

The Massachusetts/DMR  
Health Care Quality Initiative in  
Collaboration with CDDER/UMass

Re-Inventing Quality Conference

Thursday, July 31, 2003

## **Yale Study (2000) on “*Health Status of Individuals with Mental Retardation*” Findings: Barriers to Care**

- Uncoordinated systems of health care
- Individual may be unable to understand how behavior affects health
- Health care provider’s (HCP) lack of training in caring for people with mental retardation
- Direct support professionals (DSP) lack training to recognize health issues
- Poorly documented health history
- No standardized health care guidelines for individuals with MR
- Few programs to educate individuals with MR on disease prevention
- Ineffective communication with health care provider

# **Surgeon General's Report (2002) on Health Care Disparities for Individuals with Mental Retardation Work Group Issues**

- Attitudes of health care professionals
- Quality of health services
- Accessing health services
- Paying for health services
- Age-appropriate health services
- Health services throughout the lifespan
- Promoting health: providers
- Promoting health: individuals and caretakers

## NATIONAL INITIATIVES

- On-line curriculum recently made available to train nurses in care of individuals with MR/DD by Healthsoft, Inc. and DDNA
- Standards of Practice in DD nursing established by DDNA
- DDNA Curriculum in DD nursing piloted at UCLA School of Nursing
- Special Olympics funding development of health awareness programs for individuals with MR/DD
- AMR continues research regarding underlying health risks for individuals with MR
- A position statement on delegation to non-licensed staff

# **Review of State Initiatives on Health Care for Individuals with Mental Retardation/ Developmental Disabilities**

- Mortality Review Committees
- Governor's Advisory Councils that advise on health care and other issues for DD/MR populations
- Development of individual-specific tools to monitor health and functional changes in individuals during times of transition or high risk
- Health advisories/newsletters to educate staff and consumers
- Statewide committees to review and approve invasive procedures or nursing home placements
- Regional nurses to provide technical assistance to programs managing complicated health issues
- Databases to collect information related to health care quality and risk

# DMR/STRATEGIC MANAGEMENT PROCESS

- In 2001 DMR embarked upon a comprehensive planning process
- Wide group of stakeholders identified key areas of concern
- Quality of health care emerged as a key issue

## **OBJECTIVE OF STRATEGIC MANAGEMENT PROCESS**

- ⇒ Respond to each consumer's needs
- ⇒ Ensure a coherent department approach for addressing health care concerns
- ⇒ Work with health care agencies to assert needs of people with mental retardation

## OPERATING PRINCIPLES

- Health care should be comparable in quality to that expected by general population
- Individuals should use generic health care system
- Specialized supports should supplement not supplant generic system
- Health care advocacy should be available to assist individuals
- Generic health care system needs additional training and support to provide more skills for working with individuals with MR.

## ESTABLISHING OUR FOCUS

- Multiple issues impact on quality health care
- Critical to refine focus to areas we could influence and improve
- Looked to foundations of:
  - ⇒ Systems for routine and preventive care
  - ⇒ Early detection and intervention
  - ⇒ Supporting healthy lifestyles

## ISSUES AND BARRIERS

- Health care system increasingly complex
- Lack of clear standards for screening/prevention
- Reliance on direct support professionals (DSP) as health care advocates
- Lack of attention to health care issues in service planning
- Aging population
- Little training for the specific needs of individuals with MR in the generic health care system

## DMR Physical Health Subcommittee SPECIFIC AREAS ADDRESSED

- Ability of DSP to effectively communicate necessary information
- Incomplete histories/records
- Lack of consistent health status screening tools
- Lack of systems to observe and report changes in health care status
- Need for clinical consultation on complex issues
- Need for tools to prepare staff for health care encounters

## GOALS

- To improve the ability of direct support professionals to be health care advocates
- To improve communication and quality of interactions between individual and health care system
- To enhance prevention, early detection, treatment and follow-up

# HEALTH SCREENING AND ASSESSMENT STUDY

- “ To develop recommendations for a tool that direct care staff could use to document the health status of clients”
- Developmental Disabilities Profile (DDP) (NY)
  - Client Development Evaluation Report (CDER) (CA)
  - ‘OK’ Health Check (UK)
  - Inventory for Client and Agency Planning (ICAP)  
(several states, including TX,NE,WY)
- 
- No one assessment was found to be appropriate to meet DMR’s criteria.

# MAPPING THE DMR SYSTEM OF HEALTH SUPPORTS

- Variability in the DMR nursing coverage by region. Ratio Nurse: DMR consumer ranged from 1:460 (R5) to 1:4000 (R2).
- Providers agencies may not have nursing supports
- Preventive services were identified as a neglected area across the system.

# Key Issues for DSP in Regards to Health Care Advocacy

- Knowing what to report
- Knowing who to report to
- Knowing when and how to report
- Knowing where to get help when concerns are not addressed

# Introduction of Pilot Tools

- Preventive Health Standards
- Health Status Review and Reporting Checklist
- Observation of Signs and Symptoms
- Procedure for Health Care Appointments
- Health Record
- Procedure for a Clinical Consultation
- ISP Integration and Worksheet

# Addressing Key Issues for DCP

Knowing what to  
report

- Health Status Review Checklist
- Preventive Health Standards
- Observation of Signs and Symptoms
- Procedure for Clinical Consultation
- Drug information sheets

# Addressing Key Issues for DCP (cont.)

Knowing who to  
report to

- Provider and individual specific reporting procedures
- Observation of Signs and Symptoms
- Procedure for Health Care Appointment
- Procedure for Clinical Consultation
- ISP Integration and Worksheet
- Drug information sheets

# Addressing Key Issues for DCP (cont.)

## Knowing when to report

- Provider and individual specific procedures
- Observation of Signs and Symptoms
- Preventive Health Standards
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# Addressing Key Issues for DCP (cont.)

Knowing when  
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- Provider and individual specific procedures
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- Observation of Signs and Symptoms

# Addressing Key Issues for DCP (cont.)

Knowing where  
to get help  
when concerns  
are not  
addressed

- Provider and individual specific “chain of command”
- Provider and individual specific policies and procedures
- Service Coordinator
- Procedure for Clinical Consultation
- ISP Integration and Worksheet

## PILOT STUDY

Health care tools were developed to address the identified needs

The project structure was based on the need to enhance DCP's ability to identify and report health issues to the appropriate people

## METHODOLOGY

- 15 participating provider agencies representing all regions of MA
- Range of agency characteristics: Large/small, with/without internal nursing support, rural/urban, public/private, complex/non-complex health needs
- Pilot lasted for 2.5 months
- Included 8 Health care tools, with other protocols and instructional aids.

# FEEDBACK

- Feedback surveys from direct care professionals, health care supervisors/house managers, physicians, service coordinators, area nurses
- Over 500 feedback surveys received
- 4 Regional focus groups held to elicit detailed post-hoc feedback and discuss implementation

# OVERVIEW OF PILOT TOOLS AND OUTCOMES

## Health Reporting Tools

- Health Status Review and Reporting Checklist
- Signs and Symptoms of Illness Fact sheets

## Findings

- Tools result in empowerment of DSP to identify, communicate and advocate for individuals' health needs, both immediate and preventive
- Enthusiasm around educational sheets to guide observation of signs and symptoms of illness for training new and experienced staff
- Tools proved most effective when used in preparation for advocacy and verbal communication at the health care appointment

# Annual Physical and Health Care Appointment Tools

## General Appointments:

- Physician Encounter Form
- Procedure for a Medical Appt.
- Health Record

## Annual Physicals:

- Annual Health Screening Guidelines
- Annual Physical Exam Form
- Health Status Review and Reporting Checklist

## Findings

- Annual Health Screening Guidelines assist staff to advocating for appropriate preventive health screening measures
- Endorsement of a consistent state-wide system of health care information management
- Communication of medical information most effective when staff are able to convey information verbally

# ISP

- Health care Planning Worksheet
- Health Record
- Health Status Review and Reporting Checklist

## Findings

- Use of tools resulted in an improved focus on health issues at the ISP
- Service coordinator very enthusiastic about improved health information
- Family health histories were discussed and recorded

# **BARRIERS AND CHALLENGES TO IMPLEMENTATION**

- How to balance needs of large systems with intricate internal systems against simpler, smaller programs
- Providing sufficient support for agencies who do not employ nurses
- Promoting new forms or systems to physicians
- Introduction of new forms/systems without overwhelming providers
- Establishing and maintaining an environment of continuous learning for DSP

## NEXT STEPS

- Alterations to structure and tools based upon feedback and experiences
- Enhancement of training/instruction around forms to be used
- Gradual implementation of some tools for mandatory use state-wide
- Introduction of tools for agencies needing additional support
- Work with MHQP for endorsement of standards. (Established mechanisms)

## THE BROADER PICTURE

- DMR Pilot one piece of a larger puzzle
- Targets the DSP as the most essential component of an effective health care initiative
- With a strong foundation (DSP) the right clinical support can be implemented

## OTHER INITIATIVES

⇒ Strengthening orientation and training for staff:

- Supporting healthy lifestyle
- Health care advocacy
- Re-assessing emphasis on CPR training

⇒ Supporting organizational learning:

- “Living Well” publication
- Mortality Review and Reporting
- Root Cause Analysis

## ⇒Oversight and monitoring:

- Reporting on indicators of health care quality
- Building in evaluation of providers' systems of health care oversight
- Statewide Health Care Advisory Committee