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Redefining Quality Participant-Directed Services

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Redefining Quality
Participant-Directed Services

Erin McGaffigan

Summary

Since the creation of the Medicaid Home and Community-Based waiver program through the 1981 passage of section 2176 of the Omnibus Budget Reconciliation Act (OBRA), a shift in public policy that allows for community-based service delivery in lieu of facility care for elders and people with disabilities has become evident[1]. The call for systems change to enhance community-based service options dictated the need for new models of quality management that account for the multiple environments, types of services, and providers of services found within community-based services. The development of participant-directed options that allow for individuals to hire personal care workers and purchase goods and services that meet their needs has been one approach to increasing participant access, choice, and satisfaction with community-based services. With the increase in participant-directed options for elders and people with disabilities, there is once again a need to rethink how we approach quality. A disconnect exists between traditional approaches in which policy makers and providers define, measure, and improve quality and the participant-directed approach. This paper explores the various participant-direction models, existing quality management strategies, and the potential for change that allows participant-directed quality management systems to remain true to the core values they were founded upon.

Major Points

- The Centers for Medicare & Medicaid Services (CMS) has increased the availability of participant-direction opportunities through federal funding made possible under the Social Security Act, including the new options under the Deficit Reduction Act (DRA).

- States that choose waivers to finance community-based supports, regardless of whether such services are participant-directed, are required to address waiver assurances through the development of a quality management system. States that choose to support participant-direction through the DRA option are also required to address basic quality standards for their services.

- A quality management system for participant-directed services may be systematically similar to traditional programs, while basic functions may be performed and evaluated differently. To ensure a strong participant-directed program, program administrators must incorporate the individual into the quality management system in a direct and meaningful way. While this paper focuses on participant-direction, this practice may

[1] LeBlanc, A., Tonner, M., & Harrington, C. (2001).

be adopted in all programs, regardless of whether they are considered participant-directed or not.

- With a shift to a participant-directed service delivery approach, states are challenged with implementing new methods to assure health, welfare, and accountability for the use of public funds, while at the same time respecting the principles that are the foundation of participant-direction.

- No single quality management approach will meet the needs of every state or every model of participant-direction. It is the responsibility of the state to develop a quality management system that meets the needs of its participant-directed program, state objectives for health and welfare, as well as federal assurances. Effective quality management systems, regardless of program design, include methods to identify and address quality concerns in a timely manner while concentrating on ongoing improvement.

Background

Long-term care has traditionally been affiliated with nursing home and institutional care for elders and people with physical, intellectual, and mental health disabilities. Medicaid is a major funder for many low-income populations requiring long-term care. Since the independent living movement of the 1970s and the closure of institutions driven by class action law suits, there has been a demand for community-based services for people with disabilities. Such efforts were solidified by the 1999 Supreme Court ruling of *L.C. & E.W. vs. Olmstead*, a decision that required states to support individuals in the most integrated and least restricted environment possible.[2] As a result, a substantial shift has occurred in Medicaid funding from institutional and facility settings to more individualized community-based settings. A significant financing mechanism for this shift has been the use of Home and Community-Based Waivers (HCBS) (1915c) as well as Research and Demonstration Waivers (1115).[3]

While existing community-based support models may be successful in meeting the needs of many individuals, advocates have communicated a desire for increased choice and control in how services are received. A growing worker shortage and a retiring "baby boomer" generation reinforce the need for innovative service delivery options. Participant-directed services are documented as a successful method to provide choice and control while also expanding access to services.[4] Participant-direction is a model in which a participant (and/or his or her representative) has decision-making authority over the workers who provide services and/or decision-making authority over the participant's budget for services.

While participant direction dates back as early as the 1950s, the roots of existing models are grounded in state programs developed in the early 1990's such as Oregon's client-employed program and the Robert Wood Johnson Foundation's (RWJF) Self-Determination Initiative, which began in 1997, as well as the Cash & Counseling Medicaid Demonstration (a joint partnership between RWJF and the Assistant Secretary for Planning and Evaluation), which began in 1998. The success of these and other state models led to the CMS' *Independence Plus* initiative, first announced in 2002. *Independence Plus* provided templates that allowed states to create participant-directed flexible budget programs using 1915(c) or 1115 authorities. More specifically, the *Independence Plus* model provided the opportunity for participants to:

- participate in a person-centered planning process to identify their needs and to design their plan;
- hire and supervise workers, including friends, family, and neighbors;
- purchase goods and services to meet their needs;

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[2] *Olmstead v. L.C.* Available at: http://supct.law.cornell.edu/supct/html/98-536.ZS.html.
[3] Social Security Act §1915c. Available at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm; Social Security Act §1115. Available at: http://www.ssa.gov/OP_Home/ssact/title11/1115.htm.
[4] Foster, S., Dale, R., Brown, B., Phillips, J., Schore, B., & Lepidus, C. (2005).

- receive information, training, and technical assistance from program staff (often called a support broker or consultant);
- receive assistance with employer-related functions such as taxes, insurance, and payroll, as well as assistance with purchasing other goods and services (often called fiscal agent);
- appoint a representative to assist in decision-making if necessary; and,
- use participant protections such as emergency back up, incident procedures, and grievance procedures.

Currently, there are eleven Independence Plus waivers that exist within ten states. Of these waivers, eight are 1915(c) including two combination 1915 b/c, and three are 1115 Demonstration waivers. States also provide a participant-direction option, mostly the opportunity to self-direct personal care, through state funded programs or existing waivers. For the most part, this paper will explore quality management strategies that are implemented in flexible budget models, although much of what is stated can be applied to programs that strictly allow participant-direction of personal care.

Existing flexible funding programs i.e., Cash & Counseling have resulted in tools and guidance on methods to create effective quality management systems.[5] Person-centered planning models using individual budgeting methods for people with cognitive disabilities have also led to an increased understanding of methods to address quality.[6] Many of the methods and tools developed to date emphasize the importance of an individualized participant-driven approach for an effective quality management system. This paper will explore opportunities in which to modify traditional quality methods to better fit with the paradigm shift required for quality management in a participant-directed program.

Utilization of Participant-Direction under the Deficit Reduction Act

The Deficit Reduction Act (DRA) of 2005 provides an opportunity for states to implement a participant-directed program through a Cash & Counseling State Plan Option. Under this option, states may elect to provide participant-direction through their state plan rather than through a waiver. Individuals do not need to meet institutional level of care, but need to be eligible for the state's personal care option or home and community-based services. Even though services are not provided under a waiver, state-wideness and comparability are not required. Under this option, individuals may hire legally responsible individuals, and unlike waivers, there is no cost neutrality mandate (need for home and community-based services not to exceed institutional costs). Quality requirements for participant-direction provided under the DRA are expected to be similar to those under waivers. States are currently assessing whether or not they will develop a participant-directed program using the new options.

[5] Applebaum, R., Schneider, B., Kunkel, S., Davis, S. (2004).
[6] Lakin, C. (2001) and Geron, S. (2000).

Two Participant-Direction Models

States have at least two options for designing their participant-directed waiver programs: the use of an Agency with Choice model or the use of the Fiscal/Employer Agent model, referred to from this point forward as Employer Agent. Current distinctions between the two models may lead to differences in design and implementation of quality management strategies. Even so, some may argue that if implemented perfectly, these two models should look identical. Although this may be the case, this paper will reflect upon existing differences between the two models and quality management strategies that reflect such differences. The table below outlines the existing differences between the two models.

Agency with Choice Model	**Fiscal/Employer Agent Model**
Participant is the Managing Employer with recruitment, training, and management support provided by an agency, as needed.	Participant is the Managing Employer.
Agency is the Common Law Employer.	Participant is the Common Law Employer/Employer of Record.
Participant recruits, interviews, and selects attendant (may call on agency for support with recruitment).	Participant recruits, interviews, and selects attendant (may call on agency for training).
Agency completes the required paperwork.	Individual completes the required hiring paperwork, but often calls on a fiscal agency to file employer-related taxes and payroll.
May or may not require an individual budget.	Individual budgeting process is utilized.
Individual sets hours and wages (within constraints of the agency).	Individual sets hours and wages.
Individual supervises and approves timesheets.	Individual supervises and ensures completion of timesheets.
Agency may provide training, as needed, to the individual and/or the worker.	Agency may provide training, as needed, to the individual.
Agency may purchase other services on behalf of the individual.	Individual is responsible for purchasing services, but can seek guidance from the support broker and payment from the fiscal agent.
Medicaid Provider Agreement is executed with the Agency.	Medicaid Provider Agreement is required for 1915c Home and Community-Based waivers.
Representative role may be used to assist individual with responsibilities.	Representative role may be used to assist individual with responsibilities.

Source: Flanagan, S., & Green, P. (1997). Consumer-directed personal assistance services: Key Operational Issues for State CD-PAS Programs Using Intermediary Service Organizations.

Although the Employer Agent model affords participants the most choice and control in their services, an Agency with Choice approach can provide participant-direction opportunities to individuals who may be less familiar and/or less interested in having full management responsibilities of workers. Within this model, individuals are provided support with management responsibilities, including support with recruitment, oversight, and payroll for individual workers.

Texas has three options in which elders and people with disabilities may receive personal assistance: agency-based, Agency with Choice, and Employer Agent. The Department of Aging and Disability Services has found the Agency with Choice model, known as the Service Responsibility Option in Texas, to be a beneficial option to supplement its already existing agency-directed and Employer Agent participant-directed services for elders and people with disabilities. Individuals have the choice between these three options, as well as the mobility to move from one option to the other, depending on their needs. The Agency with Choice model, provided through the state plan rather than a waiver in Texas, has become popular among people with diverse disabilities, including individuals with physical disabilities and elders. The distinct differences between the Agency with Choice model and the Employer Agent model and how they impact quality roles and responsibilities is further explored below.

CMS Quality Expectations for Waivers

There are specific CMS requirements, known as assurances, which need to be incorporated into all waiver quality management systems, regardless of whether or not they are participant-directed. The CMS waiver assurance requirements pertain to level of care determination, plan of care development, existence of qualified providers, health and welfare of participants, and administrative and financial accountability. States with waivers are required to produce evidence that assurances are being met, which has become the foundation for waiver quality management systems. In addition to meeting assurances, states are required to develop a quality management system that meets the unique needs of their program and population served.

CMS Waiver Assurances
- ✓ Level of care determination
- ✓ Plan of Care
- ✓ Qualified Providers
- ✓ Health and Welfare
- ✓ Administrative and Financial Accountability

In collaboration with states and national associations, CMS developed the Home and Community-Based Services Quality Framework and related performance indicators to support states in their efforts to improve quality in their home and community-based waiver programs. This framework, in addition to the Quality Workbook produced by Edmund S. Muskie School of Public Service, provides guidance for individual outcome measures associated with the receipt of home and community-based services. However, CMS emphasizes the statutorily-based waiver assurances as required pre-requisites for operating home and community-based waiver services. In other words, the assurances represent the terms of the contract between a state and CMS. Thus a continuous quality

improvement process applied to the assurances in mandatory for all 1915(c) programs, while the outcome measures associated with the Quality Framework are meant to be optional. The Framework is recognized as a beneficial tool for states seeking to further the quality in their waiver programs by focusing on both standards and measures.

A Shift in Quality Focus

When defining, measuring, and improving quality in a participant-directed program, or any person-centered program for that matter, a shift in approach is required to ensure a transition from a traditional provider perspective to an individual participant perspective. With this shift, challenging questions surface about assurances, liability, freedom of choice, and health and welfare. These challenging questions, often acknowledged in discussions pertaining to participant-direction, also exist in traditional models of service delivery where individual preferences and choice are important as well. A shift in quality focus to an individual's perspective should not only be reflected in participant-directed programs, but all programs seeking to support individuals with choice and dignity.

In traditional models of supports and services, program administrators typically define quality and then design the system of supports and services based on that definition. While basic assurances and core quality requirements pertaining to health and welfare continue to exist in a participant-directed model, the primary role of defining and evaluating quality shifts to the individual. Each participant's definition of quality will differ based on his or her functional needs, life experiences, culture, and other personal attributes. This requires a flexible method for defining and evaluating quality. For an individual whose goal is to work, quality may be defined as having a support worker that enters the home in the early morning to assist that individual in preparing for work. Quality for another individual may be defined as having meals prepared with traditional ethnic ingredients or having access to transportation to the local food store to purchase needed ingredients. Given these differences, quality systems should provide participants with a leading role in defining the quality of services and supports provided.

This shift in quality does not mean the agency is responsible for less quality monitoring, and in fact, quite the opposite is true. As individual perspective drives the definition and evaluation of quality of services, the program itself takes on an equally important role in ensuring participants are well informed and receive necessary services to support decision-making. Training, technical assistance, and ongoing support to participants is critical for informed decision-making, particularly in the areas of identifying need, hiring and managing workers, and ensuring safety. For flexible budget models, such training and support is also required for designing a spending plan, purchasing goods and services, and monitoring finances. Examples of the variance in potential quality definitions are provided below.

Quality according to…	
Individual	✓ Services are provided at the right time. ✓ Services are provided by the right person. ✓ Services are provided in the right manner.
Representative	✓ Services are provided at the right time. ✓ Services are provided by the right person. ✓ Services are provided in the right manner. ✓ My actions are driven by the needs and desires of the individual rather than my own.
Support Broker	✓ Participant receives information on existing community resources. ✓ Participant receives the required support and training to effectively manage his or her services. ✓ Participant is able to manage his or her services free from abuse, neglect, or injury to him/herself or others. ✓ Participant knows what to do in the case of an emergency. ✓ Participant is satisfied, is achieving desired quality of life, and is integrated within his/her community. ✓ Participant is receiving the services in the scope and frequency outlined in his or her Plan of Care.
Fiscal Agent *(may not be applicable to all programs)*	✓ Participant is receiving accurate financial information in a timely manner. ✓ Services and supports are purchased in a manner that is consistent with state and federal requirements. ✓ Services are being rendered at frequency expected. ✓ Employers are completing required training and paperwork.
Oversight Agency	✓ Basic assurances are being met. ✓ Quality of the program and support components is improving. ✓ Participants have access to the training and services needed. ✓ Participants are safe and are achieving individually defined outcomes.

Determination of Level of Care and Assessing Need

There is partial consistency in the method to meet waiver assurances across provider and participant-directed service delivery models. This appears to be especially true for the determination of level of care for participants. States are required to use approved tools and processes to perform annual level of care evaluations, monitor the results of these evaluations, and build a Plan of Care based on determinations. Processes used to meet these expectations are similar across agency and participant-directed models.

Assessing Need

- ✓ Allow for participant-defined areas of need
- ✓ Build on existing informal support network
- ✓ Provide opportunity for introduction of participant-directed model
- ✓ Provide opportunity to assess level of support needed to direct services

Although determination of care may be similar, the approach to assessing need may look different in a participant-directed model (or any person-centered model) than an agency-driven model. The individual's own identification of existing needs and resources should be paramount in a participant-directed model. Utilizing assessment methods that ensure the individual and his/her support network are involved in the identification of needs is reflective of participant-directed principles. States may use the assessment phase to initiate discussions pertaining to the participant's definition of quality and desired outcomes related to choice, independence, and community integration. Minnesota's participant-direction waiver uses a global assessment tool to identify individual needs as well as their existing resources, which in turn becomes the foundation for the participant's service plan. Individuals performing assessments who are trained in strength-based approaches and participant-direction philosophy may provide potential participants an early glimpse into the uniqueness of the participant-directed model and participants' roles and responsibilities. States that have adopted a person-centered assessment planning process across programs, such as Connecticut, may not find this process to be unique to participant-directed programs.[7]

Plan of Care

In a participant-directed program, the Plan of Care is similar to what is often produced in traditional wavier programs, and typically includes all services, regardless of whether or not they are participant-directed. In participant-directed programs that allow individuals to direct a flexible budget, the Plan of Care may lead to the development of an individual budget and spending plan to drive how some or all of the services are provided.

[7] Readers might be interested in Wyoming method developed by Jon Fortune. Similar to Minnesota, it establishes the institutional level-of-care services to define needed services, and is tied to a method to determine amount for an individual budget.

The creation of the spending plan in a flexible budget model is a joint responsibility of the support broker and the participant.[8] Personal goals are set by the individual and are developed within the confines of the program itself. Prior to the development of the spending plan, there is often a training process for ensuring that the support broker and the individual are well informed of their roles and responsibilities related to the development, implementation, and monitoring of the spending plan.

These practices may be true for both the Employer Agent model and the Agency with Choice model; although once the spending plan is designed the described roles may be different. Within the Texas Agency with Choice model, an agency staff member meets with the individual prior to an initial meeting with the home health agency providing the workers to ensure that the individual is clear on the program's purpose, the role of the individual, and the role of the home health agency. The home health agency is then required to meet with the individual within fourteen days to initiate the development of the plan and recruitment process. The responsibility of assuring that the spending plan designed meets the program requirements set by the state is a joint responsibility of the participant and the support broker. Sign off on the plan from both the participant and the support broker is one method to ensure that program requirements are met prior to plan implementation.

In participant-directed flexible funding programs, participants often initiate revisions to their plan as they learn new and innovative ways to meet their needs. Routine in-person meetings between the participant and the support broker are used to identify needs and to modify the plan. The frequency of meetings between the support broker and the participant may be dependent upon the individual's experience, comfort with participant-direction, and level of identified risk. Within an Agency with Choice model, agencies often choose to monitor the plan and related support more closely than in Employer Agent models, given their role in providing workers. In this case, frequency of meetings may be best negotiated between the individual and the agency to ensure the process remains participant-driven. Those participating in an Employer Agent model have responsibility for monitoring the plan. When the individual decides a service is not effective, he or she takes the action required to replace such services. The role of the support broker in this instance is to provide the training and information to assist the individual, facilitate changes when desired by the individual, and ensure that the existing plan meets program requirements.

Developing and Monitoring Spending Plans

- ✓ Apply a person-centered planning process
- ✓ Create a plan based on unmet needs identified during the assessment process
- ✓ Ensure knowledge of how to use existing support infrastructure, such as the support brokerage and fiscal management support
- ✓ Communicate roles and responsibilities for designing and monitoring the Plan
- ✓ Assist to address barriers related to purchasing goods, worker recruitment, and worker management

[8] Throughout this paper, the role of the participant may also include his/her informal support network, as well as a representative if one exists. Individuals may choose to involve their support network and/or representative to varying degrees depending on the need of the individual.

Allowing choice in direct care providers, an expectation when developing a Plan of Care, may be addressed differently in an Employer Agent model compared to an Agency with Choice model. Within both models, participants have the opportunity to hire neighbors, friends, and family as workers, which often increases availability of direct care providers. Even so, Agency with Choice models often require more education and/or training, given the role agencies play in managing workers. This may ultimately lead to a different pool of workers than what may be found when administering an Employer Agent model.

Qualified Providers

As in agency models of personal assistance, individuals who self-direct under a waiver are required to have access to qualified providers. States ultimately have the responsibility for setting qualifications for allowable providers. Traditionally, provider qualifications are documented by education, certification, experience, criminal background checks, and mandated training. When reviewing qualifications through the lens of a participant rather than an agency, some of these standards may not be as important as others. To be responsive to individual needs, the state may include minimal, flexible qualifications, allowing individuals to choose additional qualifications based on their needs. Employer Agent models often utilize worker qualifications identified by the individuals themselves, while also providing participant access to criminal background checks, worker registries and training on effective recruitment strategies. More often, states administering an Agency with Choice model have stricter requirements for personal care providers in the area of criminal background checks and training due to liability concerns.

Employer Agent models vary in minimum requirements they set for directly hired workers. Existing qualifications pertain to age, education, criminal background/abuse registry checks, and driver's licenses (for those who provide transportation). Some Employer Agent models are requiring criminal background check clearance while other models leave the final hiring decision to the individual when minor infractions are found. Most states, if not all, are providing participants with the resources to conduct criminal background checks even if they are not mandated. Within Agency with Choice models, agencies may take a more involved role in determining provider qualifications. Provider qualifications in Agency with Choice models may be similar to qualifications set for agency models and may include pre-determined level of education, clearance of criminal background checks, as well as training in first aid and CPR. What makes the determination of qualified providers unique in participant-direction is the individuals' ability to determine what constitutes "qualified" above and beyond basic state requirements.

Documenting Qualified Providers

- ✓ Participant-defined job descriptions
- ✓ Availability of criminal background checks
- ✓ Training provided to the participant by the program
- ✓ Training provided by the participant to the worker
- ✓ Driver's license and insurance if providing transportation
- ✓ Worker agreements

To meet this assurance while allowing for individual flexibility, Employer Agent models

are often requiring participants to document required worker qualifications and responsibilities through job descriptions. A worker agreement signed by both the participant and the worker is a tool programs may use to ensure that the employer documents the training and tasks requested of his/her worker.

Training of the participant is an essential component to acquiring qualified providers. States find that using multiple training formats, such as one-on-one training, brochures, fact sheets, and videos, are helpful in ensuring individuals are trained in their role in hiring and managing workers, which can then impact the quality of providers chosen. Colorado produces a brochure for participants that outlines safety and prevention strategies, including methods for how to: recognize abuse, exploitation and neglect; plan back-up care; prepare for a disaster; minimize risk or theft; and prepare healthcare emergency information. Connecticut's participant-directed model, which serves people with intellectual disabilities, provides similar information in the form of fact sheets and informational booklets, both for the participant and the worker. Connecticut's worker fact sheets include expectations and communication strategies for hiring and managing employees, self-determination, human rights, handling emergencies, reporting signs of abuse and neglect and physical restraint, and other incidents. In addition, Connecticut will soon provide employers and workers with access to online learning as another tool to ensure proper training of workers.

Web-based recruitment of directly hired workers is used effectively in many states. One example is rewardingwork.org, a website currently available to individuals hiring workers in Massachusetts, Rhode Island, New Jersey, and Connecticut. For a small fee (sometimes paid for through the individual budget), individuals can search a database for potential workers based on various characteristics such as available hours, access to transportation, and preferences pertaining to type of work. Individuals who use rewardingwork.org are responsible for their own screening and training of workers.

Health and Welfare of Recipients

Within a participant-directed model, the individuals themselves complete the majority of monitoring that takes place. Given this reality, states are often puzzled by how to meet the waiver assurance of health and welfare while at the same time respecting the individual's right to control his or her own services. As within an agency model of service delivery, defining health and welfare can often be seen as subjective: a challenge that is magnified in a participant-directed program. Some states, like Minnesota and Connecticut, have chosen to define risk of health and welfare by using the same indicators found in their traditional service programs, such as imminent risk of hospitalization, emergency services, and abuse and neglect. Setting standards for risk that are more stringent than those created for publicly and privately funded agency services may be unjust, given that findings from the Cash & Counseling demonstration document no increase of abuse and neglect.[9] A challenge more unique to participant-directed programs is how to monitor risk, given that agencies are often less involved in the services provided to individuals. Because of this, methods of assessing risk may be critical in assuring health and welfare in a participant-directed program.

[9] Foster, S., Dale, R., Brown, B., Phillips, J., Schore, B., & Lepidus, C. (2005).

Assessing risk

Assessing risk in a participant-directed program can be problematic, given the potential conflict in defining risk from the program and individual perspective. Programs are challenged with how to define and assess risk without being intrusive or imposing agency principles on a participant-directed program that emphasizes dignity of risk. Minnesota's participant-directed waiver serving elders and people with physical disabilities uses support brokers to assist the individual to identify personal risk and risk management strategies: They often face conflicting risk perceptions between the two. A support broker may recommend a walker to an elder participant for safe mobility inside and outside of the home, but the participant may disagree. To address this challenge, support brokers document the recommendation, but then also take the steps necessary to assist the individual to identify other potential methods to remain safe in the home: methods that the participant supports as well.

Methods to Assess Risk

- ✓ Participant/support broker communication
- ✓ Standardized tools and training
- ✓ Review of participant's existing challenges managing services

Methods to Address Risk

- ✓ 1:1 training
- ✓ Purchase of additional services and supports
- ✓ Appointment of representative
- ✓ Increased support broker visits and communication
- ✓ Signed risk agreements

New Jersey uses a participant-directed questionnaire when assessing risk in its Personal Preference program that serves adults with disabilities. Based on the assessment results, individuals are informed of their potential risks. Increased monitoring strategies may be provided by the support broker to assist in addressing and monitoring risk. Texas practices a similar approach. Prior to individuals enrolling in one of their three options Employer Agent, Agency with Choice, or Agency-directed, program staff use a standard tool to work with the participant to determine the level of participant-direction that will meet their needs, including the potential need for a representative. This tool is for discussion purposes only, and is not used to screen individuals out of participant-directed services.

Connecticut's program serving people with intellectual disabilities has modified its assessment tool to include elements of risk assessment. The tool assesses risk in various areas, including medical, e.g., diabetes and routine health and medical care, mobility e.g., falls, need for assistance with bathing and eating, and risk for exploitation. Based on the information provided during the assessment, a report of potential areas of risk is provided to the individual and his/her support network. As in Texas, the information resulting from the tool is used for planning purposes only, not for screening out participants. Training, planning, and additional community services are often recommended to address identified risks.

Ongoing participant training and monitoring are additional methods of addressing risk. The ability to increase support broker involvement based on the needs of the individual may be beneficial when addressing risk. In this case, the frequency of visits to the

individual's home is negotiated between the agency and the participant to ensure the model is consistent with participant-direction principles.

The use of representatives

Another method to ensure health and welfare under a participant-directed program is the use of representatives. Representatives, known as surrogates in some programs, are appointed by the individual to assist in managing his/her participant-directed services. Particular roles of a representative in an Employer Agent model may include hiring and managing workers, completing and signing off on time sheets, purchasing services and supports, and monitoring overall quality. In an Agency with Choice model, the role of the representative may be similar, but limited to the actions often managed by individuals themselves such as interviewing and training workers, signing off on time sheets, and monitoring quality. To avoid conflict of interest, most states are mandating that representatives do not act as paid caregivers. Representatives are often trained in using the same methods in which individuals are trained. Some programs are mandating the use of a representative as an eligibility requirement if the individual is determined to need assistance with participant-direction and training attempts have been unsuccessful. Programs do not appear to be implementing representative qualifications or screening mechanisms for representatives.

The use of emergency back-up plans

As in agency models, individuals receiving personal care from a worker in a participant-directed program rely heavily on the worker to support their daily functioning. For some individuals, a worker who does not report to work can put the individual's health and welfare in immediate jeopardy. In traditional programs, back-up policies are often in place if and when an assigned worker becomes unavailable. Even with such practices, existing worker shortages make providing access to back-up services a continued challenge.

States have implemented a similar approach in their participant-directed models. When designing their spending plan, individuals are often required to identify back-up support for critical services. Some individuals identify more than one replacement worker depending on their risks. Back-up supports identified in the plan often include both paid and unpaid supports. Individuals who receive support through an Agency with Choice model often have access to agency workers in addition to their own personal back-up. In addition to individual back up-plans, participants are often trained in methods for seeking emergency support through local organizations, police, and fire, if and when their back-up plans fail or there is a larger emergency.

Useful tools have been designed by programs to assist individuals to plan for back-up support. As part of their participant's program brochure, Colorado provides information for individuals to consider when planning for back-up support,

Assuring Health and Welfare

- ✓ Similar definitions and reporting requirements as used in traditional programs
- ✓ Clear roles, responsibilities, and training on recognizing and reporting abuse and neglect
- ✓ Routine communication and involvement of support broker
- ✓ Use of representatives
- ✓ Emergency back-up plans that are evaluated routinely

which include: medical signs that emergency care may be needed, specific tips for those who live in rural areas, addressing workers who are late or do not arrive, and what to do in a community-wide disaster. A decision tree is also provided in the brochure to walk individuals through the steps of seeking back-up support and/or emergency care when needed.

Monitoring the use of emergency back-up services is seen as a method to assure health and welfare as well. In Minnesota, support brokers meet with individuals who are frequently using their back-up plans to identify ways to address why the participant's primary source of support is failing. In this program, the participant and the support broker hold joint responsibility to review back-up plan utilization rates and to identify methods to strengthen existing services.

Administrative and Financial Accountability

For all waiver programs, documenting administrative and financial oversight is a required assurance. In agency models, agency record reviews and financial audits assure administrative processes are being performed as expected, services in the Plan of Care are being provided in the frequency and duration documented, and payment is made in accordance with services provided. These methods are valid within participant-directed programs, but the focus of such review may be slightly different within Employer Agent models given the shared responsibility between the participant and the program. Within such models, record reviews can ensure required forms (i.e., spending plans, worker agreements, roles and responsibility documents, and fiscal employer forms) are completed, signed, and up-to-date. Record reviews may also be used to guarantee individual budgets are being spent in accordance with program requirements and approved spending plans. The use of routinely produced, easy-to-read and accessible financial statements is a method to ensure participants remain informed about their financial spending and that spending remains within allocated budgets. A review of paid invoices is a method to document evidence of appropriate and on-time payments. Within an Agency with Choice model, administrative and financial monitoring may look similar to methods used within agency models given that an agency is administratively and financially accountable.

Additional Quality Discovery and Remediation Methods

Home Visits and Surveys

As within agency-based waiver services, home visits conducted by quality management agency staff are used in participant-directed programs to discover and remediate quality concerns. States build off of their existing waiver quality management systems to monitor quality in their participant-directed programs. Many ensure a percentage of waiver clients chosen for home visits are receiving participant-directed services.

The change in focus of a home visit may be necessary to reflect the shift from an agency to a participant-directed model. Discussion topics that may be pertinent within an Employer Agent model may include the individual's comfort and success with decision-making, effectiveness managing his/her services, as well as existing road blocks to

accessing services. Individuals' abilities to effectively recruit, train, manage, and retain workers, complete timesheets, make modifications to the spending plan, and manage their monthly allowance may also be important areas of discussion. Home visits conducted within Agency with Choice models may be more reflective of traditional home visits methods with a focus on satisfaction with direct services provided. Even so, the individual's role in managing workers should lead to discussions pertaining to the level of comfort with this role, responsiveness of workers, as well as access to manager training materials.

A Sample of Existing Survey Tools

- ✓ "Ask Me" Survey developed for a Participant-Driven Survey Process in Maryland
- ✓ National Core Indicators Consumer and Family Surveys developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services
- ✓ Participant Experience Survey developed by Medstat-Thomson

In addition to home visits, some programs use surveys to discover and remediate quality concerns. As is true with all surveys, the determination of paper-based, telephone, or in-person interviews is often dependent on resources. The intended use of information, level of detail desired, anticipated response rate, complexity of questions, and characteristics of individuals interviewed should be factors when determining what type of survey method to use. Some states conduct structured interviews with participants of participant-directed programs, using the same tools used to interview individuals receiving agency-based services. Examples include the Personal Experience Survey developed for elders and individuals with disabilities and the National Core Indicators survey developed for individuals with intellectual disabilities.

Assessing individual satisfaction with directly hired services and supports within an Employer Agent model, although informative, may be confusing for some. This is due to the fact that the individual is responsible for the quality of direct services provided, and therefore is responsible for adjusting services and replacing providers as needed. Asking questions pertaining to individual satisfaction with services, as done in traditional models, may lead some participants to think someone else will be addressing concerns. Evaluating individuals' satisfaction with their workers and/or directly hired services within an Employer Agent model should include clear communication with the participant pertaining to the intent of such questions and the responsibility of the individual to address satisfaction with services and supports. Instead of determining satisfaction with direct services, program administrators may choose to evaluate the individual's experiences with the program supports put in place to assist the individual to exercise control.

While some programs have used traditional methods when designing and conducting interviews and/or surveys in participant-directed programs, others have created methods based on the principles of participant-direction. Some programs hold focus groups or advisory group meetings to assist in the identification of survey content areas, as well as to assist in the design and piloting of the tools themselves. Others collect data related to

quality and then present findings to a group of independent stakeholders, including people with disabilities, to seek guidance in interpreting the data and understanding areas of significance. Intriguing to many states are interviews conducted by peers, as seen in the Maryland ASK ME model. Maryland's ASK ME model trains people with disabilities to conduct peer interviews with the intention that peer communication will result in genuine feedback about the results of the program and areas that need improvement. Some states are exploring the feasibility of similar methods for their programs.

<table>
<tr><th colspan="2">Potential Areas for Quality Measurement in Participant-directed Models</th></tr>
<tr><th>Agency with Choice Model</th><th>Employer Agent Model</th></tr>
<tr><td>✓ Satisfaction with workers
✓ Support provided by support broker (i.e. worker management)</td><td>✓ Support provided by support broker (i.e., designing and monitoring spending plan, training, accessing community resources)
✓ Support provided by fiscal agent (i.e., easy to read expenditure statements, timely purchasing, customer services)</td></tr>
<tr><th colspan="2">Both Models</th></tr>
<tr><td>✓ Training/ education needs met
✓ Clear understanding of roles and responsibilities
✓ Choice and control
✓ Independence
✓ Community integration</td><td>✓ Quality of life
✓ Back-up availability
✓ Grievance and incident procedures
✓ Health and welfare
✓ Utilization of informal supports</td></tr>
</table>

Support Broker Involvement

Support brokers, especially in flexible budget models, play a significant role in discovering and addressing quality concerns. In-person meetings provide the support broker with an opportunity to answer questions and assess training needs. While some programs have a minimum requirement of monthly in-person communication, other programs require quarterly meetings between the support broker and participant. Many programs use more frequent meetings when a participant first enrolls in the program, given the complexity of participant-direction and the learning curve associated with new responsibilities. Some states are using different levels of support brokerage intensity to meet the diverse needs of individuals who choose to self-direct.

Within Texas, support brokers assist individuals to develop an individualized quality management plan that is monitored by the participant and support broker on an annual basis to determine if the self-identified quality standards are being met and/or need to be modified. The plan is built on a participant-direction quality management framework and is used to ensure quality strategies are in place that are related to service planning, back-up plans, heath and safety, provider capacity, as well as participant choice and satisfaction. A discussion often takes place between the participant and the support

broker if the support broker identifies quality areas that are not a priority to the participant. Both the individual and the support broker sign the Quality Management Plan upon agreement.

The role of support brokers is unique given their responsibility to monitor health and welfare while at the same time advocating for participant control and independence. Understanding this shift may be especially challenging for traditional agency case managers. A training model for case managers that emphasizes this important shift and their new role supporting decision-making has been developed by Boston College.[10]

Grievance Procedures

As within traditional waiver programs, participant-directed programs use grievance procedures to discover and address areas of participant concern. Data provided through grievance procedures can be used to remediate real-time complications, as well as be reviewed in the aggregate to identify areas for systematic improvement. For the most part, states have adopted procedures used in agency models for their participant-directed programs. It is important to recognize the distinction between models and the impact this may have on grievance topics and procedures. This seems especially true for the Employer Agent model since challenges with workers and services are managed by the individual rather than the program itself. For example, if a participant has a worker who is frequently late, the individual is responsible for communicating this concern to the worker, not the agency. Within an Employer Agent model, grievances may more often relate to brokerage support i.e., unresponsive to participant concerns, or fiscal support i.e., inaccurate or late financial statements or delayed payment. If participants are using grievance procedures to communicate concern about workers, such action may flag the need for training pertaining to roles and responsibilities or a need for management training or support which should be followed through by the support broker. Grievance forms and policies should reflect this shift in grievance focus. Given the importance of open communication between the participant and the support broker, participants should be encouraged to communicate their concerns, including worker concerns, directly to their support broker for as long as they feel comfortable. Within an Agency with Choice model, participants may use grievance procedures to communicate worker issues, given the role of agencies in providing management support for workers.

Since participants are dependent on the support they receive, they may be apprehensive to file a grievance. Additional lines of communication beyond grievance procedures are often developed within the program to ensure that participants feel comfortable communicating concerns. States may also want to consider methods in which to infuse participant-direction into their grievance procedures. In New Jersey, a grievance committee comprised mostly of program participants reviews grievances.

Incident Management

Participant-directed waiver programs, like agency-based models, are using incident management procedures to ensure immediate communication pertaining to health and welfare concerns, and action plans to restore a safe environment. As with grievance

[10] McInnis-Dittrich, K., Simone, K., & Mahoney, K. (April 2006).

procedures, incident data in the aggregate form can be used to address system concerns pertaining to health and welfare. The biggest challenges participant-directed programs face in regard to incident management is the ability to define an incident, determine who is responsible for reporting incidents, and decisions related to steps to address incidents once they occur.

Minnesota, Montana, and Connecticut, are using the existing categorical definitions and mandates for reporting critical incidents, such as physical or sexual abuse, neglect, medical injury to the participant or his/her worker, attempted self-harm, fire, unsafe environments, and use of restraint. Many states use a more simplified version of incident management procedures and forms than what is used for agency models. Connecticut, informs participants of the availability of the state's abuse 800 call-in lines.

While the role that support brokers and fiscal agents play in reporting incidents may be obvious, states vary in their identification of reporters beyond that process. This may be due to the difference in implementing an Agency with Choice model versus an Employer Agent model, as well as the level of perceived vulnerability of the population served. In some states, individuals receiving services, their workers, and support brokers are trained in incident management procedures. In Connecticut's Agency with Choice model serving people with intellectual disabilities, workers hired by the individuals are trained to be mandated reporters. In this model, the worker reports the incident to the employer (the individual and/or family) as well as to the program. Self-training fact sheets are provided to the worker to explain his/her role in reporting incidents. The worker also signs a form acknowledging responsibility to report incidents. Paid family members are also included as required reporters. Montana includes caregivers as mandated reporters, and like all mandated reporters, they are expected to send in documentation of the incident within ten business days.

Addressing incidents may be approached as a collaborative effort between the individual and the support broker within a participant-directed model. Individuals with documented incidents most often work with their support broker to address the incident and then to identify methods to ensure the mitigation of future incidents. Negotiation of risk is key in a participant-directed program.

Appeals Procedures

Within a participant-directed model, the use of appeals procedures may point to flaws in the design of the program itself. The focus of appeals procedures as a discovery and remediation method will depend directly on the level of control the individual has in determining the type, frequency, and duration of services. Within a flexible funding model, participants' concerns related to their individual budget allocation and/or a denial of a specific purchase they have requested are two examples in which appeals procedures may be utilized. With participant-directed personal care, an example of a potential appeal topic may be the number of personal care hours one is approved for. As with grievance procedures, it is important for appeals procedures to be reflective of the principles of participant-direction, and methods to involve people with disabilities in appeals processes may be beneficial. As with aggregate data collected within grievance and incident

procedures, data collected from appeals procedures may be helpful to programs to identify areas in which policies are not accurately reflecting or addressing the needs of the population served.

Involving Stakeholders in Systems Design and Improvement

The design and improvement of participant-directed programs can be strengthened with the involvement of recipients of services. There are methods in which elders and people with disabilities can be included in systems design and improvement. Montana requests that consumers participate in focus groups when a new program is being developed, as well as when there is a need for review and modification of the current service system due to budget constraints. Michigan's topic-specific taskforces are chaired and run by consumers. In Maine, consumers are recognized as experts in quality and are named "self- advocate expert advisors," given their role in sharing direct experience to make the service system stronger.

Strategies for involvement of stakeholders have been mandated by the Texas Legislature for its Employer Agent model. As a result of legislation, a Consumer Directed Services workgroup meets quarterly to review and address relevant topics related to the program. A product of the meetings is an annual report provided to the Legislature. The role of this workgroup will soon be expanded to include Texas' new Agency with Choice model. Most of the waiver programs in Texas have been designed through the use of task forces diverse in consumer, provider, and state agency representation. Annual conferences provide an opportunity to seek the input and perspectives of a diverse group of stakeholders, including consumers, caregivers, providers, and advocates. Montana holds an annual conference and invites diverse stakeholders to learn about existing programs, receive training, and provide input on programs. When involving participants in systems design and improvement efforts, it is essential to ensure that appropriate resources are devoted to training and supporting individuals through this role. It is also important to recognize that these methods should not replace, but instead complement one-on-one interactions with participants to learn about their personal experiences within the program.

Addressing Liability

Risk and liability are concerns often raised by agency providers and external stakeholders when participant-direction models are discussed. Cash & Counseling evaluation findings indicate no increase in risk compared to agency-based services.[11] A careful review of potential liability within the Cash & Counseling model conducted by Sabatino and Hughes found that involved government and agency entities are no more liable in the Employer Agent model than in traditional agency models.[12] Sabatino and Hughes' findings do indicate the opportunity for increased liability on behalf of the individual and his/her worker, given the removal of agency involvement as a supplier of direct services.

[11] Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B.L. (2003).
[12] Sabatino, C.P., & Hughes, S.L, (2004).

Participants and their workers should be well informed of their potential liability and methods to address it. Since an Agency with Choice model includes the involvement of agencies to assist in managing workers, Sabatino and Hughes' findings may not apply equally to this model.

Although not extensive, liability concerns do exist for government entities as well as for agencies providing support brokerage and/or fiscal support in a Fiscal Agent model. Methods used by states to assess, address, and document risk using standardized tools appear to be beneficial in proactively identifying and addressing concerns pertaining to participant health and welfare. Quality systems that measure and improve methods for training and information sharing, particularly related to individual roles and responsibilities, will ensure an informed consumer. Ensuring an informed participant can potentially alleviate liability. Ensuring participants are receiving services required can also potentially lessen liability. Methods for monitoring fiscal practices to ensure timely and accurate payment for services will lead to service utilization as planned. Prompt review and analysis of data related to incidents, grievances, and appeals are useful in addressing risk.

Participant-directed programs often use representatives as an approach to provide individuals with additional support in designing or managing their services, while also addressing concerns pertaining to health and welfare. The appointing of representatives, to date, has been a participant-driven process for the most part. Clear criteria for appointing representatives and potential methods for evaluating the role of the representative could be beneficial in ensuring that a representative is working in the best interest of the participant.

The quality management system for a participant-directed program could play an important role in addressing liability concerns. Program administrators are encouraged to review the Sabatino & Hughes report and implement quality management strategies that address potential liability concerns.

Conclusions

This report has highlighted the shift in methods for quality design, discovery, remediation, and improvement that is necessary to ensure an effective quality management system for participant-directed services. Similar to agency models, quality management systems for participant-directed waivers are required to document waiver assurances in areas related to level of care determination, plan of care development, provider qualifications, health and welfare, as well as administrative and financial accountability. Even so, participant-directed programs face unique challenges in meeting federal requirements while remaining faithful to the principles of participant-direction. Also, unique methods to define, evaluate, and improve quality are required for participant-directed models since for the most part the participant rather than an agency is responsible for the quality of services provided. While the quality of direct services are participant-defined and evaluated, the program itself plays a critical role in ensuring participants are well informed and well supported in order to participate meaningfully in

participant-directed services. Quality management systems should be designed to evaluate and improve the quality of participant-directed services as defined by the participant, while at the same time allowing for evaluation and improvement of the systems of support that make participant-direction possible. The design of quality management systems in participant-directed programs may vary based on the chosen participant-directed model. Although perfect implementation of Agency with Choice and Employer Agent models may ultimately lead to the same level of choice and control regardless of model, it is recognized that the difference in these two models as they are implemented today lead to different strategies to monitor and improve quality. Well-defined roles and responsibilities are essential in a participant-directed program and will directly influence the design of the quality management system as well as the monitoring, evaluation, and improvement of quality.

Useful Resources

Existing Resources on Quality and Participant-Direction

- ✓ Cash & Counseling Lessons Learns and Implementation Strategies at www.cashandcounseling.org
- ✓ Blueprint for Quality in Consumer Directed Programs, R. Applebaum, B. Schneider, S Kunkel, and S. Davis, 2004
- ✓ Clearinghouse for the Community Living Exchange Collaborative, www.hcbs.org
- ✓ Quality Mall, Research and Training Center on Community Living, www.qualitymall.org
- ✓ CMS Waiver Quality Expectations, http://www.cms.hhs.gov/IndependencePlus

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