CONSULTANT TRAINING PROGRAM

Module One
Facilitating the Paradigm Shift for Consultants/Support Brokers

Module Two
The Dynamics of Choice and Decision-Making for Participants

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Appendix A:  
Annotated Bibliography

Section One: Participant-Direction/Aging


This study describes a pilot cost share program in Florida that examined differences between two models of delivering community based services (CBS), case management and service coordination, and the factors that determine which model should be used for individual clients. The study employed Anderson's model of health care utilization to explain the relationship between predisposing, enabling, and need characteristics in the case management and service coordination models.

Service coordination is an innovative approach to providing CBS and an alternative to the case management approach traditionally used under the Older American’s Act, where the case manager decides what CBS will be provided to the client. It reflects both an effort at cost reduction and enhancement of consumer choice. Service coordinators have a more limited role than traditional case managers in that clients (as opposed to case managers) are the decision makers regarding service use.

The service coordinator model is more cost effective because service coordinators spend less time with clients and, by the nature of their more limited role, are less costly to employ. The critical challenge is how to determine whether individual clients need the more intense case management services or the less intensive supports provided by service coordinators. The authors found that elders were more likely to be assigned to a service coordinator in the Florida CBS program if they had fewer ADL and IADL impairments, no caregiver, and were living alone. Frail clients who lived alone, had a caregiver, and had multiple ADL and IADL limitations were more likely to be assigned to a case manager. Thus, clients received either service coordination or case management based upon their level of need.


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, 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.


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.


The basic tenets of two popular theoretical approaches in social work and their application to consumer-directed programs for older adults who face physical, mental and resource-related challenges are explored in this article. The authors, each of whom advocates for one of the models, discuss similarities and differences between these two approaches, as well as their application in consumer direction. Both approaches stress work across various levels of practice (personal, interpersonal and political) and the potential of older adults to be active participants in decisions and actions that affect their quality of life. The strengths-based approach focuses on emphasizing elders’ strengths, not deficits, in planning and providing services to help them maintain their independence. The empowerment approach supports strong client participation and mutuality
in the helping relationship, two tenets espoused in consumer-directed programs. While these approaches are not identical in their philosophy, they share a similar commitment to maximizing the involvement of elders in determining and directing the services they need in their lives. In conclusion, Chapin and Cox challenge professional social workers and social policymakers to re-examine their assumptions about the abilities of elders to participate in decision-making.


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). It describes the ethical and philosophical underpinnings of consumer-directed care, least restrictive alternatives, and the concepts of “respect for person” and “most liberating alternative,” as they apply to the development of home care services directed by care receivers. A comprehensive overview of the historical development of publicly funded services is presented, with an emphasis on distinguishing between medically-supervised services and personal assistance services of a non-medical nature.

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 not only payroll functions but also 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 recognize that consumer-directed personal care is under-utilized by families caring for an individual with Alzheimer’s or other dementing illness for the following reasons: lack of publicity, inability to hire immediate relatives, and lack of understanding of the program by potential clients, case managers and hospital discharge planners who commonly refer clients for services, and labor unions. In order for persons with cognitive limitations to participate in a CDPAP, they must have a surrogate who can access extensive supportive services. In addition, making this option available to persons with cognitive limitations will require the development of broad based advocacy support beyond that of individual agencies (like the Alzheimer’s Association), especially to reach non-English speaking populations.

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 relate 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 reports the results of telephone interviews of 883 older adult clients in the Massachusetts Home Care Program, which is administered through 27 local, private non-profit Home Care Corporations (HCCs) and serves 33,000 clients. The survey was designed to determine whether elderly home-care consumers were willing to assume more responsibility for planning and supervising their own care by hiring, paying, scheduling, supervising and/or firing their home-care workers.

Although respondents reported high levels of satisfaction with the services they were receiving, a quarter to a third felt they were capable of taking more responsibility for supervising a worker, and needed less assistance from their case managers. A respondent's willingness to assume greater responsibility was associated with: prior experience in directing an in-home worker; receiving home care services for a longer period of time; greater current involvement in directing a home-care worker; and less satisfaction with current services. The authors point out that their findings were influenced by the fact that people with less severe disabilities were more likely to participate in the survey, and respondents may have indicated a willingness to accept less attention from a case manager but did not necessarily want less. For this reason, they suggest that pilot projects are needed to develop and test options for older people with disabilities to self-direct their own personal assistance. Offering more options for self-direction might be cost-effective, in addition to giving older adults more independence and control over their lives.

Focusing on case management as defined and practiced by social workers, the author explores a wide variety of long-term case management models currently being used in providing community based services to older adults in the community. The author compares and contrasts the following models: Channeling; PACE (Program of All-Inclusive Care of the Elderly); Social HMO; Project CARE (Community Action to Reach the Elderly); HMO Case Management; Community-Based Long Term Care; Modified Community-Based Long-Term Care; Geriatric Evaluation and Management (GEM); GEM-VA (Geriatric Evaluation and Management—Veterans Administration); Post-Acute Care Management; and Physicians Practice Case Management. These models reflect the traditional Moxley (1977) case management model in that they are system-driven, cost-constraining, and behavior controlling. The major locus of control is the agency providing the services and the case manager who functions as gatekeeper to access services. Despite the growing interest in consumer-driven case management, these models fail to demonstrate any effort to develop or maintain self-help options for older adults. Hyduk recommends modifying current case management models for older adults to include: (1) a broader definition of “frail elder” that would include elders with some limitations, but not the extensive disability required to make them eligible for services under the current definition; (2) a greater effort to reach out to minority elders and develop culturally sensitive case management approaches; and (3) a greater emphasis on strengths-based, consumer-directed approaches to case management.


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, and acting responsibly to promote their health and safety. The authors put this ethical dilemma into 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.” They 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 assumptions by their surrogates 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 summarizes the work of the National Institute on Consumer-Directed Long-Term Services as an introduction to the concept of consumer-directed care, specifically as demonstrated in the Cash and Counseling Demonstration and Evaluation Program. Polivka suggests that such a model is particularly appropriate for frail elders for the following reasons. First, elders value their autonomy, especially with regard to remaining in their own home. Second, choice is important to elders in the selection and delivery of services. Finally, the evidence suggests that consumer-directed options result in greater satisfaction among recipients and are a cost-effective alternative to institutional care or services provided by an agency.


This presentation, based on telephone interviews conducted with 20 policy experts in the aging and disability communities, documents a paradigm shift in the aging community to embrace the philosophy and orientation of the disability community concerning the delivery of home-and community-based service. It examines existing barriers to consumer-directed Personal Assistance Services (PAS) for the aging community that allow informed consumers to make choices regarding the services they receive. These include: paternalistic attitudes toward the elderly; skepticism regarding whether elders want such services; and the traditionally limited goal of merely keeping older consumers out of nursing homes. Factors are discussed that have led to a collaboration
between the disability and aging communities, including: funding issues; the Health Care Reform Task Force of the Clinton Administration; and changing demographics brought about by the aging baby boomers. In conclusion, the author stresses the need for a shared language between the two communities and further study on how to implement consumer-directed services for people with disabilities of all ages, the impact of managed care on consumer-direction, and the diverse characteristics of consumers.


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 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.

Section Two: Participant-Direction/Persons with Developmental Disabilities


The purpose of this article is to introduce the reader to two new players in the developmental disability field—the “Personal Support Agent” and the “Community Service Brokerage”—in the context of a case study from Oregon, and explain how they relate to each other. A Personal Support Agent (PSA) is “someone specifically hired to take over the coordination of the details of daily life or other identified responsibilities so that the employer does not have to worry about them.” As such, they are employees of the persons whose life they are helping to manage. PSAs have no prescribed set of tasks or official job description. In contrast to traditional case managers, who are responsible to the system, the role of PSAs is intended to be flexible and to support consumers’ daily life, their independence and their relationships with others and with the system. In Oregon, the PSA role has been included in its Medicaid Waiver Proposal for home- and community-based services, allowing individuals and families to access Medicaid dollars to pay for a PSA.

The Community Service Brokerage (CBS) is a new type of independent agency that supports self-determination in the lives of adults with intellectual disabilities and their families by assisting them to plan and manage their human support resources. Rather than providing direct services itself, the CBS functions as an intermediary between the self-advocate/family and the array of support options available. It provides four basic services: (1) planning and consultation; (2) identifying resources and supports; (3) service as a fiscal intermediary; and (4) finding PSAs. The authors conclude that these new strategies may not be for everyone, but feel they are a useful application of the values underlying the self-determination movement. The target population for this article is the practitioner working with individuals with developmental disabilities or interested in learning more about self-determination.

This article presents the results of a survey of 97 families of relatives with developmental disability (DD) who used paid respite or personal assistance services provided either by the Illinois Home Based Support Services Program (HBSSP) or by traditional agencies. It focuses on the outcomes associated with consumer control of services such as: recruiting, hiring and firing; training; selection and scheduling of services; and negotiating staff wages. The survey addressed how the extent of the family’s control over the management of services related to: caregiver appraisals (e.g., caregiver burden, caregiving satisfaction, and caregiving self-efficacy); satisfaction with services; community involvement of individuals with DD; and employment of the mothers outside the home. In addition, families were asked whom they hired to provide respite/personal assistance, and what their experiences were with recruitment and staff turnover.

The results indicated that greater control over respite and personal assistance services was associated with benefits for both caregivers and individuals with DD. Families who had more control over the management of their services were more satisfied with those services, although increased control did not affect caregiver appraisal or decrease caregiver burden. Greater control was also associated with increased community involvement of individuals with DD and increased employment of mothers outside the home. Families tended to hire friends, neighbors, and often other family members, which was associated with an increased community involvement of individuals with DD. Increased control was also associated with less staff turnover. The authors recommend additional research on preferences and outcomes surrounding the issue of hiring relatives as caregivers to guide future policies, as this continues to be a controversial practice, especially if care provision is seen as the “moral duty” of family members.


This paper is targeted at individuals interested in changing the existing system of providing supports to persons with developmental disabilities. The author begins by criticizing the existing bureaucratic system because decisions that affect individuals are made with little or no knowledge of the individuals themselves. She then proposes building a new network of supports based on Personal Agents who use the principles of self-determination—the autonomy of decision-making, self-advocacy, and opportunity—to enhance the lives of individuals they support. She recommends that Personal Agent teams be led, mentored, and supervised by a “Coach,” who has authority to organize the teams within a hypothetical “North Star unit” and to problem solve to make positive changes in the lives of the people they support. Each team takes responsibility for a specific number of individuals served and has freedom to redesign itself in whatever manner best serves their clients. Among the most important characteristics of a Personal Agent are: a strong sense of social justice; a commitment to and understanding of self-determination; empathy with the people supported; a belief in the value of every human life, despite disability; courage to take a stand on behalf of the persons supported, etc. A North Star unit must have an understanding of how money flows, must put decision-making in the hands of individuals with disabilities, and must support a cultural shift from a bureaucracy to one that focuses on individual outcomes.

This paper is targeted at those wishing to learn about possible changes to the existing system of providing supports to people with developmental disabilities. It begins with the author’s plea to put systems change and responsiveness to people with disabilities onto a faster track, one facilitated by two new entities. The first is the “Personal Agent,” who represents “a hybrid of support coordination and brokering,” and can transform the case management system into one more sensitive to the needs of the individual. Personal Agents, under contract to provide a variety of supports, work most effectively in a unit that is separate from the funding agency, preferably a private, nonprofit. Their responsibilities include implementing the principles of self-determination in the way in which they do their work and in the lives of those they support. These individuals should have, among other things: a strong sense of social justice; a capacity for empathy with the people they support; an ability to develop close relationships with those who receive support and all of the people who are important in that person’s life; a belief in the value of every human life, despite disability; and the courage to take a stand on behalf of those they support. The job involves working flexible hours, developing close relationships with the people they support, building a circle of friends, and negotiating with service providers on behalf of the individual.

The second entity to support systems change is the “Independent Broker,” who works to provide linkage with needed support or information in the community. A broker may provide expertise in only one area (like housing) or in a variety of areas. The characteristics desirable in Independent Brokers are the same as those for Personal Agents, but their job description is more specialized and depends on their area of expertise. Brokers can remain independent, work together as a collaborative, or work as a unit similar to those for Personal Agents. Cummings concludes that, “the cultural change needed is vast and deep, but quite doable and enjoyable to those who step out in front to try this new way of providing support.”


This paper, which is directed at professionals interested in implementing person-centered planning (PCP) or incorporated PCP into existing programs, presents results from a focus group discussion that explored PCP practices and their outcomes from the perspectives of nine participants engaged in one specific PCP planning model—Personal Futures Planning. The focus group consisted of consumers, parents, a friend, case managers, and service providers. Four themes emerged from the discussion:

1. Evolution of PCP circles or teams;
2. Inhibitors to the PCP process;
3. Supports to the PCP process; and
4. Longitudinal satisfaction with PCP activities and outcomes.

The circle development process was said to have similarities in all circles. First, circle of support groups began the process by identifying ways to meet the individual’s needs within the community. Next, they utilized the team’s resources to deal with problems as they arose, expanding the
team’s membership as needed. Finally, they celebrated their accomplishments and planned ways to implement their activities. Barriers to successful PCP included the limitations of the focus person/consumer (such as behavioral, intellectual, or family issues) and circle issues (such as scheduling meetings and commitment of circle members). PCP was supported first by the focus person/consumer and the family and, given time, by their community. Longitudinally, PCP appears to have had a positive impact on the consumers, as they were gradually making connections in both their families and their communities. All involved focus group participants expressed a willingness to continue with PCP.


This article is targeted at administrators and supervisors in the field of developmental disability. It explores obstacles to adopting person-centered planning (PCP) within an agency, particularly the difficulty workers may experience in accepting the values of PCP. Administrators can model a collaborative discovery process to help consumers get what they need. This involves accepting, from the beginning, that PCP is accompanied by a variety of concerns, and encouraging open discussion about differences of opinion among agency staff about the conceptual and practical difficulties inherent in its adoption. The authors suggest ways to deal with their skepticism, concerns, and varying degrees of acceptance of PCP values, as well as the issue of financially compensating professionals for the extra time the will have to spend with consumers. They feel that agency staff must be involved in the PCP process, since they have a vested interest. An important premise of this article is that ‘employees’ reservations are well-founded and should be addressed in order to facilitate understanding and eventual reconciliation of unavoidable conflicts that emerge when person-centered planning is undertaken by agency employees.” To this end, they recommend ways to enlist the assistance of employees who will be affected by any proposed changes, beginning with one person at a time. Next, the article addresses the need to develop resources within the community to support the individual at the center of the PCP process. Without these resources to fulfill the needs of consumers, PCP cannot succeed. The authors also indicate that there must be a redistribution of monies within the system to accommodate allowing consumers and their families, rather than existing agencies, to decide what is best for them.


This article provides an overview of consumer-direction, beginning with its origin in the Independent Living movement and definition—“a philosophy and orientation to the delivery of home- and community-based services whereby informed consumers make choices about the services they receive.” It provides a rationale for a shift from traditional services to consumer-directed care that includes promoting self-determination and the dignity of people requiring personal assistance and cost saving when programs are properly designed. The author attributes the current interest in consumer direction to awareness that future recipients of publicly funded long-term services will probably differ from current recipients and have different expectations. Further, the system will have to respond to a new demanding population—people with disabilities who are living into old age. Lastly, the author identifies the major players in consumer direction: charitable foundations such as The Robert Wood Johnson Foundation (RWJF); federal policymakers, especially the Office of the Assistant Secretary for Planning and Evaluation (ASPE)
in the U.S. Department of Health and Human Services; state-level policymakers; and advocacy
groups such as The National Council on the Aging.

A brief summary is provided of the Cash and Counseling Demonstration and Evaluation Project
funded by ASPE and three RWJF projects: The Self-Determination Project developed in New
Hampshire in 1993 to address the high cost of care, growing waiting lists, and consumer dissatis-
faction; the Self-Determination for People with Developmental Disabilities Project, an expansion
of the New Hampshire program; and the Independent Choices: Enhancing Consumer Direction
for People with Disabilities grants program, which funded 13 demonstration projects to develop
home- and community-based services for individuals across disabilities. The purpose of these
projects was to encourage states to develop services for individuals wishing to manage their own
care and to facilitate flexible funding. Nadash concludes that, until recently, there were only a few
isolated consumer-directed programs. However, these new initiatives should set consumer-direct-
ed practice on a firm basis for the future.


   In this paper, directed at professionals in the disability field who are interested in system change,
Nerney explains why the time has come to begin fashioning what human services for individuals
with developmental disabilities should look like in this century. He advocates for fundamentally
re-structuring human services and changing the Federal Medicaid and Social Security income
programs in ways that will “remove irrational prohibitions on living, working and truly being
part of one’s community.” The current crisis in the Medicaid program—with scarce Medicaid
resources, a shrinking workforce, and an increasing population of elderly and people with devel-
opmental disabilities who need services—may be viewed as “The Perfect Storm” that will destroy
the existing developmental disability system. He says that now is the time to forge a new and cost
effective “system of the future” based on the principles of self-determination, which include:
freedom in decision-making; authority; responsibility to use monies wisely; and confirmation that
individuals with disabilities and their families need to be included in re-designing the system.

   Nerney introduces the reader to The Freedom Initiative, a planning template for an actual SSI/
Medicaid set of Waivers that grew out of the work of a small public/private think tank in Wash-
ington, DC that was hosted by the President’s Committee on Mental Retardation and The Office
on Disability in the Department of Health and Human Services. The goals of this initiative are to:

- Secure a waiver under Social Security to allow individuals enrolled in self-determination to in-
  crease their income and assets;
- Secure a 1115 Medicaid Waiver that permits waiving those aspects of the Medicaid program that
  hinder living and working in the community;
- Allow individuals to enroll in both the proposed Social Security and 1115 Medicaid Waivers in
  order to encourage creative approaches to housing, work, and meaningful lives;
- Determine the cost effectiveness of this increased flexibility and reduction of disincentives
to work;
- Create a statewide training effort to maximize the effectiveness of using both waivers
  simultaneously; and
Develop a model systems re-design for developmental disabilities that can be replicated and is cost effective.

Nerney concludes that, when the current ceilings on income and asset limitations are raised and Medicaid funds can be used more flexibly, individuals will “overcome their resistance to earning money privately, take their place as ordinary citizens and resolve housing and transportation problems more efficiently.”


The target population for this article is individuals providing direct service to youth with disabilities. The paper discusses the development of self-determination skills by students with disabilities and underscores the role of professionals in helping youth develop these skills. Paraschiv sees the role of professionals as integral to the success of self-determination since they can provide the information and skills training needed by individuals with disabilities. Moreover, they can work to change the system to provide more opportunities for self-direction. The author presents 25 elements of self-determination and basic and secondary leadership characteristics, and discusses the importance of developing self-advocacy groups and other endeavors initiated by and for individuals with disabilities. Barriers to leadership for individuals with developmental disabilities are also identified. This paper supports the position that people with disabilities can be self-advocates or community leaders if they possess qualities of leadership (such as skill in dealing with people, capacity to motivate, and the need to achieve), and are given both opportunity and support. Further, it highlights how reforming systems can provide greater opportunities for choice and self-direction. It also compares self-determination and leadership skills, and provides a list of what professionals can do to enhance the self-determination process.


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 provide examples of strategies to overcome obstacles. These examples include observing what workers do, not just listening to what they say, and recruiting the people who
are being helped to provide input and put pressure on the system and workers for change. Tables are provided to illustrate the new paradigm, culture shift, and what needs to change within the system, as well as to summarize the work. 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 use of an implementation group and its roles in the process of change are also explained. 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 paper is one of a collection of papers commissioned by the Joseph Rowntree Foundation to explore the experiences in the UK of using person-centered planning (PCP) and to develop a better understanding of what is being achieved PCP and what barriers exist to its continued development. It defines PCP as “a process of continual listening, and learning” that focuses on what is important to someone now and for the future. Based on a completely different way of seeing and working with people with disabilities, PCP is about sharing power and community inclusion. It should be used by self-advocates, families, friends and paid support staff. Sanderson identifies the five key features of PCP as:

1. The person is at the center;
2. Family and friends are partners in planning;
3. The plan reflects what is important to the person, his/her capacities, and what support is required;
4. The plan results in actions that are about life, not just services, and reflects what is possible, not just what is available; and
5. The plan results in ongoing listening, learning, and further action.

Sanderson also explains what should be included in a person-centered plan and how to recognize good person-centered planning, and introduces the reader to a number of common planning styles—PATH, MAPS, Essential Lifestyle Planning, and Personal Futures Planning. She explains the differences between styles and when each style should be utilized, and points out that assessments done using PCP focuses on the individuals’ capacities, not their impairments, and reflects actions they wish to take, not just the services they need. Sanderson concludes that PCP should be used primarily with individuals and families who get the least from the service system, and should incorporate a circle of support. PCP “creates opportunities for us to change our lives and our relationships, to share power and listen in a deeper way, and discover what inclusive communities are really about.”

This paper is directed at supervisors or administrators working with persons with developmental disabilities who are interested in changing to person-centered planning (PCP) or are in the process of changing to PCP from a traditional medical service delivery model. The authors feel that the key issues in training caseworkers are to allow them to have ownership of the new program and ensure that their ideas and suggestions are incorporated into the change process. They caution that, if resources are not in place before changing the method of service delivery, any attempt at change will fail. They feel that the community needs to also be active in the planning process to ensure that direct line staff have community contacts in a wide variety of areas to call upon as needed. They conclude that PCP is a process, not something that happens without forethought and planning.

**Section Three: Participant-Direction/Cross-Disability**


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 article, written by a private duty nurse, provides a brief review of the current movement toward consumer-directed care and the differences between consumer-directed and traditional services provided by an agency. The author reminds the reader that, prior to the implementation of Medicare in 1965, consumer-directed care was the sole method of providing services to individuals in need of home-based care. It was only after the federal government got involved in paying for home-based services that the agency-based model of care gained prominence. The author stresses that, not only does consumer satisfaction remain high under the consumer-directed model, consumer-directed care represents a significant cost savings (estimated at only 30% of the cost of agency-based care). Care under the consumer-directed model is associated with continuous one-on-one personal care services, the ability to modify care plans as needed, and an increased feeling of control for consumers who can select and regulate their own services. Moreover, there is no evidence that the services provided under consumer direction are either substandard or inappropriate. Catalano urges policymakers in both the public and private sectors to continue working to make alternative models of care available to consumers and their families.

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.

Consumers who were currently receiving a limited number of agency-based services were more interested in the cash option than those who were receiving a greater number of services. 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 almost three-quarters of survey participants had a high school education or less, suggesting that outreach and marketing materials must be simple and straightforward to ensure that consumers are able to grasp the purpose of the program and make an informed decision regarding enrollment.


This report presents the findings of a telephone survey of both consumers and personal assistance workers that compared two alternative approaches to delivering publicly-funded personal assistance services (PAS) to the elderly and disabled in California’s In-Home Supportive Services (IHSS) Program—a consumer-directed model (CDM) and a professional management model (PMM). The purpose of the research was to find out whether these alternative modes of service delivery were more, less, or equally likely to bring about a variety of positive outcomes such as: greater client satisfaction with services; greater client empowerment; improved health status; greater reliability and continuity of service; greater ability to attract qualified workers; and higher job satisfaction for workers. The study also examined whether one or the other service
delivery model was more likely to produce negative outcomes such as: more reported incidents of abuse, neglect, or mistreatment; a higher level of concern for safety among clients; more unmet needs; or poor working conditions for home care workers.

The study’s most significant finding is that, whereas both models had positive client outcomes overall, the CDM significantly outperforms the PMM within three broadly defined areas—client satisfaction with services, empowerment, and quality of life—whereas there were no significant differences between the two models in reports of unmet needs or abuse or mistreatment. CDM consumers who hired family members as paid workers reported a greater sense of security, more choice and control about how worker performed their tasks, and a closer rapport with their workers than did consumers who hired non-relatives. Further, CDM clients were more likely to receive unpaid help from relatives and friends than were PMM clients.

With respect to home care workers, the study found significant differences between the two models in pay and benefits. Workers in the PMM received, on average, higher hourly wages and were also more likely to receive health and other benefits from their employer than were workers in the CDM. However, workers in both models reported generally high levels of job satisfaction. PMM workers experienced more positive emotional states than CDM workers and less worry about client safety, whereas CDM workers expressed more closeness and compatibility with consumers. The frequency of family members as workers in the CDM probably accounted for the greater concern about client safety in the CDM group.

Critics of the CDM, concerned about client safety, have suggested restricting consumer direction to a minority of clients judged by social workers to be capable of hiring, firing and directing their workers. Further, they have questioned the appropriateness of allowing public program clients to hire family members as providers. The authors conclude that study findings do not support restricting availability of the CDM. Nor do they support hiring only unrelated workers because family workers were more likely to provide a higher quality of service than unrelated workers.


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 MED-
STAT 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 article is specifically targeted at nurses, but has useful information for other healthcare providers. The author gives an overview of the consumer-directed home care model piloted by numerous Medicaid programs, and explains the rationale for a change to a consumer-directed service delivery model (CDM). First, the need for assistance with activities of daily living (ADLs) does not render individuals incompetent to make decisions about their care. Moreover, people should be maintained in the “least restrictive environment,” and there is a pressing need to cut the cost of services. Hanchett looks briefly at the impact of the change on traditional health care providers, evidenced by loss of potential revenue and a shortage of qualified agency staff. She feels that the success of the CDM is difficult to assess due to the current scarcity of outcomes research, and she calls for more research to compare its success in relation to traditional models. After discussing the impact of the Internet on health care delivery and the use of “patient-directed models” by pharmaceutical companies, she concludes by encouraging nurses to embrace CDM. There is an excellent table illustrating the differences between agency-directed and consumer-directed services.


In this paper, the author identifies five different models of home care service delivery:

1. The civil service model (in which a government agency runs the home care program and provides the services);
2. The contract model (in which the government contracts for services with a private home care agency);
3. The home-care agency model (in which the consumer contracts directly with a home-care agency);
4. The government as fiscal agency model (in which the consumer contracts directly with a provider but the government acts as the fiscal agent); and
5. The consumer-directed model (in which the consumer is given a cash benefit or voucher and is responsible for all aspects of employing the home care worker).
These models present a diversity of legal and social policy concerns in the areas of: professional malpractice; funding sources; labor law issues; licensure restrictions; the role of the family; and questions regarding the consumer's rights in cases of diminished mental capacity. While the consumer-directed model promises to minimize the paternalism associated with the agency-based model's design and implementation of care, Kapp cautions agency administrators and program planners to determine how to balance a consumer's right to make individual decisions regarding his/her care with the State's responsibility to protect the consumer from being exploited.


This article targets both professionals and non-professionals with an interest in learning about options available to health care consumers. The author discusses the advantages of consumer choice, such as leading to a more competitive, efficient health care marketplace and a reduction in consumer stress due to an increase in autonomy. He feels all healthcare personnel, including physicians and physical therapists, should be informed about available options for consumers. Websites are recommended that offer information to consumers about their options.


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 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.

While consumer-directed care is designed to encourage active involvement among persons with disabilities in the design of their own care, as well as a sense of being in control, another benefit appears to be a significantly increased ability to overcome disability to become or to remain productive in society. Based on a series of surveys of persons with disabilities in Virginia, this report compares persons receiving personal assistance services with a similar group on the waiting list for services. Individuals who were using consumer directed personal assistance services showed greater productivity than those on the waiting list for services. Productivity was defined in terms of activities (i.e., paid work, attending school, homemaking, home maintenance, volunteer work, recreation, and self-improvement). The authors conclude that supporting people with disabilities with consumer-directed personal assistance services could have a substantial positive effect on their employment and literacy rates, tax revenues, and the overall productivity of society.


Drawing from two research-based projects (The American Bar Association and World Institute on Disability studies), this article examines the legal, regulatory, and administrative environments surrounding supportive homecare or personal assistance programs and the variables that influence the extent of consumer direction that can be achieved and the goals of consumer choice and control. The two studies assessed the impact on consumer direction and choice of four issues related to the design of programs and their service delivery systems:

1. Limitations placed on who can be a provider;
2. Agency limitations on service provision;
3. The consumer’s role in determining a care plan; and
4. The need to train the consumer.

Study results indicated that, although an array of provider types exists (e.g., agency provider model, independent provider model, and government employees), consumers themselves have limited choice regarding the type of provider they prefer. Rather, the program makes that choice. Of all provider types, the independent provider model offers consumers the greatest choice, but may also bear the greatest risk surrounding the quality of services. Different provider models also result in significant differences in worker pay and benefits, with consumer-paid providers receiving the lowest pay and smallest number of benefits and agency-paid providers receiving higher pay and more benefits.

With respect to services provided, agencies restrict service provision to a menu of services such as assistance with activities of daily living, light housework, and meal preparation, while independent providers have greater flexibility in the range of assistance provided. The consumer’s role in determining a service plan varies. However, the authors recommend that consumers be afforded a clear statement of rights and a formal contractual agreement between consumer and provider. Regardless of the provider type, there is a need to train the consumer in the ongoing management of services. Training should concentrate on developing skills in supervision,
communication, and negotiation; and how to exercise one's rights, understand the range of services, and evaluate providers.


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 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, directed at policymakers, 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. Payments to family caregivers range “from coverage of a limited amount of respite care under Medicare to tax credits to individuals who provide dependent care for household members with disabilities.” 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 authors detail research methods and design and examine the significance of consumer background and demographics.

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. Inter-
ested 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 addresses the many unanswered questions regarding how to implement consumer-directed personal assistance services—in general, and especially for older persons. The authors report on 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 Cash and Counseling (C&C) program found 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 since it was not clear, either way, whether family decision-making might override consumer choice.

- Fraud and abuse. Overall, abuse was not a problem in the C&C program, although preliminary study results demonstrated a need to provide specific training and assistance to consumers with the tasks associated with being an employer.

- The level and type of training needed by consumers. The C&C program made training in handling financial responsibilities available to consumers. They provided handbooks to consumers who were capable of utilizing them and arranged for fiscal intermediaries in the majority of cases.

- 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, although each of the three studies provided essential information for planning the
CCDE, examining them 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 article addresses the policy and practices of care management (i.e., the system for assessing care needs and arranging services to meet them) developed under the legislative framework of the National Health Service (NHS) of the United Kingdom and 1990 Community Care Act. The author begins by contrasting the rhetoric of “client empowerment,” as espoused in traditional social work professional education, with the “disempowering” reality of providing care management within a service system that limits the ability of consumers to participate in the coordination and provision of their own care. Tanner discusses conflicts contained within the legislation and associated guidance and cites contradictions inherent within the development of care management as a policy and evident at the level of practice. The paper argues that organizational processes and procedures decrease opportunities for client empowerment and reinforce the power of care managers at the expense of service users.

The true implementation of consumer empowerment (as is intended in models of consumer-directed care) makes the following assumptions:

- Consumers are free to assess their own needs;
- Consumers are afforded the opportunity to assess their needs;
- Services exist to meet those needs and resources are available to pay for necessary services; and
- Consumers, rather than an agency or professional, can choose and monitor their services.

Tanner points out that it is rare for all of these conditions to exist, which greatly restricts the choices available to the consumer. Further, although policy makers may design service delivery systems with the intent of encouraging consumer empowerment, limited resources together with an organizational culture of “professional as expert” challenge the successful implementation of consumer-directed models. The real hope for empowerment lies in the encouragement and support of user-led initiatives in service planning, evaluation and provision.


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.
Appendix B: Annotated Bibliography

Paradigm Shift/Adult Learning


This book, directed at educators of adults, focuses on the philosophical and epistemological foundations of the process of transformative learning. Since its introduction by Jack Mezirow in 1978, transformative learning, a process designed to develop autonomous thinking, has been a topic of research and theory building in the field of adult education. Cranton explains that it has evolved over two decades “into a comprehensive and complex description of how learners construe, validate, and reformulate the meaning of their experience.” She identifies the essentials of adult learning styles and needs, and presents a full discussion of a number of critical responses to Mezirow’s original theory that have emerged over the years. She defines transformative learning as the process of examining, questioning, validating and revising one’s perceptions that involves a fundamental shift in one’s assumptions and values about why or how things happen. With adults, this process involves empowering the learner to see him or herself as a decision-maker, encouraging the self-reflective process to identify current assumptions and beliefs, and revising those assumptions to reflect the reality of a changed situation. She concludes that, because people learn in different but interwoven ways, educators should not see transformative learning as the only goal of education.


This book provides the educator of adults with a clearly written guide to understanding the complex aspects of techniques and methods of the teaching and learning encounter. It offers a rich overview of the basic principles of adult learning, both as a process to be understood and as a specific method and approach to education, and emphasizes the importance of the educator’s attitude and enthusiasm. Part One, “Understanding and Facilitating Adult Learning,” examines: characteristics of a good teacher; understanding adults as learners; philosophical and teaching style orientations; designing instruction; motivation strategies; and ethical reasoning. Part Two, “Methods and Techniques,” describes an array of methods and techniques to use in the classroom. The premise of the book is that, by acquiring a greater understanding of the process of helping adults learn and the methods that can enhance this process, teachers and adult learners can increase their chances of sharing a positive, meaningful, and developing educational experience.

Based on her own work in the theory of transformative learning, Imel reframes the discussion of adult learning in terms of the significance of change as an integral part of the learning process. She points out that adult educators frequently act as change agents, although they may not be conscious that they are playing this role, so they need to recognize the connection between adult education theory and practice and the role of change. Because a change agent deliberately tries to bring about change, some adult educators may feel conflict in helping adults become more aware of how society is structured and how their own experiences have been shaped by such factors as gender, race, and class. However, they need to understand that the educational process involves putting the adult learning into a contextual environment if they are to understand how their interests affect their motivation to learn. She concludes that there is a constant need to revise and reassess the learning process to give adult learners opportunities to apply what they have learned.


The author explores the basic principles of adult learning as they pertain to the development of workshop and training programs. Teaching adults is currently known as “andragogy,” as opposed to “pedagogy,” which is the traditional teaching of children. Andragogy identifies learners as self-directing rather than directed by a teacher. Adult learners should not be dependent on workshop leaders or trainers, as they bring a vast store of experience to all learning situations and are able to determine their learning needs and desires. Three basic principle of adult learning are discussed in detail, with suggestions for ways in which to translate these principles into teaching/learning practices. First, adults bring extensive experience to a training situation. Therefore, they have a lot to contribute to the actual training session and a lot to lose should this experience not be validated by the trainer or others participating in the training session. Second, adults want training that focuses on real life—here and now problems and tasks. Third, adults are accustomed to being active and self-directed. Their most successful learning experiences occur in a cooperative and collaborative environment. Klatt concludes the chapter with a discussion of the different learning styles (accommodator, diverger, assimilator, and converger) and their implications for developing training sessions.


As the premier theorist of transformative learning, Mezirow offers an in-depth discussion of how this learning process, also known as the emancipatory paradigm, contrasts with the traditional objectivist and post-modern interpretist paradigms in regard to the explanation of how adults “know.” The objectivist paradigm identifies knowledge as objective—i.e., reality is rational and observable. This contrasts with the interpretist paradigm that attributes knowledge to understanding as a social act, contingent on an individual’s social construction of reality and the reaction to that perception of reality. He identifies the emancipatory paradigm as espousing that learning occurs when existing schemes of an individual’s perception of meaning are reframed, thus precipitating a need to change the way one acts. New behavior comes from
a critical reflection of one’s assumptions and changing those assumptions in the process of developing a new understanding of life events. He discusses the emancipatory paradigm as a dialectical synthesis of the objectivist an interpretive paradigms. His discussion is primarily epistemological, but provides a helpful explanation, on a theoretical level, of the differences between more common theories of knowledge and the transformative approach.


This book is an introduction to the basics of training that is applicable to most human services fields, as well as to businesses—the original intended audience. Beginning with an overview of the “why and how of training” in Chapter One, the author explores the purpose and processes of training. His review of the principles of adult learning and how adult learners differ from younger learners in Chapter Two is a concise, thoughtful assessment of the fundamental difference between “telling” and “training.” Chapter Three, “Analyzing Training Needs,” offers specific suggestions for determining the demographic, educational, job performance, and motivational factors that must be assessed in the process of establishing training objectives. Chapter Four focuses on detailed training objectives and “learner-centered” learning goals that are based on observable behavioral changes that can be measured. The four levels of evaluation (reaction, learning, behavioral change, and results-oriented evaluation) are discussed in Chapter Five, followed in Chapter Six by concrete suggestions for construction of lesson plans. Chapter Six also presents a comprehensive list of what to provide to trainees to maximize participation in training programs and the long-term effectiveness of the training, as well as compiling “learner packages,” the materials trainees should have in hand during the training session and for future reference. Chapter Seven concludes the book with an overview of skills and tools trainers often find helpful, such as Power Point, videos, and workbooks. This is a resource for trainers who are developing training materials or adapting existing training materials.


This monograph begins with an extensive review of all empirical and theoretical work that has been done on the concept of transformative learning (the process of making meaning of one’s experience), from Mezirow’s early theoretical work on rational transformation in the 1970s through Boyd’s concept of individuation and Freire’s view of social transformation to the present. The review identifies gaps and areas of controversy in Mezirow’s presentation, as well as research findings that attempt to elaborate on and broaden the theory. It is a concise summary of the common themes in several decades of academic research. An important assumption of this paper is that, although the theory is much discussed, the practice of transformative learning has been minimally investigated and is inadequately defined and poorly understood. To help improve practice, Taylor identifies specific teaching methodologies and techniques that promote transformative learning and delineates the roles and responsibilities of educators-as-facilitators and of learners in creating an environment supporting critical reflection and exploration of alternative perspectives. He admits that the time-consuming nature of transformative learning, if applied in its purest
form, and the essential presence of a predisposition of the learner to an intense learning experience are limitations of this approach. The appendices contain extensive bibliographic references to the use of specific activities that enhance transformative learning. One appendix organizes sources in the literature relevant to specific teaching-learning techniques, and a second tabulates the purposes and salient results of 46 research studies on transformative learning.


This paper summarizes the results of numerous empirical studies on fostering transformative learning (the process of making meaning of one's experience), all of which are heavily based on the work of Jack Mezirow who pioneered the concept. The studies reviewed support Mezirow's recognition of the importance of rational discourse and critical reflection for transformative learning in adults. Taylor suggests that future research needs to focus on the role of subjective factors in the classroom, including the role of relationships, how to manage emotions to promote reflection, and the educational outcomes of transformative learning.


Taylor offers a critical review of over thirty empirical studies of the transformative approach to adult learning based on the theoretical work of Jack Mezirow. He concludes that, although this approach has been accepted in mainstream thinking on adult education, there is insufficient evidence that it is effective in promoting significant transformation in the learning of adults. He suggests that additional research is needed to support the validity of this approach, including: greater attention to the significance of the context of learning; critical analysis of the role of demographic factors (e.g., race, ethnicity, age, and gender) on the transformative process; and exploring alternative ways of “knowing” other than critical reflection and dialogue. In particular, Taylor recommends that the affective component of learning be addressed as a necessary precursor to critical reflection, the mainstay of the transformative theory of learning.


This is the first of Jane Vella's seminal books on promoting effective adult learning by recognizing that adults learn in decidedly different ways than do children—“adult learning is best achieved in dialogue.” She presents 12 basic principles of dialogue education that are intrinsically related to one another. The approach to adult learning based on these principles holds that “adults have enough life experience to be in dialogue with any teacher about any subject and will learn new knowledge, attitudes, or skills best in relation to that life experience.”
The principles are:

- Assessment of specific learning needs must precede the development of training or educational programs.
- Adults learn more effectively in safe environments.
- Sound relationships must exist between teacher and learner and among learners.
- Learning activities must be sequenced and reinforced.
- Action on learned principles is contingent on reflection or learning by doing.
- Adult learners must be respected as decision-makers.
- Learning is composed of ideas, feelings, and actions.
- Adults need to see the immediate relevance of their learning.
- Teachers and adult students need to function in equal roles.
- Adult learners need to use each other in the learning process.
- Adult learners need to be engaged in the learning process.
- Learning is reinforced by accountability.

The text develops these principles through use of many examples from her work as an educational consultant for academia, human services, and international development.


The basic assumption of this, and Vella’s earlier books, is that adult learning is most effective when teachers involve their students in the learning process. She shifts the focus from “teaching tasks,” those things the teacher needs to accomplish in adult learning, to “learning tasks,” which actively involve the adult in the learning process as a “doer” rather than a passive recipient of information. Learning tasks are open questions that lead to open dialogue between the teacher and the learner. Specific examples are provided of the use of action-oriented verbs to identify learning tasks that can involve intellectual, affective, and psychomotor aspects of the learning process. To illustrate this unique approach, Vella provides seven steps to planning learning-centered courses, four types of learning tasks, a checklist of principles and practices, critical questions for instructional design, key components for evaluation, and other learning tools. She also shares real-world examples of successful learning programs, including online and distance-learning courses.


This paper presents a less theoretical description and discussion of transformative learning that most papers on this subject, with an emphasis on the importance of concrete behavioral change as “the hallmark of genuine learning and transformation.” The authors identify the contexts for transformational learning, including transformation for creativity and innovation, for problem resolution, and for cultural change—all of which are germane to developing the context for paradigm change. Consistent with the basic principles of this philosophy of adult education,
they identify several mechanisms by which transformative learning occurs—critical reflection, action oriented learning activities, and the power of dialogue between learners. The paper’s strength lies in its in-depth explanation of the importance to an organization of leadership perspectives that foster transformative learning, such as the promotion of safe, open learning environments and the recognition of the value of feedback and self-assessment.
Appendix C:
Annotated Bibliography

Evaluating Training Programs


The premise of this article is that the informal workshop evaluation style is being replaced by an outcomes-oriented approach. Andrews says that old myths center around: the hesitation to give tests as a form of evaluation; the perceived limitations of adult learners; and the misconception that participants will give feedback on their own if the program is not satisfactory. These myths have begun to be questioned as information has developed about the capacity of adults to learn.

The article separates evaluations into five categories according to type of workshop participants:

1. Individual Learners;
2. Learner-Interested Second Parties (e.g., supervisors or employers);
3. Program Developers;
4. Administrators; and
5. Certifying and Regulatory Agencies.

Andrews separates workshop evaluations into four basic types: (1) Individual; (2) Program; (3) Organizational; and (4) Performance. He explains the importance of integrating evaluations into the learning process, and allowing stakeholders to play a role in the evaluation process. The evaluation design should reflect the needs of all of the stakeholders, including the instructor, participants, and employer. Andrews then presents a model to integrate evaluation and feedback into program planning and the International Association for Continuing Education and Training's ten possible assessment plans (1991).


This book describes the process of evaluation for trainings in the for-profit sector including planning an evaluation, developing appropriate data collection instruments and associated data analysis models; obtaining data to evaluate training; systematically compiling and analyzing information; and reporting results and making recommendations.

The most important implications for this work concern recommendations for the creation of a questionnaire based on Kirkpatrick's first level (reaction). Examples of questions were given to assess general feelings about the learning experience, how well the actual training met course objectives, course strategy, perceptions of the instructor, and general opinion of the course. Each example includes multiple scales to measure each training concept. The author recommends paying careful attention to the structure of questions used in the evaluation process, emphasizing clarity, direct connection to the purpose of both the training and the evaluative process, and an approach that does solicit defensiveness on the part of the respondent.

This chapter identifies common sources of resistance to training evaluations and suitable responses to overcome this resistance. Evaluation data are categorized into two types depending on whether they are obtained by process or outcome evaluations. Process data are generated before and during the training, and evaluations based on process data compare what actually happened during the training to what was supposed to have happened according to plan. Outcome data reflect how the goals of the training were met. The text focuses on outcome data and the evaluations that are based on outcomes. The authors’ discussion follows Kirkpatrick’s (1979) definition of the four types of outcome—reaction, learning, behavior change, and organizational results.

The authors examine each of the four outcome categories separately and discuss suitable evaluation tools for each, such as reaction questionnaires (guidelines, benefits and drawbacks) in the reaction category. In the learning category, outcomes are divided into declarative knowledge (measured through pencil and paper tests, primarily multiple choice), strategic knowledge (involving probed protocol analysis), and procedural knowledge (measured through concept tests or paired comparisons). Strategies for measuring skills and attitudes are presented in the discussion of the learning category. Behavioral change is measured through interviews, questionnaires, direct observation, and performance records once the participant has returned to the workplace. Finally, organizational results can be evaluated via performance and productivity measurements at consistent intervals. Evaluation design limitations and benefits are discussed and information is provided for cost savings analysis, cost-benefit and cost-effectiveness evaluations.


This report describes the experiences of nineteen states funded by the Robert Wood Johnson Foundation to affect widespread system change in implementing self-directed services for persons with disabilities. Project funding ranged from $100,000 (for a 1-year period of implementation) to $300,000 (3-year period of implementation). Self-determination principles that guided projects concerned the role of the individual, specifically freedom, authority, access to support, and responsibility for their own lives within communities.

The evaluation concluded that systems based on self-determination need to be flexible to adapt to the wide range of available life choices. Families and individuals need the option to select services from both traditional agency services and innovative services available to them in the community. Successful implementation of self-directed services will require training of care managers, consumers, consumers’ support systems, and formal representatives. Extensive training is of particular importance in the development and implementation of consumer budgets as well as in training consumers in new roles as employers of the workers who provide service to them.

This chapter discusses the impact of training in terms of benefit to the organization as a result of the training—i.e., “impact of training is normally construed as the organizational benefits that ensue when improvements in competence are manifested in improvements in job performance.” Beginning with Leonard Nadler’s (1980) three training purposes (training, education, and development), the author breaks corporate training down into seven categories:

- **Type A**: Current Job Performance. This is the largest category and includes skills and knowledge development. Skills are regarded as either “soft” (communications, values) or “hard” (technical training).
- **Type B**: Advancement and Promotion
- **Type C**: Organizational Capacity
- **Type D**: Orientation and Acculturation
- **Type E**: Employee Capacity
- **Type F**: Leadership Capacity
- **Type G**: Personal Benefits

Brinkerhoff regards performance as the key indicator of training impact because training produces capability. However, the performance that results from that learned capability produces impact. Four strategies are presented to put impact evaluation into use. Strategy One assesses the partial effects of training. This is done through an experimental design (i.e., control group with a post-test for job production and effectiveness) to provide information on training effectiveness. The author notes that this evaluation may be too complex and expensive for most practitioners’ use. Strategy Two applies the Kirkpatrick Model (1975). The focus is on long-term training impact. However, the author notes that the model looks at training too simplistically and shows training leading directly to overall benefit, which may not always be the case. Strategy Three involves evaluating the immediate results of training. Evaluation at this stage typically measures employee satisfaction. The author explains that this type of evaluation reinforces the idea that the central goal of training is solely employee satisfaction, as it is often the only method used. Knowledge or skills acquisition are often not measured. Finally, Strategy Four involves the quality management process. Quality management focuses on consumers (as defined in the corporate context) and their goals and definitions of quality. The needs of the consumer must first be determined, and then the training and evaluation are designed to address those needs.


This article focuses on the gap in the present research concerning person-centered planning with a specific focus on the planning process. The study examines and provides examples of the person-centered planning process in action to clarify the mechanics of program implementation, participation in the planning process, and the nature and impact of the plans.
Facilitators were first trained on person-centered planning using a “natural supports approach” during a 2-day seminar. The steps involved in this approach include setting up and organizing time and physical space for planning, development of a profile of the person, development of a future vision, development of action steps to put the plan into action, and ongoing implementation support with networking Friends, family members, and staff members also attended these meetings. Data was obtained over a six month period via meeting observations, document analysis, and in-depth interviews. Data was analyzed with an emergent themes approach.

Participants in the study generally found the meetings and process valuable and energizing. They felt a stronger sense of community, felt responsibility was shared, and enjoyed the clearer focus of the process. However, many inequalities emerged, especially in terms of peer participation. Peer relationships, while strongly desired, remained few in number. The study revealed an unexpected sense of negativity in what was thought to be a positive process; the lack of meeting control by the individual and facilitator, and an unclear relationship between the planning and outcomes. In addition, program planning efforts and success in connecting persons to both social networks and resources were inconsistent. The authors conclude that person-centered planning may not be scalable for mass market implementation, at least in terms of a quick fix to complex issues. It may be most successful in reframing the relationship between the person, available resources, and the community at-large.


In this chapter, Kirkpatrick divides the evaluation process into four sequential levels: reaction, learning, behavior, and results. The first level—reaction—measures how participants respond to the training. If satisfied, they will be more motivated to learn. Measuring reaction, typically by having participants fill out a reaction form, helps to both evaluate the program and provide quantitative information for trainers and managers.

Level two measures learning as the extent to which attitudes change and knowledge or skills increase as a result of the training. A control group is recommended for measurement. Evaluation should take place before and after the training. For the measurement of knowledge and attitudes, a paper and pencil test is recommended, and a performance test can be used to measure skills acquisition.

Level three measures how behavior has changed as a result of the training. Conditions that allow for optimal behavior change are noted, including involving the organization in training development. A control group is recommended for evaluation. The evaluation must take place after the training, when participants are back at work, and sufficient time must be allowed in order for behavior change to take place. Evaluations should be made before and after training in the form of a survey and/or interview of trainees, supervisors, and/or subordinates and coworkers.

Level four measures the final organizational results that occur due to the training. It can include measurements of productivity, quality of work, sales, or costs. Final training objectives should be stated in terms of desired results. Determining which results are due to training is difficult, so using a control group is recommended. Other recommendations for this level of evaluation include
allowing proper time to elapse before evaluating, measuring before and after training, repeating measurements at appropriate times, and analyzing the costs versus the benefits.


In this chapter, Klatt focuses on the value of evaluation and how to evaluate performance as a training leader. Value is defined as how well the training has met its intended goals and outcomes. The article references Kirkpatrick’s four levels of evaluation—reaction, learning, behavior change, and results—and describes how to evaluate both the training and the leader at each level. At the reaction level, an evaluation form can be used to assess participants’ reactions to the training. To evaluate at the learning level, pre- and post-testing are recommended in addition to written or oral tests. An interview or quiz can be used to assess learning retention about 1 month after the workshop. Behavior change is measured through observed performance in training, demonstration of skills, and/or pre- and post-assessment of worker performance on the job. The results level can be measured through assessment of organizational change in terms of reduction in costs, increase in quality, or increase in sales, etc. Klatt breaks down each evaluation level further to provide additional information about training program evaluation. This includes the use of face-to-face discussion to measure reactions, measurement of skills through role-play, and evaluation of attitudes and knowledge before and after training. Finally, an appendix is provided with sample evaluation and pre-evaluation forms.


This book is a guide to helping managers understand how to derive the most benefit from employee training programs. Topics covered related to training services include determination of employee performance problems and how to address them, ensuring employees obtain needed job-relevant skills, training efficiency, determination of non-training solutions to meet certain problems, and financial projections for training hardware. In the organizational context, trainers are expected to provide employees with the skills and self-confidence to perform their jobs. Managers, on the other hand, are expected to provide employees with opportunities to perform in their jobs and a supportive environment.

Training will be most valuable to the organization if trainees are given clear expectations about what accomplishments they will be expected to produce and ample opportunities to exercise the new skills provided by the training within a short time after returning to work. Trainees also need to be given the tools, authority, place, and time to use the new skills and know that management will be checking the application of skills for satisfactory performance. Finally, trainees need to be given positive feedback when newly learned skills are applied.

Based on Kirkpatrick's four levels of evaluation, this case study outlines the process for the development of an evaluation model of performance and organizational learning initiative outcomes. The authors felt that Kirkpatrick's evaluation model was easily understood by stakeholders and learners not familiar with evaluation models and successfully differentiated between satisfaction, learning, applied learning, and return on investment.

Of particular interest was the focus on reaction/satisfaction and learning evaluation levels. To measure satisfaction, a questionnaire with six questions linked to program objectives was devised. To measure learning, the authors identified learning outcomes to demonstrate competence and included a self-assessment component. This second questionnaire was replaced by facilitated dialogue with the trainer in which trainees reflect on program content and identify knowledge gained. This approach yielded sound evaluation data and was recommended for future evaluations.


The purpose of this study was to measure the effects of training on employees' attitude and behavior. The study included all employees from different departments of the City of Palm Desert, California. A pre- and post-test were used to measure attitudes using a Likert scale. The post-test was administered directly after the training, and a control group was used. Participants and their supervisors were given a pre- and post-test survey to measure behavioral change, again using a Likert scale and control group. Pre-testing was done right before training and the post-test was administered 6 months later. The study results did not show any statistically significant change in the attitude or behavior of the experimental group. The author suggests that trainings aimed at behavior and attitudes are more difficult both to learn and to evaluate. There may also have been a lack of reinforcement on the job. The author raises questions as to whether the training itself works and if its effects can, in fact, be measured.


In this chapter on training evaluation, the author makes a distinction between formative and summative evaluation. Formative evaluation is intended to improve the training process, whereas summative evaluation is used to determine how employees change. Five outcomes measures used to evaluate training programs are identified and discussed in terms of measurement techniques. They are: cognitive outcomes (paper and pencil tests, work samples); skill-based outcomes (observation, ratings); affective outcomes (interviews, attitude surveys); results (performance records, data from information systems); and return on investment (compares costs and benefits of the program). The relevance, reliability, discrimination, and practicality of these measured outcomes are also discussed.
The article explains that different training evaluation designs are judged in terms of their validity—i.e., the believability of the results obtained and whether they are generalizable. Pre- and post-tests, comparison groups, and random assignment are techniques used to control validity. A number of evaluation designs are also described. The “post-test only” design can be used if trainees have similar background knowledge before the training, and this design can be strengthened with the use of a comparison group. The “pre-test/post-test” design is used when all employees (regardless of background knowledge) are required to participate in the training. Since this design has no comparison group, its validity can be influenced by other factors. Addition of a comparison group to this design, however, will alleviate concerns regarding validity. A “time series” design collects data at intervals both before and after the training, which facilitates measuring observable outcomes. Finally, the “Solomon four-group” design consists of a pre- and post-test of an experimental and control group as well as a post-test evaluation for another experimental and control group. This design is helpful in controlling internal and external validity.

The chapter concludes with a discussion of return on investment.


Much like other sources, this book relies heavily on Kirkpatrick’s levels of evaluations. The authors state that specific objectives for training should be developed in conjunction with each of Kirkpatrick’s levels. This should help provide direction to program designers, trainers, and analysts to keep the process on track. Good objectives specifically state what is expected, at what time frame, from which individuals, and with what type of data. Objectives are also an important feedback tool helpful to determine expected and actual training outcomes so that the ultimate goals of the training can be achieved. Many useful tips and downloadable forms are given to explore the relationship between data obtained at each level and return on investment.

Asking the trainee how s/he will apply what s/he learning n the training or having trainees assess the impact of the training on his or her work are among a number of important questions to ask in assessing the value of training. The more specific the trainee can be in terms of what measures of the work unit were enhanced by the training and the degree to which training improved employee performance are critical to quantifying the value of the training to the employee.


This study provides a pilot test of a 30-hour, competency-based training course in a large urban health department. The evaluation processes included a strategic, baseline assessment of organizational capacity by the agency; trainee demographic data; a pre- and post-training inventory of beliefs and attitudes; a post-training trainee satisfaction survey; and a 9-month post-training follow-up survey and discussion of learning usefulness and organizational impact. The organizational capacity was measured through annual program plans both before and after the training.

The results indicated that trainees did not react well to completing lengthy evaluations and some measures were thought to be redundant. For this reason, the authors suggest that evaluations be designed with sensitivity to time and also contain interactive activities to hold the attention of the
class. The trainees also expressed interest in anonymous surveys. Participation in the 9-month follow-up survey and discussion was poor. However, the authors still recommend giving feedback to trainees after training to increase their retention of the material. Trainers were appreciative of the qualitative data provided by open-ended questions. In conclusion, the authors feel that this pilot experience offers some important practical lessons for training evaluations in the future.


The authors have created a model for training, based on Kirkpatrick’s levels of evaluation, to maximize the impact of training programs. Components of this model include a shift from activity-based training to training approaches that emphasize impact, creating strategic partnerships with management to connect business needs and clients, diagnosis of organizational needs, making training decisions, and building evaluation and tracking systems into training.

Of particular value is material related to the evaluation of participant reactions to training. Common mistakes that are made include not clearly or inaccurately defining the purpose of the evaluation, trying to create a “one size fits all” evaluation instrument and poorly constructed survey questions. Using only open-ended questions or use of unbalanced questions (i.e., predominantly asking for positive or negative feedback) misses much of the trainee reaction to the training. Insufficient time for a thorough evaluation and not maximizing an opportunity to collect useful information (i.e., only asking about the program itself and disregarding difficulties in applying training skills, management expectations of training, trainee motivation or confidence, etc.) further limits the value of the evaluation. Specific guidelines are given to determine the purposes of the reaction evaluation, determine how data will be tabulated, and create high-yield questions.


This article addresses the relation of reaction and learning measures (the first two levels of Kirkpatrick’s evaluation model) via paper-and-pencil measures to the actual learning imparted by the training program. The authors suggest that training evaluators need to view criteria to determine training effectiveness as multidimensional. Learning outcomes can be divided into three different types:

1. cognitive—reflect knowledge and cognitive strategies (analogous to Kirkpatrick’s learning criteria)
2. skill based—reflect constructs such as automaticity and compilation (analogous to Kirkpatrick’s behavior criteria)
3. affective—reflect constructs such as attitudes and motivation (analogous to Kirkpatrick’s reaction criteria)

In addition, the authors grouped reaction criteria into two categories: affective and intention. The affective category includes typical measures of reaction such as trainee’s feelings about the training program. The intention category taps into a trainee’s cognition and behavioral intention.
concerning the training program. This model asserts that reaction measure items that tap into trainee intentions have a stronger relationship with behavior and learning than items that only tap into the affective category.

A sample of 283 automotive technicians from a large, Midwestern company participated in a training program and provided feedback data to the researchers. Results showed that both affective and intention reaction measures were correlated with learning and behavior outcomes. However, regression analysis showed that trainees that disliked the training program showed higher levels of learning than trainees that liked the training program; a negative reaction evaluation significantly predicted trainee learning. There was a positive correlation between a negative evaluation rating and pre-training knowledge. These results concur with previous studies that found no correlation between trainee perceptions and posttest training scores.
Web Site Index

Links to Additional Resources
Here are some links to provide you with additional information regarding aging and developmental disability as they are related to person-centered planning and consumer direction. Some sites include additional information on training. Please note that the information contained in these websites changes frequently, and the content provided here is just a snapshot of a moment in time.

1. [www.aarp.org/il/beyond_50_il.html](http://www.aarp.org/il/beyond_50_il.html) The American Association for Retired Persons produced a report on independent living and disability. It contains information regarding the justification for placing consumers in control of their decision-making and provides examples for ways of assisting with their care.

2. [www.acf.hhs.gov/programs/add](http://www.acf.hhs.gov/programs/add) The Administration on Developmental Disabilities, which is a national organization, sponsors this website. It provides information on national issues of concern to those working with individuals with developmental disabilities. It also provides links to individual state programs.

3. [www.allenshea.com](http://www.allenshea.com) This is the website of Allen, Shea and Associates, a private agency, that provides resources for professional development in the field of human resources, particularly developmental disabilities. The site provides excellent links to articles on support brokerage and person-centered planning, including some written by Michael Smull, a leader in the field.

4. [www.thearc.org](http://www.thearc.org) The Arc is a national organization promoting independence of individuals with developmental disabilities. The website provides good resources for families, as well as links to their published materials, which includes information on person-centered planning.

5. [www.consumerdirection.org](http://www.consumerdirection.org) This is the website for the consumer direction program sponsored by The Robert Wood Johnson Foundation, National Council on Aging and the National Association of State Units on Aging. It is an excellent source of information on consumer directed care. It provides information on a consumer directed tool, currently being used in five states to develop consumer directed reforms. The website also has links to publications, which include an overview of a consumer direction model, consumer satisfaction information, results from states who have participated in the consumer direction program.


7. [www.ctserc.org/library/bibstorz.shtml](http://www.ctserc.org/library/bibstorz.shtml) This is the website for Connecticut’s educators and families, which provides information and professional development. The bibliography library contained on the site has listings of articles and publications related to self-advocacy and self-determination.

8. [www.ici2.umn.edu/pcplanning/default.html](http://www.ici2.umn.edu/pcplanning/default.html) This is the website for the South Carolina Person-Centered Planning Facilitator Training Project. It provides link to case histories, chatrooms for trainees, training information, free publications, as well as a list of other related websites.
9. **www.inclusion.com** Inclusion Press is a small press that promotes integrated communities. Their website contains information on inclusion networks, person-centered planning, as well as training information.

10. **www.iod.unh.edu** The Institute of Disability located at the University of New Hampshire produces this website, which contains an abundance of information on the projects currently underway at the Institute. It also provides a listing of their publications, policy papers and other web-based resources. Links to their training resource materials are also included.

11. **www.nasua.org** The National Association for State Units on Aging sponsors this website. There are assessment guides and fact sheets on the use of consumer direction, available free of charge in the bookstore section of the site.

12. **wwwrtc.umn.edu/main/index.html** The Research and Training Center (RTC) is located at the University of Minnesota. The center provides research, training and technical assistance in the field of disability. The website contains specific links www.QualityMall.org, which can provide free information on person-centered support and the College of Direct Support, which offers some interactive multi-media training curriculum.

13. **www.rwjms.umdnj.edu/boggscenter** This website is produced by The Boggs Center on Developmental Disabilities. It provides links to the publications by their staff, as well as links to their products, some of which are free. It also has an excellent listing of additional resource links.

14. **www.self-determination.com** The Center for Self-Determination supports this website, which provides policy information, links to papers on self-determination and related topics, as well as links to additional web-based resources.

15. **www.self-determination.org** The National Program office on Self-Determination is currently restructuring this website. It previously had links on self-determination and person-centered planning, including some information on training in these areas.

16. **www.soeweb.syr.edu/thechp** This is the website for the National Resource Center on Supported Living and Choice, whose mission is to help people with developmental disabilities participate in their communities. The site contains links to publications and resources related to developmental disabilities, training and policy development. There are also links to publications by John and Connie O’Brien, leaders in the field of person-centered planning. All publications are free and some highlights include: 1. Deliberate-Fire: An Account of Organizational Transformation, 2. Finding a Way Towards Everyday Lives- a good overview of Person-Centered Planning, 3. Politics of Person-Centered Planning.

17. **www.state.vt.us/dmh** Vermont’s Department of Developmental Disabilities and Mental Health produces this website, which contains an overview of Vermont’s services and trainings, as well as links to their publications on self-determination.

18. **www.trinc.com** This is the website for Training Resource Network, Inc, which provides trainings on supported employment, self-determination, person-centered planning and supported living. Most resources require a fee, but there are a few free of charge.