Best Practices in Consumer Direction

Prepared for:

The Centers for Medicare & Medicaid Services

Prepared by:

Pamela Nadash
Suzanne Crisp

Medstat
125 CambridgePark Drive
Cambridge, MA 02140

July 19, 2005
Appendix B:
An Annotated Bibliography of Articles Related to Consumer Direction

Acknowledgements: This bibliography was compiled by Gloria Gordon.


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

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


   The objective of this investigation was to determine whether people who receive consumer-directed personal assistance services (PAS) in Virginia are more satisfied with the services they receive than persons on the waiting list to receive those services and currently receiving PAS that are not consumer-directed. A survey was conducted by mail and telephone to evaluate long-term outcomes in 92 Virginia residents with physical disabilities living in the community. Approximately two-thirds (60) of these individuals were receiving consumer-directed PAS, and one-third (32) were receiving agency-directed PAS while on the waiting list for consumer-directed PAS. The authors found that consumers using consumer-directed services were more satisfied with their PAS. Specifically, consumer-directed services ranked higher on
such issues as: cost; control over the choice of worker and work schedule; authority to direct workers; and the availability of assistance off-hours or in an emergency. The two groups showed no difference in their perception of needs being met, the dependability of the worker, and personal safety. The authors emphasize how important it is to people with disabilities to be able to choose their own personal assistant, which is more likely to result in the selection of a worker who is best suited to the individual consumer and can meet a more flexible work schedule that allows the consumer to pursue and maintain employment. They conclude that consumer satisfaction over time and across circumstances is essential to the successful implementation and continuation of a consumer-directed model of care.


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

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

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

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


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

Most workers were young or middle-aged females. Agency workers were more likely to have less than a high school diploma, whereas consumer-directed workers were more likely to have some college education. Agency workers had more personal care experience than did consumer-directed workers, and consumer-directed workers were more likely to hold another job. Agency workers earned more, had more clients, spent fewer hours with any one client, and had more formal training and supervision. However, consumer-directed workers received considerable recipient-specific informal training from families, physicians, home-health nurses, and therapists. Consumer-directed workers were much more likely than agency ones to perform additional service tasks without pay, and related workers were much more likely to provide unpaid hours than non-related workers. Consumer-directed workers reported outcomes equal to
or more positive than agency workers on most dimensions of stress and satisfaction. Whatever the service model, adequate training and pertinent information on the recipient’s condition are associated with more satisfaction and less stress. Efforts to improve the work life of home-care workers should acknowledge the strengths of consumer-directed approaches and target workers across models.


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

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


   This article explores the role of a “supportive intermediary” to assist the surrogate decision-makers of cognitively impaired older adults to secure home-based personal assistance in a 3-year demonstration project conducted in New York City as part of the Medicaid Consumer-Directed Personal Assistance Program (CDPAP). The surrogates (usually family members) came to the program with considerable experience and dissatisfaction with agency-supervised personal assistance services, where their extensive responsibilities included managing personal care attendants, business and financial matters, medical and therapeutic interventions, and socialization. Surrogates expressed the need for more flexibility to schedule and utilize personal
care attendants and the desire for more control over their hiring and firing. Under CDPAP, personal care attendants are selected, trained, and supervised by the person with the disability or an assigned surrogate, and a fiscal intermediary handles payments to workers. The fiscal intermediary services provided by Concepts of Independence included management of payroll functions, fringe benefits such as health and dental insurance, pension plans, and Workers Compensation.

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


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

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

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

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

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


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

The IndependentChoices program increased consumer satisfaction and reduced unmet needs at a cost that was slightly less than agencies would have incurred if they had supplied the number of hours approved in recipients’ plans of care. Findings at 1 year post enrollment for 2,008 individuals indicated that PCS expenditures were about twice as high ($4605 versus $2349) for the treatment group than for the controls, due primarily to the control group receiving far less care than it was authorized to receive. This $2,256 increase in PCS costs was partly
offset by a $726 savings in expenditures for nursing facility, home health, and other Medicaid services, resulting in Medicaid costs only 14% higher for the treatment group than for controls.

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


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

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

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

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

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

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


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

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


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

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


This article presents the findings of telephone surveys of over 600 elderly and/or physically disabled Florida residents receiving in-home services. The survey was designed to: (1) assess their interest in a consumer-directed cash option to pay for personal care services in
lieu of agency-based services; and (2) identify what characteristics of the cash option are most attractive to consumers. This information was to be used to design various cash option components (including counseling services) in the Cash and Counseling Demonstration and Evaluation Project states (Arkansas, Florida and New Jersey) and develop social marketing approaches to enable consumers and surrogates to make an informed choice between these options. Recipients of agency-based services were satisfied overall with the services they received, but were attracted to the cash option because they thought they would receive more services than were currently provided under the agency-based model. If they elected to participate in the cash option, consumers indicated they would most likely purchase more hours of services; housekeeping, transportation, laundry, and respite care services; and adaptive and/or other types of needed equipment. They also expressed an interest in training on how to obtain worker background checks, and assistance with payroll taxes and worker management. The survey data offered detailed guidance to help Florida design the cash option and formulate the social marketing and outreach materials for Cash and Counseling. Survey results indicated that educational level should be a consideration, as almost three-quarters of survey participants had a high school education or less.


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

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

Family caregivers of consumer-directed participants reported greater well-being and provided slightly fewer hours of assistance compared to family caregivers of those receiving traditional services. They were also less likely to report high levels of physical, financial and emotional strain; they worried less about insufficient care and safety; they were more likely to be very satisfied with recipients’ overall care arrangements and less likely to report that caregiving
impinged on their privacy, social lives and job performance. Further, they perceived their own health to be better and were more satisfied with their own lives. Significantly fewer caregivers of consumer-directed participants reported that caregiving conflicted with paid employment outside the home.

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


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


This report presents a descriptive inventory of publicly-funded programs offering home- and community-based personal assistance services through consumer-directed service delivery models. It addresses: the prevalence, age and permanence of programs; the number and characteristics of participants served; restrictions on participation; funding sources and covered services; the use of Intermediary Service Organizations of all types; relationship to Managed
Care Organizations; employment status of consumer-directed workers; Medicaid's relationships with ISOs and consumer-directed workers, especially in relation to provider agreements and contracts; and quality assurance.

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

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


This article compares and contrasts alternative approaches to administering Medicaid personal care services (PCS) programs for elderly and disabled persons, and identifies administrative features that tend to either facilitate or inhibit consumer choice and satisfaction. Data on state PCS programs were collected from: (1) mail questionnaire surveys of all Medicaid PCS programs in 1984 and 1988 by the World Institute on Disability; and (2) site visits to six programs in 1990-91. State officials were asked why various administrative features were adopted and to what extent their decisions were motivated by philosophical values and/or practical considerations. The selected states (Maryland, Massachusetts, Michigan, Montana, Oregon, and Texas) exemplified contrasting approaches to service financing and delivery on dimensions relevant to consumer choice and control. In Maryland, Massachusetts, and Michigan, Medicaid PCS aides were exclusively or predominantly "independent providers." In contrast, Montana, Oregon, and Texas required almost all aides to be employees of Medicare or Medicaid certified home health agencies. The states also varied in their requirements for formal quality assurance and how strictly they chose to interpret federal Medicaid prohibitions against
hiring family members as PCS aides. Data on perceptions of choice and control and satisfaction with attendant services were obtained via face-to-face in-home interviews with samples of Medicaid PCS clients (aged 65 and older) in three states (Maryland, Michigan, and Texas), drawing equally from urban and rural areas.

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


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

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

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


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

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


This article describes a study of in-home respite care provided through the California Caregiver Resource Centers. It compared the preferences and satisfaction of 168 family caregivers of adults with cognitive impairments who either paid providers for in-home respite care directly (direct pay) or received professionally managed (i.e., agency-based) respite services. Respondents in both groups identified the same “most important” reasons for preferring their respective mode of respite: wanting to be sure their loved one was safe; and having good, reliable and trustworthy help. However, the data revealed a clear preference for consumer direction in respite care in the home. Recipients who used the direct-pay model...
(reflecting the tenets of consumer-directed care) expressed greater satisfaction with the care – due primarily to their feelings of greater control over the situation. They could select a respite care provider and secure more service hours for the money they were allotted for care. The authors conclude that consumer-directed respite should be offered as an option, but is not appropriate for all consumers, especially those with cognitive limitations. The option can, however, still be made available to family members of those individuals. Practical implications are addressed for improving the delivery of in-home respite care.


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

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

The authors conclude that the key to success for an ISO, whether a full-service entity (e.g., an Agency with Choice or a Spectrum ISO) or one that only provides tax and payroll services (e.g., an IRS Employer Agent or Vendor Fiscal ISO), is a commitment to the Independent Living philosophy and the belief that persons with disabilities can self-direct and are capable of managing their own lives. The growth of the Independent Living Movement, together with the current trends in public health policy toward consumer empowerment and responsibility, make this an auspicious time to expand the availability of consumer-directed personal assistance programs to persons with disabilities and chronic conditions of all ages through the thoughtful implementation of ISOs.
This report presents findings from IndependentChoices, the first Cash and Counseling Demonstration program in Arkansas, in which telephone surveys were conducted to assess differences in quality of care received by Medicaid recipients randomized into control (receiving agency-directed services) and treatment (the consumer-directed model) groups. Respondents (1,739 elderly and non-elderly adults) were queried about: their satisfaction with the reliability, schedule, and performance of their paid caregivers; unmet needs and satisfaction with care arrangements; adverse events, health problems, and general health status; and overall satisfaction with life.

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

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

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

Results of telephone interviews conducted 9 months after baseline indicated that IndependentChoices markedly increased the number of consumers who were very satisfied with
their PCS. Specifically, they were more satisfied with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way paid caregivers performed their tasks. The program also reduced some unmet needs and greatly enhanced quality of life without compromising consumer health, functioning, or self-care. Both elderly and non-elderly adults fared better under Independent Choices than they did with agencies. In addition, 96% of all treatment group respondents, including disenrollees, said they would recommend the program to others, which confirms that even disenrollees found Independent Choices to be a desirable alternative to agency care. From a quality of care standpoint, Arkansas and federal Medicaid administrators have compelling evidence to support their October 2002 decision to continue Independent Choices after the end of the demonstration period.

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


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

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

The authors conclude that consumer direction markedly benefits both care recipients and their primary informal caregivers. Improvement comes about because some informal caregivers become paid workers and because beneficiaries make service arrangements that seem to alleviate
caregiver burden. In both cases, the benefits to caregivers, Medicaid beneficiaries, and perhaps the Medicaid program, are substantial.


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

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


This report summarizes the results of two 2004 surveys and one set of interviews with state administrators regarding 58 consumer-directed HCBS programs for older people in the United States. While most states (43%) currently only serve 500 persons or fewer, several states have highly developed programs that serve thousands of older persons. Consumer direction developed mainly in response to: perceived gaps in service delivery; an inadequate supply of providers; consumer demand and advocacy; federal and state policies; and cost considerations. It
is regarded as an effective means to address cultural diversity, workforce shortages (particularly in rural areas), and the needs and preferences of non-traditional and hard-to-reach consumers.

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

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


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

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

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


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

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


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

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


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

The authors hypothesized that the nurse intervention would decrease hospitalization rates and reduce the probability of skilled home health care use, since the majority of skilled home health care occurs after hospitalization. However, the nurse intervention alone had no effect on the probability of using either type of home care. On the other hand, use of the voucher alone increased the probability of accessing personal assistance services (which could be paid for with the voucher) by 13%, but not skilled home health care (which was not covered by the voucher). The combination of the two interventions appears to have had a synergistic effect on increasing the probability of personal assistance services use by 18%. This was attributed to the nurse advising patients on how to spend the voucher. The authors conclude that a modest consumer-
directed voucher benefit under Medicare improves access to much-needed personal care services without increasing the probability of use of more costly skilled home health care services.


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

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

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


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

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

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


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

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

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

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

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


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

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

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

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

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

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


This report discusses lessons that were learned in the original Cash and Counseling demonstration states (Arkansas, Florida, and New Jersey) about designing and implementing this expanded model of consumer-directed supportive services. A synopsis is provided of the program features that make Cash and Counseling adaptable to consumers of all ages and with all types of impairments. The program provides a flexible monthly allowance for consumers to hire their choice of workers, including family members, and to purchase other goods and services. It requires consumers to develop plans for spending the allowance, but provides counseling and fiscal assistance to help them or a designated representative to develop their plan and manage their fiscal and employer responsibilities. Preliminary results indicate that the great majority of consumers in the three original programs were very well satisfied, disability-related health outcomes for treatment group members were at least as good as those for controls, and treatment group members had fewer unmet need and greater satisfaction with their supportive services.
Key lessons are presented in the areas of: outreach and enrollment; the role of consumer representatives; spending plans and counseling; the use of the cash allowance; issues involving workers; structure and procedures for counseling and fiscal services; preventing exploitation and abuse, and program costs. The authors stress that states benefit from technical assistance when implementing Cash and Counseling, especially with fiscal issues. Direct outreach to eligible beneficiaries works best, with easy to understand materials that address the language and literacy level diversity of the Medicaid population. This model is attractive to substantial minorities of both elderly and non-elderly adults with physical disabilities, and to children and adults with developmental disabilities.

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


This report describes the design and implementation of IndependentChoices, the Arkansas model of Cash and Counseling. It covers: outreach and enrollment; program structure; counseling and fiscal services; and the program features participants found either attractive or unattractive. The report is based on in-person interviews conducted with state officials; IndependentChoices staff; representatives of advocacy groups; and staff of agencies that provided counseling and fiscal services and agencies that provide traditional Personal Assistance Services (PAS) in Arkansas. The IndependentChoices protocol offered a cash benefit in lieu of traditional PAS provided under the Medicaid state plan or a Medicaid waiver. Equal numbers of participants were randomly assigned to the treatment group (receiving the cash benefit) or the control group (receiving traditional services). About 2,000 people participated in the demonstration (in both groups combined), roughly 10-15% of PAS recipients annually. Almost all consumers who received a cash benefit hired a worker, usually a family member or friend. Some consumers purchased assistive equipment, personal care supplies, and nonprescription and prescription medications (when these medications were not covered by Medicaid). A few purchased materials to modify their homes.
The outreach to eligible beneficiaries involved: a community information and enrollment campaign conducted by state nurses; a direct marketing campaign with mailings to each beneficiary receiving state plan PAS services; and a toll-free telephone number. Consumers who wished to participate but were unable to manage their own services were allowed to designate a representative to act on their behalf if they were selected for the cash benefit. The State contracted with two human services organizations to provide counseling and fiscal services – one a for-profit organization with expertise in rehabilitation services and the other a nonprofit organization providing schooling and supportive services to children and adults of all ages. Fiscal services were provided to consumers without charge and included preparation of payroll documents, check-writing, and bookkeeping services. Nearly all consumers elected to use the fiscal services. Those who did not were required to demonstrate sufficient knowledge and competence before assuming payroll responsibilities.

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


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

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


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

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

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

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

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


This report is a detailed analysis of nurse practice acts and regulations in relation to consumer-directed care in 50 states. It examines current state nurse practice acts and their implementing regulations to determine the extent to which they permit consumer direction in home- and community-based services for older adults and people with disabilities. State regulations that govern the practice of registered professional nurses often affect the extent to which consumers are permitted by the state boards of nursing (who are responsible for protecting the public) to direct care received from unlicensed assistive personnel (UAPs). Three key issues affecting state policy and practice with regard to consumer-directed care are reviewed. First is the statutory and regulatory language that pertains to delegation, including: who may delegate; tasks (especially medication administration) that may be delegated; in what setting and with what supervision can tasks be delegated; and what are the training requirements for individuals who provide the delegated services. Second is the legislation of exemptions by some states that permit nursing tasks to be performed by persons who are not nurses. The last is the issue of liability or the “accountability” of the nurse for delegation.
The report presents multiple approaches to support consumer-directed care with varying degrees of flexibility. A handful of states have made substantial progress in developing nurse practice policies that specifically address consumer direction. Consumers in these states have been active in the policy debate, although the emphasis has often been more on independent living settings and personal assistance programs than on the full continuum of home- and community-based care, including assisted living. The author recommends that stakeholders (nurses, consumers, and policymakers) in targeted states meet with representatives from model states to learn by their example how to: put policies into practice; balance consumer protections and independence; and implement demonstration programs and evaluations as needed.


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


This comprehensive report analyzes liability issues that may arise for each person or entity involved in consumer-directed personal assistance (CDPAS) programs (the worker, the consumer, the consumer’s representative, the fiscal agent, consultants, and the State), and
suggests steps to reduce their exposure to such liability. It addresses the Cash and Counseling Demonstration programs implemented in Arkansas, Florida and New Jersey; California’s In-Home Supportive Services Program (IHSS); and New York’s CDPAS Program.

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

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


This report presents 25 detailed case studies of adults with disabilities who received a cash allowance of at least $200 per month in the New Jersey Personal Preference program, focusing on how “care units” (composed of consumers and/or representatives, paid workers, and counselors) interacted around issues of consumer-directed care. The report addresses these questions: (1) has Personal Preference made a difference in the lives of consumers, representatives, and workers and, if so, how; (2) how does participation in Personal Preference
compare with previous arrangements; (3) how are services provided; and (4) how does the program work?

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


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


This article discusses the IndependentChoices intervention in Arkansas, in which consumers received a monthly allowance to purchase care-related goods and services that promoted independence or increased mobility. IndependentChoices did not screen applicants for
appropriateness, in part because such screening was inconsistent with the philosophy of consumer direction. The program enrolled 2,008 beneficiaries who were randomly assigned to the consumer-directed (treatment) group or the control group (eligible for agency-delivered personal assistance services, as usual). Counseling and bookkeeping services were provided at no direct cost to consumers. Counselors reviewed spending plans and monitored consumer well-being and the use of the allowance. Consumers were permitted to select representatives to assist them in directing care or making decisions. Data was compiled from in-person interviews with program staff, a mail survey of program counselors, and telephone interviews with consumers who had received the cash allowance.

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

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


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

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

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


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

The question of who should train providers remains controversial. While the aging home-care community believes providers should be trained by professionals, the consumer community believes that training should be done by the consumer. Policy experts and providers believe that it is also essential to train family members who may play an important role in care
decisions for the consumer. Policymakers also believe that technical assistance on quality assurance and legal issues involved in consumer-directed care should be provided to both policymakers and payers. Access to “best practices” currently employed in consumer-directed programs may provide both technical knowledge on implementing consumer-directed programs and answers to questions about the mechanics of waivers, alternative implementation models, and policy options.


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


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

- The consumers’ ability to manage consumer-directed services and the need for flexible programs to accommodate diverse consumers and consumer preferences. The C&C experience indicated that consumers who knew their caregivers already or were paired with representatives were most likely to have their needs met.
The potential for family decision-making to override consumer choice. The C&C experience indicated that more research is needed in this area, as not enough data was available to decide whether or not this is a valid concern.

The potential for fraud and abuse. Overall, abuse was not a problem in C&C, although the study indicated a need to provide specific training and assistance to consumers about the tasks associated with being an employer.

The level and types of training needed by consumers. C&C provided training in handling financial responsibilities, handbooks for consumers capable of utilizing them, and arrangements for fiscal intermediaries in the majority of cases.

Worker shortages. C&C found that family members were most often hired as care providers, thus canceling the need to find outside workers. Emergency back-up services remained a challenge for most consumers.

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

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

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


This article presents findings from a telephone survey of 491 Medicaid personal care clients that was designed to: assess their interest in a consumer-directed cash option to pay for personal care services in lieu of continuing to receive agency-based services; determine what types of consumers would choose to self-direct; and identify what features of the cash option are
most attractive to consumers. This information was to be used by the Arkansas Cash and Counseling Demonstration and Evaluation Project to design various cash option components (including counseling services) and develop social marketing approaches that would enable consumers and surrogates to make an informed choice between the consumer-directed and traditional agency options. Pre-survey consumer focus groups had difficulty understanding this new concept, and the effort to inform was complicated by the prevalent lack of high school education in Arkansas (>80% of survey participants).

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


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

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

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


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

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

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

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

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

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


This study examined the experiences of a functionally impaired Medicare population participating in a consumer-directed model for in-home care that was being tested as part of a Medicare demonstration from July 1998 to June 2002 (*A Randomized Controlled Trial of Primary and Consumer-Directed Care for People with Chronic Illnesses*, CMS #95-C-90467/2-01). Participants in parts of West Virginia/Ohio and Western New York State were offered a maximum $3000 per year consumer-directed benefit that they could use to pay for augmented home care. Participants were reimbursed 80% of the cost of these services on a monthly basis. The goals of the study were to: evaluate how a “medically vulnerable” Medicare population will use and manage a consumer voucher benefit; determine if cognitively intact and cognitively impaired Medicare beneficiaries differ in the way they use and manage the voucher benefit; and describe the types of local agency supports needed to help impaired Medicare beneficiaries use and manage the consumer-directed benefit.
To meet these goals, researchers conducted a series of focus groups with consumers/family caregivers who: hired in-home workers directly; used in-home workers from agencies; or used the voucher primarily for supplies and equipment. Further, they conducted in-depth personal interviews with 21 consumers and/or their informal caregivers; evaluated six case studies of consumer direction “in action;” and analyzed the results of satisfaction surveys completed by all participants at 10 and 20 months. They found that: satisfaction with the consumer-directed model was very high, due primarily to the model’s flexibility; Medicare beneficiaries were willing and able to self-direct; and cognitively impaired individuals were able to participate in consumer direction, provided they had someone to manage services on their behalf. Both cognitively intact and cognitively impaired participants needed help in managing services, identifying workers, handling the paperwork associated with employment, etc. The authors recommend that any future model include a fiscal agent to assist with paying workers and allow the hiring of relatives as workers. In conclusion, a consumer-directed model is a viable option for a Medicare population, including those with cognitive impairment. It serves to extend in-home care for a growing group of beneficiaries who otherwise would go without these services. A flexible consumer-directed benefit yields high satisfaction among beneficiaries without jeopardizing quality of care.


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

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

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


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

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

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

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

---


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

Study results indicated that quality of life and quality of care improved without any negative impact on service quality or consumer safety. Consumers reported high satisfaction with self-direction and strongly endorsed the program because it supports autonomy and choice.
Both consumers and case managers believe that this program prevents utilization of more expensive services to provide routine care, such as nursing homes and emergency rooms. The program was well implemented – with few logistical issues or barriers to ongoing service. The biggest challenge was assuring adequate staffing, which is part of a broader labor issue affecting consumers and workers in all long-term care settings.

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