

Rutgers Center for State Health Policy

NATIONAL ACADEMY for STATE HEALTH POLICY

April 2005 Discussion Paper

Community Living Exchange

Funded by Centers for Medicare & Medicaid Services (CMS)

Discovery Methods for Remediation and Quality Improvement in Home and Community Based Services

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The Community Living Exchange at Rutgers/NASHP provides technical assistance to the Real Choice Systems Change grantees funded by the Centers for Medicare & Medicaid Services.

We collaborate with multiple technical assistance partners, including ILRU, the Muskie School of Public Service, National Disability Institute, Auerbach Consulting Inc., and many others around the nation.

This document was developed under Grant No. 11-P-92015/2-01 from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal government. Please include this disclaimer whenever copying or using all or any part of this document in dissemination activities.

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Introduction

This is the second of three papers synthesizing the ideas and practices of states as they seek to improve the quality of home and community based services (HCBS) and supports for older persons and persons with disabilities.

In 2003, the Centers for Medicare & Medicaid Services (CMS) awarded grants to 19 states to enhance their quality management (QM) programs for HCBS programs.¹ CMS contracted with the Community Living Exchange Collaborative² to assist states in their grant activities by promoting information exchange and facilitating discussions on topics of common interest. As part of its work with the Community Living Exchange Collaborative, the Muskie School of Public Service, together with grantee states, identified three priority topics for working papers:

- 1. Quality Management (QM) Roles and Responsibilities
- 2. Discovery Methods for Remediation and Quality Improvement
- 3. Data Analysis and Use of Performance Measures

As part of the technical assistance provided to states, a sub-group of grantees was formed to contribute to the development of this paper. An early outline was shared with the subgroup. The process for developing this paper included collection and review of sample data instruments, forms, policies and interviews with a number of states.

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;
- to discuss ways to prioritize activities and select quality improvement activities.

Because of the unique nature and history of home and community based services, there is no one model of quality assurance or quality improvement that has evolved. Instead states have developed a variety of approaches and methods to match the individualized and state-specific program designs. Furthermore, the approaches that are used vary greatly within and across states depending on the groups of individuals served by a particular waiver program.

By looking at some of these methods in more depth, we want to promote the transfer of knowledge from state to state and identify innovative or emerging practices and policy

¹ QA/QI grantee states include: California, Colorado, Connecticut, Delaware, Georgia, Indiana, Maine, Minnesota, Missouri, North Carolina, New York, Ohio, Oregon, Pennsylvania, South Carolina, Tennessee, Texas, Wisconsin, and West Virginia.

²The Community Living Exchange Collaborative is a partnership of the Rutgers Center for Health Policy, the National Academy for State Health Policy and Independent Living Research Utilization. Under contract with the Technical Exchange Collaborative, the Muskie School of Public Service is the lead for providing technical assistance in the area of quality assurance/quality improvement.

that may be of interest or benefit to other states. These practices may be embedded in program operations at a state level; developed as local activities within a sub-state entity, such as a county; or be part of a broader quality improvement effort within a department.

This paper will specifically address the following questions:

- Why are discovery methods important?
- What are the outcomes that discovery methods seek to assess?
- What is a discovery method?
- What are the features of a reliable and robust system of discovery methods?
- What is a comprehensive yet focused system of discovery methods?
- What evidence or other reports are produced from the discovery methods?
- How do states move from discovery to action?

Why are discovery methods important?

Studies show that people who receive long term services and supports prefer to live at home or in their communities. Medicaid home and community based waivers are one of the primary ways that states provide services to people in the community who are otherwise eligible to be in an institution. Waiver programs provide states with greater flexibility in designing systems that meet the individual needs and preferences of people in the community. The ability to create more balanced delivery systems by shifting from institutions to home and community based services is a major policy goal of states.

HCBS waiver programs serve a diverse cross-section of individuals with a variety of complex and often high level of need for care and services. Waivers serve people with physical or other disabilities, people with brain injuries, people with AIDS, people with mental retardation or developmental disabilities and older frail adults. These individuals are often particularly vulnerable to isolation, exploitation and/or are at risk if their needs are not met in a reliable and timely manner.

With the continued growth and expansion of home and community-based service options, program managers need to know that the services they provide and programs they administer are meeting the needs of the people they serve. They need to know how well they are achieving the goals they have identified and built into the design of their HCBS systems.

External stakeholders including family members, community advocates, legislators and the general public are increasingly interested in knowing how well home and community based care systems are performing, whether people are satisfied with the services and supports they receive and whether quality services and supports are being provided.

State and federal agencies responsible for funding HCBS programs have statutory and fiduciary responsibilities to monitor and assess the quality of services for which they are paying. They want to know whether public funds are being appropriately spent, whether resources are allocated efficiently and that high quality care and services are being provided.

Discovery methods are tools for assessing performance of a process, program, policy, provider or contractor. Discovery methods produce data that can be used to guide program management, inform policy development, measure program outcomes and identify areas for quality improvement.

Take-Away Lesson

In order to be responsive to multiple stakeholders and interested parties and to meet federal requirements for HCBS waivers, states need to develop comprehensive and reliable systems for monitoring program performance.

What are states trying to discover?

A discovery method is a tool for assessing program performance. In 2003, the Centers for Medicare & Medicaid Services (CMS) released the HCBS Quality Framework which outlines the major areas of focus in the design of a HCBS program and the quality management functions that are used to assess program goals. The quality management functions identified in the Framework are:

Discovery: the process of collecting data, analyzing results, assessing performance and identifying areas of strength and opportunities for improvement;

Remediation: the process of taking action to remedy a specific problem, usually at the individual level although there may be remedies at the system level as well;

Continuous Improvement: using analyzed data and other information to take actions that lead to continuous improvement.

The Framework identifies seven major areas of focus and the desired outcomes for each program area. The quality management functions of discovery, remediation and quality improvement are tools that are applied across each focus area and each set of outcomes. The major areas of focus and desired outcomes outlined in the HCBS Framework are as follows:

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.

Federal statute also requires that states make certain assurances in their waiver applications. These include assurances that:

- states have taken the necessary steps to protect the health and welfare of participants,
- qualified providers serve participants,
- plans of care are responsive to participant needs,
- states evaluate and re-evaluate the level of need for services,
- people are informed of and provided choice of home versus institutional services; and
- states have financial oversight systems to assure payments are made appropriately and follow approved reimbursement methods.

Minimum Requirements: At a minimum, state discovery methods should address the waiver requirements and assurances covered in the CMS Interim Procedural Guidelines³. One approach that states have used is to map the requirements in the Procedural Guidelines against discovery methods and/or data that is available to address that area.

What are states trying to discover?	What is the discovery method?	What data are available?
Level of Care		
Participants provided level of care evaluations.		
Annual evaluations are conducted.		
Approved instruments and processes are used.		
States monitor level of care decisions and act as necessary.		
Individual Plan (IP)		
Individual plans address needs and personal goals.		
The state monitors IPs and takes action when inadequacies identified.		
Individual Plans are updated/revised as needed.		
Services are delivered in accordance with the POC.		
Participants are afforded choice between waiver services and institution.		
Participants are afforded choice between/among waiver services/ providers.		
There is an adequate number of providers.		
Qualified Providers		
Providers meet required standards.		
The state monitors non-licensed providers.		
The state responds where providers do not meet requirements.		
The state implements policies for verifying training.		
Health and Welfare		
State addresses/prevents abuse, neglect and exploitation.		
Administrative Authority		
Medicaid or operating agency conducts oversight of waiver program.		
Financial Authority		
State conducts financial oversight to assure proper payment and compliance with reimbursement methodology.		

³ In May 2004, CMS issued the Interim Procedural Guidelines to establish the process for waiver review during the time that CMS transitions its quality oversight approach to one that incorporates both the assurances of statutory requirements and promotion of quality improvement.

The Interim Procedural Guidelines and in particular Attachments A and B of that document provide a very helpful guide and a set of probing questions that are useful in examining and addressing gaps in a state's system of discovery methods. http://www.hcbs.org/moreInfo.php/source/60/ofs/50/doc/722/Interim_Procedural_Guidan ce_for_Assessing_HCBS_Wai

Other Areas of Discovery: While it is clear that it is necessary to meet federal requirements and assurances, state requirements and the areas of interest or concern expressed by managers, advocates, participants and the general public will extend beyond those minimums. One way to expand beyond minimum requirements is to use the CMS Quality Framework, which encompasses the waiver assurance areas, as a guide for organizing discovery methods and prioritizing potential indicators.

Priority Setting: The challenge for any state in designing a system of discovery methods is to find an appropriate balance between the amount of information that is collected, the resources available to collect the information and the ability to act or focus on the outcomes of the reviews or data collection effort.

Some states are assessing whether there are gaps in the types of discovery methods they use and whether data can be collected and analyzed to meet minimum requirements. In other states, the challenge is not an issue of too little data but potentially too much data and/or too much data without a clearly defined end use. In one state, it was recommended that fewer items be included as part of the data collection process.

Because of the number of levels of organizational responsibility for overseeing, managing and providing services in the HCBS system, the priority setting exercise will undoubtedly need to involve all levels of agencies (i.e., operating agency, state program office, sub-state entities and contractors). It is useful to conduct a structured and methodical analysis of the purpose, use and audience for the analysis of the data that is produced. This will provide a way to identify redundancies and/or gaps in a system of discovery methods.

Take-Away Lesson

It is important to be clear about the focus of the discovery method, the locus of responsibility, the end use of the data, and the audience.

What is a discovery method?

For purposes of this paper, a discovery method is defined as a systematic and organized activity to assess, review, evaluate or otherwise analyze a process, program, operation, provider or outcome. The end product of a good discovery method is reliable data that provides "evidence" to support a conclusion or action either at the individual or system level. In order to produce systematic and reliable data, certain core features should be present in a discovery method. These include:

- protocols for data collection
- qualified reviewers/interviewers
- sampling methods that allow conclusions
- standard data collection instruments
- reliable and accurate data
- ability to aggregate, analyze and report data

These will be discussed in greater detail in the next chapter.

The systems of discovery methods that states use vary considerably across programs and across states. While there are many common elements and approaches, there is no standard or model. This reflects the variety and administrative complexity of the waiver programs and their history. The operational functions that are generally performed as part of a waiver program include program administration, assessment and care/service planning, case management, direct service provision, service monitoring, financial oversight and payment. Some of these functions are performed by the state at a central or regional level. Commonly, many of these functions are conducted through contracts with sub-state governmental entities (e.g. counties) or other private agencies.

Thus, the points of accountability for conducting discovery may be layered within and across agencies and organizations. Furthermore, the cycle of data collection, remediation and analysis, which may be well defined within an organizational entity, may not be completed through systematic reporting to the next level agency or organization. States may contract with an organization to perform certain quality assurance functions and then conduct "look behind" activities to see how well the subcontractor has performed those functions.

The types of discovery methods that states use range from the more common forms of quality assurance where records are reviewed for compliance with certain standards to more innovative approaches that include participants, peers or family members in the review process.

A list of the most common types/categories of discovery methods follows:

Discovery Methods	
Interviews/visits (informal or structured)	
Structured surveys (in-person or mail)	
Contacts with individuals (e.g. by care/service coordinators)	
Observation	
Record/chart review	
Financial record review	
 Receipt, retrieval and analysis of operations data Reportable events, incidents, complaints Adult protective services Fair hearings and appeals Administrative and claims data Utilization review Waiting lists Results of licensure and certification reviews 	
Review of contracts, policies and business practices	
 Key informant input and findings Quality review committee meetings Stakeholder meetings Focus groups 	

Multiple discovery methods may be used to assess a specific aspect of a state's waiver program. For example, it may be possible to "discover" or learn about the experience and satisfaction of participants from a number of different sources. This may include a formal mail survey conducted by an independent organization using a standard survey instrument, monthly contacts by case coordinators, interviews with QA staff and/or data collected as a result of incident management reports, complaint logs and fair hearings.

Similarly, states usually have a number of discovery methods to learn about the performance of providers. These may include interviews with individuals, family members and workers; observation of the services being delivered and/or the environment (in day programs and residences); record and chart review; review of contracts, policies and procedures; review of complaints and incidents; and financial practices and expenditures. The focus and purpose of these reviews may be to examine: the appropriate implementation of individual plans; worker qualifications and agency training practices; staffing patterns and staff reliability; availability of services; and/or administrative and organizational capacity. The following table provides an example of how multiple discovery methods can be used to inform the state about program performance.

Who/what function is focus of review	Discovery Methods
Assessment of individual needs/preferences	
Accuracy and reliability of assessment	Interviews/surveys Record reviews Analysis of operations data
Level of care determination	
Accuracy and timeliness of level of care	Record reviews Automated tracking reports
Individual plan development	
 Adequacy/appropriateness of individual plan Needs/personal goals met Service plan implemented Service needs match assessed needs Individual plan changes as needs change Choice 	Interviews Surveys Record reviews Review of operations data Case management monitoring notes
Care/service coordination function	
 Coordination of services Frequency, resolution of contacts and issues Availability and timeliness of response by service coordinators 	Interviews Surveys Record reviews Review of contracts, policies and procedures Review of operations data (e.g. claims data, contact notes)
Providers of services	
 Environmental conditions (facility based services) Implementation of individual plan Worker competence and reliability Staffing patterns Availability and timeliness of services 	Interviews Record reviews Observation Review of contracts, policies and procedures Review of operations data (e.g. licensing, certification, complaints, incidents) Financial record reviews
Participant satisfaction and outcomes	
 Satisfaction with individual plan and services Satisfaction with providers/case coordinators Satisfaction that needs are being met Knowledge of rights/complaint processes 	Interviews/surveys Record review Case management contacts Complaints/Incidents Analysis of operations data

The following sections discuss each of these discovery methods and the contents and areas of focus of the discovery methods.

■ Interviews/visits

Talking directly with waiver participants and/or their families is the most fundamental form of a discovery method. Typically this would involve a visit to the place where the person lives. It may also involve either a visit or phone conversation with other people who are close to the waiver participant such as a family member, case coordinator, or other people involved with the person's services. Interviews/visits are usually conducted by a specially trained staff or team. People may be identified for an in-home visit or interview based on a sampling plan or may be referred for review because of special circumstances (e.g. complaints, critical incidents or abuse).

■ Structured surveys

Structured surveys, using a standard survey instrument, are also a method for collecting information at the individual level. Surveys are used to collect information from consumers, family members, guardians and workers. States use a variety of methods to collect survey data from consumers. In Indiana, quality monitors in field offices conduct the surveys. Case managers are encouraged to be present with the survey interviewer. If extenuating circumstances are identified during the visit, the case manager is able to follow-up. In other instances, states contract with agencies or organizations, such as survey research organizations or a University, to conduct surveys. (For further discussion of surveys see **Appendix A**).

State Example: Surveys in South Carolina

South Carolina contracts with First Health Services of South Carolina, Inc. (a Peer Review Organization) to conduct its quality assurance review of providers. Reviews include onsite record reviews, consumer interviews, family surveys, provider surveys and a consumer satisfaction mail survey. Survey and interview questions are based on National Core Indicators for their source. Interviews with consumers are conducted by First Health Services staff. The family surveys are mailed and used as a supplement to the consumer review process.

A number of states are also conduct provider surveys. These include surveys to assess organizational characteristics, mission, board composition, staffing patterns, cultural sensitivity and awareness and/or finance and utilization patterns. Other provider surveys are directed at the workers to assess worker satisfaction, retention and recruitment issues. Still other states have developed provider self-assessment surveys.

State Examples: Provider self-assessment in California

The California Department of Developmental Services developed a Handbook for Providers of Services and Supports called, "Looking at Service Quality". The handbook is designed as a guide which assists providers through a self-discovery process in assessing 25 quality of life outcomes. The self-assessment includes a summary of areas of strength and a plan of action for areas where follow-up may be needed. The handbook is supplemented with 70 hours of direct service provider training across a two year period. The training provides a more comprehensive look at the areas covered in the handbook. The handbook and the curriculum can be found at http://www.dds.ca.gov/Publications/pdf/LookingServiceQuality.pdf

Example: Program assessment tools -

The Cash and Counseling program has also developed a set of tools for program self-assessment. This review also includes examples of tools used in other states.

http://hcbs.org/moreInfo.php/topic/216/doc/819/A_Guide_to_Quality in_Consumer_Directed_Services

Contacts with individuals

One of the core functions of HCBS waiver programs is service monitoring usually by case managers or service coordinators. This monitoring typically involves regular, scheduled contact with individuals to find out whether services are being delivered, whether services provided by more than one agency are appropriately coordinated, to assure that a person's goals and needs are being met and to address any other issues that may have arisen. Analysis of data that may be collected as part of these contacts is one type of discovery method that is available to states.

■ Observation

Observation usually involves an assessment of the environment where a person lives, works, or otherwise spends time during the day (e.g. day programs). Activities include observation of safety issues, interactions with staff, interactions with other residents, and review of other features of the home or residence such as cleanliness, atmosphere, temperature, lighting, furnishings, and/or homelike environment.

Record and Chart Reviews

Record and chart reviews are usually conducted by specially trained staff who follow standard protocols or review procedures and often have standardized forms and questions that are used. The review may include protocols for doing an expanded review or drawing additional cases to include in the sample in certain circumstances. A variety of records may be reviewed at a number of different organizational levels. There may be reviews of the records related to level of care determinations, plans of care, case manager notes or service provider records. These reviews may cover areas such as: timeliness of service initiation, participant involvement in the individual plan process, comparison of individual plan and services, re-assessment schedules, level of care re-determinations, changes in condition, areas of unmet need or areas for quality improvement.

A variety of scoring criteria are used to evaluate items under review (e.g. met/not met; best practice/satisfactory/needs improvement/follow-up needed). If the review takes place in a provider setting, there may be pre-visit, post visit and follow-up/remediation protocols. While the results of the individual review may be tabulated and maintained in an individual's record, summary results from all reviews may or may not be tabulated for a more systematic analysis.

State Example: Record Review in West Virginia

For **West Virginia's** review of providers in its MR/DD waiver, there are several areas that are assessed. The Medicaid agency has nursing staff who do the reviews. The review tool includes several modules. Modules such as Documentation Only Review (timeliness, accuracy and current status of required forms), Participant Review (documentation of forms) and Billing Review (review of service documentation and billed services) are some of the areas looked at. http://www.wvdhhr.org/bhhf/resources.asp

■ Financial Record Review

A review of financial records is a common part of a financial audit, contract review and/or licensure review. This may include a review of cost report information, payment and utilization data, calculation of amounts owed or due to a provider, financial practices and expenditures. It may also include a review of financial statements, relationships with other entities and financial solvency or profit.

■ Receipt, retrieval and analysis of operations data

Most HCBS waiver programs have programs or operations which focus on individual remediation of certain events (e.g. reportable events, complaints, adult protective services, fair hearing and appeals). These systems are typically designed to respond to and resolve individual cases as they arise. The aggregation and analysis of data from these systems represent important methods of discovery for HCBS waiver programs. Similarly, data collected from other program operations, (such as claims payment, other

administrative data, or waiting lists) provide useful information on patterns and trends of utilization. A discussion of these systems follows:

• Complaints and Incident Reporting

The ability to collect and track complaint and incident information is fundamental to ensuring health and welfare. A good complaint and incident management system captures meaningful data in a way that supports timely follow-up actions at the individual level, as well as system-wide quality improvement. While each state must determine what constitutes an incident or complaint and whether or not reporting is mandatory, states generally regard incidents as preventable events that involve direct harm, or risk of harm, to the individual and consider complaints to be lower level events with less potential for immediate harm. Incident categories include death, medication errors, abuse or neglect; whereas complaint categories are more likely to capture a participant's experience receiving services (e.g. dissatisfaction with PCA's quality of work, violation of a consumer's right to privacy and/or staff not showing up on time).

Complaint and incident data can be gathered through a variety of different sources and mechanisms, including required reports from providers, consumer hotline calls, in-home visits, survey and certification activities and occasionally consumer surveys (although respondent confidentiality often becomes an issue here). Once information is received, it is either stored in a centralized paper file, or entered into a computerbased system where there is greater potential to manage individual incidents and responses, as well as analyze system patterns and trends over time. In part due to consent decrees and legal action, MR/DD waivers programs tend to be farther along in the development of incident and complaint management systems and may have forms, definitions, data systems and other resources that can be modified and/or leveraged for other waiver programs within a state.

Most states are currently moving away from paper-based formats and have developed or are in the process of developing web-based reporting systems. Web-based management systems offer an automated and common means of collecting information about incidents and complaints and may have the capability to look up clients' complaint and incident histories, produce targeted alerts, identify "high fliers" and outliers, deliver automatic e-mail notifications and link to other relevant data systems. Data analyses and reporting are also facilitated.

Examples of some of the reportable events forms used by other states are included in **Appendix A. Appendix B** provides a comparison of reportable events by select HCBS Programs.

State Example: Ohio's Incident Reporting and Tracking System

The **Ohio** Department of Mental Retardation and Developmental Disabilities (ODMRDD) developed and implemented an internet-based centralized reporting system to report and track major and unusual incidents in its state MR/DD system. The system is used by county boards to report major and unusual incidents (MUIs) to the state, and by the state to follow up on investigations and remediation related to MUIs, as well as for analysis of patterns and trends related to MUIs.

System highlights include: common data entry and access to ODMRDD and County Boards; analysis of incident trends and patterns; alerts about program practices issued by state to County Boards, providers, and advocates based on trend analysis; special report conducted of providers with history of high number of MUIs; and weekly reports prepared for ODMRDD director.

http://www.cms.hhs.gov/promisingpractices/datareadinessOH.pdf

• Adult protective service systems

Adult Protective Service systems are often administered and managed outside the operation of the home and community based programs. Because of confidentiality and other issues, it may not be possible to determine the outcome of a case that is referred to APS or to receive reports on participants in the waiver programs. Improving communication and coordination between APS systems and other reporting systems is often an area of improvement identified by states.

• Fair hearings and appeals

All states must provide the right to a fair hearing. It is important to have a discovery method that includes an analysis of the number, type, pattern and results of the appeals.

• Administrative and other data

Analysis of data from ongoing program operations is one of the most efficient and reliable forms of "discovering" issues or analyzing trends. It is efficient because the data is usually being collected and or generated for another purpose (e.g. claims data for payments, assessment data for determining levels of care or plans of care, complaints and incidents) and thus does not require a separate data collection effort. It is usually possible to analyze information on all participants and not just a subset or a sample of the population.

Claims data, for example, are a good source of information for utilization trends and costs. It also includes demographic information (e.g. age, sex, residence), program information (eligibility codes); clinical information (e.g. primary and secondary diagnoses, medications) and provider information (e.g. provider types, procedure codes). Maine has used its claims data to examine use of medications (e.g. number of medications, use of psychotropic medications, use of inappropriate medications for

the elderly); hospitalizations and emergency room use; and rates of preventive screenings (e.g. breast cancer screening, mammography screenings, diabetes screenings). Some of these indicators require linking Medicaid and Medicare data for people who are dually eligible.

Some of the ways that program and administrative data are used for quality assurance are:

State Example: Automated Case Management System in South Carolina

South Carolina has an automated case management system where reports are used to monitor quality assurance and program compliance. Reports include assessment reevaluations that are past due, timeliness of level of care determinations and service authorizations.

State Example: Waiver Tracking System in Ohio

Ohio developed a Waiver Tracking System. This system provides central MR/DD staff with a system for processing all waiver applications received, enrollments, re-determinations, disenrollments and denials. It also enables staff to track level of care determinations.

State Example: Report on Mortality in Wyoming

A recent study in **Wyoming** examined death rates in the general population with death rates for people with DD. The results of this study identified areas for further study and possible focus for identifying risk factors and other possible preventive practices. It also identified gaps in reporting procedures, data collection and communication. (University of Wyoming, 2004)

State Example: Automated Client Assessment and Planning in Oregon

Oregon. Oregon has an automated client assessment and planning system that is connected to remote locations. Case Managers throughout the state enter information into the central database to determine service eligibility and scope (through built-in algorithm) and to generate plans of care. Information from this system can be easily accessed and aggregated to monitor quality in waiver services for seniors and people with physical disabilities.

State Example: Automated Client Assessment in Maine

The Maine Bureau of Elder and Adult Services has an automated client assessment system. Any person seeking long term care services in the state must receive an assessment to determine eligibility for state and Medicaid funded long term care services. A single state-side agency conducts the assessments. Nurses conduct assessments at home or other settings to determine eligibility, develop a plan of care and provide consumers with choice of services. The information is uploaded to a central data system for use in ongoing program administration and program monitoring. A separate agency conducts care coordination, implements the plan of care and contracts with providers for services. This agency also has access to the assessment information. http://www.maine.gov/dhhs/beas/provider.htm

• Utilization Review

Utilization review is often a central function performed as part of the general administration of the Medicaid program. This includes a review of the appropriateness and accuracy of the services provided and amounts paid for services.

• Waiting Lists

Most states maintain some kind of waiting list for people who are seeking services. Sometimes these waiting lists are maintained at the state level and other times they are maintained by individual providers. The ability to keep accurate and timely information on the number of people waiting for services, the length of time that someone has waited and the services needed is an important source of information for state policy makers. The ability to aggregate and analyze waiting list information is often critical to program management and resource allocation.

• Results of licensure and certification

Results of the inspections and surveys conducted as part of licensure and certification are another source of information that can be included in a system of discovery methods. Often the results of these surveys include information on deficiencies, scope and type of deficiencies and action plans. Analysis of patterns and trends from such reports can inform policy makers, consumers and providers.

State Example: Review of Providers in Massachusetts

In Massachusetts, the survey process is an integrated review that includes a review of licensure outcomes as well as a review of certification outcomes. The survey consists of two components: the review of the impact of the provider's supports on the quality of life of the individual and the organizational review. The review of the individual includes: observation, discussion with the individual and key people in his/her life and review of documentation. The intent of the organizational review is to determine how the agency positions itself to support quality and includes interviews with key managers to determine ways in which the agency is committed to service enhancement, supporting staff and safeguarding individuals.

http://www.qualitymall.org/products/prod1.asp?prodid=80

State Example: Review of Providers in Indiana -

Indiana recently passed a law that establishes the standards for surveying licensed and non-licensed providers. The law requires all providers to have an internal quality assurance and quality improvement system that focuses on the individual and the needs of the individual, and includes an annual satisfaction survey, documentation of reviews and remediation results, analysis of reportable events and analysis of effectiveness and appropriateness of supports and instructional techniques. The state is developing standards for surveying providers, including survey tools and interpretive guidelines. All providers including many licensed providers (such as behavior consultants with PhDs and Health Care Coordinators with RN or LPN licenses) will be surveyed.

Certain licensed providers that already undergo an in-depth survey through the Department of Health will be exempt from the new requirements (e.g. home health agencies) although there will be efforts to supplement the survey conducted by the Bureau of Health with questions from survey instruments used for other providers. Case managers must also monitor and document the quality, timeliness and appropriateness of the care, services and products provided to individuals.

http://www.in.gov/legislative/iac/title460.html

Review of Contracts, Policies and Business Processes

Discovery methods may include formal and informal reviews of business processes, policies, and other business procedures. This can include a review of internal operations (.e.g. timeliness of eligibility determinations; communication protocols for complaint resolutions); or a review of relationships and contract parameters with sub-state entities or providers (e.g. review of quality assurance requirements for contractors; data submission requirements; reporting requirements).

Many states contract with sub-state entities (e.g. counties), case management organizations (e.g. Area Agencies on Aging) or other agencies to perform various program functions (e.g. assessment of medical eligibility, case management). These arrangements are usually conducted on a contractual basis and these contracts include specifications of work to be performed, policies to be followed and in some instances contract performance requirements, (e.g. Maine and Alaska). States perform a variety of quality assurance activities that include review of forms and instruments that are used, reliability of data submissions, the adequacy of documentation, how well policies and procedures are being followed, and whether processes and procedures are being followed. Other quality review activities may include assessment of sampling criteria, number and type of data elements that are reviewed, and the efficiency and cost-effectiveness of the quality assurance activities.

Key Informant input and findings

Information obtained from key informants, consumers, subcontractors, providers, and other stakeholders often provide a way to identify or spot emerging issues (e.g. worker shortage areas or communication gaps), or other areas of concern (e.g. timeliness of payments, waiting lists). Providing opportunities to regularly obtain this kind of input and feedback often provides a way to address or respond to an issue early on. Most states have one or more advisory committees, systems groups, regional quality advisory groups or stakeholder meetings that provide a way to hear more directly from and report to interested and concerned parties. Although the information gathered from these meetings is usually qualitative rather than quantitative, it often provides a way to guide or focus further inquiry or data analysis. Some of these methods of key informant input are discussed below:

• Quality Review Committee Meetings

Many agencies and organizations have quality review or quality management committees that meet periodically to review individual cases, reports, or issues that have arisen. Such meetings provide semi-formal ways to "discover" areas for remediation and improvement.

• Stakeholder Meetings

Stakeholder meetings provide a way to review patterns, trends and other analysis; to identify issues or areas for improvement; and to spot other issues or areas of concerns that may or may not be surfacing through formal mechanisms.

• Focus Groups

Focus groups provide an informal method for identifying issues, obtaining initial spontaneous responses to an idea or concept, and/or assessing needs. Usually six to nine people are brought together to discuss issues and concerns or respond to semi-structured questions. Focus groups can be held with consumers, family members, workers or other stakeholders. The results of focus groups are considered qualitative rather than quantitative. However, the results of focus groups are often used to develop more structured questions in a questionnaire, identify issues that may need further investigation, spot themes or trends of concern, and/or provide initial response to proposed policy or practice.

Take-Away	It is important to have a mix of formal and informal discovery
Lesson	methods that cover all the areas of importance to key audiences.

What are the features of a reliable and robust system of discovery methods?

The end result of a discovery method is management information that is reliable and timely and can be used to draw reasonable conclusions or identify areas for further inquiry. The following have been identified as important components of a reliable and robust system of discovery methods.

- Protocols for data collection
- Qualified reviewers/interviewers
- Sampling methods that allow conclusions
- Standard data collection instruments
- Reliable and accurate data
- Ability to transform data into useful and actionable information

Each of these will be discussed below:

Protocols for data collection

Data collection protocols include guidelines for how often to schedule onsite reviews or home visits, who should be part of the review team, whether the review is part of an announced or unannounced visit (if it is a review of a provider or a contractor), whether it is necessary to get informed consent and what records or other information should be made available during the review. If the review is with a provider or contractor, this will include protocols for meeting with the administrators and staff, procedures for reviewing records and other information, a tour of the residence, interviews with participants and family members, and exit interviews.

If the data are being collected as part of a home visit, the protocols will include contacting the participant and/or family member, scheduling the visit and specifying areas for review and remediation. The protocol will also include guidelines for follow-up activities or processes when there are areas of deficiency or areas of improvement needed.

State Example: Protocols for conducting reviews in Florida

The Florida Agency for Health Care Administration has contracted with the Delmarva Foundation to develop Provider Performance Review Procedures for the Developmental Disabilities Home and Community-Based Services Waiver Program. These review procedures are for a variety of services: adult day training, non-residential support services, residential habilitation, support coordination, supported employment and supported living coaching. The manual specifies the other providers that will be monitored as part of a desk review and the procedures for provider performance review site visits. These include pre-site visit procedures, opening conference, onsite activities, record review, checklists and other tools for assuring compliance with program requirements. Protocols for the final report and the exit conference are included. Further description of the review tools is included in Appendix A. <u>http://www.dfmc-florida.org/</u>

Federal Examples: Nursing Facility and Home Health Reviews

Nursing Homes: The protocols for conducting nursing home reviews and home health reviews are included in the CMS State Operations Manual. Nursing home surveyors use the NF quality indicators to help schedule nursing home reviews, to select residents for a sample, to identify issues for the review team prior to the visit. The nursing home survey teams also have standardized forms for conducting the reviews including a resident roster/sample matrix; a quality of life assessment, family/resident interview forms and a resident review worksheet. http://www.cms.hhs.gov/manuals/107_som/som107index.asp#toctop

Home Health: Similarly, the OASIS Home Health Quality Indicators are used to structure the scope and focus of the home health reviews. Home health surveyors use a functional assessment form to record information obtained during home health visits and clinical record reviews. <u>http://www.cms.hhs.gov/quality/hhqi/</u>

■ Qualified reviewers/interviewers

When data are collected as part of a formal quality review activity, it is important to have people trained in the content area being reviewed. Many review activities are conducted by people who either have special qualifications (e.g. a nurse) or who have been trained in the conduct of the quality assurance activity. Policies, manuals and ongoing training programs provide a way to assure the consistency and reliability of the data that are collected. Protocols for assuring that there is no conflict of interest between the person conducting the review or interview and the person/agency being reviewed are also important.

A few states have developed innovative review programs that include individuals with disabilities as reviewers.

State Example: Independent Monitoring for Quality in Pennsylvania -

The goal of **Pennsylvania's** statewide Independent Monitoring for Quality (IM4Q) project is to allow for the monitoring of MR services by individuals and families who are knowledgeable, trained and independent (do not provide services) with a strong role for people with disabilities. A two to three member interview team (consisting of a mix of consumers, community members, and family) administers a personal quality of life survey to a random sample of 1/3 of consumers receiving MR supports and their families when appropriate (6,373 adult and children were interviewed in fiscal year 2004). Teams conduct confidential interviews with individuals receiving MR services either at their home or at another place of the consumer's choice. All interviewers are supported by independent agencies that are not tied to providing hard services. Their role is to recruit, train and oversee interviewers thereby maintaining the independence of the program.

http://www.dpw.state.pa.us/Disable/MentalRetardationServices/003670114.htm

State Example: Ask Me! Project in Maryland

In **Maryland**, the Ask Me! Project employs individuals with developmental disabilities to administer a close-ended quality of life questionnaire to over a thousand persons annually who receive services through the Developmental Disabilities Administration. Interviews are conducted exclusively by individuals with DD; however, Arc of Maryland project staff support interviewers by contacting provider agencies to arrange interview times, scheduling transportation, and being on-site during the interviews to help with coordination. While providers were initially skeptical about the quality and accuracy of data collected by consumers, the project has held firm to the notion that persons with developmental disabilities are in the best position to elicit meaningful consumer satisfaction/quality of life responses from peers. The project is in its 7th year, and has hired an individual with DD to serve as a quality consultant, observing each interview pair twice a year and providing critiques that are recorded and later processed.

http://www.thearclink.org/state/news/article.asp?ID=MD&article=350

State Example: VOICE in Minnesota

Five out of eleven Region 10 *Minnesota* counties participate in the Value of Individual Choices and Experiences (VOICE) Review. VOICE Reviews use teams of two trained interviewers (including parents, guardians, self-advocates, residential and work providers, case managers, and advocates) to conduct a comprehensive set of openended interviews with individuals with developmental disabilities and their most important supports (e.g. providers, employers, case managers, family). The VOICE tool includes sample questions for interviewers new to the experience, but is viewed more as a structure which guides the interview team through eight life and service domains while allowing flexibility to follow the direction of the consumer and what he/she deems as most important. Data collected through this process is used to monitor and improve the supports provided to folks with DD, as well as to inform licensing decisions. A minimum of three interview sets (or 5 percent of people served) are conducted per each provider program up for a license. www.mn-voice.org

State Example: Community Interviewing in Vermont

Vermont conducts a consumer survey of adults with developmental disabilities. The interviews are conducted by contracted workers, including two consumers, trained in the administration of the survey. Approximately 375 people with developmental disabilities are identified to participate. Approximately 150 - 200 consumers are interviewed each year with demographic information collected for all 375 participants.

For those surveys where a peer/consumer is involved in the interview, the consumer is paired with another interviewer and actively participates in the administration of the survey. All members of the interview team are paid. The survey instrument used is a state-based quality of life survey developed specifically for use in Vermont and match relevant questions with the National Core Indicators Consumer Survey for comparison on a national basis.

Sampling methods that allow conclusions

It is usually necessary to draw a sample of records to review and/or individuals to interview. If the reviews are being conducted by a sub-state entity such as a county, the requirements for sample selection may be specified in the contract. In Oregon, the state selects the sample for each regional agency and provides the list of names to the agency.

Selection of a sample usually involves selecting a certain percent of cases for review with a minimum number of cases per agency or provider. In some instances, there may be criteria for excluding some cases as part of a sample. It may be appropriate, for example, to exclude cases where people have been on the program for a short period of time. It is important to select cases using statistical sampling methods that assure the results and conclusions that are drawn based on the sample are generalizable to the larger population of interest.

In some instances, there are protocols for adding people or cases to a sample if "red flags" are identified during the review process. This may occur if the percent of deficiencies exceeds a certain threshold or if the reviewer identifies any specific concerns or issues during the review. Protocols and interpretive guidelines provide a way to specify the circumstances under which such additional cases should be selected.

Another sampling method is to "stratify" the sample. This means that certain subgroups are identified and a sample is selected for each subgroup. A stratified sample may be developed in order to review people with certain conditions or circumstances (e.g. people with hi-risk conditions, people with high cost cases, recent deaths). A sample may be stratified by region or other demographic criteria.

It is also possible to identify certain sub-groups for whom a different approach may be used to collect information. If information is being collected through interview or with a survey, it may be necessary to develop alternate ways of collecting information from people with high levels of cognitive impairment or others who may not be able to understand, to speak for themselves or make themselves understood. It is also important to identify people with interpretive needs as part of the sampling plan.

Whatever the criteria, the goal is to select a sample that allows for an efficient use of resources and will yield information that can be used to draw conclusions or identify areas for improvement.

Standard data collection instruments

The foundation of any discovery method is a standard and reliable set of data collection instruments. A data collection tool is a method for gathering information from multiple sources in a consistent manner that allows results to be aggregated.

Data collection instruments include:

- Forms for business operations: eligibility determination, assessment, care planning and case management function;
- Incident and complaint reporting forms;
- Consumer, family and provider surveys;
- Forms for conducting the quality assurance review function;

A standard form usually includes instructions, definitions of terms and items, and protocols for data collection and data recording. Some forms may have been tested for reliability or validity. Others have been developed as part of state-specific activities.

Appendix A includes a discussion of examples of instruments that are used for assessment, care/service planning, incident reporting, consumer surveys and quality assurance review.

Reliable and accurate data

It is important to periodically review and analyze the reliability and accuracy of data that are collected. A number of ways to assure or assess reliability and accuracy are as follows:

Use reliable data collection instruments: In some instances, the data collection tool may have been developed as part of a larger research initiative that included testing the items on the instrument for reliability. The Minimum Data Set for Home Care (MDS-HC), for example, is a standardized assessment instrument for people receiving home care services. The items on the instrument have been tested for reliability. This means that if two people use the instrument and ask the same questions of the same person, they are highly likely to get the same answer.

Compare documentation in record with other sources of information: Another way to check for reliability is to compare the documentation on a record with information gathered from direct observation, interviews or other sources of data. In Maine, case records were reviewed for reliability as part of an inter-rater reliability process. An MR document review and protocol was prepared and reviewers examined case records and supporting documentation to determine the accuracy, completeness and reliability of records. This was a resource intense process conducted as one component of a consent decree. In other instances, a quality assurance review team may compare information in an individual's record with information gathered from personal interviews or as part of the assessment process. Similarly, audit teams may compare information from claims (e.g. payment for services) with other documentation (record, interviews) to determine the accuracy of the claim.

"Look Behind" reviews: In the administration of home and community based systems, there may be multiple layers of agencies involved in quality review activities. A state may contract with an agency to provide case management and the case management agency may, in turn, contract with individual providers to deliver services. The state may require the case management agency to monitor the quality of the providers with whom

they contract and they may require the agency to conduct its own internal quality assurance and quality improvement activities. In these instances, the state's role may include reviewing the agency's internal quality assurance activities and reviewing the agency's review of contract providers' quality activities. In this case, the state is examining how well the subcontractors performed their activities.

■ Ability to aggregate, analyze and report data

One of the most important attributes of a reliable discovery method is the ability to aggregate and report the data that are collected at the individual level. In some states, an individual review may be conducted using standard forms and protocols but the results of the review and the remediation are not aggregated into a summary report. While this approach may work when the number of waiver participants is small, it does not provide work with larger populations. States need summary level information to determine whether an issue is a single incident or represents a pattern across a number of cases. Many states are developing the capacity within their information systems to generate routine reports addressing specific areas of quality. In addition, some states are also developing data warehouses that store data collected from a variety of sources and which provide states with access to more information and the ability to develop reports that provide a more robust view of the system's performance.

Converting standardized forms that are often paper documents into electronic databases is a critical step in the design of a robust system of discovery methods. This conversion is often labor intensive and expensive for states. As part of this process, it is important to remain focused on the core data elements that need to be included in an electronic database for reporting purposes. It may be that a subset of items from a standard form can be computerized thus reducing the time and cost of maintaining the data.

Another step in the discovery process is the production of management reports that cover the focus areas of discovery that have been identified. Ideally, reports are reviewed by managers and other stakeholders on a periodic basis to monitor key indicators and identify areas for improvement or further investigation. This will be discussed further in a later chapter.

Appendix C is a sample report of a review of the robustness of a system of discovery methods for a fictitious Waiver Program.

Take-Away	It is important to assess the discovery methods conducted by all
Lesson	entities and review them for reliability and robustness.

What is a comprehensive yet focused system of discovery methods ?

One of the challenges in developing a system of discovery methods is to determine whether the system is:

- comprehensive does it provide a way to assess all the outcomes of interest,
- focused will the results of the discovery methods provide the information that is of most importance to managers, policy makers and other stakeholders;

As states' ability to automate the collection of information increases, the challenge becomes one of focus and data management. A number of states have found that the issue is not whether they have enough data, but how to organize, report and use the data in a timely and cost-effective way.

A number of the QA/QI grantees have undertaken an analysis of their systems of discovery methods and quality assurance activities to identify areas of weakness, redundancy or strength. This kind of "gap analysis" is a useful first step to identify what information is collected, what outcome areas are covered by the data collection, who collects the information and how it is used.

Some of the questions to ask in determining whether a system is comprehensive, focused and efficient are:

- Do the discovery methods produce the evidence CMS requests as part of its waiver reviews?
- Do the discovery methods produce data that informs or serves to improve the policy, management, or operational aspects of the program?
- Do the discovery methods produce data that is of importance to key stakeholder audiences?
- How will key audiences use the data?
- Are there redundant or inefficient methods of discovery?

■ Do the discovery methods produce evidence that CMS requests as part of its waiver reviews? As discussed earlier, it is important that states be able to meet the minimum requirements for producing evidence to support the assurances set forth in its waiver applications. Furthermore, the discovery methods should be able to easily and efficiently produce this data as part of the usual and customary part of operations.

Appendix D provides a sample report of one way to map CMS assurances against a state's system of discovery methods.

■ Do the discovery methods produce data that informs or serves to improve the policy, management, or operational aspects of the program? Beyond the evidence required by CMS, program managers need information to develop their quality management plans and to monitor and manage their programs. The CMS framework provides a way to structure an assessment of whether current discovery methods can produce information to meet this need.

State Example: Conducting a gap analysis in Minnesota

Minnesota: Minnesota conducted an extensive inventory using the CMS Framework. For each domain and sub-domain in the Framework, there was an assessment of whether data was available, whether it was required by statute, and whether it was a priority. Furthermore, for each domain and subdomain, the possible sources of evidence were identified.

■ Do the discovery methods produce data that is of importance to key stakeholder audiences? There are many audiences who are interested in examining the performance of HCBS systems. CMS and state program managers are key audiences. Other audiences include the Medicaid agency, sub-state entities, providers, legislators, consumers, family members and the general public. Each group may weigh or value certain areas or quality indicators more than others. Determining what areas are of most importance to key audiences and why will help to focus the collection, analysis and management of data. Providing a process for stakeholders to be involved in setting priorities for data collection and analysis helps to prioritize activities. This could include a priority setting exercise where members of various stakeholder groups vote on the importance of various outcomes and the weight they would like to give those outcomes.

■ How will data be used by each audience? Each audience will have a different use for the information that is produced as a result of a discovery method. In general, the data that is produced from a discovery method will serve to inform a particular decision or prompt certain actions. For consumers, it may be useful in terms of selecting providers or making choices among programs. For providers, performance information may help to focus internal quality improvement activities. For program managers, results may identify areas for further training or policy change.

■ Are there unnecessarily redundant or inefficient methods of discovery? Data collection and analysis can be a costly and time consuming process. Resources in most states are limited. The interests of the various stakeholder groups always need to be weighed against the reality of the costs and benefits to the program. Mapping all discovery methods used by all levels of organizations and agencies that are responsible for program operation and quality assurance may identify areas of overlap, redundancy and/or opportunities for collaboration and coordination.

Appendix E provides a sample report of how the review of discovery method might be prioritized.

	Actively engage stakeholders in developing a balanced and
Take-Away	
	comprehensive discovery system. Define the audience, purpose and
Lesson	use of final analysis and reports.
	dse of final analysis and reports.

What evidence or other reports are produced from the discovery methods?

States are in the early stages of being able to produce comprehensive reports on the results of their discovery methods. In the spring of 2004, CMS released its Interim Procedural Guidelines which included a Guide for Assisting States in Producing Evidence for review by CMS. This tool is organized around the statutory assurances associated with HCBS Waiver programs. The Guide includes probing questions and illustrative examples of evidence that could be provided in each area of assurance.

In addition to the evidence that states produce for CMS, a number of states have produced quality reports on their home and community based systems.

State Example: Massachusetts Department of Mental Retardation Quality Assurance Report

The Massachusetts Quality Assurance Report is the result of a strategic planning process to develop a department-wide quality management and improvement system. Stakeholders identified 10 outcome areas as important to measure and report on. These outcome areas are: health, protection from harm, safe environment, human and civil rights, decision-making and choice, community integration and membership, relationships, achievement of goals, work and qualified providers. Outcomes, indicators and measures are identified for each area with positive and negative trends reported. http://www.hcbs.org/files/56/2788/

State Example: South Carolina Report of Provider Reviews

South Carolina produced an annual report on the performance of 11 providers, The data reflects the aggregate and individual performance of providers in the four regions of the state. Each provider experienced two types of reviews: compliance and consumer. The compliance review evaluated the provider's compliance to Federal standards and critical policies. The consumer reviews captured the perceptions of support and satisfaction with services using the National Core Indicators. For more information, contact Bob Jones at jonesbo@fhsc.com.

State Example: Key Indicators of Performance in Colorado

Colorado has prepared a Key Indicators of Performance report that provides a short list of performance measures that were adopted as a way to provide an overall picture of the health and welfare of the Colorado service system for people with developmental disabilities. The key indicators were selected based on stakeholder input. The key outcome areas include: effectiveness and outcomes, standard of care, health and safety, accessibility to services and resources, organizational stability. Results are shown over time.

http://www.cdhs.state.co.us/ohr/dds/KeyIndic02.htm

State Example: Georgia PERMES Report -

The Georgia Performance Measurement and Evaluation System (PERMES) is a comprehensive outcome evaluation and performance measurement system. Its purpose is to reflect levels of performance, mark progress and guide policy decisions to improve responsiveness, quality and impact of the state's mental health, developmental disability and addictive disease system. Information used by PERMES is drawn from multiple sources of data, including the Division's information system, administrative databases, consumer and family surveys and individual outcome assessments. The Division is currently in the process of redesigning the portion of PERMES that relates to performance and outcomes for people with developmental disabilities and their families. Particular emphasis will be placed on indicators that will measure choice, inclusion, least restrictive environments, quality of services, individualization of services and adaptability to change.

State Example: Incident Management System in Connecticut -

Connecticut has an incident reporting and management system where reports are generated by region, by provider, and by type of program/service. The reports include benchmarks, provide comparisons with state-wide averages and show trends overtime.

Example: National Core Indicators -

The National Core Indicators is a collaboration among participating National Association of State Developmental Disabilities Directors member state agencies and the Human Services Research Institute (HSRI) with the goal of developing a systematic approach to performance and outcome measurement. The core indicators are the foundation for the project. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes outcomes that are important to understanding the overall health of public developmental disabilities agencies. Associated with each indicator is a source from which the data is collected. Sources of information include a consumer survey (e.g., empowerment and choice issues) a family survey (e.g., satisfaction with supports), a provider survey (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc).

http://www.hsri.org/nci/index.asp?id=reports

Take-Away	Reports from a number of states provide examples of quality
Lesson	reports for HCBS services.

How do states move from discovery to action?

At the end of the day, the purpose of the discovery process is to produce information that can inform decisions and point to actions for remediation and quality improvement. This paper has focused on ways to develop a reliable and robust set of discovery methods as a foundation for an overall quality management system. Moving from the production of accurate and reliable data to presentation of understandable and actionable information requires a number of additional techniques and tools. A full discussion of ways to move from discovery to action and quality improvement is beyond the scope of this paper. However, some of the questions that frequently arise when converting data to useful management and/or publicly available information are:

- How do you verify data accuracy?
- What questions are you trying to answer?
- How do you analyze data so that conclusions are valid and point to action?
- How are quality measures constructed? Adjusted?
- How will data be used? How often and by whom?
- What skills and training are needed in an organization to use data wisely?
- How do you move from analysis to action?
- How do you select and develop quality improvement projects?

A number of these questions have been discussed in the HCBS Quality Workbook (<u>http://www.cms.hhs.gov/medicaid/waivers/hcbsworkbook.asp</u>). The workbook is a tool for states to improve the quality of home and community based programs and supports (HCBS) programs and can be used in a number of ways including:

- To understand the components of a quality improvement process for HCBS programs;
- To guide the design and implementation of a quality improvement project; and
- To document and monitor progress of a state's quality improvement activities.

The next in the series of Quality Management working papers will address these questions in more depth. As states work to improve their systems of discovery methods, it is helpful to keep these questions in mind.

In conclusion, the development of an efficient and effective quality management system is an incremental and iterative process. Discovery methods provide the building blocks for the production and analysis of data that can be transformed into information to:

- improve program operations,
- guide policy development,
- inform public audiences, and most importantly,
- support the overwhelming preference of people who receive long term services to live in their homes and communities.

Appendices

Appendix A: Forms

■ Assessment Forms

Assessment forms are generally used to determine program eligibility and to develop plans of care. Some states also use the information in their assessment instruments to make payment based on needs.

By and large, it appears that the wide variety of forms that states use for managing their program operations and for assessing quality are state specific. In the early 1990's, the Colorado Division of Developmental Disabilities contracted with consultants to examine state of the art and best practices in quality assurance instruments throughout the country. The report concluded that most tools: (1) did **not** consider alternate methods of data collection for persons with limited communication skills; (2) had not been studied for reliability or validity; (3) were not been standardized; (4) did not focus on quality of life and (5) did not offer interpretive guidelines. Since that time, a number of instruments have been developed in individual states that are being adopted or adapted for use by others. A recent survey of statewide DD practices continued to find great variation in the use of standard assessment practices. http://www.cpinternet.com/~bhill/icap/

Examples of some of the types of assessment forms that are in use are discussed below.

Assessment Instruments for Older Adults and Adults with Disabilities. A number of states are using a standard assessment instrument for older adults that is based on the MDS and is called the MDS-HC. The MDS-HC was developed to provide a common language for assessing the health status and care needs of frail elderly and disabled individuals living in the community. The system was designed to be compatible with the Long Term Care Facility system that was implemented in US nursing homes in 1990-91. http://www.interrai.org

According to the developers, the HC was designed to highlight issues related to functioning and quality of life for community-residing individuals. It consists of the Minimum Data Set for Home Care (MDS-HC) and Client Assessment Protocols (CAPs). The MDS-HC is a 5 page tool, designed to collect standardized information on a broad range of domains critical to caring for individuals in the community, including items related to cognition; communication/hearing; vision; mood and behavior; social functioning; informal support services; physical functioning; continence; disease diagnoses; health conditions; preventive health measures; nutrition/hydration; dental status; skin condition; environment/home safety; service utilization; medications; and socio-demographic/background information. Multiple trials have been conducted in several countries that establish good inter-rater reliability of MDS-HC items.

Maine uses an early prototype of the MDS-HC that was developed to determine eligibility and develop plans of care for all its long term care services including home and community based waiver services for older adults and adults with disabilities. A single statewide agency conducts the assessment for all people seeking long term care services in the state. Assessors have laptop computers and conduct the assessments in a person's home, or in another setting (e.g. nursing home, assisted living, hospital). The assessment data is electronically stored and accessible by the state and the statewide home care coordination agency. The statewide home care coordinating agency implements the authorized plan and contracts with providers to provide services. A number of states have adopted or are using the MDS-HC as a standard assessment instrument for the HCBS programs.

Assessment Instruments for People with MR/DD. For MR/DD programs, a number of states use the Inventory for Client and Agency Planning or ICAP. The ICAP is used to assess the type and amount of special assistance that people with disabilities need. This assistance may be in the form of home-based support services, special education, vocational training and supported work or special living arrangements such as personal care attendants, group homes or nursing homes. In 2003, an inventory was conducted of statewide DD Assessment Practices. A number of states use the ICAP but there is still considerable variation in the type and standardization of assessment used. http://www.cpinternet.com/~bhill/icap/ and http://www.qualitymall.org/main/

■ Case Management Forms

Like the assessment instruments, it appears that case management forms tend to be statespecific and non-standardized. One of the challenges in the use of a standardized instrument for case management is the variation in functions performed by case managers. In a report on State-funded Home and Community-Based Service Programs for Older People, it was found that the role of the case manager differs from state to state. In most of the 34 programs surveyed, case managers acted as a service coordinator and monitored the appropriateness of services. They are less likely to consistently be responsible for other functions such as determination of financial or functional eligibility, or to determine whether care plans are established within certain financial guidelines. (Summer and Ihara, 2004) In the GAO report on Medicaid Home and Community Based Services, the most frequently identified quality of care problems in waivers serving the elderly involved failure to provide authorized or necessary services, inadequate assessment or documentation of beneficiaries care needs in the plan of care and inadequate case management (U.S. GAO Office 2003).

■ Incident Reporting Forms

Variation in incident report formats reflect the variation in definitions of reportable events and other incidents used by state waiver programs. Further, incident reporting and adult protective reporting systems are often operated separate from a HCBS waiver program so communication with HCBS program managers may not be well established or routinized. **Appendix B** is a chart of the different definitions of reportable events in seven states. The definitions and categories of reportable events have been grouped into the following areas for ease of presentation: death, hospitalizations, serious injury, abuse/neglect/exploitation, damage to consumers' property, medication errors, law enforcement interventions, missing persons, restraints and other.

Examples of other incident report forms are:

- Maine MR Reportable Events Form, Procedures and Instructions http://www.maine.gov/dhhs/bds/mrservices/APS/index.html
- New Mexico Cross-Waiver Incident Report Forms, Regulations, Reports http://dhi.health.state.nm.us/imb/index.php

Consumer and Family Surveys

A survey is also an example of a standard data collection instrument. Structured surveys will generally include instructions on how to complete the survey, whether it is a mail survey or a face-to-face survey, definitions of terms and response categories. Some of the more common consumer surveys that have been developed include:

- Participant Experience Surveys (for older adults and adults with disabilities; for people with mental retardation and developmental disabilities). A state-specific modification of the participant experience survey was developed in Maine for people with disabilities who self direct their own services. http://www.cms.hhs.gov/medicaid/waivers/consexpsurvey.asp
- National Core Indicators surveys for people with mental retardation and developmental disabilities. <u>http://www.cms.hhs.gov/medicaid/waivers/consexpsurvey.asp</u>
- Other surveys for people with mental retardation and developmental disabilities have been developed by the Council on Quality and Leadership. <u>http://www.thecouncil.org</u>
- The Administration on Aging is sponsoring an effort to develop and field-test a core set of performance measures for state and community programs on aging operating under the Older Americans Act (OAA). http://www.gpra.net. The Performance Outcomes Measures project (POMP) helps States and Area Agencies on Aging assess their own program performance, while assisting AoA to meet the accountability provisions of the Government Performance and Results Act (GPRA) and the Office of Management and Budget's (OMB) program assessment requirements. OMB uses their Program Assessment Rating Tool (PART) to evaluate program performance.

■ Forms used as part of a Quality Assurance Review

More formal regulatory activities generally include standardized forms, guidelines and other tools for conducting quality assurance reviews. Reviews conducted as part of licensure and certification of nursing homes, ICR/MRs, and home health agencies as well as reviews conducted by professional quality assurance agencies provide helpful illustrations of the types of forms that are used during a review. The following provides a brief review of some of the forms and tools used by others:

Nursing Home Reviews. Nursing home surveyors use the following forms:

- Resident Roster/Sample Matrix (includes resident name, resident characteristics, issues noted by surveyor);
- Quality of Life Assessment
- Family and Resident Interview Forms;
- Resident Review Worksheet (includes resident room review; daily life review; assessment of drug therapies; comparisons of MDS items and observations; resident census and conditions of residents; surveyor notes worksheet. http://www.cms.hhs.gov/manuals/107_som/som107index.asp#toctop

Home Health Reviews. Home health surveyors use:

 the Functional Assessment Instrument Form (FAI). The FAI is used to record information obtained during home health visits and clinical record reviews and includes 5 modules and a calendar worksheet. The modules are used to collect information to determine appropriateness of care of services being furnished; progress in meeting potential functioning, other information appropriate to the patient's specific conditions or services provided. <u>http://www.cms.hhs.gov/quality/hhqi/</u> (See also State Operations Manual.)

Reviews by Quality Assurance Organizations

Organizations that conduct quality assurance reviews as a core business activity also have developed and use standard data collection tools and protocols.

Delmarva and the State of Florida have developed a set of tools for evaluating the Developmental Services Waiver. These include:

- Core Review Protocols: Outcomes Review and Enhancement Protocol
- Core Review Protocols: Collaborative Outcomes and Enhancement Procedures
- Waiver Support Consultation Coordination Tool and Procedures
- Personal Outcome Measurement Tool and a Core Assurance Monitoring Checklist and Protocol. <u>http://www.dfmc-florida.org/</u>

■ Self Assessment Reviews

Cash and Counseling demonstration developed a set of personal outcome surveys and program self-assessment tools as well as examples from 3 states (Arkansas, New Jersey and Florida)

These include:

- Personal Outcomes Survey and Training Material
- Quality Improvement Committee 10 steps to implementation
- Program Self- assessment <u>http://hcbs.org/moreInfo.php/topic/216/doc/819/A_Guide_to_Quality_in_Consum</u> <u>er_Directed_Services</u>

Regional Office Review Worksheets

Attachment D of the Interim Procedural Guidelines is the worksheet used by the regional offices to review the evidence produced by states for each discovery method.

Appendix B: Definition of Reportable Events by Select HCBS Programs

	California ¹ (DD)	Maine (MR/DD)	New Mexico ² (DD , E/D , TBI^{3})	Oregon (DD)	Pennsylvania (MR)	South Carolina (DD)	Wisconsin (DD, E/D)
Death	All deaths regardless of cause.	All deaths regardless of cause.	Both unexpected and natural/expected deaths.	Any death if individual is case managed by county or state.	All deaths are reportable.	If the death is accidental; of a suspicious nature; or law enforcement is involved.	Unexpected deaths. ⁴
Hospitalizations	Any unplanned or unscheduled hospitalization due to the following: Respiratory illness; Seizure-related; Cardiac-related; Internal infections; Diabetes related; Wound/skin care; Nutritional deficiencies; Involuntary psychiatric admission.	See Serious Injury.	Emergency Services, i.e. an admission to a hospital or psychiatric facility or the provision of emergency services that results in medical care which is unanticipated and/or unscheduled and would not routinely be provided by a PCP.	Hospitalization, defined as an injury or illness requiring admission and overnight stay at the hospital. Psych hospitalization. ER visits for injury or illness. Does not include ER visits for routine health care or to immediate and urgent care facilities.	Hospitalization, defined as an inpatient admission to an acute care facility for purposes of treatment. Psych hospitalization, including crisis facilities and the psych depts of acute care hospitals, for evaluation or treatment, whether voluntary or involuntary. ER visit, including situations that are clearly emergencies as well as those when individual is directed to ER in		

		Definition of Repo	ortable Events	by Select HC	BS Programs		
	California ¹ (DD)	Maine (MR/DD)	New Mexico² (DD, E/D, TBI ³)	Oregon (DD)	Pennsylvania (MR)	South Carolina (DD)	Wisconsin (DD, E/D)
Serious Injury	Serious injury/accident including: Lacerations requiring sutures or staples; Fractures; Dislocations; and Puncture wounds, Bites, Internal Bleeding, Medication errors/reactions and Burns that require medical treatment beyond first aid.	Serious injury or illness, include any change in medical conditions caused by accident or illness that requires hospitalization; non-routine treatment not identified in the person's plan; significant adverse reactions to meds; sexually transmitted diseases; etc.	Required if falls under Abuse or Neglect.		Injury requiring treatment beyond first aid. Treatment beyond first aid includes lifesaving interventions such as CPR or Heimlich, wound closure by professional, casting or immobilizing limb.	Required for accidents which result in serious injury (e.g. factures, serious burns, loss of limb, lacerations requiring multiple sutures, etc.)	
Abuse/ Neglect/ Exploitation	Reasonably suspected abuse/exploitation including: Physical; Sexual; Fiduciary; Emotional/mental; or Physical and/or chemical restraint. Reasonably suspected neglect including failure to: Provide medical care; Prevent malnutrition or dehydration; Protect from health and safety hazards; or Assist in personal hygiene or the provision of food, clothing or shelter.	Abuse includes inflection of injury; unreasonable confinement; intimidation or cruel punishment; sexual abuse/exploitation; verbal abuse; mistreatment. ⁵ Neglect means a threat to the individual's health and welfare by physical or mental injury, impairment, deprivation of essential needs, or lack of protection. Exploitation is illegal or improper use of individual or individual's resources for profit or advantage.	Abuse includes the willful inflictions of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain, or mental anguish. Neglect includes the failure to provide goods and services necessary to avoid physical harm, mental anguish, or mental illness. For Exploitation, see below under Damage to Property.	Includes Physical Injury (non- accidental); Willful infliction of physical pain or injury; Sexual harassment or exploitation; Failure to act/neglect leading to physical injury or possible injury; Financial exploitation; Verbal mistreatments.	Abuse includes Physical; Psychological; Sexual; Verbal; Improper or unauthorized use of restraint Neglect includes the failure to provide needed care such as shelter, food, clothing, personal hygiene, medical care, protection from health and safety hazards, attention and supervision, and other basic treatment and necessities needed for physical, intellectual and emotional capacity and well-being.	Abuse includes Physical abuse; Emotional, mental or psychological abuse; Verbal abuse; Threatened abuse; Sexual abuse; Abuse by complicity; and Furnishing non- prescribed drugs or other harmful substances. Neglect is the failure to provide for basic needs or supervision resulting in risk to the consumer's life safety. Exploitation is the manipulation of consumer or his/her resources for profit or advantage.	Includes physical harm and/or mental/emotional harm due to abuse, neglect, and/or exploitation.

	California ¹	Definition of Repo	ortable Events	by Select HC Oregon	BS Programs	South Carolina	Wisconsin
	(DD)	(MR/DD)	$(DD, E/D, TBI^3)$	(DD)	(MR)	(DD)	(DD, E/D)
Damage to Consumer's Property	Reporting required in the case of larceny or burglary (i.e. consumer victim of crime).		Misappropriation of property means the deliberate misplacement, exploitation, or wrongful, temporary or permanent use of a resident's belongings or money w/o the resident's consent.	If included under Financial exploitation.	Misuse of funds, i.e. an intentional act which results in the loss or misuse of an individual's money or personal property.	Extensive damage to property due to consumer or staff actions, accidents or vandalism (e.g. valued at \$300 or more).	Includes substantial loss in the value of personal or real property of an enrollee due to theft, damage, or exploitation.
Medication Errors and Management	If resulting complication required medical treatment beyond first aid.	Medication error includes wrong person, dose, medication, time, route, method of admin or omission. Medication refusal is any circumstance in which staff has knowledge of a client who does not take the medication as prescribed. Also required reporting for missing meds.			Medication error, includes omission and wrong dose, time, person, medication, route, position, technique/ method and form.	Medication administration errors resulting in serious adverse reactions/poisoning.	

			Definition of Reportable Events by Select HCBS Programs											
	California ¹ (DD)	Maine (MR/DD)	New Mexico ² (DD, E/D, TBI ³)	Oregon (DD)	Pennsylvania (MR)	South Carolina (DD)	Wisconsin (DD, E/D)							
Law Enforcement Intervention	If consumer is victim of crime including: Robbery; Aggravated assault; Larceny; Burglary; or Forcible rape.	Emergency Services, i.e. any use of law enforcement, fire, rescue, or crisis service impacting consumer.	Law Enforcement Intervention, i.e. the arrest or detention of a person by law enforcement, involvement of law enforcement in an incident, or placement of a person in a correctional facility.	Any emergency in which police, fire dept, or ambulance is called. Any situation where referral is made for criminal investigation or police are called (such as individual running away or probation violation)	Law enforcement activity in following situations: consumer charged with crime; staff or volunteer charged with crime on-site; consumer victim of crime; vandalism or break-in occurs at provider site; crisis intervention; citation given to staff while operating agency vehicle or transporting consumers.	Possession of firearms, weapons or explosives; Possession of illegal substances; Criminal arrest; Law enforcement involvement. All apply to staff or consumers.								
Missing Person	If consumer is missing and vendor or LTC facility has filed missing persons report with law enforcement.	If consumer is lost or missing when s/he cannot be located after a reasonable time and inquiry and no information exists as to the individual's whereabouts.			Consumer missing for more than 24 hrs. w/o prior arrangement or if in immediate jeopardy and missing for any time.	Consumers missing or elopements of 1 hour or more from time discovered missing.								
Restraints		Personal/physical/chemical or other restraints that are not part of an approved plan. Reporting of Mechanical devices and supports used to w/o medical order restrict a persons' movement also required.		Restraints w/o a physician's order unless arranged for and agreed to in ISP or individual's actions present an imminent danger, then only until other appropriate actions are taken by medical, emergency, or police personnel.	Restraints (physical, mechanical, and/or chemical), <u>including</u> those approved as part of ISP and those used on an emergency basis.									

	Definition of Reportable Events by Select HCBS Programs											
	California ¹ (DD)	, 8 ,			8							
Other	An event or unusual occurrence reported by a vendor or LTC facility to Licensing and Certification pursuant to IR requirements of respective agencies.	Assault; Dangerous situations; Licensing violation; Physical plant disasters; Rights violations; Suicide attempts, threats, and self- injurious behavior; Medical orders involving persons under guardianship.	Environmental Hazard, when an unsafe condition creates an immediate threat to life or health.	Restricting individual's freedom of movement, e.g. dragging individual across room, staff blocking doorway, shutting off electric wheelchair, placing individual in timeout room, etc.	Disease reportable to Dept. of Health; Emergency closure; Fire; Consumer-to- consumer abuse; Rights violation; Suicide attempt.	Many 'Other' categories. See notes. ⁶						

Key:

DD: Developmentally Disabled E/D: Elderly and Disabled IR: Incident Reporting ISP: Individual Service Plan LTC: Long Term Care MR: Mentally Retarded PCP: Primary Care Provider TBI: Traumatic Brain Injury

¹ With the exception of death and crime, which are reported regardless of when or where they occurred, special incident are only reported if they occurred during the time the consumer was receiving services and supports from any vendor or long-term health care facility.

² Incident does not require reporting if at the time of the incident the consumer was not under the direct care or supervision of a DOH-funded or ICF-MR provider. Incident falls outside the jurisdiction of mandatory reporting if the alleged perpetrator is not a paid employee of the provider agency.

³ New Mexico's Reportable Incident Definitions also cover the Medically Fragile Waiver, Developmentally Disabled State General Fund Program, Behavioral Health State General Funded Program; Family, Infant and Toddler; and Medicaid Certified Intermediate Care Facilities/Mentally Retarded (ICF-MR) facilities.

⁴ Any death that: must be reported to the coroner or medical examiner; is reported to the Dept. of Reg. and Licensing or Dept. of Health and Family Services; results from trauma; occurs under suspicious/ unexplained circumstances; or occurs while a grievance, appeal or fair hearing is pending.

⁵ Mistreatment is any action adversely impacting an adult with mental retardation or autism that is not in keeping with established norms of care.

⁶ Other South Carolina Incident Categories: (1) Accidents involving several people regardless of seriousness of injuries; (2) Severe natural disasters; (3) Hazardous contamination of facility or immediate area; (4) Fires; (5) Epidemic outbreaks; (6) Consumer suicide or serious suicide attempt; (7) Contracting life threatening communicable disease; (8) Significant acts of aggression by or against consumers; (9) Known or suspected staff theft or misuse of state, private or consumer funds/property in excess of \$100.

Appendix C: Discovery Method Assessment: Sample Waiver

		Waiver Pro	gram: AT HOME	E Central Prog	ram Office		
Discovery Method	Data collected by:	Data collected for sample or all participants?	Are the waiver participants a subset of a larger group?	If yes, can waiver participants be identified?	Sampling method	Number of records in a year:	Location of data
Analysis of admin. Data	Agency staff	All	Yes	Yes	N/A	2000	Central office
Appeals	Agency staff	All	Yes Yes		N/A	Depends	Central office
At-home visits	Quality coordinator	Sample	Yes	Yes	Non-random sample	100	Database
Consumer Surveys	Case managers	Sample	No	No	Random sample	400	Case management agency
Incident reporting	Quality coordinator					all	Central office

Appendix C: Discovery Method Assessment: Sample Waiver

Discovery Method	Is standard data instrument used?	Can data be aggregated?	Is the data stored electronically?	Are routine reports produced?	How often?	What is the purpose of the reports?	Who reviews the reports?	Is the data used for quality improvement?	Priority level for improvement?
Analysis of admin. data	Yes	Yes	Yes	Yes	Monthly To schedule level of care determinations		Quality coordinator	Yes	Medium Priority
Appeals	No	Yes	No	Yes	As needed To identify trends		Appeal coordinator	No	Medium Priority
At-home visits	Yes	Yes	Yes	Yes	Yearly For reporting to CMS		Program No Manager No		High Priority
Consumer Surveys	Yes	Yes	Yes	Yes	Annually	To identify issues and training needs.	QI committee	To improve training	Medium Priority
Incident reporting	No	No	No	No	Only as requested	- legislative		Quality coordinator No	

Appendix C: Discovery Method Assessment: Sample Waiver (continued)

Appendix D: Discovery Method Waiver Matrix: Sample Waiver

]	Level	of car	re		-	Ir	divid	lual p	lan			Q	ualifi	ied Pr	ovide	rs		lealth Velfai			Admin. hority		tate Fina ccountal	
Legend ✓ Yes Improvement !!! High Priority !! Medium Priority ! Low Priority	Individual LOC evaluations	Periodic LOC reevaluation	LOC process obeys waiver standards	State documents reviews of LOCs	Change in-need triggers POC update	POCs address needs & goals	State monitors POC development	People offered choices	State can show it reviews POCs	State documents corrected POCs	State monitors POC process	State monitors participant choice	State monitors licensed providers	State monitors non-lic. providers	State corrects sub-standard providers	State monitors that training is given	State documents corrective actions	State is vigilant on abuse & neglect	Sate can show it acts when member's health/welfare is neglected	State analyzes abuse/neglect trends	State engages in routine waiver oversight	State shows monitoring obeys MoU & it acts on program-level waiver problems	State financial oversight assures proper claims coding obeys waiver	State shows results of its oversight of proper financial bookkeeping	State has results of claim reviews & periodic financial oversight site visits
AT HOME Central																									
Analysis of admin. data	\checkmark	\checkmark																			\checkmark				
Appeals	\checkmark	\checkmark	\checkmark		\checkmark	\checkmark		\checkmark											\checkmark	√ !!	√!!				
At home visits	\checkmark	\checkmark	\checkmark	√!	√!	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark				\checkmark	\checkmark		√!!	!			
Consumer Surveys						\checkmark		\checkmark													\checkmark	\checkmark			
Incident Reporting					!!	!!									\checkmark			√ !!!	√!!!	√!!!	√!!!				
Quality Review Committee Mt.																					√ !!				
Stakeholder Meetings																					√ !!				
Unlicensed Providers Review					\checkmark	\checkmark	\checkmark	\checkmark	✓	✓				~	\checkmark		✓				\checkmark				
Counties																									
Consumer Surveys					√	✓		✓				✓						✓	\checkmark		✓				
Incident Reporting					✓			\checkmark										✓	✓	✓	✓				
Providers reviews					\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	✓	✓	✓	✓	\checkmark	\checkmark	\checkmark	✓	\checkmark	✓	✓	✓	L		L	
Record Reviews				1	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	✓	✓	✓						\checkmark	✓						
Medicaid Agency																									
Provider Reviews													✓		✓	✓	✓	✓	 ✓ 		✓				
Utilization Review				1							1	1									\checkmark		\checkmark	\checkmark	\checkmark

Appendix D: Discovery Method Waiver Matrix: Sample Waiver

Edmund S. Muskie School of Public Service HCBS Discovery Methods

Appendix E: Discovery Method By Priority: Sample Waiver

Appendix E: Discovery Method by Priority: Sample Waiver

		Need for Improvement: High Priority						
Discovery method	Used by	Description of use	Reason for improvement					
At-home visits	AT HOME Central Program Office	Central Office staff visit a sample of consumers to assess compliance with individual plan and level of care.	Need to develop better sampling plan and schedule for reporting to management					
Incident reporting	AT HOME Central Program Office	Incidents, complaints and reportable events are collected in Central Office	Need standardized data collection instruments and information system. Need coordinate incident reporting with Adult Protective Services and other waiver programs that have automated systems.					
Discovery method	Used by	Need for Improvement: Medium Priority Description of use	Reason for improvement					
Analysis of admin. data	AT HOME Central Program Office	Program staff conduct monthly analysis of assessment data for level of care determinations.	Need more timely and user friendly reports					
Appeals	AT HOME Central Program Office	Appeals are tracked to identify issues and trends.	Need to standardize data collection instrument and reporting					
Consumer surveys	AT HOME Central Program Office	Consumer survey conducted every other year to determine consumer satisfaction and experience with program	Need more cost effective ways to conduct survey. Need to be able to identify waiver participants separately.					
	Counties	Counties conduct consumer survey	Concern that this may be a redundant activity.					

- Allen, Shea and Associates. (2000). *Quality Measurement Instrument Review: Excerpts 1-24* [Web Page]. URL http://www.allenshea.com/onetotwentyfour.html [2005, January 25].
- Booth, M., Fralich, J., & Bowe, T. (2005). *Home and community-based services: Quality management roles and responsibilities.* New Brunswick, NJ: The Community Living Exchange Collaborative at Rutgers Center for State Health Policy and the National Academy for State Health Policy. http://www.hcbs.org/files/60/2955/Narrative_QM_Roles__Resp_REPORT.pdf
- Booth, Maureen, and Fralich, Julie, *Work Book: Improving the Quality of Home and Community Based Services and Supports*, April 2003, Centers for Medicare and Medicaid Services. <u>http://www.cms.hhs.gov/medicaid/waivers/hcbsworkbook.asp</u>
- California Department of Developmental Services. *Looking at service quality: Provider's handbook*. Sacramento, CA: California Department of Developmental Services. http://www.dds.cahwnet.gov/Publications/pdf/LookingServiceQuality.pdf
- Gettings, R. M. (2001). Building a comprehensive quality management program for public developmental disabilities service systems: Organizing principals and primary operating components. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services. http://www.openminds.com/indres/quality.pdf
- Lakin, K. C., & Prouty, R. (2003). Medicaid home and community-based services: The first 20 years. Policy Research Brief (University of Minnesota: Minneapolis, Institute on Community Integration), 14(3), 1-12.
- Lakin, K. C., & Hewitt, A. (2000). Medicaid home and community-based services for persons with developmental disabilities in six states. Minneapolis, MN: Research and Training Center on Community Living. http://rtc.umn.edu/pdf/sixstates.pdf
- Siegel, G. (2002). A review of current trends in quality assurance of services provided to persons with developmental disabilities. St. Louis, Missouri: Institute of Applied Research. http://www.iarstl.org/papers/DDQualityAssuranceLitReview.pdf
- Summer, L., & Ihara, E. (2004). State-funded home and community-based service programs for older people. (PPI Issue Paper #2004-11). Washington, DC: AARP Public Policy Institute. http://research.aarp.org/il/2004_11_hcbs.pdf
- United States General Accounting Office. (2003). Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened. (GAO-03-576). Washington, DC: United States General Accounting Office. http://www.gao.gov/new.items/d03576.pdf
- Wyoming Institute for Disabilities. (2004). Living well with CMS funding: A study of mortality in Wyoming. Laramie, Wyoming: University of Wyoming, Wyoming Institute for Disabilities, Wyoming Department of Health, Developmental Disabilities Division.

Appendix G: Resource List

ASK ME! PROJECT: The Arc of Maryland

Ask Me!sm is a Consumer Satisfaction Evaluation administered by The Arc of Maryland for the Developmental Disabilities Administration (DDA) in collaboration with the Maryland Developmental Disabilities Council. http://www.thearclink.org/state/news/article.asp?ID=MD&article=350

Assessment Instruments (Adults with Disabilities) Maine Bureau of Elder and Adult

Services Links to Maine's Medical Eligibility Determination assessment instrument for adults with disabilities. http://www.maine.gov/dhhs/beas/provider.htm

Florida Statewide Quality Assurance Program

Website for the Developmental Services Home and Community Based Waiver offers resource center, consumer resource, provider resources and useful links. <u>http://www.dfmc-florida.org/</u>

Guide to Quality in Consumer Directed Services

This guide is designed to provide states and programs involved in consumer-directed services with a practical handbook on ensuring and improving the quality of services. http://hcbs.org/moreInfo.php/topic/216/doc/819/A_Guide_to_Quality_in_Consumer_Directed_S ervices

Home Health Quality Initiative, Centers for Medicare & Medicaid

Home health quality measures are available to consumers to help them choose a home health agency and are available for home health agencies nationwide. http://www.cms.hhs.gov/quality/hhqi/

Interim Procedural Guidelines, Centers for Medicare & Medicaid

Interim Procedural Guidance for oversight of Medicaid waivers to all CMS Regional Administrators with documents including the memo from Mr. Stanton, a diagram detailing the HCBS Waiver Quality Life Cycle and several attachments. <u>http://www.hcbs.org/moreInfo.php/nb/doc/722/Interim_Procedural_Guidance_for_Assessing_H</u> <u>CBS_Wai</u>

ICAP User's Group Home Page

The Inventory for Client and Agency Planning (ICAP) is a 16 page booklet that assesses adaptive and maladaptive behavior and gathers additional information to determine the type and amount of special assistance that people with disabilities may need. http://www.cpinternet.com/~bhill/icap/

IM40 Independent Monitoring for Quality

Independent Monitoring for Quality, also known as IM4Q, is a system of measuring quality that relies on information gathered from individuals receiving services and their families by people in the community who are independent of the services being delivered. http://www.dpw.state.pa.us/Disable/MentalRetardationServices/003670114.htm

Indiana Non-licensed providers

Indiana Administrative Code: Title 460 Division of Disability, Aging, And Rehabilitative Services

http://www.in.gov/legislative/iac/title460.html

Indiana's web-based incident reporting system

BQIS Web-Based Incident Reporting System: Incident Initial Report and Incident Follow-Up Report.

https://secure.in.gov/apps/fssa/bdds/ifur/ifurServlet

interRAI

A collaborative network of researchers in over 20 countries who's goal is to promote evidencebased clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of elderly, frail or disabled persons who are served across a variety of health and social services settings.

http://www.interrai.org

Maine MR Reportable Events Form, Procedures, and Instructions

Documents include regulations, policy, procedures, instructions and forms for MR reportable events.

http://www.maine.gov/dhhs/bds/mrservices/APS/index.html

ional Core Indicators, Reports

The aim of the National Core Indicators initiative is to develop nationally recognized performance and outcome indicators that will enable developmental disabilities policy makers and participating states to benchmark the performance of their state against the performance of other states.

http://www.hsri.org/nci/index.asp?id=reports

New Mexico Cross-Waiver Incident Report Forms, Regulations & Reports

Documents include Cross-Waiver Incident Report Forms, Regulations & Reports. http://dhi.health.state.nm.us/imb/index.php

Participant Experience Survey

The PES is one tool that States may consider using as part of their quality management program to monitor several aspects of quality in their waiver programs. http://www.cms.hhs.gov/medicaid/waivers/consexpsurvey.asp

Patient Safety Authority, Pennsylvania

The Authority is charged with taking steps to reduce and eliminate medical errors by identifying problems and recommending solutions that promote patient safety in hospitals, ambulatory surgical facilities and birthing centers.

http://www.psa.state.pa.us/psa/site/default.asp

Performance Outcomes Measures Project (POMP) of the Administration on Aging

The Performance Outcomes Measures project (POMP) helps States and Area Agencies on Aging assess their own program performance, while assisting AoA to meet the accountability provisions of the Government Performance and Results Act (GPRA) and the Office of Management and Budget's (OMB) program assessment requirements. http://www.gpra.net

Quality Mall

A place where you can find lots of free information about person-centered supports and positive practices for people with developmental disabilities. http://www.qualitymall.org/main/

QUEST Survey and Certification Process

QUEST is a licensing and evaluation process used by Massachusetts that looks at consumer outcomes such as rights, individual control, and relationships which are then measured and used for quality enhancement and to license an agency. http://www.qualitymall.org/products/prod1.asp?prodid=80

State Operations Manual, Centers for Medicare & Medicaid

Chapters include Program Background and Responsibilities; The Certification Process; Program Administration and Fiscal Management; Complaint Procedures Survey and Enforcement Process for Skilled Nursing Facilities and Nursing Facilities; Standards and Certification. http://www.cms.hhs.gov/manuals/107 som/som107index.asp#toctop

The Council on Quality and Leadership

The Council on Quality and Leadership is at the forefront of the movement to create opportunities for people to lead the lives they choose and to improve the quality of services and supports for people with disabilities and mental illness. http://www.thecouncil.org

West Virginia Bureau for Behavioral Health and Health Facilities

A list of links for Resources, MR/DD Resource, and Financial Resources in West Virginia. http://www.wvdhhr.org/bhhf/resources.asp.

Wisconsin Functional Screen

Wisconsin's Functional Screen system is a web-based program that collects information on an individual's functional status, health and need for assistance from programs that serve the frail elderly and people with developmental or physical disabilities.

http://www.dhfs.state.wi.us/LTCare/FunctionalScreen/Index.htm