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A Guide to quality in consumer directed services

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PREFACE

Between 1999 and 2003, three states (Arkansas, Florida, New Jersey) participated in a test of a new approach to service delivery, allowing consumers with disability the opportunity to direct their own in-home services. In the National Cash and Counseling Demonstration and Evaluation, consumers were given the opportunity to use Medicaid funds in more flexible ways. For example, funds could be used to hire a relative, neighbor, or friend, rather than requiring services to be received through a home care agency. The allowance could also be used to purchase goods and services that helped the individual meet his or her personal assistance needs. Results from the evaluation showed that self-directed consumers fared significantly better than a control group on a range of factors including satisfaction with services and overall quality of life (Dale et al., 2003; Foster et al., 2003). Simply stated, the evaluation results presented a picture of an option that offered a much improved service system for interested consumers and their families. These results, and current policy initiatives, suggest that this option will likely become more widely available.

From the inception of the demonstration, there was a steady stream of questions about how quality could be assured in such an intervention. Results of the evaluation found that in addition to positive outcomes for consumers and families, program participants also had fewer negative outcomes, such as falls or incidents of abuse or poor quality care. As consumer directed services become part of the national delivery system, an effective quality management needs to be developed. Such a system must reflect the needs of program consumers and be policy responsive.

To address this issue, an additional component of the demonstration was the development of this guide to quality. This guide is designed to provide states and programs involved in

consumer-directed services with a practical handbook on ensuring and improving the quality of services. This guide is based on a philosophy that the views of the major program stakeholders – consumers, families, program staff, regulators, funders – are the necessary starting point for the design of a quality system. In particular, consumers are the key to developing a system that balances quality assurance activities with consumer-centered quality improvement.

This quality initiative is one of several projects being undertaken in the field of community-based long-term care. Two complementary efforts commissioned by the Centers for Medicare and Medicaid Services (CMS) also examine quality in community based long-term care. One project involving CMS, Medstat, the National Association of State Units on Aging (NASUA), the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and the American Public Human Services Association (APHSA) developed a framework for quality in-home and community-based services. The framework is designed to focus attention on critical dimensions of service delivery and outcomes. A second effort, completed by the Muskie School of Public Service at University of Southern Maine, resulted in a Work Book for states and agencies administering home and community-based waiver programs. The Work Book is designed as a tool for states to understand, design, and document a quality improvement process for its home and community-based waiver programs. Appendix C includes web references for materials about these two initiatives.

To achieve our goals in developing this guide, we needed the help of many individuals. Staff from the three state programs provided us with ideas, access, and support throughout this effort. These folks shared with us freely the lessons they learned, both successes and mistakes, in order to create a better system for consumers. Their pioneering efforts provided inspiration for this work. We could not have completed this guide without the help of Suzanne Crisp, Sandy

Barrett, Debby Ellis (Arkansas), Bill Ditto, Carolyn Selick, Renee Davidson (New Jersey), Tom Reimers, Shelly Brantley, Susan Kaempfer, Lou Comer (Florida). Staff from the National Program office – Kevin J. Mahoney, Kristin Simone, Lori Simon-Rusinowitz - had the vision to push for this topic from the outset of the demonstration and were really part of the study team throughout the effort. Marguerite Schervish from CMS provided valuable comments on multiple versions of this guide. At Scripps, Kathy McGrew was instrumental in conducting and analyzing focus groups. Valerie Wellin helped make the document more "guide like," and Betty Williamson and Jerrolyn Butterfield ably prepared the guide. Finally, over the course of our work, we had the privilege of talking with many consumers and families about quality. Their views profoundly influenced how we thought about quality and what a quality system should look like. We hope this work has done justice to their wisdom.

A Guide to The Guide

The guide is divided into five major sections, plus three Appendices. The first section – Blueprint and Steps for Quality -- provides background materials for the quality model developed and tested in the demonstration. The next section -- Planning Phase -- includes a set of activities that are designed to build quality into the program from inception. The Consumer Support Activities provide the resources and information necessary for consumers to be active participants in quality improvement. The final sections -- Monitoring and Quality Improvement -- present specific approaches for assuring and improving the quality of consumer directed services. The Appendices are designed to provide practical reference materials for consumer-directed programs.

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BACKGROUND

The home care industry has evolved significantly from the early days when providers informed consumers that their services would be delivered in four-hour blocks at specified times and days. Recognizing the personal nature of in-home services, program and policy leaders have implemented a range of options for consumers to be in charge of their own services (Wilber, 2000; Kane, 2000). The rights and abilities of consumers to assess their own needs, decide how best to meet those needs, and evaluate the quality of the services they receive are at the heart of the consumer-directed model. The Cash and Counseling Demonstration, numerous state programs, and the Centers for Medicare and Medicaid Services (CMS) Independence Plus waiver initiative, culminate an evolutionary process in the development of in-home care service options (Simon-Rusinowitz, Bochniak, Mahoney, & Hecht, 2000a).

Just as traditional home care systems have struggled with definitions of quality care and methods of assuring that quality care is delivered, consumer-directed programs have also grappled with these issues (Simon-Rusinowitz, et al 2000a). The unique challenge for consumer-directed service programs is to devise a comprehensive system of quality that balances the consumers' desire for autonomy and their capacity for assessing the quality of the service they receive with the need for oversight and

accountability by agencies and states with publicly funded programs. Consumer-centered definitions, measures, and processes for quality have to be balanced with policy-driven mechanisms focusing on accountability, monitoring, and compliance.

In this project we attempt to balance the needs of consumers to receive quality services that work best for their life circumstances, with the needs of program administrators, funders, and regulators to ensure quality within a publicly financed long-term care program. In some instances the needs of these various stakeholder groups are similar, in other cases they differ. The challenge is to create a quality program and quality management system that works for each group, particularly the consumers who have been largely ignored in formal long-term care quality efforts.

The Challenge for consumer-directed programs is to devise a system of quality that balances consumers' needs and abilities with policy-based mandates for accountability.

The purpose of this guide is to assist programs and states as they develop quality systems for consumer-directed services. It is designed to provide practical assistance for states and programs as they design or revise consumer-directed services. Throughout the course of the Cash and Counseling project, we have come to understand that "quality system" refers to two distinct but related aspects: designing and maintaining a high quality program, and establishing an effective quality monitoring and improvement system. The phrase, "quality system" is intended to imply both an excellent program, and a quality monitoring and feedback system.

Programs need to be planned, reviewed, and refined so that consumers have what they need in order to achieve quality; the program also must be responsive to regulatory and accountability agendas. An effective quality monitoring system will review the extent to which these goals are recognized, and will be part of an ongoing feedback system to continuously assess and improve the program.

For this guide, we sought input from consumers, agency staff, family members, workers, consultants, and fiscal agency staff about their views on quality. This information was then organized as a Blueprint for Quality in Consumer-Directed Programs. The blueprint describes two major "construction" projects: 1) building a high quality consumer-directed program that supports consumers in their quest for quality, and 2) building a quality management system that is useful-- and used-- for consumer-directed services. The guide provides strategies, suggestions, instruments, and helpful hints for implementing the blueprint. We discuss experiences with, and suggestions for, setting up a program, designing consumer supports, and establishing information and feedback systems that promote quality improvement. Table 1 (page 19) provides an overview of the detailed steps involved in implementing the blueprint.

HOW THE GUIDE WAS DEVELOPED

This guide was based on the experiences of consumer-directed programs. We reviewed existing consumer directed programs, and completed in-depth interviews with 15 established state and local programs across the U.S (See Appendix A, pg.38). Interviews explored quality challenges faced by these programs and the strategies developed in response. We then focused on the lessons being learned by the three states involved in implementing the National Cash and Counseling Demonstration and Evaluation, (Arkansas, New Jersey, Florida). Our goal was to hear from the major stakeholders involved in the receipt of quality services including; consumers, family members, workers, program staff, state regulators, and community advocates.

At the outset of the Cash and Counseling (C&C) demonstration, each of the states developed extensive quality management plans. To supplement the work done as a normal part of the demonstration we added some research activities that would not typically be completed during program implementation. To collect data about quality we visited Arkansas and New Jersey during their initial year of program operations. During the visits we conducted a series of individual interviews and focus groups to gain

an understanding of what each stakeholder group thought were the most important aspects of quality. Eight focus groups were completed with consumers, family members, consultants, and workers. More than 30 individual interviews were completed with program staff, state regulators, community advocates, home care providers, consultants, fiscal intermediary staff, and consumers.

Additionally, after programs had gained substantial operational and quality management experiences we created a detailed summary of their quality approaches (See Appendix A, pgs. 25-37). We then visited all three of the demonstration states to interview program staff for their assessment of the quality strategies used. Based on these experiences we developed additional quality strategies and worked with sites to test and review recommended quality areas. Their ideas are reflected in the organization and content of the guide.

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In this section we provide the results of focus groups and interviews with stakeholders involved in consumer directed services. We also describe our Blueprint for Quality, which includes the essential components necessary to develop a high quality program; incorporating quality into program design, and a sound quality management system. Steps in the development of these quality efforts are introduced. They will serve as the organizing framework for the remainder of the guide.

THE DIMENSIONS OF QUALITY

While there was variation in the weight given to different aspects of quality, four interrelated but distinct dimensions emerged from the conversations with stakeholders: independence and control; relationships; knowledge and support; and, health, safety, and accountability. Below is a summary of what stakeholders had to say about these dimensions of quality.

Four Dimensions of Quality:

1. Independence/Choice
2. Relationships
3. Knowledge and support
4. Health, safety, and accountability

Independence, autonomy, choice, and control – Quality is achieved when consumers are able to have things done their way. Whether it is choice of services or worker, control of resources, or program flexibility, consumers consistently talked about choice and control. Almost all of the participants in the program were previously served by a traditional home care agency. Consumers consistently reported that the home care agency controlled their lives. As one person put it, "I had no choice about who was sent as a worker and little choice as to when this person would come."

Receiving support in the way that they wanted it was raised repeatedly. An 84 year old focus group member from Arkansas provides an example of the importance of this principle. "I like to wash my socks and hang'em on my kitchen wall. My worker didn't like that, said it made the wall dirty. So for a while, I didn't do it. But when that worker didn't work out, first thing I did was hang

those socks back up in the kitchen. It's my house, my wall, and my socks." There were numerous other examples of consumers describing quality in terms of having things done the way they wanted, in the way they would have done it. Workers and consumers talked about how well it worked for everyone when it was clear that the consumer was in charge. One worker stated that having the consumer as his employer "cuts out the middle man. I know who my boss is."

Consumers and workers discussed the importance of independence. Consumers wanted the right amount of assistance, geared toward their own needs. Workers echoed this idea about quality service. They talked about helping consumers to be as independent as possible. As one worker put it, "If you can make the consumer feel good about themselves, they'll feel better overall. They'll get up and they'll do more and they'll have a better outlook on what they have planned for the day." Program administrators also talked about the importance of independence as a hallmark of quality in consumer directed services. They saw consumer direction as an approach to system design and service delivery by which individuals with disabilities develop the skills to take increasing control of their lives and their environment.

Relationships – In the majority of cases consumers hired close family members, other relatives, or friends to deliver the support services. In practically every instance, even when the caregiver was not a friend or relative, consumers emphasized the importance of having a good relationship with the person providing the care. For example, one focus group participant stated clearly, "Quality is the ability to hire people you trust and people who care about you."

Another consumer discussed how the program helped her maintain her independence by allowing her to choose an aide that she knows and trusts. She says that this has allowed her to establish a meaningful long-term relationship with her worker.

In addition consumers described the importance of feeling secure. One consumer, who was bed-bound talked about bad experiences with workers before she entered the consumer directed program. "I can't get out of bed, so I never knew what was happening outside of this room." She described incidents of theft that she suspected but went undetected, sometimes for months at a time. When she was able to hire a friend whom she had known for many years, trust was no longer a concern.

Consumer-employed workers also defined quality in terms of the relationship. They mentioned going beyond their prescribed duties as examples of good quality. For instance, if the workers are

in the neighborhood, they might stop by to see if the consumer needs anything.

Knowing that the consumer is in charge, and providing services according to his/her preferences, was a consistent theme. One focus group participant provided an example:

"Well, I had never made them [sunny side up eggs] before, because I didn't know how to make the eggs, you know, sunny side. So I went in the kitchen and she said, 'Baby, let me tell you what to do.' She gave instructions and I went in and I did it..... She said, 'See baby, it wasn't hard.....You stick around long enough we're going to become good friends', and she told me, 'I just love you. You're so special.' And that made me feel good."

Knowledge and support - Consumers said they need information in order to have quality. In some instances, information needs were related to program components such as how money could be spent, whom to call when a check didn't arrive, or whom to call if problems with workers arose. In other instances, questions were about care or training. Workers and family members said that they would like to know more about some of the physical and cognitive conditions of their consumer, including Alzheimer's disease and its progression.

Consumers emphasized that their responsibilities under such a program are new and different, so that they need to have training about the many aspects of hiring, firing, and managing workers, as well as the fiscal and payroll responsibilities One consumer summarized this general need by stating that being in a consumer-directed program is like running a small business. The type of training needed varies by individual consumer. Consumers were very positive about the opportunity provided by the focus group to talk with each other. They suggested that a mechanism for ongoing communication such as a newsletter, web-site, or peer support groups should be developed. Some of the focus group participants exchanged e-mail addresses and other contact information.

Health, safety, and accountability - All of the stakeholders identified accountability and monitoring for consumer safety as important aspects of quality. There were differences among the stakeholders in the relative weight given to accountability and autonomy. For example, consumers want to be in charge of their own services and their own safety. Administrators are more concerned with monitoring the appropriate use of public dollars and for minimizing risk of negative outcomes for consumers. To illustrate, one administrator recalled worrying about a "disaster" in the early days of operations. Safety and public accountability are important dimensions of quality.

QUALITY THEMES

In addition to the dimensions of quality that emerged from the focus groups and interviews, stakeholders helped us to uncover some important themes and principles of quality that serve as the foundation for a quality system.

Quality is achieved because of choice, not in spite of it. - In the early days of consumer-direction, there was concern that consumer choice and autonomy, and the absence of "outside" provider agencies in the consumer's home would create greater potential for fraud, abuse, and poor quality care. To the contrary, stakeholders consistently made it clear that consumers will choose quality if they have the opportunity to do so.

Lessons Learned:
Quality is achieved because of consumer choice, not in spite of it. Consumers are the agents of quality.

Consumers are the agents of quality. - With appropriate supports, resources, and information, consumers are the experts on quality. The consumer and/or their representative can and should take on primary responsibility to make sure that they receive high quality services. Program planning and refinement helps to put supports and resources in place to help consumers in this role. There should be meaningful consumer participation in all aspects of program design, review, and improvement.

Programs can be designed to maximize consumers' ability to achieve high quality services. - Because of this powerful lesson learned from consumers and other stakeholders, this guide will focus on two related aspects of program quality: building a quality program that includes consumer supports and program operations necessary for consumers to get high quality services, and building a quality management system that is useful and utilized.

Monitoring and accountability efforts can and should coexist with consumer-centered program activities in a quality system. - Principles and program goals, which embrace consumer-centered and policy-responsive definitions of quality, should be explicitly reflected in the quality monitoring system. A platform of health, safety, and risk management allows consumers secure footing from which to exercise choice and control in their lives. Consumer-centered processes, including but not limited to, consumer satisfaction and consumer-defined goals and outcomes, are essential aspects of accountability for achievement of program goals.

Quality management activities should be part of a feedback and improvement loop, with clearly identified roles, responsibilities, and communication links. - A quality monitoring

system should include clearly delineated and intentional opportunities for gathering and using information of all kinds to assess program impacts, hear from consumers, and improve services.

It is our assertion that any quality program will be based on these underlying themes and principles. These ideas provide the foundation for the remainder of the guide.

BLUEPRINT FOR A QUALITY SYSTEM

The blueprint presented in Table 1 (page 19) describes the two interrelated mechanisms used to build a quality program—1) incorporating quality into program design, and 2) developing a comprehensive quality management system. Designing a High Quality Consumer-Directed Program, represented in the left hand column of the table, includes three major steps—establishing program goals and principles, planning activities, and consumer support strategies. Planning activities include the areas that any new program must develop before consumers are served. Training of consumers and consultants, and creating a good method of communicating with consumers are examples of strategies described. Although quality assurance models often concentrate on monitoring activities once a program has started, this section emphasizes front-end work that can have a major impact on quality. For example, a strong training program for both consumers and consultants could reduce subsequent quality problems during implementation.

Keep in Mind:
Quality Management starts from the first day of program planning, not the first day that a consumer receives services.

Consumer support is the other major component of this section of the blueprint. It is based on the feedback that we received from consumers, -- if they have the information and necessary tools, consumers will choose quality. Use of consultants, the fiscal

intermediary, and peer supports are examples of strategies recommended.

The second column shown in Table 1, Developing a Quality Management System, includes quality monitoring and quality improvement activities. Quality monitoring includes tracking performance indicators, independent audits of consumer records, interviews with consumers, and organizational audits of both the consultant and fiscal intermediary functions. While these types of activities are used in many ongoing programs, our experience suggests that program developers don't always have a good sense of how to organize and use this information. Many programs do not have management information systems to process data, and even fewer organizations have developed formal mechanisms for using these data to improve program quality.

Keep in Mind:
Although thinking about quality before a program begins is essential, no matter how good a program is, you cannot think of everything. Good quality programs include continuous improvement efforts, in recognition that the program will continually evolve and improve.

In response to these concerns, this guide addresses quality improvement efforts. Creating a continuous quality improvement system requires the involvement of consumers, and the use information to make good decisions. Three activities are highlighted in this section: collecting personalized outcomes data from consumers, establishing a quality improvement committee comprised of key program stakeholders, and conducting a program self-assessment to reflect upon how program structure and policies

affect consumers. Any quality management system must build in mechanisms to hear from consumers.

Three points are emphasized in this area: engaging and listening to consumers is an essential piece of quality management, a mechanism for processing information is critical, and these data must be used to improve the program. It is also necessary for programs to identify the specific outcomes of interest. As programs choose and refine their quality strategies they will then need to incorporate efforts to measure, collect, and analyze outcomes data into their quality management system.

TABLE 1
STEPS TO QUALITY

Designing A High Quality Consumer-Directed Program	**Developing a Quality Management System**
1. Establish program goals, principles and quality definitions. (See Dimensions of Quality Section)	1. Establish expected outcomes and measures for program. (See Dimensions of Quality Section)
2. Planning for quality: a. design roles b. design processes c. plan for communication d. develop program written materials e. plan staff training f. select information system g. develop performance standards h. design program supports to address population needs	2. Translate outcomes into internal and external program procedures and contracts. 3. Design quality monitoring strategies: a. complaint hotline b. program performance indicators c. agency and record audits d. independent review of consumers e. consultant monitoring activities
3. Identify activities that will support consumers in their desire to receive quality services: a. consultant activities; b. fiscal intermediary activities; c. worker registries; d. development of individual and system wide emergency back-up procedures; e. peer support; f. criminal background checks; g. provide ongoing information to consumers.	4. Develop quality improvement strategies which include: a. personalized outcomes; b. a quality improvement committee; c. program self-assessment. 5. Design process for data analysis of monitoring and improvement strategies and examine how data can be used to identify areas for improvement. 6. Implement improvement strategies and use data to monitor effects of quality efforts.

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This section identifies the range of activities that should initially be addressed before a program begins to deliver services.

Planning Phase Strategies

Many programs devote all of their energy to launching and then superimpose quality mechanisms once operations begin. Building quality into a program during the design phase can help limit operational problems as well as reducing gaps or overlaps in the quality management approach. We have identified a number of activities important for quality that need to be addressed during the planning phase that will effect quality including: clarification of staff roles, development of sound processes and written materials, a comprehensive training strategy, good information systems, clear performance standards for providers, and an approach for accommodating consumer populations with varying needs.

For each of these areas, we offer general issues and practical examples as reported to us by C&C program staff and consumers and by the other 15 consumer-directed programs interviewed.

Designing Roles - As programs are developed, it is important to define staff roles and responsibilities as clearly as possible. An example from the C&C demonstration highlights this point. The consultant and fiscal intermediary functions are the primary consumer support functions and are critical to quality management. People performing both functions work closely with consumers as they learn to manage their budgets and workers, so the boundaries between the two roles must be clear. When the

consumer understands whom to contact for what, the number of phone calls is greatly decreased. Including consumers in the planning of these roles should help identify areas potentially confusing to them.

It is necessary to have appropriate and informed expectations when designing roles. For example, the C&C demonstration learned that consulting is not less time or labor-intensive than case management with traditional clients at first; though over time, as consumers become more skilled at self-directing, it often becomes less time-intensive. Consumers needed significant training and support initially. In order to honor the goals of the program, consultants need to know what amount of help they are permitted and expected to provide consumers. Program goals may vary on the nature, scope, and frequency of contact between consumers and consultants. Some programs encourage formal, less frequent, and very purposeful contacts, while others expect consultants to serve as a resource for whatever assistance consumers may need.

Tip:
Role and Boundary Issues
It is helpful to ask questions about the processes used to work with consumers. For example: Who will answer questions about what can be included in a purchasing plan; whether a live-in helper gets overtime pay; whether a check has been cut or sent; or how to find a Spanish-speaking worker. Project staff will have to make sure that roles and responsibilities are clear to consultants, fiscal intermediary staff, and consumers.

Designing Processes to Serve Consumers - Anyone who has had the opportunity to get a drivers license or transfer a car title can testify to the effect that complexity and red tape can have on the quality of the service experience. To enhance quality, processes should be as simple as possible. Every extra person involved in a

transaction increases processing time and the possibility of error, so the smaller the number involved, the better. Using detailed flow diagrams during the planning of all processes can help identify and eliminate complications and unnecessary steps.

We provide an example by examining two processes that are typically complicated in consumer directed programs: approval of the consumers' purchasing plans, and making changes in the purchasing plans over time. These occur frequently, so any efficiency can have a big payoff. To streamline the approval process, Cash and Counseling sites developed for consumers and consultants a standard list of pre-approved items that could automatically be included in a purchasing plan. Plans with only pre-approved items were allowed to be submitted directly to the fiscal intermediary. The quality of the approval process could be assured by reviewing the first few purchasing plans from each consultant, then periodically reviewing information about the needs of the consumer, with monitoring to identify problems.

Changes in purchasing plans often created problems in the early months of the program. Consumers made changes more frequently than anticipated, requiring a streamlined mechanism to make and track changes. Policies that allow telephone, fax, or computer notifications helped to track these changes. Some consumers had or purchased computers (with accommodations for

Case Example:
One of the C&C programs required state office approval of all purchasing plans because the consultants were not program employees and most would never have more than a few consumers. This required extensive state staff time in review. It also involved a state staff member in the communications between consultants, consumers, and the fiscal intermediary whenever errors were identified. In time, some consumers learned that the state staff person was able to answer questions better than their consultants, so they called her first, with predictable overload for a position not designed as a first responder. There were two problems here: the consultants didn't have enough authority to make decisions about what could be on the plan and they didn't have enough cases to learn the many details of the program well. To address this, the program moved to concentrating cases in a small number of agencies and fewer consultants and will eventually have the consultants approving the purchasing plans.

disabilities) to help them manage their plans and workers, so policies and processes should take this possibility into account.

Planning For Communication - Communication is essential to operations. Quality of communication is enhanced when it is easy, quick, and error-free. Programs can take advantage of technology to help with communication. In particular:

- There should be a toll free number to call the program office for questions. This will speed communications from consumer and consultant, especially allowing the consultant to call with questions from the consumer's home without incurring long distance charges. The number should also be offered for reporting concerns and complaints.

- Consider using other electronic aids- cell phones, internet connections, facsimile machines, computers/laptops, especially for consultants. All of these speed communications and can reduce the possibility of errors.

- All electronic communications should require an answer or receipt to ensure they are received.

Other technologies used to facilitate communication included web pages, email, automatically generated letters or faxes of notification, automatically generated reports, and teleconferencing. Program procedures should address requirements for maintaining documentation and confidentiality when electronic communications are used.

Another characteristic of a process is the amount of time it takes to complete it. Unnecessary time spent in any process is frustrating to consumers and a waste of resources for the program. Establishing targets or goals for the amount of time expected for completing each step in the process can promote streamlining. Then people know what to aim for and the program can monitor whether the goals are being met. An important quality indicator is the time it takes for the consumer to submit their initial purchasing plan and start to self-direct. A goal of 45 days or 60 days to self-direct assures that the consulting process moves along instead of being put on a back burner.

Case Example: Service Tracking
In one C&C state, the length of time it took for consumers to receive services was tracked and reviewed weekly. The state program office sent an electronic report to consultants when a consumer's deadline for completing the purchasing plan was approaching.

Consultants agreed that phone calls to monitor consumers' progress in completing the purchasing plan encouraged quicker completion of the process.

If possible, allowing consumers to start receiving their cash allowances whenever their purchasing plans and other paperwork are ready would also reduce time lags. If a policy states that consumers can only start employing their workers at the beginning of a month, the time it takes to achieve self-direction is increased and a worker may accept work elsewhere. One program had a process for covering an advance of up to two weeks, so consumers didn't have to wait until the first of the month to begin managing their own services.

Other examples of requirements that caused delays included the need for a consumer signature for every change on the purchasing plan (rather than telephone approval), and the requirements that the purchasing plan match the budget to the penny. In some cases, federal or state rules may dictate these policies.

Another time lag potentially affecting the ability of the consumers to keep workers is the lag between submitting a time sheet and getting a check. In some cases workers may live paycheck to paycheck and while this period was shorter in C&C than in some programs we reviewed, it was still was a cause of concern to some consumers. The process should be designed to minimize this time .It is also important to inform consumers accurately how long it will take, so they can tell their workers.

Case Example: Timesheet/Pay Schedules
One C&C state developed a calendar for the year, showing which dates to submit timesheets, when the checks would be cut, and when they could be expected in the mail. This information was provided to consumers and consultants. The fiscal intermediary will want to adhere to promised schedules in order to avoid a flood of calls inquiring about whether checks have been sent.

Involving consumers in planning helps sensitize the program to "consumer time". To a consumer waiting for a return phone call 24 hours could be very long time. To a program person a 24 hour response may seem like very timely service. This is another advantage to hearing from consumers.

Developing Written Materials - Written materials and program forms such as application materials, purchasing plans, and employee time sheets, provide important guidance for program staff

and consumers alike. Consistency and simplicity are enhanced if all program participants use the same materials. When developing materials for the staff to use in training consumers, it is important to get input from the professionals who will be working directly with consumers. Also, it is critical to include consumers in the development of consumer-friendly materials.

Tip:
Account Balances
All three C&C states identified challenges associated with the fiscal intermediary's task of regularly reporting account balances to consumers. These reports were not consumer-friendly and generated many phone calls to the fiscal intermediary and consultants as consumers struggled to understand them. Because these agencies could not respond to the overwhelming number of calls staff were stressed and consumers were unhappy. In response, sites had the fiscal intermediary get feedback from consumers and consultants about the report, so that revisions could be made and tested.

- Instructions and forms should be clear and consumer-friendly forms and instructions for the forms. C&C aimed for approximately the 6th grade reading level. To avoid overwhelming readers, use formats that are less dense than long paragraphs (such as lists, bullets, graphics, white space). Pretest materials with consumers. Depending on the program's population, materials should be available in alternative formats and other languages. Provide examples that are already completed correctly. Organize the materials by steps.

- The design format of the purchasing plan is particularly important. It should be consumer-friendly and should assist consumers with goal setting and calculations. Making the calculations easy and clear, even automatic if possible, will save many steps and hours of error correction. Include consumers in the design phase. (See Appendix B, pgs.45-54.)

- Standard written communications from the fiscal intermediary to the consumer and consultant should be reviewed to make sure they can be easily understood.

Planning Staff Training - Training program staff is critical to the quality of the program. Developing a comprehensive training plan for the program from the beginning will ensure that all the bases are covered. The plan should address such questions as:

- Who will do training for each type of staff, (i.e., consultants, fiscal intermediary staff)?
- When, where and how often will it be done?
- What content must be covered?
- Will the responsibility for training change once the program starts?
- What follow-up support will be provided?
- How will the training efforts be evaluated?

Case Example: Transition From Case Manager to Consultant
In the C&C experience, the transition from case manager role to the consultant role was not an easy one, especially for those serving older people. It required training, retraining, time, and successful consumers to win over some of the consultants, who were genuinely worried about their clients' condition. Case managers have traditionally been trained to be the professional and this may be more directive than the consultant role appropriate in consumer directed services.

To enhance consistency, everyone doing training should be adequately equipped with standard curriculum and materials, and not required to design their own. It is useful to plan a period for revisions of the training materials based on feedback from consumers and consultants. If revisions are not built into the process, trainers might individually adapt the training and the opportunity to improve the standardized training is lost.

A training plan should recognize that new staff will be added over time, in response to expansion or turnover. Trainings need to be frequent enough to deal with new staff so that on-the-job training from peers doesn't become the norm by default. (If on the job training is the plan, standard procedures and measurement should be developed, along with oversight to ensure consistency). Without adequate ongoing training, turnover can be a threat to quality. In C&C, turnover among consultants was higher than

initially anticipated and training was identified as an ongoing problem.

The staff training plan should also include a mechanism for periodic updates to keep everyone abreast of changes. For example, consultants in C&C scheduled regular meetings with each other and program staff. These meetings provided updates, peer support, and transfer of knowledge, thus improving quality from the consultants' perspective.

Consultants told us that their training should:

- Occur close to the time they will start serving consumers;
- Include multiple modes of teaching, not just lectures;
- Give a picture of the entire job, not just how to fill out forms;
- Provide comprehensive materials;
- Include practice time;
- Include as trainers people who have done consulting and consumers who have successfully self-directed;
- Help them understand how much help they are permitted and expected to provide consumers who are struggling with their responsibilities;
- Identify a source for answers to ongoing questions;
- Address specifically how to fulfill multiple roles of what is expected, (for example, providing information and assistance for the consumer and a monitoring role for the program).
- Define how consulting is different from their previous roles.

A necessary area of training for the fiscal intermediary staff is customer service training. In particular, those having phone contact with consumers need to be prepared to communicate patiently and courteously with consumers with various disabilities.

Information System - An important quality improvement principle is that programs need to have good information to make good decisions. The organization needs to decide what information is needed. What performance indicators and consumer outcomes should be tracked for quality management? What data are required by the federal and state oversight agencies? Once these decisions are made, data collection approaches need to be put in place. Finally, a mechanism for processing the information must be established.

The program should have the ability to:

- Track consumers through the progressive steps of enrollment and self-directing, with relevant dates for each step, and through changes (phone number, address, whether has a rep, number of hours in plan, etc.).

- Track consultants and which consumers they serve, and track consultants through changes (phone number, address, agency), and be able to communicate with all of them.

- Track purchase and service payments from Medicaid to fiscal intermediary to consumer, along with dates of transfer, and balances, taxes paid, savings.

- Track what changes have been made in the purchasing plans and when and know what is currently in force.
- Track dates of last reassessment and reauthorization for Medicaid and the due date of the next one.
- Include outcomes data for consumers over time.
- The databases need to be linked and allow for queries.

Our experience with the C&C sites and other consumer directed programs staff highlighted numerous barriers to information systems that work. Although such challenges are not unique to consumer-directed programs, the need to track consumer outcomes and program expenditures is critical. Programs should spend time during the development stage to design an information system that will provide the information necessary to make high quality decisions.

Developing Performance Standards - In many instances consumer-directed programs do not provide all of the support functions in-house. The consultants and fiscal intermediary agencies are likely candidates for partnership. Prior to choosing providers of theses services, it is important for the program to clearly articulate the tasks, roles, and responsibilities to be performed. Definitions of acceptable performance, and the performance indicators that will be used for monitoring purposes are extremely useful.

Consumer direction is a relatively new and somewhat uncommon program. Agencies implementing and supporting consumer direction are often paving new ground. A program can get better partner agencies if it provides some training and resources about consumer direction to those organizations interested in applying. Some of the operational protocols from the Cash and Counseling demonstration are included in Appendix A. The Arkansas protocol, which includes performance standards and indicators, was incorporated into the program's contracting procedures with the consulting and fiscal intermediary agencies. (See web link in Appendix C)

Designing Program Supports to Address Population Needs - In planning the program, it is important to identify whether any anticipated consumer population will require different approaches or features to be successful in consumer-direction. To accomplish this objective, programs should include a range of consumers in the planning process. Plan to accommodate these needs, even if it creates different policies for different people. For example, allowing consumers to choose representatives to help them manage their caregivers encourages the inclusion of consumers less able to manage on their own, such as people with Alzheimer's disease or children with disabilities. Two of the C&C demonstration decided that allowing representatives to also be paid

caregivers presented a conflict of interest. However, one state allowed this option. Prohibiting this practice did create some hardship for single-parent households of children with developmental disabilities because the parent would have to choose one role or the other.

To ensure access for some types of consumers' special policies may be required. For example, a circle of friends might function as the representative, if the parent wanted to be the paid personal assistant. Although flexibility is encouraged in responding to these types of challenges, the state experiences in C&C indicate that the same person should not serve as the representative and the paid caregiver.

The program staff we interviewed suggested one important way that quality challenges may differ among consumer populations. This concerned the issues surrounding hiring family members for paid care. Respondents from aging service programs assumed there was inherently more safety and quality if a family member was the provider. A major concern of these respondents was for people who did not have family members to hire. On the other hand, the adult disabled program respondents reported more concern about abuse and lack of consumer independence and empowerment if a family member was the provider. A major issue from this group of respondents was how to help consumers find

non-family workers. Respondents from programs serving those with developmental disabilities identified a third perspective. Their view was that the family is a natural provider and is safer, but may limit development and be less effective in handling medical and behavioral issues. Some of the aging/disability respondents did also express concern about the ability of the consumer to be independent if family was providing care. Several respondents discussed the need to train consumers how to combine family and employer relationships.

CONSUMER SUPPORT STRATEGIES

Blueprint and Steps for Quality

Planning Phase Strategies

Consumer Support Strategies

Monitoring Strategies

Quality Improvement Strategies

Appendix A: Quality Materials

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Appendix C: Resource Materials

Consumer Support Strategies

This section identifies the types of support strategies that aid consumers in making good decisions about their care

Consumer Support Strategies

The activities and functions in this section are based on the premise that consumers will choose quality if they have the information and resources to do so. The primary supports are the consulting and fiscal intermediary functions. Other support activities are the worker registry, the emergency back-up system, peer support, criminal background checks, and the provision of high quality information to consumers. The program's flexibility and responsiveness to the consumers' preferences should be evident throughout these activities. It should be noted that these support activities were implemented differently across the three C&C states.

Consultant Activities - *Training and monitoring are two* core consultant activities for assuring quality of the consumer's program experience. Consultants in the Cash and Counseling demonstration described many practices and details they believe contributed to quality in the program. Providing good information to consumers at all stages was considered to be a top priority for consultants.

Consumer training - The most important strategy for providing information to consumers is the initial training provided by the consultants. This is critical to the success of the program. Most consumers will have little idea of what will be expected from them. The initial training has to be sufficient to allow consumers (with assistance from a representative if chosen) to understand basic components of the program. This includes their responsibilities as an employer developing their purchasing plan, and managing their budget, their workers, and their care. Essentially, consumers will have to know almost everything the consultants know, but they will generally need time and support to learn it.

Consultants told us that to provide quality training to consumers they should:

- Contact the consumer as soon as possible after receiving the referral.
- Use the initial phone call to begin orienting the consumer.
- Have clear and consumer-friendly training materials, with some sent to the consumer ahead of time.
- Be able to adjust the pace of training to each consumer.
- Be able to assist as requested by the consumer (calculations, repeating, answering questions).
- Include in the training, with the consumer's permission, their representative (if there is one), family caregivers, and the designated workers (if known).

- Provide more training at a later date, depending on the consumer's need and ability.

Providing good information includes whom to call with what question. Training should help consumers establish realistic expectations and an understanding of program procedures from the beginning (e.g., about how rapidly the consultant can be expected to return calls). Another example important to consumers is information about when to send in time sheets and how long it takes to get checks sent to them.

Tip:
Clarifying Expectations
To a consumer, right away may mean within 15 minutes, while to a consultant a 24 hour response seems timely. In the C&C demonstration, some consumers initially called supervisors, the state office, and the fiscal intermediary when their consultant didn't respond within a brief period. Clarifying expectations for consumers and consultants through training helped to reduce communication problems in this area.

Necessary information for consumers who are self-directing will include rules and regulations surrounding hiring and paying workers. Examples include minimum wage rules, overtime compensation, collection and payment of taxes and social security, and what types of questions may legally be asked when interviewing a potential worker. While the fiscal intermediary may do some of the related tasks (collecting and paying the taxes), the consultant needs to be able to explain all this to consumers so they don't overspend their budgets. This type of information is best provided in a manual that can be referenced as necessary.

Assist consumers with developing and implementing the purchasing plan - As a result of the initial training the consumer (with the representative, if desired or necessary) should be able to

develop the purchasing plan. This lays out how the consumer wants the funds to be used to purchase the needed personal assistance. Consumer choice and control, and consumer accountability begin in earnest at this point. This involves articulating the consumer's goals for being in the program, to ensure that the plan supports this goal and also contributes to the later process for identifying specific personalized outcomes.

In C&C, errors in the calculation on the purchasing plan, particularly in the initial stages of a consumer's career, were relatively frequent and corrections were time-consuming. Tables for calculating rates of pay and taxes were developed to help both the consultant and consumer and samples are included in Appendix B, pgs.60,61. Over time and through the use of these aids, errors were decreased considerably.

Tip:
Completed Purchasing Plan
Having an example of a completed purchasing plan helps to illustrate how to fill out the form; but consultants warn that consumers may end up using them as is.

The purchasing plan must also include a written back-up plan describing what the consumer will do if a worker doesn't show up or quits. Helping the consumer plan for this possibility increases their sense of security that they will have help and that they are in control of the situation. The back-up plan must also fit within the budget. Once the consumer is self-directing, the consultant should periodically discuss the back-up plan to make sure it is still viable.

Responsiveness means that throughout this process, the consultant doesn't make any decisions but lays out the options and provides whatever information the consumer needs to make informed choices.

Once the purchasing plan is completed, consumers may need assistance with completing the paperwork required of employers (Workers Comp, I-9's, etc). This paperwork is typically the least consumer-friendly of all program materials. Specific instructions and examples of completed forms should help reduce errors. Frequent references during training to the consumer's "being the boss" reinforce the importance of this paperwork to the workers. Consultants also used this technique to underscore the consumer's authority relative to caregivers.

Finally, an important aspect of informing the consumer is telling them the consequences of fiscal mismanagement. For example, the program may require submission of a Corrective Action Plan and repayment of money over a period of time.

Ongoing Contact - Monitoring of consumers is the second core function of consulting. The purpose is both support for the consumer and accountability for the program. Once the consumer begins self-directing, consultants maintain regular contact. While the three states in the C&C demonstration had differing monitoring

guidelines, the consultants reported being comfortable with face-to-face visits every three months and monthly phone calls. Once consumers were managing well, the visits were reduced to every six months in one state. Both calls and visits were used to monitor the consumer's situation, management of money and workers, and satisfaction with the workers and representative. Depending on the role defined for the consultant, the visits included checking receipts for purchases. Also the viability of the back-up plan can be reviewed. Self-directed consumers are expected to call the consultant when questions or problems arise. Consultants could also make additional, even unannounced, visits if they had any concerns about any aspect of the home situation. They saw this as important to ensuring the consumer's safety.

Some programs tailor contact schedules to consumer situations. For example, more frequent monitoring of children with developmental disabilities was used when the family provided all the care and served as the representative. In another program, monitoring was more frequent at first when the consumer was using a representative – until the consultant was comfortable that the representative was acting for the consumer and not for him/herself. Consultants also made a practice of speaking with the consumer, even when they had a representative, and asking about their satisfaction with the representative, and reminding them they

could change if desired. No program asked the consumer what level of monitoring they would prefer, but some consumers did express a desire to be more independent.

Assisting Consumers in their role as employers - Another important aspect of quality in consumer directed services is the evaluation of the worker by the consumer. Consumers may not recognize that, as an employer, they have evaluation responsibilities. They may need information and assistance from consultants or training from others to develop these skills. Once workers are hired, the consumer should be encouraged and assisted to evaluate their workers on an ongoing basis. The consultant can help the consumer develop realistic expectations – neither too high nor too low.

Consumers should also be assisted to evaluate their own performance as an employer. For example, they should think about how well they communicate with their workers and how effectively they solve problems with workers. Consumers may need help in their efforts to discipline or fire a worker.

Reporting abuse - Incidents of exploitation, neglect, or abuse of the consumer, or the budget were almost nonexistent in C&C. Nevertheless, performance standards should require that consultants report to the state program office immediately any

suspicions of exploitation, neglect, or abuse of the consumer, or the budget allowance. This reporting procedure and the process for investigating and following up should be clear to all consultants. Several programs also emphasized the importance of training consumers to recognize and report to the consultant any possibly abusive behavior. One C&C state included in the first consultant's visit after the consumer began self-directing an assessment of the risk for abuse in the household.

Other quality issues - Other issues identified in the C&C demonstration have implications for quality. These include potential conflicts of interest, the influence of consulting reimbursement approaches, and the impact of certain enrollment practices.

- **Potential conflicts of interest** – It is useful to explicitly examine the planned consultant role for potential conflicts of interest (e.g., advocate/monitor). The consultant who is expected to be a strong consumer advocate may argue to increase care plan hours, thus having an impact on the overall program costs. In one of the states the consultant is hired and fired by the consumer and may be reluctant to report problems that require corrective action for fear of losing income. Dual responsibilities are not necessarily a bad structure, but supervision or controls will be needed to identify these tendencies and address them.

- **The source and rate of payment for consultants** – The rate structure for reimbursing consultants affects quality because it interacts with the amount of assistance that will likely be provided. If the

consultants are not paid for enough time to teach consumers this new approach, they are likely to take short cuts. It takes less time for the consultant to write the purchasing plan him or herself, instead of assisting the consumer to do it. They may not spend enough time to allow the consumer to really understand, resulting in more calls with questions and more mistakes to correct later. On the other hand, if unlimited reimbursement is available for this task, there may be an incentive to take more time training than the consumer actually needs, delaying their ability to self-direct.

- **Consultant caseloads must be manageable. –** The consultant job, while different than traditional care management, is no less time consuming in the initial phase. It is critical that consultants have reasonable caseloads especially at the inception of a program.

- **Other disincentives. -** Some enrollment practices can have an unintended negative affect on the rate of consumer participation. If consultants are expected to add consumer-directed clients to an already excessive caseload, they may discourage people from participating. If they are paid less to do consulting than to do case management, they may discourage people from participating. If they are asked to select those clients who will be offered the opportunity to self-direct, they may nominate very few at first, as most of their clients will be deemed "unable," "uninterested," or "too sick."

Consumer Support Provided by Fiscal Intermediary

- The fiscal intermediary performs two functions that significantly impact the quality of the program; fiscal support, and fiscal monitoring.. To support consumers the fiscal agent handles employment and payroll paperwork, receives ongoing timesheets and generates payment for workers. The fiscal agent plays a crucial role in providing consumers with needed information to succeed as

an employer. A second major function of the fiscal intermediary is to manage, track, and document the flow of money from the public entity to the consumer. The fiscal intermediary provides the program with the necessary documentation for accountability and review. (See the Arkansas Operations manual reference in Appendix C for sample requests for proposals for the fiscal intermediary function.) The fiscal intermediary function will always attract substantial attention from both consumers and the public, heightening the importance of developing a sound quality assurance and improvement process for this activity.

Tip:
Paperwork Error Check List
One C&C site recommends the fiscal intermediary develop a cover sheet with check list to send back with paperwork that was incomplete or contained errors, so the consultant or consumer could easily identify what was wrong and correct it.

Fiscal support for consumers - To support consumers, the fiscal intermediary provides a range of services and information. Quality in the financial support activities is defined by accuracy, timeliness, and responsiveness. Support of consumers includes the following activities:

- Assistance with the paper work necessary to hire workers;
- Review of purchasing plan in the context of budget allocation;
- Processing of time sheets, issuance of payroll checks, and withholding of necessary taxes;
- Payment of non-labor invoices;
- Processing of modifications to the purchasing plan;
- Providing an expenditure report on a regular basis;

- Responding to inquiries (e.g., for account balances, date checks were sent out) and solving problems.

One of the major challenges for consumers who are hiring their own workers and managing their own funds is handling the paperwork and reports related to employment and payroll. When consumers hire workers, all of the employment-related forms (I-9's, Workers Compensation, payroll taxes, Medicaid provider enrollment) have to be filled out by the worker and/or the employer. Even when assistance is provided by the consultant, the fiscal agent typically receives and reviews this paperwork. There needs to be clear and timely communication with consumers about the status of all of the forms that need to be in place before the worker can be paid. The quality of these interactions is enhanced by clear written instructions, including examples of properly completed forms.

Tip:
Expenditure Reports
Although C&C states worked with fiscal intermediary staff, designing reports for consumers was an ongoing challenge. Fiscal intermediary software presented barriers to constructing consumer-friendly reports. C&C state staff indicated that development time spent in designing and testing the format and content of expenditure reports with consumers is well worth the effort.

In addition, the fiscal intermediary reviews the purchasing plan after it has been developed and forwarded by the consumer and consultant. In most cases, the fiscal agent uses the purchasing plan to set up an account for the consumer and his/her workers. Then the purchasing plan provides a guide against which payroll and other claims are compared and reconciled on a monthly basis. The nature and extent of responsibility held by the fiscal agent for

the verification of time sheets and invoices against the purchasing plan depends on agreements among the various agencies involved.

Consumers typically send in time sheets twice a month and the fiscal intermediary issues checks. Most programs sent the checks to the consumers, who then give them to their workers. Because timeliness is an important quality issue for the fiscal intermediary services, internal procedures need to be as efficient as possible. However, receiving time sheets and mailing payroll checks can also be affected by mail delays. Some programs accept fax copies of time sheets, but require that the original signed copy be sent in also. Other possibilities such as direct deposit to the worker's bank account could speedup reimbursement.

Clear and timely expenditure reports are essential for consumer success and program accountability. In general, consumers need information to check on how their funds have been spent, check on specific items, and on the status of their accounts (monthly balance and accrued savings). Consultants need to see that the consumer is managing funds appropriately without going over the spending limit and without spending on unapproved items. For both purposes, the information needs to be timely so that problems don't go undetected for long periods of time. One solution to these problems is a web-based budgeting and reporting

system, which is now being developed and tested in several programs across the U.S.

Even when the expenditure report is understandable, no report can be up-to-the-minute, so the consumers will have to call the fiscal intermediary if such information is needed.

An important part of customer service is telephone communication. Many of the complaints about the fiscal intermediary were in response to customer service issues. Common concerns included: a machine answered instead of a person, calls were not returned in a timely fashion, and the person answering was in a hurry or rude. Some of these problems could be addressed through training of fiscal intermediary staff and some of these problems were related to the structure of the fiscal intermediary services.

Tip:
Fiscal Intermediary Training
The C&C states recommended the fiscal intermediary staff having consumer contact be required to have customer service training as well as training in communicating with the consumers with various disabilities.

In addition, unclear written communication often resulted in a large volume of phone calls from confused consumers and consultants. Written communications that are pilot tested with consumers will go a long way to reducing the telephone traffic.

Because consumers or their authorized representatives are the employer of record, they may receive correspondence or statements about taxes or workers' comp, despite the fact that in the overwhelming majority of cases, consumers choose to contract out that function. These will cause a great deal of anxiety, so

consumers should be warned of the possibility during training and told to send any such correspondence to the fiscal intermediary.

Fiscal monitoring and accountability - In addition to providing consumer support, the fiscal intermediary is the major source of fiscal accountability for the program. Quality will be defined by accurate and timely management, tracking and documentation of the movement of Medicaid funds and the withholding and timely payment of relevant taxes.

By helping the consumer succeed in managing funds, the fiscal agent helps to make sure that expenditures match the approved purchasing plans. At issue are who, in addition to the consumer, is responsible for verifying payroll, approving invoices, and reconciling expenditures with the purchasing plan? The exact nature of the fiscal intermediary's role in the process of verifying time sheets and invoices needs to be clarified, as does the role of the consultant and program agency staff. In some programs, the consultant verifies expenditures before sending the bills on to be paid. In others, the fiscal agency verifies the types and amount of expenditures on a monthly, quarterly, or six-month basis based upon the established purchasing plan. When the fiscal agency is less frequently involved in reconciliation, the consumer (with help from the consultant) has greater responsibility for managing the

program's money. The advantage of the latter approach is that consumers are more in charge, but the program obviously needs to make sure that there are some checks and balances in place and that roles and responsibilities are clearly communicated. For the purposes of financial integrity and accountability, the program staff, consultant, fiscal agency, and consumer must have a clear understanding about how this process will work. If consumers and consultants have the major responsibility for management of the allowance, the expenditure reports sent to the consumer must be timely and easy to understand.

Among the C&C sites, one had consultants reconcile expenditures before submitting invoices to the fiscal intermediary and one had the fiscal intermediary do it. The third site monitored expenditures after-the-fact by assigning the consultant the responsibility of reviewing them with the consumer each month.

Problems with reconciliation occurred when the fiscal intermediary paid whatever hours were presented in the time sheets in order to comply with labor laws, even if the cost went over the budgeted amount. When fair labor practices and the fiscal intermediary contract dictate that costs may overrun purchasing plans, consumers and consultants clearly have to be more involved in matching expenditures to the purchasing plan.

Since the fiscal intermediary agency receives and disburses public funds, their reports will be the major source of monitoring and accountability data. Both the program and fiscal agencies should agree about how overall program expenditures will be tracked and reported based on Medicaid requirements, program policies, and reporting formats and cycles. Reconciliation of expenditures with purchasing plans, average as well as a range of monthly costs per consumer, tax payment recording options, and consumer-specific expenditures are examples of reports that may be helpful and necessary for program monitoring. The program office will need a staff member to review the reports monthly so any problems are caught early.

The C&C Demonstration required semiannual audits of the fiscal intermediary functions; these are discussed further in the monitoring section.

Because fiscal intermediaries for consumer direction programs fulfill a unique function (i.e., providing service for a lot of employers who are using public dollars to pay their workers) there are significant and complicated IRS issues. (See Appendix C, Fiscal agency readiness review)

Worker Registries - In the Cash and Counseling programs about 80% of program participants hired family, friends, or

neighbors as their primary worker. In select instances however, individuals did report difficulties in finding workers, especially where informal supports were not available. Some consumers never got as far as self-directing because they could not find workers, and others, worried about the availability of workers, may have decided not to enroll. One response to this problem is the establishment of a registry of potential home care workers. Such an idea is consistent with our theme of helping the consumer choose quality.

Our review of consumer-directed programs identified only a few locations where home care worker registries existed. California, with its long-standing In Home Supportive Services program (IHSS), appears to have the most well developed worker registry service. Designed to match people with disability and workers it provides the following core services: (1) recruitment and screening of potential in-home workers; (2) maintenance of a list of workers and instructions for consumers on choosing a worker; (3) monitoring telephone calls to consumers who use the registry to identify any problems with workers and to assist with other informational needs; and (4) community outreach to identify other consumers in need of registry services.

The California registry is computerized and designed to match consumer requests with workers based on location, language, type of assistance needed, work schedule, and other job related preferences. From 1996-2001, nearly 1600 workers were interviewed and listed on the IHSS registry, and over 2100 consumers were sent lists of potential workers.

Our review identified several other states and programs attempting to develop registries (e.g., Washington, Oklahoma, Virginia) but this concept does not appear to be widely used. Respondents in our survey of 15 consumer-directed programs talked about the difficulty in keeping the registry up-to-date because workers did not always keep the program informed about changes in their employment status or contact information. Another concern surrounded liability issues faced by registries. For example, should registries be in any way legally responsible for workers under such an arrangement? As evidenced from our review of the California experience the development and maintenance of a viable registry requires a considerable organizational commitment of time and resources.

Tip:
Emergency Back-Up Procedure
Although the emergency back-up procedure may not be needed often, a high quality consumer directed program must have the necessary responses in place.

Development of Emergency Back-up Procedures - Because participants in consumer-directed programs typically require assistance with activities of daily living, a back-up plan,

detailing what the consumer will do if the personal assistant doesn't come to work or suddenly quits, is critical. Developing the back-up plan is an important part of the planning process and should occur at the same time as the consumer and consultant develop the purchasing plan. The development of the back-up plan invites an assessment of the consumer's needs and circumstances and a plan for responding to potential emergencies.

It is also essential for the program to have a system-wide strategy to respond if a consumer's back-up plan fails. We refer to this as an emergency back-up procedure. One of the Cash and Counseling sites served individuals with brain and spinal cord injuries, a group particularly at risk should a worker fail to provide the needed assistance. While a small program, their emergency back-up strategy is illustrative of a system-level response in support of an individual problem. When it came to developing an emergency back-up system, the program adopted a "whatever it takes philosophy." For example, in the state consumer-directed service program personal care providers need to be certified by Medicaid in order to be paid. To ensure the availability of an emergency back-up provider, this rule was waived in critical situations. The program attempted to eliminate any structural barriers that existed in its efforts to ensure that personal assistance could be provided immediately.

The emergency back-up procedure relies heavily on creating system level supports for the consultant and consumer to respond to the presenting situation. The key is to create a structure before the emergency so that consultants and consumers are empowered to seek workable solutions. For example, the consultant must be able to waive program rules surrounding worker certification or eligibility, and to have the flexibility to incur costs above the ongoing purchasing plan. This could occur for instance if more hours were required or if an agency-based or other higher paid worker was needed.

Tip:
Volunteers
In Cash and Counseling, several consumers volunteered to be available by phone to talk with people considering the program or to those already enrolled. One site actively recruited such volunteers and described their availability in the program newsletter. The volunteers reported enjoying the interactions and the feeling of contributing to the quality of the program.

Peer Support – As we worked with Cash and Counseling sites and the consumers participating in the program one principle became evident: Consumers very much wanted the opportunity to learn from and to support their peers participating in the program. This desire was seen in an early focus group held to discuss quality with consumers, when group members remained after the session to discuss issues and exchange e-mail addresses for further contacts. Each subsequent discussion with consumers highlighted the importance of information exchange and support from others in the program. Peer support, one of the cornerstones of the independent living movement and based on the belief that some assistance is best provided by people who have experienced

disability themselves, seemed an important concept for consumer-directed programs. Additionally, peer support promotes a wellness model. Finally, it supports efforts to assist consumers in choosing quality.

Peer support, in either a group or an individual setting, provides a mechanism for exchanging tangible information in such areas as working within the consumer-directed program, suggestions for hiring or supervising workers, additional service options, housing assistance and any other needed information. Interacting with consumers who have similar experiences can also assist with the promotion of the consumer-directed philosophy. The independent living movement stresses the importance of peers in helping consumers to become better self-advocates.

The lessons learned in Cash and Counseling reinforced the experiences of the independent living movement concerning the importance of peers. These experiences highlight the value to consumers in having the opportunity to share both information and support functions with their peers. Although some potential elements of a peer support program have been identified in this section, specific components will need to be developed at the program level. Our works suggests that peer support can be an

important strategy in helping consumers in their efforts to choose quality.

Criminal Background Checks - Views on the use of criminal background checks vary considerably. One perspective argues that criminal background checks should be mandatory for all workers, even family members. The argument for this approach is that the process is clear and easy for programs to follow. The opposing argument is that background checks are unnecessary and ineffective and many consumers paying privately should not hampered by this requirement. A middle-ground perspective is that criminal background checks should be an option available to consumers. Consumers who wish to do so should be able to obtain background checks and have access to results, but such checks should not be mandated.

Tip:
Criminal Background Checks
Based on these experiences it is our recommendation that criminal background information be available to consumers in their efforts to hire the right worker. Deciding to do the background checks and how to use the results should ultimately be the choice of the consumer.

Our review of the Cash and Counseling sites and a survey of 15 consumer-directed programs around the nation provide experience with these varied approaches. Of 15 programs identified, eight of them used criminal background checks. In five of these programs, background checks were mandated by state law, although in two of these family members were exempt. In the other three programs background checks were used, but not required. Local programs were consistently opposed to the use of mandatory

background checks. They reported particular concern from consumers wanting to hire family, friends, or neighbors.

When background checks were mandated, two major issues arose. One was whether to include family members, or which members. (e.g., does conducting a background check on a daughter, who has been the primary caregiver for years make sense?) Second, if background checks are mandatory then there needs to be a mechanism to evaluate results and apply these results to hiring decisions. Decisions about which offenses disqualify an applicant complicate the process but must be attended to prior to starting a program.

Providing Ongoing Information - Consumers in the Cash and Counseling demonstration were very interested in information about the program and the service system in general. The training materials developed for consumers, consultants, and the fiscal intermediary staff at the outset of the program were critical in addressing the initial needs of the consumer. However, both consumers and program staff discussed the importance of meeting ongoing informational needs. Programs recognized that as consumers gained more experience and when their care, and social and environmental circumstances changed, their information needs would change as well. What types of information do consumers

need on an ongoing basis? And how can such information be disseminated? Discussion with consumers and program staff in the demonstration described several strategies. Two of C&C programs developed newsletters that were praised by consumers. Other outside resources can address the consumer (and caregiver) desire for more information. Consultants can influence the quality of care by informing consumers of opportunities, such as talks sponsored by the Alzheimer's Association, hospitals, Area Agencies on Aging, community colleges, and advocacy and caregiver groups.

Monitoring Strategies

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In this section we present a range of activities that can be used by an organization to ensure that services are of high quality. These strategies must be linked with other quality improvement efforts to be successful.

Despite the importance of incorporating quality activities into design efforts, we recognize that publicly funded programs need to include monitoring activities.

Designing and Using Quality Monitoring Activities

We hope that careful program planning will reduce many quality challenges by the time a program begins operations. However, as a program moves into the operational phase there will undoubtedly be quality challenges that arise in even the best planned organizations. The quality management system described in this section includes a series of strategies that can be used to monitor and improve program services.

Tip:
Plan Program Monitoring Activities for Use in Quality Improvement Efforts
In our review of quality efforts in long-term care we have come across numerous examples where an organization cannot even identify the purpose of a specific monitoring activity, and data collected from the effort are not used for program improvement.

Despite our emphasis on the importance of consumers in improving and assuring quality this guide acknowledges that publicly funded programs are required to include program monitoring activities. In a quality system it is critical that these monitoring strategies be incorporated into the overall quality improvement framework of the program. This means that monitoring data must be systematically collected for use in both individual and program improvements. In this section we present monitoring strategies for consumer-directed programs with a particular focus on how such activities can be linked to quality improvement.

Complaint Hotline - A common program practice is the use of a toll-free telephone complaint hotline. Widely publicized

with consumers, family members, representatives, workers, and the long-term care network, such a strategy provides an opportunity for anyone interacting with the program to easily call if a problem has occurred. Although specific approaches vary by program, the general principle is that consumers, family members, and other stakeholders receive training concerning the purpose and use of the hotline, and anonymity of the caller and the consumer are assured. For example, one of the Cash and Counseling sites used a toll-free complaint hotline at both the main program office and the fiscal intermediary.

Upon receiving a complaint call the program has to have a mechanism for tracking, reviewing, acting upon the call, and for recording the final action. A strength of the hotline is that its use is not restricted to consumers but also from providers and other members of the community. Initially programs did report calls from providers, who in some cases were raising issues about the legitimacy of the cash and counseling approach. Even in these instances the hotline provided a way for the program to educate providers and get their by-in by explaining the monitoring and quality mechanisms built into the program.

Additionally, logging calls can provide a program with a systematic look into the nature of problems, so that a response can occur at both an individual and programmatic level. Such

aggregation can be particularly important from a quality improvement perspective, where the goal is to support program solutions to problems.

A difficulty with the use of the hotline approach is that such a line can receive many general information calls about the program. A widely publicized toll-free complaint line at one of the Cash and Counseling sites reported that the overwhelming majority of calls were for information about entry into the program. In one case the program received a hotline call requesting information about another state's program. A dual use line does not represent a problem for a program, but it should be recognized that the volume of calls will be increased substantially when both purposes are met.

Program Performance Indicators - Just as consumers require information to make good decisions, so do organizations. Selected performance indicators, based on program goals and expectations, can provide needed data for program decision making. Indicators are selected by considering what the program needs to know in order to decide if it is working as planned. This will vary by program but could include such areas as: How long does it take to respond to a consumer request for program information? Once a person enrolls how long does it take to have their purchasing plan approved? How often and for what reasons

do consumers leave the program? How frequently do the purchasing plans match consumer expenditures? The answers can then be compared to goals or expectations to learn how well the program is operating. Although data from these types of questions are important for quality management, many programs which are reviewed were unable to collect, access, or use information of this nature. We have listed a series of critical factors to help programs successfully use performance data. (See also Appendix C)

- The indicators chosen must be linked to program goals and useful for quality assurance and improvement activities.
- Collection of performance data must be built into operational practice.
- An information processing system that allows data to be analyzed is essential.
- Data needs to be constructively used to improve the program.
- Individuals involved in the collection of performance data should see the results of the data collection effort and be kept informed about how this information is being used by the program to improve.

It is important to mention that performance indicators are just that, an indication, rather than a summative measure of program outcomes. These data need to be analyzed in the context

of the program. For example, when examining data on how long it took to approve a purchasing plan one program found that on average it took 90 days while their goal was to accomplish this in 45 days. The next step could be to examine the records of consumers who took longer than expected to file their purchasing plan, maybe those over 60 days. Analysis might reveal that some consumers took an excessively long time because they could not decide whether they wanted to participate – if so this delay may be unrelated to program performance. In this instance, when these individuals were removed the average dropped close to the targeted goal. On the other hand, data may indicate that there are a large number of people over the target rate and that the problem involves the process. For example, maybe delays were caused because the consultant function was consistently not providing support in a timely fashion. Our point is that collecting and analyzing these indicator data provide the first step in a quality assessment process. These data would need to be monitored on an ongoing basis by program staff and shared with a quality improvement or advisory committee to ensure continued links to the improvement process.

Agency and Record Audits - In order to assure that the program is functioning effectively and responsibly, the host agency

will conduct program audits with the consulting and fiscal agencies. It is useful to clarify the specific questions that might be asked during such a program audit; these questions should be derived from the functions of the agency and the purposes of the review. While a program audit is a primary source of information for monitoring and accountability, it can also be an opportunity to look for ways to improve the services provided. In general, an audit should involve consumers, agency administrators, agency staff, and a record review, and it should be seen as a collaborative effort to assess and improve the way the program works.

A program audit of the fiscal agency will be driven by the functions it performs for the consumer and the program. The fiscal agencies fulfill two primary functions: 1) fiscal intermediary tasks performed on behalf of the employers/consumers, including calculating, withholding, and paying taxes and issuing payroll; and 2) accounting services for consumers, including keeping track of their expenditures and providing reports about account balances and accrued savings. In addition, the fiscal agency is often called upon to provide some level of reconciliation of expenditures and purchasing plans on behalf of the program, sometimes in conjunction with the consumer and the consultant. Examples of questions that might be addressed in a fiscal agency program audit.

- Are expenditure and account balance reports provided to consumers and consultants in a timely

fashion? Are they user-friendly and clear? What do consumers and consultants have to say about how to improve the report format, content, or schedule?

- How quickly are discrepancies between purchasing plans and expenditures noted? How quickly and to whom is such a discrepancy reported?

- What do consumers have to say about their interactions with fiscal agency staff? Are their questions answered promptly and clearly? Are there any improvements that could be made to the "customer service" provided by the fiscal agency?

- Are cost reports, invoices, timesheets, payroll, and tax records maintained efficiently and effectively? Are these reports provided to the host agency in a timely fashion?

- Are there any persistent problems with processing of employment paperwork, time sheets, or payroll?

Tip:
Incorporate a Program and Financial Audit Process
Because the fiscal intermediary functions are relatively new, the Cash and Counseling demonstration developed a program audit process to review these areas. One of the sites also added and strongly recommends an accounting audit of how funds are tracked by the intermediary.

Questions about whether consumer expenditures matched the purchasing plans were seen as particularly important at the inception of the demonstration. Because virtually all consumers used the fiscal intermediary and this entity only approved expenditures that matched the purchasing plans, this concern was not a problem in the C&C demonstration.

Similarly, the range of functions provided by consultant agencies will shape the questions addressed in a program audit. The consultant agency tasks include help in developing purchasing plans, assistance with back-up plans and with employment-related paperwork, and training for the role of employer. Some examples

of questions that might be addressed in a consulting agency program audit:

- How well do the training materials and strategies work to convey necessary information to consumers? Are there any improvements that could be made in what information is conveyed, or in how and when it is conveyed?

- How often do consultants contact consumers? What determines the frequency and nature of contact? Are consumers satisfied with the frequency and the quality of the contact with consultants?

- Are monitoring visits and calls to consumers documented appropriately? Are consumer files complete?

- Do purchasing plans meet the needs of the consumer in a way that reflects the flexibility and consumer-centered philosophy of the program? Are there differences among the plans that reflect this flexibility and variability in consumer preferences and needs?

- In what ways and how quickly, do consultants help consumers solve problems with workers or with purchasing plans?

- What is the average length of time it takes for consumers and employees to get through the paperwork necessary to begin self-directed services? Is there any way that the process could be streamlined?

Case Example: How an Audit Led to Improved Services

A good example of the way in which a program audit was used to improve services was provided by one of the Cash and Counseling programs. A record review of purchasing plans revealed that there was a great deal of similarity among the plans, even when consumer circumstances were very different. Conversations with consultants about this similarity revealed that they were having some difficulty letting the consumers be flexible and in charge of the design of their purchasing plans. They felt a responsibility for the outcomes – a worry about liability. A retraining strategy was immediately developed, and the problem was corrected.

Independent Review of Consumers - Although a common element of long-term care quality efforts in both home care and nursing homes has been an independent assessment of consumers, such an approach in consumer-directed programs presents an

interesting dilemma. Because consumer-directed programs are designed to maximize consumer choice and autonomy, how can a review process be designed that both respects the consumer, and provides the program with the needed oversight? What are the individual and program safeguards that need to be monitored? How do consumers feel about the monitoring process? And are there ways that a program can minimize any perceived negative effects on consumers?

With public dollars involved there are some basic questions that this review needs to address. For example: Do consumers continue to meet the necessary eligibility criteria? Have the right amount of funds been allocated to the consumer? Is the consumer able to develop a purchasing plan that meets their needs? Is the consumer as safe as they feel they need to be?

There are a number of strategies that can be used to address questions of this nature. An approach used in one of the Cash and Counseling sites was to have independent nurses complete an assessment of the consumer. During a regularly scheduled review, nurses employed by a separate program assessed the consumers condition and made a determination about whether the level of service and therefore the amount of dollars allocated should be modified. Nurses also provided a basic health and safety review.

The advantage of this approach was that the program was able to collect independent evidence indicating that funds were

being allocated appropriately and that consumers were safe; two areas of political concern prior to the inception of the program. The down-side to this approach was that this monitoring effort was not well integrated into the program's quality efforts. The nurses worked in a different unit, and thus there was minimal communication and contact between the program and the nurse reviewers. Program staff also felt that in some instances the independent reviewers did not know enough about the program and exhibited some biases favoring a more protective model of service. While the program gained information that was useful from a political perspective, findings were not integrated into quality efforts.

Because the independent review was done in place of the Medicaid eligibility re-determination process, it was completed for all consumers. A variant of this model would be to collect information on a sample of consumers. The sample could be selected at random or could be a combination of part random, part based on specific problem areas. For example, one of the C&C sites sent a nurse reviewer into the home in response to a complaint or a concern expressed about the consumer's condition or environmental circumstances. The random sampling strategy has an advantage of allowing a program to gain an accurate portrait of program participants in a much more cost-effective manner.

Keep in Mind:
Use the Collected Data for Quality Improvement
The optimum approach depends on the program circumstances. For example, the number of consumers served, the dollar amount of the purchasing plan, the intensity of the consultant role are factors that would influence program strategies. Regardless of the approach used, what is most important is that the data collected are integrated into the quality improvement system. Do any patterns emerge for those consumers reviewed? Are there improvements that can be made in response to the areas identified in the review? These are the types of questions that the program needs to examine after the data are analyzed.

Quality Improvement Strategies

Blueprint and Steps for Quality

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Consumer Support Strategies

Monitoring Strategies

Quality Improvement Strategies

Appendix A: Quality Materials

Appendix B: Forms Used in C&C Program

Appendix C: Resource Materials

In this section we provide recommended improvement strategies that can be used by programs.

To succeed it is critical that programs have a commitment to gaining input from consumers and using such information to improve the quality of services being delivered.

Developing and Using Quality Improvement Strategies

Despite considerable discussion about the need to shift our quality focus from quality assurance to improvement, most of the strategies, even within the home care arena, have focused on inspecting structural components of a program or service. The shift to a quality improvement model requires some important changes in how organizations and regulators make decisions. Two principles provide the basis for the improvement perspective. First, organizations must involve consumers, and second, information needs to be systematically used in decision-making. To achieve quality, an organization must use operational and outcomes data to modify and improve the program.

Keep in Mind:
The Value and Uses of Outcome Data

The strategy described in this guide is based on a recognition that outcome data are integral to assessing and improving program quality. This means that in addition to identifying which outcomes are important, programs need to think about how to use outcome data generated. If information being collected does not contribute to quality improvement or regulatory requirements then it should not be part of the system.

In this guide, program outcomes have been classified into three categories: quality of life, quality of the services, and quality of the system. Specific measures to assess whether the program has achieved positive outcomes in these areas are discussed throughout the guide. For example, in this section we present a personal outcomes measure and strategy that is designed to collect systematic information from consumers on quality of life and services. In the program monitoring section, data about how quickly a consumer can be enrolled and the length of time to receive the cash benefit contributes to an assessment of the quality of the system. Data from the independent review of consumers and

from the agency audits contribute to outcomes of safety, cost and financial integrity.

A critical principle for improving and assuring quality in consumer-directed programs involves creating an effective mechanism for hearing the voice of the consumer. Because consumers in need of long-term care assistance experience physical frailty or cognitive impairment there has been an assumption that these individuals are unable or do not wish to exercise control over the help they receive. Nursing homes and even home care agencies have been consistently criticized for not creating opportunities for consumers to provide feedback and to provide direction about the assistance received. Given the very nature of consumer-directed services, placing the consumer at the heart of the quality improvement process is essential. This first section presents a description of approaches used to hear directly from consumers when assessing program performance. Whether it is a review of the intake process, or an assessment of the performance of the consultant, or the fiscal intermediary, a program needs to have an effective strategy for getting feedback from consumers.

Personalized Outcomes - Interest in the personalized outcomes approach begins from the premise that consumers hold

differing views on what constitutes quality, and therefore an assessment of program quality must examine what is most important to each consumer. Although identifying personal outcomes begins with measuring outcomes, the ability to aggregate measures of individual outcomes into system-level measures of performance will provide critical information for quality improvement. Measuring personalized outcomes was initially pioneered in the field of developmental disabilities. The approach was developed as part of an in-depth home visit with the consumer and was designed to gain a thorough appreciation of the consumer's life circumstances and desired program outcomes. The purpose of the interview was to understand whether the consumer's quality of life--as defined by them--was being addressed and enhanced by services and providers. The interviewer spent a considerable amount of time with the individual to first understand how the consumer defined their desired outcomes, and then to assess whether the identified outcomes had been attained. Quite simply, personalized outcomes provide a tool to measure the ability of an organization to respond to the needs of individuals.

Our plan for collecting personal outcomes data is to incorporate a question about the consumer's goals into the development of the purchasing plan. Then during purchasing plan reviews, the consultant will ask the consumer whether the goals

are being met. This would keep the focus of both consultant and consumer on achieving what the consumer wants. Of course, the consumer can also reformulate goals as they wished and as their situations changed. Barriers to achieving goals should be identified, and documented. The consultant should help the consumer to address the barriers whenever possible. Barriers should be reported to the program.

As a measure of program responsiveness, aggregate information about personalized outcomes is desired. For this purpose our challenge was to develop a tool that could capture personalized outcomes, but could be administered in a standard, quick, and easy manner. The Personal Outcomes Survey is a structured tool that asks how well the program fits with what the consumers really want. It operationalizes the values that consumers defined as important to them (choice, control, flexibility, information, respect, relationships, safety, etc.). The Personal Outcomes Survey is included in Appendix A, pgs.1-11.

To test this approach we worked with one of the consulting agencies in the Cash and Counseling Demonstration, linking data collection to the already scheduled activity of 6 month home visits or phone calls. In addition a member of the state program staff used the Survey during monitoring home visits to consumers.

Although consultants were used to collect data in our test, this survey could be completed by program staff. It could survey all consumers or a sample. Data collected would be examined at both an individual and program level. At the individual level the program would attempt to respond to identified needs (e.g., help with the fiscal intermediary, help finding a back-up worker, help with a family issue, or help securing a piece of equipment). At the program level data would be aggregated and used by staff and/or the quality improvement committee to enhance the program's performance.

Another approach, involves recruiting and using volunteers to solicit feedback from consumers, which has been used in programs serving individuals with developmental disabilities. Under this strategy volunteers are recruited and trained as part of the program's quality improvement efforts. These volunteers would complete home visits with consumers and their families and could use the Personal Outcomes Survey as well. In some programs a consumer satisfaction or personal outcomes measure is also collected during the home visit. This approach has the advantage of emphasizing the importance of the consumers input and also allows the program to make individual and program changes when problems are identified.

Another possible strategy for gaining consumer feedback involves using a variant of the approach used by the A.C. Neilsen Company to record television viewing patterns of the American public. Consumers would be selected at random and asked to be test households. After receiving training about the approach, they would be asked for one week of every quarter to record their experience with the program. Although the contents of the Personal Outcomes Survey would serve as the basis for the data collected, other observations could be recorded as well. The focus would be determined, how the program is working, and identifying barriers and areas where the program needs to improve. In a test of home care recipients we found that this approach generated information useful for quality improvement. Although consumers and staff would need some initial training, it is expected that only a limited effort would be needed thereafter.

A final option would be to examine the feasibility of using the internet to communicate with consumers. The Cash and Counseling experience found a number of consumers to be both familiar with and actively using the internet. This suggests that using the internet for generating consumer feedback could be viable for certain demographic groups. A demonstration effort using this strategy could either start with consumers who already have computers or have a program pay for internet access for a

select group of consumers. Just as in the case of a volunteer effort mentioned above, it is expected that some initial training would be required. Each month/quarter select personal outcome survey questions could be sent via the internet soliciting consumer input about the program. As with all the strategies outlined in this section the emphasis would be on ensuring ongoing feedback from consumers.

Quality Improvement Committee - A quality improvement committee is a group of program stakeholders that will have an explicit responsibility to pay attention to the issue of quality on an ongoing basis. There are two major reasons for using the quality improvement committee. First, because each component of any program is complex in its own right, it is likely that staff who are responsible for one aspect of the program would focus solely on that component in order to get their particular jobs done. Although a detailed focus is important for any unit, a negative consequence is that often no one in the organization is able to see how the various units intersect, overlap or contradict. Having a committee of representatives from across a program, including consumers, provides a mechanism for ensuring a broad vision of quality. A committee focused on quality improvement is also advantageous because it creates a group with the authority to

continually challenge the organization to improve. In most organizations the amount of work exceeds the staffing available. In such an environment, stepping back to think about quality is seen as a luxury. Programs where staff members are overwhelmed and overburdened have a difficult time being able to reflect on how they can improve. In our view, having a committee with a mandate to improve will facilitate quality efforts. The quality improvement committee will have an ongoing responsibility for reviewing program performance data and identifying additional information in an effort to provide suggestions for quality improvement activities. With support from staff the committee will have responsibility for reviewing and in some cases generating information about program performance. The committee will guide the organization in using data to improve services for consumers.

- **Size and Composition**: The quality committee is a working group and as such we recommend 8-12 members. Core members would include individuals from each of the following groups: program staff, consumers, counselors/consultants, representatives, caregivers, and fiscal intermediary staff. Beyond the core members composition is expected to vary, with programs adding members based on their unique structures. Other participants could include, external reviewers, outreach staff, and independent representatives, such as community advocates. Staff members who are asked to allocate substantial time to committee work will need relief from current job responsibilities.

- **Work of the Committee:** An effective quality improvement committee requires a significant investment

of time and other resources. Agreeing on the time frame for committee activities and the expectations and responsibilities of the group will be the initial task. We would anticipate more frequent meetings, such as every two weeks, during this initial phase. Staff support will be needed to help with meeting arrangements, background work, and in some cases for data collection and processing. We believe that an important early task for the committee will be to review the information that is currently collected by the program. Additionally, we recommend that the agency self-assessment, discussed in the following section, be used as an initial exercise for a quality improvement committee. It is expected that the quality improvement committee will identify improvement efforts that are the highest priority for the program. In some cases committee members might plan improvements; in other cases, the committee might provide feedback on program activities. In all cases, an important function of the committee would be to ensure that mechanisms exist for continuous feedback.

- **Training:** An initial orientation for committee members is essential. In this session, expectations, roles and responsibilities will be discussed and agreed upon. Program commitment to improvement needs to be emphasized. Ongoing needs for training and resources will be identified as the committee begins their work.

A detailed presentation of the implementation steps is included in Appendix A, pgs.12-15.

Program Self-Assessment - Under a quality improvement model it is important for a program to continually assess its approach to service delivery. To reinforce the consumer principles identified earlier one of the strategies recommended is the use of an agency self-assessment. In completing a self-assessment a program is required to step back and examine whether their day-to-

day practices are consistent with their stated goals and philosophy. Such an approach has been developed for state assessment by a team from the National Association of State Units on Aging (NASUA) and the Home and Community-Based Services Resource Network. For this guide we have adapted the state assessment for use at the program level. Our revised assessment tool is presented in Appendix A, pgs.16-24.

This program self-assessment is designed to provide consumer-directed programs with an opportunity to reflect on how program structure and policies affect consumers--how consumer-directed the program really is. Questions focus on basics such as: How do consumers find out about and access the program? Can consumers determine which services to use and can they select, hire, and dismiss their workers? Do consumers serve on an advisory or quality improvement committee? Do consumers receive the needed resources to maintain maximum independence? Are consumers able to help design the monitoring activities of the program?

One question that arises involves how to complete program self-assessment activities. There are a range of options available, and organizations need to identify the best match with their specific needs and resources. One strategy involves using the program's quality improvement committee, or at least a sub-set of

this group. The assessment serves as a particularly good vehicle for an improvement committee to gain an in-depth understanding of program operations and quality challenges. Under this approach staff resources would be required to support the work, but committee members would be active members in the assessment.

A second option is to have program staff conduct the self-assessment and then share results with a quality improvement committee or some other type of advisory board. If this approach is used it would be critical to provide a mechanism to involve consumers in the assessment process.

Summary:
This approach reinforces our premise that consumers will choose quality, and as such, an important function of quality improvement is to make sure consumers and families have the necessary tools to do that. Program self-assessment is a mechanism for the program to better assess how well they are doing in reaching this goal. We believe this will identify improvement areas for the programs to work on.

A third option would be to use an external reviewer to assist with the assessment. Program staff and committee members could be involved, but the external reviewer would lead the process. Such an approach is a bit easier to implement because internal staff expertise is not required, but there may be less involvement and buy-in from program staff. Regardless of how the assessment is done the information needs to be reviewed by a quality improvement or advisory committee with the recognition that this is an improvement not a punishment exercise. Consumers need to be members of the group doing the self-assessment.

We believe that this is a good task to complete after initial operations have begun in order to maintain the consumer focus. For an ongoing effort such an exercise should be incorporated into

the planning cycle. The frequency of conducting such an assessment should be driven by how the results are used. The rationale for working with staff and the quality improvement committee is that weaknesses identified in the assessment can be addressed by the program and then feed into the overall improvement process. For a program that is mature and has established strong mechanisms for consumer feedback, such an effort may be less important and could be done as part of a multi-year planning cycle. For a program still developing its processes, such an activity might be useful every one or two years.

CONCLUSION

We have all had the experience of receiving a quality service or product and unfortunately in many cases the opposite experience of having a service or product that does not meet our quality expectations. What accounts for these differences, particularly in programs designed to help individuals experiencing a chronic disability? Our approach to quality in response to this question is that quality happens through two interrelated mechanisms—**building a quality program and developing a quality management system.** To this end, this guide has focused on building quality into the program from the first day of planning, and assuring and improving quality through an ongoing system of quality management. We recognize that improving quality is a continuous process. This guide has been developed to help programs in their goal of becoming an organization that everyone can say—"now that is quality." Although we believe the guide has many useful components, ultimately the success of a consumer directed program will be achieved because of the staff commitment to making it work for the consumer.

Concluding Tips:

Quality in consumer direction is built on clearly articulated principles, implemented through purposeful structures and strategies, assessed in multiple levels of outcomes, and assured through a continuous feedback and improvement system with consumers at the heart of it.

Quality is designed in from the beginning.

Program goals and consumer definitions are the basis for quality management.

Good information is essential for consumers and for the program.

Appendix

Blueprint and Steps for Quality

Planning Phase Strategies

Consumer Support Strategies

Monitoring Strategies

Quality Improvement Strategies

Appendix A: Quality Materials	Appendix A includes samples of the materials used to assure and improve quality in the Cash and Counseling demonstration. We have tried to include tools and instructions in an effort to allow programs to adopt or adapt documents as they see fit.
Appendix B: Forms Used in C&C Program	C&C sites developed an array of program management forms that assisted in their quality efforts. This Appendix includes examples of their documents and the site from which they came.
Appendix C: Resource Materials	Appendix C includes links to the national Cash and Counseling site, and the demonstration evaluator. Resource materials developed by and for the sites are included. The Appendix also includes a link to CMS sponsored quality initiatives.

Appendix A

Materials Used in the Quality Project

Three state Tables of Quality Program Components

PERSONAL OUTCOMES

Date_____

Consumer ID/Name_____ Consultant_____

Now that you have been in this program for a few months, we want to find out how well it fits with what you really want.

What do you like about being in the program?

What would you change about the program?

1. When you make decisions and choices about your life, do you have the right amount of help—not too much, not too little?

   Yes, the right amount. (detail if offered)

   No. What amount of help with decisions would be just right?

2. Do you have enough help to do the things that are important to you?

   Yes. (detail, if offered)

   No. What would you like more help with? (Is that something we should work on?)

3. Do you have as much help as you need to go out if you want to?

   Yes (detail, if offered)

   No. What kind of help would you need to go out? (Is that something we should work on?)

4. If you want to, can you easily make a change in the day (or time of day) you do things?

   Yes. (detail, if offered)

   No. Is that much of a problem for you?

5. How many paid workers do you have now?
   What are their relationships to you?
   _____ Relative(s)
   _____ Friend(s)
   _____ Neighbor(s)
   _____ Consumer did not know before hiring

6. Did you have enough say in choosing your worker(s)?

   Yes. (detail, if offered)

   No. Why didn't you have enough say?

7. Do you know who will be helping you each day?

   Yes (detail, if offered)

   No. Is that a problem for you?

8. Do you have enough say in what your worker does each day?

   Yes. (detail, if offered)

   No. Why don't you have enough say? (Should we work on that?)

9. Is the work done the way you want it to be done?

Yes. (detail, if offered)

No What would you like to be done differently? (Should we work on that?)

10. Do you have any complaints about how you are being treated by your worker?

Yes. What don't you like about your treatment?

No complaints. (detail, if offered)

11. Who would you tell if your worker hurt you or did something that you didn't like?

Who _____What is their relationship to you? _____

12. Are you satisfied with the relationship you have with your worker(s)?

Yes (detail, if offered)

No. How would you like it to be different?

13. Is being able to pay your worker important to you?

Yes. (detail, if offered)

No. (detail, if offered)

14. Do you feel safe in your home?

Yes. (detail, if offered)

No. What feels unsafe? Can we do anything about that?

15. Is your home kept the way you want?

Yes. (detail, if offered)

No. What would you like done differently?

16. Are your belongings respected?

Yes. (detail, if offered)

No. Can you tell me about some of the problems? Is there anything we can do about that?

17. Do you know what to do if you want to change something about the help you are receiving?

Yes. (detail, if offered)

No. (Discuss what consumer can do.)

18. Do you receive the information you need from the program?

Yes (detail, if offered)

No. What information would you like?

19. Is the consultant providing more help than you need or not providing enough help?

More help than needed. Could you do more for yourself now? What would you like to change?

Not enough help. What do you need more help with?

20. Is there anything you would like to change about the help you are getting from the fiscal intermediary?

Yes. What would you like to change?

No (detail, if offered)

To be completed by consultant.

1. Reason for interview

2. Number of months receiving cash benefit _____

3. Consumer characteristics:
   a. age _____
   b. gender _____
   c. race/ethnicity _____
   d. living arrangement

4. Does the consumer have a representative? No. Yes._____

5. Who responded to these questions?

6. How long did it take to complete the Personal Outcomes form? _____

7. Consultant comments about the interview or Personal Outcomes form.

Personal Outcomes
in Consumer Direction

2002

Interviewer Training Manual

Part 1 - Special instructions for pre-test interviewers

We need your help to make this questionnaire as clear and user-friendly as possible. We've tried to write questions that are clear, to provide space for recording the important information the consumer tells us, and to ask questions about all of the topics that might be important for the consumer. But we're sure that the questionnaire can be improved. Your notes about these issues will be essential to help us make these improvements. After you have completed these pre-test interviews, we will have conference call with all of you about how the interview form works. Ultimately, we hope that the information learned in these interviews, using an interview protocol revised according to your experiences, will be useful to improve an individual consumer's services, and to improve the program overall.

General Guidelines:

- We are asking each of you to complete eight interviews. Since we would like to find out as soon as possible how the questionnaire works, we'd like you to try it with the first eight people you do six or twelve month reassessments with after today's meeting.

- As you complete these interviews, please follow the instructions that follow; feel free to write your comments and questions all over the questionnaires.

- When you have completed each interview, please fax the form to Suzanne Kunkel, Scripps Gerontology Center, 513-529-1476. In the interest of protecting your consumers' privacy, please black out their names. But, since we may want to refer to individual questionnaires when we have our conference call, please do leave a consumer ID number on each survey.

- We hope to have a conference call with all of you at the end of September or early October. We'll ask your help in determining whether this is a reasonable time for you to have finished your interviews.

Pre-testing Guidelines:

- Make notes directly on the questionnaire anytime the consumer had difficulty understanding a word or phrase. Try to write down the word or phrase you used to help the consumer understand what we meant.

- Be sure to take notes about the questions regarding counselor services. Were consumers reluctant to offer suggestions or negative comments? Do you have any suggestions about how to have counselors do these interviews AND elicit necessary information about consulting services?

- Notice whether the "Yes"/"No" responses and the follow-up questions work. Would it be easier for interviewers or for consumers to have more response options or more structured questions? While we want these questions to have a conversational tone, we do not want the recording of answers and issues to become burdensome for interviewers.

- Note how long the interview took (there is space on the form to record this information). This will help us know what future interviewers should tell consumers about the process.

- Make any suggestions you can think of regarding format of the questionnaire. Does the order of

questions make sense? Do we need transition statements or explanatory paragraphs to introduce the sections of the questionnaire?

- Did we cover all of the important topics? If not, what else should we include?

Thanks so much for your valuable contributions to this project!

Part 2 - Conducting Personal Outcomes Interviews - Instructions

The Personal Outcomes Questionnaire is one way to get consumer feedback on how well the program responds to the preferences and needs of consumers. The information is intended to guide counselors' in assisting the consumer and to provide input into the Program's quality improvement process.

The following instructions will ensure that all interviewers are using the questionnaire to conduct interviews in the same way. This will allow confidence in the results when the information is aggregated and analyzed.

1. Who should you interview?
   The first choice is to interview the consumer if possible.
   If interviewing the representative, the consumer should be present to hear and contribute.
   If the issue is language, the representative (or other) should translate the questions so the consumer can answer.
   If the consumer is unable to understand, then interviewing the representative alone is fine.
   If possible interview without the worker present, but since most workers are family members, their presence shouldn't present a serious issue.

2. Before starting, remind them that their participation and their honesty will not affect the level or quality of care they receive.

3. General points:
   a. Follow instructions carefully
   b. Read the questions just as they are written, and in the order in which they appear.
   c. Circle the answer given. Use the follow-up question to get more information about a problem so you can assist the person to address it.
   d. If the answer doesn't represent a problem, but the person offers more detail that a simple "yes" or "no," record the detail in the space provided.
   e. Always ask all of the questions.

4. Don't attempt to influence responses in any way. The truth is all that really counts - what the person <u>really</u> thinks or feels about the subject.

5. Don't record a "don't know' answer too quickly. People say, 'I don't know" when stalling for time to arrange their thoughts. The phrase merely may be an introduction to a meaningful comment, so give the participant a little time to think.

6. When straight "Yes" and "No" answers are accompanied by qualifications such as "Yes, if..." or "Yes, but not..." record the comments. These responses may reveal something important about the question that was not anticipated.

7. Record any comments or remarks just as they are given. The exact words people use to describe their feelings are important, so include the consumer's language, rather than summarize the comments in your own words.

8. If a consumer does not give an adequate response to a question, or if he seems to misunderstand the question then you should repeat the question with the prefacing remarks, “Let me read that question again.” If your consumer still does not give an adequate response, reword the part that is giving them trouble. It is very important that you be careful not to put an answer in their mouth, or to suggest a 'correct" answer.

9. Get all the information you are asked to get. That means, ask every question and record every answer - in the correct place. A questionnaire with serious omissions or errors isn’t very useful. Therefore, check over the questionnaire at the end of each interview. Say, “Now, let's see if we've got everything,” to allow you to look over each statement to see that it is answered and the answer recorded correctly.

QUALITY IMPROVEMENT COMMITTEE

Role and Purpose

An effective quality improvement committee fulfills for the program significant functions that are not easily handled in any other way. With responsibility and authority for centralized oversight of quality management, the committee will have the advantage of the broadest and the most singularly focused view of quality within the organization. Because programs are so complex, multi-faceted, and often understaffed, it is reasonable for each unit or component to focus on its own work, without time or opportunity to see how their work intersects with, and affects, the work of other units. While quality is a concern of every unit and every staff person, time taken away from the provision or administration of services in order to systematically reflect on improvement is often a luxury. The quality committee provides a way for all quality management activities to be designed, conducted, and used as part of an integrated system of feedback and improvement.

The quality improvement committee will have ongoing responsibility for providing feedback and suggesting improvements to the program. With support from staff, the group will have responsibility for reviewing, and in some cases generating, information about program performance. The committee will be involved in helping the organization use data to improve services, the system, and the quality of life of consumers. The committee can help the program stay focused on the consumer-centered principles of quality.

Size and Composition

The quality committee is a working group and so should have enough members to share the work but should not be so large that it is cumbersome. We recommend an optimum size of ten members. Core members would include:

state program staff,
consumers,
counselors/consultants,
representatives/caregivers, and
fiscal intermediary staff.

Composition is expected to vary across sites, with programs adding members based on their unique structures. Other possible members could include nurse reviewers, enrollment staff, and independent representatives, such as community advocates. Staff members who are asked to allocate substantial time to committee work will need assistance with current job responsibilities.

Work of the Committee

An effective quality improvement committee requires a significant investment of time and other resources such as technical support for data processing and analysis. Scope of responsibility and authority, specific tasks to be completed, and time frame need to be established at the outset. Staff support will be needed to help with meeting arrangements, background work, and possibly data collection and processing.

An important early task for the committee will be to review information collected as part of the agency

self-assessment on consumer direction. Based on this and other work, the quality improvement committee can identify which improvement efforts are the highest priority for the program. In some cases committee members might work on planned improvements; in other cases, the committee would provide feedback on planned activities. In all cases, an important function of the committee would be to ensure that mechanisms exist for continuous feedback.

Training

An initial orientation for committee members is essential to discuss and agree upon expectations, roles and responsibilities. Program commitment to improvement needs to be emphasized. Ongoing needs for training and resources will be identified as the committee begins their work.

STEPS FOR THE DEVELOPMENT OF QUALITY IMPROVEMENT COMMITTEE

Step 1. Agree on role and responsibility of committee.

A. The detailed implementation steps that follow contain our proposal for how the committee would operate. But it is essential that we have a shared vision with the state program staff concerning the role and responsibilities of the quality improvement committee. This could be a task to complete by conference call as part of the site visit set up.

B. Write up description of scope of effort. This activity would be completed through a joint working session of the state program staff and the Scripps team prior to the site visit.

Step 2. Identify quality committee composition and invite members.

Choose members to ensure that the committee represents the points of view of the major stakeholders of the program. Potential members:

state program staff
consumers
representatives
consultant
fiscal intermediary
consumer advocacy group
others to be identified by program

Step 3. Identify staff and other resources for committee use.

After agreeing on committee scope and membership, it is important for program staff to examine the necessary resources required to support the committee. This will include identifying staff responsibilities and additional supports that may be required. Scripps researchers will work with program staff to develop resource estimates.

Steps 4-10 will be completed by the committee

Step 4. Develop a common vision of quality in the state program

A. Develop a common understanding of how program works.
Receive overview of program operations and structure.
Review program policies and consumer and consultant brochures and training materials.
Receive input from committee members involved in program operations.
Receive information about state and federal laws and regulations that effect quality.

B. Develop a common understanding about quality in the state program.
Provide background materials about quality in long-term care and consumer directed care.

C. Review and discuss the Blueprint for Quality in Consumer Directed Care.

D. Discuss some of the challenges faced in examining quality in consumer directed care (different stakeholder views and emphasis).

Step 5. Complete Self-Assessment of Consumer-Directedness of Program.

A. Review the Consumer-Direction Tool with committee members.

B. Decide on approach for how committee will complete the self-assessment:
appoint sub-committee to complete assessment, or
assessment completed by state program staff, or
complete by full committee.

C. Agree on completion strategy and identify specific steps for self-assessment to be completed.

Step 6. Review of Consumer-Direction Tool (Self-Assessment Document)

A. Committee reviews finding from self-assessment. Examine self-assessment in the context of committee's vision of quality.

B. Review detailed questions in areas where improvement activities may be warranted.

Step 7. Develop an initial list of areas for improvements based on self-assessment.

A. List areas of improvement:
   Include details of areas of concerns and examples of problems.
   Identify areas that may require additional information.
   Assess committee agreement on nature and extent of problem.

Step 8. Identify Other Sources of Data for Assessing Program Quality.

A. Systematically examine sources of quality data received by program.

B. Examine data from quality areas where available.

C. Conduct additional analysis where necessary. (Personalized outcome consumer satisfaction measures)

D. Identify potential list of quality problems based on review of existing data. Combine with list of problem areas identified in the self-assessment.

Step 9. Refine and Prioritize Areas of Improvement.

A. Committee prioritizes areas for improvement. Examine the importance of the improvement area, likelihood of success in being able to improve, and cost of improvement activity.

B. Based on these criteria, committee selects specific improvement projects and develops a timeline for efforts.

C. Committee will develop plan for how improvement efforts will be implemented. Could be done with a sub-committee from overall group, could include other individuals, or a combination.

Step 10. Develop ongoing quality improvement plan.

A. Assess the quality activities currently underway.

B. Make judgments about the importance of activities, including data collection efforts and improvement actions.
   What are the barriers to improving the quality of the program?
   Are there changes that need to be made to the approach?

VI1.2. Does the program periodically (e.g. every quarter, semi-annually) solicit input from consumers (in writing, by telephone or visit) regarding the quality of the services they receive?

VI-1.3. Are consumers asked specific questions about program quality, such as:
   a. are you satisfied with the services you receive?
   b. are you receiving the services you want and need?

c. are services provided in a manner that responds to your preferences regarding how things should be done?
d. have you had any problems and/or made any complaints about your services and/or provider?
e. were problems (including any emergencies that have occurred)handled satisfactorily?
f. do you have suggestions for improving the quality of the services you receive?
g. do you have ideas for improving the quality of home and community based services?

PROGRAM SELF-ASSESSMENT

One way that consumer-directed programs can put the blueprint into action is to monitor and improve the extent to which consumer-centered principles are at the heart of their operations. The National Association of State Units on Aging (NASUA) and the Home and Community-Based Services Resource Network have developed a self-assessment tool for consumer-directed programs. We have modified their state level assessment to be used at the program or agency level. The process begins with an objective assessment of the program in relation to an "ideal" consumer-directed program. The findings of the assessment can be used to develop and prioritize goals for improving the consumer focus of the program. In addition to the NASUA tool, which follows, we will provide some supplemental diagnostic questions to help programs pinpoint problem areas and develop quality improvement strategies to address those problems.

DRAFT Consumer Directed Program Self-Assessment Tool[1]

Rating Scale: **1 = We haven't begun to work on this yet.**
2 = We're making progress but have lots more to do.
3 = We're almost there.
4 = We are recommending our program to others.

***A.* Opportunity** **Do individuals have opportunities to participate in the community in ways that are meaningful to them?**	
1. The program is publicized so that individuals know what is available and how to apply.	
2. Services may be provided in locations chosen by the consumer. (workplace, home of other)	
3. The application process is easy to complete.	
4. Eligibility rules are based on everyday needs and support consumers who need help to live in the community.	
5. Approved hours or budgets for services are sufficient to meet the person's needs and choices in the community.	
6. Consumers can pay adequate wages to their direct care workers so they have the opportunity to recruit a qualified workforce.	
7. Individuals can choose a consumer directed option.	
8. Individuals can choose to use a representative of their choice to help with decisions and managing services	
9. Individuals can select, manage and dismiss workers.	
10. Information on consumer directed options is available, it is clear, it is complete, and it is available in alternative formats.	
11. Service standards reflect consumer direction principles. (For example, doctors and nurses don't approve personal assistance.)	

Comments on opportunity:	
B. **Meaningful Participation** **Do individuals with disabilities participate in decisions affecting their lives? Are they consulted about changes in policies?**	
1. The program involve(s) consumers in decisions about coordination services.	
2. Consumers, family members and advocates help design, develop, operate, and evaluate the program. They are on advisory groups and give feedback through consumer surveys and other means. Consumers are an integral part of the program's quality improvement system.	
3. Consumers can resolve problems promptly.	
4. Consumers can make formal complaints and receive assistance from an advocate to file appeals, negotiate disputes, and voice concerns.	
5. Consumers determine their own goals and objectives.	
6. Consumers choose the amount and types of services.	
7. Consumers decide whether to work with a service coordinator and how much assistance they need.	
8. Consumers select their service coordinator and decide whether to use a family member to arrange and coordinate supports.	
9. The program has principles and objectives that clearly reflect consumer direction and choice.	
10. Consumers have input into the outcomes measured by the program. At least some of these are personalized outcomes.	
11. Consumers direct the decisions that affect their lives.	
12. The program builds support for consumer direction with other state agencies, legislators, providers, families, advocates, and potential consumers.	
Comments on meaningful participation:	
C. **Independence** **Are individuals able to make decisions affecting their lives in the community?**	

1. Outreach for the program includes unbiased, one-on-one assistance to help consumers choose options that suit their preferences and needs.	
2. The program educates consumers about how to make sure services meet their expectations.	
3. Consumers may choose from a full range of services to meet their needs. Options include personal assistance, homemaker services, chore help, home-delivered meals, transportation, home health, rehabilitation services, adult day health, day treatment, and support at school or work.	
4. Program requirements accommodate consumers' preferences and needs. Schedules are flexible so that consumers can have their needs met outside regular business hours.	
5. Consumers may choose services, workers, schedules, and tasks to be done, even when they don't choose full direction.	
6. Consumers can choose to manage their program funds themselves.	
7. Consumers may use program funds to hire family members to provide services and supports.	
8. Consumers may use program funds to purchase appliances, assistive devices, or home modifications to meet their needs.	
9. All staff working with consumers receive training on consumer direction. Service coordinators, eligibility workers, providers, evaluators, and other workers receive this training.	
10. Consumers who choose consumer directed services can receive help with handling their responsibilities if they want it. (For example, they can receive a list of available attendants and back-up assistance when workers don't come to work.)	
11. Consumers can receive help with fiscal tasks (payroll, withholding taxes) involved in managing their own funds.	
12. All consumers receive training to manage their budgets, services, and workers. Consumers have access to training opportunities for their workers and representatives. Consumers have opportunities for peer support.	
D. Financial Security and Other Safeguards **Do programs assure that participants have enough money to support themselves? Are participants able to feel secure in the community?**	
1. Individuals who apply to the program learn about other services that they are eligible	

for, including assistance with housing, food, transportation, and fuel costs.	
2. The program coordinate (s) with educational opportunities that consumers choose to participate in.	
3. Consumers who must pay for part of their care are able to keep enough income for an adequate lifestyle in the community.	
4. Monitoring systems make sure that available supports are responsive to the needs and preferences of consumers.	
5. Consumers help design and implement monitoring systems.	
Comments on Financial Security:	
Overall Comments on Priorities:	

[1] Adopted from the NASUA/HCBS State Consumer Directed Self-Assessment Tool.

Appendix

This appendix provides additional detail that may be used to follow-up the referenced questions in the Consumer-Direction Tool (CDT). These more detailed questions are extracted from the original longer version of the Consumer-Direction Tool titled "Consumer Direction in HCBS: An Assessment Guide for States." The original numbering of their questions has been maintained so they may be cross-referenced to the longer form if desired.

Follow-up to A.1 of the CDT.

II-5.15. Is information and training regarding the program routinely given to programs/agencies that provide information/assistance or services to older persons, such as the following:

a. ombudsman and other advocacy programs?
b. information and referral/assistance providers?
c. health insurance counselors?
d. legal services providers?
e. senior centers, nutrition sites?
f. aging services providers?
g. health care providers, such as physicians, clinics, hospitals, HMOs?
h. long term care providers, such as home health agencies, nursing homes?
i. assisted living, other housing or residential providers?
j. community organizations that serve older persons and/or persons with disabilities?
k. churches, synagogues?
l. home and community based services providers?
m. agencies/staff that determine eligibility for Medicaid, other public benefits?

Follow-up to A.8 of the CDT.

II-1.2. Are all consumers who inquire about the program routinely given oral and written information:

a. about opportunities for consumers to direct their care/control decisions about services?
b. which fully describes available consumer-directed options, including resources and support for consumers who choose such services?
c. which specifies payment options, eligibility criteria, the application process and appeal rights?

II-1.4. Do written materials contain questions, checklists, comparison charts or similar tools which support individual decision-making about services?

II-1.5. Do written materials that describe consumer-directed services address typical concerns and questions of older persons and their caregivers regarding services?

II-3.8. Is information on the program available in different languages, formats and modes of communication including:

a. large-print written material?
b. publications in Braille?

c. audio tapes?
d. video tapes?
e. sign-language interpreters?
f. TTY access?
g. written materials and/or interpreters available in languages for non-English speaking consumers?

IV-5.14. Are consumers given written information which describes their rights and choices?

Follow-up to B.2 of the CDT.

I-2.5. Do consumers sit on advisory committees, task forces, and governing bodies that oversee or advise the program.

VI-4.14. Is consumer input actively sought in efforts to evaluate quality by:

a. inviting consumers to serve on committees/task forces that develop or revise service standards?
b. soliciting consumer input when the program proposes to make changes in service standards?
c. inviting consumers to help develop or modify the process currently used to oversee service quality?

I-2.7. Is input from consumers obtained via consumer satisfaction surveys, complaints and other formal and informal means, used to identify needed changes in the program.

Follow-up to B.4 of the CDT.

VI-3.11. Does the program have in place an internal process for responding to consumers' complaints?

VI-3.12. Are consumers given written information describing steps to take to get complaints resolved, including whom to contact to report a complaint and how to file an appeal?

VI-3.13. Do consumers have access to an objective third party, such as an ombudsman, to respond to complaints and concerns about their services and/or workers?

Follow-up to C.9 of the CDT.

V-3.14. Are consumers offered assistance with locating qualified non-agency providers?

VI-2.8. Does the program (via a registry of independent providers or other mechanism) provide consumers who direct their own services with information to aid their hiring decisions, including:

a. the results of criminal background and abuse registry checks?
b. employment history (e.g. previous employer, length of employment, reason for leaving, etc.)
c. a list of questions consumers should ask before hiring a worker?

d. other relevant information?

V-3.15. For consumers who hire their own workers, is back-up assistance made available when the consumer's worker does not report to work?

V-3.16. Are consumers who use consumer-directed options offered assistance with required paperwork/record keeping?

Follow-up to C.10 of the CDT.

VI-2.9. Are consumers who choose consumer-direction offered written information and training that includes specific guidance on:

a. the quality standards for the services they receive?
b. how to address problems with their worker or dissatisfaction with their services?
c. how to supervise their worker, including communicating their preferences regarding how tasks should be done?
d. what to do when the worker doesn't show up?
e. how to hire, fire and supervise workers?
f. how to complete required paperwork?

Follow-up to D.2 of the CDT.

III-3.16. Has a process been established for handing emergency needs, such as:

a. expediting eligibility determinations?
b. providing shirt-term services while eligibility is being established?

Follow-up to D.7 of the CDT.

IV-7.22. Are service plan reviews done to determine whether the plan is customized to fit the consumer's preferences and choices?

VI-1.1 Does the program include the following measures of service quality:

a. services respond to the individual consumer's preferences and needs?
b. consumers are satisfied with:
    1. the amount and type of services they receive?
    2. the way in which tasks are performed?
    3. their worker?
    4. the response they receive when problems occur?

VI-1.2. Does the program periodically (e.g. every quarter, semi-annually) solicit input from consumers (in

writing, by telephone or visit) regarding the quality of the services they receive?

VI-1.3. Are consumers asked specific questions about program quality, such as:

a. are you satisfied with the services you receive?
b. are you receiving the services you want and need?
c. are services provided in a manner that responds to your preferences regarding how things should be done?
d. have you had any problems and/or made any complaints about your services and/or provider?
e. were problems (including any emergencies that any have occurred) handled satisfactorily?
f. do you have suggestions for improving the quality of the services you receive?
g. do you have ideas for improving the quality of home and community based services?

Current Status of Quality Management Components March 2002

Component	Arkansas
1. Performance standards in contracts	Yes
a. Consultants	Contact new consumer within 2 days, home visit within 10 days. Develop cash plan within 45 days. Monitoring contact every month during the first 6 months, as needed thereafter.. Contacted at least quarterly to monitor the back-up plan Document misuse of cash allowance, report to state department within 2 days, develop CAP Communicate with state department Self-direction dates Reassessment/changes in allowance Quarterly reports (from agency) Problems, significant occurrences
b. Fiscal intermediary	– many, see RFP (Appendix B)
Sanctions	Yes Agency submits acceptable Corrective Action Plan to state office. Payments may be delayed or reduced or withheld. Contract may be terminated
2. Agency audits	Yes. Combined audit of counseling and fiscal intermediary functions.
a. Counseling function	Yes
Method, frequency	Quarterly visit by state staff to identify compliance with performance standards. Includes review sample of records. Talk with consumer/ rep/ caregiver to check accuracy.
Feedback process	Report and feedback meeting in which they discuss report and what corrective actions will be taken. State has regular meetings with agencies.
b. Fiscal intermediary	Yes
Method frequency	Quarterly visit by state staff to identify compliance with performance standards.
Feedback process	Report and feedback meeting in which they discuss report and what corrective actions will be taken
3. Case/ Chart reviews	Yes
Method/frequency	As part of agency audits. Also as needed in response to a problem.
Feedback process	
4. Periodic reports from agencies	Yes
a. type/freq	Summary Activity Report, quarterly Includes the number of assessments performed each month, the number of monitoring contacts performed (identified by phone, person or other), the number of initial contacts performed, the

	number of new enrollees, the number of active participants, the number of participants disenrolled and a summary of the uses of the cash by dollar amount, by number of participants using the identified accounting codes, and instances of misuse of funds, abuse or neglect.
Review process	Quarterly by state staff
5. Data system	Yes, state program office did all data entry, updating MIS. All reports reviewed weekly in state office. Sent info to Medicaid and C/fi as necessary.
a. report	People over 45 days without cash – not done currently because they have changed reimbursement method. Now pay a flat rate for developing CMP, then a monthly rate once on cash.
Review process	
b. report	Disenrollments, nursing home admissions, deaths, hospitalizations
Review process	Weekly. Letter to consumer to request refund if in hosp over 6 days. Close out people no longer Medicaid eligible.
c. report	Reassessments and dates.
Review process	Weekly. Can send reminders to agency if necessary.
d. report	Monitor cost
Review process	Quarterly
e. report	Do queries and studies to answer specific questions.
Review process	Ongoing
6. Outcome measures-impact of system	Yes
List/sources	HCFA 64 from Medicaid. Lists expenditures for services. Evaluator will do claims from both Medicaid and Medicare and other outcomes
7. Consumer satisfaction survey	Yes.
Freq	Quarterly, mail survey sent to random sample of 25%. (later quarters won't duplicate, so everyone should get once a year.) Pat developed for this project. First one sent out but not all back yet.
Review process	Nurse review. Follows-up on problems
8. Counselor /FI survey	No
Freq	
Review process	
9. Quality improvement committee	None for state office.
Composition	
Freq/task	
10. Toll free number	Yes

for concerns, problems	
Type	For interested persons and problems not resolved at agency level. Documented with note, including resolution, in consumer's file in state office. Also agencies are supposed to keep a complaint log. There is no place that all complaints are collected and can be reviewed together.
Review and feedback	If necessary a member of state staff will visit consumer.
11. Review of CMPs	Not at state level
Type	Reviews unusual requests or problems
12. Report to consumer from FI	Yes. Developed by each fiscal intermediary.
Type/freq	Monthly.
Review	Counselors receive copy, as well as consumer.
13. Grievance committee	Have formal state appeal process. Process used multiple times and worked each time.
Type/freq	
Tasks	
14. Ongoing training or TA to counselors	Yes
Type/ freq	Periodically (annually)
15. Consumer Handbook	No – training manual to be pilot tested spring 04
Type	
16. Nursing reassessment	Nursing visit is available as needed to investigate report of problems. Not considered a reassessment. AR doesn't require a nurse to do assessments and reassessments.
Type/ Freq	If requested by state to investigate reported problems
Review	Counselor and state office
17. Other	And as a result, a review will be done twice a year on a 20% sample.
Accountants review of handling of consumer money.	Done recently, but won't be frequent. Same is done for people in nursing homes. Reviewers don't know anything about fiscal intermediary, just looking at accounting for consumers' money.
Peer review	Have this in other state programs but not here (yet.) Review of case records.
Back-up plans	Currently a priority to improve and document back-up plans. Because of CMS interest.

CURRENT STATUS OF QUALITY MANAGEMENT COMPONENTS

March 2002

Component	New Jersey
1. Performance standards in contracts	Yes
List	Fiscal intermediary B many Consultants B contact new consumer within 48 hours. Develop cash plan within 90 days. Do monitoring visit every 3 months and submit report (state form.) Keep track of hours spent per consumer. (Agencies send invoices to state office.)
Sanctions	None
2. Agency audits	Fiscal intermediary None for counseling agencies. Would like to do this yearly.
Method frequency	Yearly. Site visit by outside consultant.
Feedback process	Report and feedback meeting in which they discuss report and what corrective actions will be taken. Before next audit, there is a review of this material.
3. Case/ Chart reviews	None
Method/frequency	
Feedback process	
4. Periodic reports from agencies	Yes
a. type/freq	Quarterly visit report- submitted by consultant after consumer is visited.
Review process	Read in state office, but not aggregated or analyzed. Plan to have Quality Committee look at this.
b. type/freq	
Review process	

5. Data system	Yes. Have developed reports from the data system. The only one that comes from somewhere else is the HCFA 64. (described under outcome measures.)
a. report	Done once per month, people enrolled but with no cash start date.
Review process	Given to state staff who reviews and calls consultants when approaching 90 days.
b. report	Need for nursing reassessment.. Query identifies anyone approaching 6 months since last assessment.
Review process	?
c. report	List of all enrollees.
Review process	
d. report	Marketing and enrollment report for fiscal intermediary. As needed, queries data system for particular county to identify all eligible people who have never received a home visit to explain the program.
Review process	
e. report	New case batch file. Weekly generate list of all new referrals to program. (From data forms sent in by home health agencies at assessment or reassessment.) this list is used to develop a mailing list and send brochures to everyone.
Review process	
f. report	Unisys transmittal report. Done monthly. Lists all participants that are supposed to be on cash for the next month. Fiscal intermediary uses it to apply to Medicaid to get the money for each consumer. Medicaid uses it to put an edit in the system that stops payment to other personal care providers.
Review process	
6. Outcome measures- impact of system	Limited
List/source	HCFA 64 from Medicaid. Lists expenditures for services.
7. Consumer survey	
Frequency	Will be quarterly. Will select 100 consumers from the data base each time. Do using phone calls and ATT language line as needed. The nurse, and other members of staff will do them.

8. Consultant/FI survey	No
Frequency	
Review process	
9. Quality improvement committee	Yes. There is a QI Committee.
Composition	14 members: chaired by nurse consultant state staff attendees Consumers Consultants Fiscal intermediary Representatives of the Home Health Alliance Carolyn says they have more consumers wanting to be on the committee than they can accommodate. This resulted from the focus groups (Scripps) and people's exchanging email addresses.
Frequency/task	Have done some work by phone. Have drafted consumer survey
10. Complaint log	Yes. One at fiscal intermediary and one by state staff
Type	Both kept long-hand in a book. At last audit, recommended that fiscal intermediary log be automated and add documentation of outcomes.
Review and feedback	Fiscal intermediary log reviewed during audit.
11. Review of CMPs	Yes
Type	State office currently reviews and approves each one. Also each change.
12. Report to consumer	Yes. Called monthly Variance Report
Type/frequency	Reports expenditures and remaining balance. Sent to consumer and state office quarterly.
Review	State does not review unless a question arises. Both consumers and state staff call fiscal intermediary if they want to know the actual balance.

13. Grievance committee	In the works
Type/frequency	Fiscal intermediary is supposed to be starting a grievance committee composed mainly of consumers. State has referred consumers to be on it.
Tasks	?
14. TA calls to consultants	Yes. Done by state staff member
Type/ frequency	Monthly
15. Consumer Handbook	Yes. In printing now.
Type	Describes who to contact for what. Gives numbers. (Does not do things like train consumer how to complete forms, hire or evaluate someone.)
16. Nursing reassessment	Yes
Type/ Frequency	By Medicaid nurse, Every 6 months or as requested. Is seen as independent review of consumer's condition. Arrives at hours of personal care needed, which is used to determine person's budget.
Review	Consultant uses to adjust cash plan as necessary. Seen as way to make sure consumer is getting enough personal care but not more than the person needs.

Current Status of Quality Management Components

March 2002

Component	Florida – Developmental Disabilities Services (DDS)
1. Performance standards in contracts	Yes. With private support coordinator/consultants dept has MoAs. (Memorandum or Agreement)
a. Consultants	Training within 15 days or notify district why not. Monthly contact to monitor condition, review expenditures, ask satisfaction with plan Home visit at 2 months, and annually Expenditure plan by 90 days
b. Fiscal intermediary	Yes - check with Department of Elder Affairs (DOEA)
Sanctions	
2. Agency audits	No
a. Consulting function	
Method, frequency	
Feedback process	
b. Fiscal intermediary	Yes – done by DOEA
Method frequency	Semi-annual visit,
Feedback process	
3. Case/ Chart reviews	Yes
Method/frequency	DDS does a sample of consumer records. Sample selected by DOEA. Records are sent in for review. There are 15 districts – will do one after another. Also done by district offices, random sample of records for monitoring as part of their regular monitoring of all programs
Feedback process	Written report District has regular meeting with sc/consultants
4. Periodic reports from consultant agencies/support coordinators	Not to DDS. State has no role in managing sc/counselors. Districts do this independently. Maybe to district office.
a. type/freq	Submit an invoice monthly, documenting that performed required tasks
Review process	District reviews. Consultants are actually hired by consumer
5. Data system	YES – done by DOEA

a. report	When people are enrolled, amount of budget, state date, disenrolled, one-time expense, name and location of consultant
Review process	monthly
6. Outcome measures-impact of system	
List/sources	Each consumer has outcome measures based on their care plan. These are developed on the district level and reviewed annually with sc/consultants .
7. Consumer satisfaction survey	Yes - Department of Children and Families has done for all their programs. None specifically for CDC. DOEA did one to identify problems with the fiscal intermediary. People we pretty satisfied actually.
Freq	
Review process	
8. Consultant survey	No
Freq	
Review process	
9. Quality improvement committee	DSS does have a whole unit that does this, meets with stakeholders
Composition	
Freq/task	
10. Toll free number for concerns, problems	Yes
Type documentation	8oo # to State office, but complaints go to district office first to resolve.
Review and feedback	State will deal with district if following-up.
11. Review of Expenditure plans	Yes, all
Type	By District Office for accuracy, allowable expenditures, and to approve amount. Then sent directly to fiscal intermediary.
12. Report to consumer from FI	Yes, they are getting them. The project is still working on making them more understandable – will do an example for people in the next 2 months..
Type/freq	Expenditures from budget, Monthly
Review	Copy to consultant, who makes phone call to consumer to review
13. Grievance committee	Each consumer gets a form for complaints. That comes to the state. It is reviewed here, but we may ask the district or

	bookkeeper to deal with. Also the consumer can appeal a corrective action.
Type/freq	Complaints may be about consultant or bookkeeper. We investigate and respond to both.
Tasks	
14. Ongoing training or TA to consultants	Yes. DDS had weekly TA calls to District Offices, with DO picking a topic each time. This has been cut back to quarterly or as needed. State also does video-teleconferencing for turnover training. Consultants needing a refresher can come to that. Currently designing a refresher for the districts to provide.
Type/ freq	DDS has limited contact with consultants. Did a FAQ to give them. District Office has monthly meeting with sc/consultants.
15. Consumer Handbook	Yes. Also a separate packet for consultants.
Type	Inclusive, completed examples of forms
16. District Office	Signs up consultants, oversees their qualifications, requires initial training as support coordinator, holds monthly meetings, provides TA on a daily basis, reviews their paper work, including cash plans.
17. Interdepartmental workgroup	Designed and monitors program, including quality efforts
18. Other quality management components	
Criminal and reference background checks for workers	Strongly recommended. (required for service providers)
Consultant does reassessments	

Current Status of Quality Management Components March 2002

Component	Florida - Aging
1. Performance standards in contracts	Yes
a. Consultants	Initial training within 15 business days. Back-up plan required. Monthly contact to monitor condition, review expenditures, ask satisfaction with plan Home visit at 2 months and annually Expenditure plan by 90 days
b. Fiscal intermediary	Yes
Sanctions	
2. Agency audits	Yes
a. Counseling function	Planned
Method, frequency	as needed based on desk review of sample of records
Feedback process	
b. Fiscal intermediary	Yes
Method frequency	Semi-annual visit,
Feedback process	Discussion, report
3. Case/ Chart reviews	Planned
Method/frequency	Desk review of sample of records
Feedback process	
4. Periodic reports from consultant agencies	
a. type/freq	
Review process	
b. type/freq	
Review process	

5. Data system	Yes
a. report	
Review process	
b. report	
Review process	
c. report	
Review process	
d. report	
Review process	
e. report	
Review process	
f. report	
Review process	
6. Outcome measures-impact of system	
List/sources	
7. Consumer satisfaction survey	Yes
Freq	
Review process	
8. Counselor /FI survey	
Freq	
Review process	
9. Quality improvement committee	
Composition	
Freq/task	
10. Toll free number for concerns, problems	Yes
Type documentation	
Review and feedback	

11. Review of Expenditure plans	Yes, all
Type	Approval by consultant Review by DOEA, for accuracy, allowable expenditures
12. Report to consumer from FI	Yes
Type/freq	Expenditures from budget, Monthly.
Review	Copy to consultant, who makes phone call with consumer to review
13. Appeal process	Yes
	Consultant agency to AAA to Project Manager and Interdepartmental Workgroup member.
14. Ongoing training or TA to consultants	Yes
Type/ freq	TA conf calls, as needed.
15. Consumer Handbook	Yes
Type	Inclusive, completed examples of forms
16. Medicaid waiver specialist at AAA	Monitoring role
Type/ Freq	Monitors Medicaid waiver programs in Lead Agencies, incidental to CDC so far
17. Interdepartmental workgroup	Designed and monitors program, including quality efforts
18. Other quality management components	
Criminal and reference background checks for workers	Strongly recommended. (required for services providers)
Consumer complaint Form	Consumer may send to state office with complaints about consultant
Assess risk of abuse, neglect, exploitation	By consultant during 2nd month home visit.

List of Consumer Directed Programs Interviewed for Study Background

Name of Program	Location	WHERE IS THE PROGRAM HOUSED?	Number of Consumers	TARGET POPULATION
The Access Center	San Diego, CA	Independent Living Center	2,500	All ages & disabilities
Alpha One	South Portland, ME	Independent Living Center	6,000	Adult disabled
California Supported Living Services (SLS) Program	California (statewide)	Department of Developmental Services	21,000	Developmental disabilities
Caregiver Resource Center Respite Program	California (statewide)	Family Caregiver Alliance	12,348	Caregivers Aging
Colorado Home Care Allowance (HCA) Program	Colorado (statewide)	Department of Human Services, Aging and Adult Services	5,786	Developmental disabilities
Illinois Home Services Program	Illinois (statewide)	Department of Rehabilitation Services	20,000	Physical disabilities, Il
Kansas Income Eligible Program (IEP)	Kansas (statewide)	Department of Social and Rehabilitation Services	12,132	Developmental disabilities
Michigan Home Help Services Program	Michigan (statewide)	Family Independence Agency	37,000	Aging, adults with physical disabilities
North Dakota's Service Payments for the Elderly and Disabled (SPED)	North Dakota (statewide)	Department of Human Services, Aging Services Division	2,000	Aging/adult disabled
Ohio Personal Care Assistance Program and Self-Determination Project	Ohio (statewide)	Department of Rehabilitation	1,000	Developmental disabilities
Oregon Client-Employed Provider Program (CEP)	Oregon (statewide)	Senior and Disabled Services Division	13, 440	Aging/adult disabled
Oregon Self-Determination Project	Oregon (statewide)	Department of Human Services, Office of Developmental Disabilities	381	Developmental disabilities
Shawnee County Community Developmental Disability Organization (CDDO)	Topeka, KS	Community Developmental Disability Organization (CDDO)	600	Developmental disabilities
Washington Community Options Entry System (COPES)	Washington (statewide)	Department of Social and Health Services	21,721	Aging & adults with disabilities
Wisconsin Community Options Program (COP)	Wisconsin (statewide)	Department of Health and Family Services	24,000	Aging, Developmental disabilities

Appendix B

Examples of Program Forms

IndependentChoices
Participant Self-Assessment

I. YOU DECIDE WHAT SERVICES AND PURCHASES WILL HELP YOU MEET YOUR PERSONAL CARE NEEDS.

1. What services do you want and need?

2. What purchases will help you?

II. YOU SELECT THE PEOPLE YOU WANT TO HELP YOU OR WHAT THING YOU NEED TO BUY TO HELP YOU LIVE IN THE COMMUNITY.

1. How will you find and select people to help you in your home?

2. How do you shop for the purchases you need to make?

3. How do you plan to train and supervise the people who work in your home?

4. How will you tell your workers what you like or don't like about their work?

5. If you are not happy with the work of the worker you hire, how will you handle the situation?

III. A COUNSELOR CAN HELP YOU LEARN HOW TO FIND YOUR WORKERS, HOW MUCH TO PAY YOUR WORKERS, HOW TO TRAIN YOUR WORKERS AND MANY OTHER THINGS.

1. Are you willing to ask for help if you need it?

_____ Yes

_____ No

IV. FAMILY OR FRIENDS CAN HELP YOU MAKE DECISIONS IF YOU WANT.

1. Do you have someone you want to appoint as your representative decision maker?

_____ Yes

_____ No

IndependentChoices
Representative Screening Questionnaire

Name of Participant:_____

Medicaid #:_____Phone #: (_____)_____

Name of Proposed Representative:_____

Address:_____

Phone #: (_____)_____Relationship:_____

If you are not a family member, please describe your relationship, how long you have known the participant and how often you have contact with the participant:_____
_____
_____
_____

Do you receive money from the participant or anyone else to care for the participant? Yes:_____No:_____

If yes, please identify the source and purpose of the funds?
_____
_____
_____

After reading the description that outlines the responsibilities of the representative, do you understand your functions and are you willing to volunteer to serve as the participant's representative?
Yes:_____ No:_____

Are you willing to sign a designation form stating that you will serve in this capacity? Yes:_____ No:_____

Do you understand that you cannot pay yourself for this role and cannot become a paid caregiver? Yes:_____No:_____

DAAS-IC-02
10/98

A.5

NEW JERSEY DEPARTMENT OF HUMAN SERVICES
State Office on Disability Services
Personal Preference Program

PARTICIPANT STATEMENT OF RIGHTS AND RESPONSIBILITIES

RIGHTS

I have the right to create a Cash Management Plan to meet my needs within the Personal Preference Program guidelines for use of the cash grant.

I have the right to change my Cash Management Plan to meet my needs within the program guidelines for use of the cash grant.

I have the right to be treated with dignity and respect.

I have the right to privacy and confidentiality.

I have the right to live as I choose, in my own home, free from judgment or interference.

I have the right to decide about how to spend my cash grant or to have someone I choose help me with decisions about the Personal Preference Program.

I have the right to bring whomever I wish to all meetings pertaining to the Personal Preference Program.

I have the right to file a complaint with the Personal Preference Program State staff at 1-888-286-3035 (**Toll Free**) for any reason, including being advised to disenroll.

RESPONSIBILITIES

I must notify my consultant within five days of admission to a hospital, nursing facility, rehabilitation facility, or any other institution. I understand that I am not entitled to my cash grant during the time I spend in a facility.

I must keep scheduled appointments.

I am responsible for hiring, supervising and firing my employees and all the responsibilities that go with hiring employees.

I must treat my employees, the consultant, and others who work with the Personal Preference Program the same way I expect to be treated.

I am responsible for what is included in my Cash Management Plan and for managing my cash grant accordingly.

I am responsible for all required paperwork and adhering to all tax and labor laws.

I am responsible for answering interview questions from Mathematica Policy Research.

I have read and /or understand these rights and responsibilities.

_____ _____
Participant/Representative signature Date

_____ _____
Consultant signature Date

PPR&R(12/98;6/99;7/99)

New Jersey Department of Human Services
Division of Disability Services
Personal Preference Program
(New Jersey Cash & Counseling Demonstration)

Representative Description

A representative may be a participant's legal guardian, a family member, or any other individual identified who willingly accepts responsibility for performing cash management tasks that the participant is unable to perform. A representative must evidence a personal commitment to the participant and must be willing to follow their wishes and respect their preferences while using sound judgment to act on their behalf. Representatives receive no monetary compensation for this service, and may not serve as an employee of the participant.

Specifically, the representative must be willing to:

- Work with the Cash & Counseling consultant to provide information to develop the cash management plan on the participant's behalf.
- Use the cash grant for the items outlined in the Cash Management Plan as the participant wishes.
- Maintain records, as required by the State, regarding expenditures and activity with the fiscal intermediary.

Representatives may be necessary for participants under certain conditions as defined below:

Voluntary Representative

The participant requests that a representative serve on their behalf, or a consultant recommends that the participant choose a representative and the participant agrees.

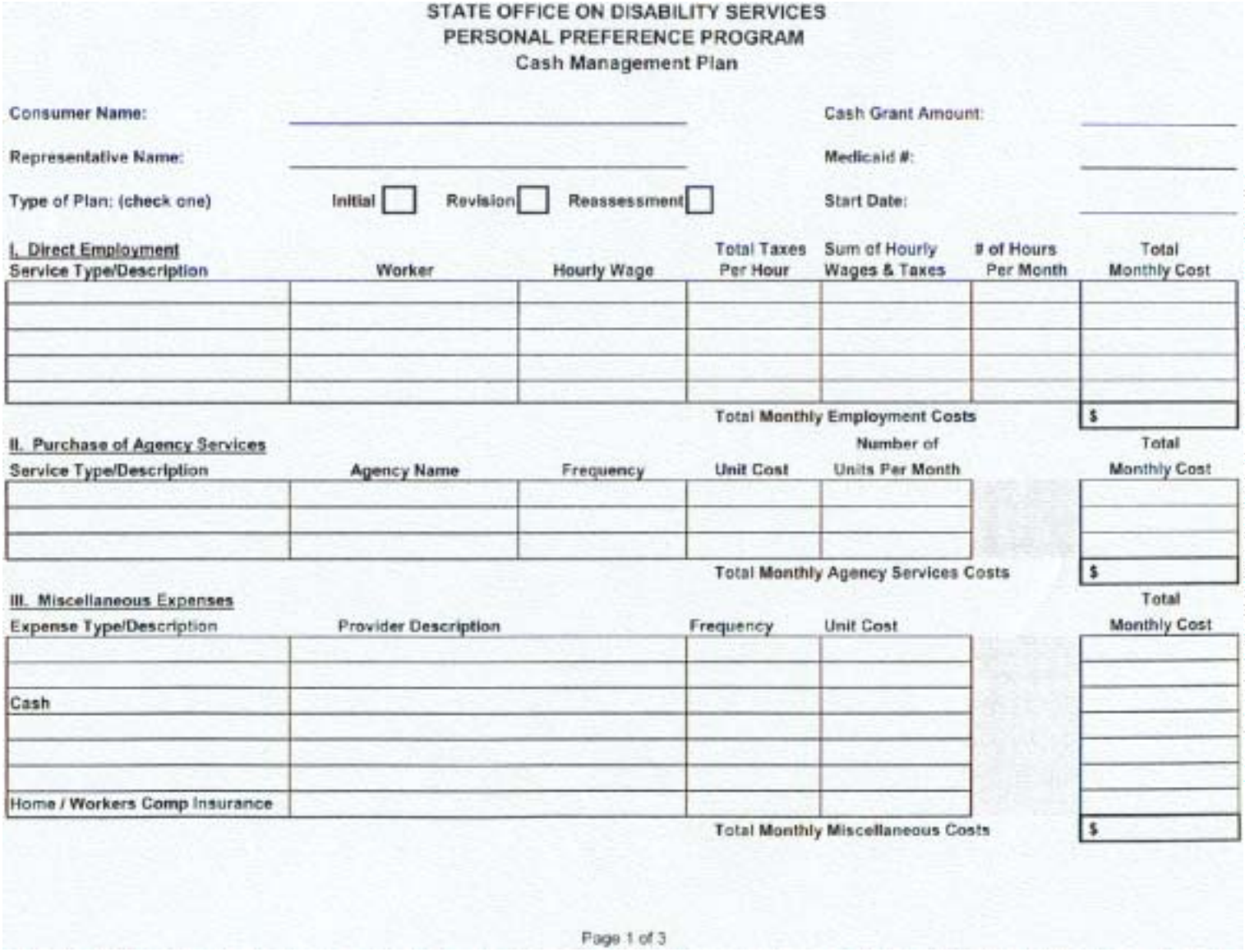
Predetermined Representative

The participant has a legal guardian or other court appointed representative in place at the time of enrollment and that individual will serve as the designated representative on the client's behalf.

Mandated Representative

The client is enrolled in Personal Preferences and has misspent funds from the cash allowance, or their functioning has deteriorated in such a way that they are no longer able to manage their cash benefit.

repres.doc 2/96:12/98:8/24/99:8/25/99:7/1/01



STATE OFFICE ON DISABILITY SERVICES
PERSONAL PREFERENCE PROGRAM
Cash Management Plan

Consumer Name: _____ Cash Grant Amount: _____

Representative Name: _____ Medicaid #: _____

Type of Plan: (check one) Initial ☐ Revision ☐ Reassessment ☐ Start Date: _____

I. Direct Employment

Service Type/Description	Worker	Hourly Wage	Total Taxes Per Hour	Sum of Hourly Wages & Taxes	# of Hours Per Month	Total Monthly Cost
				Total Monthly Employment Costs		$

II. Purchase of Agency Services

Service Type/Description	Agency Name	Frequency	Unit Cost	Number of Units Per Month	Total Monthly Cost
				Total Monthly Agency Services Costs	$

III. Miscellaneous Expenses

Expense Type/Description	Provider Description	Frequency	Unit Cost	Total Monthly Cost
Cash				
Home / Workers Comp Insurance				
			Total Monthly Miscellaneous Costs	$

Page 1 of 3

Consumer Name: _____ Medicaid #: _____

Representative Name: _____

IV. Special Purchases/Modifications

Description of Work/Purchase	Contractor/Provider Name	Proposed Purchase Date	Estimated Cost	Estimated # of Monthly Payments	Total Monthly Cost
				Total Monthly Special Purchase/Modification Costs	$

V. Fiscal Intermediary Services & Fees

Description of Services and Fees	# of Units	Unit Cost	Total Monthly Cost
Transaction Fees			
Criminal Background Investigation Fee			
Employee Health Insurance			
		Total Monthly Fiscal Intermediary Costs	$

Consumer Name: _____ Medicaid #: _____

Representative Name: _____

RECONCILIATION OF MONTHLY CASH BENEFIT

		Monthly Amount
A. Total Monthly Cash Benefit		$ -
B. LESS Cost of Direct Employment	(Section I)	$
C. LESS Cost of Agency Services	(Section II)	$
D. LESS Cost of Other Expenses	(Section III, IV)	$
E. LESS Cost of Fiscal Intermediary Services	(Section V)	$
(A minus the sum of B, C, D & E)	MONTHLY BALANCE	

Decision Tree Completed: Yes___ No___

CMP Designed By:

Consumer Signature: _____ Date: _____

Representative Signature: _____ Date: _____

Consultant Review: _____ Date: _____

(Signature and Title)

Agency Name: _____ Phone# _____

State Program Office Approval: _____ Date: _____

(Signature and Title)

PPPcmp 7/99:8/99

Consumer Directed Care Research Project Purchasing Plan

A. Consumer

Name_____ ____ _____ Social Security Number_____
(First) M.I. (Last)

Representative Name_____ ____ _____ Phone (_____) _____
(First) M.I. (Last) ☐ Consumer ☐ Representative

B. Purchasing Categories

10 Directly Hired Workers

	Name	Service	Hourly Pay	X	Total Hours Month	=	Monthly Pay	+	Taxes	=	Total Cost Per Month
1.	_____	_____	$_____		_____		$_____		$_____		$_____
2.	_____	_____	$_____		_____		$_____		$_____		$_____
3.	_____	_____	$_____		_____		$_____		$_____		$_____
4.	_____	_____	$_____		_____		$_____		$_____		$_____

Total Cost $_____

20 Home Care Agency Services

	Agency Name	Service	Unit Cost	Units Per Month	Total Cost Per Month
1.			$		$
2.			$		$
3.			$		$
4.			$		$
				Total	$

30 Equipment

	Equipment Description	Purpose	Cost
1.			$
2.			$
3.			$
		Total	$

50

40 Personal Care Supplies

	Description		
1.	_____	_____	$_____
2.	_____	_____	$_____
3.	_____	_____	$_____
		Total	$_____

50 Modify Residence

	Description	Purpose	Cost
1.	_____	_____	$_____
2.	_____	_____	$_____
		Total	$_____

51

60 Modify Vehicle

	Description	Purpose	Cost
1.	_____	_____	$_____
2.	_____	_____	$_____
		Total	$_____

70 Community Services

	Organization	Service	Unit Cost	Units Per Month	Total Cost Per Month
1.			$	$	$
2.			$	$	$
3.			$	$	$
4.			$	$	$
				Total	$

80 Cash

	Description	Purpose	Cost
1.			$
2.			$
3.			$
		Total	$

PAAS Fees

Total $

Savings

Total $_____

Overflow Items

Category Number	Name	Description	
_____	_____	_____	$_____
_____	_____	_____	$_____
_____	_____	_____	$_____
_____	_____	_____	$_____

Total $_____

C. Budget

Budget:

Amount Received $_____

Less Total Costs _____ (The grand total of section B cost totals)

Balance $_____

D. Consumer Needs

E. Emergency BackUp Plan

Notes

55

Consumer Signature_____ Date_____

Representative Signature_____ Date_____

Consultant Name_____ Signature_____ Date_____

Consumer Directed Care Research Project

Employer/Employee Agreement

This agreement between _____ ***and***

(Employer)

_____

(Employee)

is intended to make the terms of employment clear.

Employee State Date ____/____/____

WORK SCHEDULE

The employee's work schedule will be as follows:

						Total Daily Hours
Monday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Tuesday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Wednesday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Thursday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Friday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Saturday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____
Sunday	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m.	a.m. ___p.m. to	a.m. ___p.m. _____

Total Weekly Hours _____

EMPLOYER RESPONSIBILITIES:

Compensation

The employer agrees to pay the employee $_____ per hour.

The employer will withhold and send to federal and state governments all unemployment taxes, social security, federal withholdings. A summary of all payroll withholdings (w2 form) will be sent to you by the project bookkeeper by January 31st for the previous calendar year.

Job Duties

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

EMPLOYEE RESPONSIBILITIES:

Reporting To Work/Time Off

(Please Initial)

I _____ agree to report to work on time.

I _____ agree to carry out assigned duties and responsibilities as explained by my employer.

I _____ agree to tell my employer two weeks in advance when I need time off. Vacation dates will be set by mutual agreement between the employer and me.

I _____ agree to call my employer with as much advance notice as possible if I am ill or if I am unable to report to work on time due to other unforeseen emergencies (car trouble, severe weather, etc.).

I _____ understand I am expected to be dependable.

I _____ agree to give my employer two weeks written notice if I decide to terminate my employment agreement.

I have read and understand the job duties expected of me.

_____ _____

Signature of Employee Date

_____ _____

Signature of Employer Date

Consumer Appeal Form

Name of Consumer:	
Name of Representative (if applicable):	
Address:	
City/Zip:	Telephone:

Reason for appeal

- ❑ I do not agree I need assistance of a representative.
- ❑ I do not agree with the corrective action plan written by my consultant.
- ❑ I do not agree with my consultants' recommendation to return to the Home and Community Based Services Program and dis-enroll from the Consumer Directed Care Project.

What problem or situation caused your consultant to make the recommendation listed above:

What do you think should be done:

Signature:

Appeal Form Revised 5/04/99

CONSUMER DIRECTED CARE RESEARCH PROJECT
COMPLAINT FORM

Customer Name: (PLEASE PRINT)		
Name of person reporting concern (if not consumer):		
Address:		
City:	Zip:	Telephone: ( )
Problem with: ❑ Project Bookkeeper ❑ Consultant		Best time to call: ___AM ___PM
Please explain in the space below the problem you are having with the project bookkeeper or your consultant. Use back of page if additional space is needed.		
Have you told the project bookkeeper or your consultant about the problem? ❑Yes ❑No If yes, what was done?		
Please mail this form to: Consumer Directed Care Research Project 4040 Esplanade Way Tallahassee, FL 32399-7000 A project staff member will contact you. Thank You		

Consumer Aid Sheet

Week to Month Conversion: Multiply Hours Per Week by 4.33

Hourly Rate of Pay	Number of Hours Worked							
	5	10	15	20	25	30	35	40
$5.15	$28.62	$57.24	$85.86	$114.48	$143.11	$171.73	$200.35	$228.97
$5.50	$30.57	$61.13	$91.70	$122.27	$152.83	$183.40	$213.96	$244.53
$6.00	$33.35	$66.69	$100.04	$133.38	$166.73	$200.07	$233.42	$266.76
$6.50	$36.12	$72.25	$108.37	$144.50	$180.62	$216.74	$252.87	$288.89
$7.00	$38.90	$77.81	$116.71	$155.61	$194.51	$233.42	$272.32	$311.22
$7.50	$41.68	$83.36	$125.04	$166.73	$208.41	$250.09	$291.77	$333.45
$8.00	$44.46	$88.92	$133.38	$177.84	$222.30	$266.76	$311.22	$355.68
$8.50	$47.24	$94.48	$141.72	$188.96	$236.19	$283.43	$330.67	$377.91
$9.00	$50.02	$100.04	$150.05	$200.07	$250.09	$300.11	$350.12	$400.14
$9.50	$52.80	$105.59	$158.39	$211.19	$263.98	$316.78	$369.57	$422.37
$10.00	$55.58	$111.15	$166.73	$222.30	$277.88	$333.45	$389.03	$444.60
$10.50	$58.35	$116.71	$175.06	$233.42	$291.77	$350.12	$408.48	$466.83
$11.00	$61.13	$122.27	$183.40	$244.53	$305.66	$366.80	$427.93	$489.06
$11.50	$63.91	$127.82	$191.73	$255.65	$319.56	$383.47	$447.38	$511.29
$12.00	$66.69	$133.38	$200.07	$266.76	$333.45	$400.14	$466.83	$533.52
$12.50	$69.47	$138.94	#208.41	$277.88	$347.34	$416.81	$486.28	$555.75
$13.00	$72.25	$144.50	$216.74	$288.99	$361.24	$433.49	$505.73	$577.98
$13.50	$75.03	$150.05	$225.08	$300.11	$375.13	$450.16	$525.18	$600.21
$14.00	$77.81	$155.61	$233.42	$311.22	$389.03	$466.83	$544.64	$622.44
$14.50	$80.58	$161.17	$241.75	$322.34	$402.92	$483.50	$564.09	$644.67
$15.00	$83.36	$166.73	$250.09	$333.45	$416.81	$500.18	$583.54	$666.90
$15.50	$86.14	$172.28	$258.42	$344.57	$430.71	$516.85	$602.99	$689.13
$16.00	$88.92	$177.84	$266.76	$355.68	$444.60	$533.52	$622.44	$711.36
$16.50	$91.70	$183.40	$275.10	$366.80	$458.49	$550.19	$641.89	$733.59
$17.00	$94.48	$188.96	$283.43	$377.91	$472.39	$566.87	$661.34	$755.82
$17.50	$97.26	$194.51	$291.77	$389.03	$486.28	$583.54	$680.79	$778.05

Consumer Tax Table
Consumer & Employee Share FICA Tax

Worker's Wage per Hour	7.65% FICA Tax	.8% FUTA Tax	2.7% SUTA Tax	Total Cost per Hour	Worker's Wage per Hour	7.65% FICA Tax	.8% FUTA Tax	2.7% SUTA Tax	Total Cost per Hour
$5.15	$0.39	$0.04	$0.14	$5.72	$12.25	$0.94	$0.10	$0.33	$13.62
$5.25	$0.40	$0.04	$0.14	$5.84	$12.50	$0.96	$0.10	$0.34	$13.89
$5.50	$0.42	$0.04	$0.15	$6.11	$12.75	$0.98	$0.10	$0.34	$14.17
$5.75	$0.44	$0.05	$0.16	$6.39	$13.00	$0.99	$0.10	$0.35	$14.45
$6.00	$0.46	$0.05	$0.16	$6.67	$13.25	$1.01	$0.11	$0.36	$14.73
$6.25	$0.48	$0.05	$0.17	$6.95	$13.50	$1.03	$0.11	$0.36	$15.01
$6.50	$0.50	$0.05	$0.18	$7.22	#13.75	$1.05	$0.11	$0.37	$15.28
$6.75	$0.52	$0.05	$0.18	$7.50	$14.00	$1.07	$0.11	$0.38	$15.56
$7.00	$0.54	$0.06	$0.19	$7.78	$14.25	$1.09	$0.11	$0.38	$15.84
$7.25	$0.55	$0.06	$0.20	$8.06	$14.50	$1.11	$0.12	$0.39	$16.12
$7.50	$0.57	$0.06	$0.20	$8.34	$14.75	$1.13	$0.12	$0.40	$16.39
$7.75	$0.59	$0.06	$0.21	$8.61	$15.00	$1.15	$0.12	$0.41	$16.67
$8.00	$0.61	$0.06	$0.22	$8.89	$15.25	$1.17	$0.12	$0.41	$16.95
$8.25	$0.63	$0.07	$0.22	$9.17	$15.50	$1.19	$0.12	$0.42	$17.23
$8.50	$0.65	$0.07	$0.23	$9.45	$15.75	$1.20	$0.13	$0.43	$17.51
$8.75	$0.67	$0.07	$0.24	$9.73	$16.00	$1.22	$0.13	$0.43	$17.78
$9.00	$0.69	$0.07	$0.24	$10.00	$16.25	$1.24	$0.13	$0.44	$18.06
$9.25	$0.71	$0.07	$0.25	$10.28	$16.50	$1.26	$0.13	$0.45	$18.34
$9.50	$0.73	$0.08	$0.26	$10.56	$16.75	$1.28	$0.13	$0.45	$18.62
$9.75	$0.75	$0.08	$0.26	$10.84	$17.00	$1.30	$0.14	$0.46	$18.90
$10.00	$0.77	$0.08	$0.27	$11.12	$17.25	$1.32	$0.14	$0.47	$19.17
$10.25	$0.78	$0.08	$0.28	$11.39	$17.50	$1.34	$0.14	$0.47	$19.45
$10.50	$0.80	$0.08	$0.28	$11.67	$17.75	$1.36	$0.14	$0.48	$19.73
$10.75	$0.82	$0.09	$0.29	$11.95	$18.00	$1.38	$0.14	$0.49	$20.01
$11.00	$0.84	$0.09	$0.30	$12.23	$18.25	$1.40	$0.15	$0.49	$20.28
$11.25	$0.86	$0.09	$0.30	$12.50	$18.50	$1.42	$0.15	$0.50	$20.56
$11.50	$0.88	$0.09	$0.31	$12.78	$18.75	$1.43	$0.15	$0.51	$20.84
$11.75	$0.90	$0.09	$0.32	$13.06	$19.00	$1.45	$0.15	$0.51	$21.12
$12.00	$0.92	$0.10	$0.32	$13.34	$19.25	$1.47	$0.15	$0.52	$21.40

APPENDIX C

APPENDIX: Section C – Links to web resources

Cash & Counseling Program Information **www.cashandcounseling.org**

Cash & Counseling Demonstration –
http://www.hhp.umd.edu/AGING/CCDemo/index.html

Home and Community Based Resource Network –
http://www.hcbs.org/

Arkansas Cash & Counseling: Independent Choices –
http://www.independentchoices.com/ICHome.htm

New Jersey Cash & Counseling: Personal Preference –
http://www.state.nj.us/humanservices/dds/personal.html

Florida Cash & Counseling: Consumer Directed Care –
http://elderaffairs.stae.fl.us/doea/english/cdc.html

Consumer-Direction Tool –
http://www.hcbs.org//practical_tools.htm#consumer

Counseling/Fiscal Agency (CFA) Initial Readiness, Mid-Year & Annual Review Manuals (Susan Flanagan) –
http://www.hcbs.org/ptools/AR_CFA/AR_CFA/Manual.pdf

Statement of Consumer Rights and Responsibilities from the New Jersey Personal Preferences Program –
http://www.hhp.umd.edu/AGING/CCDemo/Products/Appendix%20A%20Rights%20Responsibilities%20of%20consumer%20and%20representative.pdf

You Can Do It! A Consumer Guide for Managing your Own Cash Grant for Household Employees, John Agosta –
http://www.hhp.umd.edu/AGING/CCDemo/ccbook/index.html

Arkansas Operations Manual & RFP: http://www.independentchoices.com?ICHome.htm

Mathematica – http://www.mathematica-mpr.com/3rdLevel/cashcounselinghot.htm

Quality Initiatives Involving Centers for Medicare and Medicaid Services (CMS)

http://www.cms.hhs.gov/medicaid/waivers/quality

1. Participant Experience Survey MRDD
2. Participant Experience Survey Elderly/Disabled
3. User's Guide for Participant Surveys
4. HCBS Quality Framework
5. HCBS Workbook-Guide for Improving Quality in Home Community-based Service and Support