

# Self-Determination and Person-Directed Support

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## **Introduction**

The national trend in long-term care policy and services has increasingly shifted toward models that emphasize person direction of services. The genesis of these models can be traced to the Housebound and Aid and Attendance Programs, operated by the Veteran's Administration for over 40 years (Cameron, 1993), and the independent living movement which, over the past 30 years, has promoted the development of personal assistance services for persons with physical disabilities (DeJong, Batavia, & McKnew, 1992).

The shift from institutional to community-based services has provided the first real opportunity for many adults with disabilities to make meaningful life choices and to access the services and supports they need. For example, as a result of changes in philosophy, advocacy, laws, and funding regulations, the number of institutionalized individuals with developmental disabilities has dramatically decreased over the past two decades (Braddock, Hemp, Parish, Westrich, & Park, 1998). Similar shifts have begun to occur, although more slowly, for individuals with psychiatric disabilities (Rothbard & Kuno, 1999) and for older adults.

Expanded access to person-directed, community-based services for individuals with disabilities has been facilitated by the Supreme Court ruling on *L.C. v. Olmstead* (1999) as well as by Department of Justice regulations that affirm the right of individuals with disabilities to be supported in the most integrated setting as required by Title II. of the Americans with Disabilities Act (ADA). Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" 28C.F.R. 35.130(d).

Recommendations generated by the National Blue Ribbon Panel on Personal Assistance Services also called for the expansion of most integrated setting service options (Independent Living Research Utilization Program, 1999), and the Centers for Medicare and Medicaid Services, through its Real Choice Initiative, is supporting many state initiatives to expand home and community-based long-term services for people with diverse disabilities. Most recently, the report of the President's New Freedom Commission on Mental Health features "Goal 2: Mental Health Care is Customer and Family Driven", emphasizing the development of personalized, highly individualized health management programs that will help lead the way to appropriate treatment and supports that are oriented toward recovery and resilience. "Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved" (President's New Freedom Commission on Mental Health, 2003).

### **Philosophical Underpinnings of Person-Directed Services**

The philosophy of person direction recognizes the capacity of individuals to

"assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (National Institute on Consumer-Directed Long-Term Services, p.4, 1996). The importance of personal control is validated by research showing a positive association between perceptions of control and quality of life for individuals with disabilities and elders (Hofland, 1988; Rodin, 1986), and other findings that link perceived control with health, disability and quality of life among elders (Salomon, Polivka, & Weber, 1998).

The emergence of person-directed service models is, in part, reflective of a societal shift from social benevolence toward people with disabilities to a growing acknowledgment of, and respect for, their capabilities, autonomy and personal rights (Powers, 1996). "Autonomy is understood as a cluster of notions including self-determination, freedom, independence, liberty of choice and action. In its most general terms, autonomy signifies control of decision-making and other activity by the individual. It refers to human agency free of outside intervention and interference" (Collopy, 1988, pp. 10). The growing focus on personal autonomy in long-term services has expanded the emphasis of care from the maintenance of health and safety to recognition of the roles of independence, reasonable accommodation and individual control of supports in facilitating quality outcomes.

In comparison to individuals with physical and sensory disabilities, this societal shift in perceptions and attitudes has been more subtle for older adults and for individuals of all ages with cognitive disabilities, who are often perceived as incompetent and helpless recipients of help (Scala & Mayberry, 1997). There also are significant concern among case managers regarding the perceived trade-off between autonomy

and safety (Micco, Hamilton, Martin, & McEwan, 1995; Scala, Mayberry, & Kunkel, 1996). Access to person-directed long-term services is, nonetheless, increasing among elders and adults with significant cognitive disabilities as the boundaries for the expression of autonomy have expanded to include supported decision-making and delegated decision-making by surrogates. Models are being developed that avoid the oversimplification that service users are either autonomous or non autonomous, permitting both collaborative direction of services by individuals and trusted others and delegated decision-making by surrogates.

**Person-direction of mental health services.** In comparison to other groups, significantly less progress has been made in advancing person-directed services for individuals with psychiatric disabilities (Cook & Jonikas, 2002). The evolution toward person-direction in mental health conflicts with traditional stereotypes of people with psychiatric disabilities as dangerous or malingering, unable or unwilling to take charge of their lives and requiring external intervention and control. From this perspective, self-determination is viewed as a privilege tied to adherence rather than as a fundamental human right.

Against this backdrop, mental health consumer / survivor leaders are calling for the end of forced institutionalization, intrusive therapies and medication. Leaders are advocating that personal assistance services be adapted and made accessible to individuals with psychiatric disabilities (Pita, Ellison, Kantor, 1999). They are working toward the expansion of empowerment service models, including consumer led drop-in centers, peer support and consumer-directed services (Fisher, 1998).

There is general agreement that responsive person-directed services should enable individuals to control services at the level they desire, and provide an array of supports that will maximize the customer's self-direction capabilities (Flanagan, Green, & Eustis, 1996; Scala & Mayberry, 1997). Such supports include giving individuals adequate information about service options, involving them in the service planning process, and providing resources and tools for customers to recruit, select, train and supervise their support providers (Eustis & Fischer, 1992). While effective approaches have been developed for involving individuals with physical disabilities to carry out these activities (e.g. Ulicny, Adler, Kennedy, & Jones, 1987), very little attention has been focused on providing mental health service users with such information and tools.

Furthermore, many mental health case managers, service providers and other mental health professionals have little background in the values of independent living, self-direction, personal assistance services, and ways to involve and support mental health consumers in service decision making and direction. There is a lack of understanding by some providers of the concepts of consumer choice, recovery, self-determination, and community integration, and many professionals have therapeutic rather than service coordination backgrounds. Thus, mental health professionals often do not have the orientation, knowledge or experience necessary for promoting the capacity of individuals to self-direct or to hire others to assist with activities as a method for recovery.

Researchers and policy leaders have identified as a key barrier to the utilization of person-directed services the beliefs by many mental health professionals in a "therapeutic" paradigm of services, in which their primary role is as therapist (Ellison,

Rogers, Sciarappa, Cohen, Forbess, 1995). Pita, Ellison, Farkas, & Bleeker, (2001), in reporting the results of their survey of State Mental Health Directors stated, "the majority of states viewed psychiatric personal assistance as an element of psycho-social rehabilitation rather than seeing it belonging to an independent living framework".

### **Models of Person-Directed Services**

Person-directed models of long-term services across disability and age groups generally emphasize the following elements (DeJong, Batavia, & McKnew, 1992; Kane, 1996; Fenton, Entrikin, Morrill, Marburg, Shumway, & Nerney, 1997; Scala & Mayberry, 1997):

- (a) the authority and accountability of the service customer;
- (b) individualized, customer-directed service planning;
- (c) customer selection, training and supervision of support providers;
- (d) limited oversight by medical providers;
- (e) flexible benefits that include personal assistance, assistive devices, environmental modifications, customer education, support brokers, fiscal intermediary and employment supports;
- (f) individualized funding of service plans through cash payments to customers or customer authorization of service payments by a funding agency or fiscal intermediary; and
- (g) customer definition and monitoring of service quality.

Typically, the language used to describe person-direction of services varies across the disability community. Many people from the independent living community emphasize "consumer control" and associate it with the management of personal

assistance or attendant services. In developmental disabilities, person-directed services are most often referred to as "self-determined or self-directed services". Among elders, the person-direction discourse is less well defined and may be referenced to autonomy or consumer-directed services". Terms used in the mental health and psychiatric survivor community may include "empowerment, liberation, peer-run services, and self-determination". For the purposes of our discussion, individuals who use person-directed services are referred to as "customers" unless a source is being cited that used another reference term.

A 1999 survey by the National Council on the Aging identified 185 person-directed programs throughout the United States (Velgouse & Dize, 2000). The majority of the programs served customers of all ages although services for persons with developmental disabilities and younger people with disabilities predominated. Several new person-directed, long-term service model demonstration initiatives have emerged, focused on people with diverse disabilities and elders (Mahoney, Simone, & Simon-Rusinowitz, 2000; Moseley, 2001). Many of these initiatives are specifically aimed at identifying and addressing federal and state barriers to person-directed, long-term care services.

### **Structure of Person-Directed Service Models**

Models of person-directed services can be designed to provide for varying levels of control, including (a) direct cash payments and counseling for individuals who are responsible for all facets of funding and service management, (b) fiscal intermediary programs that assume responsibility for administrative employment functions (i.e. payroll, taxes, paperwork) while customers manage their services, (c) supportive

intermediary programs that assist customers with activities such as service coordination, brokering supports or screening and training care providers, (d) self-directed case management programs which actively involve customers in decisions regarding their services, but retain control over the management of funds and services, and (e) spectrum service programs in which customers can choose among a range of the above support options (Flanagan, Green, & Eustis, 1996). Most person-directed programs offer customers only one of these options rather than a range of supports (Scala & Mayberry, 1997). Where there is a choice of services, it is typically between programs that provide cash payments and leave all service management to customers or programs that allow customers to designate all of their service management to an agency. In some cases, support is available from an agency that assists customers with administrative employment tasks (e.g. payroll issues). Three of the most dominant types of person-directed services are personal assistance services, brokered support and Cash and Counseling.

**Personal assistance services.** Historically, much of the attention in the design of person directed services has focused on the delivery of personal assistance services. Personal assistance services refer to assistance with tasks that individuals would normally do for themselves if they did not have a disability (Litvak, Zukas, & Heumann, 1987). Such services include personal care, ADL's, IADL's, communication supports, paramedical services (e.g., medication administration, catheterization, injections, ventilator care), home modifications, assistive devices, and service coordination (Doty, Kasper, & Litvak, 1996).

Among adults with physical disabilities, personal assistance services are most commonly provided through Medicaid personal care programs whereas within aging and developmental disabilities services, these services are more commonly supported through Medicaid home and community-based long-term care services waivers (HCBS) (Scala & Mayberry, 1997). Most programs that fund personal assistance services emphasize in-home services delivered by providers (e.g., attendants or personal assistants), in contrast to the broad spectrum of supports included in the above definition. Many programs also provide fiscal intermediary services and assist customers with administrative employment tasks. Although, programs that provide customer-directed personal assistance services exist in a majority of states, most are small demonstrations or, as a function of restricted funding, they are accessible to a limited number of participants.

Clearly, the major advantages of person-directed personal assistance services are the individual's control over the selection and direction of his or her personal assistant(s) and the fairly flexible, functional ways in which a personal assistant can be used. Historic challenges in these programs have been their narrow definition of services, focusing on in-home supports delivered by a provider, such as personal care, homemaking and other physical tasks that, although essential for persons with physical disabilities, may not be relevant for persons with cognitive or psychiatric disabilities. For example, users with psychiatric or cognitive disabilities may desire personal assistance to carryout homemaking activities, to make appointments, to access employment, recreational and social opportunities in the community, to manage medications, or to plan and organize activities. Although formal program eligibility requirements may

include all persons with disabilities, program service definitions may focus on the needs of persons with particular functional challenges.

A second challenge for many personal assistance service programs is a lack of information available for personal assistants and customers related to effective practices and tools for hiring, training, supervising, evaluating and firing assistants. Many person-directed personal assistance programs have struggled with reconciling their commitment to ensuring the autonomy of customers in directing their supports with the need to provide customers with information and tools that will enable them to be successful employers. Programs that limit their involvement to providing fiscal intermediary and employment supports for customers also are reluctant to become involved in customer or personal assistant education because of liability concerns. Personal assistance programs administered by independent living centers often offer peer-based support to assist customers in this area.

**Brokered support.** Brokered support is a model of self-determination-based service that has been primarily utilized with customers who have developmental disabilities, although small demonstrations are underway with other disability groups, such as the pilot brokerage being developed for individuals with psychiatric disabilities in Oregon through its Real Choice Project. Brokered support focuses on assisting customers, as they choose, to accomplish the following seven functions:

- a. Self-define their goals for life and plans to achieve them.
- b. Access opportunities, resources and supports that enable them to achieve their goals.
- c. Expand the range of employment, housing, recreational and other

- opportunities and supports available through community development and networking activities.
- d. Access information and education that increases their capacities to make informed decisions, to achieve their self-defined life goals, and to direct their supports.
  - e. Pay bills, negotiate contracts, etc. that are necessary to carry out their plans.
  - f. Do employment paperwork, background checks, and hiring, training and supervision of the people they choose to support them.
  - g. Monitor their achievement of plan goals and the quality of their supports, and to make adjustments, as desired.

Brokered support typically involves making available to customers a broker, personal agent, or coach who functions as an ally for the customer, having a primary commitment to supporting the individual to achieve his or her life goals, including determining and directing supports that are needed. It is important that the broker does not have other roles that may potentially conflict with his or her primary allegiance to the customer, such as a case manager who is also responsible for eligibility and protective services decisions, or a service provider that could be impacted by the customer's choices. Brokered support can be delivered by independent agents that customers select or by staff of brokerage organizations dedicated to providing brokered supports. Brokers may be involved with customers for limited or ongoing time periods.

Brokered support typically combines the availability of a broker with flexible funds that customers can allocate to achieve their goals, as reflected in their individualized service plan. Funds are generally assigned to the customer and held in an account

rather than given as cash. Brokered support programs typically provide fiscal intermediary services and assist customers with administrative employment tasks. Customers remain the employers of record. Customer use of flexible funds is typically defined as a function of the services included in the state's Medicaid HCBS waiver: Many states are striving to include a variety of waiver services that respond to the individualized needs of customers, however health and safety outcomes, which serve as the basis for the HCBS program, present some inherent limitations to the inclusion of some individualized supports.

Brokered support models, combining a broker with individualized funds, clearly provide a greater level of flexibility and control for the customer than do traditional "menu" based approaches. A major advantage of brokered support from an independent broker is the customer's ability to select the broker, while a disadvantage can be lack of broker expertise and training. Brokerage organizations are more easily able to train and support brokers and to provide fiscal intermediary supports than are independent brokers. However, customers of brokerage organizations may not be permitted to choose their brokers and these organizations are vulnerable to devolving into beauracratc entities that loose their flexibility to respond to individual customer needs as they institute policies, procedures and support menus that guide their work across customers and that ensure their organizational stability. If brokers have ongoing responsibility for monitoring or remaining in the lives of their customers for some reason apart from that requested by the customer, they also risk compromising their commitment to customer autonomy.

**Cash and Counseling.** Cash and Counseling demonstrations have been formally underway in Florida, Arkansas and New Jersey, and piloted in other states through Independent Choices or other initiatives. These demonstrations have involved customers with physical and developmental disabilities and elders. Customers with primary psychiatric disabilities have, for the most part, not been included.

Cash and Counseling programs offer a financial allowance instead of disability-related supportive services (Phillips, Mahoney, Simon-Rusinovitz, Schore, Barrett, Ditto, Reimers, & Doty, 2003). Customers cash out their Medicaid personal care or HCBS service benefit to pay for allowable disability-related goods and services that are included in their spending plans. Expenditures can include small amounts for incidental expenses paid in cash by the customer, such as taxi fare or ordering a pizza (rather than paying a service provider to do meal preparation), in addition to service provider payments and invoices for items such as adaptations and equipment. In most cases, fiscal intermediary and employment assistance is offered, however customers that demonstrate the ability to perform these activities are allowed to do so. Fiscal and counseling supports are provided by case managers, provider agencies and independent support coordination organizations.

Cash and Counseling generally offers the highest level of autonomy and flexibility to customers and is attractive to those individuals that desire to have authority and responsibility for their services. Findings from the Cash and Counseling demonstration (Phillips, et al, 2003) indicate that customers use the majority of their funds to pay providers, who are often family members and acquaintances. Many customers elect to have family members or close friends assist them in managing their allowance and

services. Most customers also use fiscal intermediary services if they are provided at little direct expense.

Cash and Counseling programs, like support broker models, risk having conflict of interest problems when counseling is provided by agencies that also offer traditional services. Providing adequate support and supervision for part-time counselors is also difficult. Finally, because customers often hire family members and acquaintances, those without family and friendship connections are likely to require additional support to find workers.

## **Summary**

Personal assistance services, brokered support and Cash and Counseling models are primary examples of person-directed services being offered to increasingly more customers each year. Each model emphasizes customer control and individualized supports; offering different elements with utility for customers with diverse needs. Although each model expands the range of services and supports available to customers, all share some constraints as a function of funding source and local resources, standards and attitudes.

## **Evaluation of Person-Directed Service Models**

Person-directed service models have a brief history as compared to traditional institutional and home care models. Studies conducted to evaluate the efficacy of person-directed services are highly variable in their methodological rigor. However, taken as a whole, findings to date suggest that person-direction of services may have benefits for a significant proportion of individuals. Several national and international studies have specifically evaluated the impact of person-directed models on factors

such as quality of life, control, productivity, use of preventative health care and cost.

The oldest person-directed service benefits are the Housebound and Aid and Attendance Programs, operated by the Veteran's Administration (Cameron, 1993). Over 200,000 veterans and surviving spouses receive cash benefits in place of formally provided homemaker, personal care and other services. Funds may be spent on whatever the customer believes is most necessary to meet his or her health and personal needs. An evaluation of these programs, conducted by Grana and Yamashiro (1987), suggested that the participants received similar hours of care and they were not worse off with regard to acute health care utilization than a comparison group.

Several other studies of person-directed services have focused on the evaluation of personal care programs. For example, a 1993 Louis Harris Poll of 800 persons receiving person-directed personal care services through Medicaid revealed that persons who hired independent, as opposed to agency, providers reported higher levels of satisfaction with their care, provider stability, and quality of life (Harris & Associates, 1993). An evaluation of the impact of person-directed personal assistance in Virginia compared the outcomes of a small number of individuals receiving person-directed personal care services with those on the wait list for such services (Beatty, Adams, & O'Day, in press). Person-directed services included funding for personal care from an individual hired and supervised by the customer as well as assistive technology, home modifications, and adaptive equipment. Use of consumer-directed personal care services were associated with higher levels of control over life, satisfaction with services, control over services and availability of services (Beatty, Richmond, Tepper, & DeJong, 1998), productivity and employment (Richmond, Beatty, Tepper, & DeJong,

1997), and utilization of preventative health care (Adams & Beatty, 1998).

Similar findings were obtained from a study comparing agency-directed and person-directed services for individuals with developmental disabilities. The recipients of person-directed services demonstrated significant increases in their control over decisions and quality of life. Customer-directed services were also provided at a 12% cost savings (Conroy & Yuskauskas, 1996). In their subsequent study of customer outcomes associated with participation in a Robert Wood Johnson Foundation funded self-determination initiative, Conroy, Fullerton, Brown and Garrow (2002) obtained pre and post participation data for 800 individuals in nine states. Their findings indicated that participants shifted much of their care from professionals to family and friends. Participants and those closest to them reported significant improvements in participant quality of life in all 14 life areas examined. Finally, the cost of customer participation in self-determination-based services was lower than a comparison group of individuals receiving traditional services.

Benjamin, Matthias, Franke, Mills, Hasenfeld, Matras, Park, Stoddard, & Kraus, (1998) conducted an interview study of 1,095 users of consumer-directed and professionally-directed personal care programs in California. Approximately one-half of the users of consumer-directed services were age 65 or over and 52% had severe physical disabilities in comparison to 13% of the users of professionally-directed services. The users of consumer-directed services reported significantly higher levels of empowerment over their services, satisfaction with both the technical and interpersonal aspects of their services, service quality, and emotional, social and physical well-being than did the users of professionally-directed services. They also

reported significantly higher levels of safety with their assistants, assurance of back-up assistance, and ease of arranging services, as well as lower levels of unmet needs.

Tilly and Bectel (1999) reviewed Benjamin's study and 4 additional studies of consumer-directed cash payment service models in Austria (Badelt, Holzmann-Jenkins, Matul, & Osterle, 1997), Germany (Runde, Giese, Kerschke-Risch, Scholz, & Wiegel, 1996), the Netherlands (Miltenburg, Ramakers, & Mensink, 1996) and France (Gilles, Groc, Legros, 1995; Simon & Martin, 1996). They concluded that the receipt of cash subsidies were associated with enhanced perceptions of control over services and supports, made it possible to compensate relatives for care and to purchase more services, and promoted overall quality of life. They suggested that agency and direct payment options should be broadly available to customers in conjunction with a range of supports for those customers who choose self-directed services.

The study of care in the Netherlands (Miltenburg, Ramakers, & Mensink, 1996), a rare experimental evaluation of the impact of choice between agency services and cash subsidies, involved the random assignment of 1,066 recipients to one experimental group that permitted a choice of cash or agency services, to a second experimental group that permitted a choice of cash, cash and counseling or agency services, or to a control group that provided agency services. Forty-five percent of the participants in each experimental group chose the cash benefit, while only 7% of those who chose cash also chose counseling. Thirty percent of the participants over age 75 chose the cash benefit. Participants who choose cash in the experimental groups were significantly more likely to report that their helpers were efficient, they received greater continuity of care, they had more choice and control over their services, and they were

able to purchase more hours of service, than were the participants in the agency services group. Ninety percent of the participants indicated they would chose the cash option again. Most of the cash subsidies were used to purchase services and 80% of the participants reported no difficulty obtaining services.

The Cash and Counseling initiative currently underway in the U.S. is yielding some findings related to the impact of services on participants that have been randomly assigned to receive either cash payments or traditional services (Foster, Brown, Carlson, Phillips, & Schore, 2001; Foster, Brown, Phillips, Schore, & Carlson, 2003). Results available from Arkansas suggest that disability-related health outcomes were at least as good as those for control group participants, and Cash and Counseling participants were less likely to report unmet needs and more likely to report satisfaction with their supportive services, compared to control group participants. Over 85% of the cash payment participants indicated they would recommend the program to others.

These findings suggest that, where there is a choice between direct cash payments and agency services or a fixed type of service, many people prefer direct payments. One of the major benefits of direct payments is the flexible funding of support provided by already existing family and other informal caregivers. However, a significant percentage of recipients, particularly those who are over 80 years old and/or who desire assistance to manage their supports, may elect agency services.

Several studies have found that the users of person-directed services were able to obtain more hours of service than were the users of agency services (Benjamin et al, 1998; Egley, 1994; Feinberg & Whitlatch, 1997; Miltenburg, Ramakers, & Mensink, 1996). All but Egley (1994) attributed this finding to lower hourly wages and the

provision of more unpaid hours of service by person-directed service providers. Egley (1994) found that the cost saving was due to reduced administrative costs rather than lower wages and benefits for providers. Although reduced costs associated with increased hours of service are a positive outcome from a customer's perspective, this finding raises questions regarding the status of independent care providers that is being shaped by through the wage parameters established by person-directed service programs.

### **Barriers to Person-Directed Support for Individuals with Psychiatric Disabilities**

The lack of access to person-directed support by customers with psychiatric disabilities is striking and suggests that they have been left out for reasons other than that they would not benefit from such supports. The lack of access by customers with psychiatric disabilities appears most related to their participation in separate service systems that are not linked to those available to individuals with other disabilities or elders, and to a general lag in service evolution within the mental health system. Attention to the potential benefits of using person-directed approaches may also be overshadowed by the increasing emphasis in mental health on the adoption of "effective practices" such as family psycho-education, supported employment, dialectical behavior therapy (Drake, Goldman, Leff, Lehman, Dixon, Mueser, & Torrey, 2001). These practices have been specifically developed and validated by mental health professionals, aimed at addressing specific medical and psychosocial outcomes for persons with psychiatric disability (e.g., decreased hospitalization, social adjustment, family stress and burden, behavior symptomatology, employment, and medical care costs).

Person-directed support models provide validated approaches for assisting individuals to determine and direct their support. By definition, they do not prescribe specific supports that are appropriate for any individual or group. Rather, they provide methods for customers and their trusted allies to identify those supports that individuals need to optimally promote their recovery, health and quality of life. It is likely that access to practices documented as effective for persons with psychiatric disabilities, and perceived to be of benefit by customers, will be selected by individuals as components of their personalized support plans. Thus, using person-directed support approaches and making effective practices available for customers to select are complementary aspects of developing a holistic, person-centered system of support. There is a pressing need to more clearly understand how individuals with psychiatric disabilities can benefit from accessing person-directed services as well to identify the most empowering and efficient ways to provide such supports.

### **Discussion**

Person-directed services are currently not accessible to most individuals in the mental health system. Increasing the number and scope of person-directed service models accessible to individuals with psychiatric disabilities will likely require further validation of their benefits, policy and system improvements that address the barriers to person-directed services, ongoing consumer / survivor advocacy and the strengthening of political will necessary to divert increased funds toward community-based, person-directed services.

Studies should be undertaken to investigate the types of person-direction supports needed by persons with psychiatric disability, the relative benefits of different

service models, and the organizational configuration of person-directed support programs. Collaboration between consumer /survivor advocacy organizations, mental health professionals, researchers and other long-term care stakeholders will be critical for increasing access to person-directed services. Research must focus on gathering evidence regarding the efficacy of person-directed approaches for promoting recovery from a holistic perspective with consumer /survivors actively involved in all facets of the process.

Research and thoughtful planning should take place to further investigate and promote the effectiveness of person-directed services. However, individuals with psychiatric disabilities should not have to wait for 10 or 20 years to gain the right to determine their services until professionals have conducted a multitude of demonstration and research projects. As Hagner (1996) wrote, "Historically, in education, housing, employment, leisure, and other domains, we as a field began with very restrictive, oppressive ways of treating people with disabilities, and have been engaged in a massive, decades-long effort to lighten up. That is true historically, and each less intrusive "newcomer" has been greeted with suspicion and requests for proof, but it is not true conceptually or morally. Conceptually and morally, the presumption has always been in the opposite direction. It is the unnatural supports that are on trial (p. 183)".

## References

- Adams, M., Beatty, P. (1998). Consumer-directed personal assistance services: Independent living, community integration and the vocational rehabilitation process. *Journal of Vocational Rehabilitation, 10*, 93-101.
- Badelt, C., Holzmann-Jenkins, A., Matul, C., Osterle, A., (1997, March). *Analyse der Auswirkungen des Pflegevorsorgesystems*, Bundesministeriums für Arbeit, Gesundheit Und Soziales Wien, Austria, Translated by Jon Peter Hopperger.
- Beatty, P.W., Richmond, G.W., Tepper, S., & DeJong, G. (1998, June). Personal assistance for people with physical disabilities: Consumer-direction and satisfaction with services. *Archives of Physical Medicine and Rehabilitation, 79* (6), 674-677.
- Benjamin, A.E, Matthias, R., Franke, T., Mills, L., Hasenfeld, Y., Matras, L., Park, E., Stoddard, S., & Kraus, L. (1998, September). *Comparing client-directed and agency models for providing supportive services at home final report*. Los Angeles, CA: University of California at Los Angeles.
- Braddock, D., Hemp, R., Parish, S., Westrich, J., & Park, H. (1998). *The state of the states in developmental disabilities*. (5<sup>th</sup> edition). Washington, DC: AAMR.
- Cameron, K.A. (1993, October). *International and domestic programs using "cash and counseling" strategies to pay for long-term care*. Washington, DC: United Seniors Health Cooperative.
- Collopy, B. (1988). Autonomy in long-term care: Some crucial distinctions. *The Gerontologist, 28*, 10-17.

- Conroy, J., Fullerton, A., Brown, M., & Garrow, J. (2002, December). *Outcomes of the Robert Wood Johnson Foundations's national initiatives on self-determination for persons with developmental disabilities: Final report on 3 years of research and analysis*. Narberth, PA: Center for Outcome Analysis.
- Conroy, J., & Yuskauskas, A. (1996). *Independent evaluation of the Monadnock Self-Determination Project*. Ardmore, PA: The Center for Outcome Analysis.
- Cook, J.A., & Jonikas, J. (2002). Self-determination among mental health consumers/survivors: Using lessons from the past to guide the future. *Journal of Disability Policy Studies, 13* (2), 87-95.
- DeJong, G., Batavia, A.I., & McKnew, L.B. (1992, Winter). The independent living model of personal assistance in national long-term-care policy. *Aging and Disability, 89-95*.
- Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *The Millbank Quarterly, 74* (3), 377-409.
- Drake, R.E., Goldman, H.H., Leff, H.S., Lehman, A.F., Dixon, L., Mueser, K.T., & Torrey, W.C. (2001). Implementing evidence-based practices in routine mental health settings. *Psychiatric Services, 52*, 182-197.
- Egley, L. (1994). *New federal PC Option PAS funding rules: Summary*. Berkeley, CA: World Institute on Disability.
- Ellison, Rogers, Sciarappa, Cohen, Forbess. (1995). Characteristics of mental health case management: Result national survey. *The Journal of Mental Health Administration, 22* (2), 101-112.

- Eustis, N.N., & Fischer, L.R. (1992). Common needs, different solutions? Younger and older home care clients. *Generations*, 16, 17-22.
- Feinberg, L., & Whitlatch, C. (1997). Family caregiver and consumer choice: Options for in-home respite care. In L.F. Feinberg, *State of the art: Research on consumer directed care*. Annual meeting of the American Society on Aging, Nashville, TN.
- Fenton, M., Entriakin, T., Morrill, S., Marburg, G., Shumway, D., & Nerney, T. (1997). *Beyond managed care: An owner's manual for self-determination*. Concord, NH: Self-Determination for Persons with Developmental Disabilities.
- Fisher, D. (1998, June). Recovery: The behavioral healthcare guideline of tomorrow. *Behavioral Healthcare Tomorrow*.
- Flanagan, S.A., Green, P.S., & Eustis, N. (1996, November). *Facilitating consumer-directed personal assistance services (CD-PAS) through the use of intermediary service models: Eleven states' experiences*. Paper presented at the annual meeting of the Gerontological Society of America, Washington, DC.
- Foster, L., Brown, R., Carlson, B., Phillips, B., & Schore, J. (2001, June). *Cash and counseling: Customers' early experience in Arkansas and New Jersey*. Paper presented at the Independent Choices National Symposium on Consumer Direction and Self-Determination, Washington, DC.
- Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B.L. (2003, March 26). *Improving the quality of Medicaid personal assistance through consumer direction*. Health Affairs, Internet publication  
[[www.healthaffairs.org/webexclusives/2203foster.pdf](http://www.healthaffairs.org/webexclusives/2203foster.pdf)].

- Gilles M.O., Groc, I., Legros M. (1995). *La Prestation Dependance: Experimentations Resultats des phases 1 et 2 du Programme d'Evaluation de l'Experimentation d'une Prestation Dependance* CREDOC Paris France. Translated by Jane Tilly.
- Grana, J.M., & Yamashiro, S.M. (1987). *An evaluation of the Veterans Administration housebound and aid and attendant allowance program, Project HOPE*. Prepared for the Office of the Assistant Secretary for Policy and Evaluation, Department of Health and Human Services, Washington, D.C.
- Hagner, D. (1996). "Natural supports" on trial: Day 2799? *The Journal of the Association for Persons with Severe handicaps*, 21 (4), 181-184.
- Harris & Associates. (1993). The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream. *Incitement*, 9, 12.
- Harris & Associates. (1993). The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream. *Incitement*, 9, 12.
- Hofland, B.F. (1988). Autonomy in long term care: Background issues and programmatic response. *The Gerontologist*, 28, 3-9.
- Independent Living Research Utilization. (1999). *Options, choices, and control: Attendant care in America: The report of a National Blue Ribbon Panel on Personal Assistance Services*. Houston, TX: Independent Living Research Utilization.
- Kane, R. (1996, August). The quality conundrum in homecare. *Aging Today*, 7-8.
- L.C. v. Olmstead, 138 F.3d 1485 (11<sup>th</sup> Cir. 1998).
- Mahoney, K.J., Simone, K., & Simon-Rusinowitz, L. (2000). Early lessons from the cash and counseling demonstration and evaluation. *Generations*, 24 (111), 41-46.

- Litvak, S., Zukas, H., & Heumann, J.E. (1987). *Attending to America - Personal assistance for independent living: A survey of attendant service programs in the United States for people of all ages with disabilities*. Berkeley, CA: World Institute on Disability.
- Micco, A., Hamilton, A.C.S., Martin, M.J., & McEwan, K.L. (1995). Case manager attitudes toward client-directed care. *Journal of Case Management*, 4, 95-101.
- Miltenburg, T., Ramakers, C., Mensink, J. (1996). *A Personal Budget for Clients, Summary of an Experiment with Cash Benefits in Home Care in the Netherlands*, Institute for Applied Social Sciences, Nijmegen Netherlands.
- Moseley, C. (2001). *Self-determination for persons with developmental disability: Final and summative program report*. Durham, NH: Institute on Disability, University of New Hampshire.
- National Institute on Consumer-Directed Long-Term Services. (1996). *Principles of consumer-directed home and community-based services*. Washington, DC: The National Council on the Aging.
- Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. (June, 2003). *Lessons from the implementation of cash and counseling in Arkansas, Florida and New Jersey: Final report*. Princeton, New Jersey: Mathematica Policy Research, Inc.
- Pita, D.D., Ellison, M.L., & Kantor, E. (1999). *Psychiatric personal assistance services: A new service strategy*. Unpublished data available from the Center for Psychiatric Rehabilitation, Boston University.

- Pita, D.D., Ellison, M.L., Farkas, M., & Bleeker, T. (2001). Exploring personal assistance services for people with psychiatric disabilities: Need, policy, and practice. *Journal of Disability Policy Studies, 12* (1).
- Powers, L.E. (1996). Family and consumer activism in disability policy. In G.H.S. Singer, L.E. Powers & A.L. Olson (Eds.), *Redefining family support: Innovations in public-private partnerships* (pp. 413-433). Baltimore: Paul H. Brookes Publishing Co.
- President's New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America*. [on-line]. Available: <http://www.mentalhealthcommission.gov>.
- Richmond, G.W., Beatty, P., Tepper, S., & DeJong, G. (1997, August). The effect of consumer-directed personal assistance services on the productivity outcomes of people with disabilities. *Journal of Rehabilitation Outcomes Measurement, 1* (4), 48-51.
- Rodin, J. (1986). Aging and health: Effects of the sense of control. *Science, 233*, 1271-1275.
- Rothbard, A.B., & Kuno, E. (1999, January). The success of deinstitutionalization: Empirical findings from case studies on state hospital closures. *Journal of International Law and Psychiatry, 28*.
- Runde, P., Giese, R., Kerschke-Risch, P., Scholz, U., & Wiegel, D. (1996). *Einstellungen und Verhalten zur Pflegeversicherung und zur hauslichen Pflege*, Universitat Hamburg, Hamburg Germany, December 1996. Translated by Jon Peter Hopperger.

- Salomon, J., Polivka, L., & Weber, S. (1998, October). *Quality of life in long-term care: The role of control. Aging Research & Policy Report, Florida Exchange Center on Aging*. Tampa, FL: University of South Florida.
- Scala, M.A., Mayberry, P.S. (1997, July). *Consumer-directed home services: Issues and models*. Oxford, OH: Ohio Long-Term Care Research Project, Miami University.
- Scala, M.A., Mayberry, P.S., & Kunkel, S.R. (1996, Fall). Consumer-directed home care: Client profiles and service challenges. *Journal of Case Management*, 5 (3), 91-98.
- Simon, M., & Martin, F. (1996). *La Prestation Dependance: Rapport Final du Programme d'Evaluation de l'Experimentation d'une Prestation Dependance*. CREDOC Paris France 1996. Translated by Jane Tilly.
- Tilly, J., & Bectel, R.. (1999, April). *Consumer-directed long-term care: Participant's experiences in five countries*. Washington, DC: American Association of Retired Persons.
- Ulicny, G.R., Adler, A.B., Kennedy, S.E. & Jones, M.L. (1987). *A step-by-step guide to training and managing personal attendants, Volume 1: Consumer guide*. Lawrence, KS: The Research and Training Center on Independent Living.
- Velgouse, L., & Dize, V. (2000). A review of state initiatives in consumer-directed long-term care. *Generations*, 24 (111), 28-33.