

**MASSACHUSETTS DEPARTMENT OF MENTAL RETARDATION**

**Health Promotion and Coordination Initiative**

**Training and Resource Manual**

**December, 2003**

*(Revised October 2004)*



A manual for Providers, Families, and DMR Staff to promote communication, coordination, and access to health care.

# The DMR Health Promotion and Coordination Initiative

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# **The DMR Health Promotion and Coordination Initiative**

## **Introduction and Background**

### ***The Strategic Management Process***

In March 2001 the Department of Mental Retardation embarked upon a strategic management planning process designed to address several critical areas of concern to the Department and its key stakeholders. One of the key objectives identified was to establish effective and consistent health, clinical and behavioral supports for persons with mental retardation across the Department of Mental Retardation system.

Three goals were identified within this broad objective:

1. Recognize and respond to each consumer's needs for available health, clinical and behavioral supports;
2. Ensure a coherent departmental approach for addressing health, behavioral and clinical issues and concerns;
3. Work with health care agencies and other funding sources to assert the needs of the overall population with mental retardation.

The materials that follow offer several useful tools, instruments and processes to address goals 1 and 2 above. They are presented as part of the Department's continuing commitment to supporting quality health care services.

### ***Rationale for Recommendations***

The Department of Mental Retardation acknowledges that there are a myriad of issues which impact upon access to and coordination of quality health care services for individuals with mental retardation. The material presented here is not intended to address the total array or complexity of issues. It *should*, however, be viewed as a starting point that sets out the foundations of good systems of support for preventive and routine health care.

The materials presented in this manual place a high priority on prevention, early detection and health promotion activities. Preventive and routine screening, health promotion, early detection, treatment and follow up on health care concerns represent the cornerstone of quality health care supports for everyone. Unlike the general population, however, some people with mental retardation cannot report and describe signs and symptoms of illness, some do not have full medical histories and many rely upon direct support professionals to be their health care advocates.

Through direct interviews with providers, DMR staff, and with input from family members, DMR identified several key issues that affect the quality of health care services that individuals receive. These include:

- Difficulty on the part of the individual to communicate symptoms to both direct support professionals and health care providers.
- Limited experience on the part of direct support professionals to communicate necessary and pertinent information to the health care provider during a routine, urgent or episodic visit.
- Incomplete or poorly communicated information from the health care provider that impacts on follow-up and ongoing health care management.
- Lack of complete and thorough medical histories needed to enable a health care provider to make appropriate assessments, diagnoses and treatment recommendations.
- Lack of consistent routine/preventive health care screening standards adjusted for age and specific syndromes associated with mental retardation.
- Lack of systems to observe and report changes in health and mental health status.
- Lack of systems to trigger a clinical consultation when certain health care issues emerge.

DMR has developed the following specific standards, tools, and systems in a series of projects involving DMR providers, DMR staff, health care providers and individuals working in the community. They are intended to address the issues outlined above. Included in this manual is an appendix that includes fact sheets describing the signs and symptoms of specific illnesses. The fact sheets are for providers to use for both training and on-site reference for direct support professionals. All of this material is available under "Health and Wellness Promotion" on the DMR web site at <http://www.dmr.state.ma.us>.

### ***Pilot Study of Health Care Protocols***

DMR "field-tested" the forms and systems, once developed, in 15 volunteer provider agencies from across Massachusetts. The participating provider agencies used all the forms and systems introduced here for a period of 2 months. Written feedback, focus groups, and telephone interviews helped DMR to modify the forms to ensure that they will serve their intended purpose in the community.



**The components of DMR's Health Promotion and Coordination Initiative are being introduced to the provider community in a two-phase process beginning in December 2003. In order to ensure the maximum benefit from this initiative, DMR is requiring the use of a number of the forms included in this manual. In many cases, these forms will replace current documentation requirements. The description of each specific form will indicate which are required.**

## Implementation Outline and Timetable



### Phase I

(December, 2003)

“Enhancing the quality of care and communication with the health care provider.”

#### Included:

- 1) **Preventive Health Screening Recommendations:** A schedule for primary care physicians of preventive health screening procedures, adapted from the Massachusetts Health Quality Partnership (2003).
- 2) **Preventive Health Screening Checklist (HC-1):** To be filled out by the provider in advance of the annual physical using the health screening recommendations for guidance. **(REQUIRED)**
- 3) **Health Review Checklist (HC-2):** A simple form that direct support professionals or a supervisor would use to record changes in an individual’s health status. **(REQUIRED)**
- 4) **Tools for the Health Care Appointment**
  - a. **Procedure for a Medical Appointment:** A protocol to ensure that provider staff members (or family) are prepared with all the information and materials needed when accompanying an individual to a medical appointment.
  - b. **Health Care Practitioner Encounter Form (HC-3)**
  - c. **Annual Physical Examination Form (HC-4)**



### Phase II

(April, 2004)

“Integration of health care issues into the Individual Service Plan (ISP)”

#### Included:

- 5) **Health Record (HC-5):** A form for gathering and organizing an individual’s medical history and records in one document so they are available to health care providers and program staff (*this replaces the currently required Personal Health Fact Sheet, also known as Health Care Fact Sheet, for the ISP*) **(REQUIRED)**
- 6) **Protocol for Clinical Consultation:** A protocol to initiate a clinical review by a DMR nurse.
- 7) **ISP Health Planning Worksheet (HC-6):** A format for providers and ISP teams to help integrate health care issues into the planning process.

## PHASE I – Introduction in December, 2003.

### PREVENTIVE HEALTH SCREENING RECOMMENDATIONS



**Required for use by MR provider in preparation for the annual physical examination**

#### **Background**

Currently, DMR regulations require that individuals receive an annual physical exam. The thoroughness of these exams and the specific health issues screened vary widely depending both on the physician providing the exam as well as the knowledge of the provider. Up until now, DMR has not given clear guidance with respect to standards for routine and preventive health care for individuals with mental retardation, thus contributing to the variability across the state. These materials will help assure that individuals served by the Department of Mental Retardation receive consistent and appropriate standardized preventive and routine health care screenings.

The DMR Health Screening Recommendations were developed by a group of physicians, nurses and caregivers in partnership with the Shriver Center's Center for Developmental Disabilities Evaluation and Research (CDDER) at the University of Massachusetts Medical School. The recommendations outlined screening standards that were recently developed by the Massachusetts Health Quality Partners ([www.mhqp.org](http://www.mhqp.org)) for use with the general population. They are adapted to address special or earlier screening for conditions more common in individuals with mental retardation.

#### **Purpose**

The recommendations are intended for use primarily by DMR providers and health care providers, but can be equally useful to families and service coordinators. The standards are presented in 3 formats to promote their effective use among the aforementioned caregivers.

#### **1. Pamphlet**

This brochure has been mailed to all family practice physicians, general practitioners and internists in Massachusetts with a cover letter from Commissioner Morrissey announcing the implementation of the DMR health care initiative.

#### **2. "Wall Chart"**

This landscape handout describes in more detail, recommended screenings for various age groups or diagnoses. This can be used as a reference guide by DMR providers.

#### **3. Preventive Health Screening Checklist (HC-1) (Required)**

This is a summary checklist that provider staff must complete prior to the annual physical. Designated staff of the DMR provider agency will check off those screenings for which the individual is due either because of age or risk factors. **In most instances, the checklist will not be given to the health care provider.** It should serve as a guide for the individual and support providers regarding what to request or expect during the annual physical examination.



## HEALTH REVIEW CHECKLIST (HC-2)



**Required for annual physical examination and episodic visits to primary health care provider**

### Background

Establishing a set of routine/preventive health care recommendations is only one step in assuring that individuals receive quality health care. The ability of a health care provider to do quality assessments, diagnosis and treatment, in large part, rests on the quality of the history and information that he/she receives. In the general population, information regarding health care status is usually communicated by the patient or a family member. While many people with mental retardation may be able to share information with a health care provider, others are largely dependent upon the observations of direct support professionals to record and report information. It is critical, therefore, that DMR providers have a consistent manner in which to gather information regarding health issues and changes to better inform the primary health care provider. Without this critical information, it is doubtful that a full review can be successfully accomplished. The Health Review Checklist helps to provide consistent, relevant and thorough health status information to the treating provider at the time of the medical encounter.

### Purpose

**The Health Review Checklist is generally completed by direct support professionals.** The tool asks direct support professionals who interact most directly with individuals on a day-to-day basis to respond to questions about easily observable indicators of health or illness. It does not require that staff make any clinical judgments, only that they observe and record what they see.

**The Checklist is required to be used in preparation for the annual physical exam as well as for any visit to the individual's primary care provider.** It is not required for use in preparation for specialty visits, unless the provider feels such use would be helpful. This checklist can also be used at regular intervals to monitor specific conditions or to note changes in health status.



While the checklist was developed primarily with the direct support professional in mind, it can also be used by family members or other provider staff to help prepare for a consultation or visit with a health care provider.

Consistent use of this form by direct support professionals can also assist staff to be more attuned to issues of concern and help them to become better observers of potential signs and symptoms of illness. It can also serve as historical information for new staff to have a better understanding of an individual's previous health status.

## **TOOLS FOR THE HEALTH CARE APPOINTMENT**



**Recommended for use for all health care appointments**

### **Background**

While a clear set of standards and a screening checklist for direct support professionals are important pre-requisites to quality health care, appropriate preparation and good communication of gathered information is essential to a productive medical encounter and appropriate follow up. Different types of appointments may require sharing different information. Most providers depend largely upon direct support professionals to take an individual to routine, episodic and emergency visits, to relay necessary information to the health care provider, and to accurately report back treatment and follow up recommendations.

### **Purpose**

The following forms are to be used by provider management and direct support professionals to facilitate a successful medical encounter. Included are instructions regarding the “how to’s” of a medical appointment, an encounter form and an annual physical examination form.

### **Procedure for a Medical Appointment**

This protocol is a useful tool for training new staff and can serve as an efficient checklist when any staff member is preparing for an appointment. The protocol includes relevant steps for appointment preparation and follow-up, as well as guidelines for the actual medical encounter. This protocol is recommended to ensure thorough preparation for a medical appointment.

### **Health Care Practitioner Encounter Form (HC-3)**

This form provides a clear, easy to use format for both the service provider and the health care provider. It incorporates information regarding the reason for the visit as well as the treatment recommendations as a result of the visit. It also includes a section to insure that follow up is completed on all recommended actions. Agencies are required to have an encounter form with all of the components of the form provided here. They may, however, use their own agency’s format.

### **Medication List**

A list of all of an individual’s current medications should accompany the Encounter form on medical visits. The list should also note which practitioner prescribed each medication. A sample format is provided here.

### **Annual Physical Examination Form (HC-4)**

This form is recommended for use by the health care practitioner when completing the annual physical examination.

Following is a chart that identifies the required and recommended forms for different types of health care encounters:

√ (R): Standardized DMR form must be used.

√ : Recommended documentation for appointment . Use DMR form or another form developed by provider.

Visit Type	Health Screening Recommendations Checklist (HC-1)	DMR Health Review Checklist (HC-2)	Encounter Form (HC-2) or Provider Form	Medication Administration Record (or list of meds.)
Annual Exam	√(R)	√ (R)	√	√
Episodic Visit		√ (R) (visits to PCP)	√	√
Emergency			√	√
Consultation with Specialist			√	√

**HEALTH RECORD (HC-5)**



**Required to be reviewed and updated for Annual ISP**

**Background**

While documentation of health care issues alone does not assure quality health care, it can assist the DMR provider, the health care provider and the ISP team to plan and support an individual to maintain optimal health. A complete health care history can provide a critical baseline and ongoing information that can prove to be invaluable when providing health care services. While initial compilation of a complete health record can be time consuming, once completed, the Health Record need only be updated as events dictate and annually for the ISP. The Health Record provides a concise and easy to use reference that can facilitate communication of relevant information and thereby improve the quality of health care.

**Purpose**

The Health Record is intended to serve as a guide for information that should be included in a thorough health history/record. Many providers already have extensive records in place. This format will standardize how that information is compiled and maintained, and replaces the current Personal Health Fact Sheet (or Health Care Fact Sheet) used at the ISP. **A copy of the Health Record should be maintained in an individual's file with both their Service Coordinator and their Residential Provider, if applicable. If an individual has a change in Residential Provider, their Health Record must be updated at the time of transition and must accompany the individual to their new provider.**

The 3-page format contains all the information necessary to provide a past and current history of an individual's health status. The Record will be utilized in the following manner:

**a) "Portable Record" (Page 1):** contains the most pertinent information a health care provider who is unfamiliar with the individual would need when conducting a routine, episodic or emergency visit. This should be considered the "portable" record that would provide a profile of the individual and could be copied and taken to a health care visit. When listing current medications, please refer to the sample Medication List in the previous section.

**b) "Complete Record" (Pages 1, 2 and 3):** These pages in combination, replace the current Personal Health Fact Sheet (also known as the Health Care Fact Sheet) used for the annual ISP. The format is easier to fill out as it replaces the current narrative format of the fact sheet with simple "check off" boxes wherever possible. **The Complete Record must be updated at each annual ISP.**

The Complete Health Record should be taken with an individual if they are going to the first visit with a new Primary Care Physician (PCP) or specialist. This complete version provides essential health history information for this new health care provider.

**Chronological Medical Event Record:** It can be helpful to a health care practitioner to have a list of an individual's medical events. This sample form can be completed and attached to the Health Record.

## **PROTOCOL FOR A CLINICAL CONSULTATION**

### **Purpose of Protocol**

While many individuals with mental retardation enjoy stable health and require only routine and episodic health care interventions, a small percentage of the population have complex health care issues or newly diagnosed conditions that require a more sophisticated clinical review and an in depth health care management plan.

This document sets forth a protocol for a clinical consultation for individuals with physical health care issues that by virtue of their complexity or need for management require a more in depth review than is typical of the standard ISP or other planning processes. Its primary purpose is to provide an opportunity for a clinician, in most cases an RN or NP, to offer valuable guidance to those supporting an individual regarding the specific issues a particular medical condition might present. It would also include an assessment of the types of programs and supports that will assist the person to manage effectively.

### **To Whom Does this Apply?**

All individuals eligible for DMR services may receive a clinical consultation, if deemed appropriate, regardless of whether they live in a DMR funded residential support, live independently with minimal assistance, or live with their families.

**The clinical consultation will be completed either by the provider, if they have a nurse on staff, or by the DMR area nurse if the provider does not have access to nursing support. It could also be completed if the provider nurse would find a consultation by the DMR area nurse helpful.**

### **Health Status Indicators that Require Clinical Consultation**

The following list represents several conditions or factors which should trigger the need for an in depth clinical consultation. The list is not meant to be all-inclusive. Providers and/or service coordinators may request a clinical consultation if in their professional judgment, there are issues which require further attention.

- 1) Frequent Emergency Room Visits or hospitalizations (This would apply to ER visits and hospitalizations that are not expected as a result of a particular chronic condition or as part of a protocol for management of a chronic condition. For example, visits and hospitalizations for pneumonia or sepsis would be included. Visits and hospitalizations to manage G/J tube placement or side effects from cancer treatment would not be included.
- 2) Newly diagnosed conditions including: (The conditions listed below typically require some major adjustment in the support structure for the individual especially around staff training, clinical support and appropriateness of current placement)
  - a) Diabetes
  - b) Cancer
  - c) Dementia (including Alzheimer's Disease, organic brain syndrome)

- d) Cardiac or Pulmonary condition (For example, angina, congestive heart failure, emphysema, asthma, pulmonary edema, coronary artery disease)
  - e) Autoimmune Condition (AIDS, HIV positive, Lupus)
  - f) CVA (stroke)
  - g) Dysphagia (swallowing difficulties that require specific intervention as ordered by the Health Care Provider or speech or occupational therapist)
- 3) Major chronic condition with deteriorating outcome (Conditions that would be included here are those that, other than those listed above and below, create major lifestyle adjustments for individuals and their care providers and are likely to change the level of support an individual requires. Some examples are: Traumatic Brain Injury, Multiple Sclerosis, Parkinson's Disease, Huntington's Chorea, kidney disease requiring dialysis, Cirrhosis, amyotrophic lateral sclerosis)
  - 4) Recently placed G/J tube or other implantable device (This would include pacemakers, implantable seizure management devices, devices for pain management)
  - 5) Large bone fracture or multiple fractures (The issue of safety needs changes as a result of aging or a disease process may need to be considered. Underlying cause of fractures will also need to be evaluated; for example, osteoporosis.)
  - 6) Lack of consensus re: diagnosis, treatment, treatment options or support needs (The Clinical Consultation may provide objective analysis of the situation that can help clarify and unify efforts in providing appropriate care for the individual involved.)
  - 7) Unexplained DNR (This would refer to DNRs that are put in place when there is no diagnosis or condition that would indicate a need for one.)
  - 8) Multiple pneumonias (The purpose of the Clinical Consultation in such a case would be to determine if due effort was being made to determine cause of recurring pneumonias as in chronic aspiration due to gastroesophageal reflux disease (GERD) or swallowing disorders or in management of early symptoms of respiratory infections.)
  - 9) Sudden, unexplained behavior change (Underlying medical conditions that are undiagnosed or not appropriately treated should be ruled out prior to exploring any type of behavioral intervention)
  - 10) Rapid decline in functional skills (Underlying medical conditions that are undiagnosed or untreated should be ruled out before other non-medical interventions are explored.)

### **When is a Clinical Consultation Initiated?**

A clinical consultation should be requested whenever any of the following situations occur:

- 1) Any of the abovementioned **10** factors occur

- 2) The ISP team determines that the individual's health care status requires a more intensive clinical review than is possible by the team
- 3) The completion of the provider generated "Health Review Checklist" as part of the annual ISP process reveals health issues that the team feels is of concern.

### **Who Initiates a Request for Clinical Consultation?**

A clinical consultation request may be initiated by any of the following:

- 1) A supervisor, manager, health care coordinator, RN from the provider agency,
- 2) A family member
- 3) Any member of the ISP team
- 4) DMR nurse

### **Process/Flow for Clinical Consultation**

- 1) The individual's service coordinator or service coordinator supervisor should be contacted whenever any of the abovementioned indicators are present.
- 2) If the provider has a nurse on staff who is assigned such duties, the provider will conduct the initial clinical review with consultation and support from the DMR area nurse, if requested by the provider
- 3) The service coordinator will forward a request for a clinical consultation to the DMR area nurse, if the provider does not have an RN or NP assigned such duties
- 4) The DMR area nurse will respond to a request for a clinical consultation in a timely manner
- 5) Findings and/or recommendations from the clinical consultation will be forwarded to the provider and service coordinator whose responsibility it will be to consider its inclusion in the individual's plan of care
- 6) Each area office will maintain a record of individuals who have received physical health care clinical consultations.
- 7) The area office nurse shall review and update each individual consultation at a minimum, in conjunction with the ISP process.

### **Elements of the Clinical Consultation**

The clinical consultation is comprised of the following elements:

- 1) A review of specific conditions identified
- 2) A general assessment of the supports needed to effectively assist the individual and/or provider to stabilize and support the individual
- 3) An assessment of the supports in place to meet the individual's needs
- 4) A determination of how often the support plan should be reviewed to determine its efficacy in meeting the individual's health care needs.
- 5) A recommendation regarding staff training needed to support person

**Please be aware that an Area or Regional nurse is available to you or your staff regarding any urgent issues or cases for which you feel their services could play a supportive, informative or intermediary role.**

## **INTEGRATION WITH THE ISP**

### **Background**

While attention to health care status does not await the annual ISP process, the ISP is one time during the year that all those involved with a particular individual can step back and review a person's health status and what supports, if any, are needed to assist an individual to maintain optimal health, and quality of life. Therefore, it is important that information gathered over the course of the year with respect to health status be presented in a useful, summative format.

### **Purpose**

A pre-ISP packet will be distributed to the provider to complete in preparation for the ISP meeting. Materials will include:

- a) The Health Review Checklist (HC-2)
- b) The 3 pages of the Health Record (HC-5) (in place of the currently used Personal Health Fact Sheet, also known as Health Care Fact Sheet). This would only need to be updated for any changes.

The abovementioned materials will provide the necessary background information regarding the important events of the past year with respect to a person's health. This will enable the ISP team to more effectively plan for the future needs of the individual.

The Health Planning Worksheet (HC-6) provides a documentation mechanism for the ISP team to review the current interventions, whether they are sufficient to meet the individual's needs and any anticipated future supports. This form may be filled out by the provider in preparation for the ISP, or at the ISP meeting by the service coordinator.



## **APPENDICES**

### **A. SIGNS AND SYMPTOMS OF ILLNESS**

#### **Background**

The health status of individuals does not neatly lend itself to an annual review and physical exam. Clearly, we can anticipate that individuals will be subject to episodic illness or subtle changes in health status over time that, if not addressed, can lead to more serious issues. It is critical, therefore, that direct support professionals, as the first line of defense, be knowledgeable about what issues to report on and to whom they need to report them. Accurately recognizing signs and symptoms of illness will facilitate individuals receiving timely medical care.

#### **Purpose**

The following fact sheets are intended to be used as a training tool for direct support professionals. They are formatted so that they define a condition, identify observable symptoms, and recommend action for direct support professionals. The fact sheets can be used as quick reference sheets for direct support professionals and are intentionally written so as to minimize the use of medical jargon that may be non-descriptive of symptoms that the staff may be observing.

The sections included highlight a few key issues that commonly occur and may be indicative of serious health concerns requiring prompt action. The forms do not attempt to dictate agency practice with respect to action to be taken. They are meant to provide guidance to providers regarding signs and symptoms that should trigger agency response protocols.

### **B. HEALTH OBSERVATION GUIDELINES**

This document is intended to provide a clearer understanding of the importance of some common signs and symptoms of illness. It explains why certain simple signs may be important clues of underlying conditions and stresses the importance of observing changes in an individual's normal status. It is formatted to follow the sequence outlined in the Health Review Checklist (HC-2).