

STATES' EXPERIENCES

IMPLEMENTING CONSUMER-DIRECTED HOME & COMMUNITY SERVICES

Results of the 2004 Survey
of State Administrators,
Opinion Survey &
Telephone Interviews



Acknowledgements

This report presents the findings of a national written consumer direction survey of the 56 state and territorial aging and Medicaid administrators, an opinion survey of the 56 state aging agencies, and interviews with 20 state aging directors who previously identified the existence of one or more consumer-directed home and community based service programs in their states. The report is the result of a collaborative effort and was guided every step of the way by staff at the National Association of State Units on Aging (NASUA) and The National Council on the Aging (NCOA). We gratefully acknowledge The Robert Wood Johnson Foundation for their support of the NASUA/NCOA joint project, "Promoting Consumer Direction in Aging Services," and this research.

The success of this effort is, of course, due in large part to the detailed information and candid opinions of the 40 state administrators who responded to the consumer direction survey, the 39 state aging agencies that responded to the opinion survey, and the 20 state aging directors who participated in the interviews.

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The survey instruments were developed by Matthew Greenwald and Associates, in consultation with NASUA and NCOA. The instruments were pilot-tested by state aging agencies in Maine and Washington. Boomerang.com, an on-line survey company, hosted the survey Web site. Matthew Greenwald and Associates completed an initial analysis of the results of the consumer direction and opinion surveys. Dr. Infeld, in addition to authoring the report, completed the data analysis, developed the interview protocol, and conducted and transcribed the 20 interviews.

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Executive Summary

This report summarizes the “state of the states” on consumer-directed home and community based services (HCBS) for older people in the United States. In 2004, two surveys and one set of interviews with state administrators about consumer direction for older people were conducted under a Robert Wood Johnson Foundation project, “Promoting Consumer Direction in Aging Services,” a partnership of the National Association of State Units on Aging (NASUA) and the National Council on the Aging (NCOA). The research was conducted by researchers at Matthew Greenwald and Associates, and analyzed by Dr. Donna Lind Infeld of The George Washington University. The surveys and interviews gathered information on knowledge, attitudes, effective practices, and barriers to implementation of consumer direction.

What Do We Mean by Consumer Direction?

The delivery of home and community based long term services (HCBS) in the United States ranges along a continuum from agency-administered models to consumer-directed (CD) services. The defining characteristic of a consumer-directed model of service delivery is that it allows persons with disabilities considerable choice and control over how they receive supportive services and from whom. Some consumer direction programs expand the participant’s control further by providing a cash benefit with which the participant can purchase services or pay caregivers, including family members.

Agency-administered models have long been the mainstay in HCBS service delivery. States and local agencies typically contract with home health or home care agencies, which then assign workers and handle administrative and oversight responsibilities. Although consumer involvement in decision-making is embedded in this model of service delivery, consumers generally have less control and more limited choices than in a consumer-directed model.

Methodology

In February 2004, an online survey designed to gather information on the extent and characteristics of consumer-directed services for older persons was distributed to the 56 state and territorial agency on aging directors and Medicaid directors who were asked to coordinate a single state response. After follow-up calls and e-mails, 40 completed surveys were returned (response rate = 70%).

An additional, separate on-line opinion survey was sent only to state aging administrators to examine their views about consumer direction for older people (N=39; response rate 68%). The findings of the two surveys were then supplemented by telephone interviews conducted with staff of state units on aging in states where consumer-directed programs are available to older people. Of 27 states identified as offering consumer direction for older persons, 20 states participated in the interviews (response rate=74%). These interviews further explore motivating factors, barriers, and effective practices in providing consumer direction to older people.

Findings

In 2004, administrators of 40 states and territories reported operating a total of 62 consumer direction programs that serve older persons, and provided detailed information about 58 of them. With 38% of these programs having begun in the last five years, it appears that the momentum for consumer-directed programs that serve elders has been gradually increasing.

The Aging and Medicaid agency administrators who responded to the survey show a very high level of awareness of consumer direction, with all respondents reporting that they themselves have at least minimal awareness. They reported that their colleagues in these organizations also have high awareness, with 91% of managers or supervisors and 97% of other staff being aware of consumer-directed home and community based services.

The state aging officials interviewed for the report described a wide range of experiences with consumer direction for older people. It is clear that what states call consumer direction varies widely. While some are just getting started in providing consumer-directed services, others have well-established programs that allow consumers to hire non-agency personnel, direct their own services, and terminate those services if and when they choose. While most of these states are currently only providing consumer direction to a few hundred older people (43% serve 500 or fewer), several states have highly developed consumer-directed programs that serve thousands of older persons. Clearly, there is enormous potential for growth.

The major forces that have influenced the development of consumer direction across the states include perceived gaps in service delivery, inadequate supply of providers, consumer demand and advocacy, federal and state policies, and cost considerations.

Consumer direction is viewed as helping fill gaps because services provided under this approach better fit consumers' needs. Consumer direction is also seen 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, allowing some consumers to receive more service for the same money.

Characteristics of Consumer-Directed Programs for Older Persons

Administrators were asked to provide information on program characteristics, funding sources, services offered, provider types, reimbursement methods, and quality assurance features.

- Over half of the programs (59%) apply age and disability eligibility criteria. In addition, most of the programs (72%) are means-tested.
- The most prevalent consumer-directed services are personal care (e.g., assistance with bathing, grooming, feeding, dressing, transferring, ambulating) and homemaker services (e.g., housecleaning, laundry, shopping, transportation, errands).
- The typical program offers consumers the choice of agency (88%), selection of individual worker (84%), control over one's schedule (88%) and how tasks are done (93%), and/or choice of services (84%).
- Nearly half (47%) of the consumer-directed programs identified in the survey are funded under Medicaid home and community based services waivers. Other frequent funding sources of these programs 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 support consumer-directed programs for older persons.
- Most consumer-directed programs permit friends or neighbors (83%) and relatives (79%) to be paid as providers. Two-thirds do not allow spouses to be paid and one-third prohibit payment to parents.
- Programs generally reimburse providers through fiscal intermediaries (43%) or directly (24%), rather than providing vouchers (16%) or payment to the consumer, who would then pay the provider (10%).
- A wide range of quality assurance mechanisms are used, including consumer satisfaction surveys (78%), internal case reviews (69%), criminal background checks (69%), program evaluations (62%), required certification of professional

providers (57%), emergency back-up systems (48%), case or care management (43%), and external case reviews (41%).

Barriers to Advancing Consumer Direction

Respondents perceive a range of barriers to successful implementation of consumer direction (CD) programs. When asked to rate their level of concern about a list of potential barriers to implementing CD services, survey respondents most frequently identified as serious concerns the federal Medicaid waiver process and resistance from provider organizations. Federal and state Medicaid laws, rules, and regulations, and quality concerns also received high levels of expressed concern.

While federal initiatives are clearly helpful in promoting consumer direction, some federal rules and regulations are seen as barriers to its implementation and expansion. It was not always clear to respondents whether the regulatory barriers were coming from the federal government or their states. Many of the barriers were specific to Medicaid waivers. States reported that the process of obtaining approval from the Centers for Medicare and Medicaid Services (CMS) for offering consumer direction under a Medicaid waiver took a long time, ranging from only one year to six years (in one state) before a waiver application was approved.

The state officials who participated in the interviews are especially concerned about barriers to the expansion of consumer direction for older people. These include: resistance from appointed and elected officials, long term care providers, and within aging agencies and human services departments. Strong resistance from providers was one of the more consistent messages heard, most frequently reported to be the primary barrier to implementing consumer direction.

Pressing problems that face states as they move forward in implementing consumer-directed home and community based services for older persons include inadequate funding for these programs, concerns about poor compensation and benefits for caregivers and the challenges of financial administration of consumer direction including the use of vouchers, fiscal intermediary services, workers' compensation issues and tax questions. Fewer respondents reported being concerned about potential fraud and abuse than about the quality of care delivered, but in the interviews it became clear that neither of these concerns had materialized to any significant degree.

Opportunities for Consumer Direction

States are clearly getting the message that consumer direction is a federal priority, despite concerns about federal laws and regulations that seem to send the opposite message. Consumer direction is seen as the new model of best practice in long-term care. As described by one respondent, *“The federal agencies really wanted that [consumer direction] program to be flexible and gave states room for policy decisions.”*

Despite the serious concerns about quality reported by some states, others were confident that consumer-directed programs offer quality care. As a result of satisfaction surveys and other monitoring systems, state units on aging have a pretty clear picture of consumers’ reaction to consumer direction. In general they report that older persons are quite positive, pointing out that things that most of us take for granted have a major impact on quality of life in the older years. Virtually all of those who get services were described as having “very high” satisfaction. Respondents reported hearing comments such as: *“My life is totally different. I have someone to take me to the grocery store and I can point to what I want instead of someone getting what I don’t want. I can have someone cook for me.”*

While consumer direction is not generally expected to save states money, cost implications were indicated by four states to be the most important force influencing them to pursue consumer direction. According to Aging administrators, both consumers and case managers believe they have prevented utilization of more expensive services such as nursing homes and emergency rooms. States have developed a number of effective practices to ensure the cost effectiveness of consumer-directed programs.

One interview subject admitted that he/she initially assumed that older people wouldn’t want to manage their own care, that it was just for younger persons with developmental disabilities, but had now found that *“not to be true. Plenty of older people can benefit from consumer direction. It depends on their condition, not on their age.”* It was also noted that some older people have enough capacity to know what they want for care but they can’t manage the payroll. Consumer direction can have the flexibility to meet the specific needs of older people.

Overall, Aging agencies reported that consumer direction is working well in their states. In ranking the importance of consumer-directed services in terms of policy priority given to various long-term care options from 1 (not at all important) to 7 (extremely important), eighteen (out of twenty) respondents ranked its importance from 4 to 7, with a mean of 5.76. This represents a very high priority, higher than any of the other items

ranked. This priority is reflected in a wide range of activities states hope to pursue in the future related to expanding the scope of consumer direction.

Conclusion

Policymakers debate whether home and community based services should be consumer-directed, agency-administered, or a mix of these strategies. Consumer direction programs appeal to many states for their ability to provide choices for consumers, empower them, improve access to services, and address workforce shortages. They consider consumer-directed aging service programs to be quite beneficial to consumers, with over three-quarters indicating that they are highly beneficial (4 or 5 on a 5-point scale).

Among the Aging administrators interviewed, there seems to be a general sense of optimism about consumer direction. States are actively working to address a lack of understanding about consumer direction, among professionals as well as the public, and build support for this model of service delivery. State units on aging recognize that there are major steps still ahead and they are identifying successful practices to help move consumer direction forward. In sum, they see consumer direction as effective and *"simply the right thing to do."*

Introduction

Consumer-directed home and community based services (HCBS) give consumers maximum choice and control. They allow consumers to assess their own needs, determine how and by whom these needs are met, and monitor the quality of services received. Consumers may be able to:

- Select, manage, and dismiss their workers
- Choose which services to use
- Choose what providers or workers to hire
- Decide what time of day workers will come
- Decide whether to hire family members
- Decide whether to spend available funds on things other than services (like appliances or home modifications).

The option of using a consumer-directed model of care for older people who need publicly-supported home and community based long term services has become more widespread in recent years. This report combines the findings of two web-based surveys conducted in February and March 2004 by Mathew Greenwald and Associates and twenty telephone interviews, which were part of the project, “Promoting Consumer Direction in Aging Services,” a partnership of the National Association of State Units on Aging (NASUA) and the National Council on the Aging (NCOA). The project was made possible with funding from the Robert Wood Johnson Foundation.

The data presented in this report describe a wide range of state experiences with consumer direction for older people. Some states are in the development phases or operate only small demonstration programs. Others operate several programs, some for many years. In fact respondents reflect the full range of consumer direction development, from states that are preparing to provide their first consumer-directed services to two of the original states to develop this approach as part of the Cash and Counseling Demonstration and Evaluation Program, supported by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. This report describes the range of programs and examines what they have learned and barriers they have overcome in an effort to help other states that may be moving toward expanding consumer direction opportunities for elderly persons.

Consumer Direction Survey of State Administrators

In 1996 and 1999, NCOA completed surveys with state administrators about consumer-directed HCBS. In the current 2004 study, state administrators were once again surveyed about program characteristics, funding and costs, quality assurance, problems, and effective practices. State agency on aging directors were asked to coordinate their responses with state Medicaid directors for one coordinated response from each state. In a second survey, state aging directors were asked independently for their opinions about consumer-directed HCBS. The third phase of the project involved interviews of state aging directors or their designees to expand on the information provided in the two surveys.

Organization of the Report

Following this introduction is a description of the project's methodology and a report of findings. Appendix A contains copies of the survey instruments and interview questions. Appendix B includes data on the role of Reverse Mortgages in potentially funding consumer direction. These questions were part of the Opinion Survey, but because they represent a different issue from the rest of the survey questions, they are contained in an appendix.

Methodology

Sample

A total of 56 state and territorial agency on aging directors and 56 state and territorial Medicaid directors were surveyed. Lists were provided by NASUA through NCOA. All 27 state units on aging that reported on both the CD Survey and the Opinion Survey that they offer or are in the process of implementing a consumer-directed program were contacted for telephone interviews.

Survey Instruments

All state administrators were asked about the existence of consumer-directed HCBS in their state as well as their awareness and knowledge of such programs, whether they think it is a good idea to increase such programs, and how easy it is to implement and measure the success of such programs. For those states that have current consumer-

directed programs in aging services, additional questions focused on up to three such programs. For each program, respondents were asked to provide information about funding and costs, program characteristics, quality assurance efforts, problems, and effective practices. Respondents who reported new effective practices were also asked about their willingness to participate in follow-up research about these practices. Finally, respondents were asked about reverse mortgages as funding options for consumer-directed HCBS services.

The state agency on aging directors were also asked to complete a second survey. This survey asked their opinion on various aspects of consumer-directed HCBS including: awareness of such programs within their agency, the benefits of these programs for consumers, influencing factors for developing programs, problems and benefits of such programs, barriers to implementing consumer direction, and compatibility of such programs with both the state and the state aging network.

The third stage involved interviews of state aging directors or their designees in states currently offering or developing consumer direction programs for older people and asked them to expand on factors that motivated their development of consumer direction (CD), barriers they have experienced and effective practices they have implemented.

Copies of the survey instruments can be found in Appendix A.

Procedures

The surveys were pilot tested with two state agency on aging directors; they supported the approach of requesting a joint response from the state aging director and the state Medicaid director. A pre-notification letter signed by NASUA and NCOA was mailed to the 56 state and territorial agency on aging directors and the 56 state and territorial Medicaid directors explaining the study and asking for their cooperation. Those administrators with e-mail addresses were told to expect an e-mail inviting them to complete the survey online. Administrators for whom no e-mail address was available were asked to complete a hard copy and return it by mail. For the consumer direction survey, state agency on aging directors and state Medicaid directors were asked to collaborate with each other before submitting one coordinated response. Only the state agency on aging directors received the opinion survey, which they were also encouraged to complete online.

Following the pre-notification letter, Boomerang.com, an online survey company that hosted the survey, sent the e-mail invitation. The e-mail provided a link to the survey site where respondents could complete the survey and submit their responses via the Internet. For territorial offices that do not have Internet access, surveys were mailed, and in some cases faxed, to facilitate response.

NASUA placed follow-up phone calls to state aging administrators to encourage response and a second e-mail (with a link to the Web survey site) was sent out prior to the deadline of February 13, 2004. The deadline was extended to March 12, 2004 after which the Web surveys were taken off the Internet. Five additional consumer direction surveys and six opinion surveys were faxed in after the final deadline, but were still included in the analysis.

The sample for telephone interviews was recruited from a list of the 27 states that indicated in the prior survey that they currently offer at least one program with consumer direction. Each state aging director was sent an e-mail requesting participation or that of the most appropriate staff person. Twenty-seven states were initially contacted. After two follow-up e-mails, 20 interviews were completed between April 29 and June 1, 2004. Interviews took between 20 and 60 minutes, with most lasting about one-half hour. While most interviews involved one person, some states included two or three staff members. The interview questions are attached in Appendix A. Respondents were assured of confidentiality and anonymity as part of the Institutional Review Board process to assure the protection of human subjects who participate in any type of research. As a result, individual states are not identified with their responses.

Notes were typed directly into the computer during the interviews. They were then combined and summarized to represent the full range of responses and to highlight common experiences and reactions. The findings incorporate respondents' own wording to capture their perceptions and views about implementing consumer direction for older people needing long term services. The text and bullets generally paraphrase respondents' comments. In addition, direct quotes are used to capture their specific tone and emphasis. Respondents were given the opportunity to review a draft of this report and their comments were incorporated into the final version.

Response Rate and Sample Sizes

Survey results are based on an overall response rate of 70 percent for the consumer direction survey, 68 percent for the opinion survey, and 74 percent for the telephone

interviews. A total of 40 consumer direction surveys, 39 opinion surveys, and 20 telephone interviews were completed by the following states and territories:

Exhibit 1 States participating in the consumer direction study

<i>State</i>	<i>Consumer Direction Survey</i>	<i>Opinion Survey</i>	<i>Telephone Interview</i>
Alabama	X	X	
Arizona	X	X	X
Arkansas	X	X	X
California	X		
Colorado	X	X	
Connecticut	X	X	X
Delaware	X	X	
District of Columbia	X	X	
Florida	X	X	X
Georgia	X	X	X
Hawaii	X		
Idaho		X	
Illinois	X	X	
Indiana	X	X	X
Iowa	X	X	X
Kansas	X	X	
Kentucky	X	X	
Louisiana	X		
Maryland	X	X	X
Michigan	X	X	
Minnesota	X	X	X
Mississippi	X	X	
Montana	X		X
Nebraska		X	
Nevada	X	X	X
New Mexico	X	X	
New Hampshire	X	X	X
North Carolina	X		X
North Dakota	X	X	
Ohio	X	X	X
Oklahoma	X	X	X
Pennsylvania		X	
Rhode Island	X	X	
South Carolina	X	X	X
South Dakota	X	X	
Tennessee	X	X	
Utah	X	X	X
Vermont	X	X	X
Virginia		X	
Washington	X	X	X
West Virginia	X	X	X
Wisconsin	X	X	
Wyoming	X	X	
American Samoa	X	X	

Because of these three data sources, and because not all of the respondents to each instrument offer consumer direction, the tables, charts and graphs included in this report show differing sample sizes. In general the sizes represent:

Exhibit 2 Sample sizes

	Respondents
All responses to CD Survey of State Administrators	40 states (SUA and Medicaid agencies)
Programs offering CD reported on Survey of State Administrators	58 CD programs
All responses to CD Opinion Survey of State Agencies	39 SUAs
Responses to CD Opinion Survey that offer or are starting CD	31 SUAs
Responses to follow-up interviews	20 SUAs

Analysis

Most of the analysis in this report involves descriptive statistics and graphics to present the responses from the two surveys. Relevant content from the interviews is included to amplify the data. On data from the Opinion Survey it was possible to compare three groups: States that do not have consumer-directed HCBS for older people (n=7), those that are in the process of developing such programs (n=17), and those that are currently operating them (n=28). The t-test for independent samples was used to assess the difference in mean scores on Likert-scaled items.

States Are at Different Levels of Consumer Direction for Older People

Early Development

Some states are only in early stages of developing consumer-directed long term services for older persons. For example one state unit on aging (SUA) that participated in the interviews recently received a small grant from NASUA, in partnership with the state's Alliance on Aging, to work with advocacy groups to explore developing consumer direction. The SUA is holding focus groups with Older Americans Act programs and participants, those in aging networks, consumers and their family caregivers, advocates, providers, and local officials discussing consumer-directed services and other aging services such as nutrition, in-home services, and Medicaid waiver

programs. Programs that have not provided services are included in this report in terms of their experience of barriers to establishing consumer direction. They are not included in discussion of effective practices or other questions that focus on experience with program operation.

Several other states are in the early stages of enrolling participants. For example, one that has an Alzheimer's disease demonstration grant to offer consumer direction had served 31 participants at the time of the interview.

Many states actually reflect several different levels of development across several programs. For example one state planned to implement consumer-directed services for older people in two programs within a month of the interview. However it has been operating a consumer-directed program within its Vocational Rehabilitation program for many years. When possible, responses in this report focus on a specific program. However, in many cases the responses addressed the overall experience of the state across programs.

Limited Scope

In addition to being in early stages of development, some states participating in the interviews described definitions of consumer direction that are more limited than that used in this report. For example, several states said they offer consumer direction but require that care be provided by agencies. They described consumer direction as allowing the consumer or family caregiver to have input to the care planning process. In this model, the consumer cannot hire, dismiss, train, or direct their care. The consumer would not usually be able to decide the time he/she would like a particular service performed. Since this definition of consumer-directed services is inconsistent with that generally used in the field and in this report, the experiences of these programs are not reflected in the narrative from the interviews. However they are included in survey responses because they reflect the range of states reporting that they offer CD. According to one state Aging Program manager, "if consumer direction is defined as a way of involving consumers in the process of their care, then this state is actively participating in it. On the other hand, if it is defined as the elder having the ultimate right to say yes or no to the provider, then consumer direction is not in any of our programs." However, even in this state there is one exception where consumer direction is available. In rural areas, if there is no appropriate provider on the approved list, then consumers can contact and recruit their own. For example, if a caregiver of an elderly

person wants Adult Day Care services to provide respite but there are no ADC providers in the community, having a neighbor provide the needed respite can be approved. This state was included because of its experience with a small subset of its overall program and was considered as offering a limited scope of consumer direction.

Another example of a state categorized as offering a limited scope of consumer direction is one that described a “hybrid” consumer-directed model used in its Medicaid personal care program. While most care is provided by licensed home care agencies, approximately ten percent is consumer-directed, using non-agency individual providers and paid through Medicaid. This option is mostly used in rural areas where it is not cost effective for home care agencies to operate or with consumers who have not been successful in working with agencies. While the consumer can find his/her own personal care attendant, the program nurse is responsible for hiring and supervision.

A different modification of the scope of consumer direction involves a Medicaid home and community based care waiver program in which those who use consumer-directed personal care can hire and dismiss their workers, do their own training, and direct their own care; however, the worker must be an employee of an agency.

Established Consumer Direction Programs

The next category of development of consumer direction includes states that offer one or more programs that allow for clear consumer direction. In identifying these established programs, the key issue is how services are offered, that is whether consumer direction allows for the kinds of choice and control defined earlier in this report.

A clear example is a state in which a social worker from the regional office develops care plans for consumers who can then hire either agency or non-agency personal care assistants, and can decide what will help them remain as independent as possible. This program started seven years ago and now serves approximately 500 people, nearly 70 are over age 60. To be eligible participants must have activity of daily living (ADL) needs, be on Medicaid, and between the ages of 18-65. While a pilot program was developed to serve those over 65, it does not include consumer direction.

Another example of moderate development is a state funded home services program that started in 1987 and added consumer direction in 2001. While there are approximately 11,000 in the overall program, 140 are in the consumer-directed program, most of whom are elderly.

Consumer direction is part of three programs in another state. They are an AoA Alzheimer's demonstration grant that provides services to family caregivers, a state funded senior care program that includes case management and other gap-filling services in which thirteen percent of services are provided as "Grants to Families" that pay for hiring in-home aids, buy prescription medications, or pay for personal care aids, and an Older Americans Act, National Family Caregiver Support Program.

Some of these states have been offering consumer direction for many years. For example one state has a 20-year-old state-funded consumer-directed attendant services program initiated primarily at the request of younger disabled persons. Several years ago it opened up consumer-directed services in its home and community based services waiver. A surrogate directed care model was added in which a recipient's spouse or other family member could act as the decision-maker. Fully half of waiver participants are in this program.

Another program is administered at the AAA level and involves 13 AAAs with at least one case management coordinator in each county. Consumer direction is one of 15 elderly waiver services. Providers are paid through a fiscal intermediary. Anyone can apply to become a provider, including family members, as long as they are not the spouses, whether or not they work for an agency.

Participating in the Robert Wood Johnson (RWJ) Cash and Counseling Program allowed two states to develop their consumer direction programs. One of these states is now implementing a statewide option under their Medicaid waiver, which will incorporate 130 elderly participants previously, served under the RWJ project.

Another of the states with extensive consumer direction has three separate initiatives. One is a Medicaid home and community based services waiver for people aged 60 and over that has been operating for three years and serves 170 people. In another program Older Americans Act funds are provided to Area Agencies on Aging who use consumer direction in providing Alzheimer's respite services to 530 participants. The third program is a National Family Caregiver Support Program that has been operating for a couple of years and serves 800 participants.

In some of these states the concept of consumer direction is very strong and allows considerable consumer control. In one state, consumers can bring relatives in as paid providers under the regular Medicaid program. This state also offers consumer direction in home and community based services for elders, a state operated alternative care

program for seniors eligible for nursing homes, a state-funded homecare option that allows people to bring their own worker to an agency (mostly serving younger recipients), and a small Older Americans Act funded program. This state plans to serve 2,000 elderly with consumer direction over the next three years. Under its newest program, consumer direction will allow hiring of spouses as well as other family members. There is a planning process with or without a public case manager as long as the family caregiver completes required training. County case managers authorize the care plan and are still “at the helm” for quality assurance.

Another state with a high level of development was one of the first to receive an Independence Plus Medicaid waiver for elderly and disabled. Participants in the “regular” elderly/disabled waiver have a form of consumer direction; they can hire attendants and companions. However, the new Independence Plus Medicaid waiver goes beyond this in allowing elderly and disabled participants to also negotiate pay, decide how funds will be spent, and purchase appliances and supplies. Starting in only three counties, only twenty-nine participants have been enrolled so far. However there has been twice as much interest as expected. Since the states’ two waivers for Developmental Disabilities do not allow consumer direction, its younger population also wants access to the Independence Plus program. Given that the program started with seniors, over half of the participants are elderly. This state also has a family caregiver support program under the Older Americans Act that has been operational for two years. While it primarily provides information, 4,000 people have received supplemental services or respite care, self-directing the type of respite and who provides it.

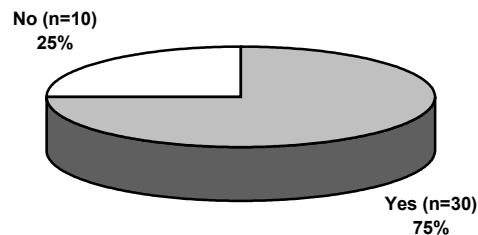
In sum, it is clear that what states call consumer direction varies quite widely. While some are just getting their toes wet in providing consumer-directed services, others have well-established programs that allow consumers to hire non-agency personnel, direct their own services, and terminate those services if and when they choose.

Descriptive Findings

Currently, three-quarters of the 40 states that responded to the data survey offer consumer-directed HCBS programs (75%). None of these states have eliminated or ended any consumer-directed home and community based services (HCBS) long term care programs since last surveyed in 1999.

Figure 1 Consumer-directed HCBS (n=40 state agencies)

“In providing services related to aging, does your state currently offer any consumer-directed HCBS programs?”

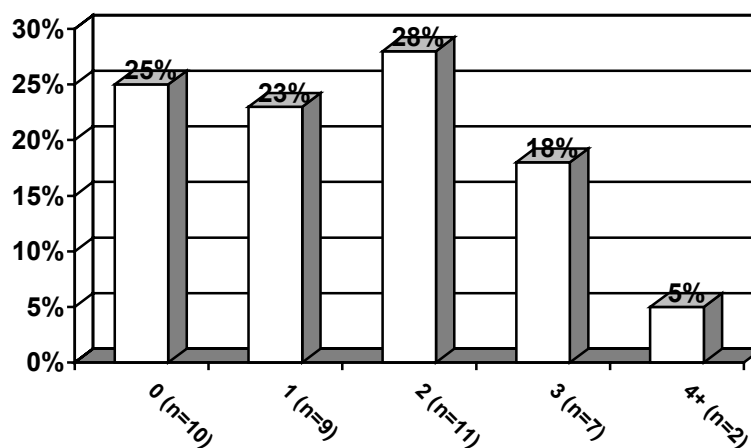


When the ten respondents who do not currently operate a consumer-directed HCBS aging services program are asked why, four in ten cite lack of resources to implement such a program (40%), while only one (10%) believes that these programs are not a good idea. Half have some other reason why they do not operate such programs (50%). The other reasons offered included that a consumer direction program is in development (2 states), the state's long term care system is being redesigned (1 state), or the state is considering applying for support for consumer direction (1 state). None answered that they don't know what to do to get started.

Figure 2 Number of HCBS Programs (n=58 programs; Missing responses n=14)

Most states that offer consumer direction actually offer two or more such programs. The mean number is 1.5 programs and the most frequent response (mode) was two programs.

“In your state, how many HCBS programs relating to aging offer consumer-directed options?”



Consumer Direction Awareness and Knowledge

As a result of operating several consumer direction programs, it isn't surprising that respondents claim very high awareness of consumer-directed programs for older adults. Specifically, 85 percent of respondents rate their own awareness of these types of programs as a 4 or 5 on a 5-point scale, with 60 percent giving the highest rating. In answering the Opinion Survey nearly half of the respondents indicate that their managers or supervisors are very aware of such programs (47% rating 5 on a 5-point scale). An additional 22 percent indicate that managers or supervisors are nearly as aware (rating of 4 on a 5-point scale), with a mean score of 3.9. Respondents also indicate high awareness among other staff, with six in ten rating their level of awareness at 4 or a 5 (63%) and a mean score of 3.8.

Respondents' ratings of their knowledge about consumer-directed programs for older adults are almost as high as their awareness level. Seven in ten respondents rate their knowledge as 4 or 5 (73%).

Table 1 Consumer-directed knowledge (*CD Survey: n=30 state agencies that offer CD*)

"How knowledgeable are you about consumer-directed programs for older adults?"

	Not at all knowledgeable			Very knowledgeable		
	1	2	3	4	5	Mean
%	--	3%	20%	33%	40%	4.2
(Number)	(0)	(1)	(6)	(9)	(14)	

Definition of Consumer Direction

Consumer direction is characterized by a broad scope of service options and by consumer control or choice over how and when those services are delivered. Therefore it is important to examine the range of services provided by states reporting to offer consumer direction. Respondents were asked to indicate whether or not they offered each of 12 discrete service options (see description in survey included in Appendix A). As indicated in Figure 3, a wide array of services is offered in consumer direction programs. While most programs offer personal care and homemaker services, only

about half provide a broader array of services. The mean number of services provided in each program is 5.9 and the most frequent response (mode) is 3. However, even more interesting is the range which goes from two programs offering only 1 service while at the other end, two programs offer all 12 services (See Figure 4).

Figure 3 Types of assistance provided ($n=58$ programs; Missing responses= 2¹)
“Which of the following types of assistance are provided through the program? (Check all that apply)”

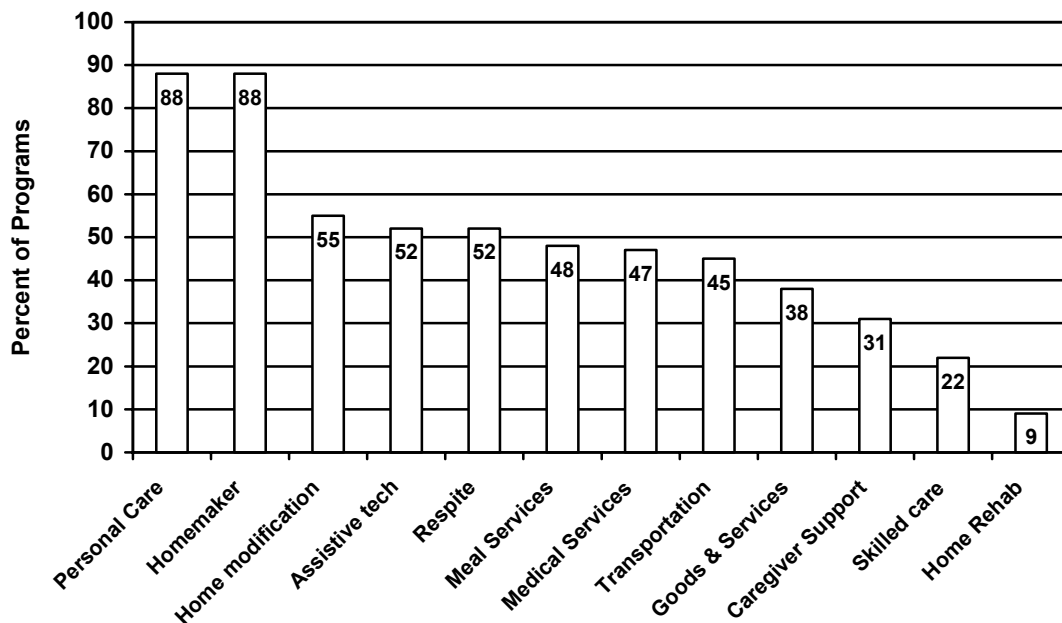
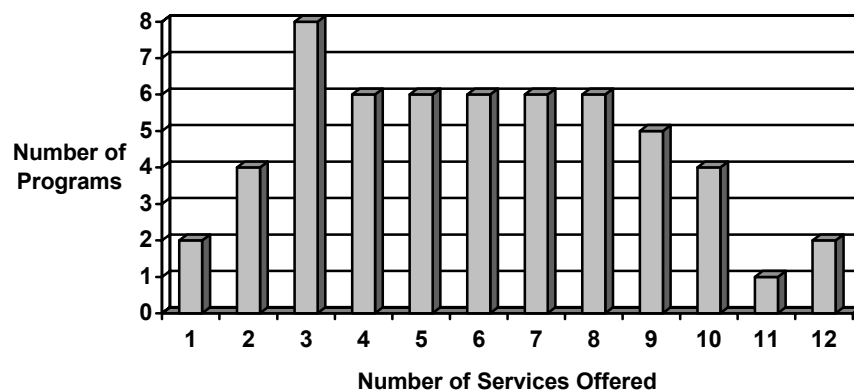


Figure 4 Number of Services Offered ($n = 56$; Missing cases $n=2^2$)



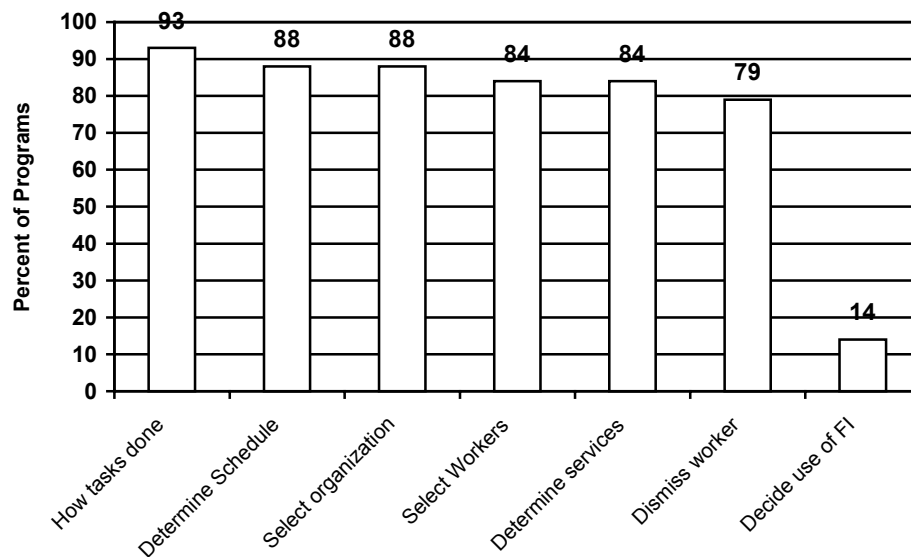
¹ Two programs left this item blank.

² Two programs left this item blank

More important than the range of services in identifying consumer direction is the consumer's control over those services. Looking at Figure 5 it is clear that consumers have substantial control over how tasks are performed, the selection of the agency and individuals who provides the services, when and what services are delivered, and even dismissal of workers. Only the choice of whether or not to use a fiscal intermediary is rarely given to consumers. However another way to look at this data is that in at least 7% of programs reporting that they offer consumer direction, consumers have no choice over how services are performed, and in 12% they have no control over who performs them or when. This is a clear indication of continuing lack of clarity of what is meant by consumer direction. Some states are offering traditional case management services, where the consumer has some input to his/her care plan, but they call it consumer direction.

Figure 5 Consumers' control over service (n=58 programs)

"Over which of the following aspects of service does the consumer have choice/control?"



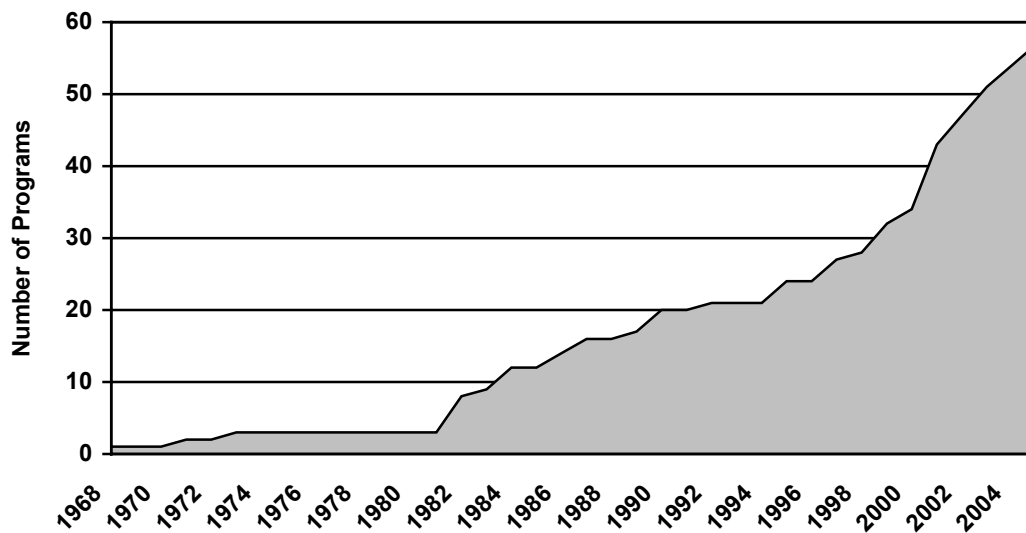
Factors That Differentiate Consumer Direction Programs

There are several characteristics that were explored in terms of how they might differentiate consumer direction programs. They are when the program started, the number of participants served, and the primary funding source.

When the program started

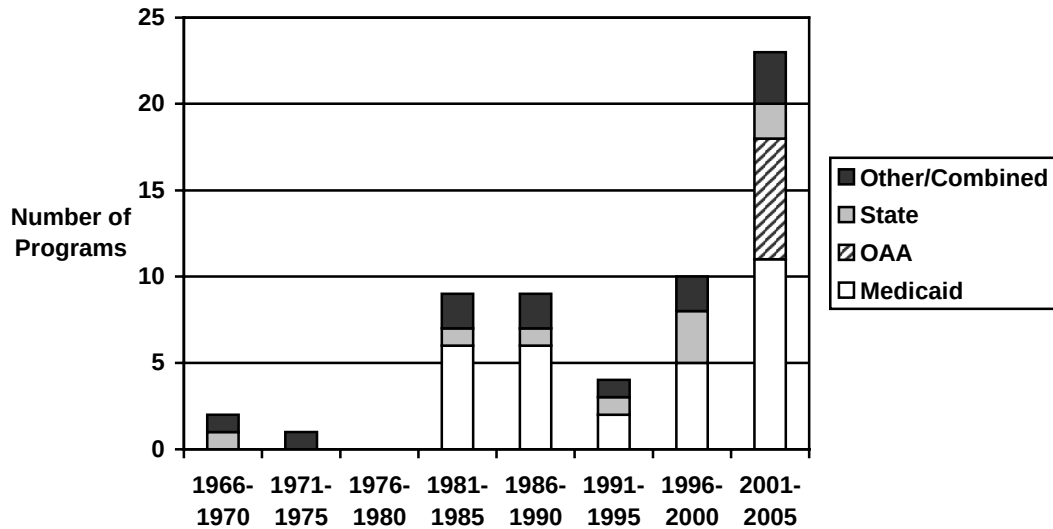
Consumer-directed HCBS programs for older people are emerging at an increasing rate this decade, with 38 percent of the programs identified in the survey having begun in the last five years. By comparison, 24 percent began in the decade of the 1990s, and 24 percent began in the 1980s. Only 7 percent began prior to that, with the oldest program dating back to 1968. Figure 6 shows the increasing number of consumer direction programs for older people, gradually growing to 58 in 2004.

Figure 6 Increasing number of HCBS programs for older people (*n*=58 programs)



As seen in Figure 7, in the early 1980s, Medicaid started funding consumer direction programs. Its impact has increased in recent years. Older Americans Act funds have also contributed significantly to consumer direction growth since 2001.

Figure 7 Number of HCBS consumer direction programs for older people by when program started (*n=58 programs identified by 40 states; Missing cases n=1¹*)

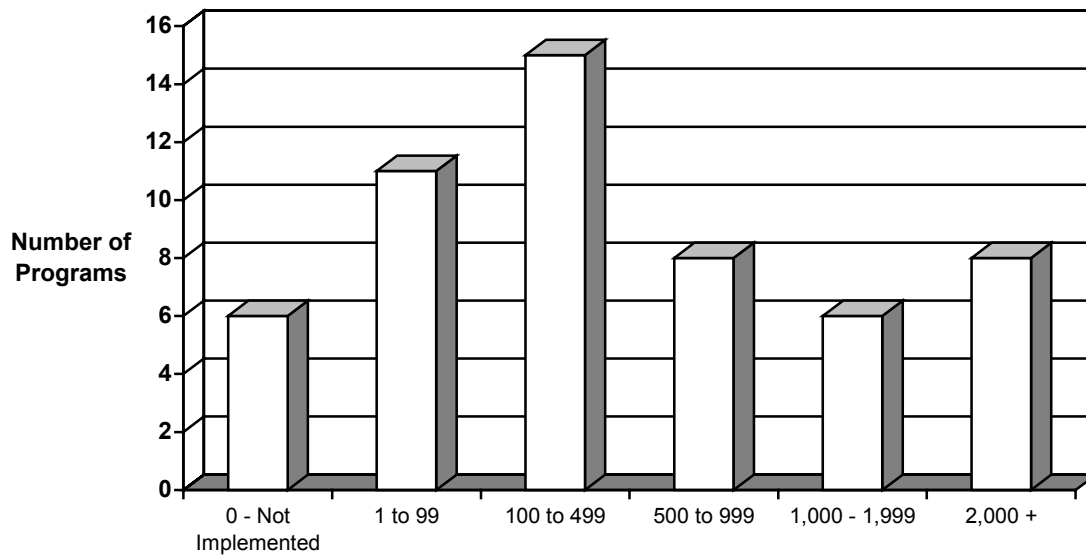


Number of participants

The consumer direction programs have an average of 1,435 participants, but they range widely in size. Four in ten have 1 to 500 participants (43%), yet 14 percent have 2,000 or more participants. The largest program has approximately 15,000 participants. Figure 8 shows the distribution of programs according to size clusters. The largest group of programs (31%) serves between 100 and 500 participants each.

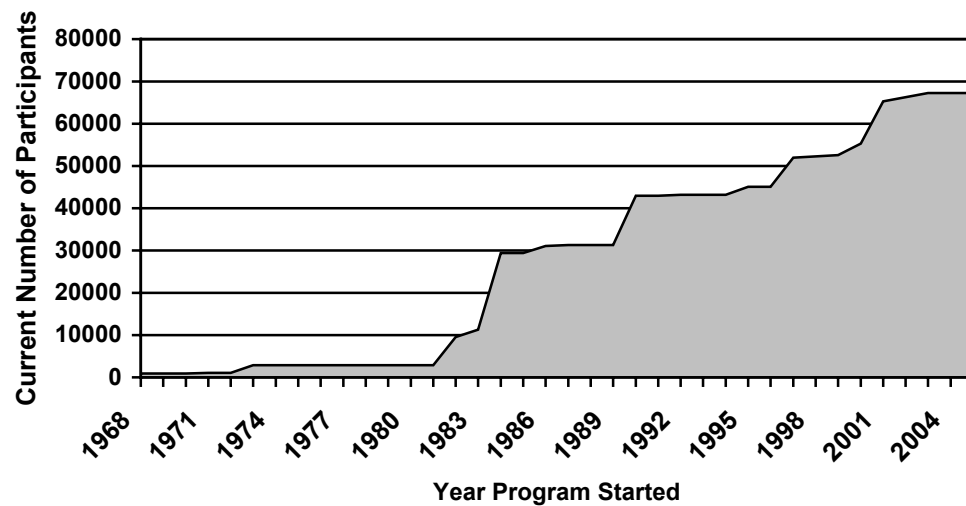
¹ One programs left this item blank.

Figure 8 Number of participants in FY 2003 ($n=58$ programs) (Missing cases $n = 5^4$)
“How many participants who chose the consumer-directed option were there in FY 2003?”



The cumulative number of older people served by consumer direction is shown in Figure 9. While that number is approaching 70,000, it is clear from the interviews conducted that many more older people could benefit from consumer direction.

Figure 9 Cumulative number of older people served by consumer direction ($n=48$ programs; Missing cases $n=5^5$)



⁴ Five programs left this item blank.

⁵ Five programs left this item blank.

As a proportion of seniors receiving some sort of publicly funded long term services, most respondents said the numbers are “very, very low,” or “almost none.” Some estimated consumer direction serves between ½ percent and 2 percent of seniors. In more developed states, a few said as many as 5 percent to 6 percent of seniors using publicly funded long term services were participating in consumer direction.

On the other hand, according to one respondent, “if you look at those who need the care the most, those who are nursing home eligible, then the percentage goes very high,” going on to estimate that as many as half of nursing home eligible seniors are receiving consumer-directed services in that state. However even there, the aging director feels there is “tremendous room for expansion.” Despite this general perception that consumer direction is appropriate for many more seniors, a few aging directors also noted that “consumer direction is not for everyone.” According to one, some people just feel more comfortable with agency-directed services.

One of the few almost unanimous responses heard in the interviews was that there are many more older people who would be appropriate candidates for consumer-directed services than are receiving them.

Program funding

Respondents were given a list of specific funding sources and asked to indicate which ones funded their consumer-directed programs in FY 2003. The Title XIX Medicaid 1915(c) home and community based services waiver program is by far the most common, contributing to nearly half of all the programs (47%). Two in ten programs rely, at least in part, on funds from the state (26%) and on Title III Older Americans Act funds (22%). Other funding sources include Title XIX Medicaid Personal Care (PC) Option (3%); county/municipal funds (3%); other Medicaid waivers (3%); and other sources not specifically identified (12%).

Figure 10 Program Funding (*n*=58 programs)

*“Which of the following funding sources were used for the program in FY 2003?” (Check all that apply)”*⁶

	<i>Single Source</i>	<i>All Sources⁷</i>
Title XIX Medicaid Personal Care (PC) Option	2 (3%)	2 (3%)
Title XIX Medicaid 1915(c) Home and Community-Based Care Waivers	27 (47%)	31 (40%)
Other Medicaid waiver	2 (3%)	2 (3%)
Title III Older Americans Act	7 (12%)	13 (17%)
State general revenue programs	8 (14%)	15 (19%)
County/municipal funds	0 (--)	2 (3%)
Other source or not specified	4 (7%)	4 (5%)
Combination of funding sources	8 (14%)	8 (10%)
Total	58 programs	77 funders

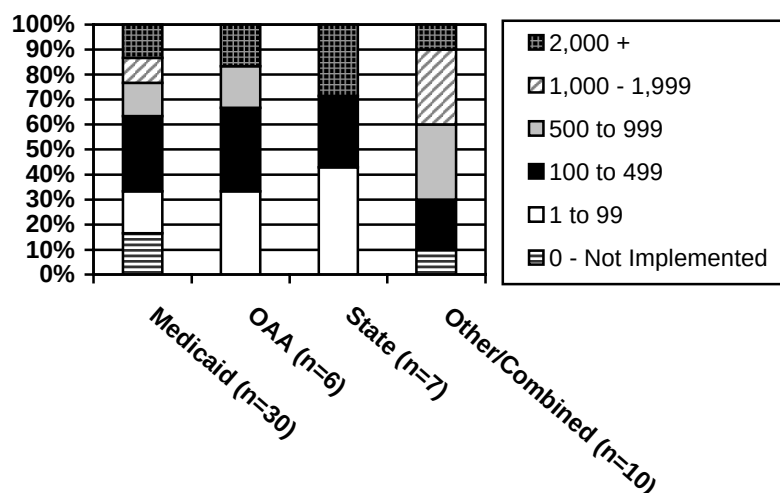
For purposes of further analysis, these funding sources have been collapsed into four groups. One group includes all Medicaid-funded programs (*n* = 33). State funding (*n* = 8) and Older Americans Act support (*n* = 7) are each discrete categories representing programs that use these sources only. The fourth category includes programs that receive funding from a combination of sources and those where the funding source was not specified (*n* = 10).

As seen in Figure 10, it is clear that Medicaid is the primary funder of programs not yet implemented while Older Americans Act and state funds are the major support for the smallest programs.

⁶ Other funding options that respondents were presented but that they did not choose include: Title XIX Community-Supported Living Arrangement, Title XIX Social Services Block Grant, Rehabilitation Act, and Tribal funds.

⁷ This column represents the number of programs that reported that at least some of their funding came from each source.

Figure 11 Number of participants varies by funding source (*n=58 programs; Missing cases n=5¹*)



Program Costs

Respondents were asked to give the approximate amount of funding for the programs in the past two years and for 2004. Spending varies greatly among programs. In 2002, program funding varied from less than \$3,000 to \$187.5 million. In 2003, costs ranged from \$20,000 to \$187.9 million. And in 2004, the budgets range from \$10,000 to \$206 million. In 2002 average spending for the programs totaled approximately \$19.8 million. This increased only slightly to \$20.0 million in 2003 but is estimated to reach \$25.5 million in 2004. Among the programs that have been in operation since 2002, the average program costs have increased from \$22.6 million to \$30.0 million in 2004.

¹ Five programs left this item blank.

Table 2 Program costs (n=58 programs)*“What are the approximate program costs for each of the following years?”*

	Range	Median
Fiscal Year 2002 (n = 19)	\$3,000–\$187.5M	\$1.7M
Fiscal Year 2003 (n = 13)	\$20,000–\$187.9M	\$1.5M
Budgeted Fiscal Year 2004 (n = 3)	\$10,000–\$206.0M	\$2.6M

Provider Payment Methods

When asked how providers are paid, respondents state that in over four out of ten programs an intermediary reimburses the provider (41%), while 23 percent of the programs pay the providers directly. Additionally, in 15 percent of programs, consumers are given vouchers to obtain services and then the program reimburses the providers, and ten percent of programs give the consumers cash to pay providers themselves. Eleven percent of programs use some other method to pay providers. Fifteen percent of programs use multiple methods to pay providers. The mean number of payment methods used is 1.34 while the most frequent response is 1.

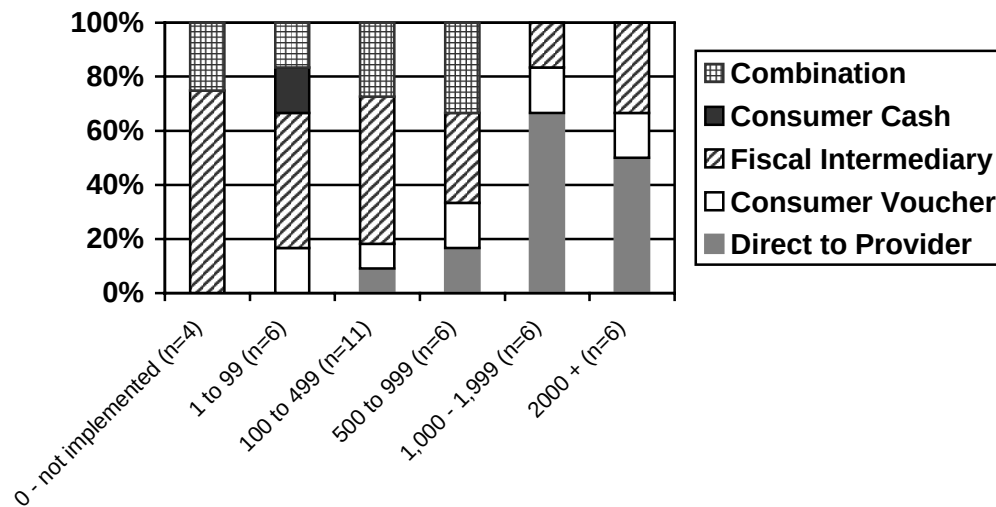
Table 3 Provider reimbursement (n=58 programs)*“How are providers paid? (Check all that apply)”*

	Programs using method	Percentage of responses
Program pays providers directly	13	22%
Program gives consumers vouchers to obtain services and then reimburses the providers	9	15%
An intermediary reimburses providers	24	41%
Program gives consumers cash to pay providers themselves	6	10%
Another method is used to pay providers	7	12%
Total	59 payment methods in 44 programs	100%

Multiple methods ¹	9	15%
Missing information	14	22%

In examining payment method by program size, there are clear differences (Figure 12). Programs yet to be implemented and smaller programs (fewer than 500 participants) are most likely to use a fiscal intermediary to pay providers. The largest programs (those over 1,000 participants) are most likely to pay providers directly.

Figure 12 Provider payment method varies by program size (*n*=58 programs; missing cases = 17²)



The smaller programs are most likely to use a fiscal intermediary to pay providers while larger programs increasingly pay providers directly. Payment method is also related to funding source as detailed in Figures 13 and 14. Only one program provides cash direct

¹ Provider + Voucher + Fiscal Intermediary (4 programs), Fiscal Intermediary + other (2 programs), Provider + Voucher + other (1 program), Provider + Fiscal Intermediary + Cash (1 program), Voucher + Fiscal Intermediary (1 program)

² Seventeen programs left this item blank.

Programs that use vouchers are either funded by the Older Americans Act or by a combination of funding sources. Fiscal intermediaries are most often used by Medicaid programs.

Figure 13 Provider payment method and funding source ($N=58$; missing cases=17¹)

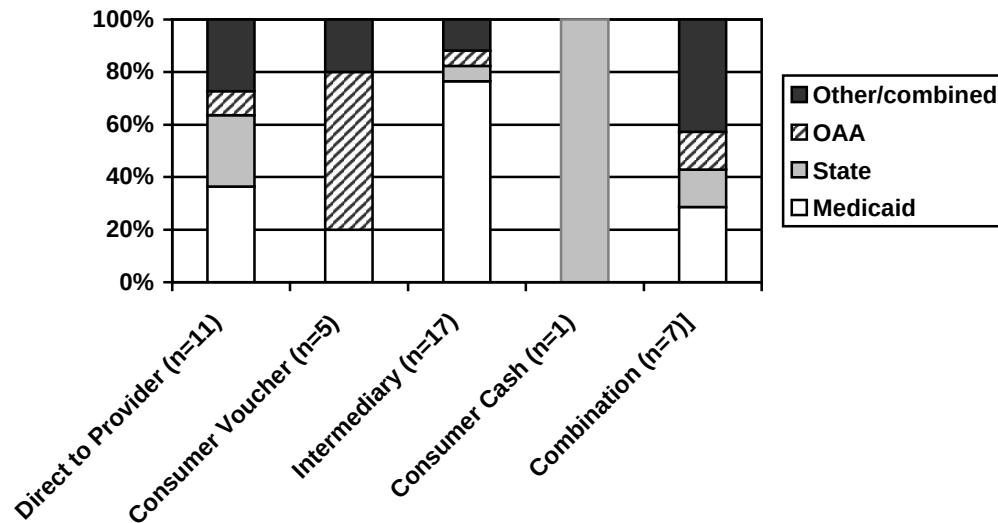
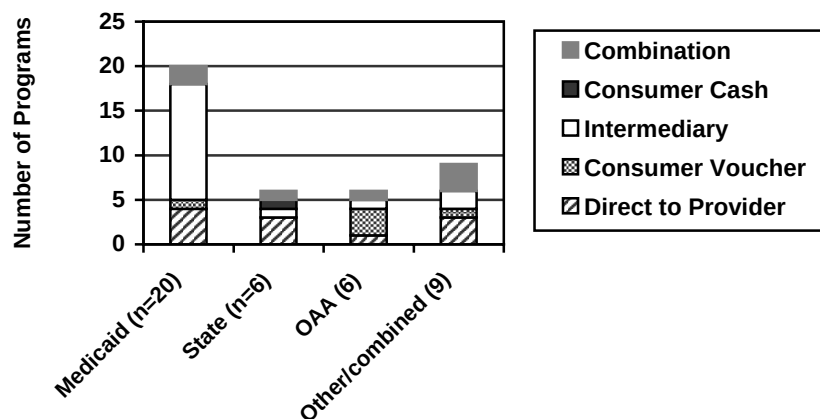


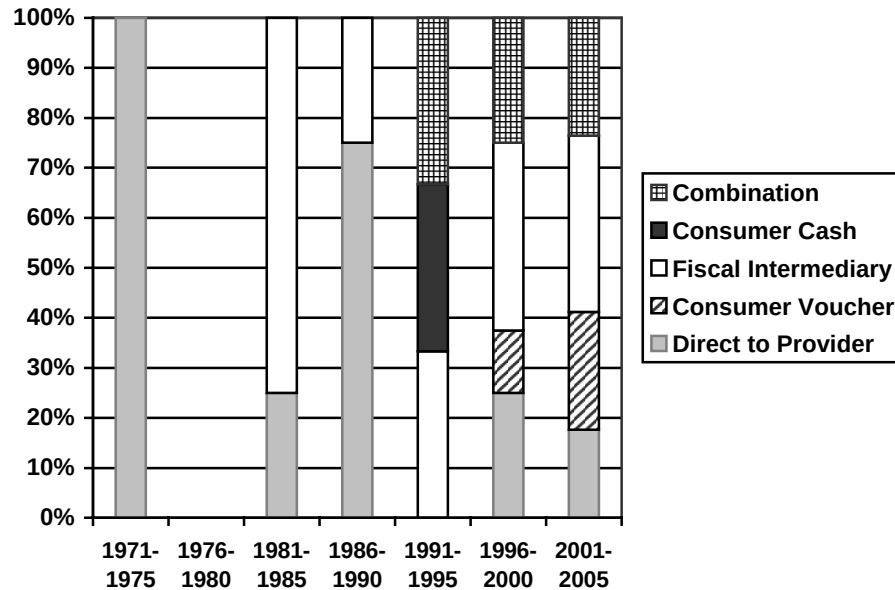
Figure 14 Provider payment method varies according to funding source ($n=58$ programs)



¹ Seventeen programs left this item blank.

When the program was implemented also influences payment method. The earliest programs paid providers directly. In the 1980s the use of fiscal intermediaries was introduced. Since 1990 there has been a greater range of payment methods and a greater likelihood of using multiple payment methods.

Figure 15 Payment method is related to when program was implemented (n=58 programs)



Program Eligibility

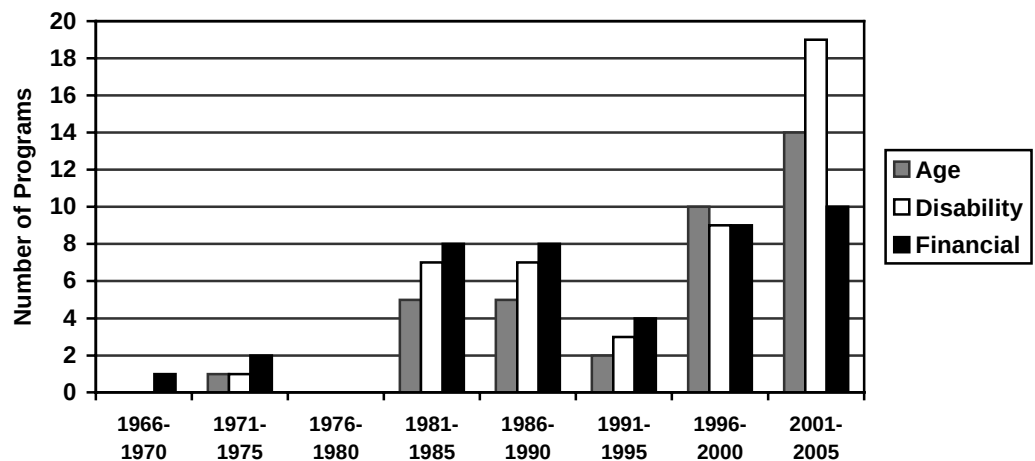
Most programs impose a combination of age, disability and financial criteria to determine eligibility for consumer direction (Table 5). However, differences in these criteria emerge when looking at the programs according to several variables. As seen in Figure 15, programs implemented before 1995 were most likely to have financial criteria and least likely to have age-based criteria. Since 1995 age has become more common and in the most recent programs, disability is the most frequently reported eligibility criterion.

Table 5 Program eligibility (n=58 programs)

“To be eligible for the program, does a consumer have to . . . ”

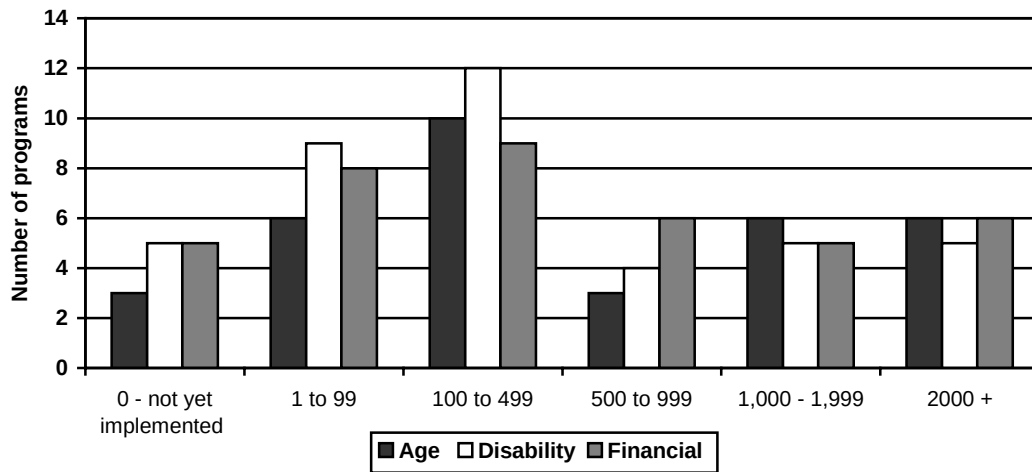
	Number of Responses	Percentage of Programs
Meet certain <i>age criteria only</i> , but not disability criteria?	4	7%
Meet certain <i>disability criteria only</i> , but not age criteria?	10	17%
Meet a combination of <i>age and disability</i> criteria?	34	59%
Meet certain financial criteria (e.g., means testing)?	42	72%

Figure 16 Eligibility criteria vary by when program was implemented (n=58 programs)



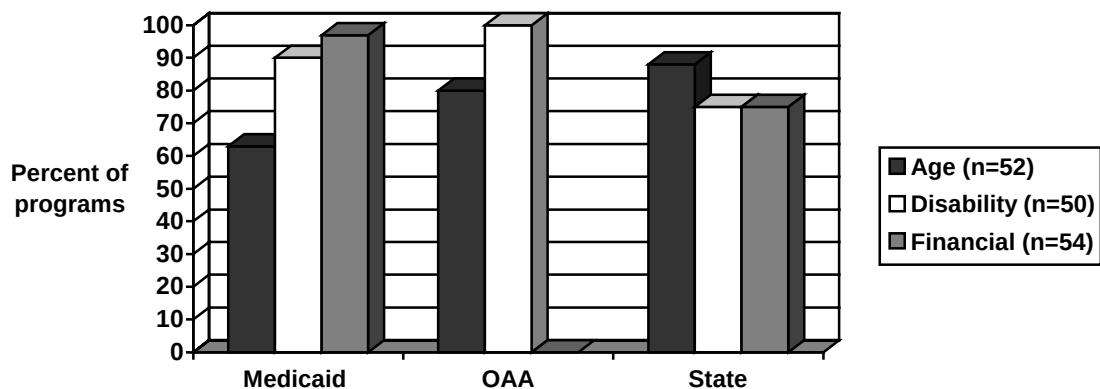
There are also differences in eligibility criteria based on program size and funding source. As seen in Figure 16, smaller programs (fewer than 500 participants) are most likely to use disability as an eligibility criterion, while larger programs more often use either age or age and financial requirements.

Figure 17 Eligibility criteria vary by program size (*n*=58 programs)



Some of this variation in eligibility criteria can be explained by funding source. As seen in Figure 18 essentially all Medicaid-funded programs require financial eligibility criteria (97%), with most also imposing disability (90%) and age (63%) requirements. It is not surprising that most OAA programs imposing age requirements (80%), but they also require some level of disability (100%) and none use financial criteria. State-funded consumer direction programs have the most evenly distributed criteria, with 75 percent to 88 percent of programs requiring each of the three eligibility criteria.

Figure 18 Eligibility criteria vary by funding source

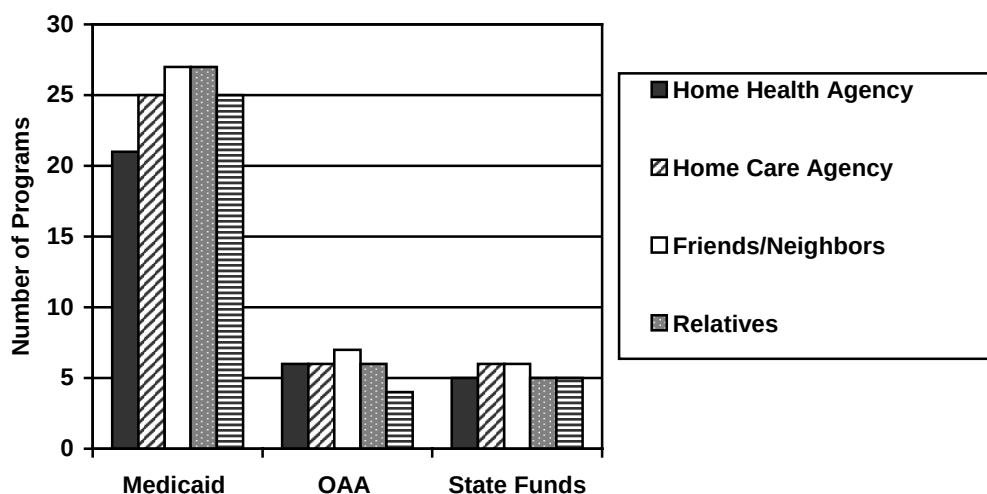


Who Can Be Paid?

Most programs allow a broad range of providers who are eligible for payment. Specifically, eight in ten programs allow payment to friends or neighbors (83%), home care services agencies (81%), and relatives (79%). About seven in ten say other individual providers who are not relatives or friends (72%) or certified home health agencies (69%) are eligible.

Figure 19 Eligible to Be Paid for Services (*n=58 programs*)

“Which of the following organizations or individuals may be paid to provide services? (Check all that apply)”



The pattern of who can be paid is slightly different across the primary funding sources (Figure 19). For example, Medicaid-funded programs are less likely to use home health agencies than are programs funded with state general funds or Older Americans Act dollars.

Who Can't be Paid?

Even though 79 percent of programs reported they allow relatives to be paid providers there are some exceptions. Two-thirds of programs do not permit spouses to be paid providers (66%), and one-third do not allow parents to be paid providers (33%) (Table 6).

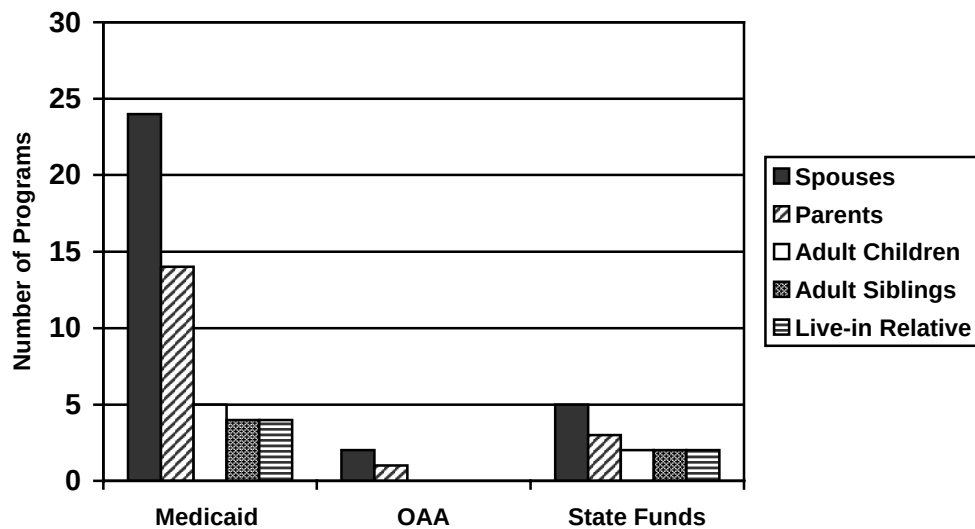
Table 6 Not eligible to be paid for services (n=58 programs)

“Which of the following relatives (if any) cannot be paid providers under the program? (Check all that apply)”

	Number of programs	Percentage of programs
Spouses	38	66%
Parents	19	33%
Adult children	6	10%
Adult siblings	7	12%
Relative who lives with caregiver	8	14%

As seen in Figure 20, across all funding sources spouses are the most likely to be ineligible to receive payment under consumer direction. Older Americans Act-funded programs do not prohibit payment to adult children, adult siblings, and live-in relatives.

Figure 20 Who cannot be paid according to funding source (n=58 programs)

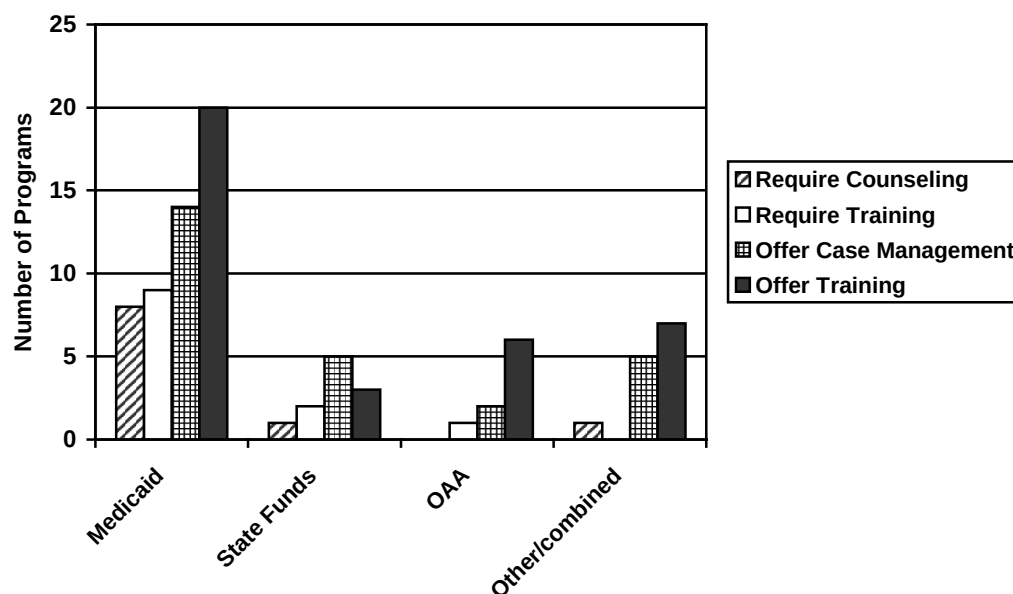


Counseling, Case Management, and Training

Only one in five (20%) consumer-directed programs requires counseling (information, advice, and training) and one in four require training (26%) for consumers who use CD. However, they are much more likely to offer supportive services. Nearly all programs provide information and/or counseling about the service options that are available (93%). In addition, 72 percent offer training and 68 percent offer traditional case management services. As seen in Figure 21, Medicaid-funded programs are more likely to require counseling than Older Americans Act or state-funded programs. Older Americans Act-funded programs do not require counseling. State-funded programs are least likely to offer caregiver training.

Figure 21 Case management, mandatory counseling, and training requirements vary by funding source (n=58 programs)

“Is counseling (information, advice, training) mandatory for all customers who use the program?”

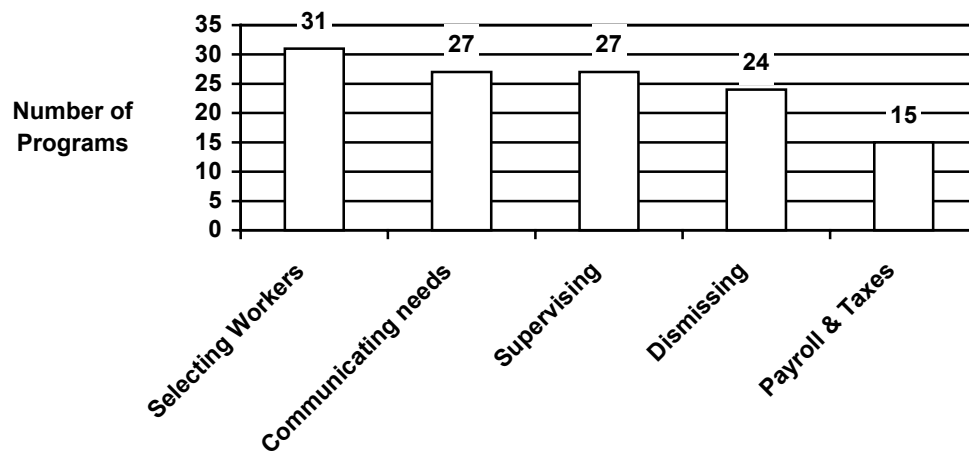


Training Topics

The respondents whose programs offer training were asked whether five specific topics are covered. Most of the programs offer training on these topics (Figure 22). Specifically, 91 percent of the programs provide training on selecting qualified workers, while 79 percent provide training on communicating needs and preferences and on supervising workers. Nearly as many provide training on how to dismiss workers (71%), while just under half (44%) provide training on handling payroll and taxes.

Figure 22 Training (n=34 programs offering training)

*“In which of the following topics does the program offer training to consumers and/or family caregivers?
(Check all that apply)”*



Examination of Experiences and Perceptions about Consumer Direction

The previous sections have summarized the characteristics of 58 consumer-directed HCBS programs for the elderly operated by 30 states. We now look more closely at the experience of states in developing and implementing these programs by incorporating findings from the Opinion Survey of State Agencies on Aging and the follow-up telephone interviews of twenty state-level directors of aging HCBS consumer directed programs.¹² The unit of analysis shifts from the program-level to the state level and the sample sizes reflect the number of states participating in the Opinion Survey and telephone interviews.

Influences on Development of Consumer Direction for the Elderly

State aging directors were asked to rate on a 5-point scale to what degree certain factors influenced them in developing consumer-directed HCBS aging services (See Table 7). A majority of respondents indicate that perceived gaps in service delivery (71%) or consumer demand (65%) had a strong influence on the development of consumer-directed HCBS programs for the elderly. States in the process of developing consumer-directed HCBS for the elderly were significantly more likely to report that perceived gaps in service delivery had a great deal of influence on their decision compared to those already operating programs. New federal initiatives were influential for over half of the respondents (53%) and statistically greater for states currently operating programs than for those that do not. Noticeably fewer state aging directors say that success in other states has had an influence on their decision to develop consumer-directed programs in aging services (31% rating a 4 or 5).

¹² This section presents the opinions and unique perspectives of state aging officials in the responding states. These states represent a broad range of experiences and knowledge of consumer direction; nevertheless, it should be noted that some states with extensive experience in consumer direction did not respond to the opinion survey or chose not to be interviewed.

Table 7 Barriers in implementing consumer-directed HCBS programs (Opinion Survey n=39 state agencies)

“To what degree, if at all, are you concerned about the following as barriers to implementing consumer-directed HCBS aging services programs?”

	Not at all concerned				Very concerned	
	1	2	3	4	5	Overall Mean
Federal Medicaid laws, rules and regulations (n=37)	8% (3)	26% (10)	21% (8)	28% (11)	13% (5)	3.2
State Medicaid laws, rules, and regulations (n=37)	8% (3)	21% (8)	26% (10)	23% (9)	18% (7)	3.3
Federal Medicaid Waiver process (n=37)	5% (2)	31% (12)	15% (6)	31% (12)	13% (3)	3.2
Other state laws, rules or regulations (n=36)	8% (3)	26% (10)	23% (9)	21% (8)	15% (6)	3.1 ¹
Resistance from appointed and elected officials (n=37)	3% (5)	31% (12)	26% (10)	8% (3)	15% (6)	2.8
Resistance within your agency/department (n=36)	36 (15)	31% (12)	10% (4)	10% (4)	5% (2)	2.1
Inadequate consumer advocacy for consumer-directed HCBS (n=36)	23% (9)	26% (10)	13% (5)	18% (7)	13% (5)	2.7
Lack of funds (n=36)	18% (7)	28% (11)	15% (6)	13% (5)	18% (7)	3.3
Quality concerns (n=36)	10% (4)	21% (8)	21% (8)	28% (11)	13% (5)	3.1
Resistance from provider agencies (n=37)	0% (4)	13% (5)	28% (11)	23% (9)	21% (8)	3.3

♣ **Federal barriers**

Forty-one percent of respondents are either concerned or very concerned about federal Medicaid laws, rules, and regulations as barriers to implementing consumer-directed aging services. While federal initiatives are clearly helpful in promoting consumer direction, some federal rules and regulations are seen as barriers to its implementation and expansion.

¹ There is a statistically significant difference between the mean scores for states not offering CD HCBS for older people (2.5) and for states that are operating them (3.3) (significance <0.05).

The shortage of providers is directly related to perceived gaps in service delivery that states described as influencing them to move toward consumer direction. Reports from local AAAs on service gaps influenced some state units on aging to pursue consumer direction.

“Because consumers can recruit their own family, friends, or neighbors, consumer direction certainly works to identify providers who wouldn’t be there otherwise.”

“This [increasing supply of providers] has turned out to be absolutely true and a huge success.”

During the telephone interviews, respondents were asked to amplify on the factors that influenced their decision to develop consumer-directed HCBS aging service programs. Many of their responses related to why these programs are better than traditional

HCBS for some older people. The following section identifies themes that emerged across several interview questions. It is an effort to capture how respondents perceive that consumer direction helps fill service gaps.

CD services better fit consumers’ needs

It isn’t just that there are more workers; the workers can do what the consumers really want and need.

- People can’t get traditional services they want when they want them.
- Consistently hear from consumers about problems of obtaining specific services; they are not happy with agency delivery of services; people don’t show up on time and are not there when they are needed.
- Heard stories like one of a consumer sitting in a chair all night long because the worker didn’t show up to help her go to bed.
- Before consumer direction, elders were required to stay in their homes to receive some services. Now homemakers can take them to church, to the beauty shop or to the mall. Consumer direction is also more effective at getting help on weekends and at night.
- Consumers are concerned about not having the same person consistently providing care. Consumer direction is effective in meeting these kinds of needs.
- Agencies tend to be much more conservative than consumers would like in terms of the types of care they are willing to provide.

CD addresses cultural diversity

Consumer direction is particularly good at meeting the needs within specific cultural groups. Some groups are more comfortable relying on family members or others of the same background to provide their care.

- Two states described particular success offering consumer direction to Hispanics. According to one, it took quite a while to learn some of the things consumers wanted and to build trust between care consultants and family members. "Once we got that down it was a lot easier to negotiate what types of service were needed." The care consultant made more frequent initial visits than for other older people. They couldn't just meet them once. They needed to have a conversation that could take three visits to get that person more comfortable with sharing some of their needs or to admit the family member had dementia.
- There is also a challenge of finding providers who are culturally competent. Building a good partnership with faith-based organizations, including funding some of them to conduct outreach, has been helpful.
- Materials about consumer direction were translated into Spanish to help with recruitment.
- Consumer direction is helpful in dealing with tribal governments and small pockets in the Asian community. It has helped address disparity levels in provision of care.

CD addresses needs in rural areas

Fully 14 out of 20 states specifically noted in interviews that consumer direction is effective at maintaining an adequate workforce and filling service gaps in rural areas because it gives rural consumers more options to find potential providers. While all agencies are having difficulty recruiting providers, rural agencies have a particularly hard time because these providers need to routinely go many miles to serve one person. It is helpful that consumers can use their neighbors rather than having to get someone from the next town.

- It is often difficult to get providers to travel the long distances required. While family members and friends may have difficulty doing this as well, some are willing to travel to help a family member and "even if it only helps a few people, it is worth doing it."
- The most important thing to rural consumers is allowing flexibility to decide on workers, negotiating rates of pay, and taking care of financial services for them. Since many consumers don't want to take on tax reporting, a voucher program has been particularly effective at reaching rural consumers.

CD addresses needs of non-traditional and hard-to-reach consumers

- Traditional personal care services don't do the job for everyone. For example, consumers with severe weight problems often have difficulty keeping aides. Family members tend to be more committed and willing and find ways to deal with that issue.
- Consumer direction is effective especially with the baby boom generation [of family caregivers].

CD allows consumers to get more service for the same state money

- Consumers receive more services to fill gaps because they can negotiate rates of pay with workers.

CD addresses constraints caused by licensing requirements

- Consumers would have performed these tasks for themselves if they were physically able; licensing requirements limited who could perform these tasks, so that led to turning to unlicensed family caregivers as consumer-directed providers.

Finally, one state noted that consumer direction is good for any situation where agency service is not appropriate. In sum, consumer direction is helping to build up the workforce and allowing family caregivers to provide services that better meet individuals' needs and preferences.

▪ **Consumer demand and advocacy**

Consumer demand and advocacy are almost as important as gaps in services and shortage of providers in terms of affecting states' decisions to pursue consumer direction. While most said that consumer demand was influential, they generally noted that younger people with disabilities were more vocal than older consumers. Some said that they really didn't hear very much from seniors about consumer direction and that "while they seem to like the idea [of consumer direction], they aren't pushing hard for it." Even in one state where advocacy groups are "very, very strong," most of the support came from the disability community. Another state put it this way, "There is not necessarily a tremendous groundswell, but more consumers are expressing interest in being more involved [in their care]." One respondent pointed out that limited support might be due to the very frail nature of the consumer population.

State agencies heard repeatedly of cases like one where a niece was living with an older person who asked, "Why can't she provide my care?" Consumers want to hire their own family members and direct their own care.

The clear consensus across the states is that advocacy has been more vocal from younger disabled persons and organizations, and somewhat from the formal aging network, but not very strong from elderly consumers and their families. When asked, elders said consumer direction seemed like a good idea, but that was not the “big push.” While seniors did express support at public hearings, they haven’t broken down the door to say consumer direction is a real need. Most states did not see organized grass roots advocacy made up of consumers, which some thought would have been more effective in promoting consumer direction. On the other hand, one state said that it was not a “hard sell” and advocacy wasn’t necessary. Sometimes the lack of advocacy was seen as beneficial because even if there had been intense advocacy, “if resources and infrastructure aren’t available, they can’t make it happen.” However, others noted that the baby boom generation is being more assertive as family caregivers and they are likely to be stronger advocates for consumer direction in the future.

To try to rectify this limited advocacy, one state is using grant funds to educate consumers and family caregivers about how to become better advocates. However, as one respondent pointed out, even with training, consumers may be afraid to advocate for themselves for fear that they might lose services. This fear does not seem to be an issue for younger disabled persons who have a longer history of advocating for their care

The overlap and interaction between younger disabled people and organizations and programs for older people has contributed to a cross-fertilization of ideas and approaches in several states. For example one state unit on aging employs several people who are disabled: “that influences policy development and helped them recognize that there are as many older people who want to take advantage of consumer direction as younger people.”

▪ **Success in other states**

Thirty-one percent of state aging agencies reported that successes in other states influenced them to develop consumer-directed programs. In the interviews they described Cash and Counseling programs, information from attending conferences where other states described their experiences, reading about other states’ experiences, and the role of NASUA in introducing them to the concept. Program managers’ exposure to the experiences in other states was noted as particularly effective in getting them to understand, accept, and promote the approach.

However, others seemed relatively unmoved by other states' experiences. According to one, it was really "personal commitment from agency leadership that this was obviously something good to do" that was the driving force behind consumer direction in their state.

▪ **The right thing to do**

In an open-ended question, when probing for additional forces that influenced states to pursue consumer direction, a comment that came up repeatedly was that "it was the right thing to do." Two states reported that this was the most important reason they developed consumer direction. According to one, there was a "strong sense within the aging agency and Medicaid agency that it's the right thing to do." The following statements capture some of these perspectives on why states moved toward consumer direction:

- "Simply a good idea to do this; it gives consumers more control and helps them get meaningful services rather than service that fits into a mold."
- "We had seen results of things to be happy about, such as clinical outcomes. The models have been shown to have worked. In the current political environment, giving responsibility and saving money are good."

▪ **Experience with consumer direction for younger disabled consumers**

Interviews explored whether aging disabled persons were a force influencing the development of consumer direction for older people. However, younger people with disabilities who had received consumer-directed services do not move into aging services in significant enough numbers to be an important influence on development of consumer direction for the elderly. This was true even in a state where a younger disabled person on a disability waiver is required to switch to an elderly waiver at the age of 65. The perception among these states is that there are simply too few people in this situation to make a difference at this time. However, some respondents noted that this could be more of an issue in the future. In several states, consumers tend to stay on the developmental disabilities waiver as they age because of higher funding levels.

Other state units on aging reported that they don't collect information to know whether many consumers move from state developmental disability programs to aging programs. This lack of information was generally due to separate agencies serving each population.

Barriers to Implementing Consumer Direction for the Elderly

Respondents who have a HCBS program were asked to rate how easy or difficult it is to implement a consumer-directed HCBS aging program using a scale of 1 to 5 where 1 is very difficult and 5 is very easy. While some respondents find it very difficult to implement a consumer-directed HCBS aging services program, others feel it is neither difficult nor easy. Specifically, one-third of respondents (33%) rate this a 1 (very difficult), while 40 percent rate this neutral (score = 3). None of the respondents indicate that it is “very easy.” The mean rating is 2.2.

State aging directors were presented a list of 10 potential barriers to implementing consumer-directed HCBS programs for older persons in both the CD Survey and the Interview. Respondents express the most concern about resistance from provider agencies and the federal Medicaid Waiver process (44% each rating these factors a 4 or 5 on a 5-point scale). Over four in ten respondents express concern about state Medicaid laws, rules, and regulations (41%), federal Medicaid laws, rules, and regulations (41%), and quality concerns (41%) as barriers (rating each of these factors a 4 or 5 on a 5-point scale).

Nearly as many are concerned about other state laws, rules, and regulations being a barrier to implementing such programs (36% rate this concern a 4 or 5), with states without CD programs significantly less concerned than other states, and states operating programs significantly more concerned than all others. Three in ten states report being concerned about lack of funds (31% rate 4 or 5) and inadequate consumer advocacy for consumer directed HCBS (31% rate 4 or 5). Comparatively, state aging directors report less concern about resistance within their own agency or department (15% rate a 4 or 5), and resistance from appointed and elected officials (23%). The following section amplifies on the scores provided in Table 8 based on comments expressed in the telephone interviews.

Table 7 Barriers in implementing consumer-directed HCBS programs (*Opinion**Survey n=39 state agencies)**“To what degree, if at all, are you concerned about the following as barriers to implementing consumer-directed HCBS aging services programs?”*

	Not at all concerned				Very concerned	
	1	2	3	4	5	Overall Mean
Federal Medicaid laws, rules and regulations (<i>n=37</i>)	8% (3)	26% (10)	21% (8)	28% (11)	13% (5)	3.2
State Medicaid laws, rules, and regulations (<i>n=37</i>)	8% (3)	21% (8)	26% (10)	23% (9)	18% (7)	3.3
Federal Medicaid Waiver process (<i>n=37</i>)	5% (2)	31% (12)	15% (6)	31% (12)	13% (3)	3.2
Other state laws, rules or regulations (<i>n=36</i>)	8% (3)	26% (10)	23% (9)	21% (8)	15% (6)	3.1 ¹⁵
Resistance from appointed and elected officials (<i>n=37</i>)	3% (5)	31% (12)	26% (10)	8% (3)	15% (6)	2.8
Resistance within your agency/department (<i>n=36</i>)	36 (15)	31% (12)	10% (4)	10% (4)	5% (2)	2.1
Inadequate consumer advocacy for consumer-directed HCBS (<i>n=36</i>)	23% (9)	26% (10)	13% (5)	18% (7)	13% (5)	2.7
Lack of funds (<i>n=36</i>)	18% (7)	28% (11)	15% (6)	13% (5)	18% (7)	3.3
Quality concerns (<i>n=36</i>)	10% (4)	21% (8)	21% (8)	28% (11)	13% (5)	3.1
Resistance from provider agencies (<i>n=37</i>)	0% (4)	13% (5)	28% (11)	23% (9)	21% (8)	3.3

▪ Federal barriers

Forty-one percent of respondents are either concerned or very concerned about federal Medicaid laws, rules, and regulations as barriers to implementing consumer-directed aging services. While federal initiatives are clearly helpful in promoting consumer direction, some federal rules and regulations are seen as barriers to its implementation and expansion.

¹⁵ There is a statistically significant difference between the mean scores for states not offering CD HCBS for older people (2.5) and for states that are operating them (3.3) (significance <0.05).

When asked to name the most significant barrier to developing consumer direction, 5 out of 17 comments related to federal Medicaid laws, rules, regulations and limitations.

It was not always clear to respondents whether the regulatory barriers were coming from the federal government or their states. Many of the barriers were specific to Medicaid waivers.

Medicaid waivers and consumer direction

Forty-four percent of states reported being concerned or very concerned about barriers caused by the federal Medicaid waiver process. Experiences of applying for consumer direction under a Medicaid waiver ranged from taking one year to one that took six years to obtain approval.

The six-year waiver approval process reported by one state resulted in part from inconsistent advice about whether to use an 1115 waiver or a 1915 c waiver.

Some states described positive experiences with the Medicaid waiver process. For example:

- The Independence Plus “template” was helpful.
- The [waiver application] process was “pretty efficient.”
- CMS is continuously driving consumer-directed services and are developing all types of alternatives through the waiver program, including several managed care options.
- Federal Medicaid rules and regulations have “lightened up” to make consumer direction a reality.

Other states had more mixed reactions. They said, for example:

- “It [the Medicaid waiver application process] is a pain, but we can deal with it.”
- CMS is making an effort with the new Medicaid waiver application. It is a quicker process, but it still seems a lot to go through to keep someone in their home.
- The “Feds” are committed, but bureaucratic.

Most of the comments were critical of the Medicaid waiver process. In addition to several focused on the general Medicaid waiver process, a few were specific to consumer direction:

- The approach to waiver reviews by CMS is the most serious barrier to consumer direction.
- When the waiver was up for renewal there were still “lots of hoops to go through,” even though the program had been proven to be cost effective and resulted in high levels of consumer satisfaction.

- Consumer-directed care is already part of the system, but every time you want to make an adjustment, it's difficult to change the waiver and that limits [states'] enthusiasm to do it.
- We had difficulty convincing both federal and state administrators about the need for the consumer to be employer of record. We wanted the provider to be paid by the consumer with the fiscal intermediary doing bookkeeping so that the agency wouldn't be the employer of a lot of independent contractors. There seemed to be confusion about whether the fiscal intermediary should be a service or an administrative function, particularly when using federal funds.
- Even after going through the waiver application process to participate in Cash and Counseling, the waiver process is still a barrier to expanding programs to include the purchase of goods and other services that Medicaid might not typically cover.

In addition to issues related to the application process, some states described other frustrations caused by Medicaid waivers. Several states would like to expand their coverage to allow greater flexibility about what goods and services can be purchased

Several respondents argued that consumer direction should be part of regular Medicaid services and all populations should be incorporated into one big waiver. "The whole system is backwards. You should need a waiver to put someone into a nursing home, not to keep them out."

under consumer-directed waivers. One state had a particular issue about a requirement for a "formal backup system" to be in place for both informal and formal providers. Since this is not a requirement for any other waiver they did not understand why it was necessary with consumer direction. Other problems include CMS's requirements about the wording of contracts that were unfamiliar and threatening to consumers, and the need for vendors to keep records for an audit trail. This is an issue when a consumer wants to purchase a small appliance such as a blender, but retailers are reluctant to develop the special record keeping system required of vendors in

the consumer direction program for a small number of transactions. Other barriers prevent consumer direction from being used when consumers are already enrolled in another program, by requiring that state plan services be exhausted first, and by limiting self-direction to only selected providers.

▪ **State laws, rules, and regulations**

Forty-one percent of respondents are concerned or very concerned about state laws, rules and regulations that act as barriers to pursuing consumer direction. Of specific concern are nurse delegation laws and health regulations that affect delivery of

medications and medical treatments by non-licensed personnel. In one state changing the nurse delegation law allowed consumer direction to be implemented. However, a new law in another state requires that everyone providing service be an employee of a home health agency or other qualified agency, severely limiting the scope of consumer direction there. In general it appears to be a challenge to make sure that rules and regulations affecting managed care, health services, waiver services, and other long term services are all consistent.

Some of the specific issues states have had to address include:

- Overcoming legislation that created a barrier to consumer direction by requiring a worker registry. Potential providers who don't want to be listed in a database are discouraged from participating. To overcome this problem the state unit on aging is trying to encourage caregivers to participate by making a notation on the list that they don't want to be contacted by other consumers.
- A requirement that people participating in the state run attendant care program be subject to the nurse practice act (which has now been addressed).

The most specific state-level barrier to consumer direction deals with workers' compensation requirements. Issues include:

- Problems with developing a system for paying into workers' compensation and dealing with labor laws preventing consumers from being their own employers with public money.
- The fiscal intermediary was not allowed to pay directly into workers' compensation in one program in which consumers employ their providers.
- In another program, there was resistance to using funds to pay for workers' compensation since it was perceived as reducing the amount of money available for direct services. Their law was interpreted as exempting providers who worked less than 26 hours per week from having to pay into workers' compensation. While there are still different interpretations regarding state agency liability, the agency has not had to pay any of the workers' compensation claims that have been awarded.

Access to consumer direction is also seen to be limited as a result of various state rules and regulations. In one state the Medicaid waiver only includes consumer direction when a family member is enrolled as a Medicaid provider, which is a very difficult process. Consumer direction is not offered to most consumers because demonstration programs offered in several states only have a limited number of spaces.

- **Lack of funds: “Budget areas are always a concern”**

Many states are concerned or very concerned about *inadequate funds* for consumer-directed services causing a barrier to implementation (26% of respondents).

When asked to name the most serious barrier to establishing consumer direction, 4 out of 17 responses focused on lack of adequate funding.

Many states felt they had inadequate resources to build the necessary infrastructure, implement a program, arrange for a fiscal intermediary, and train staff. Funding shortages are felt across the states and in local jurisdictions. The addition of new services and the increased number of program participants have added to state Medicaid matching costs. State aging agencies would have liked for consumer direction to be a service under the Medicaid state plan instead of the waiver so it would be clear that elders being served are also eligible for all other Medicaid services and that consumer direction is just a different way of providing those services. However, it was also recognized that the shortage of funds is not true only for consumer direction. “There are long waiting lists for all state-run programs.”

Several states did not receive any new moneys for consumer direction waivers; rather, funds were carved out of other waivers. Essentially all states approached consumer direction with the expectation that it would be cost neutral. (States with Medicaid waivers are required to develop cost-neutral programs.) Based on the experience of Cash and Counseling programs one state thought that consumer direction involved important needed changes that wouldn’t cost “a bundle of money.” They felt that after setting up the infrastructure, they would be able to offer consumer direction without a lot of new resources.

However, having said that, several also indicated they hoped that consumer direction might save money by keeping people out of nursing homes. According to one respondent, if it saved money, “it would be icing on the cake.”

- **Inadequate consumer advocacy**

Almost one-third of respondents (31%) indicated concern that inadequate consumer advocacy was a barrier to implementing consumer-directed HCBS. When asked about this in the interviews they said essentially the same things that have been described previously in the section about consumer demand as a force that influenced states to

develop consumer direction for older people. Essentially consumer demand is viewed as the same thing as advocacy. While in the survey they indicated that consumer demand was a significant factor influencing development of consumer direction for older people, the flip side is that they didn't see the lack of advocacy as a barrier to its development. In both cases they talked about relatively weak organized advocacy by senior groups and they didn't feel that strong advocacy had been necessary for CD development.

▪ **Resistance from appointed and elected officials**

Almost one in four (23%) respondents is concerned or very concerned about barriers to consumer direction caused by resistance from appointed and elected officials. As described in the interviews, the experience of these twenty states spans receiving strong support from their governors to staying "below the radar screen." Several governors have given direct public support for consumer direction. A consumer direction bill in one state passed unanimously in 2002, because it was viewed as a "train bill" for legislators who all wanted to jump on and add their language since it was so clear it would pass with total support on "both sides" of the political aisle. Another state reported that although legislation supporting consumer direction was recently defeated, it wasn't "dead" and they were hopeful for success in the future.

However, in most states there is concern that legislators oppose consumer direction for a range of reasons. As described by state unit on aging managers, legislators argue that consumer direction "is just a way for the state agency to get more people on the program" and that "providing care should be a family's obligation. The state shouldn't replace informal care with paid care, sometimes provided by the same person who had been providing it as informal care." Other views on legislators' positions on consumer direction include:

- Appointed and elected officials have a "paternalistic" view of caring for the aged and disabled.
- Elected officials seem to be interested in moving forward with consumer direction but "maybe for the wrong reason," that is, they expect to see cost effectiveness.
- Officials are concerned that consumer-directed care would cost more.
- Some fear that it might be "fraught with fraud and abuse."

State units on aging also reported some success in dealing with resistance among policymakers and other influential leaders. One state negotiated with policymakers to convince them of the value of paying for services provided by spouses and parents. They were able to provide evidence of the "wonderful things" families can do if they

have the resources. Resistance on the part of one AAA director who was very influential challenged another state. An “amazing and dramatic change from resistance to acceptance” resulted from educating that one opinion leader. Meetings at which information about consumer direction is shared across AAAs were noted as being very successful at reducing resistance.

According to another respondent in a state with a well-established program, the political landscape has changed since consumer direction was first introduced and it is now more supportive. Earlier negative attitudes held by many in government have changed as a result of the momentum from grassroots advocacy by the developmental disabilities community that became a national groundswell. While there is not total acceptance yet, “the door is opening.” Further, the earlier assumption that quality of care would go down has been disputed by the Mathematica findings from the Cash and Counseling programs. The whole notion of fraud seems to not have materialized. These findings have changed peoples’ attitudes. Another agreed with this view noting, “The fact that it has worked has created a shift in thinking among policymakers.”

▪ **Resistance within aging agencies and human services departments**

Resistance from within the state unit on aging was least likely of all of the potential barriers to hinder development of consumer direction. Still 15 percent of respondents were concerned or very concerned about this factor. As elaborated in interviews, some resistance can be attributed to staff members being stretched to the limit and their seeing any new programming as difficult. Other states have found that not all staff embraces consumer direction; they want to solve other problems first. Respondents mentioned, for example, resistance by AAAs and the conservative nature of providers and case managers. According to one respondent, “Case managers are concerned about safety and possible negative outcomes. As a result they err on the side of caution.”

However, staff resistance seemed to have been successfully overcome in some cases. For example one state reported that at the beginning the state unit on aging had to go through a management exercise to get people on board, but “we went through it and now [consumer direction] is out there.” Another described “quite a bit of apprehension” because consumer direction was such an “unknown.”

Those who did not see staff resistance as a problem said most staff would really want to make it happen; the question is how to do it with limited resources.

In addition to resistance from within their own agency or department, some states reported problems of gaining support for consumer direction from other state agencies. They were frustrated that there wasn't more support for amending other waivers to allow consumer direction. Other resistance is just because some divisions, like Medicaid, have other big issues to deal with.

- **Quality concerns**

While some states were not at all concerned about quality of care under consumer direction (10%), others reported being very concerned (13%). Some of those who were not very concerned said things such as, "this is a red herring but not a real obstacle," and "there is no evidence of problems with quality; consumers [in consumer-directed programs] are usually happier."

On the other hand, several states reported that quality was either a potential or a current concern. For example, "if this were to become a full-fledged program, then the state would want to set into place some quality controls so individuals aren't facing any abuse." Another state indicated that case managers would like to do more monitoring, but there is not enough money to hire more staff to monitor the program. In fact in that state, some AAAs don't use consumer direction because of suspicion of abuse. Another

When asked about concerns about quality of care delivered under consumer direction, most respondents focused on being concerned about potential fraud and abuse.

very concerned state said the problem is that you are "working in consumer direction with people who don't have formal training." Another had "heard horror stories about how personal assistants can behave."

State managers who were not concerned about quality of care (31% not concerned or not at all concerned) offered general comments about how control over the time and location of care means better quality for consumers, pointing to evidence of letters of

appreciation. "It is seen as very important to recipients that a third party is not making the decisions about what constitutes quality."

- **Resistance from long term care providers**

Forty-four percent of respondents were concerned or very concerned about resistance from long term care providers. This was also one of the stronger messages heard throughout the interviews, reported most frequently as the single primary barrier to

implementing consumer direction. At the end of the continuum where states reported significant concern about provider resistance one said “the network of formalized provider agencies are very much opposed to consumer direction because it allows individual workers or independent providers.” As described by another, “they feel threatened by it and tend to say anecdotal negative things about it.” Another respondent referred to “a certain amount of protectionism.” In a similar vein, another said, “providers lump all older people together because of ageism.”

In one state the provider agencies are trying to get legislation passed that would specify qualifications for certification of independent providers that would be difficult for family members to achieve. Agency workers in another state can require consumers to sign restrictive contracts. Some of those consumers would like to use consumer direction but because of their existing provider relationship, they aren’t able to switch.

In one state where providers are well organized politically, they expect strong negative reaction when they roll out consumer direction. To prepare for this resistance the state unit on aging has identified the need for the agency head to talk with legislators about consumer direction, using statistics from other states to show how well it works and lay the groundwork to gain support.

Cultural changes need to take place for provider agencies and professionals, including licensed personnel and case managers, to feel more comfortable and embrace consumer direction. Several states reported there is some case manager reluctance to encourage consumer direction, especially when the consumer is uncertain.

While there were several respondents who felt provider resistance was a serious barrier, that experience was far from unanimous. In one state a provider agency is taking the lead in implementing one of their consumer-directed services and they are very “gung ho.” Representing minimal provider resistance, one state reported that they are unaware of provider resistance primarily due to the fact that they have not been involved in a dialogue with provider agencies on the topic of consumer direction. This state has recently received a grant that will allow them to get feedback from providers. A few states referred to general grumbling from providers, but also feared that as the program grows, so could the resistance. However, since many home health agencies are having difficulty finding workers, they are less likely to complain about allowing consumers to find their own caregivers.

A few states indicated that while agencies were nervous at the beginning, as things evolved, providers had to adjust. Providers in one state never anticipated that consumer direction would grow as much as it did. They have been surprised, but they didn't actually resist. Two states reported that they had originally seen provider resistance but it has diminished over time.

As the program evolved it was more oriented toward doing consumer-directed care because "it is the right thing to do," because they [providers] now know that it works. They have seen the impact on people's lives. Consumers have a choice and providers know that if they want to be part of the services system they have to buy into it, including consumer direction.

Problems in Consumer Direction Programs for the Elderly

When presented with eight problems that might be encountered in consumer directed HCBS aging services programs, respondents generally indicated that these problems are not very significant. States currently operating CD HCBS aging services are significantly less likely to view inadequate funding as a significant problem than other states. Two funding-related problems emerge as most serious. Specifically, four in ten rate inadequate funding (44%) and poor compensation and benefits for caregivers (44%) as problems (4 to 5 on a 5-point scale). Nearly as many respondents indicate a problem with a reduction in funds (38%).

Approximately one-quarter (26%) reported that inadequate quality of services was a problem in their state. States in the process of developing CD HCBS for older people scored inadequate quality significantly lower as a problem than other states. Few respondents indicate fraud or misuse of funds (15%) or abuse or exploitation of consumers (15%) as significant problems (4 to 5 on a 5-point scale).

Table 8 Problems in consumer-directed HCBS programs (*Opinion Survey: n=32 state agencies that operate Consumer Direction HCBS for the elderly*)

“To what degree, if at all, have the following been problems in your consumer-directed HCBS aging services programs?”

	Not a problem at all				Very significant problem	
	1	2	3	4	5	Overall Mean
Reduction in funds (n=29)	9% (3)	16% (5)	28% (9)	25% (8)	13% (4)	3.2
Inadequate funding (other than a reduction) (n=30)	9% (3)	16% (5)	25% (8)	25% (8)	19% (6)	3.3 ¹⁶
Fraud or misuse of funds (n=31)	53% (17)	19% (6)	9% (3)	6% (2)	9% (3)	2.0
Abuse or exploitation of consumer (n=31)	47% (15)	19% (6)	16% (5)	6% (2)	9% (3)	2.1
Poor compensation and benefits for caregivers (n=30)	16% (5)	22% (7)	13% (4)	31% (10)	13% (4)	3.0
Loss of business for traditional service agencies (n=30)	34% (11)	34% (11)	3% (1)	16% (5)	6% (2)	2.2
Inadequate quality of services (n=30)	38% (12)	13% (4)	19% (6)	13% (4)	13% (4)	2.5 ¹⁷
Other types of problems (n=29)	28% (9)	16% (5)	16% (5)	-- (0)	13% (4)	2.3

The list of potential problems was not explored directly in the interview questions. However, several problem areas emerged from those conversations. The two main categories of problems are financial administration and lack of consumer information.

▪ **Problems with financial administration of consumer direction**

Serious difficulty handling fiscal processes was a common theme in CD implementation. A wide range of issues dealing with paying for care plagued many states. While these

¹⁶ The mean score for states currently operating programs (3.2) is significantly different from the score for states with programs in development (4.0) ($t=3.083$; significance = 0.0005).

¹⁷ The mean score for states with CD programs in development (2.0) is significantly different than for states with operating programs (2.5) ($t=-0.902$; significance = 0.007).

problems were not insurmountable, many states were learning by trial and error or were seeking technical assistance to help in these areas.

States reported problems with both voucher and fiscal intermediary approaches to paying for services. One state reported that most of their family caregivers would prefer not to use vouchers. The forms need to be completed in triplicate and they have trouble completing them correctly and figuring out who needs which copy. After trying to work with vouchers for a year, the state changed to a system whereby consumers pay up front and are then reimbursed. This system is much cleaner from the tax point of view and the state has received fewer consumer complaints.

Contracting out the payroll process has also caused some “bumps in the road.” It was a challenge to get to be efficient, accurate, and timely. Very occasionally a provider was not providing the hours he/she was being paid for. However that state now uses case management teams for oversight and has not had any more problems in this area.

One state reported difficulty with claims processing because the consumer-directed program, which is not administered by the Medicaid agency, has a different software system that has problems exchanging data with the Medicaid system. In addition the two systems have difficulty processing claims because the Medicaid system only accepts a flat rate per provider and under consumer direction consumers are allowed to negotiate pay rates with workers. After two years they are still in the process of making it work well.

Another state overcame the challenge of their fiscal intermediary agent going out of business. They had to scramble to close out their business and find another agency. The problem was primarily due to the original agency being too small to handle this program. In another state, enrollment in the Medicaid waiver consumer direction program was delayed for a year due to difficulties establishing a fiscal intermediary system. During their readiness review, CMS required the fiscal intermediary be fully staffed before allowing enrollment. The fiscal intermediary had difficulty with training, staff turnover, changing accounting software, and the processing of monthly statements to track budgets and expenditures.

Some states faced confusion about whether the consumer can be the employer of record. There was concern that in addition to the tax liability issues when a cash payment goes to a family caregiver it could impact their eligibility for food stamps and Medicaid. A Cash and Counseling state noted that technical assistance was a major help

with fiscal intermediary and other operational issues. Technical assistance focused on critical financial issues such as how to get the cash to people and who does the tax withholding.

A state that was using AAAs to handle the financial processes in its demonstration was concerned that if they expanded consumer direction to the entire state, they would need new systems. Another respondent felt that the state is in its “infancy” in terms of payments to family caregivers.

There are difficulties in the financial process from the consumer’s perspective as well. For example, state aging staff reported:

- Families are not willing to accept tax responsibilities so the program is concerned about keeping the amount families are paid under the tax threshold
- Consumers need help with processes dealing with labor and employment laws
- People don’t understand how to deal with payment and taxes. Whether to report on a Form 1099 or as income on a W2 form is unclear.
- There continues to be confusion about whether consumer payments should be treated as taxable family income.
- The responsibility pieces are difficult for families and federal and state laws are not necessarily easy or “in sync” with each other to help consumers overcome these barriers.

“The challenge is how to take money that has been allocated to categorical services and redistribute it and put it in under control of consumers. How can that money be converted to spending authority for those individuals?”

However, in one rural area where a state agency expected difficulty implementing consumer direction they found that because many consumers had been independent businessmen, these employment issues were less of a barrier. According to another,

administrative details, dealing with Medicaid systems, and creating new entities to handle some of the roles like counseling and fiscal intermediary services are challenges that can be overcome.

In addition to needing clear answers and support to a range of fiscal questions, states also feel a need for a case management infrastructure to support consumer direction. One state that had never invested in a case management system in its Older Americans Act Programs needed additional personnel as well as funds to support case managers.

- **Lack of consumer information**

Lack of communication and consumer awareness about consumer direction were described repeatedly. Consumers simply don't know about what's already there. Many older people don't attend programs at congregate sites where they could hear about services or read about these programs, especially in the rural areas. This barrier was reiterated by numerous states. There is a lack of knowledge among families, providers, state, local, and fiscal offices. Utilization of CD is especially limited because consumer direction is such a new concept. People don't know what it is and so they don't think about it first.

Favorable Factors and Outcomes of Consumer Direction for the Elderly

Respondents were presented with five factors that might be favorable outcomes of consumer directed HCBS aging services programs (See Table 10). Eight in ten respondents indicate that two outcomes have been particularly favorable: providing choices for consumers and empowering consumers (81% rating each of these outcomes a 4 or 5 on a 5-point favorability scale). In addition, six in ten indicate improving access to service (59%) has been highly favorable in their program implementation, while over half say addressing workforce shortages (53%) has been highly favorable (4 to 5 on a 5-point scale). Comparatively, few respondents indicate saving money (19%) has been favorable in their program implementation (4 to 5 on a 5-point scale). This list of favorable factors was not pursued directly in the interviews. However many of these items were discussed as factors that influenced development of CD. In addition, respondents identified several other favorable factors and outcomes of consumer direction including encouraging federal and state policies and the potential for cost savings.

Table 9 Favorable factors in implementing CD HCBS programs (Opinion Survey: n=32 state agencies that operate CD HCBS for the elderly)

“To what degree, if at all, have the following been favorable in your implementation of consumer-directed HCBS aging services programs?”

	Not at all favorable				Very favorable	
	1	2	3	4	5	Mean
Saves money (n=29)	6% (2)	13% (4)	53% (17)	9% (3)	9% (3)	3.0
Provides choices for consumers (n=31)	6% (2)	6% (2)	3% (1)	22% (7)	59% (19)	4.3
Empowers consumers (n=31)	9% (3)	3% (1)	3% (1)	31% (10)	50% (16)	4.1
Improves access to service (n=30)	13% (4)	6% (2)	16% (5)	22% (7)	38% (12)	3.7
Addresses workforce shortage (n=29)	9% (3)	9% (3)	19% (6)	31% (10)	22% (7)	3.5

▪ **Federal and state policies**

States are clearly getting the message that consumer direction is a priority at the federal level. Consumer direction is seen as the new model of best practice in long term care. Every time a new grant is announced (such as Systems Change Grants) the aging agency and Medicaid agency in one state decide jointly whether to apply. One state indicated that it has been helpful to be able to say to senior centers and providers that these programs are coming from the top. New programs have also allowed states to “start fresh” with AAAs and move to a new mindset.

“What used to be difficult to figure out and to pay for is now easier to accomplish.”

“The federal agencies really wanted that [consumer direction] program to be flexible and gave states room for policy decisions.”

While it is clear that the federal government supports consumer direction, one state pointed out something of a mixed message in federal policy. This respondent expressed the opinion that while CMS

is encouraging choice and control through consumer direction, it is also reducing choice and control by expanding managed care.

The policy priority given to consumer direction has been conveyed, in part, by the availability of funding for consumer direction. Funding was seen as a significant factor influencing development of consumer direction in most of the states. These are funding sources that were reported to influence the decision to pursue consumer direction, not necessarily those from which these states are currently receiving funding:

- RWJ Cash and Counseling (4)¹⁸
- AoA Alzheimer’s demonstration grants (2)
- Systems Changes Grants (2)
- Family Caregiver Support Program – Innovation Grant
- Medicaid Waivers (demonstration and non-demonstration) (1)
- NASUA/NCOA project “Promoting Consumer Direction in Aging Services” (1)

▪ **Cost-savings expectations and experience**

New funds were critical in helping states develop the necessary infrastructure to run consumer-directed programs, particularly for establishing complicated fiscal intermediary processes and supporting training activities.

Another state unit on aging noted that “it may look like there will be a big saving from having paid \$20/hour for home health personal care services to paying \$8–\$8.50

Cost implications were offered by four states as the most important force influencing them to pursue consumer direction.

¹⁸ Two states were original Cash and Counseling states. Nine of the respondents reported that their states were applying for Cash and Counseling grants. Eight states were not planning to apply because, for example the Medicaid agency wasn’t interested in taking the lead, the agency needed to take more “intermediate steps” first, and since success has been demonstrated by the Cash and Counseling projects one state wants to pursue a permanent waiver instead.

plus fringe benefits (total \$10–11/hour) under consumer direction. That represents a lot of money.” However, the state didn’t expect it to be a big saving because they didn’t think that many people would take advantage of consumer direction. “Really the results were that they avoided a lot of costs, perhaps millions of dollars. Any time you can find a service frail elderly people like and it saves money, that’s a success.”

While some people may view consumer direction as a way to save money, one state urged caution. In practice, those who want consumer direction are often those who are most dissatisfied with their current care and those with the most complex care plans. They get more services for the same money but it does not result in cost savings, especially if you look at all costs, not just Medicaid costs. Some states are finding that frail elders with greater needs are selecting consumer direction and therefore costs are high. The maximum spending allowed on a consumer-directed waiver isn’t always adequate to purchase the care or goods that are needed. According to one respondent, “consumer direction becomes not useful if there is not enough money.”

Others are finding that while the program is cost-neutral to the state, individual consumers can get more hours of service for the same dollar amount of support.

“There are always more people who need the service than can be provided for, but that’s true for all programs.”

Some state programs are limited to spending the same amount as during the prior year because of fears about how the money might be used. In general, *lack of funds is “always an issue”* whether it is state match or funds to initiate [a new service] with state money.” There is also concern that decision-makers will see consumer direction as a way to increase services without increasing budgets. Some think it will save money and they can simply cut budgets. There is concern that this idea is creeping into the thought process about consumer-directed care. One state argued that savings in nursing home dollars should come back to home and community based programs.

Another way that state budgetary pressures are affecting consumer direction is through the availability of *adequate personnel to administer the program*. State units on aging described shortages of state level staff and case managers. This shortage has resulted from staff layoffs in several states. Even with federal dollars to fund consumer direction, states are cutting staff and are concerned about impacts on program capacity. As described by one interview subject, “A shortage of state level staff doesn’t allow a lot of experimentation.”

States Are Addressing Quality Concerns and Monitoring Consumer Satisfaction

When asked to indicate what measures programs have in place to ensure consumers' needs are met, the most common technique, employed by about three-quarters (78%) of the programs, is consumer satisfaction assessments and/or surveys (See Table 11). Two-thirds employ internal case review processes (69%) and criminal background checks (69%) to ensure quality. In addition, a majority of programs in this study conduct program evaluations (62%) or require certification of professional providers (57%). Nearly half of the programs provide for emergency back-up (48%), while four in ten monitor services through traditional case or care management (43%) and external case review processes (41%). Currently, no programs report the use of an ombudsman for consumers receiving in-home care as a method of ensuring that needs are met.

Table 10 Methods to ensure needs are met (n=58 programs)

“Which of the following methods are used to help ensure consumers’ needs are being met?”

	Number of Programs	Percentage of Programs
Monitoring through traditional case or care management	25	43%
Program evaluation	36	62%
Consumer satisfaction assessments and/or surveys	45	78%
Required certification of professional providers	33	57%
Internal case review process	40	69%
External case review process	24	41%
Ombudsman for consumers receiving in-home care	0	0%
Criminal background checks	40	69%
Emergency back-up	28	48%

States have widely varying experience with measuring program outputs other than consumer satisfaction. In an interview one said, “We need to get better with it, we haven’t done well there. In the future we hope to be able to describe outputs more clearly.” One state unit on aging reported having a sophisticated process for screening, assessing and authorizing services, so they have a lot of information on consumers. Another state has a system that quantifies services based on care plans. States that

participated in the RWJ Cash and Counseling Program had a detailed evaluation completed by Mathematica Policy Research.

One of the more elaborate systems is in a state that is using grant funds to contract for an in-depth evaluation conducted by a School of Public Health. Telephone interviews of consumers and the management team will gather outcome data. They will be making changes to the program as the evaluation is conducted. This state is also making action plans and budgets a part of its management system. Originally the planning process involved two visits, one from the case manager to create a service plan and a second from the care advisor to facilitate a person-centered action plan. Now the process has been fine-tuned to eliminate any duplication of effort.

Based on this range of quality assurance and assessment methods, respondents reported a moderate level of confidence in their ability to measure program success. Forty-three percent are either confident or very confident while only 10 percent are not confident in their ability to measure program success (See Table 12).

Table 11 Measuring the success of HCBS programs (*n=30 state agencies: missing n = 2*)

“How confident are you that you can measure the success of a consumer-directed HCBS aging services program?”

	Not at all confident				Very confident	
	1	2	3	4	5	Mean
Percent Agencies	-- (0)	10% (3)	40% (12)	33% (10)	10% (3)	3.5

▪ **Older consumers are generally happy with consumer direction**

Over three-quarters of the state aging directors interviewed (78%) indicate that consumer-directed HCBS aging services programs are highly beneficial to consumers, rating the level of benefit a 4 or 5 on a 5-point scale. The mean is 4.1. Only 2 out of 32 state aging directors say they believe the programs are not at all beneficial (6%), as shown by Table 12.

Table 12 Consumer-directed HCBS programs beneficial to consumers? (*Opinion Survey: n=32 state agencies that operate CD HCBS for the elderly: missing = 2*)
“How beneficial is a consumer-directed HCBS aging services program to consumers?”

	Not at all beneficial					Very beneficial		
	1	2	3	4	5	Mean overall	Mean develop	Mean operating
Percent Agencies	6% (2)	3% (1)	6% (2)	34% (11)	44% (14)	4.1	4.3	4.1

As a result of satisfaction surveys and other monitoring systems, state units on aging have a pretty clear picture of consumer reaction to consumer direction. In general they report that recipients are quite positive about it. During the interviews, in responding to a request to rank the reaction of older adults to consumer direction on a scale from 1 (poor) to 7 (extremely positive), 12 states gave scores from 3 to 7. Since a neutral

Some family caregivers have trouble thinking about what would be helpful. One case manager asks, “If I was Santa Claus...what would you ask for?” They have found they ask for things that will make their life easier like a blender to be able to crush ice.

reaction would receive a score of 3.5, the mean of 5.5 shows a clearly positive response by seniors.

Some of those who didn’t provide a number rating said things like, “They love it.” However another was not so sure. “Most of the people who we give services to are family caregivers; they are the ones arranging services. While consumer direction is generally well received by them, it is not always the case. Family caregivers like being able to give input about how to spend the resources, but they don’t always want the extra responsibility. Another respondent

thought the reason for different reactions to consumer direction might be related to the consumer’s age. Younger elderly (60–65) seem to embrace consumer direction while the oldest old are “a little leery.”

Virtually all of those who get services have very high satisfaction. They say, “my life is totally different.” While the reaction by most consumers was seen as positive, one respondent didn’t give a higher score because some people have trouble hiring workers. Things that most of us take for granted make a major impact on quality of life in the older years.

"I have someone to take me to grocery and I can point to what I want instead of someone getting what I don't want. I can have someone cook for me."

"I can sleep late and not need to be bathed early in the morning."

Another interview subject admitted that he/she initially assumed that older people wouldn't want to manage their own care, that it was just for younger developmentally disabled people but had now found that "not to be true." Plenty of older people can benefit from consumer direction: "it depends on their condition, not on their age." Some respondents felt it doesn't work if consumers have dementia, then they need a surrogate. Some older people have enough capacity to know what they want for care but they can't manage the payroll. Care managing agencies also think

it's great because they can give consumers more options. Overall satisfaction has been high. Both consumers and case managers believe they have prevented utilization of more expensive services such as nursing homes and emergency room visits.

Effective Practices

Twenty-one states reported a total of 43 effective new practices, or approximately 2 practices for each state that reported any (See Table 14). While 18 states reported no effective practices, 10 reported one, 5 reported 2, and 4 reported 3. Two states identified five or more. Thirty-seven percent of respondents reported the development of practices that provide effective educational materials to consumers, while 27 percent developed practices that improve the quality of long term care services. In addition, 23 percent reported effective practices for combining with another program (to use existing capabilities, gain efficiency, minimize costs, etc.). Other new practices involve reaching out to rural consumers (20%), dealing with regulatory/policy barriers (20%), and reaching other hard-to-reach consumers (13%). Very few agencies indicate they tried new practices that did not work out.

Table 13 Effective new practices (n=30 state agencies that operate CD HCBS for the elderly)

“If you have developed any new practices that are effective in reaching the following goals, please check the box in Column A. If you tried any new practices that did not work out as hoped to reach the following goals, please check the box in Column B?”¹⁹

	Column A	Column B
	Effective practices	Practices that didn't work out
Improving the quality of long term care services	27% (8 agencies)	0% (0)
Reaching rural consumers	20% (6)	0% (0)
Reaching other hard-to-reach consumers	13% (4)	3% (1)
Providing effective educational materials to consumers	37% (11)	0% (0)
Minimizing program administration and overhead	3% (1)	0% (0)
Combining with another program (to use existing capabilities, gain efficiency, minimize costs, etc.)	23% (7)	3% (1)
Removing or dealing with regulatory/policy barriers	20% (6)	0% (0)

▪ Practices to improve quality of long term care services

During interviews several respondents expanded on practices that they see as effective in providing quality of services. Several focused on improving quality of services provided to various ethnic groups. One Alzheimer’s grant focuses on Hispanic family caregivers and people residing in outlying areas of one county. What they heard from those who used consumer direction was that they felt comfortable with the person they knew, their belief systems were valued because they had a person of the same ethnicity/race/culture, so they felt they had an increased quality of care because the person knows them, their needs and wants, and could deliver care in the manner they wanted. Similarly others argued that people who know you best could provide better service.

Several effective practices related to systems used to monitor the quality of care. Four states described using consumer satisfaction surveys to assess quality of care. A

¹⁹ Other practice options that respondents were given but did not choose include: improving cost-effectiveness, maintaining program capacity in spite of staff shortages, and qualifying and measuring program outputs.

university evaluation found that consumers have a higher level of satisfaction with workers and with the program after six months on consumer direction compared to when they started. Another consumer satisfaction survey of family caregivers provided feedback that they are very happy they are able to get critical needs met.

One state has a fairly sophisticated quality assurance system. As a result they are feeling more confident about quality. They had to convince the home care industry that consumer direction was being used with appropriate people. At focus groups, agency providers argued that frail, vulnerable older people are at risk of being victimized by scams and need adequate supervision. As a result, the pilot consumer direction program will have a stronger supervision component.

Screening for appropriate use of a consumer-directed model is critical. Consumer direction is not for everyone. For example, some SUAs said that when an elderly person has cognitive issues and no family support they should not be in consumer direction. However, figuring out how to draw that line and balance protection with autonomy is

One state is hoping its consumer direction plan will improve its current home care model using agencies because it will be a voluntary model that will compete with agencies and push them to improve to compete.

the real key to success of the model. Explaining to providers that participation in consumer direction is voluntary has also pushed back their fears. While it seems to be okay as long as a family member is watching, there is still some concern that someone needs to watch the family members sometimes.

One program includes an electronic monitoring system. That component was seen as improving quality because the case manager or provider agency

can see if a worker has checked in or checked out as well as electronically submitting a payment request. That system meets the CMS requirement for a formal emergency backup system. They also found that it helps improve quality of services. If you have someone dependent on a provider to get out of bed, the case manager or advisor can check on the person and be sure the care is being provided.

From the research done on the RWJ Cash and Counseling Program and stories that have been collected, research shows extremely high satisfaction with consumer-directed care. Participants in focus groups held in those states place huge value on the ability to direct their own care.

- **Reaching rural and other hard to reach consumers**

While several of the programs reported effective practices used to reach rural (20%) and other hard-to-reach consumers (13%), most of their comments have already been described in the section discussing factors that influenced states to implement consumer direction. In general they were not able to identify specific practices they used to reach these consumers; rather they argued that consumer direction in general is effective at meeting their particular needs.

- **Educational materials and information practices**

Having recognized the widespread lack of information about consumer direction, many states have developed effective practices to address this problem. For example, one Alzheimer's program offers one-on-one training and information for family caregivers as well as for recipients. The care consultant goes out to the family and provides training specific to their needs. If the family caregiver needs to be more familiar with lifting or transferring, the care consultant goes through that process. Care consultants also provide information on dementia and dementia services including support groups and activities that help reduce family caregivers' stress as well as helping fill out applications either during individual sessions or at support groups.

Another state unit on aging developed a guide and video to explain the consumer-directed program and their roles and responsibilities. They were designed at the 5th grade reading level to address a wide range of reading skills. The management team at the state level developed the materials in conjunction with a state university. They based the materials on experience from the Cash and Counseling program but decided to simplify the material and move from a predominantly paper format to video. They are still working on a web-based system to help consumers understand a variety of things including how to select a provider.

States are generally very proud of their educational efforts and satisfied that they are starting to make a dent in the general lack of knowledge about consumer direction in the community. Some are receiving help to address this lack of public awareness. Grants to states under the NASUA/NCOA project have supported public forums, hearings, and focus groups that enable consumer input into the development of consumer direction. Cash and Counseling states also received technical assistance that was valuable in

addressing the change in philosophy of care represented by consumer direction and taught providers how to counsel consumers about making informed decisions.

Other examples of effective consumer education activities include:

- Educational materials specific to consumer direction provided as part of the “Counseling” component of Cash and Counseling
- Booklets for agencies and senior centers on self-directed care and hiring in-home help
- Convening an annual conference on personal care for consumers, providers, and agencies that includes information on consumer direction

A few states also focus on teaching case management agencies about consumer direction so they can more effectively counsel older consumers. Their ultimate goal is to reduce fear among older adults about hiring, firing and monitoring care givers because “consumers were afraid that they were being left on their own.” The agency found it to be helpful to describe consumer direction in terms of the continuum of help seniors may need. While some may just need help with tax paperwork and workers compensation, others might need help with supervising providers.

▪ **Practices to reduce gaps and increase supply of providers**

Several states have described effective consumer direction practices that help them fill service gaps and add to the supply of providers. For example, a few described efforts to bring new workers into the overall pool of providers who may ultimately serve additional consumers. In an Alzheimer’s grant program, for example, one of the eight or nine workers recruited into consumer direction has moved on to a general pool of certified nursing assistants. While consumer direction can potentially alleviate some of the workforce shortage, its effect is very small at this point. Similarly, another respondent said that having the consumer find the provider and getting him/her hired and trained by an agency has expanded the number of people available to provide service. The ability to address staff shortages was the single most effective aspect of consumer direction according to one respondent.

▪ **Practices to address Medicaid waiver issues**

States described several administrative strategies to address Medicaid waiver issues. Some examples include:

- Combine consumer direction with existing waivers so as to not need to apply for a new one.

- Pick up some of the services for people on the waiver through the Medicaid personal care program.
- Create a fiscal intermediary model that can serve both the consumer direction waiver and the developmental disability waiver.

According to one interview respondent, the results of Cash and Counseling suggest that when starting consumer direction, it is best to engage new staff because it is hard to retrain old staff in this new philosophy. However, this state found that Medicaid is such a complicated program that staff need to have a long learning curve. Bringing in people without a Medicaid background bogged down the program. Now they have shifted strategy to retraining existing staff. This state has worked with CMS to create a “one-time provider agreement.” They try to enroll non-traditional Medicaid providers (such as Target or Wal-Mart) so that instead of going to a durable medical company the consumer can go to local store to buy a needed household items such as a blender or a washing machine. Working with CMS the state developed an agreement to enroll vendors, and policies and procedures whereby consumers can get a price quote, get their care coordinator to authorize the purchase and cut a check, and buy what they need. They started doing this in their first pilot under a Medicaid 1115 waiver. However, in the 1915c waiver, they are not allowed to give consumers cash so they needed these agreements with one-time-only providers to assure accurate recording for their budgets. These consumers have real-time Web access to their budget so they can check payments made by financial management services. In their other (Family Caregiver Support) program, there is very little money available for the consumer to access, generally capped at \$500/year. If they need a household item to support their caregiving, they have to purchase it and present a receipt in order to get reimbursed.

▪ **Practices to address state policy issues**

State units on aging are showing considerable initiative in working through various policy barriers and developing effective practices. For example, they are:

- Coordinating with the state’s Medicaid program. When people in the (non-Medicaid) consumer-directed care program (administered by the state unit on aging) apply for Medicaid, assistance is provided with the application process. A significant number of people have been transferred to the Medicaid consumer-directed program. While there is not a formal process, as potential clients have required particular services, the aging network has increasingly explored more linkages with the Medicaid waiver program across the state.

- Developing a single waiting list for all home and community based services to ensure that elders receive other services for which they are eligible while waiting for consumer direction.
- Working to make policies work across funding sources and populations to ensure consumer direction fits within a common infrastructure, common policy, and common messaging for all populations.
- Building support for consumer-directed programs during the pilot stage so they can be maintained after grant funding expires.
- Creating a position of consumer direction coordinator, to coach, teach, and monitor consumers to make sure exploitation does not occur.
- Developing an online process that will include applications, budgets, employment costs, a FICA formula, and tax forms so that the approval and management processes for the consumer direction program can work more simply and quickly.
- Trying to change labor laws to be more conducive to consumer direction.
- Reviewing the regulatory processes across aging, disability and health care financing; trying to find areas of contradiction in rules so that they can be coordinated.

While states reported a wide range of state level barriers to consumer direction, the general consensus was that they were not insurmountable.

▪ **Practices to address cost effectiveness**

States have developed a number of effective practices to ensure the cost effectiveness of consumer directed programs. One state uses the “Care Call” system to monitor the time providers are delivering care. In this system workers are required to call a central number when they arrive in the consumer’s home and again when they leave. In the first couple of months the state saved several million dollars because the program only paid for actual provider time in the home. Previously they paid for one hour even if the provider was there for only five minutes. Using this system, the state also has evidence that can be used to prosecute providers if they call in from places other than the consumer’s location.

Another practice that has been found to be effective at ensuring cost effectiveness is a process involving monthly utilization reports (including units and hours of service provided) that can be reviewed against the contractor’s authorized amount of care. The data can then be examined for trends in service use and costs.

▪ **Practices to address provider resistance**

One practice that was found to be effective in building provider support was to allow agency care in the daytime and consumer-directed services at night. Another state unit

on aging addressed provider resistance by holding meetings and making a series of presentations. Providers seemed to think that consumers were being encouraged to leave agency workers. In response, they were given the message that if they are really providing what the consumer wants, the consumer will stay with them. They were told that if a worker had a good relationship with a consumer, then the care coordinator would encourage the consumer to stay with that provider.

Another effective practice involves quarterly meetings with provider organizations to brainstorm about how the state is doing things and to gain their support. At one of these meetings staff from an agency using consumer direction described the program, including how they are able to write a check to the family to do what is needed. The state unit on aging felt this type of presentation was the most successful way to get provider agencies to consider offering consumer direction.

Getting to the right person at the right time helps move development along. Respondents indicated the need to win people over to support consumer direction. Individual personalities clearly affect acceptance of this approach. For example, one program manager didn't want to pursue consumer direction because of concerns about liability issues. A case manager who loved the idea was able to help change the program manager's mind. In sum, in most of the states that experienced provider resistance, it appears that the momentum supporting consumer direction is strong enough to withstand that resistance.

▪ **Practices learned from providing consumer direction to younger persons**

States reported a wide range of things they learned from consumer-directed services for younger persons that helped them in implementing their aging programs. Some were specific ways to make consumer direction work:

- How to educate individual consumers about being an employer;
- How to do planning differently;
- How to “tweak” services to make them more age friendly;
- How to work with a limited budget and be more flexible with spending;
- How to use fiduciaries to handle payroll, employee hours, and taxes;
- How to prevent potential use of consumer-directed care as an income supplement by implementing monitoring by project consultants.

Others were more general lessons about public reactions to consumer direction:

- Most people think that consumer direction only refers to personal care attendants, whereas the disabilities community has a very open mind about consumer direction.

That helped open the [aging] agency's eyes to let go of historical obstacles to providing a wide array of services;

- The population is not necessarily different. Age is not a factor in determining success of or desire for a consumer-directed program;
- What works for older persons may not work for younger consumers;
- People are competent to direct their own care;
- Everyone has preferences and they like to have those preferences met;
- Built in family support gives a higher possibility of success;
- Consumer direction can be used effectively as backup for other HCBS services;
- Technology provides real capabilities to enhance care through web-based information and budget support;
- Everything we learned about consumer direction came from younger consumers involved in the waiver because they are very vocal.

▪ **Practices related to use of the media**

Four state units on aging described substantial media coverage for consumer direction. In one the governor held a press conference which resulted in articles and editorials. As a result the state unit on aging was flooded with calls, especially from other states. In fact this state reported it has learned that when they start a new pilot area, they are not going to hold another governor's press conference. The response was too overwhelming and generated more demand than they could handle. This state has also presented at CMS conferences, the American Society on Aging (ASA), and at the Administration on Aging. Every one of these events resulted in more requests for information.

Another governor was on the "News Hour with Jim Lehrer" talking about consumer direction. Several articles on consumer direction were published as a follow-up to the television news broadcast.

Other states have gotten some attention without involvement of their governors. For example, one produced several press releases. They found that the media tends to focus on younger people with developmental disabilities. Attention to elders is "sort of secondary." However media exposure has generated interest among professionals, especially about how to market consumer direction.

A state that has been involved in the Cash and Counseling Program described an overwhelming and positive reaction from the media. There have been personal stories and feature articles: "they tell the story." There have been numerous features focusing on family members in the newspaper, as well as on TV. When the [consumer direction]

bill was being considered, legislators would reach out and ask for a senior/consumer and the media would flock to them. They wanted to know what this is like. The Robert Wood Johnson Foundation hired a public relations firm to help states develop key messages including outreach staff talking about consumer direction in local communities. Articles were published in national publications, such as *Newsweek*.

However, most states had not received any media coverage. The experience of these states can be summed up as: “The public doesn’t care until they have a family member involved.”

Policy Environment

Consumer Direction for Older People Generally Works Well and Fits with States’ Policy Directions

Overall, state units on aging reported that consumer direction is working fairly well in their states. When asked, during the interviews, to rank how well consumer-directed services for older people are working (from 1 = not working at all to 7 = working extremely well), fifteen (of twenty) respondents provided scores ranging from 3 to 7. The mean of 5.03 is clearly more positive than a neutral reaction, which would have received a score of 3.5.

While some expanded on these ratings with phrases like “fine,” or “extremely well,” others offered some qualifications:

- It works pretty well, but it’s certainly not for everyone.
- Our grant is so tiny and so targeted. I’m not sure if we could handle a larger response fiscally or with our current infrastructure. This may ultimately result in lower customer satisfaction since we may be viewed as unable to meet the demands.
- We started small but we have been successful with what we’ve done. It took a year to figure out what we were doing. We didn’t know how complicated it would be. We found a national expert who provided help on legal and financial considerations.
- Consumer direction is a “work in progress; we are still facing issues with a new fiscal agent and HIPAA.”

The most serious concerns were expressed by a state that said that while its respite voucher program is operating, they still face interagency and intra-agency systems issues including not enough staff and changes in the state’s financial computer system that resulted in delayed payments. These problems affect how the program is working. Now

that they have publicized consumer direction, people are hearing about it and demand is increasing. But there is not enough funding to meet the demand of all consumers. Since there are no caps on consumer direction, it is first come, first served and they have run out of money in some areas of the state. In addition they haven't yet looked at developing a quality control system.

Others would like to see more growth in the program. About half of the state aging directors interviewed indicate that HCBS programs are compatible with the direction in which other programs are moving (49% rate a 4 or 5 on a 5-point scale), the philosophy of the state government (49% rate a 4 or 5), and the skills of their current staff (46% rate a 4 or 5). (See Table 15) States in the process of developing consumer-directed HCBS scored the compatibility between these programs and the direction other programs are moving significantly higher. State aging directors report less compatibility of consumer-directed HCBS programs with the resources of their current system (26% rate a 4 or 5). States that do not operate CD HCBS for the elderly saw significantly lower compatibility between their resources and this approach.

Table 14 Compatibility of consumer-directed HCBS programs (*Opinion Survey: n=39 state agencies that operate CD HCBS for the elderly*)

“How compatible are consumer-directed HCBS aging services programs with the following?”

	Not at all compatible				Very compatible	
	1	2	3	4	5	Mean
Philosophy of the state government (<i>n=37</i>)	5% (2)	13% (5)	28% (11)	31% (12)	18% (7)	3.5
Direction other programs are moving (<i>n=37</i>)	8% (3)	8% (3)	31% (12)	23% (9)	26% (10)	3.5 ²⁰
Skills of current staff (<i>n=37</i>)	3% (1)	13% (5)	33% (13)	28% (11)	18% (7)	3.5
Resources of current system (<i>n=38</i>)	3% (1)	23% (9)	46% (18)	21% (8)	5% (2)	3.0 ²¹

Several major long term care initiatives are under way across the states in addition to consumer direction. These include systems change initiatives and Olmstead plans and activities. Some states are involved with as many as five systems change grants that they feel relate to consumer direction. Systems change grants have allowed states to pursue a range of activities supporting consumer direction. Two areas of mutual support between systems change grants and consumer direction were identified by several states:

- Consumer information and education activities including development of a web-based data system under systems change grants.
- Nursing home transition programs dovetailing with consumer direction. One state reported deinstitutionalizing at least 150 people and providing them consumer-directed community services.

²⁰ The mean score of states where CD programs are in development (4.3) is significantly different from the overall mean (including states with no CD programs and those with operating programs) ($t=2.100$; significance = 0.043).

²¹ The mean score for states without CD HCBS program for older people (2.4) is significantly different from the overall mean (including states with programs in developing and operating programs) ($t=2.06$; significance = 0.046).

Other relationships between systems change grants and consumer direction were noted only by individual states:

- Infrastructure development activities including advisory committees, management teams, and development of a uniform budget methodology that supported consumer direction and nursing home discharge efforts.
- Quality improvement systems enhancements, including development of goals, assessment tools, and other new procedures for HCBS programs, including consumer direction.
- Personal care attendant grants to train and build a personnel registry for consumer direction.
- Support for developing Cash and Counseling and Medicaid waiver applications.
- Support to design models for consumer direction including key operational functions of a self-directed delivery system and a self-determination master plan.
- Pilot projects for self-determination for adults with serious mental illness and one for self-determination activities to be developed jointly with other state departments.
- Workforce development support including allowing nontraditional providers to provide services.

Most states have some type of formal Olmstead Plan; however, the level of direct connection with consumer direction varies widely. Several states said they did not see a direct connection between their Olmstead plans and consumer direction initiatives. For example, in one of these states the focus of Olmstead is on information and access, not on service delivery. One state's Olmstead commission has discussed consumer direction but is not particularly pushing it. While some states indicated that there was no formal reference to consumer direction, it was clear that the purpose of the Olmstead plan was consistent with greater consumer control and increased access to information about community based services. On the other hand, some states saw clear and direct linkages between their Olmstead plans and consumer direction. For example, in one state the Olmstead plan lead directly to the decision to apply for a systems change grant that helped support consumer direction. Some state unit on aging directors are on their state's Olmstead Task Forces. In one state the aging director was asked to play a prominent role in a newly formed Olmstead study and policy group in order to promote consumer direction in their discussions.

Several states are using nursing home transition grants to support their Olmstead plans. For example, one governor's goal is to move 1,000 disabled and elderly residents out of nursing homes into affordable homes with consumer-directed services. Other states are focusing on avoiding inappropriate initial placements. As described by one program

director, we “would do systems change and consumer direction even without Olmstead, but it provides extra wind in the sails.” Another went so far as to say that their Olmstead plan was the “stimulus to the momentum for consumer direction in every one of their programs.”

Consumer direction plays a prominent role in many state aging plans and policy agendas. In some cases it is specifically mentioned in state plan goals. Five states described actions by their governors that sent signals of support for consumer direction. In one state, the governor recently asked the state aging director to submit an agency plan about how to expand consumer direction statewide within 15 months. That state is also looking at the possibility of adding consumer direction to personal care aide services and adopting the federal definition of family members (to include those in the household as long as that person is not legally responsible). That state is submitting a grant specific to CMS for “Money Follows the Person.” “The bottom line is that it is a very high priority in the state.” The governor bought in early in his administration, kicking the program

“We misjudge when we think older people can’t direct their care; they just need a little help.”

“It can be cost effective for them [consumers], the state, and the federal budget.”

“Boomers are going to be more knowledgeable and will want more control of their care.”

off with a press conference and continuing to be supportive through work with the National Governor's Association.

In some states, the policy priority for consumer direction is directly tied to Olmstead activities. In one, the Governor’s Olmstead task force has a large impact on the direction the state is going and consumer direction is “a real high priority for the aging network and the governor.” That governor is working to balance the services that are available between communities and institutions; his strategic plan to improve long term support for people with disabilities addresses expanding the waiver program for consumer direction.

Other phrases used to describe the policy priority given to consumer direction include: “Right at the very top of the list,” “very high,” and “way up there because the state thinks it is something that older people can truly benefit from.”

“One state agency described three main strategic areas that the agency is focusing on in concert with the governor’s office. (1) Provide long term care services that are to be consumer centered and provided in the most efficient way; (2) increase awareness about

programs and services; and (3) increase caregiver support. All three of these priorities are related to consumer direction.

In responding to a request in the interviews to rank how important consumer-directed services are in terms of various long term care options from 1 (not at all important) to 7 (extremely important), 18 respondents ranked importance from 4 to 7, with a mean of 5.76. This represents a very high priority, higher than any of the other items they were asked to score.

However, a few states say that, at least as viewed from the Department of Aging, consumer direction is not really a priority. “While the Secretary and Deputy Secretary support this type of service, health promotion is a bigger policy priority” in one state. Another reported that Medicaid, in general, is a higher priority. In another state, the “number one priority is getting funding to expand services we already have. There is a tremendous waiting list in Medicaid and for Older Americans Act programs.” However, according to another, “the only issue that’s bigger is overall Medicaid spending.”

Further, because of the small number of programs and people involved, consumer direction was not seen to be a driver of policy direction. Rather it was viewed as “a very important component of policy decisions.” In one state it was seen as a catalyst in getting support for passage of a law to broaden nurse delegation to permit

delegation of tasks historically done only by nurses to unlicensed staff and people self-directing care. According to one respondent, a lot of people were being pushed toward residential services because they couldn’t find someone licensed to do certain tasks such as medication administration.

States’ Goals for Consumer-Directed HCBS for the Elderly

States’ high level of interest in consumer direction is reflected in the range of activities states hope to pursue in the future:

- One state is developing a statewide reform agenda that focuses on consumer direction. The process involves setting up consumer groups and public forums to get a “good handle” on what is available, what is needed, and how to address those needs. Their goal is to be sure that providers offer some sort of consumer direction.
- Several states want to take Alzheimer’s and other demonstration programs that offer consumer direction statewide.

A state early in consumer direction development said it is setting the program up as a pilot so they can work out the kinks. "It is clear that we will have a widespread program that covers more than the current Alzheimer's demonstration project. We need to move closer to an approach where consumers have spending authority and can buy the services, period."

Another state is going statewide [with consumer direction] by 2005.

- Consumer direction fits into a broader agenda in some states.

Right now some agencies don't provide evening or weekend services. The short term goal is to try to change those practices. We need to tackle the issue of moving money from institutional services to home and community based services but we realize that it will be extremely hard politically. Even the grant where "Money Follows the Person," is only taking initial steps; no one has taken on the difficult challenge of convincing legislators how to move the money.

- Some states hope to expand the array of programs to which consumer direction can be applied.

We want to offer consumer direction in as many services as we can, not just Medicaid home and community based services. It is a real possibility in the Older Americans Act, National Family Caregiver Support Program and other OAA services as well as state funded home and community based services. We want to use vouchers that consumers can take to whomever they want to provide the services, no matter what program they are using.

We are likely to expand [beyond Cash and Counseling] "by leaps and bounds."

We hope to expand consumer direction by getting one of the new Cash and Counseling grants.

- Some states are combining programs and services.

Our goal is to take the consumer-directed "flavor" and merge it into a single waiver.

We want a new consumer direction program across funding streams and across populations.

We want to have consumer direction broadly incorporated across Medicaid programs and across aging services for Alzheimer's patients.

We want to add the disability population to the elderly, under one umbrella, to combine funding streams.

- States are strengthening the definition of consumer direction

We have to be more attentive to what people want and depend less on how we think they should get it. We expect to move to more clearly self-directed services that do not require hiring from an approved list.

- One state plans to incorporate consumer direction with managed care

Consumer-directed care will be fused into managed care for seniors and will change and look different.

- State reorganization may provide an opportunity for consumer direction in one state

The result [of reorganization] may be to reallocate some funds to consumer direction. Since the governor supports consumer direction, the timing is right. The state unit on aging will continue to work collaboratively with the Governor's Council on Developmental Disability and the Mental Health agency, holding a statewide conference in the fall. "We will keep it on the agenda, and it will get bigger."

- States are applying for funding to support consumer direction

We applied for an Alzheimer's grant that uses a very extensive tool to support individual self-determination and participation in the development of one's own service plan. "As much as can generate interest we would expect it to grow."

We are applying for a Medicaid 1115 waiver within the year. We would like to have a pilot program with 300-500 persons in consumer-directed services over the next couple of years in lieu of using a home care agency. We are also talking about doing OAA meals programs in a consumer-directed manner, about changing other programs and we keep asking for more money to expand the respite voucher program as well.

Cash and Counseling programs have shown the program does save money in the end but expenses are front-loaded and there are costs at the beginning. Federal Medicaid match is available for administrative costs that allow for the needed infrastructure investment. Based on this experience one of the Cash and Counseling states gave this advice: "States considering consumer-directed services need to do their homework and invest enough resources in startup. They need top management investment in this. You can't short-change it or try for quick implementation. The consulting role and fiscal intermediary function are very complex. Developing consumer direction requires long-term commitment."

Finally, respondents to the Consumer Direction Survey were asked to rank how good an idea they think it is to increase CD services in publicly funded programs for older adults. As seen in Table 16, a large majority (80%) indicated it was a good idea or a very good idea. While 15 percent were neutral, none reported that it was not a good idea. This sums up the clearly positive message heard in most of the interviews. Consumer direction is an idea whose time has come.

Table 15 Increased Use of Consumer-Directed HCBS (CD Survey: n=30 state agencies offering CD for the elderly)

“How good an idea is increasing consumer-directed services in publicly-funded programs for older adults?”

	Not at all good idea		Very good idea			
	1	2	3	4	5	Mean
Percent Number	-- (0)	-- (0)	15% (3)	30% (9)	60% (18)	4.4

Conclusion

In conclusion, it is clear that there is enormous variability in states’ experiences with consumer direction. While most states are currently only providing consumer direction to a few hundred older people, a number of states have extensive, longstanding, and well-developed consumer direction programs that serve thousands of older persons. However, there is general agreement that there is enormous potential for growth. The lack of general understanding about consumer direction, among the public as well as professionals, is a clear barrier that states are working to address.

States were definitely motivated to pursue this approach by staff shortages and perceived gaps in services, particularly in rural areas. Federal initiatives, including available funding, also influenced states to pursue consumer direction. State units on aging are using several funding sources, including Medicaid, Older Americans Act, and state general revenue funds, to infuse consumer direction into a wide range of programs. While organized advocacy from younger people with disabilities often put consumer direction on the state’s agenda, few experienced much organized advocacy representing elderly consumers.

Many barriers to implementation of consumer direction were identified. The most frequently mentioned include Medicaid rules and procedures and infrastructure issues such as working out details of paying providers and problems addressing workers’ compensation and taxes. States reported problems with vouchers, fiscal intermediaries, and direct reimbursement systems. Issues included staffing, computer systems, and CMS standards causing delays in program implementation. States are continuing to experiment with these payment issues and are seeking technical assistance to improve their processes.

Despite these difficulties, there seemed to be a general sense of optimism about consumer direction. State units on aging recognized that there are major steps still ahead, but they are identifying successful practices to help move consumer direction forward. In sum, they felt that consumers are generally satisfied with having more control over their care and they recognized that consumer direction is “the right thing to do.”

Appendices

Appendix A Survey Questionnaires

2004 CONSUMER DIRECTION SURVEY OF STATE ADMINISTRATORS

The results of this survey will be supplemented by qualitative research that NCOA is conducting with program administrators. Together, they will provide much needed information about consumer-directed services at the state level.

EXISTENCE OF CONSUMER-DIRECTED HCBS AGING SERVICES PROGRAMS

Please read the following definition.

Consumer-Directed Home and Community Based Services give consumers maximum choice and control. They allow consumers to assess their own needs, determine how and by whom these needs are met, and monitor the quality of services received. Consumers may be able to:

- Select, manage, and dismiss their workers
- Choose which services to use
- Choose what providers or workers to hire
- Decide what time of day workers will come
- Decide whether to hire family members
- Decide whether to spend available funds on things other than services (like appliances or home modifications)

1. Since 1999, have you eliminated or ended any consumer-directed home and community based services (consumer-directed HCBS) long-term care programs?

☐₁ Yes

☐₂ No

2. In providing services related to *aging*, does our state currently offer any consumer-directed HCBS programs?

☐₁ Yes

☐₂ No

If you answered "Yes" to #2, please skip to #4.

If you answered "No" to #2, please continue.

3. If you're not currently operating a consumer-directed HCBS aging services program, and you do not have one in development, what has prevented you from doing so? (Check all that apply.)

☐₁ Don't think it's a good idea

☐₂ Don't have the resources to implement

☐₃ Don't know what to do to get started

☐₄ Other _____

If you answered "No" to #2, please skip to the text box before #33 and complete the remainder of the survey.

EXISTENCE OF CONSUMER-DIRECTED HCBS AGING SERVICES PROGRAMS (cont')

4. In your state how many HCBS programs relating to aging offer consumer-directed options?

_____ # your department funds **without** other state agencies

_____ # your department funds **cooperatively** with other state agencies

_____ # Total

5. How aware are you of consumer-directed programs for older adults?

Not at all
Aware

Very
Aware

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

6. How knowledgeable are you about consumer-directed programs for older adults?

Not at all
Kn'able

Very
Kn'able

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

7. How good an idea is increasing consumer-directed services in publicly-funded programs for older adults?

Not at all
Good Idea

Very
Good Idea

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

8. Please list the names of the three HCBS programs that offer consumer-directed programs in aging services about which you will be able to provide the most detail.

i) _____

ii) _____

(b) _____

Please list any other programs at the end of this survey.

FUNDING AND COSTS

Most of the remaining questions will relate to these three programs. The questionnaire is arranged so you can mark your responses to questions in a separate column for each program you listed in Question #8.

	First Program (i)	Second Program (ii)	Third Program (iii)
9. Which agency funds this program?	_____	_____	_____
10. Which agency operates this program?	_____	_____	_____
11. What year did the program begin?	_____	_____	_____
12. How many participants who chose the consumer-directed option were there in FY 2003?	_____	_____	_____

FUNDING AND COSTS (continued)

	First Program (i)	Second Program (ii)	Third Program (iii)
13. Which of the following funding sources were used for the program in FY 2003? (Check all that apply)			
a. Title XIX Medicaid Personal Care (PC) Option	☐ ₁	☐ ₁	☐ ₁
b. Title XIX Medicaid 1915(c) Home and Community-Based Care Waivers	☐ ₂	☐ ₂	☐ ₂
c. Other Medicaid waiver	☐ ₃	☐ ₃	☐ ₃
d. Title XIX Community-Supported Living Arrangement	☐ ₄	☐ ₄	☐ ₄
e. Title XIX Social Services Block Grant	☐ ₅	☐ ₅	☐ ₅
f. Title III Older Americans Act	☐ ₆	☐ ₆	☐ ₆
g. Rehabilitation Act	☐ ₇	☐ ₇	☐ ₇
h. State funds (other than Medicaid match)	☐ ₈	☐ ₈	☐ ₈
i. County/municipal funds	☐ ₉	☐ ₉	☐ ₉
j. Tribal funds	☐ ₁₀	☐ ₁₀	☐ ₁₀
k. Other source	☐ ₁₁	☐ ₁₁	☐ ₁₁
14. What are the approximate program costs for each of the following years?			
a. Fiscal Year 2002	\$ _____	\$ _____	\$ _____
b. Fiscal Year 2003	\$ _____	\$ _____	\$ _____
c. Budgeted for Fiscal Year 2004	\$ _____	\$ _____	\$ _____
15. How are providers paid? (Check all that apply)			
a. Program pays provider directly	☐ ₁	☐ ₁	☐ ₁
b. Program gives consumers vouchers to obtain services and then reimburses the providers	☐ ₂	☐ ₂	☐ ₂
c. An intermediary reimburses provider	☐ ₃	☐ ₃	☐ ₃
d. Program gives consumers cash to pay providers themselves	☐ ₄	☐ ₄	☐ ₄
e. Another method is used to pay providers	☐ ₅	☐ ₅	☐ ₅

PROGRAM CHARACTERISTICS

	First Program (i)	Second Program (ii)	Third Program (iii)
16. To be eligible for the program, does a consumer have to...			
a. Meet certain <u>age</u> criteria <u>only</u> , but not disability criteria?	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No

PROGRAM CHARACTERISTICS (continued)			
b. Meet certain <u>disability</u> criteria <u>only</u> , but not age criteria?	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No
c. Meet a combination of age <u>and</u> disability criteria?	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No
d. Meet certain financial criteria (e.g., means testing)?	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No
17. Which of the following types of assistance are provided through the program? (Check all that apply)			
a. <u>Personal care assistance</u> (help with bathing, grooming, feeding, dressing, transfer, ambulation, etc.)	☐ ₁	☐ ₁	☐ ₁
b. <u>Homemaker services or chore assistance</u> (housecleaning, laundry, shopping, transportation, errands, etc.)	☐ ₂	☐ ₂	☐ ₂
c. <u>Medical services</u> (help with oral medications, range of motion, catheter care, etc.)	☐ ₃	☐ ₃	☐ ₃
d. <u>Skilled care by a licensed professional</u> —LVN, LPN, or RN (IV medication administration, wound care, etc.)	☐ ₄	☐ ₄	☐ ₄
e. <u>In-home rehabilitation therapy</u> (physical therapy, occupational therapy, speech therapy)	☐ ₅	☐ ₅	☐ ₅
f. <u>Respite services</u>	☐ ₆	☐ ₆	☐ ₆
g. <u>Assistive technology</u>	☐ ₇	☐ ₇	☐ ₇
h. <u>Home modifications</u>	☐ ₈	☐ ₈	☐ ₈
i. <u>Meal services</u> (delivered or in a congregate setting)	☐ ₉	☐ ₉	☐ ₉
j. <u>Transportation services</u>	☐ ₁₀	☐ ₁₀	☐ ₁₀
k. <u>Caregiver support other than services above</u> (such as information about caregiving resources, training, support groups)	☐ ₁₁	☐ ₁₁	☐ ₁₁
l. <u>Purchase of goods and services</u>	☐ ₁₂	☐ ₁₂	☐ ₁₂
	First Program (i)	Second Program (ii)	Third Program (iii)
18. Which of the following organizations or individuals may be paid to provide services? (Check all that apply)			
a. Certified home health agency	☐ ₁	☐ ₁	☐ ₁
b. Home care services agency	☐ ₂	☐ ₂	☐ ₂
c. Friends or neighbors	☐ ₃	☐ ₃	☐ ₃
d. Relatives	☐ ₄	☐ ₄	☐ ₄

PROGRAM CHARACTERISTICS (continued)			
e. Other individual providers who are not relatives or friends	☐ 5	☐ 5	☐ 5
19. Which of the following relatives (if any) cannot be paid providers under the program? (Check all that apply)			
a. Spouses	☐ 1	☐ 1	☐ 1
b. Parents	☐ 2	☐ 2	☐ 2
c. Adult children	☐ 3	☐ 3	☐ 3
d. Adult siblings	☐ 4	☐ 4	☐ 4
e. Relative who lives with consumer	☐ 5	☐ 5	☐ 5
20. Does the program offer training for consumers and/or family caregivers? (If yes, answer question 21, otherwise skip to question 22.)	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No
21. In which of the following topics does the program offer training to consumers and/or family caregivers? (Check all that apply)			
a. Selecting qualified workers	☐ 1	☐ 1	☐ 1
b. Communicating needs and preferences to workers	☐ 2	☐ 2	☐ 2
c. Supervising workers	☐ 3	☐ 3	☐ 3
d. How to dismiss workers (if necessary)	☐ 4	☐ 4	☐ 4
e. Handling payroll and taxes	☐ 5	☐ 5	☐ 5
22. Does the program require paid caregivers to be trained or to take part in training offered by the program if they have no previous training?	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No
23. Does the program offer traditional case management services?	☐ 1 Yes ☐ 2 No First Program (i)	☐ 1 Yes ☐ 2 No Second Program (ii)	☐ 1 Yes ☐ 2 No Third Program (iii)
24. Is counseling (information, advice, training) mandatory for all consumers who use the program?	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No	☐ 1 Yes ☐ 2 No
25. Over which of the following aspects of service does the consumer have choice/control?			
a. Selection of company/organization to provide services	☐ 1	☐ 1	☐ 1

PROGRAM CHARACTERISTICS (continued)			
b. Selection of individual worker to provide services	☐ ₂	☐ ₂	☐ ₂
c. Dismissal of workers	☐ ₃	☐ ₃	☐ ₃
d. Determining what services will be provided	☐ ₄	☐ ₄	☐ ₄
e. Determining when services will be scheduled	☐ ₅	☐ ₅	☐ ₅
f. Deciding whether or not to use a fiscal intermediary	☐ ₆	☐ ₆	☐ ₆
g. How certain tasks are done (instructing workers as to personal preferences, e.g., for meal menu, manner of grooming, product brands used, etc.)	☐ ₇	☐ ₇	☐ ₇
26. Does the consumer receive information and/or counseling about service options that are available?	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No	☐ ₁ Yes ☐ ₂ No

QUALITY ASSURANCE, PROBLEMS, AND EFFECTIVE PRACTICES			
	First Program (i)	Second Program (ii)	Third Program (iii)
27. Which of the following methods are used to help ensure consumers' needs are being met?			
a. Monitoring through traditional case or care management	☐ ₁	☐ ₁	☐ ₁
b. Program evaluation	☐ ₂	☐ ₂	☐ ₂
c. Consumer satisfaction assessments and/or surveys	☐ ₃	☐ ₃	☐ ₃
d. Required certification of professional providers	☐ ₄	☐ ₄	☐ ₄
e. Internal case review process	☐ ₅	☐ ₅	☐ ₅
f. External case review process	☐ ₆	☐ ₆	☐ ₆
g. Ombudsman for consumers receiving in-home care	☐ ₇	☐ ₇	☐ ₇
h. Criminal background checks	☐ ₈	☐ ₈	☐ ₈
i. Emergency back-up	☐ ₉	☐ ₉	☐ ₉

The remaining questions pertain to consumer-directed HCBS for aging services generally, not to any specific program. NCOA and NASUA would like to learn about “effective practices” being discovered in consumer-directed HCBS programs related to aging services, as well as any significant learning about practices that were tried, but turned out not to be effective.

QUALITY ASSURANCE, PROBLEMS, AND EFFECTIVE PRACTICES (cont'd)

28. If you have developed any new practices that are **effective** in reaching the following goals, please check the box in **Column A**. If you tried any new practices that did **not work out** as hoped to reach the following goals, please check the box in **Column B**. Finally, check the box in **Column C** if you do not report any practices in Column A or B.

	Column A	Column B	Column C
	Effective Practice	Practice that Didn't Work Out	No Practices to Report
a. Improving the quality of long-term care services	☐ ₁	☐ ₂	☐ ₃
b. Reaching rural consumers	☐ ₁	☐ ₂	☐ ₃
c. Reaching other hard-to-reach consumers	☐ ₁	☐ ₂	☐ ₃
d. Providing effective educational materials to consumers	☐ ₁	☐ ₂	☐ ₃
e. Minimizing program administration and overhead	☐ ₁	☐ ₂	☐ ₃
f. Improving cost-effectiveness	☐ ₁	☐ ₂	☐ ₃
g. Combining with another program (to use existing capabilities, gain efficiency, minimize costs, etc.)	☐ ₁	☐ ₂	☐ ₃
h. Removing or dealing with regulatory/policy barriers	☐ ₁	☐ ₂	☐ ₃
i. Maintaining program capacity in spite of staff shortages	☐ ₁	☐ ₂	☐ ₃
j. Quantifying and measuring program outputs	☐ ₁	☐ ₂	☐ ₃

29. [IF YOU CHECKED ANY BOX IN COLUMN A OR B IN #28]

We would like to learn more about the practices you discovered. May we share your survey and contact information with a researcher who will be gathering and compiling information that can be used to help consumer-directed HCBS programs? If so, you would be called to learn more about your experiences. Your help would be greatly appreciated.

☐₁ Yes (If yes, please provide your contact information)

☐₂ No

Name: _____

State: _____

Agency: _____

Phone #: _____

E-mail: _____

QUALITY ASSURANCE, PROBLEMS, AND EFFECTIVE PRACTICES (continued)

30. Please list any other consumer-directed HCBS programs in aging services about which you did not provide details in this survey:

31. Based on your experience, how easy or difficult is it to implement a consumer-directed HCBS aging services program?

Very
Difficult

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very
Easy

32. How confident are you that you can measure the success of a consumer-directed HCBS aging services program?

Not at all
Confident

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very
Confident

Tapping home equity through a reverse mortgage can give “house-rich-and-cash poor” seniors additional funds to pay for consumer-directed HCBS. A reverse mortgage is a special loan available to homeowners age 62 and older. With these loans, the bank pays the borrower either a lump sum, monthly payments, or through a line of credit. There are no restrictions on how a person can use the money from a reverse mortgage. The loan becomes due when the borrower or co-borrower dies, sells the home, or moves. The total amount owed can never exceed the value of the home.

33. How knowledgeable are you about reverse mortgages?

Not at all
Kn'able

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very
Kn'able

34. How aware are you that reverse mortgages are an option for funding for consumer-directed HCBS services?

Not at all
Aware

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very
Aware

35. How interested do you think your state agency would be in exploring the feasibility of increasing the appropriate use of reverse mortgages as a way to pay for long-term care and to support consumer-directed HCBS?

Not at all
Interested

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

Very
Interested

36. Whom may we contact if we have questions about the responses in this survey?

☐

Check here if we should use the information provided in #29.

Name: _____

State: _____

Agency: _____

Phone #: _____

E-mail: _____

Please use this space to briefly clarify any previous response. Be sure to identify your response by question number.

THANK YOU SO MUCH FOR COMPLETING THIS SURVEY!

2004 CONSUMER DIRECTION OPINION SURVEY OF STATE AGENCIES ON AGING

1. Does your state have any consumer-directed HCBS aging services programs in operation? ☐ Yes ☐ No
2. Do you have any consumer-directed HCBS aging services programs in development? ☐ Yes ☐ No

If you answered "No" to both #1 and #2, skip to #8.

If you answered "Yes" to either #1 or #2,

3. To what degree are others in your State Unit on Aging aware of your consumer-directed HCBS aging services programs? Not at All Aware ☐ Very Aware ☐

a. Managers or supervisors

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

b. Other staff

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

4. How beneficial is a consumer-directed HCBS aging services program to consumers?

Not At All Beneficial ☐ Very Beneficial ☐

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

5. To what degree, if any, did the following factors influence you to develop consumer-directed HCBS aging services programs for consumers?

No Influence At All ☐ Influenced a Great Deal ☐

a. Success in other states

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

b. Perceived gaps in service delivery

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

c. Consumer demand

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

d. New federal initiatives

☐₁ ☐₂ ☐₃ ☐₄ ☐₅

6.	To what degree, if at all, have the following been problems in your consumer-directed HCBS aging services programs?	Not a Problem at All				Very Significant Problem
	a. Reduction in funds	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	b. Inadequate funding (other than a reduction)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	c. Fraud or misuse of funds	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	d. Abuse or exploitation of consumer	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	e. Poor compensation and benefits for caregivers	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	f. Loss of business for traditional service agencies	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	g. Inadequate quality of services	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	h. Other types of problems	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7.	To what degree, if at all, have the following been favorable in your implementation of consumer-directed HCBS aging services programs?	Not At All Favorable				Very Favorable
	a. Saves money	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	b. Provides choices for consumers	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	c. Empowers consumers	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	d. Improves access to service	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	e. Addresses workforce shortage	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

8.	To what degree, if at all, are you concerned about the following as barriers to implementing consumer-directed HCBS aging services programs?	Not at All Concerned				Very Concerned
	a. Federal Medicaid laws, rules, and regulations	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

	b. State Medicaid laws, rules, and regulations	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	c. Federal Medicaid Waiver process	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	d. Other state laws, rules, or regulations	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	e. Resistance from appointed and elected officials	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	f. Resistance within your agency/department to consumer-directed HCBS approach	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	g. Inadequate consumer advocacy for consumer-directed HCBS	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	h. Lack of funds	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	i. Quality concerns	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	j. Resistance from provider agencies	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9.	How compatible are consumer-directed HCBS aging services programs with the following?	Not At All Compatible				Very Compatible
	a. The philosophy of the state government	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	b. The direction in which other programs are moving	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	c. The skills of your current staff	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
	d. The resources of your current system	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please use this space to briefly clarify any previous response. Be sure to identify your response by question number.

Thank you very much for your participation.

Interview Questions

Consumer Directed Services for Older People

1. (a) What percentage of older people receiving some type of publicly supported (e.g., Medicaid, Medicaid Waiver, Older Americans Act, state general revenue, etc.) home and community based services (HCBS) are actually using some type of consumer-directed services?

(b) Do you have a significant number of persons with disabilities receiving home care who have “aged” into the long-term care system? (If so, is this part of the reason you have pursued consumer-directed program(s)?
2. (a) How do consumer-directed services for older adults fit in your policy priorities for the next several years?

(b) How important are consumer-directed services in terms of various LTC service options? (Scale of 1 to 7: not important at all to extremely important; plus narrative)
3. If your state is involved in the following activities, how do the consumer-directed HCBS aging service programs in your state relate to:
 - (a) Systems Change Grants
 - (b) Olmstead Requirements
 - (c) Cash and Counseling Program
4. Have you learned things from consumer-directed services with younger persons with disabilities that have been useful in implementing consumer-directed services with older people? Please explain.
5. Question 5 of the Opinion Survey of the State Agencies on Aging asked about factors that influenced your decision to develop consumer-directed HCBS aging service programs. Please expand on your response (provide response).
 - a. Success in other states
 - b. Perceived gaps in service delivery
 - c. New federal initiativesDid other factors have an influence?
 - a. State law or policy
 - b. Programmatic decisions
 - c. Funding became available (identify source)
 - d. Advocacy efforts
 - e. Inadequate supply of providers
 - f. Cost implications
 - g. Other:

6. On the 2004 Consumer Direction Survey you recently completed there was a question (#28) that asked about whether you have developed any new practices that are either effective or ineffective in reaching various goals related to long-term care services. I would like you to expand on those practices you indicated have been effective in your state.

- a. Improving the quality of long-term care services
- b. Reaching rural consumers
- c. Reaching other hard-to-reach consumers
- d. Providing effective educational materials to consumers
- e. Minimizing program administration and overhead
- f. Improving cost-effectiveness
- g. Combining with other program (to use existing capabilities, gain efficiency, minimize cost, etc.)
- h. Removing or dealing with regulatory/policy barriers
- i. Maintaining program capacity in spite of staff shortages
- j. Quantifying and measuring program outputs

Which have been most effective?

7. Beyond the items identified in Survey Question #28, can you give me any examples of successes achieved in consumer-directed services?

8. Now, please expand on those practices that didn't work out in your state. (If indicated in Survey Question #28)

- a. Improving the quality of long-term care services
- b. Reaching rural consumers
- c. Reaching other hard-to-reach consumers
- d. Providing effective educational materials to consumers
- e. Minimizing program administration and overhead
- e. Improving cost-effectiveness
- f. Combining with other program (to use existing capabilities, gain efficiency, minimize cost, etc.)
- i. Removing or dealing with regulatory/policy barriers
- j. Maintaining program capacity in spite of staff shortages

- j. Quantifying and measuring program outputs

If more than one practice was identified, which have been most problematic?

- 9. Question 8 of the Opinion Survey of the State Agencies on Aging asked about various barriers to implementing consumer-directed HCBS aging service programs. Could you please expand on those barriers that you are concerned about? (Only ask about those they indicated concerned or very concerned)
 - a. Federal Medicaid laws, rules and regulations
 - b. State Medicaid laws, rules and regulations
 - c. Federal Medicaid Waiver process
 - d. Other state laws, rules, or regulations
 - e. Resistance from appointed and elected officials
 - f. Resistance within your agency/department to consumer-directed HCBS approach
 - g. Inadequate consumer advocacy for consumer-directed HCBS
 - h. Lack of funds
 - i. Quality concerns
 - j. Resistance from provider agencies

If more than one barrier was identified, which have been most problematic?

- 9. Beyond the items identified in Survey Question #8, can you give me any examples of challenges you have overcome in implementing consumer-directed services with older people? How have these challenges limited consumer-directed services for older adults?
- 10. What has been the reaction of older adults to consumer-directed services? (Scale of 1 – 7: not working at all to working extremely well; plus narrative)
- 11. Overall, how well would you say consumer-directed services for older people are working in your state? (Scale of 1 – 7: not working at all to working extremely well; plus narrative)
- 12. Has there been any media reaction or coverage for consumer-directed services for older people?
- 14. Where do you hope to go in the future with consumer-directed services?

Appendix B Reverse Mortgages and Consumer Direction

Table 16 Knowledge of reverse mortgages (*n=40 state agencies*)

“How knowledgeable are you about reverse mortgages?”

Not at all knowledgeable	Very knowledgeable				
1	2	3	4	5	Mean
13%	40%	25%	20%	3%	2.6

Respondents' awareness of reverse mortgages as an option for consumer-directed HCBS services varies widely. One-quarter rate their awareness a 5 on a 5-point scale (25%), while a similar proportion rate their awareness a 1 (28%). The remaining respondents rate themselves somewhere between these two extremes. The mean rating is 2.9.

Table 17 Reverse mortgages as a funding option (*n=40 state agencies*)

“How aware are you that reverse mortgages are an option for funding for consumer-directed HCBS services?”

Not at all aware	Very aware				
1	2	3	4	5	Mean
28%	18%	18%	13%	25%	2.9

Few respondents indicate interest in their agency exploring the feasibility of increasing the appropriate use of reverse mortgages as a way to pay for long-term care and to support consumer-directed HCBS. Only one-quarter (25%) rate their interest as 4 or 5 on a 5-point scale. The mean rating is 2.8.

Table 18 Increased use of reverse mortgages for HCBS (*n=40 state agencies*)

“How interested do you think your state agency would be in exploring the feasibility of increasing the appropriate use of reverse mortgages as a way to pay for long-term care and to support consumer-directed HCBS?”

Not at all Interested	Very Interested				
1	2	3	4	5	Mean
13%	28%	35%	18%	8%	2.8

Few respondents consider themselves to be knowledgeable about reverse mortgages; only one in four rate their knowledge as 4 or 5 on a 5 point scale (23%). In fact, half give themselves low ratings of knowledge (53% rating themselves a 1 or 2). The mean rating is 2.6.