
Best Practices in Consumer Direction

Prepared for:

The Centers for Medicare & Medicaid Services

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Table of Contents

Executive Summary	1
I. Introduction: Section 648 of the Medicare Modernization Act	9
II. Methods.....	9
III. What Is Consumer Direction?	10
IV. Overview of Existing Programs Offering Consumer Direction	11
A. Cash and Counseling	12
B. State-Administered Consumer-Directed Options	14
C. Managed Care	15
D. Medicare-Only Models	16
E. Private Sector Options.....	20
V. How Do People Fare Under Consumer Direction?.....	21
VI. Parameters of Consumer Direction:.....	24
A. Target Population/Size	24
B. Benefits Available Under Consumer Direction	28
C. Necessary Supports.....	30
D. Recruiting Potential Participants	34
E. Data Collection	35
F. Quality Management.....	36
G. Budget Impact and Cost Issues.....	38
H. Workforce Issues.....	41
I. Provider Reception.....	43
J. Liability Issues.....	44
VII. How Relevant Are Previous Experiences with Consumer Direction to the Medicare Home Health Population?	46
VIII. Discussion of the Challenges of Consumer-Directing Medicare Home Health	48
IX. Lessons Learned	52
X. Next Steps.....	55
References:.....	58
Appendix A: A Glossary of Terms Relevant to Consumer Direction and the Medicare Home Health Benefit	62
Appendix B: An Annotated Bibliography of Articles Related to Consumer Direction.....	69

Executive Summary

Consumer direction is a movement originating in the 1960s that provides individuals the opportunity to exercise more choice and control over long term care services. This opportunity for increased control includes both younger and older people with disabilities, as well as individuals with developmental disabilities. Although real-world models of consumer direction vary, it generally gives consumers the right to select, manage, and dismiss staff providing personal care services and to make other purchases based on their needs.

Section 648 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 requires the Secretary of Health and Human Services to evaluate methods for improving the quality of care provided to Medicare beneficiaries with chronic conditions. The purpose of the demonstration is to test consumer direction of personal care services in Medicare; currently, these services are not a separately defined benefit and are available only under the Medicare home health benefit. This report presents best practices in consumer direction, and was required under law to inform the design of this demonstration. The report is based on information collected from a review of the published and unpublished literature on consumer direction, as well as from interviews with 19 key informants; members of the proposed demonstration's Technical Advisory Group also contributed by commenting on an early draft of the report.

Consumer direction is available across the country

The following section presents summary highlights of both literature reviews and expert interviews.

Many publicly-funded programs offer consumer direction. The investigation finds that consumer direction is no longer a marginal, experimental option for delivering personal care services, nor is it a single model. Rather, a variety of consumer-directed programs have become integral to states' long term care systems, with at least 139 publicly-funded programs operating in 49 states across the country (Doty & Flanagan, 2002), and at least 62 of these serving older people (Infeld, 2004). Some of these programs have operated for over 30 years; one serves more than 370,000 people, although the average program is much smaller.

Managed care organizations (MCOs) offer consumer direction. Consumer direction is available through some managed care organizations serving people with long term care needs. A 1999 study of 64 MCOs providing long term care found that about one-third of those responding allowed consumers to hire and fire personal care staff, while nearly half gave consumers a "major say" over the type and amount of personal care services (Meiners, Mahoney, Shoop, & Squillace, 2002).

Consumer direction is widely practiced in the private sector. The purest form of consumer direction is when individuals purchase services on the open market using their own money, unrestrained by the rules governing public programs. Roughly 20% of long term care expenditures are paid out of income or savings, while an estimated 9% comes from private long term insurance (Government Accountability Office, 2005). A study of private long term care

insurance claimants found that those receiving cash benefits had higher rates of satisfaction than those whose services were reimbursed directly by the insurer (Cohen, 2002).

Medicare has limited experience with consumer direction. The Medicare program has supported two tests of consumer direction: 1) The Monroe County and Mid-Ohio Valley Project and 2) The Medicare Consumer Directed Durable Medical Equipment (CD-DME) Demonstration. Unfortunately, the CD-DME project yielded few important results, mainly because of implementation problems. However, the Monroe County and Mid-Ohio Valley Project was able to demonstrate that a modest add-on consumer-directed cash benefit of around \$200 per month can yield high satisfaction levels among beneficiaries without jeopardizing quality of care. Its results on cost were less promising: while long term care costs were lower for people receiving the consumer-directed benefit, their Medicare costs were higher.

The Cash and Counseling Demonstration and Evaluation has provided a comprehensive test of consumer direction in the Medicaid environment. The most well-known and well-studied example of consumer direction is the Cash and Counseling Demonstration and Evaluation (CCDE), based in Arkansas, Florida, and New Jersey. Funded by the Robert Wood Johnson Foundation and the federal Department of Health and Human Services, the demonstration randomly assigned participants to a treatment group receiving the cash benefit and a control group receiving traditional agency-based services. The individualized budget was based on the dollar value of a consumer's plan of care, and was used to purchase goods and services to meet personal care needs – most often, to hire family, friends, or neighbors. Consumers also had access to two types of support: counseling provided information and support in using the cash benefit, while financial management services (FMS) helped to ensure that directly hired staff were paid in a timely manner and that taxes and other deductions were made correctly. The independent evaluation studied a range of programmatic and individual outcomes and produced strong and favorable results, particularly regarding participant satisfaction and reductions in unmet needs, although findings on cost were more mixed.

Outcomes for participants in consumer direction are largely positive

Although most evidence regarding consumer direction comes from the CCDE, results from studies of other consumer directed programs (which represent different models of consumer direction) combine with the CCDE results to strongly support the effectiveness of consumer direction. A recent review (National Council on Disability, 2004) found that, compared to program participants using traditional agency-based services, participants in consumer direction:

- Reported higher levels of satisfaction
- Scored higher on measures of control and empowerment
- In general, reported fewer unmet needs
- Scored the same or better on measures of health status
- Scored the same or better on measures of participant safety
- Reported a better quality of life.

In a separate analysis, the CCDE found that, compared to the informal caregivers of people receiving traditional services, informal caregivers of participants receiving individualized

budgets experienced significantly lower levels of stress in two of the three CCDE states and were less likely in all three states to say that their physical health suffered as a result of caregiving.

Findings on cost, however, are mixed. Treatment group costs were higher than control group costs for most (but not all) of the groups compared by CCDE evaluators (who compared the different population groups enrolled in each state during their first and second year of enrollment). These higher costs resulted primarily from the fact that control group members did not receive services listed in their care plan, mostly due to staff shortages. Reductions in other Medicaid costs mitigated the effect of these higher costs on total Medicaid costs for most treatment group participants, but total Medicaid costs were nonetheless higher among treatment participants for most of the groups compared, although not significantly so in many cases (Brown, Carlson, Dale, Foster, Phillips, & Schore, 2005).

Challenges for the proposed Medicare demonstration

The differences between the Medicare home health benefit and the consumer directed programs featured in this Best Practices report have important consequences for the proposed demonstration. Most of these programs have been developed in a Medicaid context and their relevance to the Medicare program is not clear. Some key differences include:

- **Availability of personal care services** – Medicare does not currently cover personal care services as a separately defined benefit, but as one of the services provided under the Medicare home health benefit: home health aide services. In contrast, the consumer directed programs discussed in this report may allow consumer direction for personal care services only, or for a broader array of services.
- **Eligibility requirements** – Medicare home health eligibility requires that beneficiaries be homebound, require skilled nursing or rehabilitation therapy services, and have a care plan signed by a physician. In contrast, eligibility requirements for most consumer-directed programs are based on functional and financial status, often requiring a need for assistance with at least three Activities of Daily Living (ADLs). Some programs require individuals to meet nursing home eligibility requirements (normally, a higher standard) to qualify for services.
- **Relevance of state and local factors** – While the Medicare program is administered by the federal government, consumer-directed programs are influenced by a variety of state and local factors. Not only does a state's Medicaid program affect the entire context of care provision in the state, other state-specific factors, such as Nurse Practice Acts, have an impact.
- **Regulatory regimen for agencies and individual providers** – Home health agencies must meet strict Medicare certification requirements that govern virtually every aspect of agency operation, including the standards that agency staff must meet. In contrast, the programs reviewed for this report fall under a variety of regulatory regimens

dictated by both state and Medicaid law, which are generally less rigorous than Medicare regulations.

- **Entities responsible for oversight of service recipients** – Under consumer directed programs, the case management or counselor role has been designed to support consumers’ efforts to control their lives, an approach that differs from the nurse’s role in Medicare home health agencies. Nurses are required, under federal regulation, to emphasize care coordination and medical oversight for those receiving services from Medicare home health agencies. Agencies are legally responsible for all services delivered under the home health benefit.
- **Reimbursement mechanisms** – Home health agencies receive case-mix adjusted payments at the beginning of a 60-day “episode” of care. These payments are intended to cover all services provided in an episode, based on the average cost of services for a particular case mix group – making it impossible to separate out home health aide expenditures. In contrast, the consumer-directed programs reviewed for this report tend to reimburse services on a fee-for-service basis.

Because previous experiences are shaped by the Medicaid program, their relevance to the proposed Medicare demonstration is unclear. Lessons that appear to be relevant are highlighted in the next section.

Relevant implementation lessons, based on experiences with consumer direction

Our review of the existing literature and interviews with key informants yield 16 key lessons for implementing consumer direction in home health services. While these lessons are based on experiences in non-Medicare settings, their relevance could be tested in a Medicare setting through the proposed demonstration. Any implementation of the proposed demonstration should consider the following “lessons learned”:

1) Work closely with home health agencies to integrate their concerns into program design. Integrate these agencies into the planning and implementation activities, ideally through a formal process. Reach out to providers by providing information about consumer direction and the implementation of the demonstration.

2) Provide outreach to front-line workers in home health agencies to educate them about consumer direction. These workers are often a main information source for consumers and would be central to the recruitment process for the Medicare demonstration.

3) Ensure that appropriate supports are available. Overwhelmingly, those with experience in consumer direction emphasize the importance of providing program participants with counseling and support in managing the financial aspects of employing staff. A considerable body of evidence has been developed, mainly from the CCDE, on how to establish, reimburse, and manage providers of support

4) *Consider enrolling dual eligibles and allowing them to combine Medicaid personal care or waiver service funds with the Medicare consumer-directed allowance.* This would allow the Medicare demonstration to take advantage of an already functioning infrastructure for consumer direction and expand the potential amount of the cash benefit.

5) *Give careful thought to recruitment.* Participation levels are highly sensitive to recruitment methods. Using well-informed recruitment professionals with positive attitudes toward consumer direction is critical.

6) *Develop a tailored and quick enrollment process.* It is important that consumers understand their rights, risks, and responsibilities under consumer direction, but also that they receive this information from a positive, well-informed person. Given the limited lead time that would likely exist under any Medicare home health demonstration, enrollment must be speedy.

7) *Do not screen participants.* Evidence from the CCDE, as well as from other consumer-directed programs, indicates that screening of participants is unnecessary. Use of representatives enables the participation of individuals with cognitive impairment who might otherwise be screened out. However, it may be sensible to exclude individuals who are likely to use hospice services within the next 60 days, because the lead time to operationalize consumer-direction may require several weeks.

8) *Do not restrict the pool of potential workers.* Allowing participants to employ family members, neighbors, and friends supplements the staffing pool with individuals who would not normally work as home health aides. Restrictions to the staffing pool based on credentialing or training requirements are unnecessary, given the evidence demonstrating that a lack of formal training for directly hired staff does not result in poorer outcomes for participants in consumer direction.

9) *Allow nurse delegation where state law permits.* Allowing this form of delegation in the demonstration would provide an opportunity to collect evidence on its safety and effectiveness and also provide a means of reducing overall costs.

10) *Allow flexible use of the benefit.* Evidence from the CCDE, which permitted funds to be spent on a broad range of items and to be saved from month to month, shows that recipients of individualized budgets used them wisely, with little evidence of misuse of funds.

11) *Assess the program design to ensure there are adequate protections against liability risks.* Although very few legal cases have arisen under consumer direction, prudent program administrators will institute simple steps to limit liability risk. A key recommendation is to require consumers to take out workers' compensation insurance to protect their staff and protect themselves against claims.

12) *Develop a comprehensive approach to cost control.* The CCDE offers many lessons on design features that help control costs. These include instituting careful control over reassessments and rigorous oversight of expenditures under individual budgets. Another important cost control feature is the ability to recoup unspent funds from an individual budget.

13) *Develop systems to ensure that emergency back-up is available. Of the specific quality improvement steps that can be taken, the development of an emergency back-up system is among the most important. Poor outcomes can result if demonstration participants do not have access to an alternative source of services when their usual service provider is suddenly unavailable.*

14) *Develop methods of integrating consumer concerns and issues into program design, implementation, and management. Consumer participation in program design and implementation helps to ensure the appropriateness of design features. Methods for tracking consumer issues can flag design flaws and help prevent adverse outcomes.*

15) *Design data collection methods to capture relevant evaluation data. Data collection efforts should capture the information necessary to evaluate key areas of interest. At a minimum, collect information about cost, health and functional outcomes, and satisfaction. To avoid unnecessary (and burdensome) data collection activities, focus exclusively on information that will be used in the evaluation, program management, or quality management.*

16) *Ensure that quality management techniques are adapted to the unique requirements of a consumer-directed program. Some specific design features include informing consumers clearly of their rights and responsibilities under consumer direction; monitoring FMS providers and consumer expenditures; developing emergency back-up procedures; establishing consumer feedback mechanisms; and ensuring that consumers have access to a comprehensive system of supports.*

Significant and serious challenges to a Medicare demonstration persist

Even with careful program design, informed by the experience of other consumer direction programs, the proposed Medicare demonstration project will face significant barriers to success. These are outlined below.

Sufficient numbers of eligible and interested individuals for a viable demonstration may not exist within the Medicare home health population.

While preliminary analyses indicate that there may be enough potential participants to make a demonstration feasible, the potential population is small. Attaining sufficient participants for evaluation will depend on many factors. Any serious obstacles to beneficiary participation will undermine the success of the proposed demonstration.

A lack of cooperation from home health agencies will make the proposed demonstration difficult to implement.

Only agencies will have access to information that will identify beneficiaries as appropriate for the demonstration. Without their cooperation, it will be next to impossible to recruit sufficient numbers of participants. Agencies will also necessarily be involved in the tasks associated with transitioning participants to a consumer-directed benefit in a timely manner. Ensuring their

cooperation with a demonstration and enabling them to fulfill a recruitment role may involve reimbursing them for associated costs; in addition, intensive outreach and education to the affected agencies may be costly.

Lead time may not be adequate

Participants will need to have arrangements for consumer-directed care in place to ensure continuous access to needed services. Implementing this within a short time frame to maximize the time spent in receipt of a consumer-directed benefit will pose a considerable challenge. Evidence from the CCDE indicates that a 120-day time frame is ambitious.

Ensuring the availability of needed supportive services may prove difficult

This paper has noted the importance of two different types of supportive services - counseling and FMS – to the success of consumer direction. For these supportive services to be effective, familiarity with consumer direction is essential. The demonstration will either have to rely on existing infrastructure for supportive services (and therefore be located in an area where consumer-directed services are already available) or invest in building infrastructure, which can be costly.

Assuring budget neutrality will be challenging.

The budget neutrality specified under Section 648 requires that the cost of demonstration services may not exceed the cost of services that would otherwise have been provided under traditional service delivery. This poses considerable challenges to the demonstration design in three key respects:

- **Determining the correct amount for individualized budgets** – Because the Medicare home health benefit is paid on a capitated, rather than a fee-for-service basis, it will be difficult to parse out the costs of the home health aide portion of the benefit.
- **Funding start-up costs** – Demonstrations generally rely on additional financing for start-up expenses, including project staffing, recruitment costs, and developing demonstration infrastructure.
- **Reimbursing supportive services** – Finding a mechanism for funding supportive services under Medicare regulations may be a challenge. Deducting the costs from the budget available to consumers under the demonstration will reduce their ability to purchase services and derive benefits from the services received

Integrating consumer-directed services with other Medicare home health services may be difficult.

Medicare home health beneficiaries are the legal responsibility of home health agencies and, by definition, have a need for skilled services. Agencies will require protection from liability for outcomes resulting from consumer-directed services they do not control. They are also likely to

resist a model of care that is seemingly contrary to a vision of quality that emphasizes care coordination and communication among providers of home health services.

Agencies will need to see consumer direction as a benefit rather than a threat.

Traditional home care providers can be resistant to consumer direction. However, experience has shown that many of their concerns are not borne out and can be mitigated through education and by integrating home care providers into the planning process for consumer direction. Legitimate cost concerns regarding reductions in agency payment that result from the carve-out of the consumer-directed budget will need to be addressed.

Responsibility for day-to-day implementation of the demonstration is unclear

An entity for overseeing implementation will need to be identified to replace the role played by state or local governments for most consumer-directed programs. Any Medicare home health demonstration will be labor-intensive; appropriate service delivery will require substantial interaction with local service providers as well as an understanding of local factors.

Conclusion

Evidence from existing consumer-directed programs indicates that while consumer direction may be a viable option for selected Medicare home health recipients, the challenges to implementation are significant. Programs such as the CCDE have enrolled many highly impaired Medicare-eligible older adults and have reported positive outcomes. Further, there is a rich body of experience in implementing consumer-directed programs from which a Medicare demonstration can draw. Even so, substantial challenges remain. Key among these is the question of whether a large enough group of potential participants exists in a given geographical location to warrant a demonstration. Another challenge is the need to translate design features developed largely in a Medicaid and state-specific context to the Medicare environment. These issues and many others will be addressed during the next stages of the demonstration design process.

Best Practices in Consumer Direction

I. Introduction: Section 648 of the Medicare Modernization Act

Section 648 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 directs the Secretary of Health and Human Services to carry out a Consumer-Directed Chronic Outpatient Services Demonstration. This demonstration is intended to evaluate methods for improving the quality of care for Medicare beneficiaries diagnosed with one or more chronic health conditions (as defined by the Secretary of Health and Human Services). The method specifically mentioned in the legislation is consumer direction of personal care services (typically defined as assistance with activities of daily living (ADLs), such as bathing, dressing, grooming, transferring, and meal preparation).

Consumer direction of personal care services has been shown empirically to be associated with significant improvements in a variety of outcomes – including consumer satisfaction, health status, and quality of life – for disabled and elderly Medicaid enrollees. Although Medicare does not currently cover personal care services as a separately defined benefit, these services are available under the home health benefit to beneficiaries who need skilled nursing or rehabilitation therapy services provided in the home and meet other eligibility criteria. Among the services provided under the home health benefit are home health aide services, which include personal care services. The demonstration would allow Medicare home health care recipients to exercise more choice and control over who provides such services, when they provide those services, and how those services are provided. Further, it will test whether cost-effectiveness, patient outcomes, and beneficiary satisfaction improve when beneficiaries are allowed to direct their own personal care services.

This report is an additional requirement of Section 648, which specifies that the demonstration's design be based on a study of best practices in consumer direction in Medicaid, group health plans, the private sector, and other areas. The report describes these best practices as they relate to the Medicare program and examines Section 648 demonstration design issues, including factors that would impact budget-neutrality. A more in-depth treatment of many of the topics explored briefly in this paper will be available through a series of memoranda on specific design issues, mandated as part of the demonstration design activity under Section 648.

II. Methods

To compile this Best Practices report, Medstat performed two main tasks: a review of the literature on consumer direction, including both published and unpublished materials, and a series of interviews with key informants. The literature review involved a search of on-line databases of peer-reviewed articles and Internet sites dealing with consumer direction, such as the Community Living Exchange Collaborative at www.hcbs.org and the Cash and Counseling Project at <http://www.cashandcounseling.org> (which contains a complete listing of reports published by the evaluators of the project). The literature review also included unpublished papers recommended by key informants, such as reports to funders.

This report is limited by a scarcity of rigorous research on participants in consumer-directed programs. Although the number of such programs and program participants has increased dramatically over the last decade, only a few programs have been evaluated carefully. For this reason, the literature review relies heavily on quantitative findings from the Cash and Counseling Demonstration and Evaluation (described below) and a few other studies, in addition to impressions elicited from key informants – which are, by definition, partial and subjective. An annotated bibliography of articles relevant to consumer direction and the implementation of consumer directed programs is contained in Appendix B.

Key informants fell into two main categories: individuals knowledgeable about consumer direction and others knowledgeable about the needs of the Medicare-eligible population with chronic conditions likely to be served by this demonstration. Thirteen interviews were conducted with 19 individuals, representing a combination of both group and individual interviews.

A draft of the report was reviewed by the Technical Advisory Group (TAG) of the Section 648 Demonstration Project. This TAG included representatives from the home health industry, researchers on Medicare home health and consumer direction, consumer advocates, and experts in consumer direction. TAG comments were incorporated into the final draft of the report.

III. What Is Consumer Direction?

Consumer direction is a movement that began in the 1960s among younger people with disabilities who organized to advocate for more control over the services they received. These advocates objected to their passive role in long term care services that, by their personal nature, determined much of their daily lives – such as when and how they slept, ate, bathed, and performed other daily activities. Their advocacy spread to other population groups, including older people and people with developmental disabilities. A common definition of consumer direction was advanced in 1996:

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services.¹

¹From National Institute of Consumer-Directed Long-Term Care Services (1996). *Principles of Consumer-Directed Home and Community-Based Services*. Funded by a grant to the National Council on Aging and the World Institute on Disability, and sponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

In practice, this means that consumers have the right to select, manage, and dismiss an attendant or other provider of personal care services. Although consumer direction is often identified with the Cash and Counseling Demonstration and Evaluation (CCDE), existing models vary widely in the extent of choice and control they offer. However, all models of consumer direction reflect three central beliefs:

- People with disabilities (or their chosen representatives) have a unique understanding of their personal care needs.
- Many people with disabilities are competent to oversee the delivery of personal care (and sometimes other) services.
- Service recipients – rather than service providers – have a right to control the personal care services that significantly affect their day-to-day existence (for example, the time that they receive a bath or are moved from one location to another).

Because this movement evolved in many different environments over a considerable period of time, significant variations in terminology exist. Appendix A contains a glossary of key terms frequently found in the research literature and in practice.

IV. Overview of Existing Programs Offering Consumer Direction

Numerous publicly funded programs around the country provide service recipients with various elements of choice and control; they vary considerably in their structure and organization, and in the model of consumer direction offered. Some have existed for many years – as in Washington State, which has operated a consumer-directed Medicaid program since 1970. The number of individuals served also varies widely: while most programs serve 1,000 or fewer participants, the California In-Home Supportive Services (IHSS) Program serves approximately 370,000 individuals. While most are financed through the Medicaid program, many receive money from a variety of funding sources.

Major variations among programs include:

- **Which services consumers can self-direct and the extent of control individuals have over those services.** At a minimum, all consumer-directed programs allow consumers to select their own staff. In addition, some programs allow consumers to use the cash benefit to purchase goods and services not available in the traditional system, such as assistive equipment or home modifications, and to carry over funds from month to month in order to purchase larger items.
- **Who may be hired.** Most programs allow consumers to hire family members to assist them with daily activities. In some states (New Jersey, Florida, and Minnesota), consumers may even hire legally responsible relatives, such as spouses and parents of minor children, even though such providers are generally prohibited under Medicaid law.
- **Ways in which programs ensure that legal obligations are met.** All programs incorporate features to ensure that consumers meet their legal obligations as the

employers of personal care staff. In some cases, where the consumer is not the employer of record, staff recruited by the consumer are employed by an agency whose role is limited to deducting taxes and ensuring that the staff is paid appropriately. The consumer continues to be the managing employer, responsible for hiring and supervising the staff and controlling what tasks will be performed and when they will be provided. In other programs, consumers act as the employer of record and are responsible for identifying a fiscal agent to provide payroll functions. In yet another scenario, the state contracts with a single entity or a small number of entities to perform payroll functions for all program participants. Only a small number of states have chosen to make financial management services (FMS) a direct state administrative function.

- **The amount and type of support available to consumers.** Programs vary in how “hands-on” they are with regard to care planning and providing support and counseling to program participants (or whether they offer the latter at all). Some programs provide intensive counseling on how to hire and manage a consumer directed worker – a peer mentor, for example, who might even sit in on interviews – while others offer no support at all.

The section that follows describes a variety of programs relevant to the Medicare Demonstration, including the CCDE, other Medicaid and state-administered programs, as well as managed care and Medicare experiments associated with consumer direction.

A. Cash and Counseling

In many ways, the programs that grew out of the original Cash and Counseling Demonstration and Evaluation (CCDE) in Arkansas, Florida, and New Jersey constitute the archetype of consumer direction. This rigorously reviewed demonstration evaluated both programmatic and individual outcomes of providing Medicaid participants with the opportunity to arrange and manage their own personal care services using an individualized budget rather than traditional agency services. A key feature of the CCDE was its randomized design. The demonstration was also required to be budget-neutral.

The demonstration and evaluation were funded by The Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services. Each of the three states received roughly \$750,000 of federal money over a five-year period to design and implement the demonstration; because the federal contribution was matched by the participating states, their implementation budgets reached roughly \$1.5 million. The first two of these five years were intended for start-up activities, and the remaining three years for demonstration implementation. Funding for the demonstration was typically used to hire state staff to develop and manage the program, and to hire outreach workers to enroll participants, produce informational pamphlets, and participate in meetings with the National Program Office (NPO) at least twice annually. Beginning in 1996, the NPO provided each state with a comprehensive technical support strategy, which helped them to craft approaches to financial management services, social marketing and outreach, and quality management. Based on the success of this first initiative, The Robert Wood Johnson Foundation, ASPE, and the Administration on Aging authorized a new national program to support 12 states' efforts to replicate the original CCDE model in October, 2003.

Of the three demonstration states, the Arkansas and New Jersey projects were most similar. Both focused on people receiving Medicaid state plan personal care – individuals aged 18 and older who typically require assistance with at least two or more Activities of Daily Living (ADLs)². In addition to services received through the CCDE, many demonstration participants in Arkansas were eligible for home and community-based waiver services, indicating that they met the higher nursing facility admission requirement. Nearly a quarter of the Arkansas population was cognitively impaired, and about one-half of those receiving the cash benefit appointed a representative to manage services on their behalf. (Comparable figures are not available from the other CCDE states) Total enrollment reached 2,000 in Arkansas and 1,700 in New Jersey, although only half the participants received an individualized budget due to the CCDE's randomized design. Both programs were offered statewide. Arkansas began enrollment in December 1998 after two and one-half years of intense program planning, while New Jersey began in November 1999.

Florida recruited 2,820 participants from three different home and community-based waivers that served younger persons with disabilities, the elderly, and children and adults diagnosed with developmental disabilities. All participants met admissions criteria for either a nursing home or intermediate care facility for the mentally retarded. Although the program was available to children and elders throughout the entire state, developmentally disabled adults could not enroll in six northern counties (where a state funded program was being piloted), and adults with physical disabilities could enroll in only 19 counties. Florida implemented its program in June 2000.

The amount of the individualized budget varied considerably from state to state. Arkansas, for example, provided an average monthly budget of \$350, while New Jersey's average budget was \$1,400. Florida's average was \$975 for elderly adults and adults with physical disability, rising to \$1,825 for adults and children with developmental disabilities (Phillips & Schneider, 2003; all figures are from the end of enrollment). These budgets were based on the dollar value of an individual's plan of care -- which was developed in the same way that plans are developed for those receiving traditional services -- using traditional functional, medical, and social assessments.

Program participants had broad flexibility in deciding how to spend the allowance (which is also known as an individualized budget). Most used the budgets to hire family, friends, or neighbors to substitute for traditional agency staff. Other common expenditures included goods or services that help participants meet their personal care needs, such as assistive devices and equipment or environmental modifications.

People receiving the individualized budget could access two types of support for consumer direction. First, they could take advantage of "counseling" services – information and support to help them use the cash benefit effectively and appropriately. In many cases this meant assistance with the tasks of hiring and managing staff. Second, they could use a financial management service (FMS) to ensure that staff are paid in a timely manner and that taxes and other deductions are made correctly. All of the CCDE sites have implemented strict policies to ensure that

² These activities include such tasks as bathing, dressing, transferring, and grooming.

participants comply with the legal obligations associated with employing a provider of personal assistance services. Additional information on these supports appears later in this report.

Although consumers in the demonstration were offered the opportunity to manage their individualized budget without the use of a FMS, fewer than four in a thousand elected that option. This meant that most of participants' individualized budgets was not directly available to participants as a cash benefit. However, each state allowed participants to receive up to 10% of their budgets as cash to be spent on miscellaneous expenditures (Florida allowed up to 20% to be used); roughly half of all participants (37% in Arkansas, 42% in Florida, and 51% in New Jersey) chose to exercise this option.

The three original CCDE states have been studied extensively by Mathematica Policy Research, the demonstration evaluators. The design of the evaluation was strong, primarily because it randomly assigned participants to the treatment group (which received the cash benefit) and the control group (which received agency-based personal assistance services). Therefore, any differences found between the two groups were clearly attributable to the use of the cash benefit. The evaluation examined a wide range of outcomes, including the demonstration's costs, the quality of services, the experiences of staff hired by study participants, and participant satisfaction.

Evaluation results were largely positive and will be discussed in more detail below – although data are still being analyzed and more results will be forthcoming. Participants receiving the cash benefit were significantly more satisfied with their supportive services and had fewer unmet needs than those receiving traditional services, while their health outcomes were comparable. Early cost results show that personal care expenditures were higher among the people receiving cash benefits, primarily because control group members did not receive services listed in their service plans, mainly due to staffing shortages. These higher costs, however, were partly offset by lower costs for other long term care services, including nursing home expenses.

B. State-Administered Consumer-Directed Options

Even though the CCDE has received much of the publicity surrounding consumer direction, a 2002 survey found that 139 publicly funded programs offered consumer direction in every state except Tennessee and The District of Columbia (Doty & Flanagan, 2002). A 2004 survey focused on consumer-directed programs serving older people, identifying 62 of them (Infeld, 2004). The Infeld report further noted that this number had increased considerably in recent years and pointed out that no consumer-directed program for the elderly had been eliminated in the last five years. The survey provided evidence that nearly 70,000 older adults participate in these programs. Twelve states are participating in the expansion of CCDE (totaling 15 CCDE states) and 19 states participated in the Self-Determination Initiative, which promoted self-determination for people with developmental disabilities.³ In short, consumer direction is practiced among a variety of populations across the country.

Publicly financed consumer-directed programs vary considerably and are generally operated under state Medicaid programs, either within their home- and community-based waiver(s) or

³ Self-determination expands the scope of consumer control from a focus on personal care to a more holistic approach to an individual's life plan, addressing issues such as where program participants live and work.

their state plan personal care option. However, a significant number of consumer-directed programs for older people are financed through state general revenues (15 of the 58 programs responding to the Infeld survey) or receive Title II Older Americans Act funds (13 of the 58 programs).

Although many consumer-directed programs have been operating for some time (over 30 years, in some cases), their significance to the Medicaid program has only recently been recognized through the Independence Plus waiver initiative, an initiative that reflects the support consumer direction has achieved at the level of the federal Medicaid program. The initiative is designed to “give states tools to create programs that will allow people with disabilities and their families to decide how best to plan, obtain and sustain community-based services, placing control into the hands of the people using the services.” (CMS, 2002). The goals of Independence Plus include providing guidance and technical assistance to states that develop and implement consumer-directed service alternatives and developing and applying Medicaid waivers or demonstrations supporting consumer direction. States wishing to offer consumer direction in these waivers must submit a waiver application or amendment that offers participants a comprehensive approach to consumer direction, including detailed and specific health and welfare safeguards. At the time of this report, New Hampshire, South Carolina, Louisiana, Florida, North Carolina, Maryland, Delaware, California, and Connecticut are operating approved Independence Plus programs.

Although the majority of these programs have not been evaluated with the rigor applied to the CCDE, evidence does exist regarding other programs, most notably the California IHSS program (Benjamin & Matthias, 2004, Benjamin & Matthias, 2001; Benjamin, Matthias, & Franke, 2000; Benjamin, Franke, Matthias, & Park, 1999). Positive results regarding the California program are significant because the program lacks many of the consumer supports built into the design of the CCDE.

C. Managed Care

In addition to consumer direction, an important policy trend for older people and people with disabilities is the integration and coordination of health and long term care through various types of managed care programs. These programs range from fully integrated plans, such as the well-known Program for All-Inclusive Care for the Elderly (PACE), which combines Medicare and Medicaid payments into a single payment managed by one entity, to partly integrated plans, which have a more limited scope and include fewer benefits in the capitation amount (Nadash, 2002).

The concepts of managed care and consumer direction are often thought to be incompatible. While consumer direction aims to put control in the hands of consumers, managed care generally involves control by the managed care entity. However, some managed care organizations (MCOs) that focus on people who need supportive services offer consumer direction. Indeed, an individual budget can be described as a capitation amount – a bundled payment that allows flexible use of funds. Rather than contracting with an agency to deliver personal care services, these MCOs contract with or develop organizations that manage a consumer-directed benefit.

In 1999, Meiners, Mahoney, Shoop, & Squillace (2002) conducted a survey of attitudes

concerning consumer direction and consumer-directed practices in 64 MCOs in 17 states that provided long term care benefits, including personal assistance services, to their Medicaid eligible clients. Results indicated that about one-third of the responding MCOs allowed consumers to hire and fire personal care staff, while nearly half gave consumers a “major say” in determining the type and amount of personal care services. A quarter of respondents said they would consider making the most advanced form of consumer direction available to all participants – that is, a Cash and Counseling-type benefit – while a further 45% thought it might be suitable for some participants. Among this latter group, 75% served only elderly participants (Mahoney, Meiners, Shoop, & Squillance, 2003). PACE sites were least likely to be interested, as they felt that the approach was inconsistent with the PACE model.

Three examples of programs combining managed care and consumer direction include:

- Participants in the Minnesota Senior Health Options (MSHO) program can opt to receive the same consumer-directed services available to older adults receiving fee-for-service Medicaid home- and community-based (HCBS) services. Nearly 6,000 people participated in MSHO as of March, 2005.
- Participants in Wisconsin’s Family Care program can opt to receive any of the unskilled services included in their care plan as a consumer-directed benefit. The program has developed its own infrastructure to allow participants to either hire their own FMS to pay their staff or use the program’s “co-employment option,” where an agency acts as the employer of record while allowing the consumer to hire and manage staff. Nearly 25% of Family Care’s 9,000 participants opted for consumer direction in August, 2004.
- New York’s Independence Care Systems is an MCO that allows participants to access consumer-directed services through the State’s Consumer-Directed Personal Assistance Program (CD-PAP). As of March 2005, it enrolled nearly 700 people, about 20% of whom chose to direct their personal care services.

D. Medicare-Only Models

Medicare has limited experience with consumer direction, mainly because consumer direction has been generally confined to services (such as personal care) and items (such as microwave ovens and home modifications) that do not require skilled medical judgment to either manage or purchase. The Medicare program provides few such benefits. Indeed, the Medicare home health benefit was originally intended to provide a finite, post-acute care benefit and does not generally support a beneficiary’s ongoing needs for assistance with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs).

Some background may be useful to explain the Medicare home health benefit’s role in providing long term care.⁴ During the 1990s, much care related to assistance with ADLs and IADLs was provided under the Medicare home health benefit, for three main reasons:

- A 1988 federal court case (Duggan v. Bowen, 1988) caused the relaxation of Medicare rules regarding the provision of home health benefits to beneficiaries who did not show the potential for rehabilitation.

⁴ This history is adapted from Feldman, Nadash, and Gursen, 2004.

- Medicare rules allowed Medicare beneficiaries who qualify for part-time or intermittent skilled nursing or rehabilitation services to obtain a significant amount of home health aide-provided personal care.
- The move toward prospective payment for inpatient hospital services by Medicare MCOs created pressure to shift patients out of hospitals and into homes. At the same time, payment for home health care continued to be based on per visit costs, providing an incentive for home health agencies to admit all types of patients and provide care generously.

Between 1990 and 1997, these factors led to increases in both the proportion of Medicare beneficiaries receiving home health care and the number of visits per person. Over that period, the number using home health rose from 57 to 109 per 1,000 beneficiaries served. Similarly, the average number of visits increased from 36 to 73 per user (Government Accountability Office, 2000).

This trend toward increased use of the home health benefit for long term care was reversed by the Balanced Budget Act (BBA) of 1997, which mandated a new prospective payment system for the home health benefit with the explicit intent of reducing long-term use of the home health benefit (McCall, Komisar, Petersons, Moore, 2001). The legislation had a significant impact on the home health benefit. Home health agencies went out of business; the average number of visits received by home health beneficiaries declined; the proportion of visits categorized as aide visits dropped; and home health expenditures were significantly reduced (McCall et al., 2001; Murkofsky, Phillips, McCarthy, Davis, & Hamel, 2003; National Association for Home Care & Hospice, 2004).

To date, there have been only two experiments with consumer direction within the Medicare program.

1) The Monroe County and Mid-Ohio Valley Project

The first Medicare demonstration, formally known as “A Randomized Controlled Trial of Primary and Consumer-Directed Care for People with Chronic Illnesses,”⁵ tested consumer direction among community dwelling, functionally impaired Medicare beneficiaries with recent significant health care services use in western New York and the Mid-Ohio Valley of West Virginia/Ohio. The demonstration began in July 1998 and ended in June 2002. Each beneficiary was eligible to remain in the demonstration for two years. The study operated under the Section 222 waiver authority, which allowed for the purchase of in-home supportive services and covered intervention costs, including reimbursing the additional personnel expenses of nurses and Voucher Specialists.

Demonstration participants in two of the three treatment groups received a “voucher,” an additional benefit that did not replace existing services. (This feature distinguishes it from the CCDE and the proposed Medicare demonstration.) The voucher was a receipt-based payment system that allowed participants to act as the employer of in-home staff they hired directly

⁵Eggert, GM and Wamsley, B (2004). *Consumer Direction and Medicare*. Jointly published by the Center for Aging and Healthcare in West Virginia, Inc., Parkersburg, WV and the Monroe County Long Term Care Program, Inc. Rochester, NY.

(participants were specifically prohibited from hiring family members) or to purchase agency in-home services and/or supplies, equipment, and environmental modifications. Participants were required to contribute a 20% co-payment. (For those who received the maximum monthly benefit, this would be \$50, 20% of \$250, leaving an effective monthly benefit of \$200.) It is interesting to note that participants rarely spent the full voucher amount, using on average only \$87 of their monthly benefit, despite the fact that any unspent monies could not be recouped. Voucher recipients received information and advice from Voucher Specialists; they did not have access to FMS because the project could find no way to fund these services except from the limited voucher benefit.

The convenience sample of 1,605 subjects was recruited from primary care practices; 1,081 completed the intervention, 320 died, and 204 disenrolled. The target population was defined as community-dwelling individuals with at least two ADL or three IADL needs and prior Medicare use – specifically, a hospital admission, nursing home admission, or home health episode in the previous year. Subjects were randomly assigned to four study groups:

1. The Consumer-Directed Group (n=419), which received a voucher of up to \$200/month to pay for augmented home care (e.g., personal assistance and companion services, in-home respite, transportation, environmental modifications, supplies and equipment);
2. The Primary Care Affiliated Nurse Group (n=382), an additional service designed to improve disease self-management and coach participants to adopt healthier lifestyle practices;
3. The Combination Group (n=420) in which participants received both the \$200/month voucher and the services of a primary care affiliated nurse; and
4. The Control Group (n=384), which received usual care.

The demonstration evaluation examined a broad variety of domains. In addition to investigating the costs of the interventions, evaluators assessed participant satisfaction, functional and other health outcomes, use of the vouchers, and a number of other parameters. Although study results have not yet been finalized, positive results were found. Compared to the control group, contrasts were found in the following areas:

- Satisfaction – Participants in all of the treatment groups exhibited greater levels of satisfaction, although lack of access to FMS was cited as a reason for reduced satisfaction. Satisfaction was highest among the two voucher groups (the Combination and Consumer-Directed groups) and drop-outs were fewest in these groups.
- Functional Outcomes – Among those completing the intervention, outcomes were better for those in the Primary Care Affiliated Nurse group, but no worse for the other treatment groups. There were no differences among groups when all participants were included in the analysis.
- Costs – While all treatment group participants had lower long term care costs (which are reimbursed out of Medicaid or personal funds), their Medicare costs and overall costs – which include Medicare, Medicaid, and personal expenditures – were higher. For those who completed the intervention, Medicare costs were higher, but overall costs were lower than the controls for the Primary Care Affiliated Nurse group, higher

for the Combination group, and identical for the Consumer-Directed group. Early findings from subgroup analyses indicate that certain disease groups may have better cost outcomes (Eggert, 2005, personal communication).

In addition, researchers discovered that vouchers were successful in increasing access to personal care and did not increase Medicare home care costs beyond the additional costs of the interventions themselves (Meng, Friedman, Wamsley, Mukamel, & Eggert, 2005).

The findings on cost are complex. Although survival was similar across all of the comparison groups, costs for individuals who died were higher among treatment group participants than for the control group. This factor, to a large extent, contributed to the higher total and Medicare costs among all treatment group participants, as did the cost of the voucher benefit, which increased the overall costs of voucher recipients because it did not substitute for existing services or result in lower expenditures.

The study demonstrated that consumer-directed care can be feasible for a Medicare population, including those with cognitive impairment, who made up 26% of the sample. A modest consumer-directed benefit that emphasizes flexibility, control, and choice yields high satisfaction levels among beneficiaries without jeopardizing quality of care. In addition, among survivors, the Primary Care Affiliated Nurse intervention demonstrated considerable potential to preserve function.

Achieving cost neutrality will be a challenge, however, particularly for a model of consumer direction that provides cash as an additional benefit, rather than one that substitutes for existing services. Both the Primary Care Affiliated Nurse and two voucher interventions have the potential to be cost neutral, if individuals needing palliative care are transferred to a more appropriate program. Program administrators also felt strongly that cost results would have been improved had the interventions been tested over a longer time period; two years was considered an insufficient period for implementing the intervention, educating and involving primary care physicians, and having an impact on costs. In addition, further analyses may substantiate preliminary findings suggesting that targeting certain disease groups may help to control costs.

2) The Medicare Consumer Directed Durable Medical Equipment (CD-DME) Demonstration

The second Medicare experiment with consumer direction was a much smaller effort. The purpose of the Medicare Consumer-Directed Durable Medical Equipment (CD-DME) Demonstration⁶ was to explore an alternative to the DME procurement process for wheelchairs and related medical devices that would shift control to the consumer and give disabled and elderly beneficiaries a greater say in the selection of equipment suited to their needs. The demonstration involved using third-party consumer-oriented and -directed organizations, Centers for Independent Living (CILs), to help beneficiaries with physical disabilities navigate the complex Medicare payment system for wheelchairs and related equipment. An additional

⁶Glazier, RE, Landino, C, & Reardon, L (August 2003). Evaluation of Wheelchair Purchasing for Medicare Beneficiaries with Physical Disabilities in the Consumer Directed Durable Medical Equipment (CD-DME) Demonstration and Other Fee-for-Service and Managed Care Settings. Process Evaluation Draft. Contract no. 500-00-0032/ TO# 6. Department of Health and Human Services, Centers for Medicare and Medicaid Services.

benefit for beneficiaries was that savings accrued from negotiating product discounts from suppliers could be used to purchase other equipment and accessories (whether or not these were covered by Medicare).

The benefit was tested for three years at four CILs across the country. Each CIL received a one-year development grant of \$150,000. An additional \$280,000 was paid to CIGNA, the insurance company selected by CMS to process claims for the demonstration.

Unfortunately, participation levels were very low, with too few enrollees to ensure a meaningful quantitative evaluation. The limited enrollment was ascribed to a poor demonstration design. Key problems with the design were that the process of obtaining approval for the voucher amount was onerous and required the cooperation of suppliers (thus reducing the consumer's ability to negotiate with those same suppliers at a later date); there were few savings to be made through negotiation because of low profit margins; and dual eligibles had to obtain approvals from both the Medicare and Medicaid programs (using different forms). In short, observers felt that the design – in particular, the approval process for the voucher – was too complicated and offered limited potential benefit for consumers, although they were attracted by the concept and liked the idea of using money saved for other needed items.

Two central lessons from this demonstration relevant to the Section 648 demonstration include: (1) entry into the demonstration needs to appear simple to potential participants; and (2) consumers need support for using their consumer directed benefit, once it is obtained – in this case, from the CILs. The CILs provided helpful information on the different types of equipment available. However, their ability to help clients was limited by a CMS-imposed “firewall” that prevented CILs from knowing how much consumers were authorized to spend. Furthermore, while CILs were pleased with the consumer-empowerment aspects of the program, they perceived a lack of encouragement and timely feedback from CMS project officers and felt that the demonstration was “over-sold” to beneficiaries, whose expectations could then not be met.

E. Private Sector Options

Another model – arguably the purest example of consumer direction – is offered by the private sector. Individuals who use their own money to hire personal care staff are not bound by many of the restrictions common to the public sector. Money for personal care may come from a payout from a private long term care insurance policy or, more commonly, from personal savings or income. While only 9% of long term care expenditures are estimated to be paid out of private insurance policies, about 20% are paid out-of-pocket (Government Accountability Office, 2005). Although the private pay market for personal care is large, information about people's experiences in it is limited.

Research does provide information on private long term care insurance, however. It is becoming an increasingly important source of payment, either as a per diem amount or a cash benefit. More than 80% of all policies reimburse the costs of care up to a daily maximum, while less than 10% pay cash benefits to disabled policyholders without regard to service use (Cohen, 2002.) Cohen found that participants using the cash benefit had higher rates of satisfaction (at 95%) than did those whose policies limited payment to agency staff (whose satisfaction rate was 60%).

Insurance representatives report that the majority of claimants who receive a cash benefit use it to hire attendants who are not agency-affiliated.

Individuals receiving insurance payouts are different from Medicare home health beneficiaries. To qualify for long term care insurance benefits, claimants do not need to demonstrate a need for skilled care (as they do for the Medicare home health benefit). Typically, claimants must require assistance with three ADLs or be cognitively impaired, and most insurance companies employ nurses to check up on claimants periodically – by phoning every 60 days or so, for example.

Claimants receiving policies that reimburse costs face many of the same challenges that cash recipients face: they must identify an agency, work with the agency to find a suitable provider, and negotiate with the agency over hours and tasks that the worker is to perform. Consequently, many aspects of long term care insurance claimants' experiences are similar to those of participants in the CCDE.

Findings from a study of claimants of private long term care insurance policies (Cohen & Miller, 2002) indicated that:

- About a third of claimants, all of whom were receiving home care services, felt they had not purchased enough home care benefits.
- Many claimants felt they needed more help in managing providers to receive the care they needed when they needed it.
- Despite their overall satisfaction with their insurance policies, a sizeable minority of claimants (23%) felt that not all of their functional needs were being met. Reasons for this included lack of service availability, scheduling difficulties, gaps in continuity and coordination of paid and unpaid caregivers, difficulty satisfying their particular preferences, and unsatisfactory quality of care.

Based on these findings, it is clear that recipients of private long term care services confront many of the same issues experienced by participants in public programs that offer consumer direction. The main lesson emphasized by the two key informants knowledgeable about private long term care insurance is that any demonstration proposal should incorporate a component that provides consumers with support and assistance in managing their benefit.

V. How Do People Fare Under Consumer Direction?

Alternative service delivery methods need to show that they improve upon the status quo. This is particularly true of consumer direction, where concern often exists about the potential for fraudulent behavior as well as for the safety of service recipients. At the time of writing, enough evidence has accumulated from rigorous studies to lend confidence in consumer direction as a method of service delivery that is as safe and clinically appropriate as an agency-directed approach.

The National Council on Disability (NCD, 2004), which published a report reviewing evidence on consumer direction, looked at seven studies that examined outcomes, one of which was from

the CCDE. (See Table 1.) Cost outcomes specifically associated with consumer direction are missing because the NCD report did not include any such studies. Information on the cost implications of consumer direction is discussed in section G of this report. The NCD findings are summarized below.

- **Satisfaction** – In the five studies that compared the satisfaction of people under consumer direction with people using traditional agency services, all found significantly higher levels of satisfaction among the consumer directed groups, although all respondents were generally satisfied with their care.
- **Control and empowerment** – In the three studies that examined this parameter in the context of consumer-directed services, all found the consumer directed group to have more favorable outcomes than people receiving traditional services (although the way that this conclusion was reached varied considerably among studies). A fourth study found that older adults with high scores on measures of consumer direction were more satisfied than those with low scores.
- **Unmet needs** – Three studies compared unmet needs between those receiving consumer directed services and those receiving agency services. One discovered that the consumer directed group had fewer unmet IADL needs but more unmet ADL needs; however, this group also had significantly higher levels of impairment. Another study found that individuals receiving consumer-directed services had fewer unmet ADL, IADL, and transportation needs than the group receiving agency services.
- **Health status** – Only one study investigated this outcome. For the consumer-directed group, health outcomes were not significantly different from those using traditional services; in the two cases where a significant difference was found, outcomes were better among those receiving consumer-directed services.
- **Safety** – In the three studies that explored this outcome, two found no differences in safety between those who received consumer-directed services and those who received agency services. In the third study, participants in the consumer-directed group had better outcomes.
- **Quality of life** – The single study that examined this outcome discovered that individuals receiving consumer-directed services reported a better quality of life than people receiving agency services.

For nearly all of the outcomes reviewed by the NCD, results were more favorable under consumer direction than under traditional agency services. The Monroe County and Mid-Ohio Valley project also found increased access to personal care among recipients of an individualized budget (Meng, Friedman, Wamsley, Mukamel, & Eggert, 2005) – as did the CCDE.

In addition, the CCDE examined the impact of cash and counseling on informal caregivers (defined as people, often family members, who receive no payment for supporting a person with long term care needs). The evaluators found that informal caregivers of participants receiving individualized budgets experienced significantly lower levels of stress in two of the three CCDE states, compared to the informal caregivers of people receiving traditional services. In all CCDE

Table 1: Outcomes Associated with Consumer Direction

Author(s)	Title	Year	Program Studied (Sample Size)	Satisfaction	Empowerment/Control	Unmet Need	Health	Safety	Quality of Life
Beatty, Richmond, Tepper, DeJong	Personal assistance for people with physical disabilities: consumer-direction and satisfaction with services.	1998	Virginia Personal Assistance Services (92)	+	+			N	
Benjamin, Matthias	Age, consumer-direction, and outcomes of supportive services at home.	2001	California In-Home Supportive Services (1,095)	+	+				
Benjamin, Matthias, Franke	Comparing consumer-directed and agency models for providing supportive services at home.	2000	California In-Home Supportive Services (1,095)	+		+/-		+	
Benjamin, Franke, Matthias, Park	Consumer direction and in-home services: recipient perspectives on family and non-family service provision.	1999	California In-Home Supportive Services (1,095)	+	+			+	
Doty, Kasper, Litvak	Consumer-directed models of personal care: lessons from Medicaid.	1996	Maryland (300), Michigan (276), and Texas (303) state plan personal care programs	+	+				
Feinberg, Whitlatch	Family caregivers and in-home respite options: the consumer-directed versus agency-based experience.	1998	California respite care program (168)	+	+				
Foster, Brown, Phillips, Schore, Carlson	Improving the quality of Medicaid personal assistance through consumer direction.	2003	Arkansas CCDE (1,739)	+		+	N	N	+

Source: Adapted from National Council on Disability. Consumer-Directed Health Care: How Well Does It Work? 2004.

+ = Statistically significant and positively associated with consumer direction.

- = Statistically significant and negatively associated with consumer direction.

N = No statistically significant association.

Blank cell = Not studied or reported.

states, informal caregivers of people receiving the individualized budget were 10%–13% less likely to say that their physical health suffered than were informal caregivers of control group members – representing a statistically significant difference in each state (Foster, Brown, Phillips, Schore, & Carlson, 2003a and 2003b). A more complete discussion of the effects of consumer direction on family caregivers is available from Doty (2004) and Brown, Carlson, Dale, Foster, Phillips, and Schore (2005).

VI. Parameters of Consumer Direction:

The Section 648 Demonstration involves a range of program design issues. Based on our interviews and literature review, we have identified a number of key issues in consumer-directed programs that are relevant to these design issues and summarized some of the important lessons learned from program experience.

A. Target Population/Size

One of the key design questions for the Section 648 Demonstration concerns the appropriate target population and sample size for a viable demonstration. Not only must this group contain enough individuals who are eligible (in terms of their functional impairment), but it must also contain sufficient numbers of individuals willing and able to self-direct. When considering the subject of target population and size, four central questions emerge, which are addressed below.

1) Is screening appropriate under consumer direction?

There is a view, held by many informants and reflected in the written materials on consumer direction, that questions about the suitability of different population groups for directing their own care are irrelevant to discussions of consumer direction. As one key informant argued, all consumers of personal care services, regardless of age or health status, have the right to choose consumer direction.

This approach was adopted by the CCDE, which did not formally screen applicants for their suitability or appropriateness because it was considered inconsistent with the philosophy of consumer direction. In addition, there was concern that beneficiaries deemed inappropriate might bring legal challenges. Consequently, any individual eligible for traditional services could apply for the CCDE, including those with cognitive deficits or behavioral problems, such as substance abuse or serious mental illness. To allow such individuals to participate, the CCDE permitted them to appoint representatives to act on their behalf. These representatives received the individualized budget and acted as the managing employer of hired staff.

However, some *de facto* screening did take place, due to an element of self-selection among those who opted to participate in the demonstration. Not only did potential participants have to understand and agree to the concept of randomization, they also had to agree to the responsibilities and risks involved, including a substantial amount of paperwork.

Moreover, Cash and Counseling programs did reserve the right to terminate consumers from the program under certain circumstances, although this right was rarely exercised. For example,

Arkansas' IndependentChoices program terminated only three of the 1,004 mostly elderly consumers who enrolled. Criteria for terminations varied by state, but they included the inability to follow program goals, misuse of funds, and inability to manage staff. The CCDE's positive outcomes, plus the very few reports of abuse of consumers or of the allowance, support the argument that appropriateness screening was unnecessary.

2) Do certain populations have stronger preferences for consumer direction than others?

The National Council on Disability (NCD, 2004) reviewed seven quantitative studies that investigated differential preferences for consumer direction based on age, gender, race or ethnicity, and nature or severity of disability. In three of the studies, more than half of the respondents surveyed expressed interest in consumer direction. The greatest level of interest (among 78% of participants) was found in the largest study, a national sample of randomly selected individuals with disabilities over the age of 50 (Gibson et al., 2003). The lowest level of interest found among the seven studies was in 29% of one study's participants.

The studies reviewed by the NCD also examined differences in preferences among the following four sub-groups:

- **Age.** Although some of the studies discovered an age-related difference in preference for consumer direction, the large national study did not. In all of the studies, a substantial proportion of older individuals expressed an interest in consumer direction.
- **Gender.** Six of the seven studies found no difference in preference between men and women, while the seventh found that men are more likely to favor consumer direction.
- **Race or ethnicity.** Five of the seven studies discovered an association between race or ethnicity and preference for consumer direction, but the findings were inconsistent across studies. Four reported a higher preference for consumer direction among African-Americans and/or Latinos than among whites, while a fifth found a higher preference for consumer direction among Chinese-Americans. Latinos, in contrast, were more likely to prefer traditional services. Of the two studies that did not find an association between race or ethnicity and preference for consumer direction, one had limited sample sizes. The NCD report concluded that local factors were more likely to be important than race or ethnicity alone.
- **Nature or severity of disability.** None of the seven studies looked specifically at the type of disability. Two studies examined preferences among surrogate respondents caring for people with cognitive impairments and reported preference rates for consumer direction of 44 and 69%, respectively. Three studies found an association between more severe disabilities and an increased preference for consumer direction, which disappeared following multivariate analysis in all but one study. In a study not considered by the NCD, Glazier (1999) reported that preference for consumer direction was positively associated with a higher number of approved service hours, but negatively associated for individuals who experience worse health, greater pain, and a disease etiology.

Many key informants with experience with the Medicare home health population tended to agree that older people were as interested in consumer direction as younger people. Project managers

from the Monroe County Mid-Ohio Valley Project reported little difficulty in recruiting for the demonstration, using primary care practices as their recruitment base. This was true even though their target population was primarily 65 or older and 52% had received Medicare home health services in the year prior to enrollment. In the end, 87% of participants in that demonstration were 65 or older.

There was disagreement, however, about whether certain health conditions might make individuals less suitable for consumer direction. For example, some informants noted that many Medicare home health beneficiaries qualify for home health because of a new or exacerbated health condition and argued that it would be difficult for them to manage both their unstable health and a consumer-directed benefit. Informants from the Monroe County Mid-Ohio Valley Project specifically noted that the inclusion of individuals who were severely impaired or at the end of life was detrimental to the project, resulting in high costs. They felt that this population probably needed a different type of intervention to address their specialized needs – perhaps a consumer-directed hospice benefit. Based on the experience of the CCDE, this approach may have merit. Each of the CCDE states categorically eliminated participants who were in a hospice-type program. Rationale for this elimination was based on the fact that the consumer-direction approach takes time and involvement from the participant. A hospice situation may not allow sufficient time to develop the key consumer-directed mechanisms.

One set of key informants (interviewed as a group) from integrated programs that enrolled dual eligibles questioned whether their clients would be appropriate for consumer direction; they suggested that individuals with such acute needs would likely have unstable conditions that would make consumer direction difficult. One informant among these was plainly hostile to the idea of consumer direction, saying categorically that older people are not interested in this option.

3) Who actually enrolls in consumer-directed programs?

The studies cited above focused on the stated preferences of individuals who were not receiving consumer-directed services and had varying levels of knowledge about what the concept might actually entail. Although it would be useful to know whether people who express an interest in consumer direction actually enroll, the only existing evidence of this kind is for the CCDE. This evidence is problematic because of the CCDE's randomized design; potential participants may have been reluctant to enroll because they were not certain to receive the consumer-directed benefit. In New Jersey, roughly 40% of the eligible population (participants in the state's personal care option program) expressed an interest in consumer direction, while only 14% actually enrolled in its CCDE. In Arkansas and New Jersey, younger adults with physical disabilities are somewhat more likely to enroll than are the elderly (Phillips & Schneider, 2003). The National Program Office (NPO) for the expanded CCDE projects that 10-15% of a program's eligible population will opt for cash and counseling (Cash and Counseling NPO, 2005). However, this figure is based on the experience of the original CCDE and is therefore likely to be artificially low, because that figure reflects the problems associated with recruiting participants into a program with random assignment.

However, enrollment in consumer-directed programs appears to be highly sensitive to the recruitment strategies employed. The highest level of participation in a voluntary consumer-

directed program appears to be in Kansas, where roughly 80% of participants in two of the state's waiver programs (one for people with physical disability and one for people with traumatic brain injury (TBI)) choose consumer direction. Participation is lower, however (about a third of waiver participants) in the state's waivers for the frail elderly and for people with mental retardation/developmental disabilities (CMS, 2005a). This difference between participation levels is most likely the result of proactive efforts of Centers Independent Living, which focus on serving younger people with physical disabilities and people with TBI, while no equivalent exists in the other two programs.

Although California's In-Home Support Services (IHSS) program has the highest level of enrollment in consumer direction in the country, enrollment for this program is not voluntary in the 46 out of 58 counties that do not offer agency-delivered services as an alternative. Despite the mostly involuntary nature of the program, high levels of satisfaction with consumer direction are reported (Benjamin, Franke, Matthias, & Park, 1999). However, the positive outcomes associated with this program may be due to supports available through another program that some (approximately 10,000) IHSS participants are eligible for – the state's waiver program for frail elders, which serves nursing home-eligible individuals.

4) Do different populations fare better or worse under consumer direction?

Because many people have predicted that older people would not be suitable for consumer direction, the NCD report reviewed studies that examined the actual experiences of older adults in consumer direction and found that age did not significantly affect their outcomes. Two quantitative studies (Benjamin & Mathias, 2001; Foster et al., 2003a) compared the experiences of older and younger people in two different consumer-directed programs. The Benjamin study found that both groups were equally satisfied, with the exception of one measure: the younger group was more satisfied with their workers' ability to get things done inside and outside the house as compared to the older group. On the other hand, the Foster study discovered that in general older participants were more satisfied than younger people, although younger persons' satisfaction increased over time. In addition, the Foster study examined quality of life and health outcomes and found that quality of life outcomes were much better (nearly 20% higher) for people participating in consumer direction in both age groups, while health outcomes for both groups were equivalent to the outcomes for those not participating in consumer direction.

The NCD report did not contain data on outcomes for individuals who cannot or do not wish to direct their care themselves, but do so through the use of a representative. This a group that includes individuals with cognitive impairment, people with developmental disabilities, and people who simply prefer to have another individual managing their care. Use of representatives was common in the CCDE. For example, in Arkansas, slightly less than half of the population of older adults receiving the cash benefit (about half of whom were cognitively impaired) appointed a representative (Phillips & Schneider, 2003). The experience of the CCDE is that these individuals were as successful in Cash and Counseling as any other group. Empirically, only 15% of the 139 consumer-directed programs surveyed by Doty & Flanagan (2002) were found to prohibit participation by individuals who are unable to direct their own care, suggesting that many programs have found such prohibitions unnecessary.

There appears to be no other evidence regarding differences in outcomes based on population differences.

B. Benefits Available Under Consumer Direction

Consumer-directed programs vary considerably in the benefits they provide. Broadly speaking, the full benefit package can include the range of goods and services that can be purchased with the individualized budget, as well as the full range of supports available (discussed below). Here, we discuss only the goods and services available through the consumer-directed benefit, which can assume the form of an individual budget, cash allowance, or voucher (see Appendix A). Some of the elements addressed by program design are:

- **Who can be hired with the benefit?** Although all consumer-directed programs allow program participants to select their staff, the choice of staff can be constrained in various ways. In the most restrictive cases, consumers may only choose among staff already employed by an agency or agencies they are required to use. Although this is promoted as a form of consumer direction, it is arguable whether it really qualifies; as Infeld (2004) notes (p7), it is “inconsistent with [the definition of consumer direction] generally used in the field and this report.” In the least restrictive cases, programs allow consumers to choose any staff they would like. A survey of 62 consumer-directed programs for older people found that 79% of respondents allow family members to be hired as staff, although only one-third allow spouses to be paid and another one-third prohibit parents of children with disabilities from being paid (Infeld, 2004). Programs may further restrict the range of staff available by forbidding the hiring of any individual who fails a criminal background check, as mandated by certain state laws. This requirement can be controversial if, for example, the consumer wishes to hire a relative who had a prior drug conviction but no longer uses drugs. States may also require potential staff to complete formal training courses.
- **What can be purchased with the consumer-directed benefit?** Generally, funds are used to hire staff to provide personal care (assistance with ADLs) or homemaker services (assistance with IADLs). Some programs allow money to be spent on items that are related to personal care (such as a microwave oven, which would reduce the need for assistance with the IADL in planning and preparing meals) but they may also allow a variety of other services to be consumer directed. Infeld (2004) identified the following services in her survey of consumer-directed programs serving elders (listed in decreasing order of prevalence): personal care, homemaker, home modification, assistive technology, respite, meal services, medical services, transportation, caregiver support, skilled care, and in-home rehabilitative services. Two of the 58 consumer-directed programs that responded offer only one of these, while most offer three of the listed services and two offer all twelve.
- **Can consumers set the rate of pay for their staff?** Some programs allow consumers discretion in what they pay their staff, while other programs set a standard payment rate or allow the organization that administers payment to determine the rate of pay. Regardless of who determines the rate, Department of Labor laws (minimum wage, overtime, etc.) must be considered where they apply.
- **Can the benefit be saved and carried over month to month?** Some programs allow individuals to save a portion of the cash benefit for larger purchases. This has proved

to be a valuable feature of the CCDE. However, programs need to develop procedures for recouping funds from consumers who have left money unspent because their budget allocation was too great and the funds were genuinely not needed (Phillips & Schneider, 2005).

The Infeld study indicated that some programs (27 of the 58 consumer-directed programs that responded) allow medical services to be consumer directed. Such medical tasks can include relatively unskilled tasks such as medication administration, as well as fairly complex tasks such as bowel programs. Legally, under state licensing laws (known as Nurse Practice Acts), such activities can normally only be performed by nurses. However, there are two legal mechanisms that allow their performance by unlicensed individuals under consumer direction (although most states allow family members to perform these tasks regardless): nurse delegation and exemptions.

Under the nurse delegation mechanism, a nurse may delegate the performance of certain tasks to unlicensed individuals. In these cases (although the laws vary by state), nurses retain responsibility for ensuring that the task can be correctly performed by a particular unlicensed individual, but the nurses are generally not responsible for their correct performance (this is the responsibility of the unlicensed individual). Nurses are responsible for deciding whether the situation is appropriate for delegation, as well as for training the unlicensed individual to perform tasks correctly.

Reinhard (2001) identifies 11 states that offer very broad discretion to nurses about delegation, while 15 states place some limits on delegation. Among these states, three are in states where delegation is common within consumer-directed programs. One of these is Washington State, which commissioned a statewide study to evaluate the impact of nurse delegation. Currently, this study offers the only scientific evidence regarding the safety of nurse delegation within consumer direction. The study found no adverse consequences of nurse delegation to unlicensed assistive personnel who are caring for some of the most vulnerable persons in community-based settings (Young et al., 1998).

Unlicensed individuals may also perform tasks that are generally restricted to nurses under state licensing law through specific “exemptions” from the licensing requirements. These exemptions typically identify individual programs or types of care (such as care from nursing students, gratuitous care from family or friends, or paid care from domestic workers) where providers can be unlicensed. They may also detail how the exemptions can be applied: for example, they may specify the extent of the oversight and training a nurse must provide to the unlicensed individual. According to Reinhard (2002), nine states have exemptions specifically for consumer-directed programs, while a further 12 states have exemptions that could be applied to consumer-directed programs.

In short, the performance of a range of medical tasks by unlicensed personnel in consumer-directed programs is relatively common and has been an enduring feature of these programs for some time. Although the topic has been inadequately studied, there have been few reports of adverse outcomes among consumer-directed programs where such options are available. Indeed,

the fact that programs continue to offer these options suggests that they have not been problematic.

C. Necessary Supports

Nearly all of the key informants and the written literature emphasized the importance of the two main categories of supports: information and support associated with understanding and operationalizing the benefit (e.g., counseling) and help with the financial and legal tasks associated with hiring a worker (financial management services or FMS).

1) Counseling services

All of the sources consulted for this Best Practices report agree: a counseling component is essential to the success of any consumer-directed program. The need for such assistance is not restricted to the population that typically depends on Medicaid for supportive services – it is also felt among the more affluent and educated populations that receive benefits from private long term care insurance or participate in the Medicare Monroe County and Mid-Ohio Valley Project.

a) The need for counseling

Counseling is critical at many stages, because consumer direction is both a new option for most who encounter it, as well as an opportunity that conveys important responsibilities once an individual enrolls. Potential participants need to be well informed prior to enrollment through effective pre-enrollment counseling and responsible outreach. Pre-enrollment counseling may be performed by outreach staff (this topic is discussed more fully in the section on recruitment) and may or may not be performed by the same persons who fulfill the counseling role after participants are enrolled.

Counseling is also crucial as consumers lay the groundwork for consumer direction. Typically, consumer-directed programs involve a good number of tasks that must be performed fairly quickly prior to receiving services. Consumers must agree to a plan for spending the individual budget, identify potential staff, interview them, inform them of their future responsibilities under the program (ideally, through a written contract), conduct background checks (if desired), develop a plan for emergency back-up, and fill out employment paperwork. These tasks can be intimidating and counseling assistance is often needed.

Counseling is also useful once a consumer begins to receive services. Consumers need to ensure that staff are paid on time; they need to manage staff on a day-to-day basis; and they may need to replace staff or arrange temporary placements during vacations or illness. If the program allows the purchase of goods as well as services, consumers may need help in doing this within program rules.

b) Who provides counseling?

Programs that recognize the importance of the counseling component must make decisions about who should provide these services. They may be provided by:

- **Organizations that provide case management services to the traditional home care program.** Although this option takes advantage of the pre-existing knowledge case managers have about the needs of the population, they may be biased toward the existing

system. Training in consumer direction is particularly important for this group. Experience has shown that using case managers works poorly when they have a low volume of clients in the consumer-directed program, because low volume makes it difficult for them to retain interest and maintain knowledge. Dedicated staffers work best.

- **Organizations that provide consumer-directed counseling.** In the CCDE, states that specially hired and trained individuals to perform counseling had greater success in providing effective support and involving participants meaningfully in the decision-making and planning process. Typically, counselors are hired as state employees or operate under contract to the state. Some state Medicaid programs are allowing program participants to hire independent counselors not associated with an agency or the state, provided that minimum qualifications are met.
- **Other community-based organizations.** Some organizations that have filled this role successfully include Centers for Independent Living, Area Agencies on Aging, local government entities, and other human service agencies. Providers of traditional home care services tend not be ideal counseling organizations because of potential conflicts of interest.

Programs also need to decide whether to make counselors responsible for assessments. There has been concern that assigning responsibility for both assessments and counseling services to the same individual would increase the number of service hours recommended, ultimately increasing program costs. Some evidence of “care plan creep” exists in the Florida CCDE program, where consumers receiving the individualized budget received more service hours than the control group did, despite similar levels of disability (Dale, Brown, & Phillips, 2004b).

2) Financial management services (FMS)

According to the National Taxpayer Advocate FY 2001 Annual Report to Congress for the Internal Revenue Service (IRS), individuals hired to perform personal care type services in the home generally cannot be regarded as independent contractors. Consequently, some entity or individual must be designated as the employer of record for staff in consumer-directed programs. The designated employer is responsible for complying with state and federal payroll and employment tasks.

Typically, states have used two models to comply with IRS regulations. In the first (used by the CCDE states), the consumer is designated the employer of record. Under this designation, the participant has the responsibility to verify citizenship, report and pay state and federal income and unemployment taxes, and purchase workers compensation insurance (if applicable). To do so, the consumer may hire a financial management services (FMS) provider who acts as the consumer’s agent – thus the model is known as the Fiscal/Employer Agent model. In the second model (known as the Agency with Choice model), the FMS itself may be designated the employer of record, although the consumer continues to act as the managing employer, responsible for hiring, managing, and possibly firing staff. Although variety exists among models, all FMS providers ensure that participants in consumer-directed programs reimburse staff appropriately and meet the legal responsibilities of an employer. See Table 2 for a list of responsibilities that typically may be performed by FMS providers (Flanagan, 2005).

Table 2: FMS Responsibilities

<p>Help the participant to manage the individual budget</p> <ul style="list-style-type: none">Invoice the funder for expenditure plan or individual budget funds.Help with monitoring the expenditures and management of the expenditure plan or individual budget. <p>Help participants to understand payroll-related responsibilities and verify citizenship or alien status</p> <p>Help participants to complete required payroll forms</p> <p>Process criminal background checks</p> <p>Prepare and disburse payroll. Key employer-related tasks include:</p> <ul style="list-style-type: none">Collecting and processing service workers' time sheets.Withholding, filing, and paying federal, state, and local income, Medicare, and Social Security (FICA), federal (FUTA), state (SUTA) unemployment and disability insurance (as applicable) taxes.Preparing and issuing service workers' payroll checks:<ul style="list-style-type: none">Refunding over-collected FUTA and FICA, when appropriate.Processing all judgments, garnishments, tax levies, or any related holds on workers' pay.Preparing and disbursing IRS Forms W-2 and W-3 annually.Purchase workers' compensation or other forms of insurance, as applicable and/or available <p>Process and pay invoices for approved goods and services included in participants' expenditure plan or individual budgets</p>

The great majority of participants in consumer-directed programs choose to use FMS, even when they have the option to perform FMS tasks themselves. Depending on the program, choosing to perform FMS tasks can make more funds available for other purposes. In the CCDE, for example, program managers report that only 13 individuals pursued this opportunity. Moreover, when participants have a choice between a FMS provider that provides a wider range of support services rather than the bare minimum of support services (as in Wisconsin, where participants in consumer direction have the choice of two models), most opt for more support rather than less. In Wisconsin, for example, 92% of those participating in consumer direction under the Family Care program chose the FMS option providing greater support (CMS, 2005b).

There are many issues associated with developing the capability for FMS within a consumer-directed program. A well-designed program will consider the following questions when developing its FMS capability:

- **What types of organizations can act as FMS providers?** Programs can rely on a range of community-based providers; a single state-wide organization, whether it be a non-profit, for-profit, or government entity; professional payroll companies; or organizations chosen by program participants. Currently, some organizations provide FMS services to programs based in more than one state.
- **What model of FMS will the program adopt?** There are a number of different models of FMS to choose from that assign employer responsibilities and liabilities in different ways. In some cases, the FMS provider legally serves as the agent of the consumer for payroll purposes but the consumer retains the status of the employer of record. In other cases, the FMS provider is legally the employer of record, while the consumer acts as the managing employer, responsible for determining how, when, and by whom tasks will be performed.

- **What range of tasks will they be allowed or required to perform?** FMS providers may be required to perform some or all of the tasks listed in Table 2.
- **What will need to be done in order to ensure an adequate and appropriate FMS infrastructure?** Must providers be developed from scratch or must they be retrained to provide FMS services? What (if any) start-up funds will be made available to potential providers? In both New Jersey and Florida, grant funding was used to help underwrite developing the infrastructure to support FMS services and offer the organization stability while consumers enrolled.
- **What sort of quality management will be required for FMS providers?** The CCDE found that it was necessary to conduct readiness reviews at the start of program implementation as well as ongoing audits to ensure that FMS providers continue to perform their tasks effectively and efficiently.

3) Issues common to both types of supports

While some issues are particular to the type of support, several key questions arise for both types of support:

- **How will the support organizations be reimbursed?**
To answer this question, three issues will need to be considered:
 - *What is the source of payment?* The answer to this is clearly constrained by the rules governing the funding stream for services. For example, Medicaid rules determine how counseling services can be reimbursed with Medicaid programs. However the cost is financed, the program may also reimburse the provider directly or have participants reimburse the provider from their individual budgets.
 - *What payment methodology will be used?* Some methods for funding supportive organizations include block grants adjusted for case load; a transaction-based fee; a monthly per-person fee; or reimbursement linked to a consumer's length of stay in the program. Although programs have reimbursed FMS providers as a percentage of the individual budget calculated for each consumer, this method is not recommended because it does not reimburse costs accurately.
 - *How much will the program help organizations build the capacity to provide supportive services?* Will start-up funds be made available? In the CCDE, FMS providers operated at a loss for the first few months; it was estimated that a minimum case load of 200 participants was needed for providers to break even. Both New Jersey and Florida used Robert Wood Johnson Foundation grant funding to provide limited start-up costs for the CCDE Project. To date, Medicaid funding has not been available to support this activity, so programs have relied on state funds, when these are made available.
- **What minimum requirements will the state impose on potential providers of support services?** Some states, such as Kansas, impose very minimal requirements,

while others require FMS providers to be licensed under the state Medicaid program. For counseling organizations, programs may set minimum education levels for counselors, or proscribe minimum training standards. More stringent requirements may be appropriate for FMS providers, which handle funds.

- **Should organizations combine the counseling and FMS functions?** Of the CCDE states, only Arkansas allowed organizations to provide both counseling and FMS. Other states felt that locating the two functions in separate organizations would provide an additional check that goods and services in the spending plan are permissible; moreover, there was concern whether organizations would be able to perform both functions effectively. Experience, however, has shown that there are significant advantages to having the same entity perform both functions, because many of the issues for which consumers need counseling are fiscal in nature. Moreover, consolidating the functions in one organization may reduce costs and it is less confusing for consumers if one organization supplies all supportive services. Indeed, the CCDE evaluators have come out with a strong recommendation for consolidation (Phillips & Schneider, 2005) – except where a single organization lacks expertise in both areas. One CCDE state, New Jersey, is currently implementing this change.

Resolving these design issues for support services is crucial to the success of a consumer-directed program.

D. Recruiting Potential Participants

Recruitment into consumer-directed programs can be a challenge because the concept is often unfamiliar to potential participants. Where a program is new, potential participants may be suspicious of encouragements to enroll in a new program. In addition, they may have legitimate concerns about their responsibilities under this program, such as how to hire workers and ensure that they are paid appropriately. Participants who learn about consumer-directed programs as part of a normal intake process may be influenced – positively or negatively – by the information they receive during program enrollment. The CCDE faced the additional problem of having to explain the concept of randomization to potential demonstration participants.

The Mathematica implementation report (Phillips et al., 2003) noted that for the CCDE, direct outreach (which targets eligible beneficiaries) worked better than community education in generating enrollment. The most successful technique in the CCDE was a letter sent to all potential participants from the Governors of Arkansas and Florida. This was particularly important given the newness of the program and the randomization issue. Phillips & Schneider (2005) note that recruitment may be most effective when it is targeted to the concerns of different populations. For example, younger persons with disabilities may respond to messages about increased choice under consumer direction, while older consumers may react positively to messages that advertise the ability to hire relatives.

An unnamed state described in Infeld's research (2004) reported that a governor's press conference, which resulted in news articles and editorials, was highly successful in recruiting participants. In fact, the program was unable to handle the volume of calls received. The CCDE experience also testifies to the importance of personal stories in attracting participants.

Advertising for CCDE programs prominently featured individuals from a variety of population groups who had been successful in directing their own services.

Other consumer-directed programs note the importance of having individuals with positive attitudes and sufficient knowledge serve as intake counselors. This may mean that recruitment is best handled by specialized enrollment staff – an expensive option (Phillips & Schneider, 2005). However, if counselors favor traditional service delivery and have little understanding of consumer direction, potential participants may be dissuaded from enrollment. Indeed, the New Jersey Cash and Counseling program avoided using traditional agencies to recruit participants because of concerns over this possibility. Florida’s Cash and Counseling program, however, attributes poor take-up to its use of traditional agencies. The Mathematica implementation report concluded that it was best to avoid use of traditional agencies for enrollment, although the need for specialized staff may be reduced as programs become more accepted and understood. The Monroe County and Mid-Ohio Valley project was successful in using family physicians to recruit participants.

Family members of beneficiaries are often involved in the decision to participate, so outreach to them can also be useful. Easy-to-understand materials that address the language diversity of the Medicaid population are critical (Phillips et al., 2003).

E. Data Collection

Data are collected for three primary purposes: evaluation, quality assurance, and routine program management. Clearly, many data are useful for all three purposes, and it is the goal of data collectors to build as much data collection into routine program management as possible. Program administrators need to be clear during the program design stage about their data needs; this clarity often requires careful thought about monitoring, quality assurance, and what data will be needed for program accountability.

Separate data collection efforts are often needed to assess parameters that may not be a part of daily program management – such as satisfaction with services, quality of life, and qualitative information about program implementation. Because such data collection often involves personal interviews, it can be costly and complex to implement. Response rates can be low, given the frail nature of the population. Moreover, individuals with cognitive impairment may require proxies, complicating the interpretation of results. Randomized design – as used in the CCDE and the Monroe County and Mid-Ohio Valley project – can also be costly.

Lessons learned from the experience of the original CCDE have been translated into specific data collection requirements for new Cash and Counseling grantees. Grantees will collect information using a specially designed consumer direction data collection tool, Medicaid claims data, and other surveys. In addition to providing data for program evaluation, the tool will facilitate program management through enabling better communication among counselors, participants, and FMS providers. The system will also help program managers to monitor expenditures and provide data for quality assurance purposes. Key data points include:

- Number and proportion of program participants electing consumer direction
- Length of time from enrollment to receiving the individual budget allocation

- Cost per recipient per month for those electing consumer direction and those using traditional services
- Demographics (gender and age)
- For both those electing consumer direction and users of traditional services, utilization of acute hospital care; sub acute nursing home services; long-term residential care; Medicaid home health services; and outpatient physician services
- Limited information on Medicaid service use and cost
- Overall satisfaction
- Amount of paid care
- Number of paid caregivers
- Satisfaction with paid caregivers
- Level of unmet need and access to care
- Disenrollment from the demonstration (number and reasons).

The Monroe County and Mid-Ohio Valley project also attempted a thorough evaluation and collected data on a range of parameters. In retrospect, program managers felt that they attempted to cover too many parameters and collected too much data. Their advice was to hone in on key domains (which should be related to program goals) and collect high quality information in those areas. They also noted the difficulty of collecting good cost data, and reported delays in obtaining person-level Medicare cost data for other services.

A further data collection effort may be relevant to the proposed Medicare demonstration: information on drop-outs. Such information can be useful for evaluation purposes and can provide valuable information for quality assurance purposes – particularly in developing a sense of the factors that contribute to success or failure in consumer direction.

F. Quality Management

Developing effective quality strategies for consumer-directed programs presents unique challenges. Under traditional systems, program funders generally rely on the provider community to assume front-line responsibility for monitoring the delivery of services/supports and for participant health and welfare. The provider often operates under strict program regulations, implements specific training and monitoring requirements, and assumes responsibility for ensuring that quality services are delivered by qualified staff. Back-up staff is consistently available (in ideal situations), personnel problems are managed by the agency, and payroll and employment taxes are processed routinely. Consumer direction removes the traditional provider agency from the program design and replaces it with a higher level of responsibility for consumers and a system of flexible supports directed by the consumer.

A survey of consumer directed programs for the elderly (Infeld, 2004) describes some common mechanisms used for quality assurance by these programs:

- 78 % use consumer satisfaction surveys.
- 69% require criminal background checks for staff.
- 62% commission program evaluations.
- 57% require providers to be professionally certified.
- 48% require a system of emergency back-up for when staff are unavailable.

- 48% use case management.
- 41% use external case reviews.

However, the CCDE placed a special emphasis on quality management and represents best practice in this area. From its initial design, the demonstration concentrated on identifying and designing quality elements for each of the three state programs. Important built-in quality management elements included:

- **Establishing operational policies, procedures, and practices** – Policies, procedures and practices specific to consumer direction were clearly specified in order to set expectations and provide clear direction. Every attempt was made for these to be applied consistently throughout the program.
- **Informing key players of their rights, roles, and responsibilities** – Consumer direction works best and participant well-being is ensured in an environment where the rights, roles, and responsibilities of all participants are clearly defined – the person receiving support, the family, providers of services and supports, and the funder. Participants, and their families or representative, should receive comprehensive information and training about their rights and responsibilities as Medicaid participants in a consumer-directed program.
- **Addressing abuse, neglect, mistreatment, and exploitation** – Under the consumer-directed model, participants, their families, or their representatives need training to identify threats to the participant’s well being – i.e., abuse, neglect, mistreatment, and/or exploitation. The CCDE programs provided information to help consumers and those around them to recognize, understand, and address such problems. Consumers should know in advance how to summon assistance and report problems.
- **Designing a comprehensive system of supports** – As previously discussed in the “Necessary Supports” section above, consumers have a challenging array of responsibilities under consumer direction – directing their plans of care as well as selecting and managing individual providers. Because of this high level of responsibility, the service environment must be expanded to include an array of nontraditional, flexible supports. However, not all consumers will want or need the same level of support; utilization should be at the discretion of the consumer.

Counseling and FMS providers play an important role in quality management when:

- Counselors teach consumers to recognize, address, and report inadequate care and situations that potentially jeopardize their health or welfare.
- Counselors identify situations that threaten health and welfare and work with consumers to address them.
- Counselors train participants to manage their expenditure plan or individual budgets properly (i.e., by not incurring expenses in excess of their approved service plans/budgets).
- Counselors are available on an ongoing basis so they can respond to consumers’ changing needs and circumstances.
- FMS providers protect consumers against financial liability if federal, state, and local taxes are not paid in accordance with tax laws or if independent providers are

not paid in accordance with the laws of the Department of Labor and Fair Labor Standards Act (FLSA).⁷

- FMS providers protect consumers by helping them to obtain homeowners or renters insurance and pay the premiums for the individual (if permitted by the program agency), or helping to secure workers compensation insurance for staff.
- FMS providers monitor expenditures under consumers' individual budgets and check them against their plan of care. Underspending can flag quality issues with staff; moreover, programs must recoup unspent funds.
- **Ensuring the Availability of Emergency Services** – The failure of a worker to report to work can place consumers in potentially harmful or life-threatening situations. Programs should ensure that consumers develop emergency back-up plans to guard against this possibility and test them periodically.

Two specific quality concerns in consumer-directed programs providing cash benefits are the potential for fraud (misuse of the cash benefit) and the potential for neglect of the consumer. However, experience with the CCDE shows that such abuse was extremely rare. Phillips et al. (2003) note that two steps were crucial to guard against abuse of the individualized budget: 1) close review of spending plans to ensure that they contain only permissible goods and services, and 2) mechanisms to verify time sheets and check requests against the spending plan. It is also important that counselors be alert to situations where people might attempt to enroll relatives in CCDE for their own gain, i.e., obtaining the allowance for their own use.

Another approach to quality within consumer-directed programs emphasizes mechanisms to support the consumer's role in defining and ensuring quality. In a guide to quality in consumer-directed programs, Applebaum et al. (2004) notes that consumers need clear, appropriate, and ongoing information, since consumer needs change as they gain experience with consumer direction. The authors recommend instituting consumer support activities such as those used in the CCDE: initial and ongoing consumer training, assistance with developing and implementing purchasing plans and various employer issues, and designing back-up plans. They also recommend strategies to incorporate the feedback and opinions of consumers, such as complaint hotlines and consumer involvement with program design; this latter approach is also recommended by the CCDE evaluators (Phillips & Schneider, 2005).

G. Budget Impact and Cost Issues

Assessing the budgetary impact of consumer direction is a challenge, particularly given the lack of rigorous studies on this topic – the CCDE is the only source of relevant information. Historically, the first step in determining the budgetary impact of consumer direction has been to compare the direct per capita costs of a consumer-directed program with the direct costs of traditional services (an effort that would be challenging when the traditional service is a capitated benefit such as Medicare home health). Using this methodology, consumer direction generally appears to be cost-effective. Typically, the cost of an hour of worker time is considerably less under consumer-directed programs, because no overhead is being paid to an agency. Moreover, some states intentionally discount consumer budgets to ensure that per capita costs are the same

⁷ The Fair Labor Standards Act of 1938, as amended (29 U.S.C. 201, et seq.).

under consumer direction as they are under traditional services. This discounting is an acknowledgement that many services contained in a plan of care are not necessarily delivered due to factors such as hospital stays and staff illness.

An important finding of the CCDE, however, was that participants in consumer direction were more likely to receive services listed in their plan of care than were people receiving traditional services (Dale, Brown, & Phillips, 2004a; Dale, Brown, & Phillips, 2004b), resulting in significantly higher costs among treatment group participants. In Arkansas, nearly a quarter of control group members received no services at all (Dale & Brown, 2005). This under-service was mainly the result of worker shortages, which were not accounted for under the discounting mechanism used by the program. (The program discounted allowances by 14%, but it would have needed a 32% discount to cover undelivered services.) Thus, participation in consumer direction had the desirable outcome of increasing access to needed services and the undesirable outcome of increasing costs. Such an outcome is unlikely under the Medicare home health benefit, where access to services listed in a plan of care is not an issue.

Another reason for higher costs among treatment group participants was found among children and nonelderly adults in Florida (most of whom had developmental disabilities). In addition to the fact that control group members did not always receive services listed in their plan of care, the evaluators found that care plans for those receiving the individualized budget authorized more hours than were authorized for control group members, despite similar levels of need (Dale & Brown, 2005). The relevance of these findings is limited because this group does not exist in the Medicare population.

This trend in authorizing more generous care plans for treatment group members arose from problems in the program's reassessment methods, which administrators taken steps to address. The CCDE evaluators recommend that programs protect against "care plan creep" by emphasizing four concepts: staff responsibility for reassessment and for setting the amount of the individualized budget; requiring documentation of changes that justify increases in care plan hours; requiring external review of care plan hours; or adopting a standardized assessment process (Phillips & Schneider, 2005). However, the evaluators also note that assessments conducted by agency staff might be influenced by their knowledge of staff availability – in others, care managers may authorize hours only if they know if there are enough staff available to provide them (Dale & Brown, 2005).

In nearly all of the treatment groups analyzed, higher personal care costs were mitigated by lower costs for other Medicaid services (such as nursing home care). In some cases, these reductions in other costs meant that there were no significant differences between the overall Medicaid costs of the treatment and control groups (although costs were higher in all cases). This held true, in Arkansas, for nonelderly participants in Year 1 of the demonstration and for all age groups in Year 2; in New Jersey, it was true for all age groups in Year 1 of the demonstration, but not in Year 2; and, in Florida, it was true only for the elderly in Year 1 (Dale & Brown, 2005). It is difficult to draw any overall conclusions about cost from these patterns of effects; however, it is notable that the largest reductions in Medicaid long term care costs were found in the states and age groups that had the largest increases in access to care (Dale & Brown, 2005). The demonstration had no impact on Medicare costs.

Another major cost issue for the CCDE was concern about the “woodwork effect.” Observers feared that any per capita savings would be negated by increased enrollment attributable to the appeal of a cash benefit. This could be observed by monitoring the proportion of new enrollees to old enrollees, on the assumption that an explosion of new enrollees would indicate that the cash benefit was attracting individuals who might not otherwise have enrolled. To guard against this possibility, procedures were introduced to limit the enrollment of such individuals. In New Jersey and Florida, only individuals already receiving services could opt into demonstration participation. In Arkansas, two-thirds of demonstration participants had not received services prior to demonstration enrollment, providing some evidence of a woodwork effect, although the high proportion of new service recipients is also likely due to worker shortages (Brown, Carlson, Dale, Foster, Phillips, & Schore, 2005). In any case this, too, is unlikely to be an issue under Medicare home health.

However, there are expenses other than direct service costs that arise in consumer-directed programs that are likely to emerge in any Medicare demonstration project. Because these costs are not part of traditional service delivery, it may be a challenge to find ways of financing them under government programs that restrict reimbursement to particular service categories. Such expenses include:

- **Start-up costs** – Where such services are not already operational, FMS and counseling providers will need to develop an infrastructure to provide support services. Other start-up costs include funding for outreach programs to recruit participants; education for existing program staff and service providers; and adapting existing data collection, quality assurance, and monitoring capabilities for the new consumer-directed program. Each CCDE state received around \$750,000 in federal funds for start-up activities, funds that were matched by the state to reach of total of roughly \$1.5 million for participating states.
- **Ongoing funding for support services** – As noted previously, both a counseling and FMS component are necessary for a successful consumer-directed program. Little systematic evidence exists regarding the cost of support services and the most cost-effective caseload for these services. One state, South Carolina, spends \$15 per month for FMS and \$50 per month for other supports; two of the CCDE states (Arkansas and New Jersey) spend a total of \$75 per month for both counseling and FMS services. The Monroe County and Mid-Ohio Valley project spent \$42.64 per month for its “Voucher Specialists.” Although these were primarily counselors, they provided assistance with some employment-related tasks. FMS were not available for that demonstration because preliminary investigations found that the cost was too high and there was no way to fund it under Medicare.

While some start-up costs can be avoided by using existing infrastructure (for example, by locating the demonstration in an area where support services already exist), developing funding mechanisms for the other costs noted above will be a major design challenge.

While the CCDE has collected further information that addresses the impact of consumer direction on the total cost of Medicaid and Medicare services, results from the analysis of these data are not available at the time of writing. Other evidence regarding the impact of consumer direction on costs comes from the Monroe County and Mid-Ohio Valley project, which found higher Medicare costs for people in consumer direction. However, the relevance of the Monroe County and Mid-Ohio Valley findings is limited due to its different demonstration design, which provided a small add-on cash allowance rather than cashing out existing services (as the CCDE did).

H. Workforce Issues

For consumer direction to succeed, consumers must be able to identify and hire appropriate staff. Among the responsibilities an employer assumes, the most serious are ensuring that staff are paid regularly and that the appropriate payroll taxes are deducted. These are generally handled through use of a financial management service (FMS), discussed more fully above. Similarly, consumers may need help carrying out many management tasks – hence the need for counseling services (which are also discussed above). However, many other worker issues remain. Four of these core issues are addressed below.

1) Staff availability

Finding appropriate staff can be a challenge for both traditional agencies and consumers looking to hire independently. The consensus in the literature and among key informants is that consumer direction considerably expands the available pool of staff, a benefit that is especially valuable in rural areas where obtaining staff can be a major challenge for traditional agencies and where travel costs can become onerous for public programs. The worker pool is particularly enhanced where programs allow the hiring of legally responsible relatives (prohibited in most Medicaid programs), as well as other family members, neighbors, and acquaintances who would never otherwise consider working in home care.

Some consumer directed programs provide support for people who are unable to find appropriate staff from among their family, friends, or neighbors. Such assistance is normally provided through the counseling function and can include help with recruiting strangers – for example, by using newspaper ads or church notice boards – and may also include maintaining a registry of potential workers.

2) Staff quality

The pool of staff is only truly expanded if the quality of services provided under consumer direction is at least as good as that provided by agency staff. Existing evidence indicates that this is the case. The section on outcomes (Section V) provides evidence that outcomes under consumer direction are at least as good as those produced through traditional services, despite the lack of formal training and credentialing for directly hired staff. It is important to recognize, however, that training requirements for Medicare home health aides are normally more demanding than those for individuals providing personal care or chore services under the Medicaid program; results may therefore not be generalizable to the Medicare context.

Two studies provide detail regarding staff training. Benjamin (2000) discovered that agency staff in the California In-Home Supportive Services (IHSS) program received less training than

expected and that much of this training was about agency procedures, such as how to complete time sheets. In contrast, consumer-directed staff received more training than predicted from family physicians and home health nurses. In addition, consumer-directed staff were more likely to have received training in providing paramedical tasks (such as injections) than agency staff were, and were also more likely to say they would consult a physician about a consumer's medical problems. Outcomes for people receiving consumer-directed services were as good as or better than those for people receiving traditional agency services.

Dale et al. (2003) discovered much lower levels of formal training reported by directly hired staff than by agency staff. For example, while 95% of agency staff reported that they had been trained, only about half of consumer-directed staff reported this. However, many of the directly hired staff had been caring for the consumer prior to program participation and may have felt prepared because of that prior experience. Indeed, they were as likely as agency workers to report that they felt fully prepared to help the consumer. Directly hired workers were more likely to report feeling fully informed about a consumer's medical condition (90 percent versus 83 percent). Despite the low levels of formal training, outcomes among this population were good; Foster (2003a) reported positive outcomes in a companion analysis of this sample.

3) How are staff treated?

Consumer direction skeptics are often concerned about the well-being of staff hired directly by consumers. Because such staff do not receive the protections and employment benefits offered by agencies, there is concern that they may be exploited and have little recourse.

Two studies have examined staff experiences under consumer direction. One major study was done in California of the IHSS program (Benjamin, 2004). Using a random sample of 618 staff from both the consumer-directed and traditional programs, the study assessed differences in worker stress and satisfaction and found that staff in the consumer-direction option had more positive outcomes in most dimensions of stress and satisfaction – despite the lower pay and fewer work benefits received.

A second set of findings comes from the CCDE project in Arkansas. This study found that

In general, the Cash and Counseling model does not appear to create adverse consequences for caregivers through either a lack of training or poor compensation. Directly hired workers were paid about the same wage on average as agency workers, but expressed substantially greater levels of satisfaction with their compensation. When differences in total hours of care provided were taken into account, caregivers hired by IndependentChoices caregivers were no more likely than agency workers to suffer physical injury or strain from caregiving, despite their being much less likely to receive training. Finally, both agency workers and directly hired workers were quite satisfied with their overall working conditions. Thus, workers hired under IndependentChoices appear to be as pleased with the program as consumers are (Dale et al., 2003).

In short, existing evidence indicates that workers fare as well, if not better, under consumer direction as they do under traditional services. However, a well-designed consumer directed

program will include mechanisms to protect workers against exploitation by, for example, providing them with information about how to report abuses.

4) Emergency back-up

Under a consumer-directed system of service delivery, consumers whose staff cancel at short notice or fail to show up entirely can be left in difficult, sometimes life-threatening situations. Under traditional service delivery, an agency would be responsible for ensuring that replacements are sent and that consumers receive necessary services. Under a consumer-directed system, consumers themselves are responsible.

Planning for emergency back-up is an explicit responsibility under Medicaid waiver programs: it is the duty of states to ensure the health and welfare of Medicaid beneficiaries. Consequently, Medicaid waiver plans must provide evidence (including the specific operational steps taken) of an emergency back-up system when the failure of the staff to show up places participants in a potentially harmful or life-threatening situation. All new waiver applications or new amendments to existing waiver programs must describe a program's emergency back-up system.

States meet the requirement in a number of ways. These include allowing family and friends to fill in when staff are absent; allowing other Medicaid services – including other waiver services – to substitute for necessary care; creating toll-free emergency telephone numbers so participants can access an emergency worker registry; making emergency response devices available through Medicaid funding or individual allowances; having case managers available on-call to help in potentially harmful situations; using child or protective abuse systems; and finally, using community emergency systems through a 911 call.

The CCDE states incorporated emergency back-up planning from the start. During the assessment and service plan development process, participants were required to develop individual back-up plans, which were documented in the service plan and reviewed periodically. Emergency back-up staff, like primary staff, tended to be family, friends, and neighbors. Like primary staff, potential back-up staff had to meet all hiring requirements, such as criminal background checks and payroll paperwork.

I. Provider Reception

Providers of traditional services are often resistant to the introduction of consumer direction. Some of their concerns are:

- **Loss of business** – Will consumer direction reduce their caseload? Medicare home health agencies may be particularly sensitive to this concern due to their recent downsizing experience following the BBA.
- **Participant health and welfare** – Agencies generally perceive that their organizational procedures and training efforts are necessary for client safety.
- **Concerns over the greater flexibility allowable under consumer direction** – Agencies must comply with a host of regulatory requirements, which, among other things, limits how they provide services and involves considerable effort.
- **Lack of client oversight** – How will the state monitor program participants if there are no home visits by agency staff?

- **A reduced staffing pool** – Will consumer direction make even fewer appropriate staff available to agencies, which often have trouble maintaining adequate staffing levels? Will staff leave the agency to work directly for consumers?

A minority of states in the Infeld survey of consumer-directed programs serving older people (2004) reported that provider resistance was a serious barrier to consumer direction. Tactics that traditional providers have employed to prevent the establishment of consumer-directed programs include legislative attempts to require certification for independent providers and a successful effort to require consumers to sign restrictive contracts preventing them from switching providers. However, Infeld notes that this level of resistance was far from universal. Indeed, in one state a provider agency is taking the lead in implementing consumer direction.

Programs can work to address provider concerns by involving them in program planning and implementation. For example, Arkansas convened a task force to issue policy design recommendations on the program. Providers, including home health providers, were asked to be a part of that planning committee. Providers were also encouraged to develop and provide the support services that are required with consumer direction (counseling and FMS activities). A program newsletter was also used to inform providers in the three CCDE states (Phillips & Schneider, 2005). Providers began to see that consumer direction had benefits for them – over time, providers began referring their “difficult to serve” clients to the consumer-directed program.

In New Jersey, too, a home health sector that was initially opposed to the demonstration eventually supported the consumer-directed approach for four reasons. First, good personal relationships were developed between program staff and the industry. Second, the industry came to see consumer direction as inevitable and to understand its benefits for some service recipients. Third, program administrators were responsive to industry concerns – for example, they discouraged participants from poaching agency workers. Fourth, it became evident that the demonstration would not substantially reduce caseloads because not every program participant wanted to participate in the demonstration (Phillips & Schneider, 2003).

A recent survey of providers for Pennsylvania’s Department of Aging (PDA) found high levels of support for consumer direction among providers. This appears to result from the PDA’s consistent support of consumer-directed options in the state. While 30% of providers said that consumers can currently select their worker, 57% said they should be able to. The report concluded by noting the importance of training providers so they can implement consumer direction within their agencies (PDA, 2005).

J. Liability Issues

Concerns about liability are often seen as an impediment to consumer direction. Under consumer direction, liability can potentially be assigned to a number of parties: staff, the state, FMS providers, and home health agencies. However, respondents familiar with consumer direction argue that such fears are misplaced. First, they note that consumers, even those typically considered high-risk – people with high levels of frailty, people who are older, and people who are cognitively impaired – are generally very satisfied with consumer direction and have good health outcomes. Second, consumers who can do so often hire family members to

perform personal assistance tasks. Consequently, liability concerns are reduced because family members are unlikely to pursue compensation in the courts (Sabatino & Hughes, 2004). Third, few liability cases have actually been decided in court – and none, so far, has concerned liability issues in a consumer-directed context (Sabatino & Hughes, 2004).

Sabatino and Hughes (2004) reviewed the range of issues around liability under consumer direction based on a survey of case law involving home care workers, which allowed them to conclude that liability under consumer direction is no greater and may be less of a risk than under traditional services, as long as roles are clearly defined. They note that limited case law exists in this area, despite the longevity of some consumer-directed programs. Indeed, the researchers were unable to find a single case that arose out of consumer-directed care, and only 12 cases of caregiver negligence (against home care agencies under traditional service delivery) were identified. More recently, it appears that other cases have arisen (in the California IHSS program, in particular), although it is difficult to generalize about these in any systematic way.

Despite the lack of cases, the analysis of potential liability risks concluded that the greatest level of theoretical risk is to directly hired workers who are negligent. However, in practice, that risk is low, because such individuals are unlikely to have substantial assets and are therefore unlikely to be a litigation target.

Another important type of liability risk under consumer direction is the risk to consumers if a worker should suffer on-the-job injury. A key recommendation is, therefore, to require workers' compensation insurance when consumers hire staff. This is a combined government and private insurance program mandated and administered by states and paid for by employers (except in Oregon and Washington State). It is a no-fault social insurance system which mandates the payment of statutorily defined medical, disability, and other benefits (such as death and burial) to covered workers whose injuries and illnesses "arise out of and in the course of employment." It limits the type and amount of compensation an employee can seek and also prevents the worker from seeking other compensation, such as damages for pain and suffering.

Sabatino and Hughes also note that counselors may be thought to carry risk under consumer direction. However, because the consumer explicitly carries primary responsibility for decisions under consumer direction, this separation of responsibility should protect counselors from vicarious liability. However, they recommend that those designing programs be careful about how they describe counselors' duties under consumer direction and that counselors be trained in the limits of their responsibility.

The risks to the government are also reviewed by Sabatino and Hughes. Some key recommendations are to obtain consent from program participants; institute steps to ensure the appropriateness of representatives for consumers with reduced decisional capacity; develop procedures to deal with consumer complaints; ensure that FMS providers are independent contractors rather than employees of the state; avoid vicarious liability as the employer of workers by following the cash and counseling model; and ensure that emergency back-up systems are in place and adequate.

In short, Sabatino and Hughes found very little evidence that consumer direction poses a liability risk. To reduce risk, however, they recommend that programs should be designed with adequate quality assurance mechanisms; that each party be made fully aware of their risks and responsibilities under consumer direction; that understanding of these risks and responsibilities be documented, wherever possible; and that clear and explicit procedures be instituted for difficult areas.

VII. How Relevant Are Previous Experiences with Consumer Direction to the Medicare Home Health Population?

The Medicare home health benefit differs considerably from the Medicaid programs that have been the focus of this Best Practices report. These differences from the Medicaid program matter because the bulk of tangible evidence regarding consumer direction comes from Medicaid consumer-directed programs – more specifically, from the CCDE. Although a number of long-running programs have been operated by states using state general revenues, and consumers in the private sector have long practiced “consumer direction” whenever they have used private funds to purchase support for a family member with ADL needs, most of these experiences have been undocumented and unevaluated. Thus, their relevance to the Medicare program is difficult to establish. Moreover, many locally-administered publicly funded programs aim to supplement the Medicaid program and are therefore often constrained by Medicaid rules and eligibility categories.

Some key differences from Medicare include:

- **The availability of personal care** – Medicare does not currently cover personal care services as a separately defined benefit. However, personal care is available under the home health benefit, which provides skilled nursing care, social work services, home health aide services, and speech, occupational, and physical therapies. Only home health aide services, which include personal care services, are relevant to the proposed Medicare demonstration. However, home health agencies argue that the Medicare home health aide function is qualitatively different from the personal care function typical of Medicaid programs, because home health aides receive more training and perform some paraprofessional tasks as part of the skilled care received by home health beneficiaries. In contrast, the programs discussed in this report offering consumer direction vary widely, but are similar in that the services provided via consumer direction are predominantly non-medical in nature.
- **Eligibility requirements** – To qualify for the Medicare home health benefit, beneficiaries must be homebound (see Glossary) and require skilled nursing or rehabilitation therapy services. Moreover, physicians must certify an ongoing need for services every 60 days, and a new plan of care – specifying the types, amounts, and frequency of services provided – must be developed and signed by the physician every 60 days. These requirements mean that many home health beneficiaries are post-acute and likely to be experiencing unstable health conditions. In contrast, most consumer-directed programs base eligibility on the participant’s functional and

financial status, often requiring that participants have an ongoing need for assistance with at least 3 ADLs. Medicaid waiver programs require that participants be eligible for nursing home admission. In short, Medicaid personal care recipients are more likely to have stable and ongoing needs for care.

- **The relevance of state and local factors** – In contrast to the Medicare program, which is administered by the federal government, there is considerable variety in how most consumer-directed programs are administered. Not only are they shaped by each state’s Medicaid program, which affects the entire context of care provision in the state (particularly the infrastructure for service delivery), programs are also shaped by other state- and funder-specific factors. For example, Wisconsin’s home and community-based services are administered at the county level. Nurse Practice Acts, which determine whether and how certain nursing tasks can be performed by unlicensed personnel, also shape what is possible under a consumer directed program. Some lessons learned from existing programs will be limited in their applicability to a Medicare demonstration simply because of these state-specific factors.
- **The regulatory regimen for agencies and individual providers** – Services provided under the home health benefit must be delivered by a Medicare-certified home health agency, which must meet the Medicare Conditions of Participation, an extensive set of guidelines and requirements that govern virtually every aspect of agency operation and service delivery. Moreover, services can be delivered only by agency staff who meet specified training and competency standards and are supervised by skilled clinical staff from the home health agency. The amount, nature, and timing of all services provided must be ordered by a physician. In contrast, the programs reviewed for this report fall under a variety of regulatory regimens, dictated by both state and Medicaid law. Few consumer-directed programs have strict certification requirements for directly hired staff. Indeed, evidence shows that such requirements have little impact on the quality of services.
- **The entities responsible for oversight of service recipients** – Under Medicaid and other state-administered programs, the case management or counselor role is the locus of official responsibility for consumers who self-direct. This role, however, has been designed to support consumers’ desire to increase their control over the day-to-day aspects of their lives; moreover, states have sought to limit counselor liability by carefully constraining their role. This has often meant that consumers have more rights and responsibilities vis-à-vis service professionals than under traditional service delivery. (After all, the goal for many consumers is to minimize “over-medicalized” home environments.) Such an approach stands in contrast to that of Medicare home health agencies, which are required, under federal regulation, to emphasize the role of the nurse in coordinating a bundle of services that includes social work, therapies, and home health aides.
- **Reimbursement mechanisms** – Medicare beneficiaries receive services in 60-day “episodes” of care, and agencies are paid prospectively for each episode. The Medicare home health Prospective Payment System (PPS) was implemented in

October 2000 and provides bundled payments, adjusted based on beneficiary characteristics, which are rendered to home health agencies at the beginning of an episode of care and are intended to cover the average cost of all services delivered during that home health episode. This makes it impossible to determine exactly what is spent on home health aide services. In contrast, the consumer-directed programs reviewed for this report mainly reimburse services on a fee-for-service basis. In general, these reimbursement mechanisms are constrained by Medicaid or state law.

In short, the fact that nearly all previous experiences with consumer direction were shaped by the Medicaid program seriously limits its applicability to this project. Furthermore, there a lack of evidence that would help us to understand how the differences between Medicare and Medicaid would affect individuals' ability to self-direct.

VIII. Discussion of the Challenges of Consumer-Directing Medicare Home Health

The Medicare program is very different from any other environment where consumer direction has been tested. To launch a demonstration in a Medicare environment, the following questions will need to be considered:

Does the Medicare home health population contain enough interested individuals with high levels of home health aide use to warrant a demonstration?

The first challenge of the demonstration will be to determine whether there are enough appropriate persons receiving the Medicare home health benefit to make a demonstration worthwhile. Preliminary analyses indicate that there may be enough long-term users of the home health benefit who are also high users of personal care services (as measured by the number of home health aide visits) to make a demonstration feasible. The potential sample size, however, is small. Many additional factors make the potential success of the proposed demonstration difficult to assure.

How will potential participants be identified and recruited?

Preliminary discussions of recruitment methods for a Medicare consumer-directed benefit indicate that the cooperation of home health agencies will be critical for identifying potential participants in a timely manner. Only agencies will have access to information that will identify beneficiaries as appropriate for the demonstration. Demonstration implementation will require a large education effort involving the agency workers responsible for identifying potential participants – agency staff who might find the concepts of consumer direction contrary to their training and usual work practices. Moreover, such involvement by staff imposes costs on agencies (due to time lost in training sessions, for example). Agencies are likely to seek to minimize such costs, either by requesting reimbursement or by limiting their role.

Moreover, in order for participants to transition to a consumer-directed benefit in a timely manner, much work will need to be done prior to the transition. Individuals will need to be trained and reimbursed for helping participants during this phase. They will need to administer

the transition; educate consumers about the responsibilities of consumer direction; teach them to manage a consumer-directed benefit; and, not least, support them in identifying and hiring staff.

However, experience from consumer-directed programs shows that recruitment is most effective when potential participants are targeted directly – ideally, in the home rather than by telephone or mail – and when recruiters are committed to the philosophy of consumer direction. By and large, consumer-directed programs avoid using organizations committed to traditional service delivery as recruiters for consumer direction. If such organizations are used, the advice has been to designate a few staff as experts in consumer direction and make them responsible for recruitment and training. This helps to avoid the expense of an organization-wide educational effort and to ensure that the new option is presented in a positive light. It is difficult to see how this would work in the context of a home health agency, which will need a wide recruiting base in order to identify sufficient numbers of individuals for the demonstration.

Will there be enough lead time?

As noted above, participants will need to have their arrangements in place prior to transitioning to a consumer-directed benefit in order to ensure continuous access to needed services. Because the proposed Medicare demonstration is likely to target individuals with 120 days of home health service, doing this in a way that maximizes the time spent in receipt of a consumer-directed benefit will pose a considerable challenge; this makes early identification and education of potential participants especially important. The process developed to transition consumers from traditional home health into a consumer-directed approach must be a simple, effective one to allow a timely transition; evidence from the CCDE indicates that a 120-day time frame is ambitious.

Who will supply the supportive services?

This report has noted the importance of two different types of supportive services: counseling and FMS. While it is relatively easy to find organizations that can perform the payroll functions (indeed, it would be possible to contract with organizations that fulfill this role for existing programs, whether or not these programs are in the same state as the proposed demonstration), organizing delivery of counseling services is a good deal more complicated. The counseling function requires in-depth knowledge of consumer direction and an ability to understand and work with potential participants directly. Counseling is also labor-intensive and generally requires one-on-one interaction. While home health case managers or social workers would be well-placed to perform this function, it might be difficult to ensure that they are properly trained and personally positive about the details of consumer direction. The CCDE found that regular contact with a variety of program participants was important in maintaining expertise and interest among counselors. Ideally, the demonstration would be able to depend on an already-existing local counseling infrastructure for an existing consumer-directed program. However, such counselors would need additional training in any new requirements imposed by the new Medicare benefit.

How will budget neutrality be assured?

Section 648 specifies that the demonstration be budget neutral. This means that the cost of the services provided under the demonstration may not exceed the cost of services that would otherwise have been provided under traditional service delivery. Such a requirement poses considerable challenges to the demonstration design.

- **Determining the correct amount for individualized budgets** – Because the Medicare home health benefit is paid on a capitated, rather than a fee-for-service basis, it is hard to disentangle the costs allocated to the home health aide portion of the benefit. Moreover, payments for home health episodes are adjusted according to 80 case-mix groups (known as home health resource groups, or HHRGs) and are based on average bundles of services for individuals with differing sets of needs. As potential participants in the proposed demonstration are likely to be outliers (because, by definition, they are high users of home health aide services) any calculation of budget neutrality that is based on average levels of service use for particular HHRGs may underestimate the costs of demonstration participants. Developing methods for estimating these costs fairly will pose a challenge, and will be a subject for a future options memorandum.
- **Funding start-up costs** – All of the demonstration projects discussed in this Best Practices paper relied on additional financing for various start-up expenses, including project staffing, recruitment costs, and developing demonstration infrastructure. In the case of the CCDE, this additional funding amounted to roughly \$750,000 in federal funds – plus an additional state match for the federal monies – per participating state. The CD-DME project paid out \$150,000 in one-year development grants for each participating CIL (equivalent to a site).
- **Reimbursing supportive services** – Under Medicaid rules, states have found ways to reimburse supportive services. These include reducing consumers' allowances, charging consumers for the cost of services, or substituting new services for traditional services (by shifting funds from cash management to consumer-directed support services, for example). Finding a mechanism for doing so under Medicare regulations will be a challenge. However, it is notable that the Monroe County and Mid-Ohio Valley project was able to reimburse additional personnel (including a Benefits Specialist, who fulfilled a counseling role), under its waiver. Moreover, the CD-DME demonstration paid \$280,000 to the entity responsible for claims administration, a role that is functionally equivalent to FMS.

How will consumer-directed services integrate with other Medicare home health services?

Under Medicare home health, both the population and the legal duties of home health agencies differ from those under existing consumer-directed programs. To qualify for Medicare home health services, beneficiaries must be in need of skilled care, making them different from many individuals currently using consumer-directed services. Home health agencies are also legally liable for services provided through the home health benefit that they administer. The

demonstration will need to investigate mechanisms to protect agencies from liability for services delivered by staff recruited by beneficiaries.

Moreover, agencies often regard high quality home health services as those that are well coordinated and where good communication exists among different service providers. For example, under traditional service delivery, ideally, home health aides provide feedback to nurses about changes they observe in beneficiaries' health status. Consequently, thought will need to be given about how to retain the benefits of coordinated care while protecting consumer control over service delivery. Agencies may well have to re-think their approach and consumers may have to recognize a heightened duty to communicate with skilled staff.

Can consumer direction be a benefit for home health agencies rather than a threat?

There can be considerable resistance to consumer direction from traditional home care providers, for reasons explored in Section I, above. Experience with consumer direction has shown that many of these concerns are not borne out after a program is underway and can be mitigated by integrating home care providers into the planning process and through appropriate education. In addition, Medicare home health agencies can be encouraged to see consumer direction as another way to provide home health aide services, one that expands their staffing pool by attracting providers who would never otherwise act as home health aides and helps them to improve satisfaction, compliance, and functional outcomes among hard-to-serve clients. If nurse delegation is incorporated into the demonstration design, consumer direction has the potential to lower overall episode costs by reducing nursing visits for tasks that could be delegated to unlicensed personnel.

However, providers of the Medicare home health benefit might resist consumer direction unless they are convinced that they will not lose money. This is a complicated argument to make due to the Prospective Payment System (PPS), which bundles all home health costs – including reimbursement for nurses, social workers, therapists, and home health aides – into one payment made at the beginning of a home health care episode. Although these payments are adjusted to reflect different levels of risk, they are based on averages; specifically, they are based on average patterns of service use and average levels of risk for a given population. These averages might differ considerably from those of the population targeted for this demonstration, making it difficult to separate out an appropriate amount for an individual budget or cash allowance.

Who will be responsible for day-to-day implementation of the demonstration?

In virtually all consumer-directed programs, a state or local government entity takes responsibility for developing and implementing the program, although they may be advised and receive technical assistance from a third, non-government party such as a consulting firm, university, or other non-profit entity. Any Medicare home health demonstration will be labor-intensive and require much interaction with local service providers and an understanding of local factors to ensure appropriate service delivery. Who will take on this hands-on role? How will they obtain cooperation from local government, providers, and community groups?

IX. Lessons Learned

Based on our review of best practices in consumer direction, we suggest consideration of the following 16 key lessons learned when designing a potential consumer-directed Medicare home health demonstration:

1) Work closely with home health agencies to integrate their concerns into program design.

Experience in implementing consumer direction shows that concerns from traditional providers can be alleviated when they are integrated into the planning and implementation process and when their issues are dealt with respectfully and constructively. This means that there should be a continual dialogue involving providers. In addition, program administrators should reach out through an educational campaign, which might involve presenting at national or local industry meetings, to ensure that traditional providers are well-educated about consumer direction and informed about demonstration implementation.

2) In collaboration with the providers, conduct outreach to front-line workers in home health agencies to educate them about consumer direction.

Front-line workers will often be the main information source for consumers and among the most trusted information sources. They will be central to the recruitment process for the Medicare demonstration. It will be important to find cost-effective means of educating them.

3) Ensure that appropriate supports are available.

Overwhelmingly, those with experience in consumer direction emphasize the importance of appropriate supports for consumers, including both counseling and help with managing the financial aspects of employing staff. A considerable body of evidence has been developed, mainly from the CCDE, on how to establish, reimburse, and manage providers of support services. Some of the key insights from this body of evidence are recommendations to allow one organization to provide both counseling and FMS, but not to allow counselors to perform assessments. Cost and quality control is achieved through careful oversight of the FMS and consumer spending. For the Medicare demonstration, costs could be reduced by using existing support infrastructure to avoid start-up costs. In addition, using existing infrastructure would avoid potential implementation issues associated with start-up.

4) Consider enrolling dual eligibles and allowing them to combine Medicaid personal care or waiver service funds with the Medicare consumer-directed allowance.

The pool of potential participants can be expanded by opening participation to dual eligibles already receiving consumer-directed services through an existing Medicaid program. Dual eligibles often have intermittent use of Medicare home health, and participation in the demonstration would allow them to use their existing consumer-directed worker rather than an

unfamiliar home health aide. Moreover, if the demonstration is sited in an area where there is an established consumer-directed program, it would allow at least one of the demonstration sites to take advantage of an already functioning infrastructure for consumer direction. However, this would require that program administrators ensure that similar rules and processes apply to the consumer-directed budget, regardless of the source of funding – a challenging goal.

5) Give careful thought to recruitment.

The fact that program participation is highly sensitive to recruitment methods is evident from the very different rates of enrollment among older people into consumer-directed programs across the country. Often, low rates of enrollment are associated with poor publicity about consumer-directed programs. Direct marketing to potential participants seems to be particularly effective. It will be important to develop recruitment professionals with positive attitudes toward and accurate information about consumer direction.

6) Develop a tailored and quick the enrollment process.

Create a flexible, user-friendly, simple enrollment process that allows full inclusion of the consumer and, if he or she wishes, family members. The process itself should ideally be performed during a face-to-face home visit. Enrollment staff should be well trained in consumer direction, support its philosophy, experience no conflicts of interest, and have sufficient time to explain the project and the consumer's role in it. Consumer should understand their rights, risks, and responsibilities under consumer direction. They should also understand the program's limitations, as well as their right to return to traditional services should they so choose.

The lead time for enrolling consumers into consumer direction will be fairly short in any Medicare home health demonstration. The program design should include features that speed enrollment and ensure that the transition from traditional to consumer-directed services assures continuity of care for personal care services, as well as for services that would be delivered by the agency.

7) Do not screen participants.

Evidence from the CCDE as well as from other consumer-directed programs indicates that screening of participants over and above the level required to ensure benefit eligibility is unnecessary. Mechanisms for detecting problems among those using the consumer-directed benefit and rules that allow the program to disenroll problematic participants should ensure that difficulties are avoided. Well-informed consumers are, by and large, self-selecting. Only those prepared to accept the responsibilities of consumer direction will find the option attractive.

Even individuals with cognitive impairment can participate in consumer direction when representatives are involved. Representatives have become a common feature in consumer-directed programs and can be used not only by individuals with cognitive impairment, but also by people who do not want to assume the responsibilities of consumer direction but have a family member who does.

However, it may be sensible to exclude individuals who are likely to use hospice services within the next 60 days. Their needs are quite different from the target population for this demonstration and their costs are potentially high.

8) Do not restrict the pool of potential workers.

The staffing pool is widest when it includes individuals who would not normally work as home health aides; including this group has the added benefit of reducing conflict with home health agencies, which are legitimately concerned about staffing shortages. This group includes family members, neighbors, and friends of consumers. The CCDE expanded this group even further by allowing the hiring of legally responsible individuals, normally restricted under Medicaid rules, but found that no worrisome cases of fraud or abuse resulted. Subsequently, CMS has relaxed this rule for Medicaid waiver programs, provided that states take reasonable steps to protect against possible fraud and abuse. However, consumer directed programs have generally found it necessary to prevent representatives from acting as providers.

Restrictions to the staffing pool based on credentialing or training requirements are also likely to be unnecessary. Evidence shows that a lack of formal training for directly hired staff does not result in poorer outcomes for participants in consumer-directed Medicaid programs; it is certainly worth testing whether this result could be replicated in a Medicare environment. However, most programs do offer consumers the option of conducting criminal background checks, and some prohibit the hiring of individuals whose background checks reveal certain categories of crime.

9) Allow nurse delegation, where state law permits.

Nurse delegation has been a common feature of many consumer directed programs, although only one study has examined it rigorously in a home and community-based context. Its survival as an option implies that states have found it to be a safe and effective option. Provided it is possible under the demonstration site's state legislation, allowing nurse delegation in the demonstration would provide an opportunity to collect evidence on its safety and effectiveness and also provide a means of reducing overall costs.

10) Allow flexible use of the benefit.

Flexibility in using the individualized budget was a value and important feature of the CCDE. Evidence from the demonstration shows that recipients of individualized budgets used their budgets wisely; there was little evidence of misuse of funds. Allowable expenditures under CCDE care plans included items that could substitute for human assistance, such as microwaves. Moreover, consumers could accumulate funds from month to month to make such purchases.

11) Assess the program design to ensure that adequate protections exist against liability risks.

Prudent program administrators will institute the simple steps recommended in the Sabatino and Hughes report (2004) to limit liability risk.. A key, but expensive recommendation is to require that consumers take out workers' compensation insurance both to protect their staff and protect themselves against claims.

12) Develop a comprehensive approach to cost control.

The CCDE offers many lessons on design features that contribute to cost control. Some of them have been discussed in this report, including careful control over reassessments and rigorous oversight of expenditures under individual budgets. Another important feature is the ability to

recoup unspent funds from an individual budget. Program designers should review all procedures with an eye toward cost control.

13) Develop systems to ensure that emergency back-up is available.

Of the specific quality improvement steps that can be taken, the development of an emergency back-up system is among the most important. Under consumer direction, consumers can be left in dangerous circumstances if staff fail to report for duty. Emergency back-up systems help to ensure that this does not happen.

14) Develop methods of integrating consumer concerns and issues into program design, implementation, and management.

Consumer participation in program design and implementation helps to ensure the appropriateness of design features. Methods for tracking consumer issues can flag design flaws and prevent untoward outcomes at the individual level.

15) Design data collection methods to capture relevant evaluation data.

At a minimum, collect information about cost, health and functional outcomes, and satisfaction. Focus exclusively on collecting information that will be used in the evaluation, program management, or quality management.

16) Ensure that quality management techniques are adapted to the unique requirements of a consumer-directed program.

Specific features should be incorporated into the program's design to address the special requirements of a consumer-directed program. These features include informing consumers clearly of their rights and responsibilities under consumer direction; monitoring FMS providers and consumer expenditures; developing emergency back-up procedures; establishing consumer feedback mechanisms; and ensuring that consumers have access to a comprehensive system of supports.

X. Next Steps

The Best Practices report provides a comprehensive review of consumer-directed experiences. Its intent is neither to develop the demonstration model nor to draw final program design conclusions but to provide a large-scale overview of issues relevant to design. Specific design options and recommendations will be developed in the next stage of the project. The demonstration design team, comprising CMS, ASPE, Medstat, and Abt Associates, have selected a number of experts to participate in a Technical Advisory Group (TAG). The TAG will meet in the spring to review reports, identify and discuss critical elements of the demonstration, and provide recommendations to the contractors designing the demonstration. A series of option memoranda is being developed to look more closely at key features. These memoranda are:

- **Defining the Target Population** – This report will define the target population, including chronic diseases to be targeted and criteria for subject selection. Using data on recent Medicare beneficiaries, it will estimate the size and location of potential enrollees and estimate enrollment rates.
- **Defining the Medicare Consumer-Directed Benefit** – This report will develop options for the structure of the consumer-directed benefit and investigate ways to fund consumer-directed support functions.
- **Developing a Medicare Payment Approach and Methodology** – This report will describe options for adapting the prospective payment method to the demonstration, offer ideas for funding various design elements, and present strategies for ensuring that the demonstration remains cost-neutral.
- **Developing Evaluation and Data Collection Requirements** – This report will research various evaluation options, identify methodologies by which to measure outcomes, and recommend reporting or data collection requirements.
- **Identifying Site Selection(s)** – This report will explore the legislative reference to “site” and whether the demonstration will be selected based on geography, level of provider interest, state political environment, number of potential enrollees, existing consumer-directed infrastructures, or a combination of all features.
- **Obtaining the Cooperation of and Recruiting Providers** – This report will explore strategies for maximizing support for the demonstration among traditional providers, assess the financial impact on providers, and discuss how providers should be recruited. This report will also study and recommend options for managing consumer health, welfare, and risk issues.

The option memoranda will be drafted during the spring and summer of 2005.

XI. Conclusions

This Best Practices report has presented a substantial body of evidence indicating that consumer direction is no longer a marginal, experimental option for delivering personal care services. Rather, it has become integral to the long term care systems of many states, with at least 139 programs operating in 49 states across the country (Doty & Flanagan, 2002), and at least 62 of them serving older people with long term care needs (Infeld, 2004). The Cash and Counseling Demonstration and Evaluation (CCDE) has provided an opportunity for states to test a carefully conceived model of consumer direction, and has served as a rich source of information on many facets of consumer direction, including implementation issues, consumer satisfaction, worker experiences, cost, and health and functional outcomes. Although consumer direction is not suitable for all consumers of long term care services, the accumulated evidence – including evidence from programs other than the CCDE – shows that it is a safe and effective service delivery mechanism that can improve the quality of services for many individuals.

However, nearly all the experience with, and evaluation of, consumer direction has occurred within the context of the Medicaid program. Whether consumer direction is a viable option for

Medicare home health recipients remains largely untested. There are some encouraging indications: programs such as the CCDE have enrolled many highly impaired Medicare-eligible older adults and have reported positive outcomes. Moreover, there is a rich body of experience in implementing consumer-directed programs that a Medicare demonstration can draw on in assessing the feasibility of this model.

Even with the benefit of lessons learned, however, substantial and serious challenges remain. One of these is the need to determine whether there is a large enough group of potential participants to warrant a demonstration. Another challenge will be translating design features developed largely in a Medicaid and state-specific context to the Medicare environment. A further challenge is to encourage home health agencies to cooperate with the demonstration, which may require that they be protected against perceived financial, legal, and other risks. Still another challenge lies in recruiting participation when potential participants are such a low proportion of home health recipients. Moreover, early identification of potential participants is central to maximizing receipt of the consumer-directed benefit. A final and major challenge is maintaining budget neutrality within a Medicare context. These issues and more will be addressed during the next stages of the demonstration design process.

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Appendix A:

A Glossary of Terms Relevant to Consumer Direction and the Medicare Home Health Benefit

Activities of Daily Living (ADLs) – Fundamental self-care activities that are widely used as a basis for assessing individual functional status (including eating, bathing, dressing, transferring from bed to chair, bowel and bladder control, and independent ambulation). Eligibility for public programs is often based on the extent to which individuals have a need for assistance with ADLs. Most programs require that individuals need assistance with three or more ADLs to qualify.

Agency with Choice – This term can refer to an organization that performs financial management services (FMS) or to the role the FMS provider plays. In the Agency with Choice model of consumer-directed care, the agency and the program participant or his/her representative enter into a joint employer relationship. Typically, the agency acts as the employer of record for the program participant's service worker, while the participant (or his/her representative) acts as the managing employer of the worker. Agency with Choice services can be provided by traditional agency-based providers who wish to expand their services to offer a consumer-directed service option or by an organization that is created for the sole purpose of providing Agency with Choice services.

Balanced Budget Act (BBA) of 1997 – Legislation that introduced sweeping changes to the Medicare and Medicaid programs. Among these was a change in the way in which the Medicare home health benefit is reimbursed, which aimed to limit increasing Medicare home health costs caused by the unnecessary provision of care. Fee-for-service retrospective payments were replaced by prospective payments based on per-episode of care amounts that are adjusted according to the severity of a beneficiary's condition. The new payment methodology is known as the Prospective Payment System (PPS).

Beneficiary – A person who receives health care services through the Medicare or Medicaid programs.

Capitation – A method of payment for health services, often associated with managed care, in which a health care provider or insurer is paid a fixed monthly amount for each person served, regardless of the actual number or nature of services provided. Capitation payments are normally made prospectively – that is, before services are provided to the covered individual.

Case Manager – An experienced professional (e.g., nurse, doctor, or social worker) who works with patients, providers, and insurers to coordinate all medically necessary and appropriate health care services.

Case Management – A process whereby a patient's specific health care needs are identified and a plan is designed to efficiently utilize health care (and often other) resources and to achieve the optimum patient outcome in the most cost-effective manner. In the context of managed care, the term refers to utilization management programs that help patients to develop appropriate and cost-effective treatment plans.

Cash and Counseling – A model of consumer direction that offers a flexible monthly individualized budget that consumers may use to hire providers and to purchase services and goods they need (within state guidelines). In addition, the model offers counseling and fiscal management services to help consumers and representatives plan for and manage their responsibilities.

Cash and Counseling Demonstration and Evaluation (CCDE) – A 3-year test of the cash and counseling model that began in 1998 in Arkansas, Florida, and New Jersey. The demonstration, which was voluntary for participants and involved random assignment to the treatment group (individualized budget) and control group (traditional agency-based services), was implemented under Section 1115 waivers administered by the Centers for Medicare and Medicaid Services (CMS). The Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services funded both the demonstration and the evaluation, which was conducted by Mathematica Policy Research. The demonstration has subsequently been expanded to an additional 12 states. More information about the demonstrations, including evaluation results, is available at www.cashandcounseling.org.

Centers for Independent Living (CILs) – Organizations run by people with disabilities who have been successful in establishing independent lives, have both the training and personal experience to know what is needed to live independently, and have a commitment to assisting other disabled people in becoming more independent. CILs offer a wide variety of services, including: information and referral; independent living skills training; peer counseling; advocacy; community education and other public information services; equipment repair; recreational activities; and home modifications.

Common Law Employer (Employer of Record) – The individual who directly hires the service worker and controls what tasks the worker will perform and how they will be performed. Under IRS rules, this term refers to an individual for whom services are performed and who has the right to control and direct the individual who performs the services, not only as to the result to be accomplished by the work but also as to the details and means by which that result is accomplished. The employer need not actually direct or control the manner in which the services are performed; it is sufficient if he/she has the right to do so. The right to discharge the worker is another important attribute of the employer. An employer is also the person or entity who furnishes tools and a place to work for the individual who performs the services. The question of who is the employer of record is an important one when assigning responsibility and liability for the treatment of workers.

Cognitive Impairment – Deterioration or loss of intellectual capacity that is evaluated by standardized tests to measure impairment in the areas of (1) short- or long-term memory, (2) orientation as to person, place and time, and (3) deductive or abstract reasoning. Such loss in intellectual capacity can result from Alzheimer's disease or similar forms of senility or dementia.

Consumer Direction – “A philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor

the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services” (National Institute of Consumer-Directed Long-Term Care Services, 1996).

Counseling – Information, skills training, and assistance with the management tasks associated with consumer direction. Counselors may support consumers in performing the tasks associated with recruiting workers (such as advertising for and interviewing workers); being an employer (such as working with a provider of financial management services); and managing a service worker (such as developing a job description and setting up a schedule of work). Counseling services may be provided by a variety of entities, including: Centers for Independent Living (CILs) or other community-based organizations; providers of financial management services (FSM); or individuals directly employed by the service program, such as case managers.

Dual Eligibles – Persons who are entitled to Medicare (Part A and/or Part B) and who are also eligible for Medicaid.

Durable Medical Equipment (DME) – Medically necessary equipment that is ordered by a doctor, can withstand repeated use, generally is not needed by a person in the absence of an illness or injury, and is appropriate for use in the home. These items (such as walkers, wheelchairs, or hospital beds) are paid for under Medicare Part B and Part A for home health services.

Employer of Record – The legal employer of a worker. An alternate term for common law employer. Neither term is preferred.

Episode of Care – The services provided during a certain period of time. Medicare home health agencies receive a payment intended to cover services supplied over a 60-day episode of care.

Fiscal/Employer Agent (F/EA) – An organization that performs financial management tasks (FMS), typically under a model of consumer direction where the program participant, or his/her representative, is the employer of record for the service workers and the F/EA performs necessary FMS tasks on behalf of the program participant.

Fiscal Intermediary – An alternate term for a financial management service provider. Use of the term is discouraged because of the potential for confusion with fiscal intermediaries who are responsible for processing Medicare or Medicaid medical claims and performing other specialized administrative activities on behalf of CMS.

Financial Management Services (FMS) – Two types of supports are offered by FMS providers: (1) managing payroll functions for service workers hired by the program participant; and (2) processing and paying invoices for goods and services that are approved by the program and included in a consumer’s plan of care. The primary payroll management responsibilities are paying workers and deducting for taxes such as Medicare and Social Security (FICA), federal

(FUTA), state (SUTA), and unemployment and disability insurance. States may also require FMS to offer or conduct background checks on workers. *FMS provider* is the preferred term for an entity that offers these services, but different terms are employed across the country – including fiscal intermediary, intermediary service organization, and fiscal/employer agent.

Home- and Community-Based Services (HCBS) – Broadly speaking, these are long-term supports and services that offer alternatives to nursing home care for people with functional impairments. They are provided in a variety of settings, including private homes, assisted living facilities, and adult day services. The term is sometimes used to refer specifically to the services provided under Medicaid home- and community-based waivers.

Homebound Rule – An eligibility criterion for Medicare home health services. To qualify for the home health benefit, a beneficiary's condition must create a "normal inability" to leave home, or means that leaving home entails "a considerable and taxing effort." To meet this definition, an individual does *not* have to be bedridden. Beneficiaries may be considered homebound if absences from the home are infrequent or for relatively short periods or for medical treatment. Occasional absences from the home for nonmedical purposes (for example, going to church) do not necessarily disqualify the beneficiary. Absences must be infrequent or relatively short, and the nature of the absence must not indicate that the patient has the capacity to obtain services provided under the home health benefit outside the home.

Home Health Care – Medical, social, and supportive services provided in the home to help the recipient maintain independent functioning and avoid institutionalization. This includes skilled nursing care and a wide range of health-related services such as assistance with medications, wound care, intravenous (IV) therapy, and help with basic activities of daily living (bathing, dressing, mobility, etc.).

Home Health Care Services – Services and items furnished to an individual by a home health agency, or by others under arrangements made by such an agency, in response to a plan established and periodically reviewed by a physician and supervised by a licensed nurse. The services are provided on a visiting basis in an individual's home and may include: part-time or intermittent skilled nursing care; physical, occupational, or speech therapy; medical social services; medical supplies and appliances (other than drugs and biologicals); and personal care services.

Homemaker Services – Household services, such as shopping, cooking, and cleaning, that may be part of a home care program. These services can be delivered in conjunction with home health care, as a separate service to those with functional limitations but who are otherwise healthy, or to forestall the need for institutional care.

Individualized Budget – The total dollar value of the services and supports specified in the plan of care that are under the control and direction of the consumer in a consumer-directed program. It sets a maximum level of funding that varies for each consumer according to his or her service needs and is normally determined through a person-centered planning process. Depending on the program, consumers may have considerable freedom in how they spend the individual budget.

Informal caregivers – People, often family members, who provide unpaid ADL or IADL assistance to individuals with long term care needs.

Instrumental Activities of Daily Living (IADLs) – Activities related to independent living that include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

Intermediary Service Organization – Alternative term for an organization providing financial management services (FSM).

Long-Term Care – Non-acute care provided over a 24-hour period for 25 or more consecutive days. It involves providing a set of health care, personal care, and social services required by persons who have lost, or never acquired, some degree of functional capacity (e.g., the chronically ill, aged, or disabled) in an institution or at home, on a long-term basis.

Managed Care – A system of health care delivery that aims to control utilization and the cost of services while measuring performance. The goal is a system that delivers value by giving people access to high quality, cost-effective health care. It includes several concepts as part of its program: quality assurance, aggressive care management, peer review, and data gathering and dissemination to providers. The gatekeeper – usually a primary care physician – opens the door to the varied disciplines, providing the necessary coordinated care.

Managing Employer – The individual (program participant under a consumer-directed model) who is responsible for recruiting and training a service worker; determining which tasks are to be performed and when and how they are performed; managing the service worker's day-to-day activities; completing, signing, and submitting service workers' timesheets; and discharging the service worker from the consumer's employ, if necessary.

Medicaid Home- and Community-Based Waiver Programs – Since 1981, programs established under Section 1915(c) of the Social Security Act that waive certain federal Medicaid requirements (including statewide program coverage) to allow states to use federal matching funds to provide a wide range of services not otherwise available under Medicaid to participants who would otherwise be in an institution. These services include case management, homemaker, home health aide, personal care, adult day health care, habilitation, respite care, and others.

Medicaid Personal Care Services – Typically, non-medical services (assistance with activities of daily living, personal hygiene and grooming, preparation of meals, some household services, etc.) that enable participants with disabilities and chronic conditions to be treated on an outpatient rather than an inpatient basis. States may choose to offer personal care services as a Medicaid benefit under their state Medicaid plan and have considerable discretion in defining these services. Unlike waiver recipients, participants receiving personal care services need not qualify for admission to a nursing home. The benefit must be available to all categorically eligible groups, although states can choose to include optional groups such as the medically needy.

Medicare Home Health – Skilled nursing care, physical, occupational, and speech therapy; medical social work; and home health aide services delivered on a part-time or intermittent basis to homebound Medicare beneficiaries under the care of a physician by certified home health agencies (HHAs).

Medicaid Waiver – A plan amendment or modification to allow a state to expand Medicaid coverage or change the rules under which it provides Medicaid services. The Federal Government can permit states to waive certain federal Medicaid requirements so they may operate programs with specific design features. Among other options, waivers may be used to authorize managed care or deliver alternative services, such as home- and community-based services. These waivers are normally designated by the section of Title XIX of the Social Security Act that allows them, such as 1115 or 1915(c).

Nurse Delegation – The transfer to a competent (unlicensed) individual the authority to perform a selected nursing task in a selected situation. While the nurse is responsible for determining that the situation is appropriate for delegation, the nurse is not responsible for the performance of the task. This term also describes the different legal mechanisms that allow states to permit unlicensed personnel to provide certain services. This issue is a widespread and politically sensitive one, encompassing services provided in hospitals as well as community-based settings. In the context of consumer direction, it addresses mechanisms that allow staff hired by consumers to provide a limited array of nursing tasks (such as medication administration) in the home, which reduces costs by replacing expensive nurses with less-expensive personnel. Consumers advocate for it because it allows them to remain in their homes or in group situations such as assisted living, and because they may feel their day-to-day lives are “over-medicalized.”

Nurse Practice Act Exemption – A legal mechanism used by states that specifically exempts certain individuals (like family members or domestic servants) or programs (often consumer-directed programs) from the regulations governing delegation. In an exemption approach, the *consumer* directs his or her own care and is responsible for that care – not the nurse. The nurse can provide training for both the consumer and his/her assistant and can monitor the services provided. However, the nurse is not held responsible for the actual provision of the care.

Older Americans Act (OAA) – Federal legislation that specifically addresses the needs of older adults in the United States by providing funding for aging services (such as home-delivered meals, congregate meals, senior centers, and employment programs). This legislation created the structure of federal, state, and local agencies that oversee aging services programs.

Preventive Care – Comprehensive health care emphasizing prevention, early detection, and early treatment of conditions. It generally includes routine physical examinations, immunizations, and “well-person” care.

Program for All-Inclusive Care for the Elderly (PACE) – A program that combines Medicare and Medicaid payments into a single payment managed by one entity – making all care for an individual the responsibility of one organization.

Prospective Payment – A payment to a health care provider that is made before services are rendered.

Prospective Payment System (PPS) – The new payment methodology for reimbursing Medicare home health services that originated with the Balanced Budget Act (BBA) of 1997. Health care providers or insurers are given a fixed amount for each covered individual for a specific period of time. This amount is normally paid before services are rendered and often varies according to the health status of the covered individual, so that more money is available for the care of individuals with more severe health conditions. This payment methodology has become more prevalent over the last 20 years as a way of controlling health care costs. It replaces “fee-for-service” or “cost-based” reimbursement, where providers bill retrospectively for services rendered, a reimbursement method that provides few incentives for providers to limit the unnecessary provision of services.

Representative – An individual who manages services on behalf of a service recipient. A representative may be appointed when the consumer is cognitively impaired, has a developmental disability, or simply prefers that someone else assume responsibility for managing a directly hired worker. Representatives cannot normally be service providers under consumer direction.

Respite Care – Temporary or periodic care provided in a nursing home, assisted living residence, or at home, that allows the usual caregiver to rest or take some time off.

Retrospective Payment – Payment to a health care provider after services have been rendered under a “fee-for-service” or “cost-based” reimbursement methodology.

Self-Determination – A term that is used interchangeably with consumer direction, primarily among people with mental retardation/developmental disability, traumatic brain injury, or psychiatric conditions. Because the services that these groups access are much broader and less focused on assistance with functional needs, the term tends to encompass a broader range of supports.

Self-Direction – Another term for consumer direction.

Appendix B:

An Annotated Bibliography of Articles Related to Consumer Direction

Acknowledgements: This bibliography was compiled by Gloria Gordon.

1. Applebaum, R, Schneider, B, *et al.* (August 2004). *A Guide to Quality in Consumer Directed Services*. Scripps Gerontology Center, Miami University.

This Guide was written to address concerns about quality in consumer-directed services. It presents general issues, strategies, and suggestions for implementing quality consumer-directed programs, and provides examples of successes and failures among currently existing programs and sample instruments designed to assure and improve quality. The goals of the guide are to: aid states, programs, and agencies in the design, re-design or re-evaluation of quality consumer-directed systems; and develop continuous quality monitoring and improvement feedback mechanisms for these systems.

Quality monitoring activities (such as complaint hotlines, program performance indicators, audits of both the consulting agencies and fiscal intermediaries, and independent assessments by consumers) are strategies for systematic data collection for the purpose of improving services and overcoming barriers to satisfaction and quality. The authors stress that quality in programs designed to help individuals with chronic disabilities involves two interrelated mechanisms: (1) designing and building a quality program from the first day of planning; and (2) developing a quality management system that incorporates both quality monitoring and improvement strategies. The authors emphasize the importance of providing consumers with clear, appropriate, and ongoing information, since consumer needs change as they gain experience with self-direction. They recommend implementing the consumer support activities used in Cash and Counseling demonstration programs (initial and ongoing consumer training, assistance with developing and implementing purchasing plans and various employer issues, designing back-up plans, etc.). They conclude that improving quality is a continuous process. Ultimately a consumer-directed program will be successful if the staff is committed to making it work for the consumer.

2. Beatty, PW, Richmond, GW *et al.* (1998). Personal assistance for people with physical disabilities: Consumer-direction and satisfaction with services. *Archives of Physical Medicine and Rehabilitation* **79**(6):74-677.

The objective of this investigation was to determine whether people who receive consumer-directed personal assistance services (PAS) in Virginia are more satisfied with the services they receive than persons on the waiting list to receive those services and currently receiving PAS that are not consumer-directed. A survey was conducted by mail and telephone to evaluate long-term outcomes in 92 Virginia residents with physical disabilities living in the community. Approximately two-thirds (60) of these individuals were receiving consumer-directed PAS, and one-third (32) were receiving agency-directed PAS while on the waiting list for consumer-directed PAS. The authors found that consumers using consumer-directed services were more satisfied with their PAS. Specifically, consumer-directed services ranked higher on

such issues as: cost; control over the choice of worker and work schedule; authority to direct workers; and the availability of assistance off-hours or in an emergency. The two groups showed no difference in their perception of needs being met, the dependability of the worker, and personal safety. The authors emphasize how important it is to people with disabilities to be able to choose their own personal assistant, which is more likely to result in the selection of a worker who is best suited to the individual consumer and can meet a more flexible work schedule that allows the consumer to pursue and maintain employment. They conclude that consumer satisfaction over time and across circumstances is essential to the successful implementation and continuation of a consumer-directed model of care.

3. Benjamin, AE and Matthias, RE (2000). Comparing consumer- and agency-directed models: California's in-home supportive services program. *Generations* 24(3):85-87.

This article describes a study designed to examine the experiences of consumers and providers under two different supportive service arrangements in California's large, well-established In-Home Supportive Services (IHSS) Program – the professional agency model (PAM) and the consumer-directed model (CDM). In the PAM, available at county option in twelve California counties, homecare agencies hire and train providers and coordinate services to eligible clients. In the CDM, the consumer assumes all responsibilities for recruiting, hiring, training, and supervising the worker, who is paid directly by the State. Under state law, the CDM is mandated in all 58 counties. In counties offering both models, county-employed case managers decide which model is appropriate on a case-by-case basis, with client preference as a major consideration.

In 1996-97, telephone interviews were conducted with a random sample of 1,095 IHSS clients, stratified to ensure roughly equal numbers receiving services under each of the two models, clients over and under age 65, and clients more and less severely limited in functional status. Questions addressed service experience and five client outcomes: safety, empowerment, unmet needs, service satisfaction, and quality of life.

Study results indicated that, despite the fact that they had poorer functional status and greater service needs, CDM clients of all ages had more positive outcomes related to empowerment, quality of life, satisfaction with both the technical and interpersonal aspects of care provision, and ability to hire caregivers who were ethnically and linguistically compatible. Further, they reported that their workers had lower turnover rates and were much more likely to provide unpaid service hours. However, about one in six CDM clients reported having no one to call for backup help. On the other hand, agencies had the advantage of making it easy for clients to apply for and receive services quickly and easily due to agency coordination, although only a handful of counties maintained worker registries or provided supportive backup services. The authors conclude that, as issues regarding availability and cost of home care become more important, consumer-choice models can be a viable, possibly less costly alternative to traditional agency-based homecare.

4. Benjamin, AE and Matthias, RE (2001). Age, consumer direction, and outcomes of supportive services at home. *The Gerontologist* 41(5):632-642.

This study of participants in California's In-Home Supportive Services (IHSS) program, a consumer-directed program funded under MediCal (Medicaid), examined differences in service experience and outcomes between recipients over and under age 65. A random sample of 1,095 IHSS recipients was interviewed by telephone. Interviews were conducted in English, Spanish, and three Asian languages, and individuals with severe cognitive impairment were excluded from the study. Although younger recipients embrace self-direction more enthusiastically than older ones, there was not a statistically significant difference in consumer satisfaction once the model was implemented, and age differences were small on a majority of service outcomes. The perception of empowerment, unmet needs, and service satisfaction were not significantly influenced by the age of the consumer. Some differences were noted between the 65–74 and over 75 age groups, but these were neither consistent nor determinative. On average, older users embrace this model and manage within it much like younger users. As with other age groups, there are opportunities and obstacles to be addressed with this consumer-directed program. However, old age itself is not a barrier to successful participation. Independent Living advocates suggest that the consumer-directed model would be more attractive to older persons if guardians or surrogates were permitted to assist in managing services for those with severe cognitive limitations, and if training and support were provided to consumers who are new to consumer direction.

5. Benjamin, AE and Matthias, RE (2004). Work-life differences and outcomes for agency and consumer-directed home-care workers. *The Gerontologist* 44(4):479-488.

This study of workers employed directly by recipients examines differences in work-life and worker outcomes in consumer-directed versus agency models of care and between family and non-family workers. The authors asked: what consequences do these service approaches have for home-care workers; what other factors, if any, account for differences in worker outcomes across models; and how does the relationship between the worker and consumer affect worker outcomes, especially in programs that permit recipients to hire family members as workers. Telephone interviews of a random sample of 365 agency workers and 253 consumer-directed workers in the California In-Home Supportive Services (IHSS) program were conducted in English, Spanish, and three Asian languages between September 1996 and March 1997. Individuals working with recipients with severe cognitive impairments were excluded. The survey looked at worker characteristics, recipient case mix, and worker stress and satisfaction.

Most workers were young or middle-aged females. Agency workers were more likely to have less than a high school diploma, whereas consumer-directed workers were more likely to have some college education. Agency workers had more personal care experience than did consumer-directed workers, and consumer-directed workers were more likely to hold another job. Agency workers earned more, had more clients, spent fewer hours with any one client, and had more formal training and supervision. However, consumer-directed workers received considerable recipient-specific informal training from families, physicians, home-health nurses, and therapists. Consumer-directed workers were much more likely than agency ones to perform additional service tasks without pay, and related workers were much more likely to provide unpaid hours than non-related workers. Consumer-directed workers reported outcomes equal to

or more positive than agency workers on most dimensions of stress and satisfaction. Whatever the service model, adequate training and pertinent information on the recipient's condition are associated with more satisfaction and less stress. Efforts to improve the work life of home-care workers should acknowledge the strengths of consumer-directed approaches and target workers across models.

6. Blaser, CJ (1998). The case against paid family caregivers: Ethical and practical issues. *Generations* 23(3):65-69.

Based on experience derived from managing the Illinois Community Care Program, which provides home- and community-based care to over 35,000 older adults per month, Blaser presents the potential pitfalls of allowing payments to family caregivers and provides arguments against permitting this option in publicly funded programs. A number of Illinois homecare agencies have opted to hire family members and pay them less than the going "market" rate to provide personal care to their older relatives, a practice that was not supported by the Department of Aging. The author argues that this arrangement puts pressure on family members to make up for the shortcomings of the traditional system in recruiting and retaining qualified workers and to provide care for their older relatives for low wages and few, if any, benefits. Furthermore, this practice eliminates any incentive for policymakers and service providers to remedy the factors that contribute to the worker shortage. Home care agencies also reported incurring increased administrative costs to monitor family workers who may be inclined to defraud the system and/or coerce their frail family members into doing so.

The current Illinois policy does not allow direct payment to family members for care but offers an alternative approach – services are provided based on an evaluation of the availability of family and informal supports (i.e., it is designed to complement and supplement family support, but not replace it). In addition, the department has developed the service PLESE (Program for the Limited English Speaking Elderly), which funds 20 small service providers in the various ethnic communities to recruit and train a culturally diverse in-home workforce. This assures that the more than 1,600 non-English-speaking clients are served in culturally appropriate ways by workers who speak the same language, removing the need to recruit and pay family workers.

7. Cohen, ES, Yuskas, A, and Conroy, JW (2000). Consumer-directed personal assistant care: An inquiry into programming for cognitively impaired elderly. In MB Kapp (Ed.). *Ethics, Law, and Aging Review* 6:131-180. Springer Publishing, New York.

This article explores the role of a "supportive intermediary" to assist the surrogate decision-makers of cognitively impaired older adults to secure home-based personal assistance in a 3-year demonstration project conducted in New York City as part of the Medicaid Consumer-Directed Personal Assistance Program (CDPAP). The surrogates (usually family members) came to the program with considerable experience and dissatisfaction with agency-supervised personal assistance services, where their extensive responsibilities included managing personal care attendants, business and financial matters, medical and therapeutic interventions, and socialization. Surrogates expressed the need for more flexibility to schedule and utilize personal

care attendants and the desire for more control over their hiring and firing. Under CDPAP, personal care attendants are selected, trained, and supervised by the person with the disability or an assigned surrogate, and a fiscal intermediary handles payments to workers. The fiscal intermediary services provided by Concepts of Independence included management of payroll functions, fringe benefits such as health and dental insurance, pension plans, and Workers Compensation.

Overall, consumer satisfaction with these arrangements was high. Supportive intermediary services provided by the Alzheimer's Association-NYC Chapter included: information and referrals; short-term and/or supportive counseling for surrogates; peer group support; technical information about the responsibilities of the consumer as employer; educational seminars on dementia related issues, etc. Surrogates viewed these services as essential to the successful implementation of consumer-directed care. In conclusion, the authors strongly support consumer-direction, make recommendations for a successful program, and stress the importance of developing broad based advocacy support.

8. Cohen, MA (2002). *Private Long-Term Care Insurance: A Look Ahead*. LifePlans, Inc. Waltham, MA.

This comprehensive paper discusses the private long-term care (LTC) insurance market; the impact of its rapid market growth on providers, policyholders and their families; and the utilization of publicly financed LTC services (i.e., Medicare and Medicaid). Data were compiled from national studies of buyers and non-buyers of LTC insurance, claimants and their primary family caregivers, and published and non-published information from the LTC insurance industry.

Cohen attributes the rapid growth of the LTC insurance market to: improved product design (primarily the addition of benefits for non-institutional care); changes in state and federal policies to protect consumers and encourage market development; and greater awareness among consumers of the need to protect against “the single greatest uncovered catastrophic risk faced by the elderly.” In 2001, 3.5-4.0 million Americans had private LTC insurance policies that typically reimbursed the costs associated with skilled and custodial care in nursing homes, assisted living facilities, home care agencies, adult day care centers, and other providers of chronic care services. The key motivations to purchase the insurance are: (1) maintaining independence and (2) paying for LTC services without exhausting personal wealth. Across all care settings, more than four in five claimants – many lacking informal supports from family – were satisfied with their coverage, 75% understood their coverage, and 70% found it easy to file a claim for benefits. On average they received 59 hours of care a week, 36 of which were paid for by insurance. About half of nursing home claimants and about 35% of home care claimants did not feel their needs were being met.

Cohen concludes that LTC insurance has the potential to play a more meaningful role in financing the LTC needs of disabled elders in the future. Further, insurers appear to have learned how to underwrite the risk, while satisfying their customers with the design and price of their products and the way they manage claims.

9. Cohen, M and Miller, J (2002). *The Impact of Private Long-Term Care Insurance on Claimants: Formal and Informal Care in the Community*. The Center for Home Care Policy and Research, Visiting Nurse Service of New York. Policy Brief No. 11, Spring.

Information for this policy brief was obtained in 1999 through in-person interviews with a random sample of 693 people receiving long-term care (LTC) insurance benefits who were over 65 and living in the community, or with proxies in the case of cognitively impaired claimants. A comparison sample of 1,357 comparable community-dwelling individuals without private insurance was obtained using the 1994 National Long-Term Care Survey (NLTC). Claimants received, on average, a total of 59 hours of formal (paid) and informal (unpaid) ADL and IADL assistance per week. Privately insured individuals were much more likely to be physically impaired, while the non-insured were much more likely to suffer cognitive impairment.

The study findings suggest that private LTC insurance allows disabled elders to remain in their homes and relieves family caregivers of some of the burdens and stress of caregiving. Most claimants were satisfied with their policies and found it easy to file claims. However, about a third of claimants receiving home care services felt they had not purchased enough home care benefits. Many also felt they needed more help in managing service providers. A sizeable minority of claimants (23%) indicated that not all of their functional needs were being met due to unavailable services, scheduling difficulties, gaps in continuity and coordination of paid and unpaid caregivers, difficulty satisfying their particular preferences, and unsatisfactory quality of care. The authors conclude that LTC insurance is an important source of support for those who lack informal support from family and friends. However, claimants need help in using their benefits to obtain the appropriate level and quality of care and in understanding at the time of purchase how much protection they need.

10. Dale, S, Brown, R, and Phillips, B (2004a). *Does Arkansas' Cash and Counseling Affect Service Use and Public Costs?* Final Report. Mathematica Policy Research, Inc. Princeton, NJ.

This study examines how consumer direction under IndependentChoices, Arkansas' Cash and Counseling Demonstration program, affected the cost of Medicaid personal care services (PCS) and the cost and use of other Medicaid and Medicare services. During enrollment for the demonstration (December 1998-April 2001), Arkansans at least 18 years old and eligible for PCS under the state's Medicaid plan were randomly assigned to direct their own personal assistance (treatment group) or to receive traditional agency services (control group). IndependentChoices consumers could elect to receive a monthly allowance to hire their choice of caregivers (except spouses) or buy other needed services or goods, and were assigned counselors to help them manage their allowance.

The IndependentChoices program increased consumer satisfaction and reduced unmet needs at a cost that was slightly less than agencies would have incurred if they had supplied the number of hours approved in recipients' plans of care. Findings at 1 year post enrollment for 2,008 individuals indicated that PCS expenditures were about twice as high (\$4605 versus \$2349) for the treatment group than for the controls, due primarily to the control group receiving far less care than it was authorized to receive. This \$2,256 increase in PCS costs was partly

offset by a \$726 savings in expenditures for nursing facility, home health, and other Medicaid services, resulting in Medicaid costs only 14% higher for the treatment group than for controls.

The authors suggest that the Cash and Counseling model can be a cost-effective way to substantially improve access to care and the well-being of people eligible for Medicaid personal care. The Arkansas experience shows that the costs can be held to no more than what the State would have expected to pay, had the existing system met the needs of those eligible for PCS. If the savings in long-term care and other Medicaid costs persist or continue to grow, the program could eventually yield net savings despite the higher personal care costs. They conclude by suggesting some options for controlling initial costs in states considering a Cash and Counseling program.

11. Dale, S, Brown, R, and Phillips, B (2004b). *Medicaid Costs Under Consumer Direction for Florida Children with Developmental Disabilities*. Final Report. Mathematica Policy Research, Inc. Princeton, NJ.

This study of Consumer Directed Care, Florida's Cash and Counseling Demonstration program for children with developmental disabilities, examines the ways in which consumer direction affects the cost of Medicaid home- and community-based services (HCBS). During enrollment for the demonstration (June 2000-August 2001), children aged 3-17, who were receiving HCBS through Florida's Developmental Services Waiver program, were randomly assigned to participate in Consumer Directed Care (treatment group) or to continue receiving traditional waiver services (control group). Parents of treatment group members were given a monthly allowance to hire their choice of caregivers or buy other services or goods to meet their child's care needs. Program consultants and fiscal agents were available to help them manage these responsibilities.

Consumer Directed Care increased access to paid personal care and improved the quality of care. Waiver expenditures for treatment-group members were more than \$3,000 (about 25%) higher than waiver expenditures for controls during the first post-enrollment year, and nearly \$5,000 higher during the second. This difference resulted from: (1) control group members incurring costs that were 18% lower than expected in the first year and 9% lower than expected in the second year, and (2) the cash allowances for treatment group members being, on average, about 30% higher than expected in both years. The higher expenditures in the treatment group were partly offset in both years by lower expenditures for Medicaid home health services. Home health and Medicaid private-duty nursing expenditures increased during the demonstration in controls, but not in the treatment group. Total Medicaid costs for treatment group children averaged about 3% (\$880 per child) higher in the first year and about 8% (\$2,581 per child) higher in the second year than total Medicaid costs in the control group.

The authors conclude that Florida may need to review discount rates periodically and change them, if necessary, to ensure that treatment-group allowances are on a par with the costs of serving similar waiver recipients in the traditional program. Further, steps should be taken to ensure that children in the traditional program (who had lower-than-expected costs) are able to receive the services they need.

12. Dale, S, Brown, R, Phillips, B, and Carlson, B (2003). *The Experiences of Workers Hired Under Consumer Direction in Arkansas*. Final Report. Mathematica Policy Research, Inc. Princeton, NJ.

This study assesses the experiences of workers hired under consumer direction in IndependentChoices, Arkansas' Cash and Counseling Demonstration program. It focuses on the types and amount of care provided by paid workers, the training and supervision they received, their working conditions and well-being, and how key outcomes were affected by the worker-consumer relationship.

During enrollment for the demonstration (December 1998-April 2001), Arkansans at least 18 years old and eligible for personal assistance services under the state's Medicaid plan were randomly assigned to direct their own care (treatment group) or to receive traditional agency services (control group). IndependentChoices consumers could elect to receive a monthly allowance to hire their choice of caregivers (except spouses) or buy other needed services or goods, and were assigned counselors to help them manage their allowance. "Primary paid workers," identified by a sub-sample of consumers at their 9-month follow-up interview, were asked to complete the Cash and Counseling Caregiver Survey. Those workers who were also the consumer's primary informal caregiver at baseline were administered a longer survey instrument that included questions related to their role as informal caregivers.

Directly hired workers (generally relatives or close friends of the consumer) often filled the roles of both informal caregiver and employee, provided many hours of unpaid care and care during non-business hours, and performed a variety of health care tasks, as they were not subject to agency rules or state regulations. The well-being of non-related directly hired workers was very similar to that of agency workers, although directly hired workers who were related to the consumer were more likely to feel emotional strain. In general, the Cash and Counseling model does not appear to create adverse consequences for caregivers through either lack of training or poor compensation. Directly hired workers were paid about the same wage as agency workers, but expressed substantially greater levels of satisfaction with their compensation, and 91% reported very good relationships with the consumer. Finally, both agency workers and directly hired workers were quite satisfied with their overall working conditions. The authors conclude that workers hired under IndependentChoices appear to be as pleased with the program as are consumers, which is important since this model is sustainable only if workers have positive experiences.

13. Dale, S, Brown, R, *et al.* (2003). *The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas*. Health Affairs web exclusive.

This report presents an evaluation of survey and Medicaid claims data for 2,008 adults randomly assigned to treatment or control groups in the Arkansas Cash and Counseling Demonstration – the first rigorous comparison of agency- and consumer-directed approaches to the provision of personal care services (PCS). The IndependentChoices program has been shown to greatly improve consumers' satisfaction and reduce their unmet needs for many types of assistance, without increasing the likelihood of adverse health problems. This study examined the program's effect on the receipt, timing, and amount of PCS that beneficiaries received; the

home modifications and purchases they made to help them perform daily activities independently; and their Medicaid expenditures for PCS and other services.

The survey results demonstrated that the consumer-directed option increased the receipt of paid care and reduced unpaid care. The treatment group had higher Medicaid personal care expenditures than did the controls because many recipients in the control group were unable to access paid help from an agency. Controls obtained only two-thirds of the services to which they were entitled. By the second year after enrollment, the higher personal care expenditures in the consumer-directed group were offset by lower spending for nursing homes and other Medicaid services. The authors conclude that Arkansas' experience demonstrated that states can design a cash and counseling program that does a better job of meeting the needs of recipients at no greater cost per month of service than would be incurred under the traditional agency approach ("budget-neutrality," as defined by the Centers for Medicare and Medicaid Services).

14. Degenholtz, H, Kane, RA, and Kivnick, HQ (1997). Care-related preferences and values of elderly community-based LTC consumers: Can case managers learn what's important to clients? *The Gerontologist* **37**(6):767-776.

This article describes the development and application of a brief protocol to explore client values and preferences that is used by case managers working in community-based long-term care (LTC) for the elderly. This tool was used to collect data on the values and preferences of 790 elderly long-term care clients in a project designed to determine the effects of values assessments on clients, case managers, and care plans. The values assessment served to make case managers more aware that elderly clients are individuals with their own ideas on quality of life and distinctive preferences for their care. Significant findings of the study are reported and discussed, including: the ways which clients characterize the content of their values and preferences; what importance clients attribute to their various values and preferences; how the content of a client's values relates to their importance; and the disparity in values between new and ongoing clients.

The importance that clients placed on selected issues related to their care (e.g., privacy, daily routines, activities, involvement of family in care, the trade-off between freedom and safety, etc.) varied, as did the specific content of those issues. Topics rated as very important included: privacy; family involvement; freedom and safety; characteristics of a home; and characteristics of a helper. Practice implications are noted, including: the difficulty in training case managers to change their usual approach in order to explore the client's more abstract values and preferences, and the need for encouraging consumers to develop greater expectations regarding their own long-term care.

15. Desmond, SM, Mahoney, KJ, *et al.* (2001). Consumer preferences for a consumer-directed cash option versus traditional services: Telephone survey findings of Florida elders and adults with physical disabilities. *Elder's Advisor – The Journal of Elder Law and Post Retirement Planning* **3**(1):1-22.

This article presents the findings of telephone surveys of over 600 elderly and/or physically disabled Florida residents receiving in-home services. The survey was designed to: (1) assess their interest in a consumer-directed cash option to pay for personal care services in

lieu of agency-based services; and (2) identify what characteristics of the cash option are most attractive to consumers. This information was to be used to design various cash option components (including counseling services) in the Cash and Counseling Demonstration and Evaluation Project states (Arkansas, Florida and New Jersey) and develop social marketing approaches to enable consumers and surrogates to make an informed choice between these options. Recipients of agency-based services were satisfied overall with the services they received, but were attracted to the cash option because they thought they would receive more services than were currently provided under the agency-based model. If they elected to participate in the cash option, consumers indicated they would most likely purchase more hours of services; housekeeping, transportation, laundry, and respite care services; and adaptive and/or other types of needed equipment. They also expressed an interest in training on how to obtain worker background checks, and assistance with payroll taxes and worker management. The survey data offered detailed guidance to help Florida design the cash option and formulate the social marketing and outreach materials for Cash and Counseling. Survey results indicated that educational level should be a consideration, as almost three-quarters of survey participants had a high school education or less.

16. Doty, P (October 2004). *Consumer-Directed Home Care: Effects on Family Caregivers*. Policy Brief. Family Caregiver Alliance, National Center on Caregiving. San Francisco, CA.

This comprehensive policy brief discusses consumer direction in public programs and private insurance plans, including opportunities for family caregivers to serve as representative decision-makers and paid caregivers. It presents three models of consumer direction with varying amounts of choice and control: (1) an option to hire/fire and supervise a personal assistance worker; (2) an option to receive an individualized budget to purchase a broad range of services and supports, including personal assistance (the Cash and Counseling model); and (3) a no-strings-attached cash benefit or “disability insurance model” available almost exclusively from private insurers.

The brief explains why consumer-directed approaches to financing and delivering home care are attractive to many family caregivers, emphasizing the potential of these models to complement unpaid family care and support by allowing them to “custom-tailor” third-party financed care to their personal circumstances. Findings from the Cash and Counseling demonstrations indicated that outcomes for both elderly and disabled program participants and their family caregivers under consumer direction were at least the same and often significantly better than those in the control group receiving traditional services. Although participants made their own decisions about services and supports, their budgets were managed by a fiscal intermediary to assure the third party payer of an independent accounting of how the allowances were spent.

Family caregivers of consumer-directed participants reported greater well-being and provided slightly fewer hours of assistance compared to family caregivers of those receiving traditional services. They were also less likely to report high levels of physical, financial and emotional strain; they worried less about insufficient care and safety; they were more likely to be very satisfied with recipients’ overall care arrangements and less likely to report that caregiving

impinged on their privacy, social lives and job performance. Further, they perceived their own health to be better and were more satisfied with their own lives. Significantly fewer caregivers of consumer-directed participants reported that caregiving conflicted with paid employment outside the home.

The brief also addresses concerns regarding the potential for elder abuse, mistreatment, or financial exploitation by family members or by directly-hired workers (whether family members or unrelated individuals), and assesses the prospects for, and barriers to, expansion of consumer-directed alternatives. The authors conclude that evidence from Arkansas's Independent Choices shows that these programs can be "budget neutral" while still improving outcomes for program participants and their families.

17. Doty, P, Benjamin, AE, *et al.* (1999). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery*. US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC.

This study used telephone surveys of both consumers and personal assistance workers to compare in-home personal assistance services (PAS) using either a consumer-directed (CD) or professional management (PM) model of service delivery. The purpose of the survey was to determine whether these alternative modes of service delivery were more, less, or equally likely to bring about a variety of positive outcomes. The outcomes included: client satisfaction with services; client empowerment and health status; reliability and continuity of service; ability to attract qualified workers; consumer concern for safety; unmet needs; and worker satisfaction and working conditions. The report concluded that, whereas both the CD and PM models of delivering supportive services to the aged and disabled produce positive client outcomes overall, the CD model outperforms the PM model on several key measures –client satisfaction, empowerment, and quality of life. CD-model consumers who hired family members as caregivers reported: a greater sense of security; more control over workers; more choice regarding worker tasks; and a closer rapport with their workers. Further, they were more likely to receive unpaid help from relatives and friends than were clients receiving services under the PM model. The worker surveys indicated that PM-model workers were less worried about client safety, and had more positive emotional states and higher salaries than did CD-model workers. On the other hand, CD-model workers expressed more closeness and compatibility with consumers. The research suggests that both models can meet consumer and worker needs.

18. Doty, P and Flanagan, S (2002). *Highlights: Inventory of Consumer-Directed Support Programs*. U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy. Washington, DC.

This report presents a descriptive inventory of publicly-funded programs offering home- and community-based personal assistance services through consumer-directed service delivery models. It addresses: the prevalence, age and permanence of programs; the number and characteristics of participants served; restrictions on participation; funding sources and covered services; the use of Intermediary Service Organizations of all types; relationship to Managed

Care Organizations; employment status of consumer-directed workers; Medicaid's relationships with ISOs and consumer-directed workers, especially in relation to provider agreements and contracts; and quality assurance.

At the time of publication, there were 139 programs offering consumer-directed home and community-based services (HCBS), 88% of which were permanent. They served an estimated 486,000 individuals, with the majority of programs serving 1,000 or fewer participants. California's In-Home Supportive Services Program accounted for slightly more than half of participants in consumer-directed programs nationwide. The primary populations served included: adults with physical disabilities (73%); elders (51%); adults with mental retardation (41%); adults with developmental disabilities (30%); persons with traumatic brain injury (38%); children with mental retardation/developmental disabilities (34%); children with physical disabilities (30%); and persons with Alzheimer's Disease (29%). The most common restrictions limited participation to individuals who either have the ability to self-direct or have representatives (usually family members) willing to assist them. Most programs also restricted consumers from hiring spouses and parents or guardians of minor children. Representatives of consumers with cognitive impairments typically could not hire themselves.

Medicaid was the major funding source for consumer-directed services, with 84 programs (65%) funded in whole or part by Medicaid. Fifty-five percent of the consumer-directed programs were funded in whole or part by state revenues (other than state share of Medicaid). The most common covered services included personal care (83%), homemaker/chore (60%), respite (52%), transportation (47%), in-home rehabilitation therapies (28%), companion (19%), and medical services (18%). Most programs (88%) had formal quality assurance requirements or processes, such as monitoring of quality by case managers (employed by the State or ISO) or periodic participant reassessment for eligibility, change in service needs, or participants' health, safety, and satisfaction.

19. Doty, P, Kasper, J, and Litvak, S (1996). Consumer-Directed Models of Personal Care: Lessons from Medicaid. *Milbank Quarterly* 74(3):377-409.

This article compares and contrasts alternative approaches to administering Medicaid personal care services (PCS) programs for elderly and disabled persons, and identifies administrative features that tend to either facilitate or inhibit consumer choice and satisfaction. Data on state PCS programs were collected from: (1) mail questionnaire surveys of all Medicaid PCS programs in 1984 and 1988 by the World Institute on Disability; and (2) site visits to six programs in 1990-91. State officials were asked why various administrative features were adopted and to what extent their decisions were motivated by philosophical values and/or practical considerations. The selected states (Maryland, Massachusetts, Michigan, Montana, Oregon, and Texas) exemplified contrasting approaches to service financing and delivery on dimensions relevant to consumer choice and control. In Maryland, Massachusetts, and Michigan, Medicaid PCS aides were exclusively or predominantly "independent providers." In contrast, Montana, Oregon, and Texas required almost all aides to be employees of Medicare or Medicaid certified home health agencies. The states also varied in their requirements for formal quality assurance and how strictly they chose to interpret federal Medicaid prohibitions against

hiring family members as PCS aides. Data on perceptions of choice and control and satisfaction with attendant services were obtained via face-to-face in-home interviews with samples of Medicaid PCS clients (aged 65 and older) in three states (Maryland, Michigan, and Texas), drawing equally from urban and rural areas.

The authors conclude that consumer choice and satisfaction appear to be maximized when a public program not only permits, but also actively encourages clients to hire their own attendants and whomever they wish, in which case they tend to hire persons they know (family members, friends, neighbors, etc.). The result, for many clients, is an integration of their formal and informal support systems.

20. Eggert, GM and Wamsley, B (2004). *Consumer Direction and Medicare*. Jointly published by the Center for Aging and Healthcare in West Virginia, Inc., Parkersburg, WV and the Monroe County Long Term Care Program, Inc. (ACCESS), Rochester, NY.

This policy brief highlights findings and implications of a Medicare demonstration (*A Randomized Controlled Trial of Primary and Consumer-Directed Care for People with Chronic Illnesses*, CMS #95-C-90467/2-01) designed to evaluate consumer-direction in a convenience sample of 1,605 community dwelling, functionally impaired Medicare beneficiaries in western New York and the Mid-Ohio Valley of West Virginia/Ohio. Subjects were assigned to one of four groups for 24 months. The Consumer-Directed Group (n=419) received a Medicare waiver benefit or “voucher” of up to \$200/month to pay for augmented home care (e.g., personal assistance and companion services, in-home respite, transportation, environmental modifications, supplies and equipment). The Primary Care Affiliated Nurse Group (n=382) was designed to improve disease self-management and coach participants to adopt healthier lifestyle practices. In the Combination Group (n=420), participants received both the consumer-directed benefit and the services of a primary care affiliated nurse. The Control Group (n=384) received traditional community care.

Individuals in the three treatment groups, particularly persons who died during the course of the study, had higher Medicare costs than those in the control group. The greatest benefit in functioning was shown by the Primary Care Affiliated Nurse Group, followed by the Consumer-Directed Group. Medicare beneficiaries in the Consumer-Directed Group did as well on health-related quality of life outcome measures as the randomly assigned controls and were extremely satisfied with the consumer-directed benefit, primarily due to its flexibility. The study demonstrated that Consumer-directed care is a viable option for a Medicare population, including those with cognitive impairment.

A modest consumer-directed benefit that emphasizes flexibility, control and choice yields high satisfaction levels among beneficiaries without jeopardizing quality of care. Further, it has the potential to preserve function and to be cost neutral, if administrative costs are kept low and individuals needing palliative care are excluded. Components of a viable Medicare consumer-directed model should include: the option to hire in-home workers directly or to purchase agency home care services; a flexible benefit that can be used for a wide range of services, including in-home workers, supplies and equipment, and home modifications; primary care physicians as partners in supporting their patients to use the benefit; access to a variety of fiscal agent options;

ability to hire non-resident relatives as in-home workers; and staff support to help beneficiaries understand and manage the benefit.

21. Feinberg, LF and Ellano, C (2000). Promoting consumer direction for family caregiver support: An agency driven model. *Generations* 24(3):47-53.

This article describes the origin and development of a statewide system of 11 community-based nonprofit Caregiver Resource Centers (CRCs) in California in response to a need for support services for family members of people with cognitive impairment who did not fit into the traditional mental health or aging systems (adults with Alzheimer's disease, Parkinson's disease, stroke, traumatic brain injury, and other brain diseases and disorders). While the CRC has evolved over 16 years into an agency-driven model, it has maintained its core focus on empowering the family caregiver and adopting principles of consumer choice and direction. The CRC service staff provide traditional case management (assessment, developing a care plan, arranging service), but utilize a philosophy of care to support the ability of family caregivers to function as care managers. In contrast to the traditional case management "caseload" model, families come in and out of the system of care over many years, based on their needs and resources, which change over time because of the often-unpredictable course of dementing illnesses.

The core CRC service is family consultation, "a decision support strategy to assist family caregivers through the long-term care-planning process," and the CRCs offer respite as a flexible consumer-directed option for families whose situations differ from one another and over time. The challenges to incorporating consumer-directed principles into an agency-driven model include: the resistance to change of traditional case managers; differing attitudes about the role of the family; limited resources in the community; ethnic differences in preferences and availability of services; and involving elders earlier in the decision-making process. However, information technology and the Internet for outreach to consumers have empowered families with information and education. Preliminary findings of a study investigating CRC outcomes for family caregivers showed significant improvements in caregiver perception and competence, along with significantly fewer problem behaviors and problems associated with activities of daily living for care recipients.

22. Feinberg, LF and Whitlatch, CJ (1998). Family caregivers and in-home respite options: The consumer-directed versus agency-based experience. *Journal of Gerontological Social Work* 30(3/4):9-28.

This article describes a study of in-home respite care provided through the California Caregiver Resource Centers. It compared the preferences and satisfaction of 168 family caregivers of adults with cognitive impairments who either paid providers for in-home respite care directly (direct pay) or received professionally managed (i.e., agency-based) respite services. Respondents in both groups identified the same "most important" reasons for preferring their respective mode of respite: wanting to be sure their loved one was safe; and having good, reliable and trustworthy help. However, the data revealed a clear preference for consumer direction in respite care in the home. Recipients who used the direct-pay model

(reflecting the tenets of consumer-directed care) expressed greater satisfaction with the care – due primarily to their feelings of greater control over the situation. They could select a respite care provider and secure more service hours for the money they were allotted for care. The authors conclude that consumer-directed respite should be offered as an option, but is not appropriate for all consumers, especially those with cognitive limitations. The option can, however, still be made available to family members of those individuals. Practical implications are addressed for improving the delivery of in-home respite care.

23. Flanagan, SA, Green, PS, and Eustis, N (1998 Summer/Autumn). You can do it: State initiatives broaden access to consumer-directed personal assistance services through use of intermediary service organizations. *American Rehabilitation* **24**(2/3):21-26.

This article examines state initiatives to assist persons with disabilities and chronic conditions and the role played by a new provider type, the intermediary service organization (ISO), in achieving the best balance between the competing goals of maintaining the consumers' autonomy, choice, and control and ensuring their safety and well-being. A number of states have begun contracting with ISOs to provide the range of fiscal, administrative, and support services needed to enable consumers of varying desires and abilities to effectively manage their consumer-directed personal assistance services (CD-PAS), while meeting the legal and administrative requirements arising from an employment relationship such as ensuring that tax and labor laws are followed.

The results of an evaluation by the MEDSTAT Group of 23 CD-PAS programs in 11 states are briefly discussed. MEDSTAT identified six discrete models of ISO currently in use to provide a range of fiscal, administrative, and support services. They are: Fiscal Conduit ISO, IRS Employer-Agent, Vendor Fiscal ISO, Supportive ISO, Agency with Choice, and Spectrum ISO. The MEDSTAT study showed that programs are most successful when they provide consumers with a high level of choice, direction, and program flexibility in the type and timing of services received and the ability to choose and manage their attendants. Selecting an appropriate ISO model requires matching the desires and abilities of the various populations served with the types and amounts of assistance provided. Even the most independent consumer may wish to receive some support from time to time, so services should be offered on an “as needed” basis.

The authors conclude that the key to success for an ISO, whether a full-service entity (e.g., an Agency with Choice or a Spectrum ISO) or one that only provides tax and payroll services (e.g., an IRS Employer Agent or Vendor Fiscal ISO), is a commitment to the Independent Living philosophy and the belief that persons with disabilities can self-direct and are capable of managing their own lives. The growth of the Independent Living Movement, together with the current trends in public health policy toward consumer empowerment and responsibility, make this an auspicious time to expand the availability of consumer-directed personal assistance programs to persons with disabilities and chronic conditions of all ages through the thoughtful implementation of ISOs.

24. Foster, L, Brown, R, *et al.* (March 2003). *Improving the Quality of Medicaid Personal Assistance through Consumer Direction*. Health Affairs, web exclusive.

This report presents findings from IndependentChoices, the first Cash and Counseling Demonstration program in Arkansas, in which telephone surveys were conducted to assess differences in quality of care received by Medicaid recipients randomized into control (receiving agency-directed services) and treatment (the consumer-directed model) groups. Respondents (1,739 elderly and non-elderly adults) were queried about: their satisfaction with the reliability, schedule, and performance of their paid caregivers; unmet needs and satisfaction with care arrangements; adverse events, health problems, and general health status; and overall satisfaction with life.

The Cash and Counseling approach – designed to increase recipients’ choice and control over their personal assistance – greatly improved consumer satisfaction and outlook on life and reduced most unmet needs. Key issues that contributed to this increased satisfaction were: having intimate care performed by a person of their choice rather than a stranger; being able to obtain care at the times of day or week desired and to tell workers how they wanted their care delivered; and the increased reliability of personally selected workers.

The study demonstrated that the health of beneficiaries in the treatment group did not suffer and actually may have improved by a few measures. Program critics were concerned that untrained family members might not be able to provide appropriate care, especially in the absence of periodic visits from nurses to oversee that care. However, family members who had always provided most of the beneficiaries’ care, had ample preparation, if not formal training, to provide adequate care or to supervise the provision of care. The fact that 96% of all treatment-group respondents, including disenrollees, said they would recommend the program to others confirms that even disenrollees found IndependentChoices to be a desirable alternative to agency care. In conclusion, the data presented here provided support for the October 2002 decision by Arkansas and federal Medicaid administrators to renew IndependentChoices after the initial demonstration period ended. The results of this analysis should also be useful to states that are contemplating voluntary consumer-directed program options and organizations that advocate for the elderly.

25. Foster, L, Brown, R, *et al.* (March 2003). *Does Consumer Direction Affect the Quality of Medicaid Personal Assistance in Arkansas?* Final Report. Mathematica Policy Research, Inc.

The effect of consumer direction on quality of care was studied in 2,008 enrollees in Arkansas’s Cash and Counseling Demonstration program, IndependentChoices, who were at least 18 years old and eligible for personal care services (PCS) under the state Medicaid plan. Study participants were randomly assigned to direct their own PCS (the treatment group) or to receive services as usual from agencies (the control group). IndependentChoices consumers received a monthly allowance to hire their choice of caregivers (except spouses) and buy other goods or service. They could also designate representatives and receive help managing the allowance.

Results of telephone interviews conducted 9 months after baseline indicated that IndependentChoices markedly increased the number of consumers who were very satisfied with

their PCS. Specifically, they were more satisfied with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way paid caregivers performed their tasks. The program also reduced some unmet needs and greatly enhanced quality of life without compromising consumer health, functioning, or self-care. Both elderly and non-elderly adults fared better under IndependentChoices than they did with agencies. In addition, 96% of all treatment group respondents, including disenrollees, said they would recommend the program to others, which confirms that even disenrollees found IndependentChoices to be a desirable alternative to agency care. From a quality of care standpoint, Arkansas and federal Medicaid administrators have compelling evidence to support their October 2002 decision to continue IndependentChoices after the end of the demonstration period.

The authors conclude that, while quality and consumer satisfaction results were strongly favorable in Arkansas, factors such as the use and costs of PCS and other health care services, the experiences of informal and paid caregivers, and program implementation issues must be examined before the desirability of consumer-directed care can be fully confirmed in Arkansas and other states. While consumer-directed care is not for everyone, Arkansas is making a clear commitment to improving consumer well being by offering this option to individuals eligible for Medicaid PCS.

26. Foster, L, Brown, R, *et al.* (2003b). *Easing the Burden of Caregiving: The Impact of Consumer Direction on Primary Informal Caregivers in Arkansas*. Final Report. Mathematica Policy Research, Inc. Princeton, NJ.

This study compares the experiences of 1,433 informal caregivers in the Arkansas Cash and Counseling demonstration, IndependentChoices, in which care recipients were randomly assigned to receive a cash allowance to direct their own personal care services (treatment group) or to rely on traditional agency services (control group). Care recipients could hire their primary informal caregivers as workers (over half did) or use them as representative decision makers; adjust the amount, timing, and types of services they received; buy assistive devices or home modifications; or use the program's counseling and fiscal services to varying extents.

In telephone interviews of caregivers of both treatment and control group members between February 2000 and April 2002, about 10 months after random assignment, caregivers in the consumer-directed group reported greater well-being. On average, they provided fewer hours of assistance than did their control group counterparts and they were less likely to report high levels of physical, financial, and emotional strain. They worried less about insufficient care and safety and were more likely to be very satisfied with recipients' overall care arrangements. They were also less likely to report that caregiving impinged on their privacy, social lives, and job performance. Finally, they said they themselves were in better health and were less likely to report that their health was harmed by caregiving. They were also much more likely than their control group counterparts to be very satisfied with their own lives.

The authors conclude that consumer direction markedly benefits both care recipients and their primary informal caregivers. Improvement comes about because some informal caregivers become paid workers and because beneficiaries make service arrangements that seem to alleviate

caregiver burden. In both cases, the benefits to caregivers, Medicaid beneficiaries, and perhaps the Medicaid program, are substantial.

27. Glazier, RE, Landino, C, and Reardon, L (August 2003). *Evaluation of Wheelchair Purchasing for Medicare Beneficiaries with Physical Disabilities in the Consumer Directed Durable Medical Equipment (CD-DME) Demonstration and Other Fee-for-Service and Managed Care Settings*. Process Evaluation Draft. Contract no. 500-00-0032/ TO# 6. Department of Health and Human Services, Centers for Medicare and Medicaid Services.

This draft report presents a preliminary evaluation of a Medicare consumer-directed durable medical equipment (CD-DME) demonstration that explored an alternative to the DME procurement process for power wheelchairs that would shift control to the consumer. The demonstration involved using third-party consumer-oriented and directed organizations, Centers for Independent Living (CILs), to help beneficiaries with physical disabilities to: navigate the complex Medicare payment system for wheelchairs and related equipment; negotiate product discounts from suppliers; and use the resulting savings to purchase other equipment and accessories (whether or not these were covered by Medicare). If beneficiaries obtained equipment at a cost lower than the Medicare schedule's value, they received a credit from the DME provider (Cigna) that remained active for 3 years to purchase other items or cover future maintenance costs. The basic goals of the Demonstration were to: provide greater beneficiary control and benefit flexibility in the Medicare wheelchair purchasing process; increase beneficiary satisfaction with equipment selection, fit, modifications, maintenance, and repairs; and increase provider efficiency and satisfaction. The desired result would be improved overall beneficiary health status and quality of life.

While the four participating CILs were pleased with the consumer-empowerment aspects of the program, they perceived a lack of encouragement and timely feedback from CMS, and felt that the demonstration was "over-sold" to beneficiaries, whose expectations could then not be met. In addition, the DME vendors were not receptive to the program because they had little incentive to invest time and effort into accommodating, educating, and negotiating with a consumer who might find a better deal elsewhere and purchase the wheelchair from someone else.

28. Infeld, DL (2004). *States' Experiences Implementing Consumer-Directed Home & Community Services: Results of the 2004 Survey of State Administrators, Opinion Survey & Telephone Interviews*. The National Association of State Units on Aging and the National Council on the Aging. Washington, DC.

This report summarizes the results of two 2004 surveys and one set of interviews with state administrators regarding 58 consumer-directed HCBS programs for older people in the United States. While most states (43%) currently only serve 500 persons or fewer, several states have highly developed programs that serve thousands of older persons. Consumer direction developed mainly in response to: perceived gaps in service delivery; an inadequate supply of providers; consumer demand and advocacy; federal and state policies; and cost considerations. It

is regarded as an effective means to address cultural diversity, workforce shortages (particularly in rural areas), and the needs and preferences of non-traditional and hard-to-reach consumers.

The typical program offers the choice of agency (88%), selection of worker (84%), control over one's schedule (88%) and how tasks are done (93%), and/or choice of services (84%). Medicaid HCBS waivers provide funding for nearly half of the programs. Other frequent funding sources include state general revenues (26%) and Title III Older Americans Act funds (22%). The Medicaid state plan personal care option, county/municipal funds, and other Medicaid waivers also fund programs to a lesser extent.

States reported that the process of obtaining approval for a consumer-directed waiver from the Centers for Medicare and Medicaid Services took a long time. Strong resistance from providers was frequently reported to be the primary barrier to implementing consumer-directed HCBS for older persons. Other barriers include: inadequate funding; concerns about poor compensation and benefits for caregivers; and the challenges of financial administration (e.g., the use of vouchers, fiscal intermediary services, workers' compensation issues, and tax questions). Fewer respondents reported serious concerns about either potential fraud and abuse or quality of care. States reported that older persons are very satisfied with consumer-directed services and program administrators see it as effective and "*simply the right thing to do.*"

29. Kane, RA and Levin, CA (1998). Who's safe? Who's sorry? The duty to protect the safety of clients in home- and community-based care. *Generations* 22(3):76-81.

This article explores the consumer's right to take risks and the legal and ethical concerns of professionals who provide home- and community-based services (HCBS) when considering granting autonomy to older adults. It advises professionals who work with older consumers to strike a balance between promoting freedom for older people and not interfering with their life goals, while also acting responsibly to promote their health and safety. The authors put this ethical dilemma in perspective by saying, "Paradoxically, the desire to do no harm and to achieve safety above all other goals may actually result in harm for the consumer." The authors recommend considering the following elements when appraising potential risk to an HCBS customer: type of risk; severity and likelihood of consequences; difficulty of predicting risk; negative effects of avoiding the risk; and the role of providers.

Informed risk-taking involves: a source of trustworthy information; time for the consumer to digest the information and weight the implications; and a competent individual who is capable of understanding the pros and cons and making the choices. The concept of "managed risk contracting," which has been implemented to the greatest extent in Oregon, is described as an orderly process in which an informed consumer knowingly accepts risks and their consequences, and the provider plans in advance to mitigate those risks. Questions are raised regarding instances "when things go wrong" and consumer hurt themselves or others and "who is to blame?" Cognitive impairment in clients and surrogates' assumptions about the kinds of risks these clients prefer to take are presented as the most difficult situations when working with consumers. The authors call for the development of a new approach in HCBS that shifts away from the current practice of placing safety as the default position without consideration of the psychosocial needs of the consumer.

30. Kapp, MB (1997). Who is responsible for this? Assigning rights and consequences in elder care. *Journal of Aging and Social Policy* 9(2): 51-65.

In this article, Kapp asserts that, “A substantial impediment exists in our cultural environment that discourages families and professionals, and the agencies that employ them, from recognizing and respecting the rights of older persons in a less adversarial and more subtle, sensitive, and flexible manner.” Often families and service professionals become engaged in a power struggle with older adults regarding their ability to make meaningful decisions about their lives. This conflict often stems from the altruistic, albeit paternalistic, desire to help older people and protect them from harm. Fears of liability and reprisal, compounded by the societal and institutional bias of assigning blame and inflicting punishment, often perpetuates the tendencies of families and professionals to try to shield older people from the consequences of “bad” decisions. Kapp argues for a shift in mindset for families and professionals to one that acknowledges the right of older adults to exercise autonomy – including being allowed to reject suggestions from others – and recognizes that this right carries with it the responsibility to accept the consequences of their decisions. Applying this paradigm within the existing service delivery system is explored in several aging-related settings: assisted living; consumer-directed home- and community-based services; and medical decision making on behalf of those who are chronically ill. Finally, Kapp discusses issues that must be addressed and resolved before change can occur. He stresses the need to provide more surrogate decision-makers, clarify their roles, and implement the practice of obtaining consent decrees.

31. Kapp, MB (2000). Testing consumer-directed models of long-term care: Ethical and legal considerations. In MB Kapp (Ed.). *Ethics, Law, and Aging Review* 6:181-187. Springer Publishing, New York.

This article identifies the ethical and legal issues involved in testing consumer-directed models, specifically those in which consumers are assigned to “experimental service delivery and financing.” These issues include: the inconsistent enforcement by Institutional Review Boards of federal regulations as they apply to health services protocols; ambiguity about the validity of obtaining informed consent for participation in a health-related research protocol from persons with cognitive and/or physical limitations; and the ability of researchers to guarantee a tolerable ratio of reasonably foreseeable risk to expected benefits. Other concerns involve designing protocols with equitable subject selection and the issue of maintaining confidentiality in cases where specific data is linked to specific persons. Kapp also raises questions in the area of professional liability regarding the obligation of licensed health or social service professionals to report observed instances or suspicions of consumer abuse, neglect or exploitation. This includes suspicion of fraud in the use of benefits by family members who serve as providers or surrogates. He raises a troubling concern about the liability of health and social service providers for “permitting and abetting bad decisions by or for, and adverse outcomes to, a consumer/research subject.” He concludes that the ethical and legal dilemmas will need to be addressed and resolved as research continues in the area of consumer-direction.

32. Kodner, DL (2003). Consumer-directed services: Lessons and implications for integrated systems of care. *International Journal of Integrated Care* 17 (online Journal).

This policy paper discusses reform of the long-term care system for the frail elderly and younger people with disabilities. Kodner sees this as a continuum of strategies that includes integrated systems of care. On the one end are agency/professionally managed service packages. On the other are programs offering cash benefits, along with the flexibility to use these funds to meet individual needs and preferences. He explores the meaning, rationale and models of consumer-directed care and identifies the hallmarks of these models as autonomy, control, privacy, and respect for personal choices. This is followed by an analysis of developments, designs, and experiences of select programs in Austria, Germany, the Netherlands, and the United States. The article concludes with an examination of the lessons learned from these programs and their implications for building more responsive and effective integrated care systems for the frail elderly and people with chronic disabilities. He encourages the use of consumer-directed philosophy in integrated systems of care (e.g., recruitment of team members who respect the philosophy of client empowerment, providing information and educational services to help the client make informed decisions, and the use of technology to enhance quality of communication). Kodner asserts that, in order for integrated care programs to manage services and costs for consumers more efficiently than the current care systems they are intended to replace, they must adopt the cost-effectiveness of the various consumer-directed models and study their performance within the structure of integrated service delivery.

33. Liebel D, Wamsley, BR (2004). *Final Report: Follow-up ADL Analysis, Mortality Analysis, and Case Study Analysis*. Office of Rural Health Policy, HRSA, Washington, D.C.

This study assessed post-intervention functional status among individuals who had participated in a demonstration project that tested the effectiveness and acceptability of a primary care affiliated model of disease self-management/health promotion and a model of consumer-directed care. The demonstration aimed to reduce participants' rate of functional decline. At baseline, 224 participants were assessed, and 147 were re-assessed 22 months into the 2-year intervention. A third follow-up assessment of 89 individuals was conducted 25 months after the 22-month assessment. Analysis of assessment results demonstrated that functional gains made during the intervention were not maintained post-intervention and mortality did not differ among treatment groups. Although participants in rural areas had fewer resources, they had better outcomes than urban and suburban participants. Researchers also conducted case studies of participants and interviewed participating nurses. Case study results indicated that the intervention team was helpful in encouraging participants to begin and maintain an individualized physical activity program. The nurses noted the lack of supports for participants in maintaining functional gains over the longer term. The results suggest that a range of different supports should be tested to improve maintenance of functional gains, including the addition of physical therapy resources, telehealth options, and Physical Activity Accounts, which allow individuals to purchase a variety of health maintenance services.

34. Meiners, M, Mahoney, KJ, *et al.* (2002). Consumer Direction in Managed Long Term Care: An Exploratory Survey of Practices and Perceptions. *The Gerontologist* 42(1):32-38.

This article presents the results of a 1999 mail survey of attitudes concerning consumer direction and consumer-directed practices in 45 managed care organizations (MCOs) located in 17 states. These organizations provide capitated long-term care benefits, including personal assistance services, to their Medicaid eligible clients. The survey questions focused on understanding several alternative measures of consumer direction and the issues of concern for MCOs in choosing to implement these practices. Study results indicated that, although the majority of responding MCOs were practicing some form of consumer direction, their experience was limited and underdeveloped. Opinions regarding the profitability, benefits, and risk associated with consumer direction varied considerably depending on the extent to which an MCO provided consumer-directed options. About a third allowed participants to hire and fire their own worker, while nearly half gave participants some say in worker arrangements. Over one in five allowed neither option. Low-choice MCOs were more likely to have quality, cost, and liability concerns about consumer direction and were less likely to believe that consumer direction would result in better quality service. In contrast, high-choice MCOs were more likely to regard increasing independence as an important goal and to think that it was important to clients. In conclusion, consumer direction and managed care are two important emerging areas of interest in long-term care that seem incompatible. However, this study suggests that they can work together and provides a baseline to assess further development of their compatibility.

35. Meng, H, Friedman, B, *et al.* (2005). Effect of a consumer-directed voucher and a disease-management–health-promotion nurse intervention on home care use. *The Gerontologist* 45(2):167-176.

This article assesses the impact of a consumer-directed voucher for in-home supportive services and a chronic disease self-management–health-promotion nurse intervention on 1,394 functionally impaired Medicare beneficiaries without private long-term-care insurance. The specific purpose was to examine the effect of these approaches on the use of home care (both personal assistance services and skilled home health care), services that are vital to many older people. The study was one aspect of the 2-year CMS-sponsored Medicare Primary and Consumer-Directed Care Demonstration that began in August 1998. This randomized controlled trial in 19 counties in New York, Ohio, and West Virginia comprised four study groups: (1) disease-management–health-promotion nurse; (2) consumer-directed voucher; (3) combination (nurse plus voucher); and (4) control.

The authors hypothesized that the nurse intervention would decrease hospitalization rates and reduce the probability of skilled home health care use, since the majority of skilled home health care occurs after hospitalization. However, the nurse intervention alone had no effect on the probability of using either type of home care. On the other hand, use of the voucher alone increased the probability of accessing personal assistance services (which could be paid for with the voucher) by 13%, but not skilled home health care (which was not covered by the voucher). The combination of the two interventions appears to have had a synergistic effect on increasing the probability of personal assistance services use by 18%. This was attributed to the nurse advising patients on how to spend the voucher. The authors conclude that a modest consumer-

directed voucher benefit under Medicare improves access to much-needed personal care services without increasing the probability of use of more costly skilled home health care services.

36. National Academy for State Health Policy (February 1998). *Consumer Involvement in Managed Care Programs Serving Persons Dually Eligible for Medicaid and Medicare*. MMIP Technical Assistance Paper No.3.

This report discusses efforts in five states to offer consumers a meaningful role in the design and implementation of programs with high percentages of dually eligible consumers. It emphasizes the need for planners and managers to: implement programs that solicit and use consumer input to help them meet consumer needs; obtain needed feedback quickly; and educate consumers to create buy-in. Programs should clarify goals for involving dually eligible consumers, develop recruitment methods to target this population, and maximize participation of dually eligible people by minimizing barriers that may be related to their impairments. The report also addresses the use of surveys, focus groups, public forums, advisory committees/workgroups, and complaints/grievances methods that “take the fear and confusion out of complaining.” The report discusses the ways in which consumer and advocate input has caused states to:

- Change proposed enrollment from mandatory to voluntary.
- Change the proposed specialty clinic model to a provider network model.
- Modify the complaints/grievance process.
- Develop risk-adjusted capitation rates.
- Create more detailed and tighter RFP standards for providers.
- Modify marketing and enrollment materials to highlight issues important to dually eligible potential consumers.
- Develop training materials and tools for quality improvement efforts.

The report concludes that consumer involvement plays an important role in consumer satisfaction, which may be especially significant in keeping dually eligible people voluntarily enrolled in the program. States that have made a commitment to consumer involvement report that it has significantly helped their programs, plus they have developed relationships that help resolve issues when problems arise.

37. National Council on Aging (1996). *Principles of Consumer-Directed Home and Community Based Services*. National Institute on Consumer-Directed Long-Term Services and World Institute on Disability, Washington, DC.

This paper offers program planners, administrators, and service providers a clear and concise explanation of consumer direction as an option in service delivery, and would be particularly helpful to individuals who have had limited exposure to this model. It identifies the basic principle of consumer-directed services – i.e., individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the

source of payment for services. From that basic principle, the following five secondary principles are derived:

- Systems should be based on the presumption that consumers are the experts on their service needs.
- Different types of services warrant different levels of professional involvement.
- Choice and control can be introduced into all service delivery environments.
- Not only do consumer-directed service systems support the dignity of people requiring personal assistance, but they also can be less costly, when properly designed.
- Consumer direction should be available to all, regardless of the payer.

The discussion of these principles makes the case that implementing consumer direction works to ensure that the services provided will be appropriate and increases consumer satisfaction. In evaluating current programs and designing future programs, it is essential to examine both the service provider and the services provided and to understand why, when, and how services are delivered. Consumer-directed options may range from allowing an individual to make all decisions about services and to manage those services to the use of a representative decision maker.

41. National Council on Disability. *Consumer-Directed Health Care: How Well Does it Work?* Report submitted to the President on October 26, 2004 by Lex Frieden, Chairperson of NCD, Washington D.C.

The intent of this report is to present the National Council on Disability's evaluation of the strengths and weaknesses of the Federal Government's current research agenda related to consumer-directed health care for Americans with disabilities. It provides a systematic, multidimensional analysis of existing policy, research, and best practices in consumer-directed and consumer-oriented health care for people with disabilities, with insights from consumers, program administrators, policymakers, advocates, and researchers. The information is presented in the hope that a better understanding of the issues will lead to the adoption of policies and practices that:

- Expand opportunities for independence, social integration, and quality of life for individuals with disabilities through reduced institutionalization and greater access to flexible supports;
- Maximize autonomy among individuals with disabilities with regard to health and related services; and
- Ensure that systems of care at federal, state, and local levels offer a full range of services to meet the varied needs and preferences of consumers with disabilities.

The purpose of the report is to inform policymakers, practitioners, researchers, consumers, and advocates for health reform about:

- Current laws for consumer-directed and consumer-oriented health care;

- Program and policy trends in the financing, availability, and structure of consumer-directed and consumer-oriented health care;
- Outcomes of consumer-directed and consumer-oriented health care;
- Factors associated with the implementation of models of consumer-directed health care;
- Barriers to and facilitators of program implementation; and
- The role of federal agencies in evaluating consumer-directed health care initiatives.

The report recommends “next steps,” beginning with a change in the way government, private agencies, and consumer organizations think about organizing, locating, and managing health care for people with disabilities. It foresees a cross-disability, lifespan approach in which funds are available to meet individual needs, resources are directed to fill gaps in the service continuum, and programs meet rigorous evaluation standards for consumer-defined outcomes in domains that include not only direct satisfaction with services but also quality of life, health, mental health, and function.

42. National Mental Health Association (2004). *Consumer Control and Choice: An Overview of Self-Determination Initiatives for Persons with Psychiatric Disabilities*. NMHA Issue Brief. DRAFT REPORT.

This draft report introduces the self-determination movement for persons with psychiatric disabilities, beginning with a brief history and discussion of barriers to self-determination for persons with psychiatric disabilities, including: negative stereotypes; public mental health systems designed to manage instead of support; unemployment among the mentally ill; a separate service system; and lack of outcomes for self-directed care. The report examines: the most common forms of self-directed care, which afford the recipient varying levels of control (Personal Assistance, Cash and Counseling Programs, and Brokered Support); models of self-directed care that offer fiscal control (direct cash payments, Fiscal Intermediary or Supportive Intermediary programs, and self-directed case management programs); and funding mechanisms for self direction through various governmental agencies.

NMHA cautions consumers and advocates to carefully inspect any proposed self-determination initiative to ensure that it is adequately funded. Their recommendations or “Next Steps” are: research (national demonstration and evaluation programs to establish emerging best practice); collaboration between consumers, advocacy organizations, mental health professionals, researchers and other stakeholders; and education at all levels to inform consumers, service providers, policymakers, system administrators and the general public about approaches to self-directed care. Further, the report stresses the importance of inter-agency collaboration between federal agencies such as the Centers for Medicare and Medicaid Services (CMS), the Substance Abuse and Mental Health Services Administration (SAMHSA), the US Department of Housing and Urban Development (HUD), and the Social Security Administration (SSA) to provide leadership in the creation and development of self-directed programs.

43. Pennsylvania Department of Aging Consumer Direction Report (2005). <http://www.aging.state.pa.us/aging/lib/aging/ConsumerDirectionReport4.pdf>.

This report documents an assessment of Pennsylvania's Home and Community-Based Service system approach to consumer choice and control and identifies opportunities for improvement. The project, funded by a grant from the National Association of State Units on Aging, was conducted by the Pennsylvania Department of Aging, with input from stakeholders, and utilized the *Consumer Direction Tool Kit* to help gather information. Data were collected via surveys of: currently enrolled consumers; stakeholders (age-appropriate but non-participating individuals); and provider/agency administrators or human services professionals. The surveys focused on four key concepts: Opportunity, Meaningful Participation, Independence, and Financial Security and Other Safeguards.

While the majority of consumers said they were aware of the programs, fewer knew how to access these services. Over 50% of potential consumers were in favor of having decision-making authority and 81% said they would like participate in monitoring their services. Providers are actively discussing consumer direction, but few believe that adequate information is available for consumers. Suggestions from providers included:

- Provide more funding;
- Include a requirement for an aggregate cap in the Waiver (implemented in SFY 04–05);
- Do away with estate recovery in the Waiver;
- Allow spouses to be paid employees; and
- Exempt adult daily living services from cost-sharing requirements.

The report concludes that, although Pennsylvania is actively practicing and encouraging consumer direction, standardized statewide training and education are needed. It recommends that a training module be developed with separate sections for consumers, potential consumers, and providers –developed with input from these three populations to addresses the concerns of all.

44. Phillips, B, Mahoney, K, *et al.* (June 2003). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey*. US Department of Health and Human Services. Assistant Secretary of Planning and Evaluation. Office of Disability, Aging and Long Term Care Policy. Mathematica Policy Research, Inc.

This report discusses lessons that were learned in the original Cash and Counseling demonstration states (Arkansas, Florida, and New Jersey) about designing and implementing this expanded model of consumer-directed supportive services. A synopsis is provided of the program features that make Cash and Counseling adaptable to consumers of all ages and with all types of impairments. The program provides a flexible monthly allowance for consumers to hire their choice of workers, including family members, and to purchase other goods and services. It requires consumers to develop plans for spending the allowance, but provides counseling and fiscal assistance to help them or a designated representative to develop their plan and manage their fiscal and employer responsibilities. Preliminary results indicate that the great majority of consumers in the three original programs were very well satisfied, disability-related health outcomes for treatment group members were at least as good as those for controls, and treatment group members had fewer unmet need and greater satisfaction with their supportive services.

Key lessons are presented in the areas of: outreach and enrollment; the role of consumer representatives; spending plans and counseling; the use of the cash allowance; issues involving workers; structure and procedures for counseling and fiscal services; preventing exploitation and abuse, and program costs. The authors stress that states benefit from technical assistance when implementing Cash and Counseling, especially with fiscal issues. Direct outreach to eligible beneficiaries works best, with easy to understand materials that address the language and literacy level diversity of the Medicaid population. This model is attractive to substantial minorities of both elderly and non-elderly adults with physical disabilities, and to children and adults with developmental disabilities.

Nearly all consumers used the allowance to hire workers, usually relatives or acquaintances, which improved access to care by tapping a new labor supply. Consumers who were unable to hire a relative or friend had difficulty recruiting workers, so states may wish to provide counselors to assist such consumers with recruiting or develop referral mechanisms such as worker registries. The flexibility of the cash allowance helps consumers to meet their needs better through the purchase of goods and services not available in the traditional system. Reportedly, nearly all consumer representatives in the three programs served the interests of the consumer, although monitoring is suggested to limit conflict of interest when the same person serves as both a representative and a worker. Consumer exploitation was very rare, and abuse of the allowance was nearly nonexistent in the three programs. In conclusion, the authors indicate that the states that have experienced Cash and Counseling firsthand have already decided that they want to make the program available permanently to all eligible Medicaid beneficiaries. They caution, however, that improvement in access to care might increase overall costs, even if cost per month per recipient is constrained. Overall costs could also increase if the availability of an allowance increases demand relative to demand for traditional services.

45. Phillips, B and Schneider, B (May 2002). *Moving to IndependentChoices: The Implementation of the Cash and Counseling Demonstration in Arkansas*. Final Report. Mathematica Policy Research, Inc. Princeton, NJ.

This report describes the design and implementation of IndependentChoices, the Arkansas model of Cash and Counseling. It covers: outreach and enrollment; program structure; counseling and fiscal services; and the program features participants found either attractive or unattractive. The report is based on in-person interviews conducted with state officials; IndependentChoices staff; representatives of advocacy groups; and staff of agencies that provided counseling and fiscal services and agencies that provide traditional Personal Assistance Services (PAS) in Arkansas. The IndependentChoices protocol offered a cash benefit in lieu of traditional PAS provided under the Medicaid state plan or a Medicaid waiver. Equal numbers of participants were randomly assigned to the treatment group (receiving the cash benefit) or the control group (receiving traditional services). About 2,000 people participated in the demonstration (in both groups combined), roughly 10-15% of PAS recipients annually. Almost all consumers who received a cash benefit hired a worker, usually a family member or friend. Some consumers purchased assistive equipment, personal care supplies, and nonprescription and prescription medications (when these medications were not covered by Medicaid). A few purchased materials to modify their homes.

The outreach to eligible beneficiaries involved: a community information and enrollment campaign conducted by state nurses; a direct marketing campaign with mailings to each beneficiary receiving state plan PAS services; and a toll-free telephone number. Consumers who wished to participate but were unable to manage their own services were allowed to designate a representative to act on their behalf if they were selected for the cash benefit. The State contracted with two human services organizations to provide counseling and fiscal services – one a for-profit organization with expertise in rehabilitation services and the other a nonprofit organization providing schooling and supportive services to children and adults of all ages. Fiscal services were provided to consumers without charge and included preparation of payroll documents, check-writing, and bookkeeping services. Nearly all consumers elected to use the fiscal services. Those who did not were required to demonstrate sufficient knowledge and competence before assuming payroll responsibilities.

The procedures developed for IndependentChoices were, on the whole, successful. Arkansas' experience suggests a number of lessons for future Cash and Counseling programs in Arkansas and other states in the areas of: outreach and enrollment; counseling and fiscal services; budget neutrality (discounting, counseling/fiscal fees, and reassessment); agency cash flow; and structuring a Cash and Counseling program. Arkansas views a consumer-directed cash program as a valuable part of a package of programs designed to meet the needs of its citizens, and is working to make IndependentChoices a permanent program.

46. Phillips, B and Schneider, B (March 2003). *Enabling Personal Preference: The Implementation of the Cash and Counseling Demonstration in New Jersey*. Office of Disability, Aging, and Long-Term Care Policy. Office of the Assistant Secretary for Planning and Evaluation. U.S. Department of Health and Human Services. Mathematica Policy Research, Inc.

This report describes the design and implementation of Personal Preference, New Jersey's model of Cash and Counseling, and is based on in-person interviews conducted in April 2001, about 18 months after the program began enrolling Medicaid personal care assistance (PCA) clients. Interviews were conducted with: state officials; Personal Preference staff; organizations representing the New Jersey personal care industry; and staff of organizations providing outreach, enrollment, consulting, and fiscal services under Personal Preference. The report discusses lessons that were learned about: outreach and enrollment; determining the amount of the cash allowance; client reassessments; cash planning and uses of the cash allowance; and the provision of fiscal services. The pace of enrollment consistently fell below the contract target, despite revisions to outreach and enrollment procedures, and costs were higher than anticipated. Ultimately, about 1,750 people participated in the Personal Preference Demonstration (in the treatment and control groups combined). After developing a plan for use of the cash allowance, nearly all consumers used the funds to hire a worker – usually a family member (including a spouse) or friend. Some consumers used their allowance to purchase assistive equipment, personal care supplies not covered by Medicaid, and home modifications. New Jersey recruited a large number of human service agencies across the State to provide a choice of consulting agencies and services to New Jersey's culturally diverse population (34 agencies signed memoranda of agreement). Some were public (e.g., county departments of social services); some were private, nonprofit (e.g., a Center for Independent Living); and some were private, for-profit (e.g., an agency that provided case management services). A single

organization (fiscal agent) provided fiscal services for consumers across the State, and implemented strict procedures for comparing timesheets and check requests with the cash management plan before checks were cut. New Jersey provided the fiscal agent with start-up funds.

In conclusion, New Jersey views a consumer-directed cash program as a valuable part of a package of programs within its Medicaid state plan designed to meet the needs of its citizens. The Cash and Counseling model appears to tap a new source of personal assistance workers – family members and friends who provided care for people who could not be served fully by agencies. Program staff reported that most workers hired by consumers were willing to assist a loved one but were not interested in agency employment. Consumer who did not have family or friends to hire needed help to recruit workers, so New Jersey is developing a worker registry to provide this assistance.

48. Promising Practices in Home and Community-Based Services (2005a). *Kansas – Providing Choice among Providers of Financial Management Services*. Prepared by Medstat for the US Centers for Medicare and Medicaid Services. Baltimore, MD. <http://www.cms.hhs.gov/promisingpractices/ksawc.pdf>.

This document is one of a series of reports by Medstat on promising practices in home and community-based services. It discusses consumer direction in Kansas under the Agency with Choice (AWC) model, in which Medicaid program participants who self-direct their services and hire workers of their choice select an Employer of Record for their worker from a large number of organizations that fulfill this function (roughly 50). These organizations – generally centers for independent living and non-traditional home health agencies – provide core financial management services. Some also provide additional services to assist participants to self-direct, as well as a range of worker benefits.

Self-directed attendant options are offered under Medicaid HCBS Waivers for people with physical disabilities (PD), frail elders (FE), people with traumatic brain injury (TBI), and people with developmental disabilities (DD). They include a broad range of personal care services because the Kansas Nurse Practice Act allows workers to perform some “health maintenance activities” that other states would require to be done by nurses. The DD waiver also allows groups of parents to establish AWC providers if they meet a minimal set of requirements.

Program managers estimate that 80-85% of participants in the PD and TBI waiver programs and about 33% of those in the FE and DD waiver programs opt to self-direct their care. They ascribe the success of consumer direction to consumer education, the strong desire of consumers to gain control over their services, and the effectiveness of advocacy groups.

49. Promising Practices in Home and Community-Based Services (2005b). *Wisconsin – Supporting Consumer-Directed Services within Managed Care*. Prepared by Medstat for the US Centers for Medicare and Medicaid Services. Baltimore, MD. <http://www.cms.hhs.gov/promisingpractices/wiawc.pdf>.

This document is one of a series of reports by Medstat on promising practices in home and community-based services. It presents the Wisconsin Family Care program, which serves 17% of the State's eligible Medicaid population with flexible long-term care services and supports, to illustrate how a managed care program can incorporate consumer direction. Two consumer-directed long-term care options are offered by Care Management Organizations (CMOs) in the five pilot counties: (1) an Agency with Choice model, in which a "co-employment agency" serves as the Employer of Record and the consumer acts as the Managing Employer, and (2) an option in which the consumer assumes all employer responsibilities.

The Family Care program was developed by combining funding and services from a variety of existing programs to offer a single flexible long-term care benefit tailored to the needs, circumstances and preferences of the individual. Participants may purchase services from any qualified provider, including any family member of the participant other than a spouse. Each CMO organizes and runs its co-employment option independently. Four of five serve persons with physical or developmental disabilities and older persons. The CMO in Milwaukee County, where over half of Family Care participants reside, serves only older persons. Once enrolled, Family Care members work together with an interdisciplinary case management team to determine the member's individual budget and develop a care plan. The co-employment option merges the benefits of agency-provided care – such as fiscal management services – with key elements of self-direction, such as the ability to choose workers and reward them with better pay and/or benefits.

50. Reinhard, SC (September 2001). *Consumer Directed Care and Nurse Practice Acts*. The Center for State Health Policy. Institute for Health, Health Care Policy, and Aging Research. Rutgers University, New Jersey.

This report is a detailed analysis of nurse practice acts and regulations in relation to consumer-directed care in 50 states. It examines current state nurse practice acts and their implementing regulations to determine the extent to which they permit consumer direction in home- and community-based services for older adults and people with disabilities. State regulations that govern the practice of registered professional nurses often affect the extent to which consumers are permitted by the state boards of nursing (who are responsible for protecting the public) to direct care received from unlicensed assistive personnel (UAPs). Three key issues affecting state policy and practice with regard to consumer-directed care are reviewed. First is the statutory and regulatory language that pertains to delegation, including: who may delegate; tasks (especially medication administration) that may be delegated; in what setting and with what supervision can tasks be delegated; and what are the training requirements for individuals who provide the delegated services. Second is the legislation of exemptions by some states that permit nursing tasks to be performed by persons who are not nurses. The last is the issue of liability or the "accountability" of the nurse for delegation.

The report presents multiple approaches to support consumer-directed care with varying degrees of flexibility. A handful of states have made substantial progress in developing nurse practice policies that specifically address consumer direction. Consumers in these states have been active in the policy debate, although the emphasis has often been more on independent living settings and personal assistance programs than on the full continuum of home- and community-based care, including assisted living. The author recommends that stakeholders (nurses, consumers, and policymakers) in targeted states meet with representatives from model states to learn by their example how to: put policies into practice; balance consumer protections and independence; and implement demonstration programs and evaluations as needed.

51. Routledge, M and Sanderson, H (2000). *Work in Progress: Implementing Person Centered Planning in Oldham*. North West Training and Development Team. ISBN No: 1-8983-8528-9. <http://www.nwtdt.com>.

This book from the North West Training and Development Team (NWTDT) documents a 4-year effort to implement person-centered planning within a large learning disability service, Oldham Learning Disability Service (OLDS), Oldham, UK. The report is written for people interested in learning how to develop person-centered planning within organizations. It describes the challenges, successes, and dilemmas experienced at OLDS during the implementation process. Three stages of development and implementation are identified. In the first stage, initial learning and experimentation, people tried to make the existing system more “person centered.” This stage included training a small group of employees in Essential Lifestyle Planning. In the second stage, an implementation plan was developed, and a few people received in-depth training, while still making changes in the lives of larger numbers of people. In the third stage, the work up to that point was evaluated and new goals were set for future work. The authors also address the issues that arose during implementation that made the change difficult and suggest strategies to overcome obstacles. Outlines used for training sessions are provided, as well as case studies illustrating how person-centered planning assisted individuals. Training modules include: training individuals and their families to communicate with support professionals; training the support professionals in person-centered planning; developing support teams; the use of Personal Futures Planning; and problem-solving. The authors conclude that it remains to be seen how far OLDS can go toward shifting from a mindset of making services better toward supporting people to “build lives that are not lived wholly within services.”

52. Sabatino, CP and Hughes, SL (January 2004). *Addressing Liability Issues in Consumer-Directed Personal Assistance Services (CDPAS): The National Cash and Counseling Demonstration and Selected Other Models*. U.S. Department of Health and Human Services (HHS), Office of Disability, Aging and Long-Term Care Policy (DALTCP), and Boston College. Contract #HHS-100-02-0018.

This comprehensive report analyzes liability issues that may arise for each person or entity involved in consumer-directed personal assistance (CDPAS) programs (the worker, the consumer, the consumer’s representative, the fiscal agent, consultants, and the State), and

suggests steps to reduce their exposure to such liability. It addresses the Cash and Counseling Demonstration programs implemented in Arkansas, Florida and New Jersey; California's In-Home Supportive Services Program (IHSS); and New York's CDPAS Program.

In Cash and Counseling, the State relinquishes considerable control over services to consumers, raising concerns that, in the absence of state control, poor care may result in injury to consumers and liability for the State. However, the data show no increased risk of injury to consumers under this model and no greater risk of liability between the consumer and the worker than with agency provided care. Further, when family members serve as workers, it is unlikely that the parties will pursue compensation for personal injuries in the courts. The workers, on the other hand, face a heightened risk of liability compared to agency staff, where the ultimate responsibility for injury to the consumer lies with the agency. In the case of injury to workers on the job, liability risk is dramatically reduced by providing workers' compensation, which bars most personal injury actions by the worker against the consumer.

In Cash and Counseling, consultants carry a significant liability risk because they handle critical program functions – assisting the consumer to designate a representative and develop the spending and back-up plans; consulting about hiring, training and supervising workers; monitoring program quality; and initiating action to correct problems. This risk is, however, mitigated by the fact that the consumer bears primary responsibility for most decisions. The liability issues in the New York CDPAP program are similar to those in Cash and Counseling, except that all workers are covered by workers' compensation through Concepts of Independence, Inc., the Medicaid provider agency that contracts with the State and serves as the employer of record for purposes of employee payroll and benefits functions. The California IHSS program also provides workers' compensation, and the public authorities in each county act as the employer of IHSS workers for purposes of collective bargaining. The statutory immunity of the public authorities shields them from vicarious liability arising out of the consumer-worker relationship, but does not extend to other functions such as screening and referral of workers through employment registries; and providing training, emergency back-up support, and monitoring services. Consequently, the liability risk is proportional to the breadth and depth of the specific function undertaken by the public authority. In consumer-directed models where employer and support functions are clearly defined and separate, the liability risk of the state sponsoring agency, consultants, fiscal agents, public authorities (as in California), or consumer-directed provider agencies (as in New York) is limited to the specific tasks they perform.

53. San Antonio, PM, Eckert, JK, *et al.* (2003). *The Cash and Counseling Qualitative Study: Stories From the Personal Preference Program in New Jersey*. Report submitted to the Cash and Counseling Demonstration and Evaluation National Program Office, University of Maryland Center on Aging.

This report presents 25 detailed case studies of adults with disabilities who received a cash allowance of at least \$200 per month in the New Jersey Personal Preference program, focusing on how "care units" (composed of consumers and/or representatives, paid workers, and counselors) interacted around issues of consumer-directed care. The report addresses these questions: (1) has Personal Preference made a difference in the lives of consumers, representatives, and workers and, if so, how; (2) how does participation in Personal Preference

compare with previous arrangements; (3) how are services provided; and (4) how does the program work?

All stories were written with an eye to allowing participants to speak for themselves, but they incorporate the perspectives of all three members of the care unit – consumer, caregiver, and counselor. They describe what it is like to arrange and pay for your own care, with or without a representative's help, and how participants negotiate the program. Analysis of the stories identified common themes, including the family and community contexts of care. In addition, participants talked about the skills and qualities needed for a caregiver and the value of Personal Preference to them. Other important topics/themes included alternative uses of the cash benefit, previous experiences with agency workers, and problems encountered with Personal Preference. The report also identifies major lessons learned about outreach and enrollment, cash planning and management, the consumer as an employer, and feasibility.

54. Scala, MA, and Nerney, T (2000). People first: The consumers in consumer direction. *Generations* 24(3): 55-59.

This article discusses three populations that have been involved in the struggle toward consumer direction: older adults, younger adults with physical disabilities, and people with developmental and cognitive disabilities. After a brief history of each group in the area of consumer direction, it identifies necessary supports and special issues to consider for each population. Among persons with physical disabilities, the use of consumer-directed care has centered on personal assistance services (as opposed to medical services) provided to people in their own homes. The focus in this population is on helping individuals live independent lives outside of institutions. For older adults the interest in consumer direction focuses on reducing the costs of traditional long-term care managed by professionals. Older adults require greater initial support and direction from professionals than do younger adults. However, when they receive appropriate training, older adults (or their surrogates) can manage their own care and supportive intermediary services. The third population, persons with developmental and cognitive disabilities, has the most experience in consumer-directed care as a result of the work of the disability rights community in the 1970s. As part of the "self-direction" process, persons with developmental disabilities identify and maintain "circles" of friends and support networks. People with developmental disabilities most often need help preparing an individual budget, and generally require the assistance of supports brokers or fiscal intermediaries. The authors conclude that brokering of services and granting sufficient authority to consumer representatives are essential to the success of consumer-directed service provision in all three populations.

55. Schore, J and Phillips, B (January 2004). *Consumer and Counselor Experiences in the Arkansas IndependentChoices Program*. US Department of Health and Human Services. Assistant Secretary of Planning and Evaluation. Office of Disability, Aging and Long Term Care Policy. Mathematica Policy Research, Inc.

This article discusses the IndependentChoices intervention in Arkansas, in which consumers received a monthly allowance to purchase care-related goods and services that promoted independence or increased mobility. IndependentChoices did not screen applicants for

appropriateness, in part because such screening was inconsistent with the philosophy of consumer direction. The program enrolled 2,008 beneficiaries who were randomly assigned to the consumer-directed (treatment) group or the control group (eligible for agency-delivered personal assistance services, as usual). Counseling and bookkeeping services were provided at no direct cost to consumers. Counselors reviewed spending plans and monitored consumer well-being and the use of the allowance. Consumers were permitted to select representatives to assist them in directing care or making decisions. Data was compiled from in-person interviews with program staff, a mail survey of program counselors, and telephone interviews with consumers who had received the cash allowance.

The authors discuss: the program's goals and features; how consumers handled their fiscal and managerial responsibilities and made use of the flexibility of the program; levels of consumer satisfaction with the program; and characteristics of both participants and workers. Most consumers in the treatment group received 1-3 hours of paid care per day and three-fourths of paid workers also provided unpaid assistance. Most workers helped with housework and personal care, but many helped with routine health care or provided transportation (a service which Arkansas Medicaid did not permit agency workers to provide). Many workers also filled in when it was difficult to get help from an agency – i.e., on weekends, weekday evenings, and early on weekday mornings.

Consumer-directed personal assistance in a publicly funded program like Medicaid raises concerns among policymakers, including: whether consumer direction should be available to all PAS users; whether family members should be hired as workers; how to ensure care quality; how to ensure that workers are trained adequately and treated fairly; and how to avoid fraudulent use of a cash benefit. The structure of IndependentChoices and its procedures addressed each of these concerns to a greater or lesser extent. Allowing consumers to hire relatives appeared to have been critical to program success. Regular counselor monitoring and follow-up identified and resolved potential consumer safety and care quality issues. Although few workers were offered fringe benefits, reports of worker abuse were rare and counseling and bookkeeping procedures helped make abuse of the allowance rare. The authors conclude that many important concerns about consumer direction were addressed by the successful implementation of IndependentChoices, without major operational difficulties or adverse outcomes for consumers, their families, or their caregivers. Most consumers with a range of disabilities were extremely satisfied with the program and used the cash allowance to meet their personal assistance needs with a high level of flexibility. Agency reports of worker shortages during the demonstration suggest that some consumers who hired family and acquaintances could not have obtained care from agencies, had they been in the traditional program.

56. Simone, B. *Consumer-Directed Personal Assistance Demonstration Program for Younger Adults with Physical Disabilities, Including Dually-Eligible Medicare Beneficiaries*. The City of New York. Human Resources Administration, Medical Insurance And Community Services Administration, Home Care Services Program. Letter dated: December 22, 2004.

This document is a proposal to develop a consumer-directed demonstration program for dually-eligible physically disabled adults who have ongoing rather than short-term needs and are

able to train and direct their own personal assistants (a maximum of 100 clients within an 18-month period). It was written in response to Section 648 of the Medicare Prescription Drug Improvement and Modernization Act of 2003, which requires the U.S. Department of Health and Human Services to design and implement a Medicare demonstration of consumer-directed home care within 2 years of enactment. The objective of the demonstration is to show that Medicare-funded home health care services can be provided through the New York City Consumer Directed Personal Assistance Program (CD-PAP) model, which assumes that the consumer can teach a personal assistant to implement services that fall under the Medicare-funded home health benefit, including services that are ordinarily provided by nurses.

Administration and oversight will be provided by the City of New York's Human Resources Administration's Home Care Service Program (HRA/HCSP), which will enroll clients into the demonstration, approve the level of service, and contract for service delivery to facilitate payment from Medicare while still allowing payment from Medicaid as appropriate. A set of outcome measures will be developed, in comparison with a control group of CD-PAP clients. Special attention will be paid to outcomes for clients with diabetes, as a model to assess the reliability of the program for individuals with chronic diseases. Evaluation of the project will be conducted by an independent research entity.

Because the demonstration may require personal assistants to provide nursing services more often than they do for control CD-PAP clients, HRA/HCSP will contract with a certified home health agency to provide consumer training and monitor performance to assure the services provided meet appropriate clinical standards and do not compromise the health status of the consumer. A second organization will be hired to serve as the fiscal intermediary and to provide assistance in recruitment, retention, training and consumer guidance for the day-to-day relationship between the consumer and the personal assistant.

57. Simon-Rusinowitz, L, Bochniak, AM, *et al.* (2000). Implementation issues for consumer-directed programs: Views from policy experts. In MB Kapp (Ed.). *Ethics, Law, and Aging Review* 6:107-129. Springer Publishing, New York.

This article presents the information acquired from a 2000 telephone survey of policy experts regarding the case for and against the adoption of consumer-directed care for older adults. It focuses on the technical assistance needs of consumers, service providers, and policymakers considering the transition from agency-based services to a consumer-directed model. Two key requirements are identified: (1) education of consumers about independence and the meaning of autonomy within the paradigm of consumer-directed care, and (2) availability of a wide range of supportive services for older adults. Service providers also need help to understand specifically how consumer-directed care differs from more traditional care models, perhaps through consultation with consumer advisory groups.

The question of who should train providers remains controversial. While the aging home-care community believes providers should be trained by professionals, the consumer community believes that training should be done by the consumer. Policy experts and providers believe that it is also essential to train family members who may play an important role in care

decisions for the consumer. Policymakers also believe that technical assistance on quality assurance and legal issues involved in consumer-directed care should be provided to both policymakers and payers. Access to “best practices” currently employed in consumer-directed programs may provide both technical knowledge on implementing consumer-directed programs and answers to questions about the mechanics of waivers, alternative implementation models, and policy options.

58. Simon-Rusinowitz, L and Hofland, BF (1993). Adopting a disability approach to home care services for older adults. *The Gerontologist* **33**(2):159-167.

This article defines independence and autonomy and explains differences in the perceptions and values of the aging and disability communities surrounding these important concepts. The aging community emphasizes the physical dimension of independence and autonomy, with the primary goal of maintaining older persons with disabilities in their own homes and delaying institutionalization. The focus is on helping older disabled persons to do as much as possible to care for themselves physically. This does not necessarily include autonomy and independence with regard to making decisions about their services or increasing their involvement in a life outside the home. The disability community, on the other hand, focuses on the psychological and spiritual aspects of independence and autonomy, which involve not only more personal choice about the quality and quantity of support services but also provision of services that promote a greater involvement of the individual in mainstream activities. The authors encourage representatives of the aging community to follow the lead of the disability community and broaden their approach to service design and implementation by incorporating more consumer direction. A further benefit of increasing consumer direction in the aging community might be to give the aging and disability communities more opportunities to work together, rather than to compete for limited funds and services. The authors acknowledge that incorporating such an approach will require a careful assessment of the ethical issues in increased consumer direction, the amount and type of services available to elders, and the role of the family in caregiving for older adults.

59. Simon-Rusinowitz, L, Marks, LN, *et al.* (2002). Implementation issues for consumer-directed programs: Comparing views of policy experts, consumers, and representatives. *Journal of Aging and Social Policy* **14**(3/4):95-118.

This article discusses experiences of the Cash and Counseling (C&C) program and presents the views of policy experts (obtained through telephone interviews) and consumers or their representatives (obtained by survey or through focus groups). The following areas of concern were identified:

- The consumers’ ability to manage consumer-directed services and the need for flexible programs to accommodate diverse consumers and consumer preferences. The C&C experience indicated that consumers who knew their caregivers already or were paired with representatives were most likely to have their needs met.

- The potential for family decision-making to override consumer choice. The C&C experience indicated that more research is needed in this area, as not enough data was available to decide whether or not this is a valid concern.
- The potential for fraud and abuse. Overall, abuse was not a problem in C&C, although the study indicated a need to provide specific training and assistance to consumers about the tasks associated with being an employer.
- The level and types of training needed by consumers. C&C provided training in handling financial responsibilities, handbooks for consumers capable of utilizing them, and arrangements for fiscal intermediaries in the majority of cases.
- Worker shortages. C&C found that family members were most often hired as care providers, thus canceling the need to find outside workers. Emergency back-up services remained a challenge for most consumers.

The authors stressed the need for defining the role of the consumer representative, addressing ethnic/racial differences in consumer interest in consumer-direction (highest among black and Latino), and providing training for consumers, representatives and consultants.

60. Simon-Rusinowitz, L, Mahoney, KJ, and Benjamin, AE (Fall 1998). Payments to families who provide care: An option that should be available. In *Ethics and Aging: Bringing the issues home. Generations* 22(3): 69-75.

This article explores why an option should be available to pay family members who provide personal care to their disabled relatives and details the benefits of such a policy. The benefits identified are: increasing gender and class justice by assigning a monetary value to the labor of a predominantly female, low-income workforce; boosting consumer choice and the quality of care provided; and augmenting the worker supply. The article provides references to related research, insight into the ethical and practical issues involved in designing such an option, and a review of the efficacy of federal and state policies concerning payment to families. The studies presented cite advantages such as better quality care, improved consumer satisfaction, and economic benefits for consumers and families. However, commonly expressed concerns included: an exploding demand for benefits; poor quality service; fraud and abuse; and worker exploitation. Three aspects of the Cash and Counseling Demonstration Evaluation will support consumers and alleviate potential problems with hiring family members as personal care workers. They are: (1) the availability, and in some cases requirement for, the services of fiscal intermediaries, who can play a vital role in preventing exploitation of workers and fraud and abuse; (2) a range of supportive counseling services – including assistance in locating workers and providing back-up services for consumers as needed and wanted; and (3) regular monitoring.

61. Simon-Rusinowitz, L, Mahoney, KJ, *et al.* (Winter 1997). Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review* 19(2):73-96.

This article presents findings from a telephone survey of 491 Medicaid personal care clients that was designed to: assess their interest in a consumer-directed cash option to pay for personal care services in lieu of continuing to receive agency-based services; determine what types of consumers would choose to self-direct; and identify what features of the cash option are

most attractive to consumers. This information was to be used by the Arkansas Cash and Counseling Demonstration and Evaluation Project to design various cash option components (including counseling services) and develop social marketing approaches that would enable consumers and surrogates to make an informed choice between the consumer-directed and traditional agency options. Pre-survey consumer focus groups had difficulty understanding this new concept, and the effort to inform was complicated by the prevalent lack of high school education in Arkansas (>80% of survey participants).

The strongest predictors of consumer interest in the cash option were consumer willingness to perform employer tasks associated with managing personal care workers, and the desire of consumers to be more involved in determining the amount and types of services they receive. Interested consumers and surrogates considered it important to pay their worker more money than he or she was currently receiving, to know other consumers involved in the option, and to be able to return to their old program if they desired. The vast majority of consumers who were interested in the cash option indicated an interest in support and training. Survey respondents found the ability to hire whomever you want to provide personal care services, even friends or relatives, an attractive feature of the cash option. The authors conclude with a discussion of policy issues related to quality of services and the potential for fraud and abuse, and stress the importance of providing consumers with a choice of personal assistance services options.

62. Simon-Rusinowitz, L, Marks, LN, *et al.* (2002). Implementation issues for consumer-directed programs: Comparing views of policy experts, consumers, and representatives. *Journal of Aging and Social Policy* 14(3/4): 95-118.

This article discusses the results of three background studies that have informed the Cash and Counseling Demonstration and Evaluation (CCDE) design and implementation to demonstrate the importance of examining views from multiple key stakeholders involved in consumer-directed programs. Key issues are presented from the point of view of policy experts (obtained by telephone interviews) and consumers or their representatives (obtained either through a survey or from focus groups). In addition, the experiences in designing the CCDE and initial results from the first year of implementation provided a fourth source of data for this report. The information from all sources was synthesized to identify the following major areas of concern:

- The consumers' ability to manage consumer-directed services and the need for flexible programs to meet diverse consumers/preferences.
- The potential for family decision-making to override consumer choice.
- Fraud and abuse. Overall, abuse was not a problem in the C&C program.
- The level and type of training needed by consumers.
- Worker shortages. The C&C program found that family members were most often hired as care providers, thus negating the need to find outside workers. Emergency back-up services remained a challenge for most consumers.

The authors emphasize the need for investigating the role of representatives, addressing the ethnic/racial differences in consumer interest in consumer-direction (highest among black and Latino), and providing effective training for consumers, representatives and consultants. They conclude that examining the three studies together in the context of preliminary data from the C&C experiences and views expressed by the various stakeholders formed a type of multi-

perspective “dialogue” to expand current knowledge about implementing consumer-directed services.

63. Tilley, J and Wiener, JM (January 2001). Consumer-directed home and community services: Policy issues. Occasional Paper Number 44. The Urban Institute’s *Assessing the New Federalism* project.

This paper explores the policy implications of extending consumer direction to programs serving older people through a comprehensive review of the literature and examining the experiences of eight mature state programs with coexisting agency and consumer-directed models. It compares these two publicly funded models in relation to several issues – whether older persons want to and are capable of managing services, the quality of those services, and the effects of consumer direction on workers. States chosen for the study had to provide agency and consumer-directed services to older adults with disabilities and have at least 2,000 beneficiaries and at least 2 years of experience with consumer direction. The states that met the selection criteria (with relatively large, mature programs that permit comparisons between the two models) were California, Colorado, Kansas, Maine, Michigan, Oregon, Washington, and Wisconsin.

Interviews were conducted with state Medicaid or Unit on Aging officials and representatives of key stakeholder groups who have the most knowledge of consumer-directed programs – advocates for younger people with disabilities or older beneficiaries, unions, and home care agency associations. Most stakeholders indicated that many older beneficiaries want to and can manage their services, although the ability of persons with cognitive impairment to manage their care is problematic. Nevertheless, the use of surrogate decision-makers may still allow participation by these consumers.

Study results pointed to better quality of life for beneficiaries when they direct their own services, although state agencies have generally not provided extensive consumer or worker support or aggressively regulated quality of care. For workers, consumer-directed care has some disadvantages, including fewer fringe benefits. A major worker-related issue is that as many as half of the independent workers are family members in some of the study states, and management, training, quality assurance, and payment levels take on a very different cast if the independent provider is a family member or friend rather than a stranger. Four key policy issues were identified:

- (1) Older people are less likely to want consumer direction than younger persons, but a significant minority of older people prefer consumer direction;
- (2) Although some older persons want and do direct their own services, a significant number of stakeholders raised questions about the capacity of older people to manage their own care, largely related to the prevalence of cognitive impairment among the older population;
- (3) Quality of care should be monitored to ensure that services are adequate; and
- (4) Independent workers appear to fare better than agency workers in their work environment, but are paid less and have fewer benefits.

64. Tilly, J, Wiener, JM, and Cuellar, AE (2000). Consumer-directed home- and community-based services programs in five countries: Policy issues for older people and government. *Generations* 24(3): 74-83.

This article provides an in-depth comparison of the consumer-directed homecare programs in the United States, Germany, Austria, France and the Netherlands, based on a comprehensive review of the literature and 47 sets of interviews with representatives of government, beneficiaries, unions, and homecare agencies in each country. It focuses on the following program design features in each country: administration, eligibility, resource allocation, covered services, benefit amounts, funding sources, cost containment, quality assurance, and whether consumers can hire relatives. It offers four observations about consumer-directed programs, specifically as they apply to older adults:

- Older people are less likely to want consumer direction than younger people, but should have that choice of management models;
- Cognitive impairment (most often caused by dementia in elders) may present challenges in older persons and, for that reason, it is essential to involve elders and/or their surrogates as early as possible in the planning process;
- It is important to monitor the quality of services, as elders are at high risk for abuse. However, studies have shown that, despite this increased risk, abuse is not common and high levels of satisfaction have been observed among elders afforded the opportunity to participate in consumer-directed programs;
- While independent workers fare better in their work environments (working conditions, relationship with care recipients, etc.), they do not attain wages or benefits consistent with agency-based workers. The authors emphasize the importance of addressing the issue of worker wages as a means of insuring high quality, reliable caregiving, and suggest that policy makers may want to help consumers by providing worker registries and monitoring client satisfaction.

65. Wamsley, BR and Eggert, GE (2004). *Medicare Vouchers for In-Home Care: A Viable Policy Option?* The Retirement Research Foundation, Chicago, IL.

This study examined the experiences of a functionally impaired Medicare population participating in a consumer-directed model for in-home care that was being tested as part of a Medicare demonstration from July 1998 to June 2002 (*A Randomized Controlled Trial of Primary and Consumer-Directed Care for People with Chronic Illnesses*, CMS #95-C-90467/2-01). Participants in parts of West Virginia/Ohio and Western New York State were offered a maximum \$3000 per year consumer-directed benefit that they could use to pay for augmented home care. Participants were reimbursed 80% of the cost of these services on a monthly basis. The goals of the study were to: evaluate how a “medically vulnerable” Medicare population will use and manage a consumer-directed voucher benefit; determine if cognitively intact and cognitively impaired Medicare beneficiaries differ in the way they use and manage the voucher benefit; and describe the types of local agency supports needed to help impaired Medicare beneficiaries use and manage the consumer-directed benefit.

To meet these goals, researchers conducted a series of focus groups with consumers/family caregivers who: hired in-home workers directly; used in-home workers from agencies; or used the voucher primarily for supplies and equipment. Further, they conducted in-depth personal interviews with 21 consumers and/or their informal caregivers; evaluated six case studies of consumer direction “in action;” and analyzed the results of satisfaction surveys completed by all participants at 10 and 20 months. They found that: satisfaction with the consumer-directed model was very high, due primarily to the model’s flexibility; Medicare beneficiaries were willing and able to self-direct; and cognitively impaired individuals were able to participate in consumer direction, provided they had someone to manage services on their behalf. Both cognitively intact and cognitively impaired participants needed help in managing services, identifying workers, handling the paperwork associated with employment, etc. The authors recommend that any future model include a fiscal agent to assist with paying workers and allow the hiring of relatives as workers. In conclusion, a consumer-directed model is a viable option for a Medicare population, including those with cognitive impairment. It serves to extend in-home care for a growing group of beneficiaries who otherwise would go without these services. A flexible consumer-directed benefit yields high satisfaction among beneficiaries without jeopardizing quality of care.

66. Wamsley, BR, and Eggert, GE (2004). *Focus Group Summary Report*. The Retirement Research Foundation, Chicago, IL.

As part of a demonstration project that tested the relative effectiveness and acceptability of a primary care affiliated model of disease self-management/health promotion and a model of consumer-directed care, focus groups of Medicare beneficiaries were asked to comment on their experience using vouchers to purchase in-home services. The four focus groups of 52 respondents included: 13 demonstration participants (service recipients or their representatives) who used their voucher to hire in-home workers directly; 11 participants who used the voucher to hire agency workers; 14 participants who used the voucher primarily for supplies and equipment; and 14 in-home workers for study participants. Analysis of the responses showed that control was important to both the group that hired workers directly and the group that used the voucher to purchase agency services, but was perceived differently by the two groups. For example, some felt that in-home workers hired by participants were more responsive to direction, while others saw a benefit in agency workers who received training to perform a set of tasks reliably.

In-home workers seemed to prefer working for individuals rather than for agencies, mainly due to the limits and restrictions imposed on them by agencies. Participants who used the voucher primarily for supplies and equipment did so because they: lacked the personal resources to cover needed supplies; had an informal caregiver to substitute for an in-home worker; or felt they did not need an in-home worker, but could make do with the item(s) purchased. Participants in all groups felt that restrictions to the voucher – particularly the inability to pay workers “under the table” – were a deterrent for potential in-home workers. Overall, consumers were happy with the voucher program, but felt that support in using it was important. In addition, most believed that the voucher program should allow participants to hire family members.

67. Wamsley, BR, Eggert, GE, and Saad, Z (2004). *Program Satisfaction with the Voucher*. The Retirement Research Foundation, Chicago, IL.

This study assessed satisfaction among Medicare beneficiaries who used a voucher to purchase in-home services under a demonstration project that tested the relative effectiveness and acceptability of a primary care affiliated model of disease self-management/health promotion and a model of consumer-directed care. Subjects were assigned to one of four groups: (1) the Consumer-Directed Group that received a voucher of up to \$200/month to pay for augmented home care; (2) the Primary Care Affiliated Nurse Group, designed to improve disease self-management and promote healthier lifestyles; (3) the Combination Group that received both the voucher and the services of a nurse; and (4) the Control Group that received traditional agency services. Assessments were made of a number of satisfaction domains after 10 and 20 months. Overall, participants in all groups were highly satisfied with both their health and their health care. Satisfaction with the voucher increased over time. Participants in the combination group were more satisfied than those who received the voucher alone. Caregivers of participants in all groups were also surveyed and found to be highly satisfied, and their satisfaction increased over time. Caregivers of participants in the combination group were more likely to be satisfied than those in the voucher-only group. Participants were more likely than caregivers to: believe that the vouchers had a positive impact on health-related issues; be more satisfied generally; and report that the voucher improved their relationships with family and friends.

68. Wilner, MA (2000). Toward a stable and experienced caregiving workforce. *Generations* 24(3):60-65.

This article examines factors contributing to the current worker shortage in light of an aging population and the desire of consumers for self-directed care options, and provides suggestions to remedy the problem. Historically, the long-term care industry structured itself on the presumption of a virtually endless supply of low-income individuals (usually women and disproportionately women of color). Wilner attributes the dearth of qualified and experienced direct-care workers to: (1) poor quality jobs with low wages, lack of benefits, and a high rate of injury; (2) the full employment economy, which offers better job opportunities in the service sector; and (3) a care gap created by post-baby boom demographics that will worsen over the next 30 years. She presents the pros and cons of consumer direction from the perspectives of both consumers and workers. Consumers want reliable, competent and compassionate caregivers, while workers seek jobs that provide a living wage and safe working environment. The benefits of working for a consumer/employer include the potential to earn higher wages and obtain more stable, long-term employment with flexibility in schedules. However, the consumer-directed model may lack the checks and balances in the traditional agency model that are intended to protect workers. Wilner argues that improving working conditions would be mutually beneficial to homecare workers and consumers and suggests establishing minimum standards for working conditions, including a living wage, healthcare benefits, and access to full-time employment opportunities. Fiscal intermediaries, worker registries, public authorities and unions are identified as entities that can protect and support the interests of the worker.

69. Yamada, Y (2001). Consumer direction in community-based long term care: Implications for different stakeholders. *Journal of Gerontological Social Work* 35(3):83-97.

This article gives a brief background of the consumer-directed choice model as it grew out of the disability rights movement. It stresses the importance of independence for persons with disabilities and reducing the cost of supportive services. Yamada reviews the basic assumptions of the consumer-directed model, which are:

- Consumers know what they need and prefer to make their own decisions;
- Personal assistance is not medical assistance (which is not appropriate for consumer direction);
- Consumer direction should be available to persons in need of services, regardless of their disability;
- Consumer-directed services will be less costly than traditional case management when properly designed; and
- The consumer will spend government funds wisely.

The article addresses the concerns of all stakeholders in the consumer-directed model – the consumer, the family, formal care providers, case managers (consultants under the consumer-directed model), and the government. This is followed by a thoughtful and comprehensive discussion of both the benefits and liabilities of the consumer-directed model for these stakeholders. Yamada cautions that consumer direction should not replace all agency-based services, but should be offered as a choice. He recommends that special attention be paid to wages and working conditions for privately hired care providers under the consumer-directed model.

70. Young, HM, Sikma, SK, *et al.* (2002). Evaluation Of The Implementation Of Self-Directed Care In Washington State: Final Report. University of Washington School of Nursing, Seattle, WA.

This study of the Washington State Self-Directed Care Program during its first 2½ years was mandated by House Bill 1880 of 1998, (Section 9), which allowed for self-directed care for persons with disabilities. It was performed in consultation with the Governor’s Committee on Disability Issues and Employment and the Department of Social and Health Services (DSHS) to inform future decisions and policy-making regarding self-directed care of tasks such as medication administration, bowel care, catheter care, and injections (insulin and other medications). Data was collected by: surveys of 125 participants; in-depth interviews with 30 of these representing different regions of the state and intensity of self-directed care tasks; and review of existing databases, complaint logs and reports, and field notes by department staff. Interviews were also conducted with 30 Individual Providers and 24 case managers.

Study results indicated that quality of life and quality of care improved without any negative impact on service quality or consumer safety. Consumers reported high satisfaction with self-direction and strongly endorsed the program because it supports autonomy and choice.

Both consumers and case managers believe that this program prevents utilization of more expensive services to provide routine care, such as nursing homes and emergency rooms. The program was well implemented – with few logistical issues or barriers to ongoing service. The biggest challenge was assuring adequate staffing, which is part of a broader labor issue affecting consumers and workers in all long-term care settings.

The authors recommend: promoting Self-Directed Care; particularly in communities with low enrollment; providing more support for consumers with training and recruitment of staff, if requested; training case managers in program philosophy and implementation; continuing to address working conditions and compensation for Individual Providers; evaluating potential expansion of Self-Directed Care to agency providers; and examining “integration and articulation of varied programs (self-directed care, nurse delegation, and medication administration) across the continuum of community residences and situations to promote optimal utilization.”