- the service coordinator provided assistance to the family.

Family Satisfaction with Services and Supports for Consumer

Families also rated their satisfaction with services and supports for the consumer. (See Appendix G, Table G-6.)

- Over three-quarters of out-of-home families and nearly 60% of in-home families were satisfied, overall, with the services provided to the consumer.

- About three-quarters of both in-home and out-of-home families thought that, overall, the consumer was happy.

- Out-of-home families were significantly more satisfied with consumer services and supports than in-home families in several aspects:

  - staff could communicate in alternative ways

  - consumer had access to special equipment

  - consumer's day setting was safe

  - overall, family was satisfied with services to consumer.

Family Supports

Types of Family Supports Received by In-Home Families

Family support to in-home families varied widely. (See Appendix G, Table G-7.)

- About three quarters of in-home families (73.9%) received service coordination.

- Less than half (45.5%) received financial support.

- Less than half (43.4%) of families received respite care.

- About one quarter (24.7%) of families received other types of family support.

- Only 13% of families received staff support.

Ratings of Family Supports

In-home families rated family supports in four areas: information; choices and planning; access to supports and services; and links to community. (See Appendix G, Table G-8.)

Information

- Nearly 40% (39%) of families said that information about services and supports was available.

- Over two-thirds (69.4%) of families felt that the information provided about DMR services was easy to understand.

Choices and Planning

- More than a third (37.9%) of families said they were able to choose agencies or providers that worked with them, but only one-fifth (20.9%) said they were able to choose staff.

- Most (70.1%) felt staff respected their choices and opinions.

- About half (48.6%) felt that changes in support staff were problematic most or some of the time.

Access to Supports and Services

- Less than half of families felt that:

  - supports were available when needed (40.4%)

  - the supports offered met family needs (40.3%)

  - crisis help was provided when needed (45.0%).

Links to community

- Families were least satisfied with this aspect of family supports than with any of the other satisfaction categories.

- Nearly three-quarters (71.8%) of families said staff did not help them with links to friends and neighbors, while nearly half (47.8%) said staff did not help them with links to community supports.

Open-Ended Comments From Families

Both versions of the Family Survey included an open-ended comments page at the end of the questionnaire. Written comments were provided by 216 respondents (103 in-home families and 113 out-of-home families). Based upon qualitative analysis and coding of these comments, key findings are summarized in this section (including selected family quotes).

Positive comments

Thirty respondents provided unqualified positive comments about DMR services, particularly regarding the helpfulness of staff. Several families who had been involved with DMR services for many years noted how much services and supports had improved over time.

> *Our family is extremely satisfied with our dealings with DMR. My daughter's service coordinator is wonderful and always involved us in decision-making. She goes out of her way to be as helpful as possible and has been there for us all through some pretty tough times in the past.*

> *Our family has been involved with DMR for over 30 years. We have also been involved with agencies in other states because of job related moves. DMR in Commonwealth by far is one the best in the country . . . I feel DMR has made extraordinary improvement in the entire system.*

Need for more services/supports

Thirty-one families voiced complaints about lack of services/supports including transportation, physical therapy, medical services, and counseling. In-home family respondents frequently noted the need for respite care. Several in-home families felt that "being good parents" to their child resulted in getting short shrift from DMR, especially in getting residential placement.

> *My son . . . requires OT, counseling, and specialized dental services as well as communication devices and training. All of these come out of my pocket at some sacrifice.*

> *DMR does not help their clients as long as there is someone taking good care of them, namely my husband and myself. We provide the counseling, transportation and everything else . . . Because I can drive him, our staff person from DMR tells us there isn't any money for transportation to the program we found for him.*

Complaint handling slow/unresponsive

Another broad complaint category was DMR's lack of responsiveness to requests or complaints. Nineteen families commented that DMR was slow to handle complaints, or did not respond at all. Many families felt that the needs of the consumer and families often fell through the cracks of DMR and that promised services were not delivered.

> *If it wasn't for the fact that I have a son who is a social worker up until recently we have fallen through the cracks of DMR and not received services for years.*

Staff problems

Many families were concerned about the effect of high staff turnover rates in both residential and day settings on the stability and continuity of care for consumers. Families also voiced concerns about inadequate staff training, lack of certification of direct care staff, and low staff wages, all of which negatively affected the quality of services provided to consumers.

> *The constant staff turnover in group home is a problem and stems from the fact that salaries are totally inadequate . . . Retarded citizens need stability and continuity, and this can only happen when staffs receive sufficient financial rewards to encourage them to remain at the job.*

> *I would like to see all of the employees who work with DMR clients be screened for their abilities to do the jobs well, whether at their workplaces, or the transportation needed to get them there safely.*

Need for more information/access/contact with staff

Many families asked for more access to information about services, and more contact with staff. The need for communication with the service coordinator was frequently noted.

> *I would like to be aware of all the services available. I seem to get a run around when I ask.*

> *We receive no communications of what is available. It would be nice to know his case (DMR) worker if such a person exists.*

Aging parents' worries about the future

Among in-home families, 17 aging parents expressed the same poignant concern: "Who will care for my child when I am no longer able to?" These parents were fearful that residential placement options would not be available when they died and the child needed to move out of the family home.

> *We need to be able to know someday before we are too old or ill that there is a place for our children. No adult disabled person should have to deal with the loss of a loved one and the move to a new home all at once, but that's what it takes to get them into a group home.*

Need for more housing options/long waiting list

Related to worries about the future, 21 in-home families were concerned about lengthy waiting lists for residential placements, and the need for more housing options in general.

> *We would very much like our son to live in a community residence. We've been on a waiting list for the past 12 years and feel that he really needs to be living outside the home with his peers . . . It has been difficult maintaining him at home these past 30 years.*

CONCLUSION

Overall, most families were satisfied with DMR services and felt that their consumer was happy. Many families had positive comments about DMR services, and noted improvements in service delivery over time. However, Family Survey data also point to significant disparities in terms of who received services and who was involved in service planning.

One of the major findings of this study is that in-home consumers and their families received considerably less of all supports and services from DMR than out-of-home families. This finding is particularly important when considered in light of the fact that over half of in-home families had annual household incomes of under $25,000 and thus probably do not have the financial security to pursue services without DMR's help. This points to the need for more outreach to in-home families in lower income brackets.

Consumers living in out-of-home placements were more likely to have severe or profound retardation and more likely to have disabilities in addition to mental retardation. This may explain, in part, why consumers in out-of-home placements received more services and supports than persons living at home with families. However, even among consumers living at home, there was evidence of significant disability --one-fifth of in-home consumers had severe or profound retardation and half of them had additional disabilities. The disparity in resources cannot, therefore, be attributed solely to differences in level of retardation or additional disabilities.

Not surprisingly, in-home families who received less supports and services than out-of-home families were generally less satisfied with DMR services and felt less involved in service planning. At least one-third of in-home families said they were not able to choose providers, that staff did not help them figure out options to meet their needs, that crisis help was not provided in times of need, and that staff did not communicate in alternative ways when needed.

In-home families were least satisfied with staff assistance in helping them with "links to community." Nearly three-quarters of these families said staff did not help family with links to friends and neighbors, while nearly one-half said staff did not help with links to community supports. This points to the tenuousness of connections to services and supports for families with a disabled member living at home, and thus for the need for DMR to build stronger links to these families. This will be especially relevant with the current move toward consumer self-determination. Improvement in DMR's efforts to help in-home families and consumers avail themselves of community supports is needed.

Primary caregivers in the in-home families ranged in age from 23 to 95 years. Fully one quarter of the in-home caregivers was age 70 or older, and more than half was age 60 and over. The implications of this finding suggest that DMR target more specialized resources, such as respite care, to the in-home families. Many in-home families were worried about what would happen to their disabled loved one when parents or other relatives were no longer able to care for them at home. Most of these families' concerns were tied to uncertainty over housing options; many noted in the open-ended comments that they wished for a good residential placement for their child before the parents became too old to care for him. This points to the need for DMR to develop more housing options for adults moving out of their families' homes.

Out-of-home family respondents were also aging (mean age = 62.9 years). Although their consumers lived out-of-home, most family respondents were in frequent contact with the consumers and involved in their service planning. Almost two-thirds of the out-of-home family respondents were parents and one-quarter were siblings. This points to a generational shift in family involvement -- as parents age, siblings often assume or share responsibility for overseeing the care of the consumer. It is important that DMR offer outreach and education to siblings and other relatives of consumers to help prepare and support them in their roles as advocate on behalf of the consumer.

Many out-of-home families voiced concern over the low wages and lack of training of staff who cared for their family members; this was articulated especially well in the

respondents' open-ended comments. More attention to staff training and higher pay for direct care staff would help to reduce high staff turnover in many DMR programs and increase the quality of care received by consumers in these settings.

The Family Survey has been an effective tool to obtain family input about DMR services. As one Family Survey respondent commented:

> *First, let me say how much I appreciate the opportunity to participate in this survey. I believe it is the first of its kind that I can recall all the years our family has been involved with DMR.*

Future data gathering will allow DMR to continue to listen to and respond to the concerns of families.

IV. Family Focus Groups

INTRODUCTION

The goal of the family focus groups was to collect in-depth qualitative data from families of individuals with mental retardation receiving services and supports in a variety of settings throughout the Commonwealth, including public institutions. This data collection effort, which took place from the end of January through the beginning of May 2000, served as a supplement to the data collected via the family surveys.

METHOD

Recruitment Strategy

Focus groups were organized in targeted locations across the state, with efforts made to recruit a diverse group of families of individuals who were receiving services from DMR. Regional offices, family support agencies, advisory boards, and advocacy groups assisted by advertising and recruiting families to participate. They also helped the process by offering the use of accessible meeting spaces and in some cases, providing translators. Participants were paid a stipend of $40 for attending a meeting. Project staff made all possible efforts to schedule meetings at accessible locations (public libraries, community centers, provider agencies, etc.) and at convenient times. People chose to participate for a variety of reasons -- some were looking for information on what supports and services were available for adult consumers; others came just to participate and to voice their opinions about DMR services.

The first four focus groups were targeted toward four regions of the state: Western, Central, Southeast, and Northeast/Metro Boston (combined). In order to get input from a diverse group of families, we organized five other focus groups, each targeted to a specific group that was under-represented in the regionally based sample. These included four minority communities (Haitian, African American, Asian, and Latino), as well as families of individuals who live in institutional settings. A total of 81 family members participated in all groups combined.

Structure of Focus Group Discussions

Two project staff from HSRI facilitated each group. One led the discussion, and the other took written notes. All sessions were audio-recorded for the purposes of transcribing notes. The meetings lasted approximately an hour and a half. At the beginning of each meeting, participants were informed of the recording and assured of confidentiality. Quotations will appear throughout this chapter, but no participants will be identified. Most participants also provided basic information about their personal history and about the individual who receives services. This information is summarized in the results section.

The discussion guide, which was distributed to all participants, consisted of four questions. The initial questions were:

- In a word or a sentence, describe your recent interactions with DMR. Has this changed over time? If yes, please explain.

- Describe what works well about DMR's services and supports.

- Describe what doesn't work well about DMR's services and supports. What would you like to see changed?

- What are your family's biggest concerns right now? For the future?

Based on experiences with the first two focus groups, project staff made slight revisions to the questions. As a lead-in to the discussion, we found it helpful to clarify the types of services and supports the families in each group were receiving. Many participants were parents or relatives of children under age 18 who were receiving family support or respite; others were families of adults receiving residential or employment services. To each family, "DMR" meant something different -- e.g. the Boston office, the Regional or Area Director, facility administrators, service coordinators, or state-employed direct support workers. Some families primarily interacted with their family support provider and not directly with a representative of DMR. We also quickly discovered that participants had many questions of their own. Thus, we felt it would be valuable to allow participants to make a list of questions they had about DMR services and supports, emphasizing that while we were not in a position to answer questions, we would include them in our feedback to DMR.

The revised questions were:

- What services do you receive from DMR?

- What do you like about these services? How are they helpful to you and your family?

- What do you think should be changed about DMR services?

- How are you treated by DMR service coordinators or other DMR staff?

- What questions do you have about DMR? What information do you and other families need?

Analysis of Focus Group Data

Each discussion was recorded and transcribed. Project staff reviewed the complete set of focus group notes and transcriptions, extracting common themes among families' responses to the discussion questions, observations made by participants, and ideas suggested by participants. Findings and conclusions are described below.

RESULTS

Participant Characteristics

Most participants were asked to provide basic demographic information about themselves and their family members who receive services from DMR. This information is summarized below. *Note: Asterisk (*) indicates that these figures do not include information from families of individuals living in state facilities.*

Personal information

- 91% (72/79) were parents of an individual with disabilities

- 86% (68/79) were "primary caregivers"

- 72% (51/71) were married

- 88% (63/72) were female

Average age of participant: 47 years old

Annual household income:

- 23% (15/66) less than $15,000

- 36% (24/66) between $16,000 and $40,000

- 27% (18/66) between $41,000 and $75,000

- 14% (9/66) over $75,000

Primary language spoken in the home:

- 72% (52/72) English

- 8% (6/72) Spanish

- 7% (5/72) Chinese

- 7% (5/72) Haitian-Creole

- 6% (4/72) Vietnamese

Race/Ethnicity:

- 52% (34/65) White

- 29% (19/65) Black

- 12% (8/65) Asian/Pacific Islander

- 5% (3/65) American Indian

- 9% (5/58) Hispanic

Services and Supports Received:

- 71% (46/65) Case Management

- 64% (44/69) Financial Support

- 53% (34/64) Respite

- 49% (31/63) Family Support

Individual's place of residence:

- 75% (59/79) family home

- 8% (6/79) group home

- 10% (8/79) specialized facility

Average age of individual receiving services: 18 years (range 4-53)

Individual's level of MR:

- 10% (7/72) none

- 14% (10/72) mild

- 31% (22/72) moderate

- 25% (18/72) severe

- 17% (12/72) don't know

Summary of Discussion Themes

Families' responses to the discussion questions clustered around several themes, which are described in more detail below.

Theme #1: Information

As mentioned above, the first two focus groups quickly revealed that families themselves had a number of questions about DMR and "the way things work." Several people used the term "mysterious" to describe how DMR operates. There is a hunger for more information about what services are available, who is eligible, and what steps families need to take to get those services. Most participants had bits and pieces of information, but many expressed a need to understand the "big picture" of how the system works.   When written information is presented, it needs to be made available in a format that is easy to understand and translated into multiple languages.

> *DMR services are family driven. As a result the family needs to know what they want in order to get the desired services/supports for their family member, leading to a vicious circle. Families don't have enough information to know the available options, so they can't decide (or help their family member decide) on what they want and hence the consumer doesn't get the appropriate services and supports.*

Theme #2: Quality of communication between DMR and families

Family experiences varied widely with respect to interactions with DMR personnel. Descriptions ranged from "friendly" to "discouraging" to "need to sound desperate to get anything." Some claimed that the only way to get action is to be "proactive" and "persistent." The voice mail and automated phone system was cited many times as extremely frustrating. Ultimately the quality of communication depended upon individual service coordinators and regional staff – in many cases families had positive things to say about them.

> *Where families are in touch with the service coordinators, the service coordinators are usually very helpful and will problem-solve on the spot, however the problem is how to get in touch with the service coordinator. Voice mail is wonderful, but if messages are not returned, not very helpful.*

Theme #3: Perceptions about resources

Families in all groups perceived that funding for services is inequitable and unevenly distributed across the state. They do not understand what criteria are used to allocate resources. Many participants commented that families need increased levels of funding and that additional resources should be made available to serve more families. They are also very concerned that direct support workers are not compensated adequately for the work they do. Several families suggested that the resources in state facilities are being underutilized; that people in the community could also benefit from these resources (e.g. vans, recreational facilities, therapeutic services) but they are not allowed to because of "liability reasons."

> *We are trying all the time to get the adequate supplies and enough direct care [workers]. The ones we have are excellent.*

Theme #4: Programs that work

Families praised many programs and supports that they felt were successful and helpful to them. Specifically, the following services were noted:

- DMR/DOE partnerships (although too few) allow families to keep kids at home.

- Bilingual service coordinators are a key factor in helping minority families get the services they need. Families requested more bilingual staff in all programs.

- Flexible funding works very well.

> *Flexible funding helps you choose what you want for your child and the family can decide what it wants and when.*

- Family initiative projects.

- Respite care (in-home and out-of-home).

- Assisting families to connect with each other (e.g. support groups).

- Families of individuals living in facilities feel that their family members receive excellent care.

Theme #5: Cultural competence

Many of the families from minority communities echoed the same concern: What is DMR doing to address multicultural issues? Bilingual service coordinators are very helpful and in demand. Families also expressed a need for lists of providers with bilingual staff. Some families talked about experiencing discrimination within the service system, being treated unequally and disrespectfully because of their race or income level. The establishment of the family governing boards seems to be a positive step toward increasing cultural sensitivity and culturally appropriate services. The boards are community-oriented and family-oriented, and the participants understand each other's language, culture, background, and barriers. One member of a family governing board stated:

> *We have become a bigger family, and we are not alone. [We have] a wonderful partnership with DMR...They take time to listen to us.*

Theme #6: Service coordination

Experiences with service coordinators seem to "make or break" satisfaction with DMR services. One family reported seeing their service coordinator only twice in seven years. Another said "whenever I need her she is there." Most families had very strong feelings (either positive or negative) about service coordination. Many families reported that their service coordinators were unresponsive.   In addition, they are only available 9-5, which makes it very difficult for working families to contact them. Some families felt that service coordinators need better training and supervision, and also recognized that heavy caseloads make personal involvement difficult.   Some participants had questions about what the service coordinators' responsibilities are, and what families can expect to receive from them. Turnover was also an issue with service coordination. Particularly for families who don't speak English as a first language, the loss of a bilingual service coordinator has a more extreme impact.

Theme #7: Quality of care

There were many, many compliments about provider agencies and direct care staff. Staff were described as "excellent," "like family," and received high praise from all groups. However, rapid turnover of staff at provider agencies was of major concern to all families, and in particular to families with members living in residential settings. Also, some concerns were raised about the quality and consistency of staff training, and about the consistency of services available across regions. Families also had questions about quality control mechanisms and how to report problems and complaints.

Participants' Observations about DMR Services

In addition to the themes described above, some families, particularly those who have been receiving services for a number of years, commented on service trends they have noticed over time.

- Flexible Funding has increased family *choice and control*.

  > *We know how resources are allocated and services given to families. Because we know what's best for us, we need to know how money is allocated. This is a good change for us.*

- Services are now *family-driven*, and DMR listens to families.

- Services have *improved and expanded*.

- Care provided in institutional settings has improved, but the resources at these facilities are underutilized.

Participants also emphasized gaps or problems in service delivery that need to be improved:

- Although there have been positive changes, *responsiveness* continues to be a problem.

- The system continues to be *crisis-driven*.

- Families need more residential options for their family members. Some participants expressed a desire for something "in-between" a group home and an institutional setting.

- Families would like DMR to provide mediation with provider agencies when necessary, particularly those families who now have more control over funds but still may need assistance securing what they need. If a problem arises, DMR could have a greater impact on the situation.

- There is a major gap in communication between DMR and the school system. Transition services need to be improved.

- Transportation was reported to be a problem, particularly in extremely rural areas of the state and in inner city areas.

For many families, DMR is only one piece of a larger system of support, including other public and community-based resources. Many focus group participants talked about needing assistance and/or advocacy to navigate the many sources of support available to them:

- It is very difficult to find accessible housing; in some cases families have no choice but to place their family member out-of-home. Families, particularly those with lower incomes, need housing advocacy and assistance.

- Families need more assistance obtaining adaptive equipment, such as wheelchair lifts and other home modifications.

- Families report that they need liaisons to other service agencies, perhaps an advocate who can negotiate services across different agencies.

- Doctors' offices should have more information on early diagnosis and available resources for families.

Participants' Ideas and Suggestions

One of the benefits of focus group discussions is that they generate creative ideas and solutions to problems. In this section, we list suggestions made by the families who participated in these groups.

- Business hours limit communication between service coordinators and working families. Expand or change service coordinators' hours to include some evening and weekend hours.

- Increase the number of bilingual service coordinators and staff. One parent described a model he thought would work well: in one Boston suburb, the police department hired a Chinese interpreter to work 2-3 hours a week. People know that they can call this person if they have needs and concerns. He felt that a similar set-up for DMR, a hotline with interpreters available a few hours a week, could be very helpful to the Asian community.

- Compile lists of what services are available, by age group and by region, and who is eligible for these services. Provide enough information so that families can make informed choices.

- Inform families of things to do to ensure continuity of services (a smooth transition) from school to adulthood. Families need to know how, where, and when to apply for services.

- Allow flexible funds to be used to provide some respite to parents and caregivers.

- Standardize services available across towns and regions.

- Flexible funding should take inflation into account.

- Work with pediatricians to educate them about developmental disabilities so as to ensure early intervention and to make resource materials available in their offices.

- Elevate the status of the caregivers -- perhaps with higher pay; ensure better training for respite workers, with a certification process built in.

- Make more employment opportunities available for adults with disabilities and provide families with this information. Improve outreach to employers and businesses.

- Provide families with feedback on which providers are doing better than others, such as a report card.

- Improve communication between vendors who have trained workers, leading to a pool of trained workers who can meet the needs of clients belonging to different agencies.

- Help the service coordinators to return calls and provide families with the information that they need.

- Improve outreach through awareness campaigns in schools, colleges, medical and law schools, and through campaigns about family supports.

- Sponsor family-driven institutes for teaching and learning.

- Support families who have gone through advocate training to actually perform an advocacy role.

- Develop a centralized system/place for disseminating information.

CONCLUSIONS

To summarize, the major findings of the family focus groups suggest that:

- Families have many questions about DMR and need to be provided with more information.

- Families feel that responsiveness is a major problem with service coordination. When service coordinators are available and in communication with families, they are generally reported to be helpful and effective.

- Families perceive that services are inconsistent across the state, and that the quality of services depends up on where you live and the creativity of the service provider. Participants expressed a desire for standardized, equitable services for all families.

- Families praised many aspects of DMR services: flexible funds, family-oriented and family-driven services, good care provided in residential settings, excellent direct support staff.

- Families want more help navigating across service systems, and in particular feel that transition from school to adult services should be improved.

- Families want DMR to continue and to expand efforts toward providing culturally competent services.

V. System Data and the Provider Survey

INTRODUCTION

As a participating state in the national Core Indicators Project (CIP), DMR staff coordinated an additional effort to collect performance data through a provider survey. This information, along with selected data from the state's management information systems, was submitted to the national project and will be reported together with data from all participating states in a separate publication. This chapter provides a summary of Massachusetts' data only. Comparison data and national benchmarks will be available in a forthcoming report from the national CIP.

METHOD

The CIP refers to some data as *provider* data and other data as *system* data to reflect the source of the information. Provider data is primary data collected directly from service agencies. As a rule, this data is not currently collected on a regular basis. The system data is secondary data that is already reported and available to DMR. Service provider agencies are the original source of much of the system data as well. For this reason, the project uses the general term *system data* to describe both groups of data.

There are three types of information that DMR had to obtain directly from providers, including information pertaining to: 1) the *employment* of people with developmental disabilities, 2) the involvement of consumers and families in the *governance* of service agencies, and 3) the *stability* of agency staff. DMR adapted the CIP provider survey and distributed it to all service provider agencies.

Using management information system data, DMR also reported information pertaining to the rates of *serious injuries*, *crime victimization*, incidents involving *restraints*, and consumer *deaths*.

It is important to note that the results presented here represent *baseline data*, which are meant to be used as point of comparison over time and in conjunction with data from other participating states. Given the nature of the data, our ability to draw interpretations is limited at this time.

RESULTS

Consumer Employment

The CIP employment indicators concern the extent to which the public system is assisting individuals with developmental disabilities to secure paid employment in the community. The indicators also address the amount of income that individuals derive from work, how many hours they are engaged in paid work, and, in the case of individuals who have community jobs, how steady their employment has been.

The provider survey asked agencies to supply the following information about all individuals who were engaged in work supports during the month of October 1999:

1. *Was the consumer engaged in any of the following types of work supports[1]?*

- *FACILITY-BASED WORK PROGRAMS. Facility-based work programs take place in settings such as sheltered workshops or work activity centers. Individuals are paid a wage in exchange for their production-related activities. They are employed by the provider agency.*

- *INDIVIDUAL SUPPORTED EMPLOYMENT (Community-Based Work). Individuals have a job with a community employer and receive periodic publicly-funded assistance, training and support aimed at securing and/or maintaining employment and/or improving job skills.*

- *GROUP SUPPORTED EMPLOYMENT (Community-Based Work). Two or more individuals are employed by a community provider agency and perform work as employees of the provider agency at sites in the community (e.g., mobile crews). Group supported employment also includes persons who are employed in an affirmative industry or as part of an enclave.*

2. *What were the total gross wages of the consumer for the period of October 1,1999 - October 31, 1999, inclusive?*

3. *What were the total number of hours the consumer worked during the period of October 1, 1999 - October 31, 1999, inclusive?*

4. *Were the consumer's gross earnings at or above the state minimum wage of $5.25 for the period of October 1, 1999 - October 31, 1999, inclusive?*

5. *Was the consumer continuously employed for 10 of the last 12 months? (November 1, 1998 - October 31, 1999)*

The results of DMR's provider survey of consumer employment are displayed in the following table. Note: minimum wage figures are not shown due to inconsistencies in the data reported across agencies.

	Number of agencies reporting	*Average monthly wage*	*Average hours worked/month*	*Percent of consumers continuously employed in community*
Facility-based work program	N = 41	$109.70	83.25	--
Group supported employment	N = 43	$226.83	78.40	85%[a]
Individual supported employment	N = 47	$336.31	57.33[b]	96%
[a] N = 42 [b] N = 49				

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[1] Types of work supports are based on CIP definitions.

Consumer and Family Representation on Boards of Directors

CIP requires states to report information about the representation of consumers and families on provider agencies' boards of directors. Specifically, providers are asked to supply information about: the number of people on the board of directors, the number of voting members, and the number of voting members who are primary consumers or family members of primary consumers.

Primary consumers are defined as persons with mental retardation or other developmental disabilities who are receiving services, not necessarily from the provider that is reporting.

Family members include parents, siblings, or other relatives of primary consumers (as defined above).

Of the 85 provider agencies who submitted data:

- *4.28% of voting members on boards of directors are primary consumers; and*

- *21.89% of voting members on boards of directors are family members.*

Direct Contact Staff Turnover, Length of Employment, and Vacancy Rates

The data that CIP states compile enables the calculation of direct contact staff turnover rates, vacancy rates, and employment stability (length of employment). These are three different ways to measure concerns about workforce stability, and the results of each measure are not directly linked to one another.

With respect to direct contact staff stability, state developmental disabilities authorities have expressed that the most critical area of concern lies in the arena of residential services and supports. Thus, all CIP states are asked to collect staff stability data from agencies that provide such services. Optionally, states may decide to furnish information on day supports as well.

Massachusetts DMR collected information from 60 agencies that provide residential supports and 65 agencies that provide day supports. Although the residential and day results are reported separately, it is important to note that there is some overlap in the results since 34 agencies submitted both types of data.

Agencies derived this information from payroll data as of June 1999.

For the purposes of this survey, *direct contact staff* were defined as employees whose primary duties include hands-on, face-to-face contact with consumers. This may exclude psychologists, nurses, and managers whose responsibilities are primarily supervisory in nature.

Turnover Rates

Turnover rates for each agency were calculated based on the number of direct support staff (regardless of whether they were full- or part-time employees) who left the agency during the previous twelve months for any reason, divided by the total

number of direct support staff who were on the agency's payroll as of the end of June 1999.

- *The average turnover rate for <u>residential</u> support agencies (N = 63) was 36.08%.*

- *The average turnover rate for <u>day</u> support agencies (N = 64) was 35.63%.*

Length of Employment

Length of employment of current and "separated" staff (staff who left in the past year) was calculated as follows. For each current employee, the agency determined how many months the person had been employed in a direct support capacity (of any type) on a continuous basis. The aggregate or total number of months of employment for all current employees was reported on the provider survey. The average length of employment was computed by dividing the aggregate number of months of employment by the total number of direct support staff on the agency's payroll at the end of June 1999. For staff who left in the past year, agencies reported the number of months they had been employed up until the point they left the agency.

- *For <u>residential </u>support agencies (N = 61), the average length of employment of <u>staff who left in the past year</u> was 27.7 months.*

- *For <u>residential</u> support agencies (N = 62), the average length of employment of <u>current staff</u> was 30.2 months.*

- *For <u>day</u> support agencies (N = 55), the average length of employment of <u>staff who left in the past year</u> was 19.6 months.*

- *For <u>day</u> support agencies (N = 62), the average length of employment of <u>current staff</u> was 38.8 months.*

Vacancy Rates

Agencies reported the number of full-time direct support staff (defined as 32 or more hours per week) and part time direct support staff (defined as less than 32 hours per week) on their payroll as of June 1999. They also indicated the number of vacant full-time and part-time positions as of June 1999. The total number of positions was then calculated by adding the number of staff on the payroll and the number of positions vacant, for full-time and part-time positions, respectively. Vacancy rates are computed by dividing the number of vacant positions by the total number of positions.

- *For <u>residential</u> support agencies, the vacancy rate for full-time positions was 10.80% (N = 43), and the vacancy rate for part-time positions was 17.47% (N = 37).*

- *For <u>day</u> support agencies, the vacancy rate for full-time positions was 6.81% (N = 48), and the vacancy rate for part-time positions was 14.52% (N = 36).*

Incidence of Injuries, Crimes, Restraints, and Deaths

Using its management information systems, DMR compiled data pertaining to serious injuries, reports of crimes against consumers, incidents involving the use of restraints, and deaths. Mortality data is reported for the past three years; all the rest for just the past year. The indicators listed below represent incidents known to DMR, for the

portion of the service population for whom such incidents must be reported. The following figures were reported to the national CIP:

- *The number of adult consumers covered by the DMR incident reporting system = 28,964.*

- *The number of serious injuries reported in the past year = 83. Serious injuries are defined as "an injury that requires professional medical treatment (e.g. hospitalization, fractures, wounds requiring stitches)." Injuries that could have been treated by a layperson but happened to be treated by a medical professional because he/she was on site, do not count as serious injuries. Medical professionals include (but are not limited to) MDs, RNs, LPNs.*

- *The number of crimes (against consumers) reported to a law enforcement agency in the past year = 22.*

  Type of crime reported:
  Rape (and attempts to commit rape) = 17
  Robbery = 0
  Aggravated assault = 3
  Burglary = 0
  Larceny theft = 2

- *The number of incidents involving the use of restraints (not including those administered as part of a behavior plan) in the past year = 2131.*

  Type of restraint used:
  Manual or physical = 2024
  Mechanical = 38
  Chemical = 69

Raw figures from mortality data reported to CIP are detailed in the following two tables, listing number of deaths, by age group, by cause, and by year.

Total number of deaths (all causes), by age group						
Year End	*18-21*	*22-39*	*40-54*	*55-64*	*65+*	*all adults*
1999	4	31	71	43	107	256
1998	3	38	49	43	103	236
1997	3	41	58	49	76	227

Number of medicolegal deaths (accidents, suicides, or homicides), by age group						
Year End	18-21	22-39	40-54	55-64	65+	all adults
1999	0	0	3	3	0	6
1998	0	6	6	2	3	17
1997	0	5	9	5	1	20

CONCLUSIONS

Massachusetts DMR put an enormous effort into collecting and compiling the system data required by the national CIP. Provider agencies' cooperation and willingness to supply information were essential to the process, which was laborious and sometimes confusing. Agencies were asked to report information that, for the most part, had never been requested in any systematic way. Their efforts and input are tremendously appreciated.

One of the most difficult aspects of collecting this type of data is ensuring consistency of information, not only across states but also across provider agencies. The national CIP has worked hard to establish comparable definitions and measures for the purposes of benchmarking performance data and making cross-state comparisons. The data collected by Massachusetts DMR for this project will be useful for performance monitoring and strategic planning. In addition, the lessons that DMR has learned about the process of collecting the data will be factored in to the redesign and improvement of the surveys in future years, easing the burden on providers and improving the reliability of the information.

As mentioned earlier, the interpretation of baseline data is tricky and rather limited. However, the upcoming national CIP report will provide some further insight into the meaning of the findings.

VI. Recommendations and Implications of Findings

RECOMMENDATIONS

The following recommendations are based on the findings summarized across the three data collection components -- Consumer Survey, Family Mail Survey, and Focus Groups. Recommendations address the key issues and concerns identified by individuals with mental retardation and their families.

Recommendation 1: Create an accessible, responsive service and support system

Adopt a "customer service approach" (consumer and family-friendly) at all levels of the Department

Ensure easier access to service coordinators through night and weekend office hours

Honor the choices and preferences of individuals and families by making an extra effort to listen to what they really want.

In light of finite resources and the importance of natural supports, be creative about helping to link consumers and families to desired community resources

Recommendation 2: Make the system less mysterious for consumers and families

Simplify program eligibility

Pursue expansion of self-determination approaches

Provide concrete, accessible, and easy-to-understand information about DMR regulations, funding policies, service and support options, grievance mechanisms, and community resources

Hold regular information sessions in each region to answer individual and family questions

Do outreach with local community and advocacy groups to ensure that information is responsive to diverse cultural groups

Recommendation 3: Ensure basic service coordination and health care for all consumers

Enforce the annual ISP meeting requirement for all consumers covered

Provide timely service coordination and assistance for all consumers

Ensure annual health care exams (medical, dental, OB/GYN) for all consumers

Monitor high rates of psychological/behavioral medication use in residential programs to prevent inappropriate use

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Recommendation 4: Address perceived and apparent inequities in the service system

Avoid a system of "haves and have nots"

Develop more housing options to address needs of consumers waiting to live in community settings

Forge better connections with underserved groups whose links to DMR are often fragile, including:

- ♦ families whose family member with a disability lives at home
- ♦ persons on waitlists for services
- ♦ aging parent caregivers
- ♦ nursing home residents
- ♦ persons from minority cultures

Recommendation 5: Ensure that all consumers have opportunities to make choices and decisions about important life decisions

Expand opportunities for consumer choice and decision-making, particularly in specialized facilities and nursing homes

Provide training and supports to consumers to prepare them for decision-making roles

Provide training to staff about strategies to support and facilitate consumer choice

Encourage and support consumer involvement in self-advocacy activities

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Recommendation 6: Develop strategies to reduce staff turnover and improve quality of direct care staff

Assist agencies to reorganize in order to ensure redeployment of resources to the direct support professional level

Encourage innovative practices such as self-managed teams

Provide training to families and individuals regarding the management (e.g., hiring, firing, training) of direct support staff

Support more training and staff development activities and develop networks and partnerships with educational institutions throughout the Commonwealth

Develop a voluntary certification process

IMPLICATIONS FOR DMR PERFORMANCE MONITORING

This evaluation involved a systematic canvassing of the views of individuals and families served by DMR and their families. These findings provide rich and constructive evidence that will be useful in assessing the performance and quality of services and supports in the Commonwealth, contribute to the development of priorities for short and long-term strategic plans, suggest ideas for the content of public information materials available to families and individuals, and provide substance for training curricula for direct support and other staff.

Given the multiple uses to which this information can be put, it is important to stress the importance of making this evaluation of outcomes a permanent part of the Department's management data collection. As the Department increasingly oversees a highly decentralized and individually driven system, the necessity to continually survey customer experiences and perceptions increases. In fact, such performance monitoring should become a primary function in a changing agency and should be an integral part of DMR's oversight and quality improvement process.

To install such a system over the long haul will require that the current DMR management information system be updated from a system originally set up to monitor contracts, to one that also evaluates consumer outcomes. Reforms of the current MIS system should also take into account the emerging demands for person-centered planning and individual budgeting, and ultimately self-determination. This project and the information generated is an important step in this journey.

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APPENDIX B CONSUMER SURVEY BACKGROUND INFORMATION

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APPENDIX G FAMILY SURVEY TABLES