

A Case Study of the Massachusetts Department of Mental Retardation's Development & Implementation of Quality Councils



Prepared for the
RTC on Community Living/ICI and the
Minnesota Department of Human Services
Quality Assurance Panel

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Purpose of Quality Council Case Study

The Minnesota State Legislature convened a committee, the Quality Assurance Panel, to study the efficacy of establishing quality councils within the auspices of the Minnesota Department of Human Services. The Research and Training Center (RTC) on Community Living is providing assistance to the Panel and contacted the Human Services Research Institute¹ (HSRI) to provide consultation regarding state systems that have implemented regional quality councils for services to individuals with developmental disabilities. HSRI prepared two reports for the Quality Assurance Panel.

The first report gathered information from four states at different stages of quality council implementation: Massachusetts, Pennsylvania, Florida and Tennessee. The Panel deduced that the model undertaken by the Massachusetts Department of Mental Retardation most closely aligned with ideas for system enhancement in Minnesota and requested further inquiry into the Massachusetts experience. HSRI was to gather information on regional council membership, how information is shared between regional councils and the statewide council, costs associated with operating regional and statewide councils, and next steps under consideration by the Massachusetts Department of Mental Retardation. This case study addresses these key areas of program development and provides an overview of the Massachusetts quality council experience to date.

Definition: Quality Councils

For purposes of this case study, quality councils refer to stakeholders (including representatives from the state agency, family members, providers, and consumers) who convene to address improvement in the quality of services delivered to individuals with developmental disabilities and their families. Quality councils typically examine and review aggregate data on various aspects of system performance including consumer outcomes, family satisfaction, health and safety and other relevant benchmarks.

What prompted the Massachusetts DMR to develop quality councils?

In developmental disabilities services, the quest for meaningful data by which to measure system performance and the movement to open up quality management to greater stakeholder input and public accountability are converging with the introduction of quality councils. The leadership of the Massachusetts Department of Mental Retardation (DMR) views quality councils as the next step in advancing quality improvement methods that involve stakeholders and increase system transparency.

What distinguishes DMR's quality councils from previous opportunities for external stakeholders to engage in quality improvement activities is that self-advocates, family members, and provider representatives sit at the table

¹ Website address: www.hsri.org

alongside DMR staff to discuss, prioritize and strategize. Before the initiation of quality councils, stakeholder feedback was by nature more reactive, responding to DMR initiatives and anecdotal information on system issues. With quality councils in place, stakeholders have greater access to influence internal decision-making and to hold Department staff accountable for the accomplishment of specific priorities.

What were the initial steps to develop and implement the quality councils?

In partnership with the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research (CDDER) at the Shriver Center, DMR received federal grant funds through the Centers for Medicare and Medicaid Services (CMS) to conduct several quality initiatives -- one of which was the establishment of regional and statewide quality councils. This grant, a CMS Real Choices Quality Improvement Grant, provided \$499,000 over three years (2004-2007) to:²

1. Develop a common set of standards, indicators, measures and benchmarks to evaluate quality in the New England state Home and Community Based Service waiver (HCBS) programs or persons with developmental disabilities
2. Increase access to information and resources regarding HCBS quality, best practices and quality improvement for MRDD system stakeholders in New England
3. Increase knowledge and skill in using objective and quantitative information as a quality measurement and quality improvement tool
4. Promote communication and collaboration to foster oversight of HCBS programs between MRDD agencies, state Medicaid agencies and the CMS regional office

After receiving the grant award, guidelines were drawn up to formalize the membership, terms, and activities of the regional and statewide councils (see Attachment A for the DMR *Guidelines*). Next, DMR's Quality Management staff recruited individuals to serve on the regional and statewide councils. By March 2005, the statewide council and four regional councils (one per DMR region) were established and operational. Instituting these quality councils was done without legislative or rule change.

While the council memberships were being determined, Dr. Steve Staugaitis at CDDER prepared skills training presentations on data analysis and interpretation. The DMR Annual Quality Assurance Report was used as the foundation for these trainings. Attachment B contains one of the skill training guides developed by Dr. Staugaitis.

² Project website, UMass Medical School, Center for Developmental Disabilities Evaluation and Research Center (CDDER), http://www.dma-chpr.org/SystemsChange/grant_NEQIC.cfm.

Membership

DMR's *Guidelines for Quality Councils* addresses regional and statewide council membership, including minimum numbers and types of representatives. Most of the members are DMR staff whose participation is determined by their position. Non-DMR council representatives include providers, DMR's Citizen Advisory Board, self-advocates and family members. While the *Guidelines* suggest that at least one of each of these stakeholder groups should be included, DMR staff note that more are welcome.

Each of the four regional quality councils is to have at minimum the following membership:

- The Regional DMR Director or designee
- Area DMR Directors or designee
- Regional QE Director
- Senior Investigator
- Risk Management Director
- Regional Legal Counsel
- Human Rights Specialist
- Representative from each Citizen Advisory Board (CAB)
- Individual and Family representative(s) (may be drawn from CAB)
- Provider representative(s)

Each regional quality council nominates a liaison to the statewide council. This nomination is left entirely to the discretion of each regional council. One regional council nominated a provider, another chose an assistant area director, and one chose a self-advocate. The statewide quality council is to have the following membership:

- Deputy Commissioner and Assistant Commissioners
- General Counsel or designee
- Director of Investigations
- Director of Human Rights
- Director of Health Services
- Director of Risk Management
- Director of Survey and Certification
- Individual/family representative(s)
- Provider representative(s)
- Representative from each Regional Quality Council
- Representative from State Advisory Council
- Representative from Governor's Commission on Mental Retardation

Allocation of DMR staff time to support the regional and state QC effort. DMR has 40 Quality Management (QM) staff across its four regions with between seven and 12 QM staff per region. A principal responsibility of QM staff is to conduct the licensing and certification reviews of providers, reviews that are very time intensive. When QM staff were advised they were expected to fold quality council work into their responsibilities, they were concerned that they would not

have sufficient time for council meetings.³ However, once meetings were initiated, staff found the experience illuminating and useful, indeed a productive use of their time.

Gail Grossman, DMR Assistant Commissioner for Quality Management, provides this anecdote to illustrate the value of quality councils, "*Having this open process is surprisingly very productive. It's a very open process and there are risks with that. But having self-advocates on the councils has given us rich feedback. At one council meeting an individual who had been supported to move into an independent living situation, an apartment in which he picked the furniture, wanted to throw a celebration party. He invited guests but no one showed. He said that with all the help to move him and set up his home he was still lonely. This direct exposure to outcomes is helpful to hear.*"

As a result of the enthusiasm generated from council meetings, instead of the quarterly meetings planned, all councils (both statewide and regional) increased the frequency of meetings. Quality councils are now meeting every other month. Attachment C contains the minutes from a statewide quality council meeting held in May, 2005.

Recruitment. To recruit stakeholders to serve as council members, DMR staff spread the word to providers, self-advocates and family members. DMR wanted individuals to participate who would not be intimidated by professionals at the table and who could speak beyond their own personal experience.

Term limits. DMR staff are permanent members of the councils. Stakeholders two year term limits. This term limit was constructed in order to assure broad representation from outside stakeholders. However, DMR managers perceive that the two year term limit may need to be adjusted so that sufficient time is provided for members to gain QM expertise before their terms expire. In addition to being rotated off when terms expire, members may be terminated for cause if they violate any of the protocols for participation set forth in the *Guidelines* document.

How does DMR fund their regional and statewide quality councils?

Attachment D contains an estimate of annual costs associated with operating a statewide and four regional quality councils within the Massachusetts developmental disabilities service system. An approximation of costs for operating the statewide council with quarterly meetings is \$27,873 a year. An estimate of annual costs for a single regional quality council meeting quarterly is \$20,188; combining costs for all four councils comes to \$80,750.*

Personnel Costs. The predominant costs are personnel and most of the personnel costs are attributed to DMR staff. Salaries used for this estimate are

³ NCI Newsletter, November 2005, http://www.hsri.org/docs/786_Indicator_V1_N2.PDF

* Currently all quality councils are meeting every other month though the format was conceived to be quarterly meetings.

based at the mid-range for DMR positions; the salaries of non-DMR representatives are not based on any real salaries of current quality council members. In addition, personnel costs are limited to salaries and do not include additional employer costs such as health insurance.

At this juncture, a year and a half after instituting quality councils, Gail Grossman, DMR Associate Commissioner for Quality Management, estimates that she spends 20% of her time, roughly one day a week, on quality council work. She notes that this level of investment is roughly equivalent to the development stage as well. As the Assistant Commissioner for QM, Ms. Grossman attends each meeting of the statewide and the regional quality councils; she also prepares the meeting minutes. For purposes of estimating the annual costs, her time was split equally between the statewide and regional councils.

Self-advocate council members are paid a stipend of \$100 per meeting to support their maximal participation (\$25.00 for preparation, \$50.00 for attending the meeting, and \$25.00 post meeting debriefing). In addition, self-advocate council members are asked to identify someone to be their quality council support person. Individuals who volunteer to support self-advocate members agree to help the self-advocate prepare for meetings, attend meetings with them, and discuss information after the meetings. These support individuals are volunteers and receive no compensation.

Non personnel costs. Non personnel costs include travel (mileage and parking), meals (DMR provides lunches rather than managing per diem meal reimbursements), and printing and phone. The CMS Real Choices grant that Massachusetts received reserved funds to support skills training and provide for travel reimbursements across the three years of the grant. The grant allows \$4,500 for travel reimbursements⁴ annually. All council members may request travel reimbursement. The travel allocation also reserves funds for the Project Director's attendance at the annual CMS meetings of Real Choice grant recipients.

In addition to travel, the grant funded the costs of developing three trainings and presentations on how to understand data and make use of it for quality improvement. Dr. Steven Staugaitis, from the UMASS Medical School CDDER, collaborated with DMR Assistant Commissioner Grossman to develop the trainings on data analysis which were presented to the statewide council. Although the costs of the trainings were not specifically tracked, Dr. Staugaitis estimates that 10 hours went into preparing each training and three hours for presenting the information -- for a total of 39 hours not including his travel time. The cost sheet for the statewide council includes this training investment cost.

How do the regional councils interact or relate to the statewide council?

In Massachusetts, regional quality councils operate independently from one another. Each regional quality council is chaired by the DMR Regional Director,

⁴ 2004 Real Choices Quality Assurance and Quality Improvement in HCBS, University of Massachusetts Medical School, New England Quality Improvement Collaborative Proposal.

while the statewide quality council is chaired by the Associate Commissioner for Quality Management (QM). The Associate Commissioner for QM attends, but does not chair, all meetings of the regional councils and thus serves as an interface among all the councils. Another common expectation is that all councils direct their primary attention to the DMR Annual Quality Assurance Reports and the two targeted quality goals in place at the time.

Differences do exist among the activities and interests of the councils. The statewide council only examines and reports on statewide data, whereas data presented to the regional councils may be more tailored to a specific region. The rationale for this strategy is to eliminate, as much as possible, bias or hard feelings that may result from comparison of regional data. Another difference is that while DMR establishes two target areas for statewide systemic improvement, additional targets of local interest can be identified by each the regional councils. Presently the two statewide quality improvement targets are: 1) to improve employment outcomes and 2) to increase friendships and relationships. Regional councils have identified additional priorities, some in areas DMR has not previously tracked as QM issues, for example, safety during transportation and direct support professional staff turnover.

Although the overall quality goals have been established for the near future, DMR surveyed all stakeholder council members to solicit feedback on whether DMR is looking at the right things. Survey results were reported to the councils and used to determine what issues the statewide council should prioritize. Once an issue is prioritized, the next steps are to draw upon the expertise within the Department, create work teams, establish action plans and monitor the impact of interventions. One example noted by Assistant Commissioner Grossman was related to the identification of expanded employment opportunities as a priority. As a consequence, a Statewide Employment Solution Team was created that includes members from each of the regional councils. Interventions were determined and these strategies are tracked by the regional and statewide councils.

What information does DMR provide the councils and from what sources?

DMR's Annual Quality Assurance Report⁵ is the key source of information used to track progress on overall system goals. Quality Council members are provided information from many sources to evaluate progress, including:

- Survey & certification of providers reviews
- National Core Indicators consumer survey data
- Medication occurrence & reporting system
- Investigations
- Critical incident reporting system
- Restraint reporting system
- Employment supports performance outcome reports

⁵http://www.umassmed.edu/commed/uploads/DMR_2004_QA_Report_5_11_06.pdf#search=%22MA%20DMR%22

With so many sources of data, DMR is still figuring out how much data to provide to council members from each of the various data sources. In addition to internal data reports, QM staff recognized that at different points in time council members may want to hear from individuals outside the Department with expertise in a specific area under review and discussion. The *Guidelines* document provides for such periodic consultation; the trainings by Dr. Staugaitis to the statewide council on data analysis for tracking system performance are an example of such an external party presenting to the council.

Quality Council Accomplishments

Increased Public Accountability. According to Dr. Staugaitis, there are two principal differences that the quality councils have made in Massachusetts: 1) holding the Commissioner accountable to the public for targeted system changes, and placing important priorities on the Department's front burner; and 2) getting people to look at data and not just rely on anecdotes or a personal stories to move the Department to action.

Quality Councils are Functioning. To date, a statewide quality council and four regional quality councils have been established. Council members have been trained in the use of data and interpretation of the DMR Quality Assurance Annual Report.⁶

Self-Advocates have a Voice. People who receive services now have regular access to key department staff and staff report that this access is influential. As Assistant Commissioner Grossman notes, "*Hearing the stories of individuals in the system is good. For example when discussing employment, one of the consumer representatives on a QC brought in his paycheck and passed it around. This real life example of the impact of DMR initiatives and the impact on people's lives really motivated the council to see their work as having meaning and being important.*"

Constraints and Cautions

Quality councils operate in Massachusetts in an advisory capacity. The specific charge to council members is to examine data and look for trends, not to recommend solutions. When recommendations are put forward, these are subject to final review and approval by the regional director (for the regional councils) and the Commissioner (for the statewide council).

Dr. Staugaitis cautions other states considering the quality council model to remember that members will have a range of expertise with respect to the evaluation of data. Therefore training should begin at the basic level and address concepts such as why percentages are used instead of raw numbers, what difficulties exist when information is only presented in averages, and limitations of data such as extrapolating from information on just a few cases,

⁶ http://www.dma-chpr.org/SystemsChange/grant_NEQIC.cfm

and data gathered through self-report only (such as critical incidents when state staff are the primary reporters). He also suggests that council members build up their critical faculties by looking at multiple sources of information to find convergences. And finally, Dr. Staugaitis recommends training council members using real data, not abstract notions. When preparing his trainings to the Massachusetts statewide council, one of the information sources he utilized was DMR's mortality data.⁷ *"While we're striving to provide supports for all members to understand data and how to use it, we need to keep the group engaged and give them real work to do. If the members are just hearing from one source for all their information, it can become a top down process. So figuring out ways to keep the work based in real life and members engaged is important. That's why we used the survey approach to solicit member feedback – feedback on how well we've done making information, including the annual QA Report, accessible and ascertaining what indicators members consider most important and least important to address."*

Assistant Commissioner Grossman recommends that states developing quality councils start simply and remember to involve providers, families and individuals receiving services at the beginning stages, and work to keep them at the table. Dr. Staugaitis also notes that inclusion of self-advocates at all meetings is vitally important.

Grossman also recommends that states first determine what data is most significant to measuring specific outcomes. *"What does the State think is most important? What do consumers/families/communities think is most important?"* She stresses that any indicators of system performance in Home and Community Based Services (HCBS) be related to the CMS Quality Framework,⁸ and to remember to include indicators of quality for self-directed services.

Next Steps for Massachusetts Quality Councils

Implementing Quality Councils in 5 New England State MR/DD Systems. The website for the New England Quality Improvement Collaboration Systems Change Grant initiatives notes that the quality council model developed in Massachusetts is intended to be shared across the New England states' HCBS waiver programs for individuals with developmental disabilities.⁹ These states are New Hampshire, Vermont, Connecticut, Maine, and Rhode Island.

Extending Term Limits for Non-DMR Staff Council Members. DMR is considering increasing the term limits for self-advocates and family members to ensure they have sufficient time for orientation and immersion in the issues, as well as time to feel they are making a contribution before their service on a council end.

⁷ Commonwealth of Massachusetts, Department of Mental Retardation, 2004 Mortality Report, prepared by University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, http://www.umassmed.edu/commed/uploads/DMR_2004_Mortality_Report.pdf.

⁸ <http://www.hcbs.org/files/28/1377/QFramework.pdf>

⁹ http://www.dma-chpr.org/SystemsChange/grant_NEQIC.cfm

Regional Data. Regional quality councils are now requesting data be provided by region across all information sources and DMR is moving in this direction.

ATTACHMENT A

Massachusetts Department of Mental Retardation Guidelines for the Operation of Regional and Statewide Quality Councils January 6, 2005

I. Primary Purpose and Rationale

The primary function of the councils will be to systematically review and analyze quality assurance data from all sources with the goal of developing and achieving service improvement targets in identified areas. While areas and regions have complaint resolution teams, risk management teams, and clinical mortality review teams which serve critical functions in the Department's quality assurance system, none of these teams has the responsibility or opportunity to take a step back and systematically and holistically analyze and review all quality assurance data. That will be the essential function of the councils.

II. Essential Functions

A. Statewide Council:

1. To systematically review statewide data generated from the Annual Quality Assurance Report and other management reports,
2. To analyze the data and identify possible issues, causes and areas for further research and review,
3. To identify 3-4 priority quality improvement targets for the year,
4. To identify strategies and policy changes which might be needed to achieve identified targets,
5. To gather input and recommendations from the Regional Quality Councils regarding quality improvement targets and strategies,
6. To review statewide success in achieving targets
7. To review established outcome measures periodically to determine continued relevance and to make recommendations regarding additional ones

B. Regional Quality Councils:

1. To systematically review statewide data generated from the Annual Quality Assurance Report and other management reports,
2. To analyze the data as it relates to the specific region,
3. To identify regional factors and specific strategies to achieve the 3-4 priority targets established for the year,
4. To submit recommendations, issues, concerns to the Statewide Quality Council
5. To review progress towards achieving quality improvement targets
6. To review established outcome measures periodically to determine continued relevance and to make recommendations regarding additional ones

III. Composition of Councils

A. At a minimum, the Regional Quality Councils (the facilities will be developing a separate quality council) should have the following membership:

1. The regional director or designee
2. Area Directors or designee
3. Regional QE Director
4. Senior Investigator
5. Risk Management Director
6. Regional Legal Counsel
7. Human Rights Specialist
8. Representative from each Citizen Advisory Board (CAB)
9. Individual and Family representative(s) (may be drawn from CAB)
10. Provider representative(s)

At different points in time, the Councils may benefit from individuals with expertise in a specific area under review and discussion. Further, input from individuals outside of the DMR system, specifically, individuals from academic settings may be able to provide a unique perspective and set of skills to enable the Councils to better accomplish their work. Involvement of such individuals will be on an as needed basis.

B. The Statewide Quality Council will have the following membership:

1. Deputy Commissioner and Assistant Commissioners,
2. General Counsel or designee,
3. Director of Investigations,
4. Director of Human Rights.
5. Director of Health Services,
6. Director of Risk Management,
7. Director of Survey and Certification,
8. Individual/family representative(s)
9. Provider representative(s)
10. Representative from each Regional Quality Council
11. Representative from State Advisory Council
12. Representative from Governor's Commission on Mental Retardation

IV. Structure

- a. Council will meet at least semi-annually, but recommend quarterly meetings.
- b. Could be separate meeting or integrated into routine regional management meetings. Under this design, outside stakeholders would attend for that portion of a management meeting dedicated to a discussion and analysis of quality assurance data.
- c. Regional Council will be chaired by Regional Director.

- d. Regional Director will be supported with assistance from either Regional QE Director, Regional Risk Management Director or other designee.
- e. Minutes of the councils' meetings shall be maintained
- f. Membership:
 - 1. Employees of the Department shall have permanent membership on the Councils.
 - 2. Individuals, family members, citizen advisory board members and provider representatives shall serve a term not to exceed two years, in order to assure broad representation from outside stakeholders.
 - 3. Members may have their term on the quality council terminated for cause, if they violate any of the guidelines for participation set forth in this document.

V. Roles and Responsibilities

- a. Quality Councils will review data and information from public documents including the Annual Quality Assurance Report, the Annual Restraint Report, the Annual Mortality Report. Additional public documents will be added over time.
- b. Data reviewed will not contain any individual or provider specific information.
- c. Members will sign a statement agreeing to maintain the confidentiality of any information that might have identifying information
- d. Both the regional and statewide quality councils serve in an advisory capacity to the regional director and commissioner respectively. As such, any recommendations made by the councils are subject to final review and approval by the regional director for the regional councils and the commissioner for the statewide council.

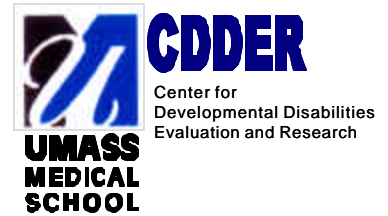
VI. Training and On-going Support

- a. Initial training sessions will be conducted with the statewide and regional quality councils.
- b. Special support will be built in to assure that self-advocates are comfortable with their role and the material being reviewed. A mentorship model will be used enlisting the support of mentors who know the individuals well and are willing to meet with the individual prior to the meeting, assist the person during the meeting and review material covered after the meeting.

ATTACHMENT B



Massachusetts Department
Of Mental Retardation



GENERAL PRINCIPLES For Using Data as a Quality Improvement Tool

A User's Guide for the Massachusetts DMR QUALITY COUNCILS

February 2005

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General Principles for Using Data as a Quality Improvement Tool

A User's Guide for Quality Councils

Introduction

The Massachusetts DMR has embarked on a major initiative to bring together and analyze a vast array of data and information pertaining to the quality of its services and supports in an effort to help guide quality improvement activities. In addition to organizing and analyzing this broad-based data, the department has made a commitment to openly share this information with its constituents and other stakeholders. The establishment of Quality Councils and the publication of the *2002/2003 Quality Assurance Report* exemplify this commitment to public accountability and data-driven performance evaluation. These efforts have been recognized nationally as representing progressive leadership within the field of developmental disabilities.

DMR has also established a partnership with the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research (CDDER) to provide orientation and training to Quality Council members in order to strengthen their ability to effectively review quality data and information and provide meaningful and helpful guidance to the department. Initially Quality Council review activities will focus on the Q.A. Report. Over time, it is anticipated that the Councils will also begin to review and evaluate data and information from a variety of other sources as well.

This brief *User's Guide* is designed to accompany orientation and training sessions that will be provided to the statewide and regional Councils that use the Q.A. report as a foundation for exploring how to use data as a quality tool. It is not intended to be a complete or comprehensive training resource, but rather is constructed to only provide some very basic background information that can supplement the material presented in the on-site training sessions.

Why is Data Important?

There is a growing recognition across almost all fields of endeavor – business, health care, education and government – that objective measurement and analysis of performance can be a powerful management tool. Such objective assessment requires data. While there are many pitfalls to an over reliance on data, when combined with other approaches to assessment it can provide an excellent means of identifying where change may be needed in a service system as well as what type of change may be the most helpful, an important role of Quality Councils.

Historically, developmental disabilities (DD) service systems have relied upon more anecdotal information (e.g., individual cases, problems in a program) to guide change. While valuable, such an approach is often open to significant bias as it is based upon

personal experiences and sometimes isolated incidents. It therefore doesn't always tell the "whole story" or provide a complete "picture" of what is and is not happening. The use of data – if properly analyzed and evaluated – can overcome many of these limitations. It is usually more objective and not as strongly influenced by personal bias. It allows information to be better standardized and therefore comparable across groups of people or service providers. Most importantly it can be organized and analyzed so that we can learn about change, trends, patterns and relationships.

It is important to also remember that data should be viewed as a means to ask more probative questions. It should and can be a mechanism for exploring not only "what" has happened, but "why," and in doing so, to drive the process of continuous and ongoing improvement to systems and the quality of their services and support.

To use data effectively requires that users have a basic understanding of the benefits and limitations of data. That is the purpose of this guide and the training sessions that will be provided to Quality Council members.

Balance is Essential

Just as the use of data can become a powerful tool, it can also be abused and misused. It is very important that any quality system *balance* the use of data with other methods of inquiry and system improvement. An over-reliance on data can just as easily hide the truth as reveal it. Data can be poorly analyzed, incorrectly interpreted and easily manipulated so that it leads to faulty conclusions. It can also quickly become confusing and overly complicated, resulting in users pushing it aside and falling back on old "tried and true" methods that are wrought with bias and inaccuracy. Or, in an effort to create the "perfect" data-based review system funds and staff can be pulled away from other equally important activities.¹⁰ This can result in as many problems as not strengthening the data-based review component to the quality improvement system. Data should therefore be viewed as a *tool* for inclusion in a comprehensive system. It is not the "be all-end all" solution to quality management!

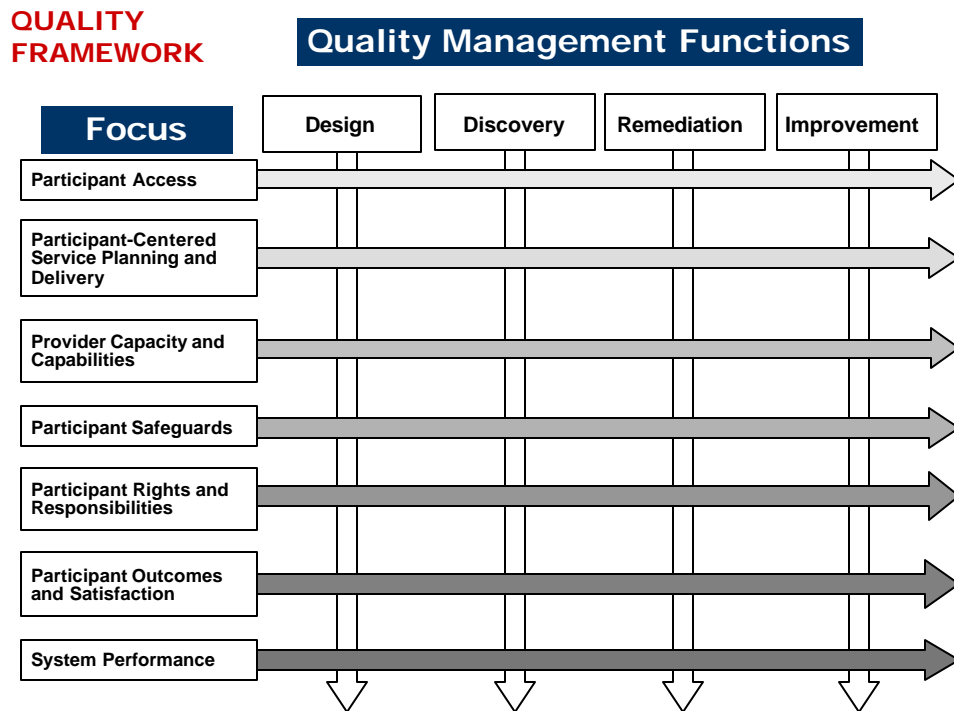
CMS Requirements

Many of DMR's programs and services are provided under the federal Home and Community Based Services (HCBS) program, operated by the Centers for Medicare and Medicaid Services (CMS). This program provides the Commonwealth with millions of dollars of federal reimbursement (about 50% of the actual cost of the service). However, in order to receive this federal funding the state must adhere to a wide variety of rules and meet rather stringent requirements in terms of the quality of services and the process for monitoring and assuring that quality.

¹⁰ A comprehensive approach to quality services in DD must pay equal attention to "building-in quality" up front by strengthening other aspects of the system such as service coordination, consumer involvement and direction, person-centered support planning, workforce development and support for direct service personnel, risk screening and planning, investigations systems, licensing and certification, incident reporting and response, contract monitoring and management, family input, access to health care and prevention, root cause analysis, mortality review systems, ongoing evaluation of consumer outcomes, use of best practice protocols, etc. The use of data can, however, help assess the effectiveness of these components.

In this regard, CMS requires that states have a comprehensive quality management system that is a planned, systemic, organization-wide approach to design, performance measurement, analysis and improvement. It must assure compliance with standards, be designed to reduce adverse events, lead to ongoing improvement, and, it must cross all waiver programs. The quality management system must also be consistent with the Quality Framework, a model that integrates four basic functions of a quality system with seven important focus areas. The Framework is illustrated below.¹¹

Objective data, if organized and analyzed appropriately, can help meet these CMS requirements. The *DMR QA Report* represents an effort to begin to use data as a quality tool, and in so doing should assist DMR meet its federal requirements.



The DMR Q.A. Report

The *2002/2003 Q.A. Report*¹² represents a synthesis of information and data from a wide variety of sources including survey and certification, investigations, incident reporting, the National Core Indicators, medication occurrence reporting, restraint reporting and employment performance outcomes reports. These data are organized and analyzed according to a pre-established set of strategic outcomes.

¹¹ A more current version of the Framework does not include the function of "Design" that is illustrated above. However, this author believes it is essential that full consideration be given to the concept of "designing" systems so that they can readily accomplish discovery, remediation and improvement across the focus areas identified in the Framework. Consequently "Design" is included in the illustration above.

¹² A copy of the Massachusetts QA Report can be downloaded from the DMR website at the following address: http://www.mass.gov/Eeohhs2/docs/dmr/quality_assurance_report_2003.pdf

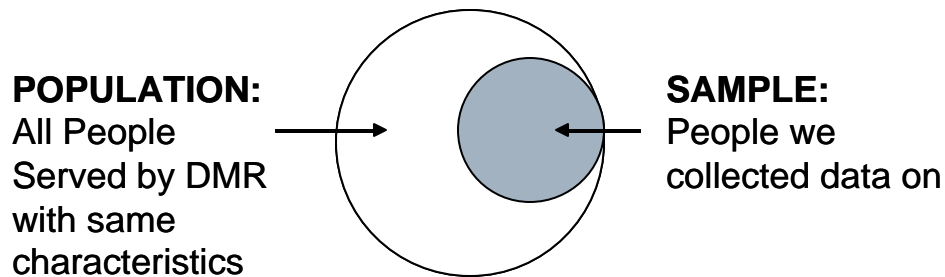
The report itself is structured around the 12 outcomes. Each of the strategic outcomes has a series of indicators and each of the indicators has one or more measures, or sets of data. The relationship between outcomes, indicators and data is illustrated in Appendix A of the report (page 60). A summary of the data sources is contained in Appendix B of the report (page 63).

The Q.A. report displays most of the data in a series of tables (charts) and figures (graphs) so that it is easier to read and interpret. Change from prior years is illustrated through the use of symbols (arrows and “plus” or “minus” signs). In general, whenever there was a change equal to or greater than 10% from the prior year, the arrow is colored, with green indicating it was a positive change and black indicating it was a negative change. Arrows that point “up” mean there was an increase and arrows pointing “down” indicate there was a decrease. Arrows that point “left to right” are used whenever there was no meaningful change or the trend was stable. Appendix C (beginning on page 65 of the report) provides a summary of the change for each of the 57 measures (data sets) where change was evaluated.

SOME BASIC PRINCIPLES FOR REVIEWING DATA

Sample Characteristics

When reviewing the report it is important to remember that in almost all instances data was NOT collected for every single person served by DMR. Rather, data was collected for a group of people. This group is called a *sample*. All the people in DMR who have the same characteristics represent the larger *population*. In some cases the sample was representative of the entire DMR population (all the people served by DMR). In other cases it is only representative of a portion of the people served by DMR (e.g., only those in a residential facility).



For example, the DMR survey and certification unit collected information and data from the review of a selected number of individuals, programs and service providers that are involved in residential and adult day/employment support programs. This data from this sample can only be applied to (generalized to) those persons served by DMR who receive a residential and/or adult/day support. It cannot be applied, for instance, to children who live at home with their family or to people who reside in a LTC facility (e.g., nursing home) and who are served by DMR.

Some important questions to ask about the sample include:

1. **Size.** *How big was the sample in relationship to the population?* If only a small number of people are included in the sample or if the percentage of people who were included is small, the sample may not be a very valid representation of the larger population. For instance, if data was collected on only 10 people out of a population of 5,000, it is very likely that the results will not be representative of the larger group.
2. **Selection Criteria.** *How was the sample chosen?* If the sample was chosen randomly (i.e., without any preconceived reason for selection) it is more likely to be free of bias and therefore representative of the larger population. If, however, data was collected because of a special concern, the sample will probably not be representative. For example, if the survey and certification unit decided to only review providers who were experiencing problems, you couldn't generalize the findings to all providers (those with and without problems).
3. **Differences from Population.** *Are there any unique characteristics of the sample that make it different from the larger population?* Look carefully at characteristics of the sample such as age, level and type of disability, presence of a behavioral health disorder, type of service or support, where they live (type of residence and geographic location) to make sure it is similar to the larger population. If there are major differences you cannot generalize, but must rather only apply the findings to the larger population of persons who have the same characteristics.

TIP: When reviewing the data and the findings from the report it is very important to keep in mind what specific population of DMR consumers the information can reasonably apply to. Do NOT over generalize the population. The analysis is relevant only for the population that is represented by (equal to) the sample.

Validity and Reliability of Data

In order for data to be truly useful it should be both valid and reliable. **Validity** refers to the extent to which the data is actually measuring what you think it is and whether or not it is logically related to the indicator it is purporting to assess. For instance, completing background checks on direct support personnel is a valid measure of DMR's efforts to protect consumers from harm only to the extent there is a relationship between abuse (or other type of harm to consumers) and the presence of staff who have a criminal history. If there is no relationship, criminal background checks are only a measure of compliance with a state requirement, and could not be considered a valid measure of protection from harm. On the other hand, if there is a relationship between the two, then criminal background checks are a valid measure. [Note: in this case there would certainly appear to be a logical relationship.]

Different sets of data will vary with regard to their validity. This means that some measures will be very valid and others only somewhat valid. Therefore it is important to look at more than one measure or data set before drawing any firm conclusions, *i.e.*, look for "convergence" of data wherein more than one measure is telling you the same thing.

Reliability is a necessary condition for there to be validity. **Reliability** refers to the extent to which the data you obtain is consistent, both over time and across measurements. Usually problems with reliability occur when the measure or its scoring are ambiguous and not clear, leading to unintended variation in the data. For example, if a respondent to a survey gives very different answers to the same questions one week later, the survey has poor reliability and the results cannot be trusted. In a similar fashion, if two different surveyors do not agree on how to rate an indicator on a certification review, that specific indicator would be considered to have poor reliability.

TIP: Think about each of the measures in terms of how valid and reliable they are. Place greater trust in those that can meet both of these tests. Use caution when drawing conclusions from those that may have questionable validity or reliability.

Watch Out for Bias in the Data

Many different factors can bias data and influence its validity and reliability. Most causes of such bias or distortion are usually not intentional and are simply artifacts of how the data was collected, organized or analyzed. Three important factors you should always think about include:

1. **System Characteristics:** *Are there any differences in the level of “motivation” to report data?*
 - a. Is data based on self-report or independent review?
 - b. Is reporting voluntary or mandatory?
 - c. Are there consequences for non-reporting? Are they applied consistently? What are the chances of being “caught?”
 - d. If reported, is there a potential for negative consequences to the reporter?
 - e. What systems are in place to identify non-reporting or inaccurate reporting?
 - f. Are there “cultural” differences between organizations/settings with re: the perceived importance of reporting?
2. **Reporter Characteristics:** *Are there any differences in the probability that data will be accurately reported?*
 - a. Who is responsible for collecting data and reporting?
 - b. Does one group work alone and the other with multiple staff present? [Very important for self reported data such as injury reports.]
 - c. Are there any differences in skill or capacity to accurately report?
 - d. Is one type of data “easier” to document and report than another?
3. **Recorder Characteristics:** *Are there any differences in the probability that reports will be accurately documented and entered into a database?*
 - a. Who receives the information?
 - b. Are there differences in how data is communicated and recorded, e.g., by phone, over the internet, filling out a form?
 - c. Are forms complicated or difficult to read or interpret? Is the language complicated and technical?

- d. Can the data be electronically transmitted and automatically put into a database?
- e. Is one group more or less likely to record data accurately and quickly?
- f. Are there any differences in skill or capacity to accurately record?

It's OK if you can't answer all the questions – as long as you have thought about them and identified any really BIG issues that might make the data unreliable or invalid. If so, be very careful about drawing any conclusions without additional evidence from other sources.

TIP: When reviewing the data make sure you think about factors that could bias the data, especially if it is based on self-report (e.g., abuse/neglect reports, Medication Occurrence reports, incident reports) v. being based on review by an independent party.

Ask about System Changes

The DMR service system is dynamic. From time to time policies, procedures and guidelines are introduced or revised to keep up with changing trends in service delivery or to provide clarification regarding reporting practices and expectations. Sometimes these changes can have a profound effect on the data that is collected and the findings that follow from its analysis. For example, if DMR establishes new rules about and methods of reporting unusual incidents, it is difficult to compare the incident data from the year prior to the changes with the data from the year(s) after the changes. Any increase (or decrease) in reported incidents may be a greater reflection of the system change than an actual increase in unusual incidents. In such instances it is important to understand the changes that have taken place and their potential impact on the data. It is also important to recognize that valid year to year comparisons may not be possible until the system has stabilized, *i.e.*, the changes have been fully implemented and are consistent across programs and over time.

TIP: If there are sudden or dramatic changes in data over time, ask about any possible changes to the service system or administrative rules that might have influenced the data. If major changes are present it may be more prudent to wait until the changes have been fully implemented and processes are consistent.

Be Wary of Small Numbers

Unlike large population studies published by the federal government or in research articles published in major professional journals, much of the data contained in the *DMR QA Report* - and other data that may be reviewed by Quality Councils (e.g., *Mortality Reports*) - is based on a relatively small number of cases. The smaller the sample (number of cases analyzed), the less likely differences will be statistically significant.¹³ Small numbers are very sensitive to changes in only a few cases, especially if there are extremes or “outliers” present in the data. Absent statistical significance, readers should

¹³ Statistical significance is simply a measure of how likely (probable) it is that the same results would be obtained over and over again if the analysis were repeated using other members of the population under study. It is determined using formal statistical tests. Most of the data contained in the *DMR QA Report* has not been subjected to such a formal statistical analysis, and therefore has not been determined to be statistically significant – or not significant.

exercise caution in reviewing the results. Again, that is why it is important to look for convergence of data or other information that can “confirm” any given finding.

TIP: Remember that when the sample size is small, only a few cases can have a large impact on the numbers, especially if there are extremes.

Numbers and Percentages

Sometimes the data that will be reviewed is presented as *absolute numbers* (e.g., the no. of cases, no. of people with or without something). Other times it may be presented as a percentage or rate. A percentage or rate is a *relative number*, *i.e.*, it reflects the relationship between the no. of cases with or without something to the total no. of cases in the sample. A percentage is equal to the no. divided by the total X 100. For example, if 25 people out of 1000 received dental care, we would say that dental care was provided to 2.5% ($25/1000 \times 100$) of the people reviewed. Rates are usually expressed as the number of cases per 1000. In the example above, the rate of dental care would be 25 per 1000.

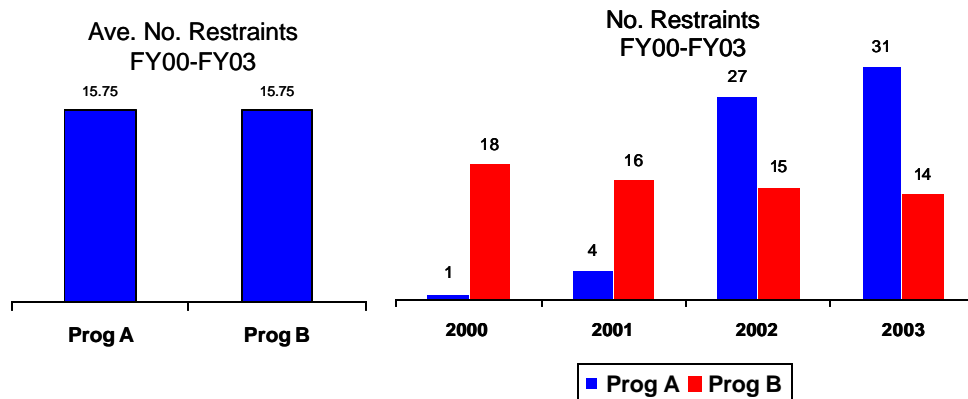
Absolute numbers (no. of cases) are useful if the size of the sample is the same over time. For example, if we were evaluating access to dental care and there were 100 people reviewed in one year and 101 reviewed the next year, it would be appropriate to use the absolute number when comparing years (25 people in year one and 28 people in year two). However, if the sample size differs, either across years or another independent variable (e.g., private provider agency), use of absolute numbers can be very misleading. For example, if in one year we sampled 100 people and 25 were found to have received dental care and in the second year we only sampled 50 and 20 received the service, use of absolute numbers (25 v 20) would look like a reduction in service. In reality however, the relative percentage or rate of care improved (25% v 40%).

TIP: Make sure that when absolute numbers are reported as the primary data in a comparative analysis that the size of the samples is the same or almost the same. If not, look for relative numbers such as percentages or rates.

Use of Averages

Very often the data that will be reported is based on presentation of the mean or average. Such data is called a measure of central tendency and is often useful to help understand what is happening “in general” or “on average.” However, the mean (average) is subject to rather wild swings if the sample size is small and there are one or more outliers (extreme scores). Use of the mean can also mask trends or patterns in the data that may be very important. For example, and as illustrated by the two graphs below, presenting only the average no. of restraints over a four year time period for two programs can hide the fact that one program has witnessed a slight but steady decline while the other has experienced a rather dramatic increase over time.

EXAMPLE



TIP: When reviewing averages, especially if the data is attempting to compare different programs or other variables over time, ask questions about the range (low to high), amount of deviation in the numbers, and the presence of any meaningful patterns or differences that may be present.

General Rules for Reviewing Data

While the consistent use of objective data can be a valuable tool in understanding and managing the quality of services it is important to remember that it is not “perfect” and must be used in an intelligent and cautious fashion. It is important to seek balance between data and other sources of information and to approach the review of data with a “questioning” mind. Try to follow these general rules and you should become an effective and valuable member of the DMR quality team:

1. **ALWAYS** make sure you:
 - a. Analyze the analysis.
 - b. Identify **BIG** issues that may compromise the data.
 - c. Do **NOT** generalize the findings beyond their limits.
 - d. **BALANCE** your review. The data is one point of reference – take into consideration other sources of information.
2. **NEVER:**
 - a. Make assumptions about the data – ask questions.
 - b. Expand the findings to the whole DMR population – unless it is appropriate.
 - c. Treat the data as “significant” unless it says it is.
 - d. Jump to conclusions without checking other sources.

ATTACHMENT C
Minutes Statewide Quality Council
May 5, 2005

Commissioner Morrissey opened the meeting by welcoming members, asking them to introduce themselves and explain how they have been involved in quality issues in the field of MRDD.

He then went on to discuss the role of the council in an overall quality management and improvement system and his goals for the council. He discussed the importance of using data to effect change, and the importance of sharing information with individuals, families, advocates and providers.

Commissioner Morrissey then turned over the meeting to Steve Staugaitis, from the Center for Developmental Disabilities Evaluation and Research (CDDER) / UMASS Medical School. Dr. Staugaitis did a presentation on the importance of data, and its uses for quality improvement. He also described the content and format of the DMR Quality Assurance Report, and highlighted some of the key findings. Dr. Staugaitis then presented the priorities that had come forward from the regional quality councils.

Council members reflected upon the data and had several comments and suggestions including:

- 1) That it is important to be clear concerning whether data presented is comparable. For example, NCI data on dental exams uses exams at 6 month intervals, whereas data from survey and certification uses exams at 12 month intervals as the measure.
- 2) That it might be helpful to get comparisons to other industry standards in addition to looking just at DMR data. (e.g., medication errors in DMR services as compared to errors in nursing homes or hospitals; unemployment in the general population in Massachusetts and the rest of the country)

Discussion then shifted to potential areas for service improvement targets. Gail Grossman indicated that the areas identified were selected from indicators in the report where improvement could be made. She indicated that while it would be important to look at the priorities from the regional councils, it would be up to the statewide council to recommend 2-3 statewide targets for Commissioner Morrissey's final approval.

There was significant discussion around the following service improvement areas:

- 1) difficulty in accessing transportation services (not currently captured in the QA report , but identified by the Northeast Region as an issue)
- 2) issues around safety with transportation services (not currently captured in the QA report, but also identified by the Northeast Region)
- 3) work – hours worked and wages paid
- 4) friendships
- 5) community involvement
- 6) dental services
- 7) direct support salaries (not currently capture in the QA report)

It was suggested that we focus on the data and outcomes that DMR was already collecting data on, but to think about what outcomes and indicators should be considered for inclusion in future reports. Any additions would have to consider what

we are trying to measure (i.e. be expressed as an outcome) and whether data currently exists or would have to be collected in new ways. Future areas discussed included:

- 1) Quality of direct support professionals
 - a. Turnover rates
 - b. Salary
 - c. Knowledge/competency

The comment was made that the quality of direct support professionals impacts upon every outcome. In addition, Janet George mentioned that gathering consistent, reliable data on the above issues has been difficult.

- 1) Correlation between work and development of friendships
- 2) Difficulty in accessing transportation (it is unclear how we would gather this information, but it was considered important)
- 3) Transportation safety (could use investigations data as a start and incident reports)

The council members were asked to fill out the survey regarding priorities for service improvement. In doing so, it was suggested that they:

- 1) Consider picking service improvement targets from a balance of easy to achieve targets as well as more challenging ones
- 2) Consider whether challenging ones should have a more incremental approach with more modest measures of progress

For the next meeting, council members were asked to read the report in depth, fill out and return the survey regarding service improvement targets to Gail Grossman within the next 10 days. In addition, the council was asked to think about how we would measure success in reaching targets.

The next meeting was scheduled for : Thursday, June 23 1:00-3:00, at the Shriver Center in Waltham, Mass. (Directions Enclosed)

Agenda:

- 1) Discuss results of survey of priorities
- 2) Discuss specific service improvement areas in more depth
- 3) Recommend 2-3 service improvement targets for Commissioner Morrissey's consideration
- 4) Discuss ways in which progress towards achievement of targets might be measured.

Respectfully submitted,
Gail Grossman

Massachusetts Statewide Quality Council Annual Estimated Costs

Annual Estimated Costs Associated with Quality Councils*

Personnel Costs

DMR Personnel:

Assistant Commissioner for QM
 Regional DMR Director
 Area DMR Director
 Director of Investigations
 Director of Health Services
 Director of Risk Management
 Director of Survey & Certification
 Director of Human Rights

DMR staff or External rep:

Nomination from Region 1 QC
 Nomination from Region 2 QC
 Nomination from Region 3 QC
 Nomination from Region 4 QC

External members:

Family member rep
 Provider rep
 Self advocate rep (\$100/mtg)
 Mentor to self advocate
 Governor's Commission rep
 State Advisory Council rep

Consultant(s) to Statewide QC:

Steven Staugaitis (3 trainings)

Subtotal: Personnel Costs

Annual Salary* Estimate	Prep per mtg (hours)	Length per mtg (hours)	Meeting time utilized per quarter (hours)	Meeting time utilized per year (hours)	% Annual Time utilized for QC mtgs.	Annual Salary* Costs	Subtotals
\$100,000	48	3	51	204	0.098076923	\$9,808	
\$100,000	2	3	5	20	0.009615385	\$962	
\$95,000	2	3	5	20	0.009615385	\$913	
\$85,000	2	3	5	20	0.009615385	\$817	
\$85,000	1	3	4	16	0.007692308	\$654	
\$85,000	1	3	4	16	0.007692308	\$654	
\$85,000	1	3	4	16	0.007692308	\$654	
\$85,000	1	3	4	16	0.007692308	\$654	\$15,115
\$600	1	3	4	16	0.007692308	\$5	
\$90,000	1	3	4	16	0.007692308	\$692	
\$75,000	1	3	4	16	0.007692308	\$577	
\$85,000	1	3	4	16	0.007692308	\$654	\$1,928
\$65,000	1	3	4	16	0.007692308	\$500	
\$80,000	1	3	4	16	0.007692308	\$615	
\$100/mtg	2	3	5	20	0	\$400	
Volunteer	2	3	5	20	0	\$0	
\$70,000	1	3	4	16	0.007692308	\$538	
\$65,000	1	3	4	16	0.007692308	\$500	\$2,554
\$100/hour	10	3	13	36		\$3,600	\$3,600
							\$23,197

Non-personnel Costs per Meeting

Meals: 19 meals @ \$11.00/lunch

Phone

Copies & printing

Subtotal: NPS per quarter

NPS quarterly costs annualized

Annual travel (mileage & parking)

Subtotal: Annual NPS Costs

\$209							
\$60							
\$300							
\$569							
\$2,276							
\$2,400							
							\$4,676

**ESTIMATED TOTAL ANNUAL
STATEWIDE QUALITY COUNCIL COSTS**

\$27,873

* Estimated costs include costs allocated to DMR as well as contributed time & salaries paid for outside of the Massachusetts DMR. Salary costs do not include other costs of personnel such as health insurance.

Massachusetts Regional Quality Councils Annual Estimated Costs

Annual Estimated Costs Associated with Regional Quality Councils*

Personnel Costs

DMR Personnel:

Asst. Commissioner QM

Regional DMR Director

Area DMR Director

Senior Investigator

Risk Management Director

Regional Legal Counsel

Human Rights Specialist

Citizen Advisory Board rep

External members:

Family member rep

Provider rep

Self advocate rep

Mentor to self advocate

Subtotal: Personnel Costs

Non-personnel (NPS) Costs

Meals:12 lunches @ \$11.00 x 4 mtgs.

Phone

Copies & printing

Travel (mileage & parking)

Subtotal: Annual NPS Costs

Estimated Annual Costs Per Regional QC

ESTIMATED TOTAL ANNUAL REGIONAL QUALITY COUNCIL COSTS ACROSS 4 REGIONS

\$80,750

* Estimated costs include costs allocated to DMR as well as contributed time & salaries paid for outside of the Massachusetts DMR. Salary costs do not include other costs of personnel such as health insurance.

	Annual Salary* Estimate	Prep per mtg (hours)	Length per mtg (hours)	Meeting time utilized per quarter (hours)	Meeting time utilized per year (hours)	% Annual Time utilized for QC mtgs	Annual Salary* Costs	Subtotals
Personnel Costs								
<i>DMR Personnel:</i>								
Asst. Commissioner QM	\$100,000	48	3	51	204	0.098077	\$9,808	
Regional DMR Director	\$100,000	2	3	5	20	0.009615	\$962	
Area DMR Director	\$95,000	2	3	5	20	0.009615	\$913	
Senior Investigator	\$75,000	2	3	5	20	0.009615	\$721	
Risk Management Director	\$75,000	2	3	5	20	0.009615	\$721	
Regional Legal Counsel	\$75,000	2	3	5	20	0.009615	\$721	
Human Rights Specialist	\$70,000	2	3	5	20	0.009615	\$673	
Citizen Advisory Board rep	\$65,000	2	3	5	20	0.009615	\$625	\$15,144
<i>External members:</i>								
Family member rep	\$65,000	1	3	4	16	0.007692	\$500	
Provider rep	\$80,000	1	3	4	16	0.007692	\$615	
Self advocate rep	\$100/mtg	2	3	5	20	0.009615	\$400	
Mentor to self advocate	Volunteer	2	3	5	20	0.009615	\$0	\$1,515
Subtotal: Personnel Costs								\$16,660
Non-personnel (NPS) Costs								
Meals:12 lunches @ \$11.00 x 4 mtgs.	\$528							
Phone	\$200							
Copies & printing	\$400							
Travel (mileage & parking)	\$2,400							
Subtotal: Annual NPS Costs								\$3,528
Estimated Annual Costs Per Regional QC								\$20,188
ESTIMATED TOTAL ANNUAL REGIONAL QUALITY COUNCIL COSTS ACROSS 4 REGIONS								<u>\$80,750</u>

