

Chapter 8: Quality Management in Self-Direction Programs

Table of Contents

A. Elements of a Quality Management System: Overview	8-1
B. Design Elements of a Quality Management Strategy	8-3
Ensuring that Service Plans Reflect Individual Needs Through Use of a Person-Centered Planning Process	8-4
Establishing Operational Policies, Procedures, and Practices	8-5
Informing Key Players of their Rights, Roles, and Responsibilities	8-6
Providing Criminal Background Checks	8-6
Managing Risk	8-7
Ensuring the Availability of Backup Services	8-8
Managing Critical Incidents	8-9
Developing Responsive and Timely Methods to Meet Changing Needs.	8-10
Providing Orientation and Training for Workers	8-10
Establishing Policies and Procedures for Participants to Return to the Traditional Agency Model—Voluntarily and Involuntarily	8-11
C. Discovery Elements	8-11
Obtaining Information from Participants	8-11
Monitoring	8-12
Critical Incident Management Systems	8-12
D. Remediation Elements	8-13
E. Improvement Elements	8-14
Systematic Collection and Review of Data.	8-14
Integrating, Analyzing, and Using Data to Improve Quality	8-14
Establishing a Quality Improvement Committee	8-15
Targeted Quality Improvement Projects	8-16
F. Overview of Federal Medicaid Requirements for HCBS Quality Management	8-17
Resources	8-19
Publications.	8-19
Web-Accessible Resources	8-21
Citations, Additional Information, and Web Addresses	8-24

Chapter 8

Quality Management in Self-Direction Programs¹

Whether a self-direction program is funded by the federal government or the state, by Medicaid or the Older Americans Act, quality has the same meaning: it is the degree to which services and supports for individuals increase the likelihood of attaining desired health and quality of life outcomes.² Many stakeholders have assumed that ensuring quality is more difficult in self-direction programs because agencies will not be supervising home care workers or protecting participants from fraud, abuse, and neglect.

The Cash & Counseling Demonstration and Evaluation (CCDE) showed that participants and their families care deeply about quality, that the programs had the same or higher quality as those using agency-delivered services, and that quality management strategies were successful *because* participants directed their own services. Successful quality management strategies in self-direction programs view participants as the experts on their services, respect the need for accountability in publicly funded programs, and place a strong emphasis on quality improvement.

Key lessons learned from existing self-direction programs are that quality assurance requires states to: (1) design quality management strategies as part of program operations, (2) provide support for participants to obtain high-quality services, and (3) use data to continually improve the program.

This chapter provides practical information about quality management elements that are relevant for *all* service delivery models; those that are unique to self-direction programs are identified as such. It also describes the key components and principles of quality management for self-direction programs. Throughout this chapter, the term *participant(s)* categorically includes representatives and families unless a distinction is being made among them.

A. Elements of a Quality Management System: Overview

The elements of a quality management system have been developed and refined for many decades beginning with concepts first articulated by Walter Shewhart and Dr. W. Edward Deming. In the 1950's, Deming proposed that business processes should be analyzed and measured through a continuous feedback loop to enable the identification of problems and changes in processes to achieve continuous improvement. To illustrate this concept, he created the “Plan, Do, Check, and Act Cycle.”

- **Plan**—Design or revise business process components to improve results

- *Do*—Implement the plan and measure its performance
- *Check*—Assess the measurements and report the results to decision makers
- *Act*—Decide on changes needed to improve the process³

While Deming’s conceptual framework was designed for business operations, it is applicable in other settings as well, including programs that provide home and community-based services (HCBS). Somewhat mirroring Deming’s work, CMS describes the primary functions of a quality management (QM) strategy as

- assessing program activity and participants’ experience to evaluate the ongoing implementation of the program,
- identifying issues and immediately addressing or remediating them, and
- improving the program based on an analysis of data and other quality monitoring information.

In a State Medicaid Directors letter dated August 2002, CMS first distributed a draft of the HCBS Quality Framework to State Medicaid Agencies.⁴ This framework applied the basic functions of quality management by using design, discovery, remediation, and improvement concepts. While CMS has modified its initial approach to quality management significantly (described further in Section B of this chapter), the original functions have become accepted standards for HCBS programs and continue to provide guidance to states as they create QM strategies. The functions are:

Design. Designing an effective QM strategy is a critical first step to ensure quality in all HCBS programs, including those with participant-directed service options. When designing a new program, however, competing demands can result in quality issues not being addressed at this stage. When this happens, quality may not be effectively addressed until participants begin receiving services and problems arise.

When an effective QM strategy is an integral part of the initial program design, that strategy lays the foundation for achieving the program’s desired outcomes. Incorporating QM activities into program policies and processes during the design—or redesign—phase will help to ensure quality during implementation and beyond. For example, having methods for obtaining participant input in program design and evaluation from the outset is a QM strategy that improves the potential for the new program to meet the needs of the target population.

The development of an organized and well-conceived program design should incorporate specific quality assurance or monitoring activities and improvement strategies into every aspect of the program’s processes and procedures. Quality assurance and monitoring activities can be incorporated into service standards,

provider qualifications, service planning processes, program eligibility processes, risk assessment and monitoring, and safeguards to protect health and welfare. It is important to remember, however, that service standards and provider qualifications for participant-directed services and supports may differ from traditional criteria.

Discovery. Discovery is the process of finding out how the program is working: Is it meeting its intended purpose? Is it operating as required by its funding source? The process includes collecting data, analyzing results, assessing performance, and identifying areas needing improvement. These activities permit assessment of the ongoing implementation of the program and associated policies and procedures. They also produce information that can be used to inform and guide management and policy development.

Remediation. Any problems identified during the discovery process are corrected during the remediation process. Remediation is problem-solving for individual situations as they arise and for system level issues. Information about persistent problems and their solutions can inform system-wide quality improvement efforts. Typically, problems are identified during the discovery process.

Improvement. Improvement is the process of using the information collected to enhance overall agency operations. Rather than focusing on one specific individual or situation, the objective of quality improvement is to modify overall program performance to ensure that system changes are made that will help to prevent reoccurrences of problems.

B. Design Elements of a Quality Management Strategy

In the traditional service delivery model, state staff and provider agencies work together to develop and implement a system of checks and balances to safeguard individuals receiving HCBS and to monitor quality. The state, in part, relies on formal provider communities to work collaboratively in developing and implementing quality management activities.

In a self-direction model, many of the responsibilities historically assumed by provider agencies and their staff are transferred to participants and counselors. For this reason, existing certifications, standards, policies, regulations, reviews, and audits that are implemented in a traditional service delivery model may no longer be applicable. In fact, the very nature of self-direction is incompatible with many traditional health and welfare safeguards. For example, strict provider qualifications may severely limit participants' ability to select the individuals they want to work for them.

Since the traditional agency providers' role in assuring and monitoring health and welfare generally is not operative in a self-direction program, or is substantially

Definitions

The terms quality assurance, quality improvement, and quality management are widely used in industry, health care, and long-term services and supports settings, but the terms have many meanings and are sometimes used interchangeably. This chapter uses the following definitions.

Quality Assurance (QA) refers to efforts to make sure that services are provided according to pre-determined standards. An example of a quality assurance activity in an agency-provided service model is licensed nurse supervision of the performance of specific tasks by a home health aide in a participant's home. In a self-direction model, participants supervise workers' performance and thus provide quality assurance.

Quality Improvement (QI) is concerned with quality assurance, but goes beyond compliance with pre-determined standards. It is an ongoing process in which an entity continually uses information to review processes and outcomes, with the goal of minimizing or eliminating defects in the service. For example, if a program wants to develop a worker registry where participants can advertise job descriptions and personal assistants can advertise availability and qualifications, the program would pilot test the registry, periodically evaluate and re-evaluate its usefulness to participants and personal assistants, and make improvements accordingly.

Quality Management (QM) refers to strategies and processes that encompass both quality assurance and quality improvement. A QM system in self-direction programs integrates a range of QM processes to measure, assess, and improve service quality, participants' outcomes, and overall program performance.

reduced through the transfer of responsibility to the participant, counselors, and financial management services (FMS) entities, states need to consider flexible and creative means to ensure quality.

The following discussion of key design elements of a quality management (QM) strategy focus on self-direction. However, all but the last one are relevant for *all* service delivery models.

Ensuring that Service Plans Reflect Individual Needs Through Use of a Person-Centered Planning Process

Self-direction programs are based on the philosophy that participants have the right and the ability to direct the process for assessing their needs, deciding how these needs will best be met, and evaluating the quality of the services they

receive. Putting this philosophy into practice has implications for many aspects of program operations.

Regardless of the service delivery option—traditional agency or self-direction—person-centered planning (PCP) should be initiated to ensure that the service plan addresses participants’ identified needs and goals. The planning process involves the participant, family members if desired, their representatives, counselors, required state staff, and other individuals participants choose. The person-centered plan becomes the “roadmap” for delivering, managing, and monitoring services. Both informal and formal methods are used as part of the PCP process to:

- identify needs and develop a plan to meet those needs;
- address key aspects of service provision;
- identify shared responsibilities, and
- identify, assess, and manage risks, and establish a backup plan.

Quality assurance activities to ensure that service plans meet assessed needs and that services are delivered in accordance with the service plan include: reviewing documentation in the case file to determine whether participants’ preferences are identified; comparing services and supports identified in the service plan with participants’ preferences; and obtaining feedback from participants on the planning process and the services they received.

Vermont’s and Florida’s self-direction programs have a participant goal setting (PGS) process to ensure that service planning is participant-centered. In this process, participants identify their personal goals, and determine—with help if needed from family members and/or counselors—which services and supports they need to help them to meet their goals. The process includes an evaluation component, which asks participants if they met the goals they identified, and, if not, whether any additional steps can be taken to assist them to meet their goals.

The follow-up also includes more structured questions about the program, such as “Do you have enough say in choosing your workers? If not, is there anything we need to do about that?” The PGS process supports the participant-centeredness of the program, and documents the involvement of participants in the planning process. A detailed discussion about collecting and using participant data is presented in Section E of this chapter.

Establishing Operational Policies, Procedures, and Practices

Policies, procedures, and practices specific to self-direction should be clearly specified to set realistic expectations and provide clear direction. These should be consistently applied throughout the program. Each of the 15 states that received Cash & Counseling (C&C) grants developed specific manuals or

operational protocols that specify the day-to-day operations of the program and clearly articulate processes and procedures. Examples of these protocols can be found on the C&C website. See the Resources section at the end of this chapter for direct links.

Informing Key Players of their Rights, Roles, and Responsibilities

Self-direction works best in an environment where the rights, roles and responsibilities of participants, family members, representatives, providers of services and supports, and state staff are clearly defined. Programs need to educate participants, representatives, and families about their rights and responsibilities. Most programs have developed an explicit “Bill of Rights” for participants and have developed charts or lists to specify roles and responsibilities. Participants should also be informed of their right to appeal decisions made by the state regarding program participation and how to file complaints. All materials should be available in a variety of alternative formats and written at an appropriate reading level.

Providing Criminal Background Checks

Typically, self-direction programs provide a mechanism for participants to obtain criminal record checks on potential workers. Many programs do not require criminal background checks when participants hire relatives or family members, but their use depends on state laws and specific program requirements. If they are not required for workers in the traditional system, states must decide whether or not to mandate their use in self-direction programs.

For example, some programs require criminal background checks only for individuals who advertise their availability as personal assistants through registries. Others require criminal background checks for all workers except family members. States that require criminal background checks must also decide whether to prohibit participants from hiring anyone with a criminal record or to designate the circumstances under which someone with a record may or may not be employed (e.g., making distinctions between misdemeanors and felonies as well as between recent crimes and those committed many years ago).

Support should be available to help participants understand and analyze the background check results to determine if findings are significant relative to the services that the worker will provide and if the potential worker poses a risk.

States must also decide whether criminal background checks will be conducted on a state, regional, or national level. Usually the cost and time to conduct the search increases as the scope of the search broadens. Programs may also consider implementing an abuse registry that participants can check before they hire a worker.

Managing Risk

Managing risk is a process that (1) assesses participants' exposure to potentially harmful situations and (2) develops a plan to prevent such exposure and to address it quickly if it occurs. It is a key component of an overall quality management strategy.⁵ A risk assessment is generally conducted as part of the needs assessment and service planning process. Requiring that risk assessment be part of service planning is an example of how states can design their programs to include policies and processes that help to ensure health and welfare.

A standardized risk assessment process is preferable and many tools are available, which can be modified as needed. One example is New Jersey's Personal Preference Program Risk Assessment Profile. This instrument collects information about an individual's environment, functional limitations, mental status, ability to communicate, and other characteristics that expose him or her to harmful or potentially harmful situations.

Each assessment area is assigned points based on the degree of risk (i.e., the likelihood of a potentially harmful situation occurring). The score can be reduced by risk reduction factors such as having a live-in caregiver or friends and relatives nearby. Once the final score is calculated—risks minus reduction factors—a plan to address remaining risks is developed. See the Resources section at the end of this chapter for information about risk assessment tools.

Once risks are identified, an individualized strategy to prevent or reduce risk should be developed. If the major risk is that a scheduled worker will not show up, then the backup plan (discussed below) becomes part of the risk management strategy. Developing such a strategy should be part of service planning for all participants, whether in the traditional or self-directed services system. In both systems, risk management strategies must be complemented by periodic and ongoing monitoring processes to determine if they are working at the individual and/or system levels.

Monitoring can take many different forms. Programs can and do use their existing quality monitoring staff—as long as training is conducted on self-direction—to oversee the performance of providers unique to self-direction, such as participant-directed workers, counselors, and FMS entities. They also may identify other staff or techniques to conduct monitoring activities. States also may require counselors or traditional case managers to assume quality oversight responsibilities to ensure that participants are receiving authorized services and that these services are adequate to meet their needs.

Components of a Risk Management System

- Develop specific program policies and procedures clearly outlining roles and responsibilities of participants, case managers and/or counselors, state support staff, and participants' workers.
- Develop a process to formally identify situations that could pose harm and assess the likelihood of their occurrence (e.g., a worker not arriving on time to administer medications).
- Discuss these potential situations with participants.
- Develop a plan to reduce or eliminate the possibility that these situations could occur and a backup plan to prevent harm should they occur.
- Ensure that a process is in place to protect participants' right to assume risk and honor their decisions.
- Monitor the service plan to ensure health and welfare.

Ensuring the Availability of Backup Services

Every participant receiving HCBS—whether through the traditional agency system or a self-direction program—should have an individual backup plan to handle situations when providers of services and supports that are essential to participants' health and welfare become unavailable.

Typically, programs create this backup process as a function of the person-centered planning process during the development of the service plan—which should include a risk assessment process. An individual's service plan should identify issues or situations that jeopardize health and welfare and specify actions to prevent and/or correct them. All participants should be educated about the availability of backup resources.

Even though a worker may have a legitimate reason for not arriving, such as illness or a childcare crisis, the consequences of worker tardiness or absenteeism can be more than merely inconvenient for some participants. In addition—although comparatively infrequent—serious situations can arise when a worker quits without giving notice.

Participants' service plans need to include individualized strategies to deal with such situations should they occur, and to prevent and lessen risks whenever possible. Not only do participants need to have already identified backup workers or agency providers that they can call for assistance, they must also have a means of summoning assistance. The latter can be especially problematic for participants with certain types of impairments, such as quadriplegia.

Components of a Comprehensive Backup Plan

- Identifies circumstances that could lead to harm if not addressed.
- Provides detailed procedures for obtaining backup support and services.
- Provides detailed procedures for obtaining assistance during an emergency or a crisis or if the backup plan fails.

Potential strategies for addressing such critical situations include purchasing a personal emergency response system (PERS) or a voice-activated telephone to enable a participant with a severe mobility impairment to summon help in the event of an emergency, arranging for a neighbor or a friend who lives nearby to serve as a backup until another worker arrives or another can be found, or both. Some participants are able to rely on family and friends to fill in whenever their worker is absent. For others who lack sufficient family support, the backup plan might include a prearranged plan with a traditional agency to provide emergency assistance or the use of a worker registry to obtain immediate access to workers.

If the backup plan includes hiring alternate workers, all of their payroll paperwork must be on file in advance. Also, having generic terms in the individualized budget (e.g., the number of hours of assistance from a worker, rather than naming a specific worker) makes it easier to handle day-to-day changes while keeping the service plan intact. The effectiveness of backup plans should be tested periodically and changes made as needed. See Chapter 9 for a discussion of concerns about health and safety risks and liability for poor health outcomes.

Managing Critical Incidents

Critical incidents include (1) abuse, neglect, and/or exploitation; (2) unexpected or frequent hospitalizations; (3) deaths;⁶ (4) serious injuries that require medical intervention or result in hospitalization; (5) medication errors; (6) inappropriate use of restraints; and (7) other incidents or events that involve harm or risk of harm to participants.

Reports of abuse, neglect, and/or exploitation by participant-directed workers in the CCDE were extremely low. Similarly, in a study comparing the experiences of California In-Home Support Services participants who employed their own workers with those who used agency services, reports of abuse, neglect, and mistreatment were very low for both groups.⁷

To ensure participants' health and welfare, states need to have a system for timely identification and remediation of critical incidents. States must have a designated entity with the responsibility and authority to take whatever actions are needed to

resolve and remedy critical incidents and prevent recurrences.

For such a system to be effective, participants and their employees need to be educated about the risk of critical incidents and what to do when one occurs. The program must ensure that everyone who has contact with participants—counselors, service and support providers, and anyone else responsible for quality monitoring—are trained to know what steps to take if they identify or suspect that abuse, neglect, and/or exploitation is occurring. Everyone involved in the program must have contact information for the entity charged with investigating and remediating critical incidents, and service providers—including participant-hired workers—must understand their legal responsibility to report such incidents.

Because critical incident reporting ultimately depends on the willingness of participants to report incidents whose occurrence may be known only to them, it is vital for states to establish policies and procedures for incident reporting that will encourage reporting and make participants feel safe doing so.

Developing Responsive and Timely Methods to Meet Changing Needs

In the traditional agency-delivered service model, when participants can no longer meet their needs with the allocated resources, the provider generally identifies and reports the increased need. In a self-direction program, participants have primary responsibility for reporting changed circumstances and increased needs to the appropriate person or agency—especially during the periods between regularly scheduled meetings with their counselor.

States need to establish a process for revising service plans and individual budgets in a timely manner to ensure that participants' needs are met.

Providing Orientation and Training for Workers

Participants—with assistance from individuals or agencies providing supportive services when needed—assume the role of orienting new workers. They need to ensure that workers understand their duties and how to interact with them. Participants also negotiate the workers' work schedule and—in some programs—their wages.

States may also require a standard orientation for all new workers (e.g., one that discusses basic principles of hygiene and safety and provides information on how to identify and report instances of abuse, neglect, or exploitation). Community educational opportunities such as courses offered by the American Red Cross should also be considered as resources.

Most participants need personal care workers to assist them with activities of daily living and homemaker activities. In many instances, this work requires minimal training and participants often are fully capable of providing it. If special

skills or knowledge are required, states need to have policies and procedures regarding who will provide the necessary training; for documenting that appropriate training has been provided; and for ensuring that workers demonstrate the ability to perform required tasks before being hired or before they are allowed to perform them independently.

Establishing Policies and Procedures for Participants to Return to the Traditional Agency Model— Voluntarily and Involuntarily

Successful self-direction requires participants to assume responsibility for multiple tasks with support and assistance as needed. When participants are not able to handle these responsibilities, states need efficient policies and procedures to enable participants to either return to the traditional agency-directed model, or to change to a mixed model in which they continue to direct some services and receive others from an agency. Policies and procedures are needed for both voluntary and involuntary transitions.

C. Discovery Elements

Discovery is the process of identifying which aspects of a program are working well and which need improvement. The discovery process has three key elements—obtaining information from participants, monitoring, and critical incident management systems.

Obtaining Information from Participants

Accurate and timely feedback from participants is the foundation of any QM strategy. Without an effective and reliable mechanism to obtain participants' feedback, programs will be unable to fully assess their performance in order to develop improvement strategies. States have many different options for seeking participant feedback, including telephone interviews, in-person interviews, and mailed surveys. For simplicity, in this section we refer to the general process of seeking formal input from participants as a survey.

States need to consider several factors when developing and implementing a participant survey. First and foremost, the purpose of the survey should be explicit. Establishing clear objectives regarding the content of the survey, why it is being conducted, and how the information will be used is the first step, and will have an impact on every other decision about what kind of participant survey process to implement. It is important to ask probing questions about the level of satisfaction with participants' supports (e.g., are they satisfied with their counselors and the FMS entity?).

Several standardized instruments are available to assess participants' experiences and satisfaction with self-directed services. Other measures ask about outcomes, or seek feedback about a specific aspect of the program. Available instruments

include the Participant Experience Survey (PES), the Participant Goal Setting instrument (PGS), the National Core Indicators, and a host of state and agency participant satisfaction surveys. See the Resources section at the end of this chapter for links to more information about these instruments.

Each of these instruments may have a slightly different focus and may ask questions in different ways. Once the purpose of the participant survey is decided, the ways in which the data will be used, and by whom, should be specified.

Additional decisions about the participant survey process include: (1) whether to survey the entire population of participants, or to select a sample; (2) which data collection strategy to use; (3) which strategies to use to include participants in the development of the survey tool; (4) who should collect the data; and, (5) how to analyze, report, and use the data. Many different approaches are possible—each with advantages and disadvantages—and states need to assess which will work best in their program.

Other means of obtaining participant feedback include the use of focus groups, public forums, telephone contacts, complaint lines, and comments expressed directly to the program staff.

Monitoring

Comprehensive QM strategies implement more than one level of monitoring. The specific staff involved will depend on whether participants direct their services as well as other program features. States can employ case managers, counselors, FMS providers, state QA staff, or all or some combination of these individuals. States may also use family and peer monitoring and/or advocacy agencies, such as family council organizations as adjuncts to the state monitoring system. All individuals and organizations charged with monitoring should be formally trained in person-centered planning and the philosophy of self-direction.

Critical Incident Management Systems

While critical incident management is described above as a program design element, the focus in this section is more on state systems for collecting and analyzing data on critical incidents. When the health or welfare of a participant has been jeopardized, local and state program administrators must have a system for gathering timely information and tracking the remediation of identified problems. Often these systems are called “Incident Reporting” or “Critical Event Tracking Systems.”

Several state waiver programs have developed automated reporting and tracking systems that provide virtually real-time information on critical events, including the status of the event, how it is being addressed, and by whom. Automating the collection of these data allows for analyses of patterns, such as the characteristics

of persons at risk, categories of critical events, and types of alleged perpetrators.

This information can be used to identify specific areas that should be targeted for quality improvement initiatives. For example, if several individuals experience the same type of incident—such as a fall or the failure of a backup plan—then there may be an underlying common problem that can be identified and addressed through quality improvement. (See discussion of remediation and improvement below). By identifying trends, the system could then help the state determine if a specific QI initiative is having the intended effect.

Over the years, many states have developed systems to report and address critical incidents. Often, the hub of these systems is the state’s Adult Protective Services (APS) Unit or the State Offices on Aging, although they often reside outside the administering agency for HCBS programs and are responsible for addressing the needs of all vulnerable adults, not just public program participants.

Because managing critical events or incidents is a pivotal function in the administration of any HCBS program, CMS encourages states to build on existing systems to improve their emergency response capacity. However, at the same time, states need to have a critical incident management system to handle critical incidents specifically for HCBS program participants.

D. Remediation Elements

The remediation process involves activities to solve specific problems as they arise as well as system level problems. The process provides information about persistent problems as well as effective solutions to address these problems. Once a problem with the quality of services or supports comes to the attention of administrators, it must be addressed and rectified as quickly as possible to protect participants, especially those in immediate jeopardy.

Remediation efforts can include educating or helping participants to deal with the problem themselves or intervening on their behalf. As remediation proceeds, an evaluation or investigation of the situation is usually warranted to determine the factors that contributed to the problem. The key elements of a remediation strategy are:

- A quick response to protect participants
- Evaluation or investigation of the situation
- Communication with appropriate entities
- Actions to prevent additional occurrences

Once there is an understanding of causative and contributing factors, then a plan can be devised to prevent similar problems from occurring in the future—not

just for a single participant but for others as well, particularly those in similar circumstances.

E. Improvement Elements

Improvement involves using the information collected to enhance overall agency operations. Rather than focusing on specific participants' problems, quality improvement (QI) activities focus on the program as a whole. Four broad and interrelated strategies are available for doing so—systematic collection and review of data; integrating, analyzing and using data to improve quality; establishing a quality improvement committee; and developing targeted quality improvement projects.

Systematic Collection and Review of Data

The systematic collection and review of data is the crucial first step not just in the discovery process (discussed above) but also in the improvement process because a program cannot be improved without knowing where improvements are needed. Data are essential for understanding a program's problems, issues, and patterns, and for targeting areas where changes would be beneficial. While anecdotal information can be illuminating, effective quality improvement relies on a well-established mechanism for obtaining data on participants' experiences and integrating these data with other information collected, such as results of participant experience surveys or assessments of participant under- or over-spending.

Integrating, Analyzing, and Using Data to Improve Quality

The ability to use data to improve a program is a critical QI principle. While programs have progressed in their ability to collect data needed for QI activities, many do not have the means to integrate, analyze, and use data to actually improve program performance. In order to use data, programs need a mechanism for entering and analyzing the information collected. Although data entry is not difficult, it requires a routine method for recording information. For example, one self-direction program kept a detailed log of critical incidents for several years and was diligent about responding to each problem as it arose. But it never systematically looked at the array of incidents to see if there were common problems that might have been prevented with a systemic solution.

Participant satisfaction surveys typically have more complicated data entry challenges. There are a number of options available for facilitating data entry such as the use of scannable forms, direct entry on lap top computers, and web-based tools. Whatever the option, it is important for programs to think carefully about the data entry approach prior to data collection.

Once data are entered, programs need to have a mechanism to analyze the information. The program may need to partner with a research unit or develop internal capabilities. Changes in computer technology and software have made internal efforts more feasible, but staff time and expertise are still required.

In the analysis phase, programs can ask questions about how the results can be used to improve program quality. See the box below for examples on how information can lead to program improvement.

Using Data to Improve a Program

Case 1. A self-direction program that collected systematic information on critical incident reports found that falls were the most common problem recorded, accounting for almost half of all incidents. In response, the program developed and implemented a falls prevention program. In the initial analysis, it was determined that the falls prevention program had some success. However, the program managers decided to conduct a more in-depth review of the data. During a second round of analysis the program identified more detailed information about individuals most at risk of falling. Based on this data, the program developed a more intensive prevention program for this group and is now collecting follow-up data to assess its effectiveness.

Case 2. An area agency on aging (AAA) that administers a self-direction program has its case managers collect satisfaction data from all participants in both the traditional and self-directed services options. The case managers collected satisfaction data on the five home-delivered meals providers in the service area. A surprising finding was that the provider that had been considered the best because of high scores on food quality, scored very low on delivery reliability. When the AAA consulted the meals provider, it found that the provider used a large number of volunteers to make deliveries. Because the schedule was typically set based on volunteer availability, delivery times varied considerably throughout the week. Bringing this problem to the attention of the meals provider led to improvements. The following year, the provider received higher reliability scores from participants.

Establishing a Quality Improvement Committee

A Quality Improvement Committee comprising a wide range of program stakeholders can help states improve program quality for two reasons. First, program staff members typically focus on their program roles or responsibilities, without necessarily seeing how separate units intersect, overlap, and duplicate or contradict each other. A committee that involves key program stakeholders provides a mechanism to ensure that quality is viewed from all perspectives,

facilitates consensus on improvement strategies, and maximizes buy-in for the strategies devised to address identified problems. Second, a committee focused on quality improvement is advantageous because it creates a group with the authority to continually challenge the administering agency to improve the program.

To ensure a committee's effectiveness, states need to carefully consider its composition, responsibilities, and the need for training and support. A committee of between eight and twelve members is a workable size. These members should represent the full range of program stakeholders. Core members should include participants and their representatives, program staff, counselors, FMS staff, community advocates, and other state officials. Additional or ad hoc appointees should be added to the committee based on the need for expertise to address specific topics.

Committee responsibility must be clearly articulated at the beginning. Reaching consensus on the scope of responsibility and the time frame for committee activities is a critical first step. In order to be an effective part of the QM strategy, members must have a clear idea about how the committee fits within the overall QM strategy and the extent of their authority.

Training and support are essential to committee success to ensure that all members have the information needed to be active and effective. Resources to support travel costs are essential and a stipend to compensate members for their time makes an important statement about the value of their activities. The committee also needs assistance from program staff to organize and implement activities by producing accessible documents and ensuring meeting space is accessible. Staff members who are asked to allocate time to support committee work should have this specified in their job responsibilities.

The committee should have an opportunity to (1) routinely review data and reports on program performance, (2) hear and comment on how the program intends to use this information to improve quality, and (3) recommend improvement strategies. Although committee members may occasionally become involved in a specific quality improvement project, the committee's primary charge is to be responsible for the program's overall quality vision and strategy.

Targeted Quality Improvement Projects

A quality improvement project that employs an in-depth examination of one problematic aspect of a program is one avenue for improving the quality of the program across the board. Often quality improvement projects are designed as pilot projects and may be restricted geographically or by some other criteria. Following a thorough review of data and stakeholder input regarding the various factors that contributed to a specific problem, a strategy may be developed to alleviate the problem by applying specific interventions.

The strategy might outline proposed changes, data collection methods, anticipated effects, measurable outcomes, and timelines for evaluation. Program changes should be tracked to determine if the modifications implemented have had the intended beneficial effects. If so, the modifications may be adopted. If not, other strategies should be considered to address the problem. It may be necessary to undertake a targeted data collection effort to measure the impact of the intervention. Once the results of a pilot project have been reviewed and the impact of the intervention assessed, the Quality Improvement Committee may decide to recommend that the strategy be implemented more broadly or applied system-wide.

The design of a program's QM strategy might require quality improvement projects at all levels of program administration and delivery. In self-direction programs, these activities might be contractually negotiated with counselors and FMS providers or managed by state staff or case managers. Collectively a state's discovery, remediation, and improvement strategies should create an ongoing circular flow of data and feedback to keep participants, other stakeholders, and the administering agency informed about the overall operation of the system and its component parts.

F. Overview of Federal Medicaid Requirements for HCBS Quality Management

In early the 2000's, CMS developed an HCBS Quality Framework to guide quality management in Medicaid HCBS waiver programs.⁸ The framework was developed with broad input from multiple stakeholders and with the collaboration of the National Association of State Medicaid Directors, the National Association of State Units on Aging, and the National Association of State Developmental Disability Directors. While CMS has not required states to use the framework, it is an excellent tool to guide the development of—or serve as a foundation for—a QM strategy in their self-direction programs. Additional information about the framework may be obtained at <http://www.hcbs.org/moreInfo.php/doc/952>.

CMS has strengthened its commitment over the past few years to improve the overall quality of services provided to Medicaid participants and to clarify federal requirements and their relationship to assurances states must provide regarding quality. CMS requires states to have systems in place to maximize the quality of life, functional independence, and well-being of participants in Medicaid HCBS programs.

While requirements vary by statutory authority—§1915(c), §1915(i), and §1915(j)—at a minimum, states must have systems in place to measure and improve their performance to ensure that:

- Service plans (plans of care) reflect individual needs

- Qualified providers meet state requirements
- Participant health and welfare are maintained
- The state Medicaid agency retains overall administrative authority and oversight of the program
- States operate their programs with financial accountability

Each authority—waiver or State Plan option—specifies required assurances that states must provide and furnishes guidance to states for describing their quality management strategies in detail, including discovery, remediation, and improvement activities. Generally, states are required to describe the

- Roles and responsibilities of entities and persons involved in collecting and analyzing information pertaining to quality and oversight
- Type, source, and frequency of data collected
- Activities to correct problems identified through the discovery process
- Strategies to enhance and improve program performance

CMS provides technical assistance to state programs to help them match quality requirements for HCBS services (under §1915(c), §1915(i), and §1915(j) authorities) to Medicaid statutory assurances, and to focus on continuous quality improvement. To aid states with their quality management plans, CMS asks programs to articulate quality improvement strategies by specifying: (1) performance measures, including those specific to self-direction; (2) data sources to collect information on the performance measures; (3) parties responsible for data collection/analysis; (4) frequency of data collection; and (5) sampling approaches.

An example of a program performance measure is the number and percentage of applicants and participants whose case files document that a choice was made between traditional services and self-directed services. The data sources are applicants and participants' files; the parties responsible for collecting and analyzing the data are the Medicaid state agency staff; the frequency is every two years; and a representative sampling approach is used.

States must provide this information when applying for or renewing a waiver program or applying for a State Plan amendment.

Resources

Publications

Applebaum, R., Schneider, B., Kunkel, S., and Davis, S. (2004). *A Guide to Quality in Consumer Directed Service*. Prepared by Scripps Gerontology Center, Miami University for USDHHS, Assistant Secretary for Planning and Evaluation.

This publication is based on a philosophy that the views of the major program stakeholders—consumers, families, program staff, regulators, funders—are the necessary starting point for the design of a quality system. A practical handbook on ensuring and improving the quality of services, it provides a detailed guide for self-direction programs as they work to establish a quality management system.

Available at: <http://www.cashandcounseling.org/resources/20060111-143548>

Centers for Medicare & Medicaid Services. (2008). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, Technical Guide and Review Criteria*. Baltimore, MD: USDHHS.

This publication contains extensive information concerning federal policies that apply to the operation of an HCBS waiver, including incorporating self-direction into the delivery of waiver services. The Version 3.5 application contains substantive changes to the Version 3.4 application in the area of quality, and contains minor, clarifying improvements throughout the document in other areas.

Available as “Version 3.5 Instructions Final 2.1.2008”, a part of the 1915(c) Waiver Application and Accompanying Materials under links and downloads at: <https://www.hcbswaivers.net/CMS/faces/portal.jsp>

Foster, L., Dale, S., Brown, R., Phillips, B., Schore, J., & Lepidus Carlson, B. (2004). *Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities?* Prepared by Mathematica Policy Research, Inc., for USDHHS, Assistant Secretary for Planning and Evaluation.

This study of Florida’s Cash & Counseling demonstration program, Consumer Directed Care, compares children’s use of services and quality of care under traditional versus participant-directed approaches to Medicaid HCBS.

Available at: <http://www.cashandcounseling.org/resources/20060120-102143>

Fralich, J., Booth, M., & Keith, R. (2006). *Data Quality and Analysis: Managing and Using Home and Community-Based Services Data for Quality Improvement*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This report describes the activities needed by programs to analyze and use data for quality management activities. It is important for a program manager to understand

the process and to provide the time and resources necessary to produce reliable and accurate data. The paper focuses on ways to ensure accuracy, discusses tools for analyzing trends and patterns, and provides tips on interpreting results.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1555>

Fralich, J., Booth, M., Gray, C., Bowe, T., & Bratesman, S. (2005). *Discovery Methods for Remediation and Quality Improvement in Home and Community-Based Services*. New Brunswick, NJ: Rutgers Center for State Health Policy & National Academy for State Health Policy: Community Living Exchange.

This paper synthesizes the ideas and practices of states as they seek to improve the quality of HCBS services. The purpose of this paper is: to promote the exchange of information among states regarding the use of discovery methods for HCBS services; to identify and share the various approaches that states are using to identify gaps, redundancies, strengths and weaknesses in their HCBS quality systems; and to discuss ways to prioritize activities and select quality improvement activities.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1253>

Freedman, R. & Taub, S. (2006). *Sampling: A Practical Guide for Quality Management in Home and Community Based Waiver Programs*. Produced for CMS by the National Quality Contractors, MEDSTAT Group and Human Services Research Institute.

This report provides advice when a program needs to select a sample of participants as part of its quality management strategy. It provide states with practical information about sampling techniques, what to consider when deciding whether to sample, and the strategies to employ in quality management work.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1552>

Galantowicz, S., Selig, B., Pell, E., & Rowe, J. (2005). *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement*. Produced for CMS by the National Quality Contractors, MEDSTAT Group, and Human Services Research Institute.

This publication contains an excellent overview of risk assessment and mitigation and identifies many useful resources, including risk assessment tools.

Available at: <http://www.cms.hhs.gov/HCBS/downloads/qualityriskmgmt.pdf>

Mahoney, K.J., Simone, K., & Simon-Rusinowitz, L. (2000). Early lessons from the Cash & Counseling Demonstration and Evaluation. Reprinted with permission from *Generations* (2004), Vol. 24 (1), 41–46.

The article provides an overview of the implementation of the Cash & Counseling program and discusses early lessons learned. The implementation lessons are

divided into categories pertaining to the different aspects of the program: program design, outreach, counseling issues, fiscal intermediary, and monitoring quality.

Available at: <http://www.cashandcounseling.org/resources/20051202-175625>

Simon-Rusinowitz, L., Loughlin, D., & Mahoney, K. (2006). *Do Consumers get Good Quality Care in a Consumer-Directed Program? Experience from the Cash & Counseling Demonstration and Evaluation*. Boston, MA: Cash & Counseling National Program Office.

This article discusses the quality of care received by participants in the Cash & Counseling Demonstration and Evaluation, including health outcomes, the potential for fraud and abuse, and participant satisfaction.

Available at: <http://www.cashandcounseling.org/resources/20080111-144811>

Web-Accessible Resources

Cash & Counseling National Program Office

Web-address: <http://www.cashandcounseling.org/>

This web-site contains several resources on quality and self-direction, for example:

Quality Crosswalk Table with the Required Waiver Assurances authored by Barbara Scheinder is a summary of nine quality initiatives, followed by a crosswalk between the required Medicaid assurances, the HCBS quality framework, and quality initiatives and tools relevant to implementing the quality framework in Cash & Counseling programs. Available at: <http://www.cashandcounseling.org/resources/20060111-144320>

Expansion of the Cash & Counseling Demonstration, Performance Indicators: Report Shells and Instructions. During the second round of C&C grants, the C&C National Program Office developed a list of performance indicators for the twelve C&C replication grantees to track how well their programs were doing. This document contains report shells and instructions for the Cash & Counseling replication project. Available at: <http://www.cashandcounseling.org/resources/20070604-123348>

Participant Goal Setting Tool. This tool was developed by Scripps Gerontology Center to help participants in Cash & Counseling programs set personal goals. The tool's three major objectives are: to provide a structured process to ensure that the participants' goals are clearly articulated and that the spending plan represents their needs and wishes; to ensure and improve quality at the individual level; and to use data collected for quality improvement at the program level. Available at: <http://www.cashandcounseling.org/resources/20080303-130304>

Centers for Medicare and Medicaid Services

Web-site address: <http://www.cms.hhs.gov/HCBS/>

The website provides an overview of quality and links to additional information about quality and HCBS, in particular:

Quality Oversight at http://www.cms.hhs.gov/HCBS/05_Quality_Oversight.asp#TopOfPage and

CMS Communications at http://www.cms.hhs.gov/HCBS/04_CMSCommunications.asp#TopOfPage

Clearinghouse for Home and Community Based Services

Web-address: <http://www.hcbs.org/>

This website is the repository for wide-ranging resources concerning state efforts to expand the delivery of HCBS for people of all ages with disabilities. The site has several publications and resources regarding the quality of services in HCBS generally and in self-direction programs specifically. For example:

CMS State Medicaid Directors Letter: Risk Management and Quality in HCBS is one of a series of quality letters and progress reports. This, the eighth letter, addresses the interrelated steps for successful risk management for individuals in HCBS waivers.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1151>

Home and Community-Based Services: Quality Management Roles and Responsibilities is the first in a series of papers from Rutgers Center for State Health Policy synthesizing the ideas and practices of states as they improve the quality of HCBS and supports for older persons and persons with disabilities.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1132>

Measuring Consumer Outcomes and Satisfaction in California: Identifying a Survey to Provide a Foundation for Quality Management. Included in the report are a comparative review of consumer satisfaction survey instruments considered for use and an analysis of California's information system with respect to the requirements of participation in National Core Indicators.

Available at: <http://www.hcbs.org/moreInfo.php/doc/1808>

Negotiated Risk Agreements in Long-Term Support Services. This article evaluates the potential for using negotiated risk contracts in consumer-directed home and community-based long-term services and supports.

Available at: <http://www.hcbs.org/moreInfo.php/doc/144>

Participant Experience Survey (PES) Tools. The PES is an interview tool developed by MEDSTAT under a contract from CMS. The surveys capture data that can be used to calculate indicators for monitoring quality within the waiver programs. Two versions of the PES are included, one for frail elderly and adults

with physical disabilities and another for adults with MR/DD. A users' guide accompanies each PES. Each survey can be conducted in a face-to-face interview in 30 minutes or less.

Available at: <http://www.hcbs.org/moreInfo.php/doc/652>

State Satisfaction Surveys. This site provides a number of reports by states that generally contain their survey tool, methodology, findings, and recommendations to improve satisfaction among key stakeholder groups. (Search for Keyword: Stakeholder Involvement—Type/Tool: Survey)

Available at: <http://www.hcbs.org/advancedSearch.php>

National Core Indicators

Web-site address: <http://www.hsri.org/nci/>

The National Core Indicators (NCI) is a collaboration among participating National Association of State Directors of Developmental Disability Services member state agencies, and the Human Services Research Institute, with the goal of developing a systematic approach to performance and outcome measurement. The website provides access to reports that describe NCI activities, methods, and results of data collection. Final or summary reports describe methods and present results for a particular set of indicators or survey tool (e.g., consumer outcomes, family surveys, provider survey).

Citations, Additional Information, and Web Addresses

- 1 Suzanne Crisp, Robert Applebaum, Suzanne Kunkel, and Janet O’Keeffe co-authored this chapter, which is based on a draft technical guide chapter developed in 2004 by Beth Jackson and Suzanne Crisp, Thomson Healthcare, under contract to CMS.
- 2 Quality Overview. May be accessed at www.cms.hhs.gov/HCBS/
- 3 <http://www.balancedscorecard.org/TheDemingCycle/tabid/112/Default.aspx>
- 4 CMS Center for Medicaid and State Operations, Disabled and Elderly Health Programs Group (August 29, 2002). *Quality in Home and Community-Based Services: The Quality Matrix and Framework*. Letter to State Medicaid Directors. Available at <http://www.hcbs.org/moreInfo.php/doc/952>.
- 5 Galantowicz, S., Selig, B., Pell, E., and Rowe, J. (2005). *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement*. Prepared for CMS by the MEDSTAT Group and Human Services Research Institute.
- 6 While all deaths may need to be reported as part of a critical incident management system, when serving an elderly population—some of whom are terminally ill—some deaths will be expected and will not require an in-depth investigation once the facts surrounding the death are known.
- 7 In multivariate models that controlled for risk factors such as level of disability, there were no statistically significant differences in reports of abuse, neglect, or mistreatment by self-directing participants as compared to those receiving agency-delivered, professionally supervised aide services. However, there were some statistically significant differences indicative of lower reported incidents of abuse, neglect, and mistreatment when aides were family members rather than un-related individuals (regardless of whether the unrelated aides were participant-directed or agency employees). Matthias, R. & Benjamin, A.E. (2003). Abuse and neglect of clients in agency-based and consumer-directed home care. *Health and Social Work*, 28 (3): 174.
- 8 CMS Center for Medicaid and State Operations. (August 29, 2002). Op. cit.