

INDIVIDUAL PROVIDERS

A Guide To Employing Individual Providers Under Participant Direction

**A product of the
National Quality Contractor**

*Developed by:
Human Services Research Institute*

And

The MEDSTAT Group, Inc.

*Developed for:
Centers for Medicare and Medicaid Services*

March 2006



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Acknowledgements

A number of people from thirteen states took the time and effort to participate in two conference calls and/or share resources and ideas for monitoring independent providers. Information from these states forms the basis of the monograph. We are indebted to the following people for their wisdom and generosity:

- Barbara Brent and Ric Zaharia, Arizona
- Debby Ellis, Arkansas
- Fred DeCrescentis, Colorado
- Elizabeth Phelps, Kansas
- Jane Gallivan and David Goodu, Maine
- Sarah Basehart, Maryland
- Gail Grossman and Sharon Oxx, Massachusetts
- Mike Marum, North Dakota
- Barbara Reed, New Hampshire
- Marylee Fay, Oregon
- Theresa Wood and Joseph Carlomagno, Vermont
- Teja Stokes, Virginia
- Donna McDowell, Wisconsin
- Jon Fortune, Wyoming

This monograph was produced for the Centers for Medicare and Medicaid Services, under CMS contract No. 500-96-006, Task order No. 2 and CMS Contract No. 500-00-0021, Task Order No. 1

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PART I: INTRODUCTION

What is the purpose of this monograph? In this monograph, we discuss program design considerations to assist states as they move toward greater individuality and flexibility in the provision of services and supports for individuals who have disabilities and/or significant functional limitations and require ongoing assistance. Specifically, the monograph outlines topics that states should consider as they expand opportunities for participants to choose and direct individual providers who provide assistance to them, including the risks and benefits of these arrangements, provider qualifications, training, person-centered planning, the role of the case manager, and safeguards to prevent abuse, neglect and exploitation.

This monograph has benefited from the experiences of states that have been addressing these challenges. These states generously shared a number of the resources they have developed, which may be helpful to other states. Information about obtaining these resources is located in Appendix C. Appendix B identifies documents and articles that may prove useful. A glossary of commonly used terms is located in Appendix A.

Why are we talking about this subject now? Over the past decade, there have been many changes in provision of services and supports for people who need ongoing assistance as a result of disability or significant functional limitations. In the 1980s and 90s, the delivery of services and supports to individuals was commonly directed and managed by provider agencies. Staff who supported individuals were, by and large, provider agency employees and the agency was largely responsible for hiring, firing, training and supervising staff. This model predominates even today. During this time, and especially during the 1990s, states started offering individually tailored and participant-directed supports primarily in individuals' own (or their families') homes. Some people are now choosing to receive their supports from individual providers that they select and manage rather than through provider agencies.

Participant-directed supports are not new; they were pioneered in the early 1970s by the independent living movement for people with physical disabilities. Now there are more than 150 participant-directed supports programs in the United States and throughout the world. During the mid-1990s, elders were offered cash allowances to arrange and direct their home care. Also in the 1990s, states began to use the HCBS waiver to offer more individualized and flexible services and supports to people with developmental disabilities. For example, Wyoming has used individual providers as a means to increase the network of available providers beyond agencies, enhance participant choice, and encourage more individualized, flexible and portable services and supports.

In 2004, the Centers for Medicare & Medicaid Services (CMS) completed the “National Inventory of Quality Assurance and Improvement Systems: Medicaid HCBS Waiver Programs for Aged/Disabled and Developmentally Disabled Individuals.” The NQIP Inventory revealed that roughly 46% of the aged/disabled and 91% of the developmental disabilities waiver programs permitted individual providers and/or family members to provide waiver services. It is becoming more and more commonplace for people with the most intensive needs for support to have the opportunity to direct and control their supports, including employing and directing individual providers. Individualized, participant-directed services will continue to grow as more and more states incorporate participant direction of services into their §1915(c) HCBS waivers. Starting with the Independence Plus initiative and through revisions to the HCBS waiver application, CMS is strongly encouraging states to make participant direction a central feature of all waivers. The revised HCBS waiver application has been designed so that states may incorporate participant direction of waiver services into any waiver (in varying degrees as desired by the state).

So, what is an individual provider? For this monograph, an individual provider is a person who furnishes services to participants as an independent practitioner and who is not an employee of a provider agency. Individual providers include personal assistants, attendants, respite workers, homemakers and others (including family and friends) who provide direct support to individuals and who are paid with public funds, either directly by the state or through an intermediary, i.e., a financial management services (FMS) entity. Rather than being employees of public or private agencies, individual providers usually work as employees of individuals or families, supporting one or more individuals who live on their own or with their family.

Participants use individual providers through two different models:

- 1 Under participant direction, the participant – rather than a provider agency – has lead responsibility and the authority for hiring, screening, training and supervision of individual providers. When a state includes the “employer authority” participant direction opportunity in a waiver, it must make available to self-directing participants two types of supports to assist in carrying out their responsibilities as employers. One form of assistance is financial management services that are provided by a third-party entity to conduct some employer-related tasks, including payroll and federal/state tax withholding. For example, Vermont’s Request for Proposal for “Payroll and Tax Services for Consumer and Family Directed Services and Independently Employed Support Workers” clearly spells out the FMS entity’s responsibility for performing employer-related tasks (e.g., criminal record, abuse registry, and driving records check of participant-selected workers). The second type of support that states must make available to participants who exercise employer authority is information and assistance, such as:
 - Aiding the participant to recruit workers;
 - Training the participant to supervise and manage their employees.

In both circumstances, responsibility for ensuring that providers are qualified and competent by monitoring the quality of the services and supports is shared between the participant, the state agency, and the FMS.

2. Under the traditional service model, many states including Colorado and Wyoming enable participants to use individual providers without having formal programs in participant direction. Some states use individual providers to increase the Medicaid program enrolled provider network, especially in areas where there are few provider agencies. As a result, it provides participants the opportunity to choose from a larger pool of qualified caregivers. Payments for services are made directly to the worker. Consumers choose from the list of enrolled providers rather than from a list of agencies that send the worker to the home. Consumers may even refer caregivers for enrollment in the Medicaid program to be able to choose them.

In some states, individual providers are selected from a list of “qualified” providers. In the case of the Wyoming developmental disabilities and acquired brain injury waivers, a list of qualified individual providers is accessible through the state website. Other times, individual providers already have a relationship with the participant but may not have worked with people with significant functional limitations before. Individual providers may be family members in some instances. States also may allow legally responsible individuals (e.g., spouses and parents of minor children) to provide supports to the waiver participant in extraordinary circumstances.

Using individual providers supports participant direction. There can be important benefits in using individual providers, such as increased flexibility and choice, greater control over the type and quality of the supports, and direct control over the workers that provide support. The waiver participant can have greater control over scheduling services and ensuring services meet his/her needs and preferences. Since the participant is the employer, the participant gains authority over the day-to-day provision of services.

Research has demonstrated that participant direction leads to increased satisfaction with services and promotes the cost-effective delivery of waiver services. The provider and individual can develop a close, caring and reciprocal relationship with one another. In some instances, the individual provider could be someone who already has a relationship with the person, such as a neighbor, relative or other community member. He or she already has the individual’s (and/or family’s) trust as opposed to a stranger referred by an agency.

However, people can be vulnerable. Individuals who receive services and supports in their own home or their family’s home sometimes can be isolated and, in the worst-case scenario, vulnerable to abuse or neglect by their providers, even when those providers are family members. Individuals may have difficulty expressing their concerns about a

provider or be reluctant to lodge a complaint or an allegation of abuse against their provider. The person may not recognize the provider's actions as abuse, may be worried about losing the provider and being without support, or even fearful of some form of retaliation.

Another concern revolves around the provision of back-up services when workers that support the participant are not available or do not show up for work when scheduled. This may jeopardize the health and welfare of the waiver participant.

It may be difficult to ascertain if individual providers are maintaining the needed skills and competencies, especially when they do not receive ongoing supervision and support from an organization. As an example, in the absence of supervision and guidance, providers may unwittingly foster dependency, diminishing the person's independence and control over his or her own life. If providers are working in isolation from other paid and unpaid individuals, they may not have a network of other people doing similar work with whom they can air concerns and share ideas. Over time, this isolation may affect the quality of the services and supports provided.

It is important to point out that many of these concerns are by no means unique to situations where participants hire and supervise individual providers. Many of the same concerns are encountered when provider agencies furnish services and supports to individuals who live on their own or with their families. The challenge is how to address these concerns when employing participant direction.

These concerns prompt the need to consider carefully how to build in appropriate and effective safeguards when individuals receive services and supports provided by individual providers while avoiding too much intrusion, diminishing individual control, impeding ready access to services or disturbing the positive relationship between the provider and individual. The next section offers some recommendations for building quality into program operations and developing quality assurance and improvement systems for individual providers.

PART II: EMPLOYING INDIVIDUAL PROVIDERS UNDER PARTICIPANT DIRECTION

What are the attributes of an effective system when individual providers support participants? Core attributes are as follows:

1. Individual providers have both basic qualifications and competencies and the necessary specific skills to support individuals.
2. The person-centered service plan incorporates individualized strategies that support the use of using individual providers.
3. The person-centered service plan identifies strategies to safeguard the health and welfare of the waiver participant without impeding or preventing the participant's exercise of authority to select and manage individual providers.
4. Individual providers know the person and the person-centered plan, including the person's preferences, goals, needs and support strategies.
5. Individuals and families have access to information and assistance in managing and directing their services, supports and providers.
6. There is an effective process for ongoing person-centered, non-intrusive monitoring of the delivery of services and supports.
7. Individuals and families have an effective means of freely expressing and securing the resolution of concerns or problems with their services, supports and providers.
8. Individual/family feedback is actively sought on the quality of services and supports by individual providers.
9. There is a means of identifying trends with regard to the quality of services and supports and implementing improvement strategies when using individual providers.

Waiver programs designed with these attributes increase the likelihood of positive outcomes, satisfaction and prevention or reduction of individual and/or system-wide problems.

INDIVIDUAL PROVIDER QUALIFICATIONS AND COMPETENCIES

Prevention is a key ingredient; therefore, it is important to build quality in at the beginning. An effective quality assurance and improvement system starts before monitoring and builds quality into the design of the waiver program, most notably by ensuring that individual providers have the necessary competencies to support the individual. Preventive systems balance safeguards of individual health and welfare with maximization of choice and access to services and capable providers. There are two levels of provider competency: 1) the basic qualifications and competences all providers should meet; and 2) the competencies needed to support the individual waiver participant, as documented clearly in the person's plan.

Level I: Basic Qualifications

When HCBS waiver funding supports the program, the waiver must clearly articulate individual provider qualifications and standards. Thus, all individual providers should meet universal, essential basic qualifications and have the training to effectively support any individual in the waiver. In the design of a waiver program, the state should balance the desire to protect vulnerable individuals with having a robust network of providers and providing participants with flexible choice of caregivers. States should consider the following as they develop these requirements:

- **Pre-screening** – According to the NQIP Inventory, most states complete background criminal checks for all individual providers (roughly 100% reported for developmental disabilities services and 77% reported for aged/physically disabled services). Some states, such as New Hampshire, require that all providers (including individuals) undergo a background check. Other states may place some qualifiers on this universal requirement. For example, a state could make an exception if the provider is a family member by “inviting,” but not requiring, a background check. Wisconsin requires that all providers have a background check for services to elders, including family members. However, a problem with the background check does not automatically prevent the provider from working with the individual. With some exceptions, Wisconsin leaves the decision to the individual and/or the case manager. Recognizing that it sometimes takes a long time for the background check results to come back, some states allow the provider to start work pending the results. However, some states put a cap on the allowable time and cut off reimbursement if the results are not available by that date (e.g., Vermont allows 60 days). States recognize that background checks may have limited utility, especially if the check does not extend beyond state borders. Therefore, background checks should be used in concert with other screening processes such as reference checks. Some states have an “abuse registry” that is included as a part of the background check.

- **Education/Age Requirements** – In the HCBS waiver application, states are required to spell out the qualifications for all providers, including individual providers. Some states require that all individual providers have a high school diploma or equivalent. However, individuals and families directing their own supports and hiring their own providers may opt to hire someone who does not have a diploma if the provider meets their needs and the state provides for exceptions to this requirement. Many states require that the provider be at least 18 or 21 years old.

- **Threshold Competencies** – States commonly require that all providers have some basic training in order to be “qualified” to support individuals, including training on some or all of the following topics:
 - Individual’s support plan
 - Respect and rights
 - Emergency procedures
 - CPR/First Aid
 - Incident reporting

New Hampshire included specific training requirements in their *Independence Plus* waiver for children, including training on topics such as: understanding the person’s disability; communicating with the person; developing age-appropriate interests, family and social roles; building relationships with family, friends and neighbors; community participation; understanding challenging behaviors and facilitating more positive behavior; and assuring basic health and safety practices.

- **Verification** – Prescreening and verification of basic provider qualifications and competencies can be accomplished in a number of ways:
 - Maintain a registry of “pre-qualified” individual providers who have a completed background check, have participated in required trainings, and meet age and education requirements. Individuals and families may then select workers from the registry. As noted previously, Wyoming maintains a list of approved providers on its website, which includes provider contact information for easy access.

 - The individual may select from the “qualified” provider list or select someone off the list, but when making the latter choice, the individual must verify to the state agency that the provider has met all requirements. This system gives flexibility (and responsibility) to the individual and family for selecting the provider. New Hampshire has developed a checklist to assist families and service coordinators in documenting that providers have the competencies

required in the state's rules as well as individual-specific competencies that the provider must demonstrate in order to support the individual. Once the individual and family attest to the provider's competencies, he/she receives an approved provider status limited to supporting the individual waiver participant. In the case of participant-directed supports in Virginia, a "services facilitator" (different from the case manager) assists the individual/family to verify that the provider has the basic competencies to support the individual including a background check and CPR training.

- Again, some states require the financial management services entity to verify that individual providers meet all requirements.

Level II: Person-Specific Competencies

States regard service provision using individual providers as a true partnership between individuals, families and the state agency. This is most apparent when ensuring that individual providers have specific competencies to meet individual needs that have been identified in the person-centered plan. Individuals and/or family members play a greater role in training the individual provider in specific areas and are often in the best position to confirm that the provider is competent. Training the provider to meet specific needs of the individual may be done primarily by the waiver participant or by the family. This enables the provision of services and supports to be tailored to the person's unique support needs and preferences. Some training is best done by professionals who have expertise in specific areas, such as how to carry out a range of motion program or implement a behavior support intervention. Support coordinators can both assist in training or arrange for expertise when needed. For example, in Oregon, personal agents, when needed, assist individuals and families in recruiting, hiring and training providers.

Some cautions... State rule or law may prohibit individual providers from performing specific activities unless they have completed a training program, most notably medication administration. Many states have rules or statutes that permit non-licensed staff with special training to support individuals in the administration of their medications. In some cases, this training may be a standardized state approved curriculum, while in other cases there is no standardized curriculum. The rules governing this practice vary in each state. In some states, these rules can be found in nurse practice statutes and regulations. The agency responsible for oversight may be the State Board of Nursing or another licensing agency such as the Department of Public Health. The support coordinator can play a key role in identifying these issues and assuring that the provider has completed the required training.

Ongoing Support to Individual Providers

Equally as important as ensuring that individual providers meet basic requirements, these workers need a means for continuing to increase their knowledge as well as identify with a larger community of peers who are engaged in similar, valued work. They may be working in isolation from other providers and, over time, lose interest or, in the absence of supervision, develop less desirable service practices. Gatherings, seminars, “list serves,” bulletin boards and websites with links to useful current information may assist individual providers to acquire new skills and with a means of sharing experiences. In the case of its *Independence Plus* waiver, New Hampshire officials routinely consult with Area Agency staff to identify training or resource needs for providers and families. Topics that have been identified include: family-centered planning, behavioral approaches, managing individualized budgets, substance abuse, individual rights, nursing-related activities, and collaborating with families. A state might consider a periodic survey of individual providers as a means of identifying their ongoing support needs. Holding periodic focus groups of individual providers can be another valuable means of gathering information about their needs.

Design considerations for states:

- Is there an easy to understand process to inform everyone about the provider’s roles and responsibilities?
- Should individual providers who have completed specific training and background requirements be “certified?” Should the “certification” be renewed periodically?
- How will training be funded?
- Who verifies and documents that individual providers have the required competencies? The individual? The family? The support coordinator? The financial management services entity?

PERSON-CENTERED PLANNING

So where does person-centered planning fit in all of this? Person-centered planning is central to assuring the quality of services and supports that individual providers furnish. There are three significant dimensions to the role that person-centered planning plays:

An assessment of individual needs and preferences is important in determining interest in managing individual providers. In addition to identifying what is important to the person and the supports that are needed to

assist the individual to function successfully in the community, the person (along with other involved people) should decide whether to take on the responsibilities associated with managing individual providers. This has less to do with the person's level of disability and more to do with the individual's (or the family's) ability (and desire) to control the supports, be assertive, and attend to the other aspects of being a good resource and risk manager when needed. Participant direction entails shouldering responsibilities that some individuals and families may not want to accept, even when the waiver provides supports to assist them in discharging the responsibilities.

There may also be some risk issues that need to be considered by the planning team. For example, an individual with complex medical needs may require intensive coordination among providers. If there are vulnerabilities, the planning team should not necessarily discount using individual providers since other supporters could step up to the plate and help out, including other family members, a support broker, and/or the FMS entity. Identifying a person's vulnerabilities and developing support strategies at this stage is an important part of prevention. No amount of monitoring will be effective if the support strategies are not well designed in the first place. Doing some form of an assessment that also addresses risk factors in direct collaboration with the participant and/or family is an important tool for highlighting any issues or concerns and coming up with potential solutions that still support using individual providers. Another monograph, "Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement" explores risk issues for participants. The monograph presents several state processes for assessing and planning for risk and includes resources from different states and across different populations.

Person-centered planning is the key process to identify people's needs for support. It is critical that the plan clearly identify the skills and competencies the individual provider must possess in order to effectively support the individual. True safeguards result when a provider is knowledgeable about the individual's support needs. This represents a shift in the roles and responsibilities of the planning teams since traditional provider agencies consider staff training as their primary responsibility. Now training is a shared activity between the individual, family, and support coordinator (and if Medicaid or other public funding is used, the state). Key support coordinator responsibilities include: making sure the person's plan identifies specific training needs/competencies, determining who will actually do the training, and verifying the individual provider possesses the requisite skills and competencies.

Have an individualized back-up plan when using individual providers. Participants who employ individual providers generally do not rely on a provider agency in an emergency. Therefore, it is especially important that service

planning include effective back-up plans in the event the individual provider is not available (especially if the person is wholly dependent on the provider and would be at risk if the provider does not show-up). The back-up plan may address such questions as:

- What would happen if the provider did not show up and in what way is the person vulnerable?
- Can the individual use the phone?
- If the person cannot use the phone, does he or she need assistive technology or another means of accessing back-up (e.g., personal emergency response system)?
- Does the person know where to call to get help?
- Is there immediate response when the person calls?

The back-up plan may identify roles for friends and relatives as well other services and resources provided by the state.

The support plan serves as the vehicle for identifying how much and in what form services and supports are monitored. Individual services and supports should also be monitored in an individual fashion. States regard monitoring by the support coordinator as the bedrock of the quality assurance and improvement system. States may require that support coordinators make a specific number of visits to individuals' homes. For its elder services, Wisconsin requires the care manager to visit at least every three months.

When individuals decide to direct their own supports in Kansas, they must agree up front to designate a case manager to review their services on a regular basis to ensure the person's needs are met and to cooperate with monitoring by the quality assurance committee of the regional "Community Developmental Disabilities Organization" (CDDO). A person who self-directs services must agree to promptly correct any situation identified by the CDDO that does or may pose a risk of imminent harm to the person. The state added the additional safeguard of requiring a local dispute resolution process, governed by a local Council of Community Members – with majority membership of individuals accessing services and their families – to address any disputes that may arise between individuals and/or families and providers.

Given all of this, what is the role of the support coordinator? In a word, pivotal! States regard support coordinators as the first line of defense in ensuring the quality of services for individuals. When a service provider is arranging all the supports, they have primary responsibility for supervision and oversight. When individual providers are used, the individual, family and support coordinator all share the responsibility, with the support coordinator taking the lead in making sure the support plan includes:

- Identification of risk factors;
- The specification of the roles and responsibilities of the individual, family and other supports (e.g., financial management services entity, other friends or relatives);
- Skills and competencies that individual providers must possess;
- How the implementation of the support plan will be monitored.

States also recognize that individuals need additional assistance in such areas as recruiting and training providers, training individuals in hiring and managing their providers, and solving conflicts between individuals and providers. In some states, support coordinators may take on these additional responsibilities. In states such as Oregon and Virginia, individuals who direct their own services also have support from another individual, sometimes called a support broker. In Arkansas, the Division of Aging and Adult Services *Independent Choices* waiver, previous RFP's requested a single organization to provide the support brokerage function (called "counseling") as well as financial management services. However, current RFP's request an individual provider for counseling and an individual provider for financial management services. The separate RFP's do not preclude a qualified entity from providing both services

Design considerations for states:

- What skills and competencies do support coordinators need when participants are using individual providers?
- Does the use of individual providers add to and/or change responsibilities for support coordinators and how does this influence caseload size?
- Does the plan identify competencies the provider will need to have in order to support the individual and who is responsible for providing training? Does the plan identify who monitors the persons' services and supports and how frequently?
- Has an individualized back-up plan been developed when necessary?
- Does the person-centered planning process include an effective process for assessing individual risk in general and specifically risks when using individual providers?
- Are support coordinators knowledgeable about how to assist people in balancing risk with the right to make lifestyle choices? Do support coordinators have the authority to act and access to resources when they determine the participant's health and safety is jeopardized?

SAFEGUARDS

How can abuse, neglect and other serious incidents be identified and prevented?

Appendix G (Participant Safeguards) of the revised HCBS waiver application emphasizes the importance of effective incident management to individual health and welfare. Many

states require mandatory reporting of serious incidents (e.g., abuse, neglect and exploitation) to the state agency responsible for the services and supports and routinely use incident reporting mechanisms to identify and follow-up on individual risk. The NQIP Inventory revealed that almost 90% of developmental disabilities and aged/disabled agencies operate under a mandatory reporter law for allegations of abuse, neglect and/or exploitation. Some states have a single entity that handles all serious incidents such as these. Others may have several reporting entities such as child protective services, adult protective services, reporting for elders and even Medicaid Fraud.

When individuals receive services from an agency, the provider usually is responsible for ensuring that the staff understands their responsibility for reporting serious incidents and taking action to protect individuals from harm once they know a serious incident has occurred. Finding out about and preventing abuse, neglect, exploitation and other serious incidents is just as critical, but potentially more challenging, when supports are provided by individual providers in the person's own or family's home. Most states recognize that, even with training, individuals, families and individual providers may not report incidents with the same consistency as traditional providers. Hence, a multi-pronged approach should be used to ensure early identification and follow-up including:

- Mandatory reporting by support coordinators, individual providers and in some states, by the individual/family;
- Training for individuals, family members, providers and support coordinators in the reporting requirements;
- An easy to access, well-publicized complaint hot-line and/or an ombudsman office;
- Ongoing monitoring by support coordinators and/or other entities such as the financial management services (if the organization has additional responsibilities to provide additional supports to the individual). Effective monitoring can lead to the early detection of problems before something serious occurs.

Another key safeguard on the individual level is equipping individuals and their families with training and information about what to do when an incident occurs.

Traditional provider agencies usually know the course of action to take when a serious incident occurs but the individual or family may not necessarily know what to do when a problem arises with an individual provider. Waiver operating agencies should review state rules and policies to ensure there is a clearly designated reporting entity or entities to investigate serious allegations, and a designated authority to take protective action when needed. It may be necessary to modify rules, policies and/or memorandums of understanding to ensure that people receiving services from individual providers who live on their own or with their family do not “fall between the cracks.” It is critical that the individual (and/or family) understand where they should call and feel empowered to exercise their right to report an allegation of wrongdoing by a provider.

Some states provide training and/or guidebooks to individuals and families on hiring, firing, supervising and training providers. States are also exploring easy ways for providers to access training materials such as through the web. An important basic safeguard is training for individuals and families in human rights and incident reporting (including abuse and neglect). The better their understanding, the more likely they will report inappropriate provider behavior. Maine's Department of Health and Human Services (DHHS) received an independence plus waiver to create an option for participant-directed services for adults with mental retardation or autism. The state is currently in the process of developing a training that will include videotapes and a workbook, which acts as a guide and a checklist. The unique aspect of Maine's design is that self-advocates are involved in every stage of development. For its consumer-directed supports, the Virginia Department of Medical Assistance Services (DMAS) contracted with Virginia Commonwealth University (VCU) to develop training materials and provide technical assistance to individuals and families. Training materials are available on the VCU website.

Design considerations for states:

- Do support coordinators have the skills and training to ask open ended questions and be alert to serious issues occurring during the provisions of services and supports?
- How are all parties informed about their role and responsibilities to report abuse, neglect exploitation and other serious incidents?
- Does everyone know how and when to report a serious incident?
- Who is responsible for protecting the individual from further harm pending the outcome of an investigation?
- When the individual receives supports in his or her own home who investigates serious incidents and ensures the qualifications of the investigator?
- What happens if the individual provider is found to have abused, neglected or exploited the person?
- Who is responsible for taking action and correcting the situation if abuse, neglect or exploitation is substantiated?
- Who ensures that individuals and families have the skills and ongoing support to manage the provider? Is there a means of providing additional support when needed?

QUALITY ASSURANCE AND IMPROVEMENT

How can states design quality assurance and improvement processes that encompass the unique aspects of using individual providers? The revised home and community-

based waiver application describes requirements for a quality management strategy. Certainly ongoing monitoring is critical for these highly individualized supports. In addition, the focus should be more on individual outcomes and less on one-size fits all program standards. Traditional monitoring processes (e.g., licensing and on-site quality assurance reviews) may be overly prescriptive and intrusive. Placing excessive regulatory requirements on individual providers may discourage talented, committed people from supporting individuals and diminish participant choice and participant direction. Following are some emerging promising quality assurance and improvement practices at the individual/provider and systemic levels:

- Data about serious incidents is an important resource for identifying and taking actions on serious individual concerns. Many states have developed automated incident management systems and have the ability to aggregate data on a sub-state and statewide basis to detect trends across providers and types of services. Some states have formed “risk management” committees to review both individual issues and make system wide improvements. More information about incident management systems is available in the Risk Management and Quality in HCBS monograph.
- Some states (Arizona, Vermont, and Wisconsin for their elder services) have a separate “consumer affairs” or “ombudsman” office to field concerns and complaints from individuals and providers and to follow-up on issues when they arise. Arizona and Vermont offer mediation services as a means of resolving issues between an individual and provider. Other states provide a toll-free number for people to voice concerns about their services. Concerns about the individual’s health or safety can trigger follow-up to determine if a serious incident has occurred that warrants further investigation and/or protective action. Taking this a step further, states can periodically compile the data on complaints lodged against individual providers and their resolution in order to make system-wide improvements.
- Arizona sends “report cards” to individuals and families to “grade” their provider. Survey results are shared with central office management and support coordinators. Follow-up occurs when the provider receives a failing grade. This can be particularly effective if providers serve multiple participants or are chosen from a list and do not comprised primarily of family and friends.
- In some states, the support coordinator reviews monthly billing submissions to identify under utilization and the possibility that providers are not doing the work (Vermont). Over billing can also be a cause for concern since it could indicate that the individual may need more support than is identified in his or her support plan or that the provider is taking advantage of the person. South Carolina has an automated billing system called Care Call whereby providers call-in when they arrive and leave. On an individual/provider level, the support coordinator may review monthly billing submissions to determine that services are delivered as authorized. Billing systems can also be used to detect statewide or sub-state trends

in use of individual providers by types of services (e.g., types of services provided, usage in different areas of the state, type of living arrangement).

- Citizen and/or peer councils are an important part of quality assurance and improvement systems in some states. These councils may fulfill multiple functions, including providing a forum for sharing resources, mutual support, and conducting local monitoring efforts that may be less intrusive than traditional quality assurance reviews (e.g., Arizona and Vermont). Vermont requires that its statewide and designated local agency “standing committees” have at least 51% individual or family membership. Both the local committees and the statewide committee review incident trends and the results of the QA reviews. Recommendations by the committees support local agencies and the state in focusing on quality improvement over time. Other states use focus groups to obtain participant input on the quality of their services and supports. For example, Virginia Commonwealth University (VCU) held eight “listening posts” around the state to learn what individuals, families, providers and other stakeholders thought of their consumer-directed services. A 2003 summary report is available on the VCU website. Important information can be obtained from processes like these. There are computer software programs that can aggregate large amounts of qualitative data in order to detect system wide trends (e.g., Atlas/ti, TextAnalyst, CDC EZ-Text, INTEXT).

- Canvassing individuals/families about their services and supports is one means of obtaining quality data about using individual providers. These surveys must be done carefully since people and their families are reliant on individual providers for their supports and, unless they feel safe and free from retribution, they may not be entirely truthful. As well, these surveys need to be used in conjunction with other data sources, such as monitoring results, incident reports, support coordinator visits, focus groups, and peer supports networks. Some states conduct routine participant/family surveys to determine satisfaction with the supports and identify issues of concern where follow-up is needed. A number of tools to canvas individuals and families are in use today including:
 - Participant Experience Survey, developed by the Medstat Group through a contract with CMS, for individuals with developmental disabilities and for the elderly and disabled.
 - National Core Indicators Consumer and Family Survey, a collaboration of NASDDDS member state agencies and the Human Services Research Institute, includes separate surveys for individuals with developmental disabilities and their family members.
 - “Ask Me” survey, used in Maryland, for people with developmental disabilities.
 - New Hampshire Developmental Services Adult Consumer Outcomes Survey and the Developmental Services Family Survey are surveys for individuals with developmental disabilities and their family members.

A number of states involve consumers, families and other interested citizens in conducting consumer surveys.

- Several states have developed person-centered review processes as a key feature of their QA/QI system (e.g., Kansas, Massachusetts, and Colorado). These processes assess the quality of services and supports as experienced by the individual and depart from more traditional, provider-centered licensing/certification processes. Some states include participant-directed supports in their person-centered review process. These processes can potentially be used to identify specific provider issues and systemically support the development of quality improvement strategies across providers. As an example, Kansas reviews all services and supports through the “Kansas Lifestyles Outcomes” (KLO) survey but the survey is modified to accommodate participant-directed supports. Following are the major outcomes assessed using the tool:
 - Opportunities of choice to support and increase independence, productivity, integration and inclusion;
 - Effective access maintained;
 - Individual rights and responsibilities supported;
 - Personal health and safety maintained;
 - Use of psychotropic medications or restrictive practices safeguarded.

Specifically excluded for participant-directed supports in the KLO is a review of individual rights and responsibilities training by the provider, medication administration policy requirements, mandatory CPR and first aid training, and some of the safeguard practices (such as human rights committee) for the use of psychotropic medications. In participant-directed supports, these issues are addressed in the person’s support plan when applicable and needed.

Quality management strategies for individual providers. Valid and reliable quality measures and data sources for these services and supports are starting to emerge. Basic measures such as whether the provider came on time and worked the correct number of hours potentially may be tracked through billing. Comparing service authorization to billing identifies that individuals are getting the services in their plan. This relies on a plan that truly reflects the individual’s need and preferences. Incident management systems can identify egregious problems. At best, these basic measures tell only a small part of the story.

An underlying theme in this monograph is that the use of highly personalized supports requires the adoption of person-centered monitoring approaches, which are the most effective method of netting information about provider performance, and detecting system-wide trends. Most states rely on several, nominally redundant, person-centered approaches to safeguard individuals and ensure they are receiving needed supports. For example, states may use a combination of interrelated approaches (including incident

management, financial management and support coordinator monitoring, and grievance reporting) so that if one process is not used, another comes into play. States are trying different approaches with many involving the participation of individuals, families and other community members. While some of these approaches are qualitative, they have the potential to re-shape how we envision quality assurance and improvement systems in the future. A Guide to Quality in Consumer Directed Services by Robert Applebaum et al can be a helpful resource to states as they think about how to integrate quality assurance and improvement measures and data sources into their overall quality management strategy.

Quality assurance and improvement considerations for states:

- Is there a means of collecting information about the quality individual providers?
- Can the information be aggregated to identify sub-state and statewide trends? For example, if the states canvasses individuals is the sample adequate to determine how they about their services and supports when using individual providers?
- Is there a process for implementing improvement strategies and are individuals and families involved in the process?
- Is information about individual providers readily to individuals and families in order to make informed choices in providers?

CONCLUDING COMMENTS

Programs incorporating individual providers are shown to improve the participant’s ability to access services by expanding the potential labor pool, building provider capacity through taping into non-traditional providers, offering participants greater choice and control over who provides services and when those services are provided, and increasing flexibility to more effectively meet personalized needs. Balancing these offerings with a comprehensive Quality Management Strategy that includes minimum provider qualifications, skills training, and meaningful supports will serve to safeguard the health and well-being of participants. Whether states elect to offer the option under participant direction or a more traditional approach, individual providers serve to strengthen the program’s ability to effectively meet participant’s needs.

Participants greatly benefit from expanded caregiver options. It might enable a participant to hire a provider who lives in his or her hometown who could be a link to community resources and social connections. An individual provider might be well acquainted with the individual and/or family and have a unique sensitivity to issues that impact service delivery. States must balance these benefits with protecting participants from harm, since they are ultimately responsible for safeguarding health and welfare. However, the balance shifts depending on who has primary responsibility for hiring and

managing individual providers. In traditional services, the state holds the provider agency accountable for hiring and managing staff. Under participant direction oversight transfers to the individual and/or family and the participant-directed supports they receive. Many states designing waiver programs, especially those building in participant direction (e.g., New Mexico), involve individuals and families since open discussion of these issues leads to the development of creative, person-centered strategies before the waiver is implemented.

APPENDIX A: GLOSSARY

Assessment is a comprehensive process to collect, analyze and interpret information about an individual for the purpose of identifying and making decisions concerning the services and supports to address the person's needs.

Financial Management Services Entity is an organization that assists the individual or family to manage and distribute funds contained in the individual budget including, but not limited to, facilitating the employment of service workers by the individual or family, processing Federal, state, or local tax withholdings/payments, unemployment compensation fees, wage settlements, fiscal accounting and expenditure reports, etc.

Incident is the alleged, suspected, or actual occurrence of: (a) abuse (including physical, sexual, verbal and psychological abuse); (b) mistreatment or neglect; (c) exploitation; (d) serious injuries; (e) deaths other than by natural causes; and, (f) other events that cause harm to individuals.

Individual Budget is an amount of dollars over which the participant or his/her family (as appropriate) exercises decision-making authority concerning the selection of services, service providers, the amount of services and how services are delivered.

Individual Provider is a qualified individual who is not employed by an agency and furnishes HCBS.

Ombudsman is an individual who assists in resolving problems concerning services. He or she is a neutral party who works with individuals, the program authority, and the provider (as appropriate) to resolve problems.

Person or Family Centered Planning (a.k.a. service planning, support planning) is a process, directed by the participant or the participant's family (when appropriate) that is intended to identify the strengths, capacities, preferences, needs, and desired outcomes of the participant. The service plan (plan of care) identifies services and supports (HCBS and other) necessary to address identified needs.

Participant-directed Supports refer to a service delivery approach whereby the participant or the participant's family (as appropriate) has direct involvement, control and choice in identifying, accessing and managing the community services required to meet their needs. Participant-directed supports are based on a person or family-centered plan. Assistance in the form of financial management services and other information and assistance is made available to facilitate participant/family direction of services.

APPENDIX B: REFERENCES

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Quality Framework, in order to facilitate a dialog about quality within Home and Community-Based Services, CMSO engaged the services of MEDSTAT, the National Association of State Directors of Developmental Disability Services, the National Association of State Units on Aging, and the Human Services Research Institute to facilitate the development of a Quality Framework.

Revised 1915(c) HCBS Waiver Application (Draft Application Version 3.3 for Use by States)

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Rowe, June. October 2002. *Analysis of five state's licensing/certification processes and requirements.*

APPENDIX C: STATE RESOURCES

Name of Tool/Product & Brief Description	State	How to Locate the Resource
<p>Request for Proposal – Counseling/Fiscal Agent for <i>IndependentChoices</i> Demonstration Project:</p> <p>Seeks qualified contractors to submit competitive proposals to be a Fiscal Agent Agency for the Arkansas Independent Choices Demonstration Project.</p>	AR	<p>http://www.independentchoices.com/ICRFP/icrfp05.pdf</p> <p>For more information contact: Deborah Ellis, Arkansas Department of Health and Human Services, Division of Aging and Adult Services debby.ellis@medicaid.state.ar.us</p>
<p>Consumer & Family Tool Box:</p> <p>A user friendly guide for individuals and families who are hiring an “independent” provider. English and Spanish versions are located on the state’s web site.</p>	AZ	<p>http://www.de.state.az.us/ddd/downloads/557ConsumerInfo/WORKING%20WITH%20PROVIDERS%20IN%20THE%20HOME.doc</p> <p>http://www.de.state.az.us/ddd/downloads/557ConsumerInfo/tool%20box%20Espanol.doc (Spanish version)</p> <p>For more information contact: Deborah Ellis Same as above</p>
<p>Kansas Lifestyle Outcomes:</p> <p>A quality assurance tool with interpretive guidelines for use in assessing outcomes for people with developmental disabilities.</p>	KA	<p>http://www.srskansas.org/hcp/css/pdf/KLOIL.pdf</p> <p>For more information contact: Frank Stahl, 785.296.3561</p>

Name of Tool/Product & Brief Description	State	How to Locate the Resource
<p>Person Centered Services Independence Plus: Maine's Opportunity for Choice and Control</p> <p>Describes a project to develop information, training materials and other tools for persons with mental retardation and autism and their family members to provide them with the option of directing their own supports.</p>	ME	<p>http://www.mainerealchoices.org/pcs_indplus.htm</p> <p>For more information contact: Vanessa Pelzer Bell, Project Director Independence Plus Project University of Southern Maine Muskie School of Public Service Institute for Health Policy ybell@usm.maine.edu</p>
<p>Ask Me Survey:</p> <p>A Consumer Quality of Life Survey administered by The Arc of Maryland for the Maryland Developmental Disabilities Administration (DDA). All community programs licensed by the State DDA participate in the survey. The survey interviews people who receive services. Interviews are people with developmental disabilities.</p>	MD	<p>http://www.thearcmd.org/programs/ask_me.html</p> <p>For more information contact: Sarah Basehart, The Arc of Maryland sbasehart@thearcmd.org</p>
<p>New Hampshire rules for HCBS in-home supports:</p> <p>Rules include, among others, provider qualifications (e.g., reference and criminal record checks) and training requirements</p>	NH	<p>http://www.gencourt.state.nh.us/rules/he-m500.html</p> <p>For more information contact: Barbara-Joyce Reed, M.Ed., Bureau Liaison Dept. of Health and Human Services Bureau of Developmental Services breed@dhhs.state.nh.us</p>

Name of Tool/Product & Brief Description	State	How to Locate the Resource
<p>Virginia Commonwealth University “Listening Post” Executive Summary</p> <p>Summarizes input from individuals utilizing consumer-driven services and people who provide them with support.</p>	VA	<p>http://www.vcu.edu/partnership/pdf/LP_exec_summary_1003.pdf</p> <p>For more information contact: Eileen G. Hammar, Community Supports Program Specialist The Partnership for People with Disabilities Virginia Commonwealth University (804) 828-3876</p>
<p>Virginia Commonwealth University Consumer Directed Services in Virginia’s Home and Community Based Services Waiver</p> <p>Provides information to individuals with disabilities, their family members, and other supporters (e.g. case managers and CD services facilitators) about how to get and to use consumer-directed services offered under Virginia’s Mental Retardation Home and Community Based Services Waiver.</p>	VA	<p>http://www.vcu.edu/partnership/cdservices/resources/mr_waiver_workbook_appdx_a.pdf</p> <p>For more information contact: Eileen G. Hammar, Community Supports Program Specialist The Partnership for People with Disabilities Virginia Commonwealth University (804) 828-3876</p>
<p>REQUEST FOR PROPOSALS Services Funded Through Division of Developmental Services <u>Payroll and Tax Service for Consumer and Family Directed Services and Independently Employed Support Workers</u></p> <p>Seeks to identify an organization(s) that will provide efficient, cost-effective, and accessible payroll and tax services as a fiscal agent to consumers, surrogates, and independent contractors who have chosen to assume responsibility for employing support staff.</p>	VT	<p>http://www.hsri.org/docs/QF_VT_RFPforIndepProviders.doc</p> <p>For more information contact: Merle Edwards-Orr, Division of Disability and Aging Services Department of Disabilities, Aging and Independent Living Email: merle.edwards-orr@dail.state.vt.us</p>

Name of Tool/Product & Brief Description	State	How to Locate the Resource
<p>A Guide for People who are Self-or Family-Managing Medicaid-Funded Developmental Services</p> <p>Provides insights regarding what tasks are required to self- or family-manage Medicaid-funded developmental services in Vermont and who is responsible for making sure these tasks are completed.</p>	VT	<p>http://www.state.vt.us/dmh/docs/ds/ddsGuideforPeopleSelfManaging2004.pdf</p> <p>For more information contact: Merle Edwards-Orr, Division of Disability and Aging Services Department of Disabilities, Aging and Independent Living Email: merle.edwards-orr@dail.state.vt.us</p>
<p>National Core Indicators Consumer and Family Survey</p> <p>The National Core Indicators is a collaboration among participating NASDDDS member state agencies and HSRI, with the goal of developing a systematic approach to performance and outcome measurement.</p>	N/A	<p>http://www.hsri.org/nci/</p> <p>For more information contact: Sarah Taub, Human Services Research Institute staub@hsri.org</p>
<p>Participant Experience Survey</p> <p>The Participant Experience Surveys (PES) solicit feedback directly from participants about the services and supports they receive under the Medicaid Home and Community-Based Services (HCBS) waiver program.</p>	N/A	<p>http://new.cms.hhs.gov/HCBS/downloads/2_Summary.pdf</p> <p>For more information contact: Sara Galantowicz, Thomson Medstat Sara.Galantowicz@thomson.com</p>
<p>Atlas/ti, TextAnalyst, CDC EZ-Text, INTEXT</p> <p>These are sites for some of the software programs that can perform analysis of text or qualitative information</p>	N/A	<p>http://www.atlasti.com/index.php</p> <p>http://www.megaputer.com/products/ta/index.php3</p> <p>http://www.cdc.gov/hiv/software/ez-text.htm</p> <p>http://www.intext.de/eindex.html</p>
<p>General Information on Participant Direction</p>	N/A	<p>http://www.hcbs.org</p> <p>http://www.cashandcounseling.org</p>

