Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs

Prepared for:

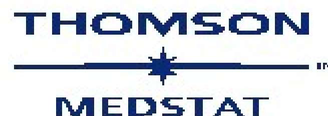
U.S. Department of Health and Human Services
Centers for Medicare and Medicaid Services
Disabled and Elderly Health Programs Group

January 12, 2004

Prepared by:

Gary Smith
Human Services Research Institute

Beth Jackson
The MEDSTAT Group, Inc.



8100 SW Nyberg Road, Suite 205
Tualatin OR 97062

125 CambridgePark Drive
Cambridge MA 02140

Contract No. 500-96-0006 T.O. #2

Table of Contents

I. Background……………………………………………………..……………1
II. National Quality Inventory Project……………………….…………..………….2
III. National Quality Inventory Survey……………………………..………….6
IV. Survey Results……………………………………………………..….……..10
A. Survey Results: Quality Framework Focus Areas……………..………11
B: Survey Results: Other Survey Topics………………………………..18
V. Discussion of Results……………………………………………………….20
VI. Recommended CMS Follow-Up Actions…………………………………22

Attachment: HCBS Quality Framework

Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs

I. Background

The HCBS waiver program supports more than 700,000 older persons and individuals with disabilities to remain in their communities

Prior to 1981, Medicaid expenditures for persons who required long-term services or supports were essentially made for institutional care provided through nursing facilities or Intermediate Care Facilities for the Mentally Retarded (ICF/MR). While a limited home health benefit was available as a mandatory Medicaid state plan service, total expenditures for community-based home health accounted only for 4% of total Medicaid long-term services expenditures. In 1981 Congress enacted the Home and Community-Based Services (HCBS) waiver program through the creation of §1915(c) of the Social Security Act to provide a community alternative to serving eligible persons in an institution, defined as a hospital, nursing facility, or ICF/MR. This program assists more than 700,000 older persons and individuals with disabilities to remain in their communities and avoid institutionalization. HCBS waiver programs provide diverse and innovative services that effectively support program participants in their homes and elsewhere in the community. States have greatly expanded the role that the HCBS waiver program plays in serving Medicaid beneficiaries who require long-term services and supports. State and federal HCBS waiver program expenditures increased from $8.2 billion to $ 16.3 billion between 1997 and 2002.[1]

There are now more than 275 waiver programs that serve diverse populations

Nationwide, there are now more than 275 waiver programs in operation. These programs serve diverse populations, including (among others) older persons, individuals with developmental disabilities, younger adults with physical and other disabilities, children with serious emotional disturbances, persons who have HIV/AIDS, individuals who have experienced an acquired brain injury and medically fragile children. In light of the diversity of waiver target populations, it is not surprising that the services furnished through waiver programs vary considerably. In addition, it is important to keep in mind that waiver services complement and supplement Medicaid state plan services. An important strength of the HCBS waiver program is the flexibility

[1] Eiken, S. and Burwell B. *Medicaid HCBS Waiver Expenditures, FY 1997 through FY 2002*. Medstat, May 15, 2003

that it affords states to craft services to address diverse participant needs and align these services with the provision of Medicaid state plan services as well as other state and locally-funded services. Moreover, participants are served through local/regional service systems and provider networks that differ from state-to-state and by target population. Although all waiver programs operate under the same federal statutory and regulatory framework, their configuration varies considerably by target population and state.

HCBS waiver service delivery networks are complex

By their very nature, waiver services are furnished at widely dispersed sites throughout the community. Moreover, HCBS waiver service delivery networks are complex. They typically include state and local public agencies, large and small private-sector provider organizations, case managers, individual personal assistants and attendants, clinicians, and, increasingly, neighbors and other community members who support individuals. Maintaining and improving quality in highly dispersed and diverse service delivery environments while also maintaining flexibility and a focus on the needs of each person is a challenge.

CMS in collaboration with its state partners has devoted increased attention to strengthening and improving waiver quality assurance

Recognizing the central role that the HCBS waiver program now plays in supporting Medicaid beneficiaries, CMS in collaboration with its state partners has devoted increased attention to strengthening and improving waiver quality assurance and improvement (QA/I). Some CMS initiatives along these lines have included: (a) developing and implementing a comprehensive Protocol to guide CMS Regional Office review of state waiver programs; (b) making direct technical assistance available to states to strengthen their QA/I systems; (c) launching the Promising Practices project to spotlight innovative state strategies in the provision of home and community services; (d) earmarking 2003 Real Choices grant dollars to assist states to make critical investments in QA/I; and, (e) the distribution of quality tools for states, including the Participant Experience Survey and Quality Workbook.

In 2001, CMS in collaboration with state agency associations initiated the National Quality Inventory Project (NQIP) in order to obtain baseline information about state HCBS waiver program QA/I systems. Through this project, an extensive survey of state QA/I systems was conducted. This report describes NQIP. It summarizes and discusses the results of this first-time, nationwide systematic survey of state waiver program QA/I systems. The report also includes recommendations for CMS follow-up.

II. National Quality Inventory Project

Purpose

The purpose of NQIP was to compile systematic baseline information concerning state HCBS waiver QA/I systems

The principal purpose of the National Quality Inventory Project (NQIP) was to compile systematic ***baseline*** information concerning state QA/I systems for Medicaid HCBS waiver programs. Heretofore, such information was not available to CMS or elsewhere because, in part, states have not been required to fully describe their QA/I systems in their waiver applications. A clear understanding of the design, operation and capabilities of state systems is vital in order for CMS and its state partners to identify effective near and longer-term strategies to strengthen HCBS waiver QA/I. Another important project objective was to identify potential opportunities for federal agency, state association and other types of technical assistance to states.

Project Organization

NQIP partners are CMS, NASUA, and NASDDDS

NQIP is sponsored by the CMS Center for Medicaid and State Operations (CMSO) Disabled and Elderly Health Programs Group (DEHPG). The NQIP partners are CMSO/DEHPG, the National Association of State Units on Aging (NASUA), and the National Association of State Directors of Developmental Disabilities Services (NASDDDS). Most NASDDDS and NASUA member agencies have direct line responsibility (including QA/I) for the operation of HCBS waiver programs for individuals with developmental disabilities and older persons respectively. The National Association of State Medicaid Directors (NASMD) also participates in NQIP. All three state associations devote considerable attention to strengthening and improving the delivery of home and community services. The MEDSTAT Group and the Human Services Research Institute provide NQIP contractor support.

Quality Framework

The NQIP partners collaborated to develop the HCBS Quality Framework

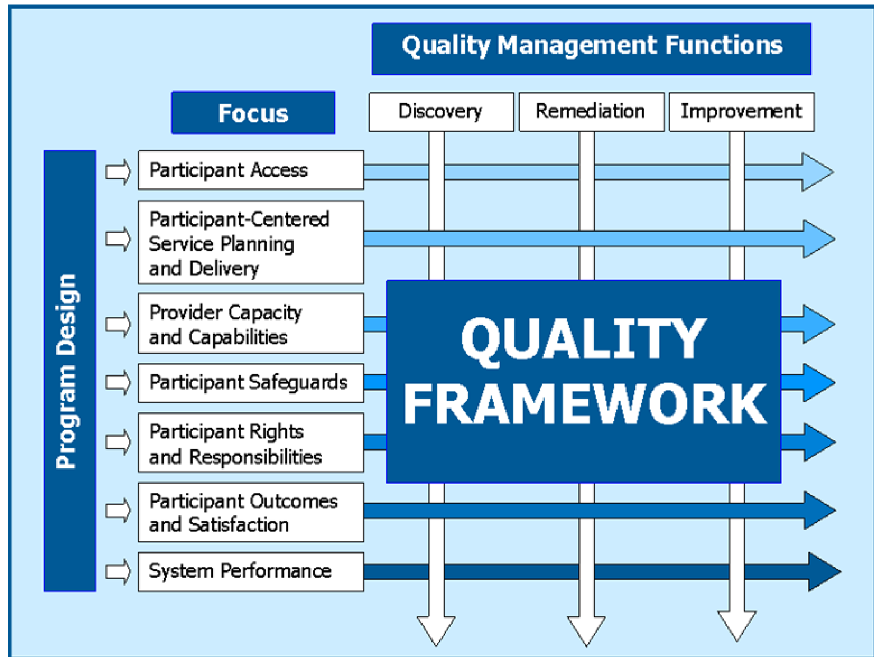
As a first step, the NQIP partners collaborated to develop the HCBS Quality Framework (see attachment). The Framework provides a common frame of reference in support of productive dialogue among all parties who have a stake in the quality of services and supports for older persons and individuals with disabilities. The Framework focuses attention on participant-centered desired outcomes along seven dimensions. The Framework's focus on desired outcomes keeps in the forefront the essential aim of the HCBS waiver program: namely, to effectively support program participants in the community.

The Framework also stresses the interplay between program design and quality management in achieving desired outcomes on

The Quality Framework focuses on desired outcomes

behalf of program participants. **Program design** sets the stage. It addresses such fundamental elements as service standards, provider qualifications, assessment, service planning, monitoring participant health and welfare, and critical safeguards (i.e., incident reporting and management systems).

The Framework encompasses program design and three essential quality management functions: discovery, remediation, and improvement



Quality management encompasses three functions:

- **Discovery:** Collecting data and direct participant experiences in order to assess the ongoing implementation of the program, identifying both strengths and opportunities for improvement.
- **Remediation:** Taking action to remedy specific problems or concerns that arise.
- **Continuous Improvement:** Utilizing data and quality information to engage in actions that lead to continuous improvement in the HCBS program.

Quality management gauges the effectiveness and functionality of program design and pinpoints where attention should be devoted to secure improved outcomes.

The Framework establishes a unified conceptual foundation for HCBS QA/I

The HCBS Quality Framework does not envision a "one-size-fits-all" model for HCBS waiver QA/I. Clearly, program design features and specific quality management strategies will vary from program to program, depending on the nature of a program's target population, the program's size and the services that it offers,

its relationship to other public programs (including services that a state provides Medicaid beneficiaries under its state plan), and additional factors. The Framework is an important step in establishing a unified conceptual foundation for HCBS QA/I.

The Framework is a playing prominent role in the ongoing dialogue between CMS and state associations concerning HCBS waiver program design, quality management and improvement

The HCBS Quality Framework was widely disseminated in draft through NASDDDS and NASUA to their members and by CMS via letter to State Medicaid Directors in August 2002. Since then, there has been ongoing and beneficial dialogue with state officials and other parties concerning the Framework. As a result of this dialogue, the Framework continues to evolve but remains anchored in its desired outcomes. The Framework was developed in partnership with NASMD, NASUA, and NASDDDS. The Framework is playing a prominent role in the ongoing dialogue between CMS and the state associations concerning modifications to the HCBS waiver application and review processes. The Framework is a springboard for increased emphasis on promoting a constructive relationship among states, CMS, and its Regional Offices that focuses on HCBS waiver program design and quality management and, most importantly, quality improvement. On their own, several states also have been employing the Framework to appraise and modify their HCBS quality management systems.

III. National Quality Inventory Survey

The NQIP partners collaborated to design and conduct the National Quality Inventory Survey

The HCBS Quality Framework guided the development of items comprising the National Quality Inventory Survey. The NQIP partners collaborated to design and conduct the National Quality Inventory Survey. As discussed earlier, the survey's purpose was to acquire baseline information concerning the design, operation and capabilities of state HCBS waiver QA/I systems. To this end, the project partners identified QA/I system features related to each of the Framework's seven focus dimensions. For example, with respect to Participant Outcomes and Satisfaction, survey questions were included that asked states whether they systematically obtained information from participants about their satisfaction with HCBS waiver program services and, if so, how this information was applied to improve quality.

The survey concentrated on the design features and structure of state QA/I systems

The survey concentrated on the design features and structure of state QA/I systems. However, it also asked states to provide information about their discovery processes, remediation tools, and quality improvement activities. The survey also requested that states provide information concerning their initiatives to strengthen QA/I and provide feedback to CMS concerning the usefulness of the HCBS Waiver Protocol and the HCBS Quality Framework. States also were asked to identify areas where CMS should step up its technical assistance capabilities in support of state QA/I efforts.

Although extensive, the survey did not attempt to probe every facet of the operation of HCBS waiver QA/I systems and the depth to which some topics were probed varied. As with any survey, it was necessary to strike a balance between the desire to obtain information and the burden on respondents to complete the survey. Survey questions were structured so that states could select from among pre-specified choices to describe how they address particular facets of QA/I. The survey contained only a few open-ended questions in order to minimize respondent burden.

It is important to emphasize that the survey was not designed to evaluate the effectiveness and/or functionality of state QA/I processes and strategies. Its main purpose was to take a snapshot of state systems in order to learn about their structure and the QA/I processes/strategies that they employ.

The survey focused on HCBS waiver programs for persons with developmental disabilities (DD waiver programs) and waiver

The survey focused on HCBS waiver programs for persons with developmental disabilities and for older persons and/or younger adults with disabilities

programs for older persons and/or younger adults with physical disabilities ("Aging and Disabled" or A/D waiver programs). These target populations account for the overwhelming majority of individuals who receive waiver services nationwide. Not included in the survey were: (a) "model waiver" programs that serve 200 or fewer individuals; (b) waiver programs that serve other target populations (e.g., persons with AIDS/HIV, persons who have experienced a brain injury, technology-dependent children); and, (c) a few relatively small, highly specialized programs that serve individuals with developmental disabilities.[2]

Two distinct survey tools were developed: one for HCBS waiver programs that support individuals with developmental disabilities and one for programs that serve younger adults with physical disabilities and/or older persons. The survey tools were quite similar and most items were the same. The differences in the tools reflected the different emphases in serving each target population.

States were not required to respond to the survey. NASUA and NASDDDS sponsorship of the survey resulted in a high response rate (see below). In addition, to secure a high response rate, states were assured anonymity and confidentiality with respect to their responses. Individual state responses have not been shared with CMS. In keeping with the assurance of anonymity and confidentiality, survey results are reported here only in the aggregate.

Survey Timeframe and Scope

The survey results are a snapshot of where HCBS waiver QA/I systems stood in early 2003

On behalf of the project partners, the contractors transmitted the survey tool and instructions in hard copy and electronically to states in October 2002. The last survey responses were received in January 2003 when the survey data collection phase ended. Thus, the results contained in this report are a snapshot of where HCBS waiver QA/I systems stood at the beginning of 2003.

The state agency operating each waiver program was asked to take the lead in responding to the survey. Since most HCBS waiver programs are operated by an agency other the state Medicaid agency, respondents also were asked to review the survey response with the state Medicaid agency prior to its submission. Altogether, 168 waiver programs were included in the survey, including 76 DD waiver programs and 92 A/D waiver programs.

[2] Also not included in the survey were 1115 Demonstration waiver programs that furnish home and community services. Arizona was not included in the survey because it furnishes all Medicaid home and community services under a demonstration waiver. Survey responses were received from the remaining 49 states and the District of Columbia.

Response Rate

The survey response rate was excellent – 87%

The overall survey response rate was 87%. The response rate for DD HCBS waiver programs was 100%. A 100% response rate also was achieved for the 22 programs that exclusively serve older persons. In the case of the 49 programs that serve both younger adults with physical disabilities and older persons, the response rate was 71%. There was a 62% response rate for the 21 programs that exclusively serve younger adults with physical disabilities. Survey responses were received for a total of 146 waiver programs (76 DD and 70 A/D waiver programs).

The survey response rate was excellent, especially since completing the survey was voluntary and state respondents had many other competing demands on their time. As mentioned previously, NASUA and NASDDDS sponsorship of the survey undoubtedly contributed to the high response rate.

Profile of Waiver Programs Surveyed

This section provides information concerning the waiver programs for which surveys were received and the organization of state waiver program operations.

Individuals Served

The table below shows the number of individuals served in the waiver programs for which survey responses were received. The number of persons served in each type of waiver program varied considerably. For example, in the case of DD waiver programs, the number of participants ranged from under 200 persons to a high of 46,000. Programs for older persons and younger adults with disabilities also exhibited a similar span in the number of participants served, ranging from fewer than 100 individuals to almost 33,000.

Number of Individuals Served in Surveyed Programs

Target Population	Total Served	Mean Number Served/ Program	Median Number Served/ Program
Developmental Disabilities (76 programs)	365,245	4,806	4,394
Older Persons Only (22 programs)	114,481	5,204	2,890
Older Persons and Adults Younger than 65 (34 programs)	247,522	7,280	1,797
Adults Younger than 65 (13 programs)	30,000	2,308	450
All programs	757,248	5,153	N/A

Operating Agency Characteristics

Most of the waiver programs were operated by a state program agency rather than the Medicaid agency

Most HCBS waiver programs for which survey responses were received were operated by state program agencies (e.g., a state unit on aging or a state developmental disabilities agency) rather than directly by the single-state Medicaid agency. State developmental disabilities agencies operated 87% of the DD waiver programs. State units on aging operated 95% of programs that exclusively serve older persons, 62% of programs for older persons and younger adults with disabilities, and 70% of all A/D waiver programs. With respect to A/D waiver programs overall, state Medical Assistance Units operated 24% of these programs but the remainder was operated by other agencies, located either in the same department that houses the Medicaid agency or another state department. In the case of DD waiver programs, state Medical Assistance Units operated only 7% of these programs. As a consequence, the operation of an HCBS waiver program usually entails collaboration and cooperation between the Medicaid agency and a state program agency.

Interagency agreements with the Medicaid agency typically assign HCBS waiver operating agencies significant QA/I responsibilities

When a waiver program is not directly operated by the Medicaid agency, there must be an interagency agreement between the operating agency and the Medicaid agency that spells out the operating agency's responsibilities. The state Medicaid agency retains ultimate responsibility for the operation of the program. Through the survey, it was learned that these agreements typically assign significant responsibilities to the operating agency for conducting important QA/I-related activities (e.g., establishing provider qualifications and conducting provider quality reviews). When state program agencies did not operate a waiver program, the survey found that they frequently provide input concerning QA/I and other aspects of program design to the state Medicaid agency that operates the program.

Local Non-State Authorities

In 44% of waiver programs, local non-state authorities have significant QA/I responsibilities

The survey also revealed that, in approximately 44% of all waiver programs (41% of DD waiver programs and 47% of A/D waiver programs), local non-state authorities (e.g., county or regional human services agencies, area agencies on aging) have significant HCBS waiver program QA/I responsibilities. Local authority QA/I responsibilities typically included the provision of case management services and on-going monitoring of participant services and health/welfare. Hence, in many states, conducting QA/I activities is distributed between state and local agencies.

IV. Survey Results

These survey results are a snapshot in time

This section reports selected survey results for each of the seven major HCBS Quality Framework focus areas as well as other topics that were probed in the survey. It is important to reiterate that the purpose of the survey was to acquire baseline information concerning state QA/I systems and strategies. These results are a "snapshot" in time and, hence, may not reflect the present status of state QA/I systems, especially in light of the fact that, when the survey was conducted, most states reported that they had major initiatives underway to modify and strengthen their HCBS QA/I systems. Hence, if the survey were to be conducted again today, the results likely would be different.

A waiver program's design features and quality management strategies hinge on a multitude of factors

When reviewing the survey results, it is important not to jump to the conclusion that, where some waiver programs were not addressing a specific QA/I function or element, there are inadequate safeguards for the health and welfare of waiver participants, or a state's overall QA/I system is deficient. It is important to keep in mind that a waiver program's design features and quality management strategies hinge on a multitude of factors, including the nature of the target population, the size of the program, the services the program offers and how those services interlock with Medicaid state plan services and other public programs. Some QA/I elements and components probed in the survey were not necessarily relevant to all programs.

In addition, some QA/I elements explored in the survey were more relevant to services for persons with developmental disabilities than for older persons and younger adults with disabilities who do not have a cognitive disability. Also, some elements were more pertinent to the provision of services to persons served in supervised living arrangements rather than individuals who live in their own homes with support. For example, oversight and program quality review strategies are quite different in programs where individuals predominantly are served in supervised living arrangements than in programs where participants mainly receive limited personal assistance in their own home or in the community.

Many QA/I topics probed in the survey extended beyond "compliance"

Finally, it also is important to recognize that the survey probed many QA/I topics that extend beyond those traditionally associated with "compliance" *per se*. For example, the survey asked states about the alternative mechanisms that they had in place to address participant complaints. All waiver programs

must afford individuals the right to contest adverse decisions through the Medicaid Fair Hearing process mandated by §1902(a)(3) of the Social Security Act. The project partners were interested in learning the extent to which states had voluntarily supplemented the Fair Hearings process by providing for alternate dispute resolution mechanisms or afforded participants access to long-term care ombudsman programs to assist them in addressing problems and issues. Probes such as this were intended to provide a more robust picture of HCBS waiver QA/I than had the survey focused exclusively on narrower compliance-related topics.

A. Survey Results: Quality Framework Focus Areas

Focus: Participant Access

This part of the survey asked states to identify how they facilitated access to waiver services. Some of the results were:

- Nearly all states reported that they were pursuing multiple strategies to promote access to waiver services, including most often collaborating with advocacy/ consumer organizations to disseminate information about services (82% of programs) and making information available via the Internet (77%) along with other strategies such as operating toll-free information hotlines (49%).

The majority of states had recently taken or had steps underway to expedite the provision of services

- The majority of states reported that they recently had taken or had steps underway to streamline HCBS waiver intake, eligibility and/or service authorization processes in order to expedite the provision of services. Some of the steps that states had taken included streamlining assessment processes, intake procedures and automating various activities (e.g., eligibility screening).
- According to states that compiled systematic information about the amount of time necessary to connect individuals to waiver services, the most time-consuming stage in the process was initial eligibility determination, which typically requires more than 30 days to complete. This may have been due to the fact that in some cases both a person's financial and functional eligibility must be determined. Once eligibility was determined, these states reported that usually fewer than 30 days were needed to prepare a service plan. Once a plan is finalized, most individuals began receiving services in 30 days or less. Only infrequently did the initiation of services require more than 60 days once a service plan had been developed.

Focus: Participant-Centered Service Planning and Delivery

This part of the survey asked states to provide information about their HCBS waiver service planning processes, the extent to which individual/family-directed services are available, case management and monitoring processes, and external case review systems.[3] Some of the results from this part of the survey were:

States typically employed several strategies to ensure that waiver service plans are responsive to the needs, preferences and goals of participants

- States reported that they typically employed several strategies – often concurrently – to ensure that waiver service plans are responsive to the needs, preferences and goals of participants. The more common strategies that states used included conducting participant interviews, external case reviews (described below), and the waiver plan of care review processes.
- According to the survey results, the most common ways that states provided information to assist program participants to exercise free choice in the selection of waiver service providers were through the case management process or making resource guides available to them. Only a few states reported that they prepared provider agency report cards.

Many states were offering the option to individuals and families to direct some or all of their waiver services

- The survey revealed that many states (42% of the waiver programs that responded to the survey) were offering the option to individuals and families to direct some or all of their waiver services. However, two points need be made. First, since the survey was conducted, more states have submitted changes to their waiver programs or launched new programs that emphasize individual/family-directed services. Second, states likely had varying interpretations of "self-direction" since many of the programs where individual/family-directed services were offered did not uniformly have in place the hallmarks of the CMS Independence Plus individual/family-directed waiver framework (i.e., support brokerage, individual budgets, emergency backup services, and financial management services).

Case managers play important QA/I roles

- Case managers play important roles in HCBS waiver program QA/I. In nearly all waiver programs, states reported that case managers had lead responsibility for monitoring the implementation of an individual's service plan and participant

[3] "External case review" is an in-depth assessment process conducted by a state agency (HCBS waiver operating agency and/or state Medicaid agency) or an independent contractor to verify that appropriate services and supports are furnished to participants and waiver requirements are met. A case review may include observation of the individual in home, work or other community settings, along with an in-depth review of his/her service plan.

health and welfare. In virtually all waiver programs, case managers received QA/I training, including the identification and reporting of abuse and neglect. States reported that they typically used multiple strategies to assess the effectiveness of case management services, including performing quality reviews of case management providers, interviewing participants, and evaluating service planning processes as part of their external case review systems.

The substantial majority of states reported that they employed one or more strategies to actively monitor participant health status

- The substantial majority of states (80% of all programs) reported that they employed one or more strategies to actively monitor the health status of participants. A somewhat lower percentage (53%) reported that they also had efforts under way to improve waiver participant access to health care services. Waiver programs vary in their inclusion of health care services and/or the level of interaction with Medicaid state plan services. This may explain in part the lower percentage.

External case review processes had been implemented in 83% of the waiver programs

- External case review processes had been implemented in 83% of the surveyed HCBS waiver programs. These external case review processes typically probed how well service plans had been implemented and included observation and direct interviews of participants. External case reviews also focused on participant health and welfare, including personal safety, health status, and participant rights safeguards.

Focus: Provider Capacity and Capabilities

This part of the survey asked states to describe their strategies to secure sufficient providers to meet the needs of participants, provider quality review processes and other facets of provider oversight. Some of the results from this part of the survey were:

Most states were actively pursuing strategies to secure sufficient providers

- In about 80% of waiver programs, states reported that they were pursuing one or more strategies to secure sufficient waiver providers. The more common strategies included active recruitment of new providers and increasing payment levels to attract new providers and assure the viability of existing providers.
- The majority of states (76% of the waiver programs surveyed) also reported that they were actively engaged in efforts to expand the direct care workforce, principally by attempting to secure additional funds so that providers could increase wages to more competitive levels. Also, in most states, additional strategies were being used, including linking up with state employment agencies to identify potential workers and collaborating with provider networks in efforts to attract more workers.

In 89% of waiver programs direct care workers must undergo a criminal history/ background check

- In 89% of the waiver programs surveyed, states required that individuals (especially direct care workers) who support waiver participants undergo a criminal history/background check as a condition of employment.
- It was less common (49% of all waiver programs) that states operated an abuse registry to check whether workers had previously committed abuse.
- In the substantial majority of waiver programs (84%), states reported that they had spelled out the specific skills that direct care workers must possess.

State provider quality reviews cover a wide range of topics

- The survey revealed that state provider quality reviews covered a wide range of topics, typically focusing on the implementation of participant service plans, safeguards, and safety. In most cases (82% of waiver programs), states reported that they used unannounced visits as a quality assurance tool, especially in overseeing poorly performing providers. It was somewhat more common for the HCBS waiver operating agency to conduct provider quality reviews in DD waiver programs than in A/D programs since A/D programs often rely on state licensing agencies to conduct such reviews.

In most states, provider quality review results are used to identify training and technical assistance priorities

- States reported that they used information garnered from provider quality reviews in several ways to improve quality. In two-thirds or more of waiver programs, this information served as the basis for modifying program rules and regulations and/or revising quality assurance procedures and strategies. In about 80% of waiver programs, provider quality review results also were used to identify training and technical assistance priorities.

Most states have multiple remediation tools to address serious deficiencies or immediate jeopardy situations

- Most states reported that they had multiple tools to remediate (a) serious deficiencies in a provider agency's performance or (b) situations where participants are in immediate jeopardy. When serious deficiencies are discovered, the remediation tools that states could bring to bear included requiring the provider to implement a time-limited corrective action plan (96% of all programs) and barring the provider from serving additional individuals until the deficiency was corrected (82% of all programs). It was a less common practice for states to use fines/financial penalties as remediation devices (42% of all programs). When immediate jeopardy is discovered, the remediation tools available to states included: (a) transferring participants to other providers (92% of all programs); (b)

termination of the provider (79% of all programs); and, (c) time-limited corrective action plans (85% of all programs).

- Relatively few states (17% of all waiver programs) employed independent quality assessment teams (i.e., teams made up of individuals with disabilities, family members, and other citizens) as part of their provider agency performance appraisal systems.

Focus: Participant Safeguards

This part of the survey asked states to describe how their quality management systems address various health and safety aspects, including the prevention of abuse, neglect and exploitation, critical incident management, the use of behavior interventions, and medication management. Particularly in this part of the survey, there were appreciable differences in some results for DD and A/D waiver programs. To some extent, these differences appear to stem from differences in the population groups served in each type of waiver programs. Some of the results from this part of the survey include:

Nearly every state had one or more methods for assessing participant risk and safety factors

- Nearly every state reported using one or more methods to appraise participant risk and safety factors, including incorporating risk assessment into comprehensive participant assessment processes and/or by conducting clinical assessments. The use of specialized personal safety and health risk assessment tools was somewhat less common. Typically, states involved participants in a variety of ways in service planning processes that address risk and safety factors. In about one-half of waiver programs, participants received education about health risk and personal safety.
- Most states (81% of all waiver programs) reported that they had taken proactive measures to reduce or prevent the occurrence of critical incidents. Some of these steps included: training case managers, providers and participants to identify and/or report abuse, neglect or exploitation; revamping the state's adult protective services program; conducting trend analyses to pinpoint areas for training and technical assistance; and, the formation of risk management committees.

In all but a few states, there were mandatory reporter laws in effect

- In all but a few states, there were mandatory reporter laws in effect that require reporting of abuse, neglect, and exploitation.
- In all but a few states/waiver programs, critical incidents had to be reported to one or more state agencies. It was more common for states to require that incidents must be reported to the HCBS waiver-operating agency in DD waiver programs (85%) than in

In nearly all states, critical incidents had to be reported to one or more state agencies

A/D programs (50% of all programs). Mandatory reporting of incidents to a state's adult protective services agency was somewhat more prevalent in the case of A/D waiver programs (81%) than DD waiver programs (71%). The survey revealed that responsibility for investigating critical incidents can involve several state agencies, depending on the nature of the incident. Nearly all states reported that there were established, formal protocols for the investigation of critical incidents and that they compiled information about incidents at the state level.

- Because the use of behavior interventions is a more commonplace practice in services for persons with developmental disabilities, it was not surprising that states more frequently provided for oversight of their use in DD waiver programs (90% of programs) than in waiver programs for other populations.
- Finally, concerns about the use of behavior modifying medications for people with developmental disabilities and participants' inability to manage their own medications potentially explains why state-initiated medication reviews (i.e., assessing the full range of medications participants receive in terms of their appropriateness) were more typically conducted in DD waiver programs (67% of programs) than A/D programs (27%). This may also be a reflection of the range of services included in waiver programs as opposed to Medicaid state plan services.

Focus: Participant Rights and Responsibilities

This part of the survey queried states about the steps they have taken to protect the rights of waiver participants. Some of the results were:

- In most states (81% of all waiver programs), a statement of individual rights that applies to waiver participants (as well as other individuals who receive community services) had been adopted in state statute and/or promulgated by rule or regulation.
- In most waiver programs (81%), participants were provided written information about their rights during the eligibility determination process. Similarly, it was relatively common practice for case managers to periodically review rights with participants. In addition, states reported that various tools were employed to sanction providers that violate participant rights.

Most states had procedures for participants to file grievances against providers

- It was relatively common for states to have procedures in place for participants to file grievances against providers (90% of all waiver programs). In more than one-half of waiver programs,

there also was provision to resolve grievances through arbitration or alternative dispute resolution mechanisms. There was systematic tracking of information about grievances in 72% of all waiver programs.

- States also reported that they offered additional avenues for waiver participants to voice and register complaints about their services. The mechanisms available to participants included toll-free numbers and assistance through state ombudsman offices (especially in A/D waiver programs).

Focus: Participant Outcomes and Satisfaction

This part of the survey asked states about their efforts to systematically compile information concerning participant experience/satisfaction with waiver services and participant outcomes.

Information about participant experience/ satisfaction with services was being compiled in about three-quarters of the waiver programs

- About three-quarters of all waiver programs compiled information concerning participant experience/satisfaction with services. In the case of A/D waiver programs, 60% of waiver programs compiled information concerning participant experience/satisfaction with services. The collection of such information was somewhat more commonplace in DD waiver programs (88%). The types of information that states collected included overall satisfaction with services as well as participant views concerning case manager and provider agency performance.
- There was a greater emphasis on collecting information about family/informal caregiver satisfaction with services in DD waiver programs (71%) than in A/D programs (27%). This was likely due to the fact that A/D programs are more likely to regard the older person or person with a physical disability as the consumer/participant and not the family member. There are also fewer instances of legal guardianship with these populations.

Systematic information about participant outcomes was being compiled in about one-third of waiver programs

- About one-third of all waiver programs were reported to be compiling systematic information about participant outcomes. This practice was more widespread in DD waiver programs (46%) than programs for other populations.
- With respect to both experience/satisfaction and outcome information, the main use to which states put such information was to pinpoint potential opportunities for quality improvement. In several states, this information also was being used to assess provider agency performance and establish performance targets/standards.

Focus: System Performance

The survey also probed the system performance focus area. Some of the results were:

- With respect to supporting individuals of diverse cultural and ethnic backgrounds, the strategies most frequently employed by states were making information about waiver services available in multiple languages and providing language interpreters when needed. A little less than one-half of all waiver programs made linguistically qualified personnel available at point of access entities.

States garnered feedback from waiver participants in a variety of ways

- States reported that they also garnered feedback concerning waiver program design and operations from participants and/or family members in several ways. The most common ways of obtaining feedback were participant interviews and surveys. Focus groups were a tool that was used more frequently in DD waiver programs (56%) than A/D programs (17%). In general, the survey revealed that it was more common that participants and/or family members were directly involved in QA/I activities in DD waiver programs (91%) than in A/D programs (49%). Many states provided concrete examples of how they had used information and/or input from program participants/families to improve HCBS waiver program design and operations.
- States also reported that they employed a variety of strategies to secure feedback from other stakeholders (e.g., providers and case managers) concerning program design and operations.

B. Survey Results: Other Survey Topics

The survey explored several additional topics. In particular:

Major initiatives were planned or underway in 78% of waiver programs to strengthen or improve HCBS QA/I systems

- States were asked whether they had major initiatives planned or underway that would be completed within two years to strengthen or improve their HCBS QA/I systems. This question was posed to learn where states were devoting their attention and resources concerning HCBS QA/I. The survey revealed that such initiatives were underway or planned in 78% of all programs and typically operating agencies had multiple initiatives underway. The QA/I elements or functions that were being addressed in these initiatives by one-half or more of all waiver programs included: (a) assessing participant satisfaction; (b) provider training; (c) service planning; (d) incident management, reporting, and tracking; (e) provider quality review practices; (f) identifying and measuring participant

outcomes; (g) individual/family-directed services; and, (h) case management/service coordination.

Many states had efforts underway to improve their data systems to better support quality management

- States also were asked to self-assess the status of the automation of various types of quality management data. This question was posed because having such data is regarded as vital to effectively conducting quality management. The survey revealed that, regardless of target population, relatively few states operated data systems that comprehensively support quality management. For example, about 44% of operating agencies reported that provider quality review results were not automated and fewer than one in six operating agencies had fully automated data about participant monitoring activities. At the same time, a substantial proportion of programs reported that they were engaged in developing or modifying their data systems to better support quality management.

- States were asked whether the revised HCBS Waiver Review Protocol that CMS issued in December 2000 had clarified federal expectations concerning HCBS waiver quality management. The majority of respondents (62%) indicated that the Protocol had clarified expectations, while the remainder said that the Protocol had somewhat clarified federal expectations.

The release of the HCBS Waiver Protocol prompted about two-thirds of states to make changes in their QA/I systems

- About two-thirds of the states reported that the release of the Protocol had triggered their making changes in their QA/I systems. These changes spanned a wide range of QA/I elements and functions, including assuring health and welfare, developing/revising data systems, designing a comparable state-level protocol, implementing a participant interview process, and revising provider quality review processes.

- States were asked whether the Quality Framework was helpful in framing dialogue concerning QA/I. Most respondents (63%) said that the Framework was helpful while the remainder characterized it as "somewhat helpful."

States identified areas for stepped up CMS technical assistance

- States were asked to identify up to four facets of QA/I where it would be most helpful for CMS to develop and/or improve its capabilities to furnish technical assistance to states. Across all waiver programs that responded to this question, the areas most frequently identified by respondents for stepped up CMS technical assistance were: (a) quality management information systems; (b) participant outcomes; (c) individual/family-directed services; (d) incident management data/reporting systems; and (e) risk assessment/risk planning.

V. Discussion of Results

The survey results provide a much clearer picture of QA/I systems

The National Quality Inventory Survey succeeded in filling the critical information void that has surrounded state HCBS waiver QA/I systems. For the first time, information is now available about the features and structure of these systems. The survey information that was collected provides a much clearer picture of QA/I systems than has heretofore been available.

States have designed and implemented a variety of strategies and approaches to assure and improve service quality

Having first-line responsibility for quality management, states clearly have designed and implemented a variety of strategies and approaches to assure and improve the quality of services furnished through their HCBS waiver programs. The National Quality Inventory Survey revealed that state QA/I systems by and large have strategies in place that address fundamental participant safeguards and include many features and components that are central to promoting participant-centered services and supports. While the survey did not attempt to gauge the effectiveness and functionality of these safeguards, it is nonetheless encouraging that state QA/I systems include critical components.

Not surprisingly, the survey also revealed that there are differences in how states are seeking to achieve the desired outcomes articulated in the HCBS Quality Framework. A variety of factors, including how states organize their service delivery systems and different emphases depending on waiver target populations, appear to account in large part for the variety of approaches that states employ in their HCBS waiver QA/I systems.

States are at different stages in the development of full-featured QA/I systems

The survey also revealed that states are at different stages in the development of full-featured QA/I systems. This result is not surprising. While states have developed their own quality management processes, only recently has a consensus begun to emerge about the range of areas that such systems should address. In addition, the development of effective QA/I strategies and supporting technologies has clearly lagged behind the rapid-paced expansion of community services. For example, only recently have effective tools been developed to support the collection of solid information about participant experience/ satisfaction with services and individual outcomes.[4]

[4] For example, the CMS-sponsored Participant Experience Survey and the NASDDDS-sponsored National Core Indicators consumer and family survey instruments.

It was especially encouraging that most states had launched major initiatives to strengthen their HCBS waiver QA/I systems

An especially encouraging survey result was the revelation that most states had launched major initiatives to improve and strengthen their QA/I systems, including making fuller use of information technology. These initiatives address important Quality Framework dimensions and reveal the seriousness of state efforts to promote quality outcomes for waiver participants.

Technical assistance to strengthen information technology capabilities to support effective quality management and improvement emerged as an area that CMS should address

At the same time, the survey revealed that many states appear to lack critical, full-featured information technology capabilities that are central to effective quality management and improvement. States clearly recognize the need to improve their information technology capabilities and many reported that they already were developing new automated systems or modifying their current systems. In addition, this quality management dimension was identified by many states as an area in which they would like CMS to provide technical assistance.

In summary, the survey revealed that states appear to be addressing many fundamental facets of QA/I, but also that state QA/I systems are continuing to evolve toward becoming more full-featured.

VI. Recommended CMS Follow-Up Actions

Four follow-up actions are recommended for CMS consideration:

1. CMS should assess its technical assistance agenda in light of the areas that states identified in their survey responses where they would like CMS to improve its capacity to furnish technical assistance capabilities. This assessment might include additional follow-up with states and/or the state associations to pinpoint the exact types of technical assistance that might prove most helpful to states, given the unique features of each waiver program and its focus.
2. The detailed results of the National Quality Inventory Survey should be distributed to states so that they can benchmark the present status of their QA/I systems to their peers.
3. CMS should use the results of the National Quality Inventory to inform the design of changes to the HCBS waiver program application and ongoing reporting requirements. For example, the survey results make it clear that, in some areas, the implementation of new requirements will need to take into account the fact that some states will require lead time to put the necessary systems and processes in place.
4. In particular, it was evident in state responses to some of the open-ended survey questions that many states are pursuing quality management and improvement strategies that might hold considerable interest for other states. This suggests that CMS may want to prioritize HCBS QA/I as a topic to explore in greater depth in the Promising Practices project as a means of sharing information about these strategies among the states. Similarly, CMS may wish to consider stepping up the flow of information to states that is being acquired in conjunction with the National Contractor technical assistance initiative.

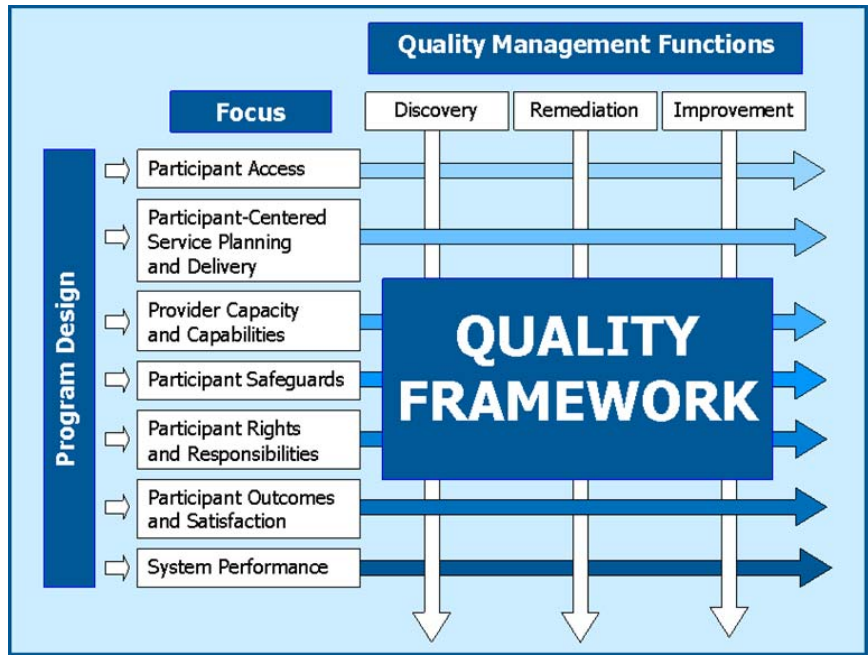
As a final matter, it is not recommended that CMS conduct a follow-up of the full-blown National Quality Inventory Survey. While arguably such a follow-up survey might provide additional information concerning the on-going evolution of state HCBS QA/I systems, broad scope surveys such as this one have inherent limitations. In addition, it is important to keep in mind that one of the main reasons for conducting this survey – the lack of information about state QA/I in the HCBS waiver application itself – is being addressed as part of the planned redesign of the application. Therefore, it would be better to reserve future survey activities to topics where the goal is to secure more in-depth information concerning a topic.

ATTACHMENT

HCBS Quality Framework

HCBS QUALITY FRAMEWORK

The Home and Community-Based Services (HCBS) Quality Framework provides a common frame of reference in support of productive dialogue among all parties who have a stake in the quality of community services and supports for older persons and individuals with disabilities. The Framework focuses attention on participant-centered **desired outcomes** along seven dimensions.



Program design sets the stage for achieving these desired outcomes. Program design addresses such topics as service standards, provider qualifications, assessment, service planning, monitoring participant health and welfare, and critical safeguards (e.g., incident reporting and management systems).

Quality management encompasses three functions:

Discovery: Collecting data and direct participant experiences in order to assess the ongoing implementation of the program, identifying strengths and opportunities for improvement.

Remediation: Taking action to remedy specific problems or concerns that arise.

Continuous Improvement: Utilizing data and quality information to engage in actions that lead to continuous improvement in the HCBS program.

Focus	Desired Outcome
Participant Access	*Individuals have access to home and community-based services and supports in their communities.*
Participant-Centered Service Planning and Delivery	*Services and supports are planned and effectively implemented in accordance with each participant's unique needs, expressed preferences and decisions concerning his/her life in the community*
Provider Capacity and Capabilities	*There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants.*
Participant Safeguards	*Participants are safe and secure in their homes and communities, taking into account their informed and expressed choices.*
Participant Rights and Responsibilities	*Participants receive support to exercise their rights and in accepting personal responsibilities.*
Participant Outcomes and Satisfaction	*Participants are satisfied with their services and achieve desired outcomes.*
System Performance	*The system supports participants efficiently and effectively and constantly strives to improve quality.*

Quality management gauges the effectiveness and functionality of program design and pinpoints where attention should be devoted to secure improved outcomes.

Program design features and quality management strategies will vary from program to program, depending on the nature of the program's target population, the program's size and the services that it offers, its relationship to other public programs, and additional factors.

The Framework was developed in partnership with the National Associations of State Directors of Developmental Disabilities Services, State Units on Aging, and State Medicaid Directors.

CMS CENTERS for MEDICARE & MEDICAID SERVICES

NASDDDS National Association of State Directors of Developmental Disabilities Services

NASUA

APHSA American Public Human Services Association

HCBS QUALITY FRAMEWORK
QUALITY FOCUS AREAS

Focus I: Participant Access

Desired Outcome: *Individuals have access to home and community-based services and supports in their communities.*

I.A Information/Referral

Desired Outcome: *Individuals and families can readily obtain information concerning the availability of HCBS, how to apply and, if desired, offered a referral.*

I.B. Intake and Eligibility

I.B.1 User-Friendly Processes

Desired Outcome: *Intake and eligibility determination processes are understandable and user-friendly to individuals and families and there is assistance available in applying for HCBS.*

I.B.2 Referral to Community Resources

Desired outcome*: Individuals who need services but are not eligible for HCBS are linked to other community resources.*

I.B.3 Individual Choice of HCBS

Desired Outcome: *Each individual is given timely information about available services to exercise his or her choice in selecting between HCBS and institutional services.*

I.B.4 Prompt Initiation

Desired Outcome: *Services are initiated promptly when the individual is determined eligible and selects HCBS.*

Focus II: Participant-Centered Service Planning and Delivery

Desired Outcome: *Services and supports are planned and effectively implemented in accordance with each participant's unique needs, expressed preferences and decisions concerning his/her life in the community*

II.A Participant-Centered Service Planning

II.A.1 Assessment

Desired Outcome: *Comprehensive information concerning each participant's preferences and personal goals, needs and abilities, health status and other available supports is gathered and used in developing a personalized service plan.*

II.A.2 Participant Decision Making

Desired Outcome: *Information and support is available to help participants make informed selections among service options.*

Working Draft

II.A.3 Free Choice of Providers

Desired Outcome: *Information and support is available to assist participants to freely choose among qualified providers.*

II.A.4 Service Plan

Desired Outcome: *Each participant's plan comprehensively addresses his or her identified need for HCBS, health care and other services in accordance with his or her expressed personal preferences and goals.*

II.A.5 Participant Direction

Desired Outcome: *Participants have the authority and are supported to direct and manage their own services to the extent they wish.*

II.B Service Delivery

II.B.1 Ongoing Service and Support Coordination

Desired Outcome: *Participants have continuous access to assistance as needed to obtain and coordinate services and promptly address issues encountered in community living.*

II.B.2 Service Provision

Desired *Outcome*: *Services are furnished in accordance with the participant's plan.*

II.B.3 Ongoing Monitoring

Desired Outcome: *Regular, systematic and objective methods – including obtaining the participant's feedback – are used to monitor the individual's well being, health status, and the effectiveness of HCBS in enabling the individual to achieve his or her personal goals.*

II.B.4 Responsiveness to Changing Needs

Desired Outcome: *Significant changes in the participant's needs or circumstances promptly trigger consideration of modifications in his or her plan.*

Focus III: Provider Capacity and Capabilities

Desired Outcome: *There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants.*

III.A Provider Networks and Availability

Desired Outcome: *There are sufficient qualified agency and individual providers to meet the needs of participants in their communities.*

III.B Provider Qualifications

Desired Outcome: *All HCBS agency and individual providers possess the requisite skills, competencies and qualifications to support participants effectively.*

III.C Provider Performance

Desired Outcome: *All HCBS providers demonstrate the ability to provide services and supports in an effective and efficient manner consistent with the individual's plan.*

Working Draft

Focus IV: Participant Safeguards

Desired Outcome: *Participants are safe and secure in their homes and communities, taking into account their informed and expressed choices.*

IV.A Risk and Safety Planning

Desired Outcome: *Participant health risk and safety considerations are assessed and potential interventions identified that promote health, independence and safety with the informed involvement of the participant.*

IV.B Critical Incident Management

Desired Outcome: *There are systematic safeguards in place to protect participants from critical incidents and other life-endangering situations.*

IV.C Housing and Environment

Desired Outcome: *The safety and security of the participant's living arrangement is assessed, risk factors are identified and modifications are offered to promote independence and safety in the home.*

IV.D Behavior Interventions

Desired Outcome: *Behavior interventions – including chemical and physical restraints – are only used as a last resort and subject to rigorous oversight.*

IV.E. Medication Management

Desired Outcome: *Medications are managed effectively and appropriately.*

IV.F Natural Disasters and Other Public Emergencies

Desired Outcome: *There are safeguards in place to protect and support participants in the event of natural disasters or other public emergencies.*

Focus V: Participant Rights and Responsibilities

Desired Outcome: *Participants receive support to exercise their rights and in accepting personal responsibilities.*

V.A Civic and Human Rights

Desired Outcome: *Participants are informed of and supported to freely exercise their fundamental constitutional and federal or state statutory rights.*

V.B Participant Decision Making Authority

Desired Outcome: *Participants receive training and support to exercise and maintain their own decision-making authority.*

V.C Due Process

Desired Outcome: *Participants are informed of and supported to freely exercise their Medicaid due process rights.*

Working Draft

V.D Grievances

Desired Outcome: *Participants are informed of how to register grievances and complaints and supported in seeking their resolution. Grievances and complaints are resolved in a timely fashion.*

Focus VI: Participant Outcomes and Satisfaction

Desired Outcome: *Participants are satisfied with their services and achieve desired outcomes.*

VI.A Participant Satisfaction

Desired Outcome: *Participants and family members, as appropriate, express satisfaction with their services and supports.*

VI.B Participant Outcomes

Desired Outcome: *Services and supports lead to positive outcomes for each participant.*

Focus VII: System Performance

Desired Outcome: *The system supports participants efficiently and effectively and constantly strives to improve quality.*

VII.A System Performance Appraisal

Desired Outcome: *The service system promotes the effective and efficient provision of services and supports by engaging in systematic data collection and analysis of program performance and impact.*

VII.B Quality Improvement

Desired Outcome: *There is a systemic approach to the continuous improvement of quality in the provision of HCBS.*

VII.C Cultural Competency

Desired Outcome: *The HCBS system effectively supports participants of diverse cultural and ethnic backgrounds.*

VII.D Participant and Stakeholder Involvement

Desired Outcome: *Participants and other stakeholders have an active role in program design, performance appraisal, and quality improvement activities.*

VII. E Financial Integrity

Desired Outcome: *Financial accountability is assured and* payments *are made promptly in accordance with program requirements.*

Working Draft