



**INDEPENDENT CHOICES:
NATIONAL SYMPOSIUM ON
CONSUMER-DIRECTED CARE
AND SELF-DETERMINATION
FOR THE ELDERLY AND
PERSONS WITH DISABILITIES**

SUMMARY REPORT

February
2002

**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

Office of the Assistant Secretary for Planning and Evaluation

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

The office develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research—both in-house and through support of projects by external researchers—of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP) is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities—children, working age adults, and older persons. The office is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, the office addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHS-100-97-0008 between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy and the National Opinion Research Center. For additional information about this subject, you can visit the DALTCP home page at <http://aspe.hhs.gov/daltcp/home.htm> or contact the ASPE Project Officer, Andreas Frank, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. His e-mail address is: Andreas.Frank@hhs.gov.

**INDEPENDENT CHOICES: National
Symposium on Consumer-Directed Care
and Self-Determination for the Elderly and
Persons with Disabilities
Summary Report**

Marie R. Squillace, Ph.D.
Federal Project Officer, National Family Caregiver Support Program
U.S. Department of Health and Human Services
Administration on Aging, Office for Community-Based Services

February 15, 2002

Prepared for
Office of Disability, Aging, and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHS-100-97-0008

Administration on Aging
Contract #SA-01-0492

INDEPENDENT CHOICES

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services. (From "Principles of Consumer-Directed Home and Community-Based Services" published in 1996 by the National Institute of Consumer-Directed Long-Term Care Services, under a grant to the National Council on Aging and the World Institute on Disability, sponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. HHS).

An inventory of consumer-directed programs completed in September 2001 found 139 consumer-directed services programs operating in every area of the country except the State of Tennessee and the District of Columbia. Although 58 percent of these programs each serve fewer than 1,000 individuals, the estimated total number being served is close to half a million people with disabilities (including elders, adults of working age, and children whose physical and/or mental disabilities are associated with a wide range of chronic illnesses or medical conditions). Two-thirds of the programs were found to have come into existence since 1990, 17 percent just within the past two years. The inventory was compiled by EP&P Consulting for the Home and Community-Based Services Resource Network, a technical assistance contractor providing assistance to states, funded by the Centers for Medicare and Medicaid Services (CMS) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE).

Because of the growing interest in consumer-directed home and community-based services (HCBS) across the country, ASPE in the U.S. Department of Health and Human Services (HHS) joined other federal and private sponsors -- including the Health Care Financing Administration (now CMS), the Substance Abuse and Mental Health Services Administration, the Administration on Aging, the Administration on Developmental Disabilities, the Robert Wood Johnson Foundation (RWFJ) and AARP -- to host "Independent Choices: A National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities," June 10-12, 2001 in Washington, D.C. Invited speakers (policymakers, program administrators, consumer advocates, service providers, and researchers) attempted to synthesize empirical data and qualitative experiences of consumer-directed models in order to identify future directions for policy development and research to promote effective and responsive consumer-directed service systems for the elderly and persons with disabilities.

Participants in the symposium, including both speakers and audience members, numbered about 300. This report presents a summary of major findings and outcomes from the dialogues that took place.

Rather than attempt to abstract individual panel presentations, the report highlights the major themes that came up again and again in the plenary sessions with illustrative quotes or paraphrases of speakers' remarks that address these specific themes.

More detailed information on the symposium, including information about intensive workshops, conference materials, speaker presentations, research reports, and attendee contact information, is available at <http://aspe.hhs.gov/daltcp/reports.htm#DALTCP6>.

“Consumer Direction” at its core means maximizing opportunities for choice and control over their long-term services for people with disabilities and their families, across the lifespan and regardless of condition.

- Andrew Batavia¹, a law professor at Florida International University and former White House Fellow during the George H.W. Bush Administration, framed the opening panel discussion by providing a definition of “consumer direction.” As a result of a spinal cord injury in his youth, Professor Batavia has been a consumer of personal assistance services for over 25 years. He contrasted the “independent living model” with the other two main service delivery models: informal support (reliance on unpaid family, friends, and neighbors) and the medical model (where care is provided under the supervision of physicians and nurses who are held accountable for it). The independent living model puts the consumer in charge of his or her services (interviewing, training, directing, managing, and dismissing workers as necessary) and may also allow the consumer to control financial resources (through a cash allowance or individual budget). Although the independent living model seems most consistent with the values of “consumer direction,” it is conceivable for consumer direction to exist to varying degrees under any long-term care model. Some consumers, for example, might opt for agency-directed services as opposed to recruiting their own aides and directing their own care, but should be afforded the same opportunity to exercise control and maintain dignity.
- Judi Chamberlin, a self-described “psych survivor” who heads the Center for Psychiatric Rehabilitation in Massachusetts, pointed out that consumer direction in mental health services may also involve consumers becoming service “providers” through self-help and peer support programs.
- Joe Meadours, a self-advocate and peer counselor for people with developmental disabilities at an independent living center in Chicago, Illinois, added that consumer direction has a politically active dimension as well. Citing a popular slogan among mental retardation and developmental disabilities (MR/DD) self-advocates, “nothing about me without me,” Joe made the case for more participation of self-advocates to help plan a more responsive service system.
- Jackie Golden, mother of an adult with severe developmental disabilities, has been active for many years both nationally and in her home state of Maryland in advocating self-determination for people with developmental disabilities. She underscored Andrew Batavia’s opening commentary, contrasting the philosophy underlying

¹ Drew Batavia died in January 2003. In the words of Steven Tingus, Director of the National Institute for Disability Rehabilitation and Research, “Drew lived a life of dignity, accomplishment, grace and humor. He will be missed.”

“consumer direction” and the traditional model which over-medicalizes services. The purpose of consumer direction, she said is to “have a life, not a just a treatment plan.”

Allowing and encouraging consumers to self direct holds significant potential to improve consumers’ quality of life, individualize service plans so that services are better suited to meet a particular individual’s or family’s needs and circumstances, reorient service use and Medicaid expenditures away from services consumers generally do not want toward those they prefer, purchase more HCBS or get “better value” for a given level of public expenditure, and, in some cases, even achieve cost savings.

- Lisa Mangieri, a Personal Preferences Program (Cash and Counseling Demonstration) consumer in New Jersey, spoke about how receiving the experimental cash allowance and being able to purchase the goods and services she thinks will best meet her needs, including being able to employ her own aides, has changed her life for the better: “My disability is limiting physically, yet with this demonstration project I have become a truly empowered person. Most able-bodied individuals cannot understand the importance of having choice and control in their daily lives. Waking up and facing daily decisions of what foods to eat, what clothes to wear, and whether I should shower or take a bath are freedoms that are inherent in most lives. With the Personal Preference Program I have been granted total choice and control over my personal care needs. I think this program is great. Every consumer needs self-direction.”
- Tammy Svihla, another New Jersey Personal Preferences Program participant, said “Six-and-a-half years ago, before I became disabled, if I was told that I would have people coming into my home telling me what and when they were going to do something, I would have thought they were crazy. And when it happened, it was unbelievable that someone had that much control over my life. It felt like the particular agency that we contracted with was babysitting me. I’m not a babysittable person. To me this program has just basically given me back my life. I was depressed for a long time; not a very happy person. Now, I’m happy. I go out into the community. I do things, things I would never imagine doing before. I can take my scooter places where it is not supposed to be (which I do quite often). And I can be an effective parent. That, to me, is the most important thing. I can parent my children again. I can be a part of their lives and not be mom in the nursing home or mom in the assisted living facility. I’m only 36 years old. For me, being a single parent now, I need the

option of flexibility. The agencies don't have that. Anyone knows that when you have a three-year-old, you need flexibility. I like the option of choosing my own employees.”

- Laura Hershey, a consumer from Colorado, drew from her own personal experience to describe how very expensive yet restrictive a personal assistance service provided via a “medical model” can be. Her attendant care is provided through the Medicaid home health benefit. Colorado spends \$227 per day on her attendant care, which multiplies out to \$6,810 per month or \$81,720 per year. Yet for that amount of money, she is restricted to ten hours of attendant care daily, and she needs more. Moreover, her attendants are paid \$11.50 per hour and receive no fringe benefits; for example, no paid vacations or sick leave and no health insurance. Including Social Security payroll taxes, Laura computed that the total labor costs for her attendant care amounted to \$57,600 annually. The remainder of what Medicaid pays the home health agency for her services -- \$24,120 annually -- represents overhead and profit. Laura went on to point out that she always insisted upon interviewing and selecting her attendants from among the agency’s workforce, rather than simply accepting a worker assigned from the pool. She also insisted upon training and directing the work of the agency attendants who delivered her care. Thus, in her case, the agency was doing very little -- other than cutting a pay check and maintaining personnel records -- to earn the \$24,120 in annual overhead Medicaid paid them for delivering her services. Laura argued that, if other Medicaid beneficiaries with extensive needs were willing, as she is, to employ attendants directly and manage them, and the state Medicaid agency was willing to allow them to do so, the high overhead costs associated with the “medical model” could be redirected, consumers would be able to purchase more services, workers could have higher pay and benefits, and the state could realize some savings.

“Consumer Direction” has progressed beyond the experimental phase. It has become a movement, one to which not only consumer advocates but also an increasing number of government program administrators subscribe.

- Sue Swenson, former Commissioner of the HHS Administration for Developmental Disabilities, issued the following challenge to the conference attendees: “How do we make consumer direction/self-determination so robust that it survives no matter what the economy is doing, no matter what the labor market is doing, no matter what the big picture is in our country?”
- Rosemary Gibson of RWJF, senior program officer for the “Self-determination” grants initiative, asked: “How radical an idea is consumer direction? Or is it really long-term

care and support catching up to the rest of the world? If there is a way to build in quality and accountability in the system, it is through consumer choice.”

Consumer-directed service options are becoming increasingly popular in other countries. This is particularly so in Europe, where consumer-directed services are most often referred to as “personal assistance” or “direct payments.”

- According to John Halloran, Director of the European Social Network, “Europe has seen a major transformation from institutional to community-based care. But that, in and of itself, has not led to people being freed-up. In many ways that has, in some cases, ‘institutionalized’ various forms of community care. People may no longer be living in large, hospital-kinds of institutions, but they can also be entrapped in their own homes, reliant on a service in which they have very little control. So, the development of direct payments or consumer-directed care is important.” (For more information on the European Social Network and to access the full report “Toward a People’s Europe” see <http://www.socialeurope.com>).

The symposium raised awareness of the common core of agreement around principles of “consumer direction” across disability constituencies. Both advocates and government officials stressed the need for coalition-building to be more effective in pursuing shared goals.

- Advocacy for “consumer direction” has arisen within all the various constituencies that use HCBS (e.g., children and families, working age adults, elders as well as persons with physical disabilities, cognitive impairments or a combination, and their family caregivers). Some groups have developed their own models, statements of philosophy, and preferred terminology. For example, “consumer direction” may be referred to as the “independent living model” among working age adults with physical disabilities, “self-determination” among persons with MR/DD and their families, “self-help” and “empowerment” among persons with severe and persistent mental illness. At times, differences in terminology have gotten in the way of perceiving the core of common values and interests.
- Jim Firman, President of the National Council on Aging, suggested that those involved with consumer direction need to develop a common language. However, many attendees reported back to the meeting’s organizers that the symposium left them with the sense that diversity in the use of terms to describe “consumer direction”

need not pose a major barrier to coalition-building. Even though various disability groups may continue to speak their own dialects, especially “at home” within their own groups, the groups could still come together and translate back and forth.

- Several state program administrators, including Cindy Hannum, Assistant Administrator of Oregon’s Senior and Disabled Services Division, and Maggie Tinsman, a State Senator from Iowa, noted that government is likely to be more responsive to a coalition of groups voicing a shared perspective on the need for more consumer-directed HCBS than to each small group speaking individually and separately on behalf of only its constituency. Senator Tinsman exhorted: “Don’t pit one group against another.”

Several speakers rebutted arguments, which they often reported having heard from skeptical government program administrators, case managers, and agency service providers, that consumer-directed services may be appropriate for younger adults with physical disabilities but not for the elderly, for individuals with cognitive impairments such as mental retardation or dementia, or for people with severe and persistent mental illness.

- Lillian Brannon, an older consumer participating in Arkansas’ Independent Choices program, was unable to travel to the conference but videotaped her views on whether elders would want or be able to “consumer-direct.” She said, “I’ll advise anybody to get on this program. I would think it would be a lot better than anything else they could get. I’m 89 and I live alone. Without this program I would be in trouble. I’ve been in a nursing home four times and could not take it. I spent more days than I should have spent there, and the longer I stayed, the worse I got. Now that I have my own employees, I can tell them what to do; I’m the boss. I have four aides that work for me. When one can’t be here the other one comes. I have no problem getting help because they’re here when I call. I keep up with my money down to the penny and kept my receipts of what I paid for. Independent Choices has really changed my life so much. It has really helped me to live more independently than I ever have. I would not trade it for anything.”
- Lynn Feinberg of the Family Caregiver Alliance in San Francisco reported on the results of a study she conducted under the auspices of the Independent Choices grants program, funded by the RWJF, through the National Council on Aging. She said that her research found that persons with mild to moderate cognitive impairment due to such conditions as Alzheimer’s, Parkinson’s, or traumatic brain injury are able to state consistent preferences and choices, and be vocal in sharing their values and

preferences about care now as well as in the future. Many request that, when they get to a more advanced stage of the disease and can no longer express themselves, family members act as their representatives or surrogate decision-makers.

- Jackie Golden pointed out that even someone with significant cognitive disabilities, like her son who is unable to express himself verbally, can direct his or her own services through a “microboard” comprised of family, friends, and other close associates who know the consumer very well and can interpret his or her non-verbal expressions. She went on to explain how her son “fired” a paid helper with whom he had no rapport. Her son’s negative reactions whenever this particular individual reported for work led the microboard to terminate his employment, even though the worker had appropriate training and credentials and had done nothing “wrong.” The microboard felt that Jackie’s son had the right to choose the individuals who were his caregivers, and if he did not like someone that was sufficient reason to let the individual go. Jackie noted that this would never have happened in an institutional or small group home setting.
- Judi Chamberlin cautioned that having family members act as decision-making surrogates for beneficiaries with disabilities affecting their minds need to be looked at on a case-by-case basis. It could be appropriate, but she also knew that many persons with severe and persistent mental illness have deep disagreements with family members. As adults who typically have not been adjudicated mentally incompetent, they would object to having family members designated to represent their best interests in lieu of making decisions themselves.

A number of barriers to consumer-direction were identified, of which the primary ones were fragmentation of the system due to multiple, complex funding sources and resistance from traditional service providers. Suggestions were made for how to overcome these barriers.

- Judi Chamberlin and other speakers representing the perspective of persons with severe and persistent mental illness felt that the impediments to consumer direction were particularly great in the mental health services field. She noted that community-based mental health services for persons with severe and persistent mental illness were funded through different funding mechanisms than HCBS alternatives to institutional care for other groups, such as individuals with MR/DD, the elderly, and younger adults with physical disabilities. She expressed the view that reliance on different and more complex funding streams for mental health service alternatives to long-term or repeated stays in mental hospitals kept users of these services apart from other disability groups.

- Several speakers cited resistance from providers under the traditional model as a barrier to consumer direction. Charles Moseley, former Director of RWJF's National Program Office on Self-Determination at the University of New Hampshire, observed that some providers have reacted to the movement for self-determination for persons with MR/DD with excitement, while others are threatened by it.
- William Ditto, Director of New Jersey's Personal Preferences Program (one of the three state projects involved in the National Cash and Counseling Demonstration and Evaluation) offered advice on how to deal effectively with obstructions to consumer direction from traditional agencies. He counseled bringing the traditional providers in early during the planning process for consumer-directed service options and including them on the advisory council so that their issues and concerns can be discussed openly. Dialogues of this nature help providers understand and acknowledge that they may not be able to meet the needs of all persons who require personal assistance services and that the clients they are unable to serve may be the very people who could be served under a "cash and counseling" model. Similarly, providers need to understand the move toward a more "marketplace economy" in services for people with disabilities and how providers might change their businesses to actually sell things that consumers would like to buy. To increase enrollment in consumer-directed services programs, Bill suggested that state program administrators consider writing to traditional home care provider agency directors, asking them to refer the people they do not like to deal with.

Some states have allowed consumers to employ their own personal care attendants for many years, and other states, for which "consumer direction" is still a new and untested idea, can learn from their experience. Some of these longstanding programs have grown quite large, proving that consumer direction can be successful on a large-scale.

- Lora Connolly, Assistant Secretary for Long-Term Care in California, noted that her state's In-Home Supportive Services (IHSS) Program has been allowing low-income persons with disabilities (elderly and non-elderly) to hire/fire, train, schedule and supervise individual providers of personal care services (PCS) for 30 years. The program currently serves approximately 200,000 clients, and 96 percent hire independent providers. In fact, if choice is restricted in the IHSS Program, it is because only 12 of California's 58 counties even have the ability to pay for agency services.
- Julia Huddleston, of Oregon's Division of Senior and Disabled Services, explained that, in 1981, Oregon was the first state to have a Medicaid-funded HCBS waiver

approved and that hiring independent providers was an option available to waiver participants from the very beginning. As of June 2001, Oregon had 15,000 Medicaid beneficiaries receiving services through the client-employed provider option.

- As of the fall of 2001, Texas planned to begin offering options for Medicaid waiver participants to employ home care workers directly (including families being able to hire respite aides or companions) in all seven of their HCBS waiver programs. Tommy Ford, Manager of the CLASS waiver that serves Medicaid beneficiaries with MR/DD (many of whom are children), indicated that beneficiaries themselves or designated representatives (such as parents of minor children) would be permitted to consumer-direct up to \$60,000 worth of services per year.

Some of the states that pioneered consumer-directed services are now experimenting with new approaches.

- Julia Huddleston reported that Oregon had received an 1115 research and demonstration waiver to experiment with giving 300 Medicaid beneficiaries in three counties a cash grant. The difference between this experimental program and Oregon's existing Client-Employed Provider Program is that participants in the experiment who hire attendants will personally take on all of the employer-related responsibilities, including filing Social Security and any other required payroll taxes. They will receive their cash grants prospectively, and they will also be permitted to hire spouses as paid caregivers, an option Medicaid law does not permit in the absence of a research and demonstration waiver.
- Mary Faherty, of Wisconsin's LaCrosse County Department of Human Services, described Wisconsin's new county-run managed care system for HCBS (called Family Care). Although the primary goal of the new system is to eliminate long waiting lists for HCBS -- a goal that has been reached in LaCrosse County -- the new system also incorporates opportunities for self-directed supports for individuals and families eligible for HCBS waiver services, regardless of age or type of disability. To implement Family Care, Wisconsin gained federal approval for a combination of 1915(b) "freedom of choice" and 1915(c) HCBS waivers.

Some early efforts are underway to incorporate consumer-directed HCBS service options into managed care plans that cover both acute and long-term care services.

- Marsha Smith, CEO of EverCare, spoke of her company's involvement in the Texas Star Plus Program. Approximately 28,000 Medicaid beneficiaries (including 14,000

“dual eligibles,” who are also covered under Medicare) were enrolled in this program as of June 2001. Participating home maintenance organizations will be required to offer those who are eligible for HCBS as an alternative to nursing home care (approximately 520 members), the opportunity to hire their own home care workers, using a “vendor fiscal intermediary service” to pay the workers and file required taxes. EverCare also works with the State of Arizona to offer consumer-directed services in a managed long-term care system, using home care agencies as fiscal intermediaries (also known as “employer agents”) for Medicaid beneficiaries for such tasks as criminal background checks on potential employees, processing payroll and filing payroll taxes.

When asked whether consumer direction and managed care are compatible, Marcia responded, “There is tremendous synergy in the objectives. This is absolutely the way to go. If we think the principles of managed care are to deliver the right service, in the right place, and at the right time, this approach is totally compatible with that. Quality care, by definition, is cost-effective care. The way you get to cost-effectiveness is by putting quality on the front end. Programs such as these, where the consumer can choose who is coming and going, and there is continuity, bring the continuum of care to a new level. When we had responsibility for delivering Medicaid benefits in the Arizona long-term care system in rural counties, we found [consumer direction] to be tremendously cost-effective, and it dramatically averted nursing home placements.”

Consumer-directed options are compatible with private long-term care insurance, and some policy designs -- though not the most widely available ones -- maximize consumer direction.

- Marc Cohen, of LifePlans, Inc., reported on findings with respect to policies favoring consumer direction that emerged from a study of private long-term care insurance claimants he conducted for ASPE and RWJF. Individuals who purchase private long-term care insurance policies whose design is similar to that of disability insurance coverage may access cash benefits once they reach the level of disability required to file a claim. In contrast, most private long-term care insurance policies require claimants to submit bills or receipts for services, and only certain kinds of services, from certain kinds of providers, will be covered. Although the “disability model” policies represent only about 10 percent of the current market, claimants with these policies have a different pattern of service use from the others. They are more likely to hire home care workers directly, rather than through agencies, and more likely to hire friends and relatives to provide care. The study found that 95 percent of the claimants with policies that enabled them to “consumer-direct” were satisfied, whereas for those with policies that only reimburse for more traditional, agency services, the satisfaction rate was 60 percent.

Existing models of consumer direction have some drawbacks, according to state officials, consumers and providers. The most frequently cited relate to the need to make it easier for consumers to find and employ qualified workers.

- Lora Connolly noted that a “potential weakness, and something that we are trying to work on, is that consumer-directed workers are primarily paid minimum wages with no benefits, historically, for the employees over the last number of years. Although we speak about individuals finding family members or church members to help, given the wage of the labor market and the high cost of California cities -- even for consumers seeking family members -- it has gotten harder and harder in the IHSS program. The IHSS Program also probably best serves individuals who are cognitively intact. We have not had the counseling or training side built into the program. These are some of the issues that we are trying to address in California.”

Lora went on to describe legislation passed by the California State Legislature in 1992 allowing counties to develop “public authorities.” The function of the public authorities is to act as “employer of record” with respect to collective bargaining over wages and benefits for consumer-employed workers (recognizing that public program beneficiaries themselves have no say in how much funding the state and the counties provide to pay IHSS workers wages and benefits). The public authorities are also authorized to establish registries to help IHSS Program participants find workers, provide training, and establish advisory groups, of which 50 percent of members must be consumers of personal assistance services. Lora reported that, as of June 2001, California had eight public authorities, some of which were already quite well established, and others under development.

- Donna Calame, Executive Director of the San Francisco IHSS Public Authority, spoke up from the audience to report that IHSS independent providers’ (i.e., consumer-directed workers’) wages had increased by 50 percent since the establishment of the San Francisco public authority and that full health care (including dental) benefits had been made available to those who worked at least 25 hours per month.
- Denise Winslow, of Utah’s Division of Services for People with Disabilities, pointed out that, in Utah and other states where Medicaid beneficiaries and/or families have control over their “individual budgets” for services, they are empowered to negotiate support staff costs with organized providers or people they hire on their own, in accordance with the value of the service that these organizations or individuals are providing to them. That is, under “cash allowance” or “individual budget” models, it is possible for consumers to hire workers at higher rates than would be paid under the traditional system.

- Beth McArthur, of the Connecticut Department of Mental Retardation, added that Connecticut facilitates consumers and potential workers connecting with one another by allowing the posting of want ads and resumes on the Connecticut Department of Labor's Internet site.
- Andrew Batavia offered a note of caution about pay and benefits: "I think it is very good that you [state officials] are trying to offer a good and living wage for personal assistants under state Medicaid programs, but you should understand that there are also implications for those of us who are not under Medicaid. We are working hard to try to make a living for ourselves and our families, and we have to compete with the wages you all come up with which are not necessarily competitive wages in the marketplace. For those of us who are individual employers (I have been for 25 years) it is not easy to compete with very generous states. Be aware that there are implications for the rest of the disabled population. I cannot access affordable insurance for my personal assistants because I would have to get an individual policy."

A number of states are seeking to maximize opportunities for consumer direction by allowing eligible Medicaid beneficiaries to manage their own "cash allowances" or "individual budgets."

- Three States (Arkansas, New Jersey, and Florida) are participating in the Cash and Counseling Demonstration and Evaluation being co-sponsored by RWJF and ASPE. Kevin Mahoney, Director of the National Program Office that oversees the demonstration and scientifically rigorous evaluation and provides technical assistance to the states, described the status of the experimental projects. Approximately 5,500 Medicaid beneficiaries had enrolled in the demonstrations in the three states as of June 2001. The Cash and Counseling Demonstration experiments required 1115 research and demonstration waivers from CMS, primarily because they give beneficiaries the option of actually receiving their benefits directly in the form of cash. In practice, most beneficiaries prefer to have the funds held for them by a provider (called a "fiscal intermediary services" organization, which also provides or coordinates with a counseling or consultant service) that actually performs the financial transactions for them. In particular, the fiscal intermediary service acts as the consumer's employer agent for purposes of payroll and tax filings for consumer-employed workers.
- Julia Huddleston of Oregon and Laura Hershey of Colorado mentioned that their states had received 1115 research and demonstration waivers to implement small

experiments similar to the Cash and Counseling Demonstration projects. Kevin Mahoney mentioned that several other states were considering applying for 1115 waivers for similar experiments.

- Charles Moseley noted that a number of self-determination projects for Medicaid beneficiaries with MR/DD had managed to incorporate “individual budgets” managed by beneficiaries and their representatives into programs operating under 1915(c) HCBS waivers, without also being required to obtain special 1115 research and demonstration waivers.
- Nancy Thaler, the Pennsylvania MR/DD Services Director, pointed out that “individual budgets” help states better predict and contain costs, so that all Medicaid beneficiaries who meet financial and functional eligibility requirements can receive HCBS, without the state having to resort to waiting lists to keep costs within the total dollar limits of legislated appropriations for MR/DD services. Nancy noted that Pennsylvania had actually “backed into” the concept of giving beneficiaries and families an individual budget and letting them make more of their own service decisions. That is, the state was not originally motivated so much by a desire to promote “consumer direction” as by a need for the agency to be able to tell the legislature, in advance, how much meeting the total need for MR/DD services would cost. She went on to say that it is very important to use objective, scientifically grounded methods to establish the size of individual budgets in relation to individuals’ assessed needs, and to be certain to provide an adequate amount of funding to meet those needs while also allowing beneficiaries and families choice of services. Pennsylvania has relied heavily on the “DOORS” methodology developed by Wyoming. Nancy said that Pennsylvania decided that, if individual budget limits were to be set, the process should be transparent to beneficiaries and families. Prior to being given individual budgets, beneficiaries and families did not know how much services cost. They did not understand the consequences (i.e., longer waiting lists for others not yet in the program) of claiming entitlement to anything and everything on the service list, regardless of cost. However, once the policy shifted to give beneficiaries and families individual budgets they could control, they tended to behave as they do with their “own” money, taking pride in stretching dollars to obtain maximum value.

Consumers and families who manage “cash allowances” or “individual budgets” tend to choose a somewhat different mix of services from somewhat different sources than they would have received in the traditional system (i.e., from professional agencies or under a plan developed by a professional case

manager, whose choices are limited to certain kinds of services and providers on a Medicaid authorized list).

- Tammy Svihla provided an example: “I’ve been able to purchase certain needed equipment around the house; it has allowed for not necessarily bigger things, but for me, more important things that Medicare or Medicaid do not pay for, different things that I tend to think of as personal care needs. With my MS I needed a couch, because my couch is very soft and is sunken in when I sit down, so I can’t get up out of it. Instead, I’m going to get a lift chair which is actually a Lazy-Boy that lifts you out. This is more logical.”
- Don Hruby, Director of the Consumer Resources and Outreach Program of the Iowa Division of Mental Health, characterized himself as “in recovery” from severe and persistent mental illness as well as substance abuse. He observed that, if people with mental illness could have access to individual budgets and purchase what they think they need, they would access different services than those the current system limits them to using. In particular, he noted the need for a way to pay for smoking cessation programs. He said some people with severe and persistent mental illness are heavy smokers and this damages their physical health. He went on to say that an aspect of taking responsibility in recovery from mental health and substance abuse is to learn different coping mechanisms for dealing with stress that will not damage one’s physical health or trigger mental illness and revolving door hospitalizations. However, the current financing system does not provide a payment mechanism for such self-help programs.
- The great majority of participants in the experimental Cash and Counseling projects, who hire workers directly, employ people they already know: family, friends, neighbors or church members. Most hire relatives, which is partly by preference, but also a reflection of how difficult it is to recruit others, especially when other better-paying jobs are available. Federal law and regulations leave it to states to decide whether to permit the hiring of most categories of family members. Only spouses and parents of minor children or other “legally responsible” relatives (i.e., those whose income and assets are deemed available to beneficiaries and therefore counted in Medicaid eligibility determinations) are prohibited by federal law and regulations from becoming paid caregivers.

Both New Jersey and Florida asked for and received 1115 waivers specifically allowing spouses and parents to be paid caregivers on an experimental basis in their Cash and Counseling Demonstrations. According to the New Jersey Project Director, Bill Ditto, objections to hiring family members usually center around concerns about a “woodwork” effect; that is, that relatives, especially spouses and parents, will now be paid for services that they would have -- and should have -- provided for free, and that this will bring more beneficiaries into the programs. He rebutted these objections by

pointing out that “What we are providing really is the equivalent of what would have come from an agency. And it all starts from a clinical assessment, so it is not necessarily creating the problem that many had envisioned.”

- Pamela Doty, a Senior Analyst in ASPE, cautioned that, without special research and demonstration authority, hiring spouses or parents as paid caregivers can create financial eligibility problems for beneficiaries who need to access other means-tested benefits such as SSI and Food Stamps. The Cash and Counseling Demonstration had to negotiate special arrangements with the Social Security Administration and the Agriculture Department so that experimental “cash allowances” paid to Medicaid beneficiaries would be excluded in making SSI and Food Stamp financial eligibility determinations.

Although California does allow spouses and parents to be paid in the IHSS Program with state general revenues, and Oregon used to allow spouses and parents to be paid with state funds and the legislature has directed state officials to seek a way to do so with Medicaid funds, there is little movement yet underway to eliminate the federal prohibition on hiring spouses or parents. At the same time, the traditional arguments for the ban are increasingly being questioned. Pamela observed: “When this was put in the statute (about 25 years ago) we were in another era. There were many more stay-at-home spouses. I think this is a case of social attitudes evolving, and the law has not caught up to them yet.”

- Sandra Barrett, the Arkansas Project Manager, added that traditional agencies used to oppose very strongly allowing any family members to be paid caregivers. However, she noted that one of the side effects of the “Independent Choices” program has been that many of the personal care agencies facing worker shortages are now hiring family members as long as the family members agree to go through a training program. Arkansas Governor Mike Huckabee explained why he supports greater involvement of family members in Medicaid-funded home care, whether as representatives to help beneficiaries manage allowances or to act as paid caregivers: “It is a myth to think that the case managers or agencies know best. How can anyone know better what the needs of the client are than the people who perhaps live or socialize with that individual?”

Consumer-directed services are not risk free. Several speakers asserted that, from a consumer and family perspective, risks needed to be balanced against the benefits to be gained from freedom to make personal choices and live as independently as possible. A variety of speakers -- including researchers, program administrators, and consumers -- observed that both

study findings and administrators’ and consumers’ own experience are showing this model of service delivery is not inherently “riskier” than professionally managed services. In some ways, consumer direction reduces risk.

- Jackie Golden said, “Giving the control to my son has reduced the risk. In the hospital setting he was subject to significant abuse and neglect. [With self-direction] he really does control people that come into his life and really care about him. He has a full, engaged life. The people that are there are there because they care.”
- Governor Huckabee pointed out “There are some myths we had to overcome in implementing the Independent Choices Program. People thought this would be rampant with fraud and abuse and individuals would be exploited. What we found in Arkansas is that, instead of seeing widespread fraud and abuse, it’s really been able to empower families to pick a family member or a friend, someone they have a trusted relationship with.... And instead of promoting or encouraging fraud, I think in many ways it has perhaps curtailed it.”
- Underscoring the Governor’s observation, Professor Ted Benjamin noted that his evaluation of California’s IHSS Program found that a high percentage of clients in the consumer-directed model hired family members as their personal care attendants and that these clients scored significantly higher than others on outcome measures related to safety (sense of security).
- Jim Firman suggested that excessive attention to protecting against “risks” and “safety” concerns came out of a “guardianship” perspective. He strongly urged that there should be a presumption of competence on the part of program beneficiaries to make decisions, rather than placing the burden of proof on consumers and families to convince program officials or case managers that they are competent.
- Joe Meadours noted that individuals with MR/DD, who have lived most of their lives in institutions or in other group settings with a great deal of professional supervision, may well need some training in recognizing and managing risks when they go out to live in apartments of their own. This was one of his roles as a peer counselor. He also noted that the Independent Living Center where he works regularly organizes seminars in which police and others educate people with MR/DD about some of the dangers they may face in living in the community and how to protect themselves.

Quantitative evaluation results from a completed study comparing client and worker outcomes for the “consumer-directed” and “professional agency” models of service delivery

were presented from California’s IHSS Program. Interim, early evaluation findings were presented for some of the RWJF-sponsored self-determination projects and for one of the RWJF/HHS-sponsored Cash and Counseling Demonstration projects (i.e., Arkansas’ Independent Choices).

- Ted Benjamin reported that, on 7 of 14 client outcome indicators, the “consumer-directed” model had statistically better outcomes than the professional agency model. On the remaining outcome indicators, there were no statistically significant differences in client outcomes related to service model type.
- Jennifer Schore of Mathematica Policy Research, the contractor for the controlled experimental design evaluation, and Kevin Mahoney reported some early findings on consumer satisfaction among the “treatment group” (i.e., cash allowance recipients) in the Arkansas “Independent Choices” project. For example, over 90 percent of the first 200 participants to complete nine months in the experiment said that they would recommend participation to others. Kevin directed audience members interested in obtaining more information on the Cash and Counseling Demonstration and Evaluation to go to the University of Maryland Center on Aging website: <http://www.inform.umd.edu/aging>. Current evaluation findings are available from Mathematica Policy Research, Inc. on-line: <http://www.mathematica-mpr.com/3rdlevel/cashcounseling.htm>.
- Jim Conroy, an evaluation consultant for the self-determination projects, reported that the New Hampshire project, one that had been most extensively evaluated to date, has dramatically improved quality of life for participants. In addition, public costs were reduced 12-15 percent.
- Valerie Bradley, President of the Human Services Research Institute, reported on the findings of a process evaluation which identified the changes that occurred in the administration of service programs for persons with MR/DD in the 19 states that received RWJF “Self-Determination” grants. She observed that funds started to flow differently in states that took the self-determination philosophy to heart through some sort of mediating entity that enabled people with disabilities to make decisions among real options rather than to the traditional providers. Along the same lines, there was also a shift away from the traditional retrospective payment of provider rates and fees toward a more prospective, budget-setting process that left many decisions about how funds would be spent open to consumers. With respect to self-determination and managed care, states did not set up formal risk reserves but, in a more informal sense, maintained a pool of resources to backstop people. Savings were automatically being channeled into emergent needs. The self-determination approach was found to place greater burden on service coordinators, in part because

they could not shed their conventional responsibilities; new ones were added. Fiscal intermediaries were developed to manage employer/employee relationships. Finally, management information systems had to be increased geometrically to be able to track someone's individual budget. According to Bradley, the "bottom line" administrative challenge is "how we make this activity simple... How we keep the complexity behind the screen so it's a fairly straightforward process for the individual."

- Jean Campbell, of the Missouri Institute of Mental Health and the University of Missouri in St. Louis, cited a study that had been conducted over 12 years ago, which established that mental health consumers did want power and self-determination. She said this statewide survey of mental health clients revealed that consumers could manage their own problems and symptoms, and could take care and do things for themselves when they discovered they were having problems. Jean also described a federally sponsored evaluation, called the Peer Protocol Outcomes Project, currently underway to examine the effectiveness of consumer-operated services when offered as an adjunct to traditional mental health services. Measures of employment, empowerment, housing, service satisfaction, social inclusion, and cost outcomes will be evaluated across three models (drop-in centers, educational and advocacy training programs, and peer or mutual support services). The evaluation methodology includes random assignment. The project is in its third of four years. For more information go to: <http://www.cstprogram.org>.

Throughout the conference, various speakers laid out broad strategies or, in some cases, recommended very specific "next steps" to promote consumer direction.

- Thomas Hamilton stressed the need to build "the system behind the system" (infrastructure, support, techniques). He urged that the Federal Government become "a facilitator, not a barrier to innovation and creativity." Thomas supported experimentation and risk-taking, observing that, "Most of our learning occurs from making mistakes. If we look at things from the perspective of self-direction and exercising choice, making mistakes -- but learning from those mistakes and doubling our efforts -- makes a difference. It also begs the question: do we look at this from a mistakes point of view?"
- A number of speakers discussed how development of infrastructure -- in particular, "fiscal intermediary organizations" (bookkeeping/accounting services to help consumer-directed beneficiaries manage their individual budgets and pay/file taxes for their workers) -- can minimize concerns about misuse of funds or financial exploitation of vulnerable individuals.

- Sue Swenson also endorsed the value of experimentation and evaluation research, emphasizing what can be learned even from failed experiments about how to make systems more responsive.
- Nancy Thaler sounded a cautionary note about “pilot programs.” She stated that “pilots often run outside the system,” and when states decide they want to “institutionalize them, they find the pilots have to be redesigned. And that’s a leap, not a small step.”
- Maggie Tinsman said, “By all means let’s have pilots, but no pilot program should go for more than three years.” In other words, three years should be long enough to make a decision whether the pilot worked or not, and if it worked, it should be incorporated into the system.
- Claude Allen, Deputy Secretary for HHS, asked rhetorically, “How do we provide states with flexible, effective options to achieve community integration and to offer consumers more choice and control?” His answer was: “Grassroots planning and public/private partnerships are a necessary part of effective change.”
- Several speakers, including Charles Moseley, addressed the challenges involved in encouraging grassroots planning and made specific recommendations. Public program beneficiaries themselves, not just paid professional advocates, need to participate more in planning services in their states. But to get them to the meetings, those consumers often need various kinds of assistance (travel stipends, handicapped transportation, access to personal attendants or other supportive helpers at the meetings).
- Several speakers addressed the problems involved in having to find “work-arounds” to antiquated or inappropriate Medicaid requirements. Bob Gettings, Executive Director of the National Association of State Directors of Developmental Disabilities Services, implied that, to remove barriers to consumer direction, Congress might need to give the Medicaid statute a serious overhaul. “We are increasingly reliant on a set of statutory programs that we are asking the federal administrating agency to bend and twist and curve -- which is seriously, at its base, flawed. We also have a convoluted system of how we go about making decisions within this process. It is a federal/state program in which we send the message that the state administers the program, but they are confined by a framework (Federal Medicaid Law and Regulations) which leads states to the point of individual budgets.”
- Suzanne Crisp, former Program Director of Arkansas’ Independent Choices project, noted Arkansas’ strong desire to convert the project from an experiment operating under a time-limited 1115 research and demonstration waiver to a permanent option within the state’s Medicaid program. This would require defining coverage under the

state plan PCS benefit (the basis in the regular Medicaid program for Arkansas' Independent Choices program) as encompassing more than just personal care attendants or other forms of human assistance. At a minimum, coverage under the state plan PCS benefit needed to be interpreted more broadly to encompass the other kinds of goods and services Independent Choices Program participants choose to spend their allowances on -- in particular, assistive technologies, home modifications, and personal care supplies (such as continence pads, creams to prevent or heal skin breakdown, etc.).

- Kerry Schoolfield, Bureau Chief for the Developmental Disabilities Program in Tallahassee, said Florida has two consumer-directed care programs: The RWJF Cash and Counseling 1115 waiver for adults with physical disabilities; children with developmental disabilities, brain and spinal cord injury; and elders. The second program is state funded, called "Choice and Control." "We have been doing these for about the past year and have found that there is a sense that we just can't get things going fast enough. In response to this, we put together a group of family members, consumers, advocates, and state employees. We used a document developed by the National Council on the Aging to assess... 'how consumer-directed is my developmental disabilities program.' We spent about four months talking about how far can we push the existing HCBS waiver to make it more consumer-directed right now.... You can change the definitions of your providers. Some of the struggles that we faced were just having adequate numbers of providers and adequate numbers of people to enroll to become providers or to accept the payment rates that Medicaid offers. Frankly, until you change who they see as in control... things never fundamentally change."
- Several speakers suggested arguments they believed might be especially effective in persuading policymakers to support consumer-directed services. Thomas Hamilton's list of compelling arguments included cost-effectiveness (both as compared to traditional home care and as a more effective way to deter use of costly institutional care), as a response to the shortage of traditional agency workers, and as a basic American "right" (to exercise choice in pursuit of liberty and freedom, and to assume greater responsibility for oneself).
- Iowa State Senator Maggie Tinsman offered a number of concrete suggestions for how to get state legislators to be receptive and responsive to consumer-directed services. Like other speakers, she stressed that being able to show the cost-effectiveness of consumer-directed services was a particularly compelling argument. However, she also emphasized quality of life arguments; that is, the importance of explaining to legislators how life changes for the better for people with disabilities when they are able to self-direct. If moving to consumer direction is likely to increase costs, or do so on a short-term basis before offsetting savings can be realized, advocates should have a plan to roll out the program over a number of years,

beginning with a “pilot project” so that legislators can see things progress. State Senator Tinsman also recommended that advocates meet with and get to know legislators personally, starting with the chairs and ranking members of the human resources and human services committees. She suggested providing state legislators with a two-page overview, including examples of how consumer direction will help their constituents and explaining successes achieved in other states; if possible, talking about other nearby states.

State Senator Tinsman was also critical of the ongoing need for states wanting to adopt consumer-directed services models to seek federal approval of “waivers.” She wanted “no more waivers.” She asked why funding for HCBS and related Medicaid services could not be block granted. This would allow states to determine their programming and be held accountable. She indicated that too much time, effort, and money was being spent on administrative matters, such as in which waiver a given individual would be served.

- Glenn Stanton acknowledged that the waiver approval process was indeed cumbersome and slowed down states’ implementation of consumer-directed services options. He announced that CMS was working on two “templates” to guide states in applying for 1115 and 1915(c) waivers involving consumer-directed services funded via Medicaid. At a minimum, states would have a much clearer idea of the information they needed to provide to CMS in their waiver applications so that there would be fewer delays related to continual requests from CMS for additional information not originally provided by the state. CMS hoped that, once completed, these templates would expedite waiver approvals.²
- Beverly Lynch pointed out that she was from Kentucky where “not much is happening.” She asked CMS to provide more technical assistance to states. In addition, she noted that states that wanted to develop consumer-directed services models often received conflicting and confusing advice from CMS’ regional offices; some regional offices were more knowledgeable and helpful than others.
- Suzanne Crisp noted that Arkansas considers itself a “southern state” with fewer financial resources available for Medicaid services or for program innovation than many other states. She did not believe that Arkansas could have made as much progress as it has, so rapidly, with respect to consumer-directed services without having received a multi-year RWJF planning and implementation grant and, along with the grant money, a great deal of technical assistance from or made available through the Cash and Counseling Demonstration National Program Office at the University of Maryland Center on Aging.

² These “Independence Plus Templates” were made available in July 2002.

- Glenn Stanton responded that CMS was aware of states' needs for technical assistance and looking for ways to address the need. He said that Thomas Hamilton continually challenged his staff at CMS by asking, "What is our product line?" and suggesting that it is or should be "solutions for states." Glenn went on to say that CMS was a co-funder, with ASPE, of the Home and Community-Based Services Resource Network (<http://www.hcbs.org>), based in Boston at MEDSTAT and Boston College, and that there would also be a technical assistance center associated with the Systems Change Grants that CMS would be awarding in September 2001.
- Don Hruby echoed other mental health self-advocates at the conference in urging that people with severe and persistent mental illness not continue to be "left out" of efforts to expand consumer-directed services options or, more generally, efforts to expand the availability of HCBS financed by Medicaid.
- Judy Riggs of the Alzheimer's Association, John Rother of AARP, and Chris Gianopoulos, Director of Maine's Bureau of Elder and Adult Services, questioned whether all of the focus should be on Medicaid reforms. They noted that many older people and many younger disabled adults would never be able to avail themselves of Medicaid-funded services (presumably because their income or assets are above the Medicaid means-test). They recommended introducing the concepts of consumer direction into the Medicare program.

Throughout the conference, but especially in the closing session, various speakers sought to put consumer direction in a broader perspective. Two such broader contexts emerged as very much on the minds of speakers and audience members who participated in discussions: the Supreme Court's "Olmstead" decision and the federal and state planning and policy activities expected to implement the ruling; and the importance of raising the public funding priority of long-term care services, especially HCBS alternatives to institutionalization.

- Several speakers, including Marilyn Saviola, an employed Medicaid consumer from New York, who works at Independence Care Systems, a prepaid plan for adults with disabilities; Bill Coffelt, a parent advocate for people with developmental disabilities from California and leader in the National Coalition on Self-Determination; and Andrew Batavia saw consumer-directed models of service delivery as being especially in tune with the emphasis in the Supreme Court's Olmstead decision on

making services available in the most integrated setting feasible and appropriate for individuals with disabilities.

- Senator Tom Harkin of Iowa was not able to speak in person but sent a taped video message in which he stated, “One of the most fundamental rights of any American is to choose where and how they want to live. No matter where you live or who you are, before you can participate in the mainstream economy, either as a consumer or in the workforce, you must first have the opportunity to live in the community, near schools, near vocational training centers, near your friends and family. In the Olmstead case, the Supreme Court...made clear is that one size does not fit all. Our long-term care systems must provide a continuum of services that allow people to live where they want to and how they want to.”
- Bobby Jindal, the Assistant Secretary for Planning and Evaluation, sounded a similar note in his remarks: “A full continuum of services is everything from services for those who want to remain in the home to institutional care, with many things in-between. How does a society provide that full continuum of care to meet each individual’s unique needs? Resources should follow the customer. The customer should be able to direct, rather than have resources frozen into programs that may not keep up to date with modern technology....”
- Thomas Hamilton spent much of his presentation outlining the connections between consumer-directed services options being developed by or under consideration in the states and the Supreme Court’s Olmstead decision. He cited CMS’ “Systems Change Grants” as a significant potential funding vehicle for seeding state efforts to plan and implement consumer-directed models of service delivery. Thomas also related CMS’s efforts to encourage and give states technical assistance with respect to adapting consumer-directed services to the President’s New Freedom Initiative.
- Many advocates who attended chose to emphasize funding, rather than promote consumer direction. Judith Heumann said, “The question is no longer validating whether persons with disabilities are able to be self-determining. The question is no longer that there is a role for family and friends to play in the area of personal assistance services. The issue is whether or not sufficient funding is going to be provided to allow this to happen. If there is not sufficient funding put into these programs, then in order to keep this issue alive -- because the demand is getting stronger and because people are no longer willing to wait to be given permission to go outside their house, to be able to go to work, to be able to do whatever it is that non-disabled people take as a fundamental right -- we really need to look at the issue of where the dollars are coming from.”
- Christine Gianopoulos specifically encouraged more spending on worker wages and benefits. She perceived worker shortages, due to inadequate wages and benefits,

as a generic issue, not one that was specific to consumer-employed home care workers. However, she noted that there can be no “consumer-directed” services unless there is a long-term care services system. She said that Maine had estimated the cost of providing all home care workers with a living wage at \$35 million dollars, which, in Maine, amounts to “real money.”

- John Rother said, “When we ask the American public where they think money should be used, health care is consistently at or near the top of that list. It is not a situation where we as a country cannot afford this. It is a situation where we have to make some decisions based on what is important. And I think we can make the case that this is very important. I don’t accept ‘the cupboard is bare,’ and I don’t think any of you should either. We make decisions every day. Some can be unmade. We have the resources to take on this problem. This is the future of long-term care for people of all ages.”

He went on to describe “Citizens for Long-Term Care.” Chaired by former Senator David Durnberger and comprised of diverse representatives (seniors, younger persons with disabilities, members of the labor movement, providers and insurers), the coalition seeks to put together an agenda for advancing long-term care systems on a national basis. He suggested that one idea that has emerged from these discussions is to “take some of the most basic social insurance programs in this country (Social Security and Medicare) and incorporate consumer-based services and a cash payment system into them.”

Finally, several speakers, including Thomas Hamilton, Lee Bezanson, and Carl Littlefield, Assistant Secretary and Development Disabilities Coordinator, Florida Department of Children and Families, sought to remind the audience of ultimate goals.

- Lee Bezanson’s comments in the final panel were reminiscent of Jackie Golden’s statement in the opening session, that the purpose of consumer direction is to enable her son and others to have “a life, not just a treatment plan.” Lee put forth as the symposium goal an eventual world in which we would no longer speak of “people with disabilities” but just “people,” because we would no longer segregate or discriminate against individuals because of disabilities. She urged the audience to keep the overarching vision in their minds as they took individual steps, sometimes necessarily incremental ones, to make her dream a reality.
- Carl Littlefield cited the historic explorations of Lewis and Clark into the then uncharted American West as a metaphor for the pioneering efforts of those

experimenting with new models of consumer direction and self-determination. He pointed out that what Lewis and Clark actually discovered in their journey was much more than what they originally set out to look for. In the same vein, he laid out a vision of success that far transcended the goal of establishing consumer-directed services programs in every state:

“[Ultimate success] is when persons with disabilities have become invisible within society once again. There was a time in our not-so-distant past that their invisibleness was a product of societal ignorance.... We segregated them without choice. Out of sight, out of mind was at the heart of all of our planning and actions. The invisible society that we speak of today has everything to do with blend and integration. It’s when society begins to value people of differing abilities and understands the greatness of contributions that each person has to give. But this end will never be achieved unless we allow ourselves to be caught up in the glory of imagination today and unless we allow ourselves to step out on that imagination. Consumer-directed care is just one wonder-filled step in a journey. It’s not the end. It’s not the destination. It’s not the reality of the invisible society for persons with disabilities. But it is certainly a big and necessary step in the right direction. Without those risks, we won’t have success. But because of those risks, one day society will have the map that we draw because of the directions we have taken and the records we have made.”