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

Executive Summary

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

## **Executive Summary**

### **Background and Purpose of Study**

The following executive summary provides an overview of the findings of an external evaluation of the experiences of adults with mental retardation 18 years of age or older and their families who are receiving services from the Massachusetts Department of Mental Retardation (DMR). The results are based on in-person interviews with over 600 service recipients as well as mail surveys from almost 650 family members. Data were collected from July 1999 through February 2000.

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, and to identify emerging priority areas in order to develop strategic responses. An additional goal was to create a baseline or benchmark that would 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 – a uniform data collection activity that includes 17 state Mental Retardation/Developmental Disabilities agencies, each collecting performance data on approximately 60 indicators.

BUSSW collected and analyzed the consumer and family data, while HSRI organized and conducted the focus groups and provided a liaison between the evaluation and the national Core Indicators Project.

The commitment of DMR to examine system performance is particularly timely given the shifts taking place in the way 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.

## **Methodology**

To identify key performance indicators for the system of services and supports to people with mental retardation in Massachusetts, three distinct methods of data collection were employed: 1) consumer survey (in-person interviews); 2) family mail survey; and 3) family focus groups.

### **Consumer Survey**

The goal of the Consumer Survey was to assess outcomes among consumers 18 years or older, including satisfaction with services and supports. The objective was to complete 600 face-to-face interviews across the Commonwealth using a standardized protocol. To assure a statistically representative sample, a random sample of 1597 DMR consumers was drawn, stratified by DMR region. To qualify for the sample, an individual had to have been receiving service coordination and at least one other service (excluding transportation) for the year prior to the sample selection in the spring of 1999. By the completion of the project, 617 in-person interviews with consumers and/or proxies had been conducted.

The survey results presented in this summary are based on the Consumer Survey data as well as background data from the DMR Consumer Registry System. These findings are based upon analyses of the sample as a whole as well as subgroups analyses (by type of residence and DMR region).

### **Family Mail Survey**

The goal of the Family Survey was to assess family satisfaction with services provided both to individuals with mental retardation age 18 or older as well as to their families. Two samples were drawn – 1) 1000 DMR consumers living at home with families; and 2) 1000 DMR consumers living out-of-home of families. To qualify, either the family or the individual had to be receiving service coordination and at least one other service (excluding transportation). The samples were both stratified by DMR region.

Of the 2000 surveys mailed a total of 610 were completed – 275 from families of individuals living at home and 335 from families of individuals living outside the home. The discussion of findings provides a comparison of in-home and out-of-home families on family satisfaction and family and individual service use data.

### **Family Focus Groups**

The goal of the family focus groups was to collect in-depth qualitative data from families of adults and children with mental retardation receiving services and supports in a variety of settings throughout the Commonwealth including public institutions. A total of 81 family members participated. This was the only data collection process that included input from families with children under 18 years of age. The average age of the family members was 47 and their children with disabilities ranged in age from 4 to 53 years old. Groups were conducted in each region (metro and northeast combined). Recruitment was conducted through various sources including regional offices and advocacy groups. Project staff also targeted recruitment of minority families (e.g. from family governing boards in Metro

Boston). Nine groups were conducted for a total of 81 participants. Each participant received a stipend of \$40.

## Summary of Results

### Consumer Survey Findings

#### Overview

- Most consumers reported positive outcomes for: Community Inclusion, Respect/Rights, Service Acceptability, Safety, Satisfaction, and Relationships
- Results were mixed for: Choice and Decision Making, Service Coordination, Service Access, and Health
- Subgroup analysis revealed significant variation in consumer outcomes by type of residence

#### Community Inclusion

*Most individuals in the sample go out into the community on errands and appointments, to shop, or to eat out, or for entertainment.*

#### Choice and Decision-Making

*Most consumers had some control or decision-making power about personal things like access to money, what to buy, or what to do for fun, either with, or without assistance. Far fewer people had control over the choices about where they lived, who provided support, or their roommates.*

#### Respect/Rights

*Most consumer rights were generally respected (privacy, phone use, mail).  
Few consumers participated in self-advocacy activities.*

#### Service Coordination

*Three-quarters of consumers reported that their service coordinators were available when needed and were able to give help when asked.  
Among consumers for whom annual ISPs were required by regulation, slightly more than three-quarters reported that they had an ISP meeting last year.*

#### Access

*About one-third of DMR consumers reported that they asked for a service and did not receive it, and the service they asked for most often was transportation.*

## **Service Acceptability**

*Most DMR consumers reported that staff treated them with respect at home, at day programs, and at jobs.*

## **Health**

*Most DMR consumers had recent physical and dental exams. About two-thirds of female consumers had an OB/GYN exam during the last year. About one-fifth had never had an OB/GYN exam. Over forty percent of all DMR consumers reportedly were taking medication for mood, anxiety, sleep or behavior problems.*

## **Safety**

*Overall, people felt safe in their homes and in their neighborhoods.*

## **Satisfaction**

*Most DMR consumers liked their jobs, day programs, and homes.*

## **Relationships**

*Most DMR consumers had friends and family and reported that they could see friends and family when they wished to. Few were “always or often” lonely.*

## **Family Mail Survey Findings**

### **Overview**

- About three-quarters of the out-of-home families and about 60% of the in-home families were satisfied overall with the services provided to the consumer.
- About three-quarters of both in-home families and out-of-home families felt that, overall, the consumer was happy.
- Consumers who lived at home with their families received significantly fewer supports and services than individuals living out-of-home.

### **Supports to Families with Consumers Living at Home**

In-home family support varied widely:

*Three-quarters of families reported that they receive service coordination. Less than one-half of families received financial supports, respite care, or other family support.*

## **Satisfaction with Family Supports (of In-Home Families)**

### **Information**

*About 40% of families felt that information about services and supports was available to them.*

### **Choices and Planning**

*About 40% of families chose agencies or providers that worked with them; one-fifth chose staff that worked with them.*

*Most families felt that staff respected their choices and opinions.*

*About half of the families reported that changes in support staff were problematic most or some of the time.*

### **Access to Supports**

*Less than half of the families felt that supports were available when needed, or that crisis help was provided when needed.*

### **Links to Community**

*Staff helped link families to community supports in about one-quarter of cases; staff help with links to friends and neighbors was less frequent.*

## **Key Family Concerns (open-ended survey comments):**

### **In-home family concerns:**

*Aging parents worry about the future: who will care for their child when they are no longer able to?*

*More respite care is needed to support family caregivers.*

*More housing needs to be available for consumers moving out of their family homes.*

### **Out-of-home family concerns:**

*Staffing concerns that affect the quality of care provided to consumers include high staff turnover rates, lack of trained staff, and low wages paid to staff.*

## **Family Focus Group Findings**

### **Information**

*The way things work is “mysterious” to families. They need easy-to-understand information about eligibility criteria, services and supports available, and the big picture of how the system works.*

## **Cultural Competence**

*There should be more diversity among service coordinators and training regarding cultural competence should be intensified.*

## **Quality Of Communication**

*Communication between families and DMR is inconsistent and varies greatly across state.*

*The voice mail/automated phone system is extremely frustrating and was a major complaint across all groups.*

## **Perceptions About Resources**

*The funding amounts seem inconsistent across the state, and it is difficult to understand what criteria one used for allocating funds.*

*Flexible funding works very well.*

*Families don't know what resources are available to them.*

*There are not enough resources for everyone.*

*Direct care staff are not compensated adequately.*

## **Programs That Work**

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

*Bilingual service coordinators.*

*Flexible funding.*

*Family initiative projects.*

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

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

## **Service Coordinators**

*If service coordinators are in touch, they are very helpful. However, it is sometimes difficult to get callbacks.*

*Service coordinators are only available 9-5, which makes it very difficult for working families to contact them.*

*Need better training and supervision.*

*Heavy caseloads make personal involvement difficult.*

# **Recommendations**

## **Context**

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.

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

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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

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

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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

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

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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**

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Avoid a system of “haves and have nots”

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

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

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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**

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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 of Findings for DMR Policies**

These findings are based upon a systematic survey of the views of individuals and families served by DMR and their families. The data provide rich and constructive evidence that will be useful in assessing the performance and quality of services and supports in the Commonwealth. This study has important implications for the development of priorities for short and long-term strategic plans, the content of public information materials available to families and individuals, and 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 of data collection. As the Department increasingly oversees a highly decentralized and individually driven system, the necessity to continually survey consumer 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.