

# Consumer-Directed Health Care: How Well Does It Work?



National Council on Disability  
October 26, 2004

National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, DC 20004

**Consumer-Directed Health Care: How Well Does It Work?**

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# NATIONAL COUNCIL ON DISABILITY

*An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.*

October 26, 2004

The President  
The White House  
Washington, D.C. 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit to you this report, titled *Consumer-Directed Health Care: How Well Does It Work?* Under its congressional mandate, NCD is charged with the responsibility to gather information on the implementation, effectiveness, and impact of federal laws, policies, programs, and initiatives that affect 54 million Americans with disabilities. In 2003, NCD decided that it was time to evaluate the evidence base for the nation's consumer-directed health care efforts. NCD determined that it was necessary to assess the nature, scope, and quality of consumer-directed health reform efforts, to the extent that federal and state policymakers rely on the outcomes of consumer-directed health reform efforts for the direction such outcomes imply for future federal health care reform efforts.

Federal and state governments and advocates have worked together over the past 20 years to explore the use of consumer-directed home and community services and long-term personal assistance services. Most recently, the *Olmstead* Supreme Court decision has provoked a wave of institution-to-community planning among states that are responsible for ensuring that Medicaid recipients are provided (health) care in the most integrated setting appropriate. Your Administration has included consumer-direction as a pillar of its legislative and program-based initiatives.

This report is a unique piece of policy research cutting across multiple departments and entities of federal and state governments. NCD's research offers a clear picture of the strengths and weaknesses of our Federal Government's current research agenda related to consumer-directed health care for Americans with disabilities. It sheds light on the relationship between consumer-directed health care and practice. And it provides a basis for policymakers who use health research evidence to inform their policy decisions (e.g., about MiCASSA, Money Follows the Person, *Olmstead*, and Real Choice Systems Change Grants) in keeping with the intent of your Administration's New Freedom Initiative (NFI).

In support of the NFI and of progress in the implementation of consumer-direction policy initiatives, I pledge our support to your Administration's commitment to ensuring that equality of opportunity, full participation, independent living, and economic self-sufficiency become realities in the lives of Americans with disabilities. Under your leadership, I remain confident that we can continue to build an America where all citizens live healthy, independent lives in the community of their choice.

Sincerely,

Lex Frieden  
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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# I.

## Executive Summary

### Need for a Study of Consumer-Directed Health Care

The past 30 years have seen a revolution in the way disability is addressed in American society. While that revolution has found expression in most social domains, health care has lagged behind. America's system of health care has traditionally maintained an institutional bias and typically insisted that services and care be directed by health care professionals, with few options for consumer direction or control. Recently, health policy shifts and practice changes have explored consumer-directed health care. For example, federal and state governments and advocates have combined over the past ten years to explore the use of consumer-directed home and community-based health care, long-term personal assistance services, and telemedicine and telerehabilitation. Most recently, the *Olmstead* Supreme Court decision has provoked a wave of institution-to-community planning among states that are responsible for ensuring that Medicaid recipients are provided health care in the most integrated setting appropriate, typically the individual's home and community.

Literature in the field of consumer-directed health care is limited. Many of the programs that test innovative models are too small to yield definitive data, and programs differ sufficiently from site to site, making meta-analysis challenging. Neither funding nor leadership has been directed to the full-scale, multifaceted evaluation required to teach us what we would like to know about consumer-directed and -oriented care for people with disabilities. Despite these limits in research, findings show that enough has been learned to support important changes in the way we plan, implement, and pay for the long-term care of individuals with disabilities.

This study includes a systematic review of the literature (both print and Web-based) on consumer-directed and -oriented care. It was shaped by guidance from a national consumer advisory board and refined based on interviews with key informants in relevant fields of research, policy, and program administration. The study addresses four critical questions:

1. What form does consumer direction and orientation take in health and related services, and to what extent have different models been studied?
2. Does consumer preference for consumer-directed or -oriented health care differ by age, gender, race, or other sociodemographic factors?
3. What outcomes are associated with consumer-directed and consumer-oriented care? Do reforms improve health status, quality of life, or other parameters for individuals with disabilities? Or do they, to the contrary, pose risks to the safety or well-being of consumers?
4. Are consumer-directed and -oriented models of care cost-effective?

## **What NCD Found**

- The best studied examples of consumer direction have been in the area of long-term care, where consumer control of resources and direction of caregivers has been tested as an alternative to agency-directed community care.
- While virtually all consumers express a preference for community-based care, interest in consumer-directed or -oriented health care models varies. Younger individuals seem to be more interested in consumer direction than older individuals, and there appear to be different preferences among race/ethnicity groups. However, sufficient local variability in preferences by race/ethnicity suggests a need for caution in generalizing these results. The type and severity of disability do not seem to determine individuals' preferences regarding care: interest in consumer direction is evident across a range of disabilities and ages.
- Although most implementation and evaluation of consumer direction have occurred in long-term care, consumer-oriented approaches are evident in other contexts as well. While the focus of this report is on long-term care, it is important to acknowledge emerging models in other areas. Appendix J looks at managed care programs that promote consumer/provider partnerships around direction of care and use of resources. We note also that implementation of medical homes for children with special health care needs and mental health parity have promoted a new emphasis on consumer-oriented, community-based

care for children with special health care needs and individuals with mental health diagnoses.

- Studies of consumer direction indicate positive outcomes in terms of consumer satisfaction, quality of life, and perceived empowerment. There is no evidence that consumer direction compromises safety—in fact, the opposite appears to be true. Individuals who have participated in consumer-directed systems express strong preference for consumer direction and satisfaction with their care.
- Variations in study design lead to conflicting results on the issue of cost-effectiveness. For example, (a) some research documents consumer-directed care as more cost-effective than agency-directed care and community-based care as more cost-effective than institutional care; (b) some studies do not account for the potential cost of services authorized by agency providers that were not, in fact, delivered to consumers owing to personnel shortages, while other studies vary in their treatment of out-of-pocket expenditures or uncompensated care provided by families; and (c) some study designs try to predict the likelihood that particular individuals would, in fact, be institutionalized without community-based services, while others do not.

## **Recommendations**

NCD’s recommendations reflect the research findings reported above. They also reflect a review of the policy literature concerning barriers and facilitators to consumer-directed care and the comments of consumer advisors and other key informants who helped the study team synthesize and interpret the research direction and findings. Because sound program and policy decisions depend on the development of a deeper knowledge base than is now available, the recommendations address research as well as program design and direction. One overarching recommendation, which touches on both the conduct of research and the design of services, is applicable to a wide range of government agencies—those that play an explicit role in disability policies or programs (e.g., the Social Security Office of Disability Determinations, the Administration on Developmental Disabilities) and those that have an impact on disability even though it is not their focus (e.g., the Administration on Aging, the Food and Nutrition Service

Food Stamp Program)—and private sector organizations. It calls for a change in the way business is conducted by funders, policymakers, and researchers in this field:

**Consumers representing a wide range of disability perspectives should be included in decisionmaking at every step in the process that ultimately shapes programs: from development and implementation of a research agenda through policymaking to program design, oversight, and evaluation. Consumers provide a truly unique source of information about the human services and health care delivery system.**

The recommendations presented briefly below can each stand alone—it is possible to implement one and reject others. But they also reflect a coherent overall approach to the design and implementation of consumer-directed or -oriented health care programs for people with disabilities. The following are key elements of this approach:

- Services need to be individualized, with consumers offered as much flexibility and choice as is feasible in relation to a given type of care.
- Services should, wherever possible, be designed to serve individuals with a broad range of disabilities. This flexibility will yield more individualized and therefore better services for individuals within, as well as across, disability groups.
- To achieve flexibility and accommodate diversity, consumers with different experiences and perspectives must be included at all stages of program design, implementation, and evaluation.

The achievement of these recommendations requires the designation or establishment of oversight authority within the federal government to coordinate and achieve their inherent goals.

## **Policy and Program Recommendations**

- A. Establish a locus of responsibility for programs and services within the federal government related to the health and well-being of individuals with disabilities.** The market has not, on its own, created the continuum of services

required to meet consumer needs: health care personnel is one example. We do not need a new clearinghouse or committee; this is a call for assigning a federal agency programmatic responsibility in the area of health and well-being of individuals across the spectrum of disability. This focal point exists for children with special health care needs in the Maternal and Child Health Bureau of the Health Resources and Services Administration, but does not exist for adults with disabilities.

- B. Make response to critical personnel shortages a first order of business for this newly identified unit of government.** The agency should address recruitment, training, and supervision of personnel to supply labor adequately and responsibly for community-based and consumer-directed care options.
- C. Incorporate opportunities for choice wherever possible, even in institutional settings.** Both studies and interviews indicate that best outcomes occur when consumers can make their own choices among services options. Even in nursing homes and other institutional settings, there is room for choice about activities and services.
- D. Do not advance choice at the expense of quality or accountability.** The option to participate in a consumer-directed program should not be traded off against accountability for entitlement programs. The right of consumers to choose among service options does not absolve agencies of responsibility for ensuring access and quality.
- E. Do not build expectations of cost savings into the start-up of consumer-directed or -oriented health care.** While cost-effectiveness is always important in publicly funded programs, start-up of new or modified program models may lead to increased costs in the early days of programs that may result in long-term efficiencies, savings, or cost neutrality.
- F. Break down barriers and create opportunities for cross-fertilization between narrow and arbitrarily defined disability sectors.** While groups may differ in the nature and extent of their service needs, program models targeted to one group may be quite relevant for another. New programs should be designed to serve



people across the disability spectrum, but with the flexibility to accommodate a range of individual needs.

Here again, there are reasonable arguments for assigning the coordinating role to a variety of different agencies. After exploring the options, NCD recommends assigning the role to the Health Resources and Services Administration (HRSA) in the Department of Health and Human Services. In part, that choice reflects the agency's experience in looking broadly at the impact of health programs and policies on the overall well-being of other vulnerable populations. NCD also notes that although HRSA plays a central role in targeted health care improvement efforts, it does not administer any of the major health care entitlement programs. NCD views that as an advantage in relation to the coordination of health and disability services, since it reduces potential concerns about conflict of interest on initiatives that might draw on resources of an entitlement program to reduce overall system costs.

## **Research Recommendations**

- A. Create a national stakeholder group to define critical terms in research on consumer-directed and -oriented care, at least for purposes of federally funded research.** Such terms as “consumer-oriented,” “consumer-directed,” “disability,” “satisfaction,” “personal care assistance,” and “choice” should be defined, making it possible for researchers to tailor studies to particular interventions while promoting comparability across and clarity within individual studies.
- B. Identify a menu of indicators for each term defined.** This is a critical second step toward ensuring a coherent body of research to inform practice.
- C. Develop protocols for federally funded evaluation studies.** Given clear definitions and meaningful indicators, guidelines are needed for the design of research and evaluation studies in this field. In the area of cost, for example, federally funded programs should require that costs to consumers, as well as costs to government and other institutional payers, be taken into account in measuring cost or cost-effectiveness of different program models. The overwhelming role of

families and individuals in paying for long-term care and the risk of cost-shifting to families as care moves out of institutional and into community settings makes it particularly critical that research in evaluating costs follow well-defined guidelines.

- D. Include measures of quality of life among outcomes studied in program evaluation.** Satisfaction with services may not capture the full impact of consumer direction. If agency-directed services are the only alternative to institutionalization in a community, there could be a ceiling effect, making it impossible to distinguish between satisfaction with any community living option (as compared with institutionalization) and further satisfaction due to a greater degree of control over those services. Consumers should be involved in a process to develop meaningful quality of life indicators.
- E. Include measures of mental health in evaluation studies on consumer-directed care.** We found no studies that looked at the mental health of clients as an outcome of consumer-directed care. Given the important impact of depression on overall health and well-being and the significant cost of depression treatment, this is a critical gap in current knowledge.
- F. Include individuals with primary mental health diagnoses in evaluation studies.** We found not a single study that looked at the impact of consumer-directed care on individuals with mental illness. There is no theoretical justification for this omission. It is essential to assess the potential of consumer direction in improving quality of life among individuals with mental illness.
- G. Strengthen the efforts of the nation's consumer-directed research to include a stronger focus on family.** Federal agencies' research efforts must recognize America's families, not only in the role of caregivers but also in the planning, management, and delivery of services and supports sustaining consumer-directed efforts to empower individuals with disabilities to achieve their potential and enjoy the fruits of their civil rights like any able-bodied citizens.

A reasonable case might be made for any of several agencies to serve as the central coordinating point for research on disability and health. Our recommendation, based on review of current

missions, research efforts, and staffing, is that this role be assigned to the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within the Department of Health and Human Services.

## **Conclusions**

Taken as a whole, these recommendations imply a major shift in the way government, private agencies, and even to some extent consumer organizations think about organizing and locating, and managing health care for people with disabilities. They imply a movement away from a narrow diagnosis-focused approach with a limited range of service options to a cross-disability, lifespan approach in which funds are available to meet individual needs. They imply a shift in the role of government from oversight of tightly defined program options to a broader responsibility for ensuring that a set of definitions and protocols are available to support the development of a knowledge base in this area, that those tools are used to assess consumer needs on an ongoing basis across disability groups and age categories, that resources are directed to fill gaps in the service continuum, and that programs meet rigorous evaluation standards for consumer-defined outcomes in domains that include not only direct satisfaction with services but also quality of life, health, mental health, and function.

## **II.**

### **Introduction**

#### **A. Background**

NCD decided to evaluate relevant policies and to identify best evidence or emerging evidence practices in consumer-directed and consumer-oriented health care for people with disabilities. This report brings together what is known about those policies and the outcomes of those practices, as well as the factors that facilitate or impede their implementation. It presumes that better understanding of best practices will lead to the adoption of policies and practices that

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

#### **B. Methods**

Information in this report was derived from the input of a Consumer Advisory Board (CAB), a review of the published and unpublished literature, and interviews with key informants and experts in the field. These methods were used interactively and iteratively in several phases of the project. The CAB was established to ensure diverse consumer input into research design, interpretation of findings, and formulation of recommendations. Eleven individuals who are disability leaders and/or parents of children with disabilities, and who represent a broad range of disability, racial, ethnic, geographic, and age groups, participated in the CAB via conference calls and e-mail discussions. Please see Appendix A for a list of CAB participants, Appendix B

for a list of CAB roles and responsibilities, and Appendix C for minutes of CAB conference calls. Views of individual CAB members were solicited through key informant interviews.

The literature review included peer-reviewed journal articles, government-funded reports, foundation-funded reports, and Web site documents. Web sources included Medline, PubMed, Lexis/Nexis, Ovid, and Biomed Central. In addition to searching databases, we conducted an Internet search of materials from more than 120 organizations that conduct work in the arena of consumer-directed care. We reviewed these publications for relevant policy and outcomes analyses. The tools developed to guide this review process are included in Appendix D.

We found 32 outcome studies through the literature review that met our inclusion criteria for discussion in this report (see Section V for criteria) and another four studies that did not meet our strict inclusion criteria but were incorporated into the findings because they focused on populations omitted from other studies. Four topic areas were addressed in sufficient detail to permit meaningful integration of findings across studies. Three of these topics—consumer preference for consumer-directed services, outcomes of consumer-directed care, and the cost-effectiveness of consumer-directed care as compared with agency-directed or, more generally, community-based care as compared with institutional care—are related to different aspects of long-term care. They are included in the body of this report. The fourth topic—outcomes of different models of consumer-oriented managed care as compared with fee-for-service models of care for people with disabilities—is included in Appendix E.

Finally, we conducted 43 key informant interviews by telephone or e-mail to review preliminary findings with key researchers, policymakers, and consumers, and to elicit their views on factors that promote or inhibit the adoption of consumer-directed reforms. Key informants were identified through the literature search or suggested by the CAB or by NCD staff. Please see Appendix F for a list of our key informants and Appendix G for key informant interview guides.

## **C. Definitions**

Definitions of key terms used in this report are as follows:

### ***Disability***

Disability is defined as any combination of medical, physical, developmental, cognitive, or psychiatric conditions that results in loss of function, employment, or age-appropriate activities. This study uses a broad definition encompassing the full spectrum of disability across the lifespan. This definition subsumes the Maternal and Child Health Bureau definition of children with special health care needs, the Supplemental Security Insurance (SSI) and Social Security Disability Insurance (SSDI) definitions of disability, and definitions that frame eligibility for federal, state, local, or privately funded long-term care services, as well as serious chronic illnesses that require more than average health care services. The aim was to be inclusive rather than exclusive and to focus on function and the need for care, rather than diagnosis.

### ***Consumer-directed Care***

The terms “consumer-directed care” and “consumer-oriented care” have different meanings. The term “consumer-directed care” has its roots in the independent living movement and is most commonly used in reference to home- and community-based long-term care and support services. Consumer direction of services grows out of a philosophical orientation that emphasizes the ability of people with disabilities to assess their own needs and make choices about what services would best meet those needs. It also reflects a view that consumers can and should have options to choose the personnel or provider entities that deliver their services, manage the delivery of services, and monitor the quality of services. Consumer-directed care is applicable across the spectrum of disability, although the language used to capture the concept varies among disability groups. For purposes of this project, consumer-directed care is considered to apply to a system or strategy with the characteristics described above in relation to any disability and for any age group. It is important to note that “consumer-directed,” as used in this report, should not be confused with the current insurance industry use of the terms “consumer-directed” and “consumer-driven” to refer to private health insurance characterized by high deductibles and low premiums.

### ***Consumer-oriented Care***

“Consumer-oriented care” has a broader definition than consumer-directed care. Decisions in the health care world are typically driven by a combination of clinical expertise and business concerns. The term “consumer-oriented care” applies to reforms and strategies within health care delivery systems that are “directed” by professionals or by provider/consumer partnerships but seek to ensure that decisionmaking is responsive to the needs and concerns of people with disabilities. Consumer-oriented practices include strategies to expand insurance coverage or benefits for people with disabilities; to promote health and well-being through primary and preventive services; to provide integrated and interdisciplinary care; and to promote the delivery of care in the least restrictive setting (Ireys et al., 2002).

In practice, the line between consumer-directed and consumer-oriented care is not precise. Some systems lie somewhere between the two and some are designed to incorporate elements of both. It is less important to make a precise distinction between the two than to recognize differences as research is carried out so that real differences among models of care are identified and analyzed as the basis for deeper understanding.

### ***Outcomes***

Outcomes were defined by the research team in collaboration with the CAB to include

- Consumer satisfaction
- Changes in health status and functional ability
- Consumer control
- Consumer choice
- Consumer participation and education
- Quality of life
- Self-esteem
- Employment and continuity of work
- Changes in emergency room and hospital utilization
- Changes in homelessness

- Provider sensitivity and cultural competence
- Cost-effectiveness

## **D. Overview of Report**

This report assesses the extent and types of knowledge about federal and state consumer-directed health care policies, programs, and practices for people with disabilities in America. By highlighting what is known about what works in the area of consumer-directed health care, the report aims to inform policy discussions among policymakers, practitioners, researchers, consumers, and advocates for health reform. The report’s specific objectives are to examine the following:

- Current laws for consumer-directed and consumer-oriented health care;
- Program and policy trends in the financing, availability, and structure of consumer-directed and consumer-oriented health care;
- Outcomes of consumer-directed and consumer-oriented health care;
- Factors associated with the implementation of models of consumer-oriented health care;
- Barriers to and facilitators of program implementation;
- The role of federal agencies in evaluating consumer-directed and consumer-oriented health care initiatives; and
- Recommended “next steps” for increasing the scope and quality of knowledge and practice of consumer-directed health care and research.

To achieve these objectives, the report provides a systematic, multidimensional analysis of existing policy and research and includes insights provided by consumers, program administrators, policymakers, advocates, and researchers. The report examines a range of interrelated issues to establish a broad-based foundation for understanding what is and is not known about consumer-directed health care and its place in America’s health reform movement.





### III.

## Legal and Regulatory Framework for Consumer Direction

Equal rights, access to care, adequate health care coverage, and the option to obtain services in community settings are important prerequisites for consumer-directed or -oriented health care. This section provides a brief review of the laws that form the framework for consumer-oriented programs. Appendix H presents the chronology of these federal legislative initiatives. Appendix I provides a more detailed overview of the laws and initiatives discussed below.

The concept of access to community-based health care services in the least restrictive environment has its roots in the Rehabilitation Act of 1973, which extended civil rights protections to people with disabilities. In 1990, the Americans with Disabilities Act (ADA) expanded the Rehabilitation Act, extending equal access requirements to facilities and replacing the earlier mandate for provision of services in the “least restrictive environment” with a more positive requirement for the “most integrated” services (ADA Web site, 2003). The ADA in turn provided critical language for the Supreme Court *Olmstead* decision of 1999, which required public entities to provide services to people with disabilities in the most integrated setting appropriate for their circumstances (CMS Web site, 2003). The New Freedom Initiative, announced in 2001, promotes implementation of the *Olmstead* decision by coordinating existing initiatives and funding new activities to enable people with disabilities to live, receive services, and participate in their communities instead of living in institutions.

The concept of access to coverage for health and consumer-oriented long-term care has its roots in the Medicaid program, established as an amendment to the Social Security Act in 1965. Medicaid is the primary source of government funding for acute and long-term care for low-income individuals with disabilities. Since 1965, Medicaid law has been amended to expand Medicaid coverage to broader populations through the Medically Needy program and, more recently, the Balanced Budget Act (BBA) of 1997, which created the State Children’s Health Insurance Program (SCHIP). One drawback to the Medicaid program is that people with disabilities who are able to find and retain employment lose their Medicaid benefits (and often

Medicare benefits as well) as a result of increased earnings or gainful employment. Two pieces of legislation, the BBA's Medicaid Buy-In provision and the Ticket-to-Work and Work Incentives Improvement Act (TWWIIA) of 1999, allow states to provide health care coverage for people with disabilities who work or want to work.

The Medicaid program has provided coverage for institutional long-term care since its inception, with amendments over time that have opened the door to community-based care. To date, only 26 states have implemented Medicaid buy-in programs, most of which are very limited. In 1981, the Omnibus Budget Reconciliation Act established the 1915(c) Home and Community Based Service Waivers (HCBS) program, allowing states to provide home- and community-based services to targeted groups of individuals as an alternative to institutional care. The BBA of 1997 permitted states to cover habilitation services in residential and day settings, removing institutionalization as a requirement for coverage of habilitation services. Finally, Section 1115 of the Social Security Act provides a framework for research and demonstration programs that involve either the Medicaid or Medicare programs, and these demonstrations have been an important vehicle for testing new models of consumer-directed or -oriented health care.

Other federal programs also fund services or benefits for people with disabilities. These programs include the Medicare program, also established under an amendment to the Social Security Act in 1965, which covers health care services for people with disabilities; and the Rehabilitation Services Administration, established under the Rehabilitation Act of 1973, which provides grants to states and a range of public and private entities for vocational rehabilitation, home care assistance services, assistive technology, supportive employment services, and independent living centers (U.S. Department of Education, 2004). In addition, Title V of the Social Security Act funds state Children with Special Health Care Needs programs to provide services, technical assistance, and support for children with disabilities and their families. Finally, support for the care provided by informal family caregivers is offered through amendments to the Older Americans Act of 1965, including the National Family Caregiver Support Program in 2000, the Lifespan Respite Care Act of 2003, and the Family and Medical Leave Act in 1993.

## **IV.**

### **Program and Policy Trends**

#### **A. Introduction**

Current initiatives that incorporate aspects of consumer direction or consumer orientation include different kinds of interventions, target different populations, and emphasize different goals and objectives, so that any attempt to categorize them has to be somewhat arbitrary. In this section, we attempt to capture the program and policy trends embodied in these diverse initiatives and how they have affected service systems. We have divided initiatives in the field into those that mainly affect financing of care; those most related to the way care is structured (how services are designed); and those most related to process (how services are managed and implemented).

#### **B. Trends in the Financing of Care**

The main sources of funding for the health and long-term care of individuals with disabilities are the Medicaid and Medicare programs, other government agencies, and out-of-pocket expenditures by consumers and their families. The Medicaid program is the largest public funder of long-term care services for people with disabilities. In 2002, nursing homes received 41 percent of their revenue, and home health agencies received 17 percent of their revenue, from Medicaid programs (AAHSA, 2002). In addition to providing coverage for nursing home care, intermediate care facilities for the mentally retarded (ICFs/MR), and home health services, Medicaid offers three important vehicles to fund consumer-directed long-term care services for people with disabilities:

- The optional Medicaid state plan benefit for personal assistance;
- 1915(c) Home and Community-Based Services (HCBS) Waivers; and
- 1115 Research and Demonstration Waivers.

Medicare is the second largest public funder of long-term care services, and in 2002 financed 10.6 percent of all nursing home care and 35.6 percent of all home health care (AAHSA, 2002). However, the Medicare program does not provide coverage for personal assistance or many of the community-based long-term care services elected by states as options in their Medicaid coverage of eligible individuals. In addition, federal tax policy encourages the purchase of long-term care by permitting an individual to include a portion of premiums paid for tax-qualified long-term care insurance along with other unreimbursed medical expenses as a tax deduction (Kreitler, 2003). This deduction is available for taxpayers who itemize and whose medical expenses exceed 7.5 percent of their adjusted gross income. The amount of the premium that can be deducted is limited by a sliding scale based on age. This federal tax deduction does not seem to be very persuasive, however, because only 7 percent of long-term care is financed by private insurance (AAHSA, 2002).

Other government agencies, at the federal, state, and county levels, are additional sources of long-term care funding. Funding from these agencies often fills important gaps between publicly funded services and what people can afford to buy on their own. Recent federal initiatives have expanded support for family and other informal caregivers of individuals with disabilities—services that are rarely covered by either Medicaid or Medicare.

Out-of-pocket expenditures for long-term care and support services are also substantial. AARP found that 84 percent of people 50 to 64 and 57 percent of those 65 or older who received long-term support services relied exclusively on informal caregivers, which implies out-of-pocket payment and/or loss of income on the part of unpaid family caregivers (Gibson et al., 2003). Another analyst estimated the total value of national spending on informal and unpaid care to be approximately \$196 billion (1997 dollars), while nursing home care was estimated to have an economic value of \$83 billion and formal home health care, \$32 billion (Arno et al., 1999).

### ***Expansion of Medicaid and Medicare Financing***

Since they were established in 1965, the missions of both Medicaid and Medicare have broadened, so that each now plays a larger role in serving people with disabilities. The Medicare program, for example, started as insurance coverage for older Americans, but within its first

decade, people with disabilities became eligible for coverage under certain conditions. Several mechanisms have been used to expand Medicaid eligibility for people with disabilities: HCBS Waiver Programs, 1115 Waiver Programs, SCHIP, and Medicaid buy-in programs. As a result, the number of people with disabilities under the age of 65 who receive Medicaid benefits has increased steadily, from 6.5 million to 8.6 million in the seven years from 1995 to 2003 (CMS Web site, 2003).

Under some HCBS Waiver Programs, Medicaid income and asset rules are relaxed to expand eligibility for community-based services to individuals with disabilities who meet the functional criteria for institutional care in nursing homes or ICFs/MR. Some 1115 Research and Demonstration Waiver Programs have expanded Medicaid eligibility for people with disabilities by raising the income cutoff for eligibility. For example, TennCare, the Oregon Health Plan, and MassHealth used savings generated by mandating enrollment in managed care plans to finance coverage of new beneficiary groups. Three other states have obtained 1115 Waivers to offer Medicaid to low-income individuals living with HIV, which, unlike AIDS, is not considered a disability and therefore does not ensure Medicaid coverage through the Medicaid-SSI link. (SHFO Web site, 2004).

SCHIP, created by the BBA, extended insurance coverage to many uninsured children (and some parents) whose families did not qualify for Medicaid. According to the American Academy of Pediatrics (AAP), the number of children receiving Medicaid and/or SCHIP coverage increased from 15.2 million in 2000 to 18.6 million in 2002 (AAP Report, 2002). Some of these children had special health care needs or disabilities.

Medicaid Buy-In programs, which allow individuals who would otherwise exceed income eligibility standards to purchase Medicaid coverage as their sole coverage or to supplement their private insurance, are another means of expanding eligibility for people with disabilities. Twenty-six states had implemented Medicaid Buy-In programs as of September 2003, and another nine states had programs or authorizing legislation pending (Jensen, 2003). Ironically, as Medicaid eligibility expansion continues through Medicaid Buy-In and SCHIP, it is being restricted in some of the major 1115 Research and Demonstration Waiver Programs. As state budget deficits mount, some states are eliminating their expansion populations or lowering the

income limits for Medicaid eligibility, thus reducing access to Medicaid coverage for many individuals with disabilities.

### Medicaid Expansion Programs: Ticket-to-Work (TWWIA) and Medicaid Buy-In Programs

State Name	Medicaid Buy-In (year implemented)	TWWIA*	State Name	Medicaid Buy-In (year implemented)	TWWIA*
Alabama		Infra	Nebraska	1999	Infra
Alaska	1999	Infra	Nevada		Infra
Arizona	2003		New Hampshire	2002	Infra
Arkansas	2001		New Jersey	2001	Infra
California	2000	Infra	New Mexico	2001	Infra
Colorado	Study stage only		New York	2003	Infra
Connecticut	2000	Infra	North Carolina		
Delaware		Infra	North Dakota	Planned for 2003	Infra
Florida			Ohio		
Georgia			Oklahoma	Study stage only	Infra
Hawaii			Oregon	1999	Infra
Idaho			Pennsylvania	2002	Infra
Illinois	2002	Infra	Rhode Island		Demo/infra
Indiana	2002	Infra	South Carolina	2000	
Iowa	2000	Infra	South Dakota		Infra
Kansas	2002	Infra	Tennessee		
Kentucky			Texas		Demo/infra
Louisiana	Planned for 2004	Infra	Utah	2001	Infra
Maine	1999	Infra	Vermont	2000	Infra
Maryland	Planned for 2005	Infra	Virginia	Study stage only	Infra
Massachusetts	Pre-1999	Infra	Washington	2002	Infra
Michigan	Planned for 2004		Washington DC		Demo/infra
Minnesota	1999	Infra	West Virginia	2003	Infra
Mississippi	2000	Demo/infra	Wisconsin	2000	Infra
Missouri	2002	Infra	Wyoming	2002	Infra
Montana					

\* “Infra” refers to infrastructure grants; “Demo” refers to demonstration grants (Jensen, 2003; CMS Web site, 2004).

### *Expanding Services*

As Medicaid and Medicare have expanded eligibility to include individuals with disabilities, they have, at least until recently, often expanded benefits to meet the needs of this population. It is important to note, however, that key informants we interviewed hinted that this trend may have

slowed or even reversed in recent years due to the dwindling of matching state funds once used to expand coverage.

Home and Community Based Services (HCBS) Waivers have played the major role in expanding the range of community-based services covered by Medicaid for people with disabilities.

Initially, HCBS programs were limited by the state's capacity for institutional care—in other words, the number of people enrolled in the Waiver could not exceed the capacity of nursing homes or ICFs/MR to accept them. However, since the early 1990s, federal regulations have allowed states to provide HCBS to individuals who meet institutional care criteria, regardless of the capacity of institutions to accept new patients. Thus, between 1992 and 2002, HCBS Waiver Programs for people with developmental disabilities grew more than 500 percent (Lakin and Prouty, 2003). Approximately three-quarters of Medicaid HCBS Waiver funds are spent on services for people with developmental disabilities or mental retardation (Doty, 2000). These programs extend case management, personal care assistance, adult day programs, habilitation services, and respite care to people who would otherwise reside in ICFs/MR.

As of February 2002, there were 263 active HCBS Waivers, with all but one state having at least one HCBS Waiver (CMS Web site, 2003). These programs vary widely from state to state and are distributed unevenly across states and Waiver target populations. New York and California alone account for 28 percent of the increase in HCBS participants, and five states (Minnesota, North Dakota, South Dakota, Vermont, and Wyoming) have twice the national average of HCBS recipients per 100,000 citizens, while five states (Illinois, Indiana, Kentucky, Mississippi, and Nevada) and the District of Columbia have less than half the national average (Lakin and Prouty, 2003). As the demand for HCBS continues to grow, further expansion may be limited by state revenue shortfalls and the requirement that states share in the cost of expansion (Lakin and Prouty, 2003).



## Home and Community-Based Waivers/Personal Care Service Under the State Plan<sup>1</sup>

State Name	PCS in state plan	Elders	Adults							Children							
			Physical Disability	MR/DD	Mental Illness	TBI	HIV	Technologically Dependent	Blind	Deaf	Physical Disability	MR/DD	Mental Illness	SED	TBI	HIV	Technologically Dependent
Alabama		X	X	X			X					X					
Alaska	X	X	X	X												X	
Arizona	X																
Arkansas		X	X	X						X	X						
California	X	X	X	X			X										
Colorado	X	X	X	X	X	X	X			X	X			X			
Connecticut		X	X	X							X						
Delaware		X	X	X		X	X								X		
Florida		X	X	C		X	X										
Georgia		X	X	X		X										X	
Hawaii		X	X	X			X				X				X		
Idaho	X	X	X	X		X											
Illinois		X	X	X		X	X			X						X	
Indiana		X	X	X		X										X	
Iowa		X	C	X		X	C				X						
Kansas		X	X	X		X							X			X	
Kentucky		X	X	X		X		X									
Louisiana		X	X	X							X						
Maine	X	X	C	X													
Maryland	X	X	X	X		X					X					X	
Massachusetts	C	X		X		X											
Michigan	X	X	X	X							X						
Minnesota	X	X	X	C		X				X				X			
Mississippi		X	X	C		X											
Missouri	X	X	X	X			X				X						
Montana	X	X	X	X		X	X			X							
Nebraska	X	X	X	X		X				X	X						
Nevada	X	X	X	X					X	X	X						
New Hampshire	X	X	X	X		X					X						

<sup>1</sup>For states marked C, there is some mention of consumer-directed or consumer-oriented services in CMS's Waiver description. In a couple of cases, the Waiver is still pending.

State Name	PCS in state plan	Elders	Adults							Children							
			Physical Disability	MR/DD	Mental Illness	TBI	HIV	Technologically Dependent	Blind	Deaf	Physical Disability	MR/DD	Mental Illness	SED	TBI	HIV	Technologically Dependent
New Jersey	X	X	X	X		X	X		X		X				X	X	X
New Mexico	X	X	X	X			X					X					
New York	X	X	X	X		X					X	X	X				
North Carolina	X	X	X	X			X					X				X	
North Dakota		X	X	X		X											
Ohio		X	X	X								X					
Oklahoma	X	X	X	X								X					
Oregon	X	X	X	X								X					
Pennsylvania		X	X	X		X	X	X		X							
Rhode Island		X	X	X													
South Carolina		X	C	X		X	X										
South Dakota	X	X	C	X								X					
Tennessee		X	X	X								X					
Texas	X	X	X	X												X	
Utah	X	X	C	X		X		X									
Vermont		X	X	X		X						X					
Virginia		C	C	X			X					X					
Washington	X	X	X	X			X										
Washington DC	X	X	X	X			X										
West Virginia	X	X	X	X								X					
Wisconsin	X	X	X	X		X						X		X			
Wyoming		X	X	X		X						X					

(CMS Web site, 2004)

It is important to note that personal assistance services, whether provided as part of the Medicaid state plan or as part of an HCBS Waiver Program, may be provided as agency-directed services *or* as consumer-directed services. Some states that offer personal assistance as a state plan benefit, such as Maine and Massachusetts, provide the benefit under a consumer-directed model. Similarly, some HCBS Waiver Programs, such as California’s In-Home Supportive Services Program, the nation’s largest personal assistance program, allow for consumer direction of long-term support services (CMS Web site, 2004).

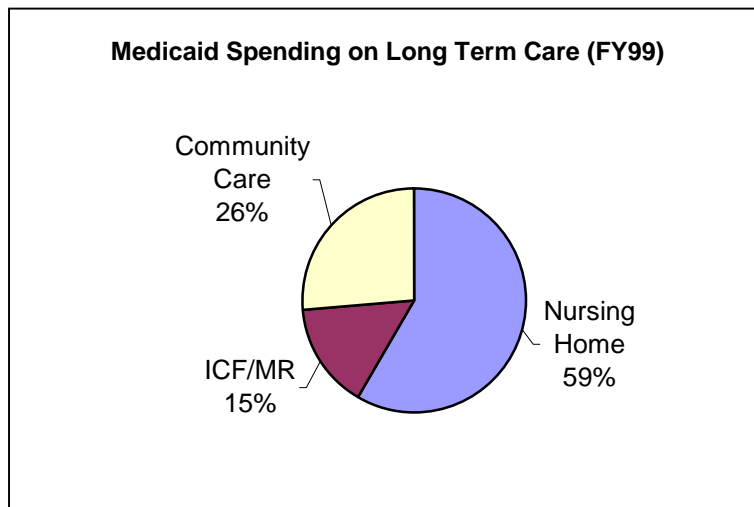
The 1115 Research and Demonstration Waivers have also been used to expand services for people with disabilities. For instance, when Florida crafted its Cash and Counseling Program under an 1115 Waiver, the state provided cash allowances that could be used for personal care, therapists, home modifications, respite, and a multitude of individually determined services. In addition, some state-managed care programs that operate under 1115 Waiver authority allow managed care plans to provide “value-added” benefits such as care coordination, expanded substance abuse treatment services, personal assistance, transportation, or home-based care. In particular, some of the programs that integrate Medicaid and Medicare funding provide expanded benefits for those who are dually eligible for Medicaid and Medicare. Programs such as the Program of All-Inclusive Care for the Elderly (PACE) and Minnesota Senior Health Options (MSHO) provide an entire continuum of community-based services, ranging from adult day health to transportation for seniors with chronic needs.

<b>State Name</b>	<b>PACE</b>	<b>Medicare / Medicaid Integration Program</b>	<b>State Name</b>	<b>PACE</b>	<b>Medicare/ Medicaid Integration Program</b>
Alabama			Nebraska		
Alaska			Nevada		
Arizona			New Hampshire		X
Arkansas			New Jersey		
California	PACE		New Mexico	pre-PACE	
Colorado	PACE	X	New York	PACE	X
Connecticut		X	North Carolina		
Delaware			North Dakota		
Florida		X	Ohio	PACE	
Georgia			Oklahoma		
Hawaii	pre-PACE		Oregon	PACE	X
Idaho			Pennsylvania	pre-PACE	
Illinois	pre-PACE		Rhode Island		X
Indiana			South Carolina	PACE	
Iowa			South Dakota		
Kansas			Tennessee	PACE	
Kentucky			Texas	PACE	X
Louisiana			Utah		
Maine		X	Vermont		X
Maryland	PACE		Virginia	pre-PACE	
Massachusetts	PACE	X	Washington	PACE	X

State Name	PACE	Medicare / Medicaid Integration Program	State Name	PACE	Medicare/ Medicaid Integration Program
Michigan	PACE		Washington DC		
Minnesota		X	West Virginia		
Mississippi			Wisconsin	PACE	X
Missouri			Wyoming		
Montana					

(NPA Web site 2004; MMIP Web site, 2004)

Despite this expansion in Medicaid funding for community-based care, more than half of all Medicaid funds for long-term care nationally still go to nursing homes (Doty, 2000).



Again, it is important to note that within this broad picture, there is significant variation by state. For example, while Tennessee spends 96 percent of its long-term care funds on nursing homes, Oregon spends nearly half of its long-term care funds on home- and community-based services (Doty, 2000).

The Medicaid Community Attendant Services and Supports Act (MiCASSA) is a new initiative proposed to expand community-based services for people with disabilities. Introduced in May 2003 as an amendment to Title XIX of the Social Security Act, MiCASSA would allow Medicaid beneficiaries who are eligible for institutional care to have a choice of receiving that care in a community-based setting without an HCBS Waiver (Novak, 2004; Adapt Web site, 2004). MiCASSA would also allow these beneficiaries the option of choosing consumer-directed long-term care services and would require that Medicaid cover services that are “based on

functional need, rather than diagnosis or age; provided in home or community settings, including school, work, recreation or religious settings; selected, managed, and controlled by the consumer of the services; supplemented with backup and emergency attendant services; furnished according to a service plan agreed to by the consumer; and accompanied by voluntary training on selecting, managing and dismissing attendants” (Novak, 2004). MiCASSA would ultimately provide consumers with consumer-directed long-term care options that could concurrently address the frequently cited challenges in the current system.

### **C. Trends in the Structure of Care**

Six trends that have affected the structure of service delivery in relation to consumer-directed or oriented health care are (1) deinstitutionalization and prevention or delay of institutionalization, (2) the disability rights and independent living movement, (3) a new role for foundations in supporting structural reforms in health care, (4) growing support for informal and family caregivers, (5) the expansion of various types of managed care, and (6) the development and implementation of the medical home model for serving children with health care needs.

#### ***Deinstitutionalization***

The trends toward deinstitutionalization in mental health began in the 1950s with the development of psychopharmacological drugs, which could dramatically affect symptoms of previously institutionalized individuals. For many former patients, adherence was feasible only in the context of ongoing support. And the reality was that many states never created the outpatient services that were supposed to provide that support. In fact, deinstitutionalization occurred for several decades before supports and other measures to alleviate the problems were implemented (Palmer, 2004). Deinstitutionalization, as implemented, was widely criticized for turning people out of hospitals to fend for themselves, too often on the street or in jails (TAC Web site, 2004).

The move to deinstitutionalize people with developmental disabilities followed deinstitutionalization of individuals with mental illness. It occurred in direct response to a series of class action lawsuits and, more generally, an advocacy movement that brought

out in the open the poor treatment of individuals in some institutional settings (Davis et al., 2000). In 1971, Congress authorized federal money for ICFs/MR as an alternative to large state institutions (Lakin and Prouty, 2003). As ICFs/MR proliferated through the 1970s, pressure increased for further community integration of individuals with mental retardation. States responded with smaller “community ICFs/MR” (4- to 8-bed residences as opposed to 16- to 32-bed residences), followed by HCBS Waiver Programs that provided supports in peoples’ own homes (Lakin and Prouty, 2003). In 1991, New Hampshire and the District of Columbia became the first jurisdictions to close all public institutions for people with developmental disabilities and develop delivery systems based entirely on community-based services (Davis et al., 2000). Since then, Alaska, Hawaii, Maine, Minnesota, New Mexico, Rhode Island, Vermont, and West Virginia have followed suit, and other states are using Waivers and other innovative means to reduce institutional care (LDDC Web site, 2004; Davis et al., 2000).

For other individuals with disabilities—especially older Americans, adults with physical disabilities, and children with health care needs—who have not been institutionalized on the same scale as people with mental illness or developmental disabilities, the trend over time has been to prevent or delay institutional care. There have been programs to move elders out of institutions—12 states participate in Nursing Home Transition Grants (Chaney, 2003) to transition individuals from nursing homes to the community and to avoid unnecessary institutionalization following inpatient hospital stays (CMS Web site, 2004)—but these programs are small. The majority of programs for the elderly focus on preventing or delaying institutionalization. These programs, generally operating under HCBS Waivers, often integrate adult day care with medical care, personal care, prescription drugs, and respite care. Some programs, such as PACE, include a nursing facility benefit to ensure a seamless transition when an individual requires more care than can be provided in the community.

### ***The Disability Rights Movement***

Concurrent with the movement for deinstitutionalization and led by many of the same key players, the more general disability rights movement took hold. The disability rights movement reflected the tenets and strategies of the civil rights movement, with a grassroots call to eliminate discrimination against people with disabilities and a strong emphasis on self-determination for

people with disabilities. For many people with disabilities, especially those with physical disabilities, these goals were most explicitly embodied in the independent living movement.

The first Center for Independent Living was founded in Berkeley in 1972; almost 500 Independent Living Centers are in existence today (IL USA Web site, 2004). Independent Living Centers promote the view that people with disabilities can do a better job of designing and implementing service programs than do nondisabled “experts.” Both the theory and practice of independent living are counterposed to what advocates term the “medical model,” which views disability as an abnormal state and people with disabilities as abnormal people to be “fixed” through medical intervention.

Disability activism focused on a range of social reforms that followed directly from the initial thrust for community living. The Architectural Barriers Act of 1968, the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990 sought to ensure that once in the community, individuals with disabilities would have access to the full range of public and private facilities, settings, services, and programs. From the 1970s through the present, disability activism has provided the impetus for many consumer-oriented and -directed reforms. Family advocates were a major force in establishing Katie Beckett Waivers. Prior to this 1981 reform, Medicaid coverage was available to children who were hospitalized for more than one month only if their families were otherwise over income for Medicaid. The Katie Beckett Waivers permitted families to retain Medicaid coverage if they chose to provide hospital-level care for their child at home. In 1992, parents of children with health care needs founded Family Voices, a national family advocacy group. One preliminary success of advocacy by Family Voices and allies was the inclusion of medical homes for children with health care needs in the Healthy People 2010 articulation of health objectives for the nation (Family Voices Web site, 2004; CDC NCHS Web site, 2004).

Elder groups such as the 35 million-member AARP have addressed concerns such as elder abuse and financial exploitation by caregivers (AARP Web site, 2004). Groups representing individuals with mental illness have fought for self-help models and patient advocate positions for residents of mental health institutions. These are but a few of the most noteworthy consumer-

directed or -oriented health care reforms that have been advanced by the disability rights movement.

### ***Foundation-Sponsored Reforms***

Although foundation funding for health and long-term care is only a fraction of government funding, foundation funds often serve as the catalyst for new initiatives. Both national and local foundations have funded consumer-oriented and -directed programs; however, several foundation initiatives related to the structure of care have had major national impact.

### ***Self-Determination Projects***

The self-determination movement for people with cognitive disabilities was launched in the early 1990s with 38 people in New Hampshire, under a foundation demonstration grant. The two populations included in the pilot were individuals with developmental disabilities and individuals with acquired brain injuries. Since the initial pilot in New Hampshire, self-determination programs have been launched in at least 20 other states. Core features of these programs include the following:

- Person-centered planning, enabling individuals and families to define their own needs;
- Independent professional support to help individuals and their families identify needs and choose services;
- Individualized budgeting, so funds can be used to address individual needs and/or preferences; and
- Fiscal intermediaries, responsible for purchasing services and handling legal and accounting matters on behalf of participants (RWJF Web site, 2004).

### ***Cash and Counseling Demonstration Programs***

In 1996, the Office of the Assistant Secretary of Planning and Evaluation in the Department of Health and Human Services (DHHS), the Centers for Medicare and Medicaid Services (CMS), and the Robert Wood Johnson Foundation joined to cosponsor Cash and Counseling Demonstration projects that allow people with disabilities to direct their own home- and



community-based personal assistance services and supports under 1115 Waiver authority. Three states, Arkansas, New Jersey, and Florida, were granted 1115 Waivers to operate programs in which individuals manage monthly cash budgets to purchase long-term supports and services. Participants receive counseling to help plan and administer the use of the funds and may designate representatives (including family members) to make decisions on their behalf. Program models and populations served are different in each state, with some states restricting the self-directed benefits to personal assistance, and other states including a broader range of services. Early evaluation results for the Cash and Counseling Demonstrations are discussed in Section V of this report. Based on preliminary results, DHHS has issued grants to additional states to begin planning Cash and Counseling programs.

### ***Support for Informal and Family Caregiving***

The role of informal and family caregivers has been underrecognized and undersupported historically, and caregiver burden may ultimately limit system capacity to ensure long-term community-based care for people with disabilities, especially individuals with cognitive impairments. State and federal policymakers have strong incentives to support the role of family caregivers, as they minimize the effect of systemic fluctuations that might otherwise render long-term community care impossible. However, programs that allow consumers to hire and pay family members for their care force the purchasers to recognize and account for the traditionally unaccounted for and uncompensated care provided by family and friends. Germany's consumer-directed cash program provides compensation for informal and family caregivers, and though satisfaction with the program is high, it increased system costs without adding new resources for care (Wiener et al., 2003). It is reasonable to hypothesize that while paying informal and family caregivers might increase costs, the practice could offer long-term savings by prolonging the period during which community care is feasible and could reallocate federal dollars for personal choice rather than paying for nursing or institutional care. The literature is ambiguous on this subject, however, since there are no longitudinal cost-effectiveness studies on the role and contributions of informal caregivers.

In addition to financial compensation, other support for family members who provide care for a relative includes counseling or respite care, tax incentives, and employer-based mechanisms

such as family and medical leave or private long-term care insurance (Montgomery and Feinberg, 2003). One national initiative in this area is the National Family Caregiver Support Program (NFCSP), established in 2000 under the Older Americans Act. Services funded by this program include respite care, caregiver education, assistance to caregivers in accessing services, individual and group counseling for caregivers, and supplemental services, such as home modifications. This program constitutes a promising start in providing support to family caregivers but does not compensate caregivers for lost income or provide services to all caregivers (Montgomery and Feinberg, 2003). Only family caregivers of older adults (60+) and grandparents or other relatives who are caregivers for children or persons with developmental disabilities or mental retardation are included in the program (AoA Web site, 2004).

The Family and Medical Leave Act (FMLA), enacted in 1993, can be considered another policy initiative in this area. FMLA was, in fact, the first federal policy intended to directly benefit family caregivers, even though it is not targeted specifically to caregivers of people with disabilities. It allows employees up to 12 weeks per year of unpaid leave in the event of a birth or adoption of a child or to care for a relative. FMLA applies only to employees in companies of more than 50 people, employees who work 1,250 hours or more per year, and employees who have been with their company for a year or more. Furthermore, FMLA does not address the important issue of lost income of family caregivers. Some states, such as California, offer more generous versions of FMLA by providing payment for family leave. Also, almost half of the major corporations in the United States offer elder care and child care assistance to employed caregivers, most often in the form of dependent care spending accounts. These policies do not appear to be a national solution for people who care for relatives with a chronic condition, but they are steps in the right direction (Montgomery and Feinberg, 2003).

### *Expansion of Managed Care*

Over the past 20 years, managed care has become the framework for the delivery and financing of health care for an increasing proportion of the U.S. population. Dramatic growth in penetration of the insurance market by managed care organizations (MCOs), especially in the early to mid-1990s, reflected a belief that managed care could contain spending and increase access to care without loss in quality (Frakes, 1997). While the centralized management inherent

in MCOs often moves control of an individual's health care away from the physician/patient interaction, some managed care systems have built consumer voices into system planning and evaluation.

The expansion of managed care as a mainstream health delivery strategy has been accompanied by the implementation of a number of small, specialized programs for people with disabilities. Appendix J describes Medicaid managed care policy trends and specialized programs.

### ***Medical Home***

The factors that promote consumer direction and orientation for adult care have engendered a parallel reform movement for the care of children with special health care needs. The term "medical home" was popularized by the American Academy of Pediatrics (AAP) in a 1992 policy statement to indicate an approach to provision of pediatric care that is "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective" (Sia et al., 2002). In a medical home setting, parents (and youth, as children mature and take on self-management of care), pediatricians, and specialists work in partnership to identify and ensure access to the services to help children with special health care needs achieve their maximum potential. These may include both clinical and nonclinical services, such as family-to-family support groups, respite for parents, and community recreation programs for children. This view of the pediatrician's office as the hub of a network of services implies a shift away from tertiary care to primary care as the center of care for children with special health care needs. The AAP model emphasizes care coordination as a central role of the medical home, implying allocation of resources from within and/or outside the primary care practice to support this labor-intensive function.

A key feature of the medical home model is the importance it assigns to parent/provider relationships. The model emphasizes the critical contribution that parents make to all aspects of children's care, from the medical management of their own individual children to a role in the development of policy at state and national levels. This core value closely parallels the emphasis placed on consumer expertise and autonomy in the adult disability world: each seeks to promote positive outcomes through community integration of people with disabilities and

through respect for consumer expertise and choice in the design or management of care. Different approaches to medical home implementation are being tested and evaluated in a wide variety of practice settings nationwide. The Maternal and Child Health Bureau of DHHS and the AAP are funding demonstration projects in 15 states. As these are works in progress, outcomes are not yet available in the published literature.

## **D. Trends in the Process of Care**

The process of care refers to the activities carried out within different service delivery structures: what gets done, how it gets done, and who does it. Process trends in long-term care include the increasing opportunities for consumer direction and consumer control of everything from the hiring, management, and firing of support personnel to consumer input into or direction of program evaluation efforts. In addition, some progress has been made in supporting informal and family caregivers.

### ***Consumer Direction in Long-Term Care***

Consumer direction is best understood as a continuum of activities in relation to the way care is carried out. At its full expression, consumer direction means money is given to the consumer to purchase desired services without the support or interference of case managers, counselors, or fiscal agents. The other end of the continuum would presumably be mandatory institutionalization. Relatively few programs offer consumers full autonomy, and these programs are usually affiliated with Independent Living Centers. Most consumer-directed programs fall in the middle of the continuum, allowing the consumer to choose personal care assistants and train them, but supporting the consumer through fiscal intermediaries and/or vendor agencies that fulfill some of the responsibilities of an employer.

Community-based long-term care programs that incorporate some degree of consumer direction have increased sharply over the past decade. In fact, 65 percent of 139 existing consumer-directed home- and community-based service programs have been implemented since 1990, and 17 percent since 2000 (Doty and Flanagan, 2002). Although the current estimate is that 486,000

individuals participate in consumer-directed care, this trend is not spread evenly across the nation, as more than half of the participants live in California (Doty and Flanagan, 2002).

The services that are most frequently placed under the direction of consumers in these models are personal care, homemaker/chore services, and respite care (Doty and Flanagan, 2002). Nearly half of all consumer-directed programs allow consumers to use Waiver funds to cover transportation, while one in five allows consumers to purchase friendly visitor/companion services or nonreimbursable medical services. Nearly half allow the purchase of miscellaneous services such as handyman services, home or other environmental modifications, special equipment, personal emergency response systems, vehicle modifications, home-delivered meals, adult day health, or training in independent living skills (Doty and Flanagan, 2002). Seventy-four percent of consumer-directed programs use intermediary service organizations (ISOs) to assist participants with payroll checks and taxes, employee benefits, and criminal background checks (Doty and Flanagan, 2002).

The majority of programs impose restrictions on the individuals who can be hired to provide support services, usually disallowing legally responsible individuals (such as spouses, and the parents or guardians of minor children) from being paid to provide care (Doty and Flanagan, 2002) and prohibiting legally designated representatives of consumers with cognitive impairments from hiring themselves (Doty and Flanagan, 2002). There are several exceptions, however. California's large In-Home Support Services program allows consumers to hire family members.

The populations most frequently included in consumer-directed HCBS programs are working-age adults with physical disabilities, followed by older Americans, adults with mental retardation or developmental disabilities, people with traumatic brain injuries, and finally children with physical or developmental disabilities (Doty and Flanagan, 2002). Most programs limit participation to individuals who have the ability to self-direct (i.e., who have no cognitive impairments or have parents who provide the direction) or require individuals with cognitive impairments to have representatives willing to assist in directing their services (Doty and Flanagan, 2002). The following table shows some of the most commonly cited consumer-directed programs, including Consumer-Directed Personal Care and Self-Determination initiatives, across the country.

## Consumer-Directed Personal Care and Self-Determination State Programs

State Name	Consumer-Directed Personal Care		Self-Determination	State Name	Consumer-Directed Personal Care		Self-Determination
	Original Cash and Counseling states	CD PCS models highlighted in the literature			Original Cash and Counseling states	CD PCS models highlighted in the literature	
Alabama				Nebraska			
Alaska				Nevada			
Arizona			X	New Hampshire			X
Arkansas	X			New Jersey	X		
California		IHSS		New Mexico			
Colorado		CD Attendant Support		New York			
Connecticut			X	North Carolina			
Delaware				North Dakota			
Florida	X		X	Ohio			X
Georgia				Oklahoma			
Hawaii			X	Oregon		Independent Choices	X
Idaho				Pennsylvania			X
Illinois				Rhode Island			
Indiana				South Carolina			
Iowa			X	South Dakota			
Kansas			X	Tennessee			
Kentucky				Texas			X
Louisiana				Utah			X
Maine				Vermont			X
Maryland			X	Virginia			
Massachusetts			X	Washington			X
Michigan		MI Home Help	X	Washington DC			
Minnesota		CD Home Care—pending	X	West Virginia			
Mississippi				Wisconsin			X
Missouri				Wyoming			
Montana							

(Cash and Counseling Web site, 2004; RWJF Web site, 2004; various literature including CMS Web site, 2004)

In June 1999, the Supreme Court interpreted Title II of the ADA as a mandate for public entities to provide services to persons with disabilities in the most integrated setting appropriate to their circumstances. The *Olmstead* decision obliges public entities to make reasonable accommodations by developing and implementing comprehensive plans to provide services in less restrictive settings and ensure that waiting lists for services in community-based settings move ahead at a reasonable pace. The Administration announced the New Freedom Initiative in response to the court decision. To encourage and support states' development of plans to restructure their long-term care systems, CMS has solicited multiple categories of Real Choice Systems Change Grants since 2001. The overarching emphasis of these grants is to build community-based and integrated systems for people with disabilities, including features of consumer-directed practices to allow consumers to make decisions about the types of services they want and the ways in which they receive them. The chart below illustrates the chronology and varied use of grant funds by state (CMS Web site, 2003).

## Olmstead and Real Choice Systems Change Grants

State Name	Olmstead Planning Grants		2003: QA/Improvement in HCBS	2003: Money Follows the Person	2003: Independence Plus	2003: Community-Integrated PAS	2003: National State-to-State Tech Assistance Program for Community Living	2003: Family-to-Family HC Info and Ed Centers	2003: Community-Based Treatment Alternatives for Children	2003: Respite for Kids	2003: Technical Assistance for Consumer Task Forces	2003: Respite for Adults	2003 and 2004: Aging and Disability Resource Centers
	X	X											
Alabama	X	X								X			
Alaska		X						X					X
Arizona						X							
Arkansas		X								X			X
California			X	X								X	X
Colorado		X	X		X			X					
Connecticut		X	X		X	X							
Delaware		X	X										
Florida		X			X								X
Georgia	X	X	X		X								X
Hawaii		X											
Idaho		X		X	X								
Illinois		X							X				X
Indiana		X	X					X					X
Iowa		X											X
Kansas											X		
Kentucky	X	X											
Louisiana					X	X							X
Maine	X	X	X	X	X								X
Maryland	X	X						X	X	X			X
Massachusetts		X			X	X			X				X
Michigan		X		X	X					X			
Minnesota		X	X										X
Mississippi									X				
Missouri	X		X		X				X				
Montana		X			X			X					X
Nebraska		X				X							
Nevada		X		X				X					
New Hampshire		X											X
New Jersey		X					X	X					X



State Name	Olmstead Planning Grants	FY 2001 grants	2003: QA/Improvement in HCBS	2003: Money Follows the Person	2003: Independence Plus	2003: Community-Integrated PAS	2003: National State-to-State Tech Assistance Program for Community Living	2003: Family-to-Family HC Info and Ed Centers	2003: Community-Based Treatment Alternatives for Children	2003: Respite for Kids	2003: Technical Assistance for Consumer Task Forces	2003: Respite for Adults	2003 and 2004: Aging and Disability Resource Centers
	New Mexico												
New York			X									X	
North Carolina	X	X											X
North Dakota													
Ohio			X		X							X	
Oklahoma	X												
Oregon	X	X				X				X			
Pennsylvania			X	X									X
Rhode Island	X									X		X	X
South Carolina	X	X											X
South Dakota								X					
Tennessee	X	X											
Texas	X	X	X			X			X				
Utah	X												
Vermont													
Virginia	X					X							
Washington	X			X									
Washington DC													
West Virginia	X	X											X
Wisconsin	X	X	X					X					X
Wyoming													

(CMS Web site, 2004; DHHS Press Release, 2003 and 2004; CHCS Web site, 2004)

### *Consumer Orientation in Different Domains of Care*

Two emerging trends that do not fit into a narrow definition of consumer direction *do* fit within a broader consumer orientation construct:

- Consumer involvement in research and program evaluation to ensure that outcomes important to consumers are studied in order to provide a baseline from which improvements can be made and
- Interventions aimed at improving provider-consumer communication.

Members of the CAB were particularly interested in examining the trends and outcomes of initiatives in these two areas. While we did not find much in the way of outcomes literature on these two topics, we did find policy literature and key informants who commented on them.

### *Consumer Involvement in Research*

The expansion of consumer-directed care means that individuals with disabilities have choices, not just between institutional and community-based care, but also within community-based options. It is important for people with disabilities to have input into the development, implementation, and evaluation of these plans and programs. It is especially important to include a consumer point of reference in developing outcome measures.

Researchers rather than consumers defined the majority of outcome measures reported in Section V. In follow-up interviews with some of the researchers, we learned that consumer focus groups informed the development of some of the evaluation measures, but the evaluation process is still largely the jurisdiction of researchers. Toward the inclusive end of this continuum, the Cash and Counseling Demonstration evaluation used consumer focus groups to identify domains for its research, and some organizations such as the National Institutes of Health, National Cancer Institute, and Department of Defense have involved consumers in setting their research agendas.

Key informants identified three organizations as doing a particularly good job in the area of consumer involvement in research: Advocates Involved in Monitoring in Oklahoma (OK-AIM), Ask Me! in Maryland, and Family Voices. OK-AIM is a consumer-guided monitoring program to ensure the quality of state-funded residential services for people with developmental disabilities (ODLC Web site, 2004). Ask Me! is a quality-of-life satisfaction survey administered by trained interviewers with developmental disabilities (DDA of MD Web site, 2004). Family

Voices participates in research projects such as the Your Voice Counts study with the Heller School at Brandeis University.

Community-based participatory research is an emerging method of public health research that aims to actively engage and involve participants (including representatives of the community and affected consumers) in all aspects of designing and conducting research efforts. Proponents of community-based participatory research consider it a way to address the social inequalities associated with disparities in health status between marginalized and mainstream populations that compromise research in the field (Israel et al., 1998).

### ***Consumer-Provider Communication***

Another area of research that the CAB asked us to investigate was the impact of consumer/provider communication on care outcomes and satisfaction. Across the lifespan and the spectrum of disability, CAB members identified communication as a key area of concern for consumer-oriented and consumer-directed care. We found very little in the published literature on this topic, although it is a cornerstone of the medical home model for children and some of the specialty managed care programs. The medical home places equal emphasis on clear provider-to-consumer communication so that parents and children understand medical information they receive and are fully informed about options for intervention, and on communication from parents and youth to providers, so that consumer experiences and information are brought to bear on clinical options.

Provider/consumer communication is also a central feature of many of the specialty managed care programs for adults and children with disabilities. In early evaluations of the Minnesota Disability Health Options (MnDHO) program in Minnesota and the Community Medical Alliance CMA program in Massachusetts, members provided many examples of how relationships with care coordinators (nurses and nurse practitioners) and primary care providers led to increased knowledge and understanding of their disabilities, chronic illnesses, and preventive care needs, enabled them to make decisions about their own self-care and life-style choices, and enhanced self-esteem (Tobias, 2002; Tobias et al., 2003). Unfortunately, none of

the research literature examines the association between consumer/provider communications and outcomes for people with disabilities.

In summary, the policy and program trends to support consumer-directed and -oriented care include the broadening of federal coverage for health and long-term care services for people with disabilities on the part of expansion of access to community-based services; a growing interest in consumer direction as a model for the delivery of community-based care; and a growing recognition that informal and unpaid family care is an important resource to support. Some of these trends are threatened by current economic constraints. The disability rights movements for children, working-age adults, and elders have been the major drivers of consumer-oriented and -directed care, supported by forward-looking foundations and policymakers who understand that consumer direction and orientation may hold promise, for both fiscal and programmatic reasons. Yet, most of our public funds for long-term care still go to institutional care, and many important policy and program questions remain untouched by the research community. Thus, there is a lot of progress still to be made.



## V.

### **Outcomes of Consumer-Directed Health Care**

A systematic review of the research literature was conducted to identify and evaluate the outcomes of consumer-directed health care. The main outcomes identified in the research literature addressed the following questions:

1. Does preference for consumer-directed health care vary by the nature of the disability, age, or other demographic, geographic, or socioeconomic factors?
2. Does consumer-directed health care lead to different outcomes for consumers, including changes in satisfaction with care, either for the consumer or for paid or unpaid caregivers, in the following areas?
  - Empowerment or control
  - Community integration
  - Extent of unmet needs
  - Health status
  - Quality of care
  - Consumer safety
3. Is consumer-directed or -oriented health care cost-effective or cost neutral?

The CAB identified other potential outcomes of consumer-directed care, such as employment and care in the least restrictive environment, but they were not addressed in any of the studies of consumer-directed long-term care. The literature review initially yielded 32 outcome reports in peer-reviewed journals, government reports, and foundation reports. The quality of the studies varied widely, however. Some had sample sizes in the thousands, while the smallest had a sample size of 11. Some were randomized control studies, others used comparison groups, and still others had unclear research designs. The populations studied also varied widely. Some were limited to individuals with developmental disabilities or individuals with physical disabilities. Some excluded people with severe cognitive impairments, while others allowed proxy responses for this population. Most included working-age adults with disabilities, and some also included elders. Only one study addressed outcomes for children, all of whom were adolescents.

In order to rationalize the review of findings, we established study inclusion and exclusion criteria. Unlike biomedical reviews, in which highly rigorous standards may be applied to hundreds of clinical studies, we were confronted with a paucity of research. Highly rigorous standards would have led to the exclusion of most of the studies identified and thus prevented even exploratory analyses of outcomes across the different age groups or disability types.

Thus, our relatively inclusive selection criteria were as follows:

- Minimum sample size = 75.
- Sample selection process = random or universal sample of program participants.
- Research design = comparison or control group preferred, longitudinal where appropriate, cross-sectional permitted for preference studies.

In the discussion below, we prioritize results from 21 studies that met our criteria. However, we also reference findings from a second set of studies that were either conducted on convenience samples or had less rigorous research designs when those studies addressed outcomes or populations that were otherwise neglected.

### **A. Does Preference for Consumer-Directed Health Care Vary by the Nature of the Disability, Age, or Other Demographic, Geographic, or Socioeconomic Factors?**

In developing health care systems, it is important for policymakers and planners to understand who wants consumer direction and how much of it they want. Preferences might differ by age, nature or severity of disability, race/ethnicity, or consumers' social or family networks and support. Seven studies were identified that address this topic directly. Six of them met our criteria for rigor in that the sample sizes were sufficiently large to permit conclusions, and the samples were either randomly selected or universal samples. We reference the seventh study, which involved a convenience sample, because the sample was large and the study included important information on the preferences of several minority populations that were not examined in any of the other studies. Below is a brief synopsis of each study.

The Gibson et al., 2003, report was based on the results of a Harris Interactive Survey commissioned by AARP of persons over the age of 50 with a disability who lived in the community. Alone among the studies, this was a national survey of individuals with a wide range of incomes and disabilities. Survey data were weighted to correspond to the national population of individuals over the age of 50 with a disability living in the community.

The Desmond et al., 2001, study was conducted among adults with physical disabilities who received services from the Medicaid Home and Community-Based Waiver Program in Florida. The study was conducted as part of a needs assessment to understand who might be interested in the Cash and Counseling Demonstration, a consumer-directed option for the receipt of home- and community-based Waiver services, and what their information and counseling needs might be. The study used a random sample design; 743 individuals participated for a 48 percent response rate. Both older and younger adults were included in the study.

The Feinberg and Whitlatch, 1998, study was conducted in California of family caregivers who received in-home respite care through a state-funded program for individuals who were not eligible for Medicaid but could not pay for services out of pocket. Unlike most of the other studies on this subject, this research examined the preferences of caregivers rather than consumers. All of the respondents were providing care for family members with serious cognitive disabilities, both older and younger adults. Families that participated in this program were given a choice between agency-directed and family-directed care. In contrast to other studies, respondents in this study had actually made a choice between service models, and thus results reflect actual rather than hypothetical preferences. All program participants were asked to participate in the study. One hundred sixty-eight responded for an 81 percent response rate.

The Mahoney et al., 1998, study was conducted with Medicaid recipients in New York who were personal care clients, as part of the Cash and Counseling Demonstration needs assessment. It was a random sample design with 493 people in the sample for a 23 percent response rate. Both older and younger adults were included in the study.

Two studies were conducted by Simon-Rusinowitz et al. The first, Simon-Rusinowitz et al., 1997, was conducted with Medicaid personal care clients in Arkansas prior to implementation



of the Cash and Counseling Demonstration. Questions were similar to those posed in the Desmond et al., 2001, and Mahoney et al., 1998, studies, and the population surveyed was similar in that all respondents were low-income Medicaid recipients with disabilities. It was a random sample design, with 491 people in the sample for a 34 percent response rate. Both older and younger adults were included in the study.

The second study, Simon-Rusinowitz et al., 2001, was conducted in Florida as part of the Cash and Counseling needs assessment among adults with developmental disabilities who received Medicaid HCBS Waiver services. Although all of the Cash and Counseling studies allowed for surrogate responses, in this study 74 percent of respondents were surrogates, whereas in the other studies, surrogates represented a minority of respondents. This study involved a random sample of 387 program participants, for a 54 percent response rate.

Sciegaj et al., in press, is the one study that involved a convenience sample. This study was conducted in Boston among home care clients who received care for at least one activity of daily living (ADL) for a minimum of 12 months from one of four community-based organizations. Its purpose was to determine if interest in consumer-directed care varied by race, ethnicity, or other factors. Study participants were recruited from organizations based in the African-American, Latino, Chinese, or white communities, and an effort was made to obtain equal representation of each group.<sup>2</sup> The study did not indicate how this sample of 731 individuals, all of whom were over the age of 64, were similar to or different from the other clients served by the home care agencies.

The table below provides an overview of the study sample sizes, locations, and basic research methods. Please see Appendix K for more information on the similarities and differences of these outcomes studies.

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<sup>2</sup>Equal representation of 200 respondents was achieved among white, African-American, and Chinese individuals; however, only 131 Latinos participated in the study.

## An Overview of the Seven Research Studies

Study	Year	Sample Size	Location	Recruitment Base	Sampling Method	Research Design	Response Rate	Actual Choice
Gibson et al.	2003	1102	Nat'l.	UNK	UNK	Cross Sectional	32 percent	N
Desmond et al.	2001	743	Florida	Personal care clients	Random	Cross Sectional	48 percent	N
Feinberg and Whittlatch	1998	168	CA	Family caregivers who used in-home respite care	Universe	Cross Sectional	81 percent	Y
Mahoney et al.	1998	493	New York	Personal care clients	Random	Cross Sectional	23 percent	N
Sciegaj et al.	In press	731	Boston	Clients of CBOs using services to assist with ADL	Convenience	Cross Sectional	N/A	N
Simon-Rusinowitz et al.	1997	491	Arkansas	Medicaid personal care clients	Random	Cross Sectional	34 percent	N
Simon-Rusinowitz et al.	2001	378	Florida	HCBS Waiver clients	Random	Cross Sectional	53 percent	N

All of the studies included individuals over the age of 65, and most included individuals with disabilities under the age of 65. Most of the studies included individuals with physical disabilities; one was conducted exclusively among individuals with developmental disabilities, and another explicitly mentioned the inclusion of individuals with cognitive disabilities. Five of the studies permitted surrogate responders, and the family caregiver study targeted family members caring for people with cognitive disabilities. Of note, none of the studies explicitly included individuals with psychiatric disabilities or families of children with special health care needs.

Findings on consumer interest in self-directed services varied widely across the studies. It was highest among the national sample of individuals with disabilities over the age of 50 (78 percent) and among family caregivers of individuals with cognitive disabilities in California (69 percent), who exercised their choice for family-directed care when given the option. It was also expressed as a preference by 59 percent of the consumers who received personal care services in Florida. In the other four studies, fewer than half the participants expressed an interest in consumer direction.

### *Age*

The studies suggest that sometimes age matters and sometimes it does not. In two of the Cash and Counseling preference studies, younger consumers were more likely to express a preference for self-direction than for older consumers. In addition, surrogate respondents for people with developmental disabilities in Florida were more likely to prefer consumer direction if the consumer was younger. However, age was not associated with preference for consumer direction in the national study of adults over the age of 50, among personal care recipients in Arkansas, nor among family caregivers of people with cognitive disabilities.

### *Gender*

The vast majority of study respondents were female, except in the national sample of people with disabilities over the age of 50 and the survey of adults with developmental disabilities in Florida. Most of the studies looked at the relationship between gender and preference for consumer direction nonetheless. Six of the studies found no significant association between gender and preference for consumer-directed care. Only Mahoney et al., 1998, found a significant relationship in multivariate analysis, with men more likely than women to prefer consumer direction.

### *Race or Ethnicity*

Five of the seven studies found that race or ethnicity was associated with preference for consumer direction. The two studies that found no difference were the Gibson et al., 2003, national study conducted for AARP and the Desmond et al., 2001, Florida study. One of the limitations of the AARP study was the small representation of racial or ethnic minorities in the sample. However, the Desmond et al., 2001, study was similar in design to three studies in Florida, New York, and Arkansas that all found a stronger preference for consumer direction among African Americans and/or Latinos than among whites. The Sciegaj et al., in press, study of older adults in Boston found that Chinese elders were more likely to express preference for consumer direction and Latinos were more likely to express preference for a traditional case management model (compared with African Americans or whites). However, with the exception of Chinese elders, the vast majority of study respondents expressed a preference for the agency-

directed model of care. In most of these studies, the association between race or ethnicity and preference remained significant in multivariate analyses.

### ***Nature or Severity of Disability***

None of the studies specifically examined differences in preference among individuals with different types of disabilities. The two studies that examined preferences among surrogate respondents caring for adults with cognitive disabilities, however, reported preference rates of 44 to 69 percent, while studies that focused more explicitly on individuals with physical disabilities reported preference rates of 29 to 59 percent. Since none of these studies explicitly analyzed differences by disability type, and reported preference rates were not broken out by age, race/ethnicity, or other potentially confounding factors, it is difficult to draw precise conclusions. However, it is clear that people with different disabilities all expressed some level of interest in consumer direction, and at the same time, within each disability group there were those who preferred agency direction. None of the studies addressed psychiatric disabilities, even though some of the study respondents may have had serious mental health conditions, and again, none reflected the preferences of parents of children with disabilities of any type.

Severity of disability was associated with preference for consumer direction in three studies, and in all three cases this preference was stronger among individuals with more severe disabilities. However, in all but one case, the association between severity of disability and preference for consumer direction disappeared in multivariate analysis.

### ***Other Factors***

Some studies looked at other factors that might be associated with preference for consumer-directed services. These factors included health status, education level, current service use, whether or not the individual lived at home, the availability of family members to provide care, the availability of informal caregivers in general, satisfaction with current services, the consumer's prior experience with hiring and paying caregivers, the consumer's prior experience with managing and supervising caregivers, and the consumer's willingness to assume responsibility for caregiver management at various levels.

In multivariate analyses, one study found that having family members in the home was a predictor of preference for consumer direction, and one did not. Two studies found that having an informal caregiver (not necessarily a family member) available was a predictor of preference for consumer direction. One study found that a higher education level was a predictor of consumer direction preference, but two did not. Although most of the studies found that respondents were generally satisfied with their current (agency-directed) services, in some studies dissatisfaction with current services was associated with preference for consumer direction, and in other studies it was not. Prior experience in hiring and paying or managing and supervising caregivers was associated with preference for self-direction in three of the studies.

In summary, it is difficult to argue that any of these factors other than prior experience with consumer direction and willingness to assume responsibility for caregiver hiring, management, and supervision make a clear or major difference in the preference of individuals with disabilities for consumer-directed care. The table below provides an overall summary of factors associated with consumer preference for self-direction across the studies.

### Factors Associated with Consumer Preference for Self-Direction

Study		Interest in Consumer Direction		Interest Associated With								
		Yes	Not Sure	Age	Gender	Race/Ethnicity	Family status	Inform. Caregiver	Prior Experience	Severity of Disability	Service Use	Education
		Desmond et al.	59%	20%	Y	N	N	N	Y	Y	Y	Y
Feinberg and Whitlatch	69%		N	N	Y	N					N	
Gibson et al.	78%		N						N			
Mahoney et al.	40%	22%	Y	Y	Y	Y		Y	Y	N	N	
Sciegaj et al.	30%				Y							
Simon-Rusinowitz et al.	29%	26%			Y		Y	Y	N	N	Y	
Simon-Rusinowitz et al.	Cons	44%	27%			Y			Y	N		
Simon-Rusinowitz et al.	Surr.	38%	29%	Y		Y						

Note: Y = Statistically significant association  
 N = No statistically significant association  
 Blank cell = Not studied or reported

Thus, the current research on preference for consumer direction provides conflicting results, perhaps due to differences in study methods or the phrasing of questions. Furthermore, there is the possibility that people who are asked to make a hypothetical choice would respond

differently when presented with an actual choice. Results from the Cash and Counseling Demonstration in Arkansas indicate that while certain populations were more likely to express interest in consumer direction in the survey conducted prior to implementation of the demonstration project, these populations did not necessarily enroll in the demonstration once it was implemented. Another limitation of existing research was the omission of certain populations from study samples. The AARP study, with its nationwide scope and broad inclusion of people with disabilities, for example, was limited by the low percentage of racial and ethnic minorities in the sample.

Even with these limitations, in some areas these very different studies seemed to point in similar directions:

- Preference differed by age, but that difference did not alter the fact that a substantial number of people over the age of 65 expressed a preference for consumer-directed care.
- Among all populations, a continuum of interest was found in consumer direction, from full interest to moderate interest to no interest.
- Interest in consumer direction often varied by race/ethnicity, but results were not consistent. Studies in different parts of the country indicated different levels of association; thus, it would be wise to assess local interests rather than making assumptions for the design of a program in one area based on studies conducted elsewhere
- Familiarity with consumer direction or experience hiring or supervising workers was strongly associated with preference for consumer-directed care.
- People with different types of and severity of disabilities, including people with cognitive disabilities and their families and people with severe physical disabilities, were interested in consumer-directed care.
- Education level rarely makes a difference in preference for consumer-directed care.
- In some groups, the existence of informal caregivers or family members who could serve as caregivers was related to a preference for consumer-directed care.

As a final note, it should be emphasized once again that the literature was silent on the issue of the preference of families of children with special health care needs or mental health consumers for consumer-directed care. In fact, among the populations included in these studies, the issue of potential psychiatric comorbid conditions and their impact on preference for consumer-directed care was never addressed.

## **B. Does Consumer-Directed Health Care Lead to Different Outcomes for Consumers?**

Outcomes considered included the following:

- Satisfaction with care—for the consumer and the paid or unpaid caregivers
- Empowerment or control
- Extent of unmet needs
- Health status
- Quality of care
- Safety

These questions are extremely important to policymakers and consumers, because consumer-directed care challenges the concept that professional oversight—usually in the form of nursing or other professional involvement—is needed to protect the health and well-being of populations who can not perform ADLs or instrumental activities of daily living (IADLs) themselves. While the Independent Living movement and advocates for people with physical disabilities have made important progress in advancing the concept of consumer direction for individuals with no cognitive impairments, concerns are still widespread about applying this model to long-term care for older Americans and individuals with cognitive disabilities. Concerns are particularly focused on issues of safety, quality of care, and health status.

We found seven studies addressing these issues that met our criteria for inclusion. In addition, we report results from three studies that did not meet our inclusion criteria owing to convenience samples or inconsistent research methods. However, they provided information about a

population that is often excluded from other analyses and included a much broader range of outcomes, such as community integration, and broader quality of life measures.

The Beatty et al., 1998, study was conducted among individuals with physical disabilities in Virginia who received personal assistance services through a state-funded program that used a consumer-directed model. A cap on program participation meant that some applicants were placed on a waiting list. The study compared the outcomes for 60 people who received consumer-directed personal assistance with the outcomes for 32 equally interested people on the waiting list who received other paid services, primarily through agencies. The study examined consumer experiences over a three-year period.

Three of the studies were conducted by Benjamin et al., who researched Medicaid SSI participants in California's In-Home Supported Services Program. Each county that participated in the study offered a consumer-directed option for in-home support services, including personal assistance. Some of the counties also offered an agency-directed program. It is important to note that consumers were not allowed to choose one form of service delivery over another—this choice was made by county caseworkers following an assessment. Consumers who were assigned agency-directed care were more likely to be socially isolated, to need relatively few hours of service, or were predicted by county staff to have difficulty finding their own provider. The consumer-directed option provided very little assistance to consumers who needed training or support to make consumer direction work. Individuals were allowed to hire family members as caregivers in this program. A total of 1,095 people were interviewed in this random sample study, which was stratified by age (over or under 65) and by service delivery model (self-direction or agency direction). Although individuals with cognitive disabilities could receive services through this program, they were excluded from the study if they were not able to participate in the interview protocol. The Benjamin et al., 2000, study included the full sample of 1,095 agency- and consumer-directed participants. This study compared outcomes for those who received consumer-directed services with outcomes for those who received agency-directed services, stratified by age group. The Benjamin et al., 1999, study examined outcomes for the 511 individuals who received consumer-directed services to understand if people who hired family members as caregivers differed from those who did not, and if outcomes were different



for the two groups. The Benjamin and Matthias, 2001, study also examined outcomes among 511 individuals who received consumer-directed services, to determine if there were differences based on consumer age.

The Doty et al., 1996, study was an analysis of findings from a Louis Harris and Associates survey of elderly personal care recipients in the Maryland, Texas, and Michigan Medicaid programs. Michigan offered a consumer-directed long-term care program, Texas offered agency-directed long-term care, and Maryland offered a hybrid model in which consumers could hire their own attendants, but county nurses oversaw and supervised care. The study was conducted using in-home interviews, but study subjects had to be competent to be interviewed. This study compared outcomes for program enrollees across the three states, stratified by the level of consumer-directed care.

The Feinberg and Whitlatch, 1998, study of family caregivers, described above, compared the outcomes for those who used consumer-directed in-home respite with the outcomes of families who used agency-directed in-home respite.

The Foster et al., 2003, study was conducted among adults of all ages with physical disabilities who were eligible for Medicaid personal assistance services in Arkansas. These individuals enrolled in the Cash and Counseling Demonstration project and were randomly assigned to consumer-directed or agency-directed services. People who received consumer-directed services were also offered counseling to assist them in developing budgets, hiring staff, and obtaining services. Consumers had the option, which most chose, to use a fiscal intermediary to pay their caregivers. Each individual was interviewed at two points, once upon enrolling in the program and nine months after enrollment. A total of 1,739 individuals participated in both interviews, with proxies providing responses for approximately 50 percent of the elderly sample and 25 percent of the non-elderly sample. Proxy interviews were also conducted for deceased individuals and with consumers who had disenrolled from the program.

The table below summarizes the basic features of these outcome studies, including sample size, location, target population, and basic research design. Please see Appendix L for more information on these studies.

## Basic Features of the Outcome Studies

Study	Year	Sample Size	Location	Recruitment Base	Sampling Method	Research Design	Response Rate	Response Bias
Beatty et al.	1998	92	VA	People receiving paid personal assistance through the state	Universe	Longitudinal with comparison group	UNK	Don't know
Benjamin and Matthias	2001	511	CA	Recipients of CD in-home supportive services	Random	Cross sectional with comparison group	78%	Younger, minorities more likely to respond
Benjamin et al.	2000	1095	CA	Recipients of CD in-home supportive services	Random	Cross sectional with comparison group	78%	Younger, minorities more likely to respond
Benjamin et al.	1999	511	CA	Recipients of CD in-home supportive services	Random	Cross sectional with comparison group	78%	Younger, minorities more likely to respond
Doty et al.	1996	879	MD, MI, and TX	Older Medicaid recipients of personal care services	UNK	Cross sectional with comparison groups	88%	UNK
Feinberg and Whitlatch	1998	168	CA	Family caregivers who used in-home respite care	Universe	Cross sectional	81%	UNK
Foster et al.	2003	1739	AK	People enrolled in AK C&C Program, 9 mos. after enrollment	Universe	Randomized, control study, pre- and post	89% tx grp, 85% control group	UNK

Six of these studies included people over the age of 65 in their samples (the Beatty et al., 1998, study being the exception), and six also included adults with disabilities under the age of 65 (the Doty et al., 1996, study being the exception). Six of the studies focused primarily on individuals with physical disabilities and chronic illnesses. Of these, one permitted proxy respondents. One study was conducted of family caregivers who cared primarily for individuals with cognitive disabilities. None of the studies addressed consumer-directed care for individuals with psychiatric disabilities or families of children with disabilities.

### *Satisfaction with Services*

Five of the studies compared the satisfaction of people who received consumer-directed personal assistance with those who received agency-directed services. In each of these studies, people who received consumer-directed services were significantly more satisfied with their overall service experience and with specific aspects of service delivery. It is important to note, however, that both groups of consumers were mostly satisfied with their care. For example, in the Foster et al., 2003, study, 90 percent of those receiving consumer-directed services and 80 percent of

those receiving agency-directed services were satisfied; and in the Doty et al., 1996, study, more than 90 percent of respondents were satisfied.

The studies used different questions to measure satisfaction. Generally, a series of questions were combined to form a satisfaction index. Most of the studies asked about the work performance of caregivers in a number of areas, such as the ability of consumers to get help when it was needed, satisfaction with the work schedule of caregivers, and satisfaction with the way personal care and housekeeping needs were met. A few of the studies also included measures of consumers' satisfaction with their control over care and over their lives. Where feasible, we incorporated assessment of that aspect of satisfaction into the discussion of empowerment and control as outcomes.

The Benjamin and Matthias, 2001, study and the Foster et al., 2003, study contained samples large enough to permit authors to compare satisfaction of different age groups—those age 65 and older and those under age 65. In the Benjamin and Matthias, 2001, study, the older population was more likely to be female, minority, and less educated than the younger population. The older group also had fewer ADL needs and slightly more cognitive impairments. Another important difference between the two groups was that while older people were more likely to hire family members, younger people were more likely to hire nonrelatives. Few people in either group hired strangers. Despite these differences in population characteristics, in multivariate analysis there was no significant difference between younger and older groups in satisfaction with services, with one exception. The younger population was more satisfied with their provider's ability to get things done inside and outside the house than the older group.

In contrast, Foster et al., 2003, found that the older group in Arkansas was more satisfied with their services than the younger group. However, over time, younger enrollees in consumer-directed care became much more satisfied with their services than they were at the beginning of the study.

Benjamin et al., 1999, examined differences in satisfaction with care between consumers who hired family members and those who hired nonfamily members. Those who hired family members were older and more likely to be Hispanic or Asian than those who hired nonfamily

caregivers. People who hired family members had less formal education and tended to live with others rather than alone. They were more likely to fall in the middle range of ADL or IADL needs rather than at high or low ends. In multivariate analysis, people who hired family members were significantly more satisfied with their care than those who hired nonfamily members, perhaps in part because they had more stable relationships and longer tenure with their caregivers.

### ***Control and Empowerment***

Control and empowerment are two related but slightly different concepts. For the purposes of this review, control refers to what a people *do* or supervise, and empowerment refers to how people *feel* about what they do and the environment in which they live. Empowerment often reflects some level of control, but it is broader than control. However, in practice, researchers often measured the same things (choosing your caregiver, satisfaction with the amount of say in your care); some called these measures of control, while others called them measures of empowerment.

Three of the studies examined differences between those who received consumer-directed care and those who received agency-directed care in relation to the level of empowerment or control they experienced. A fourth study looked at differences in empowerment or control between older and younger adults who received consumer-directed services, and a fifth study examined differences between those who hired family members and those who hired nonrelatives. Beatty et al., 1998, found that people with physical disabilities who received consumer-directed personal assistance were significantly more satisfied with the control they had over the choice of caregivers and the authority to direct their care than those who received agency services. Doty et al., 1996, looked at this issue from a different angle, and found that older adults who scored higher on four out of five indicators of consumer direction (a sort of implicit index of empowerment or control) were more likely to be satisfied with their care than people who had no indicators of consumer direction. In logistic regression, the two most important factors associated with satisfaction were knowing the aide prior to employment and supervising the aide. Feinberg and Whitlatch, 1998, created an index that included paying the aide, knowing the aide prior to employment, scheduling and firing the aide, and making sure the aide did the job he or she is

supposed to do. In multivariate analysis, family caregivers who scored higher on this index were more likely to have selected consumer-directed services than agency-directed services, and were also more satisfied with the care they obtained for their relative.

Benjamin and Matthias, 2001, compared the experiences of people age 65 and older with people under age 65 in terms of their empowerment, measured by the freedom to choose services, satisfaction with how tasks were done, preference for training and supervising workers, and desire for a major say in service provision. They found that younger consumers were significantly more empowered according to this set of indicators than were older consumers. Empowerment variables remained significant in multivariate analysis as individual predictors of satisfaction. Benjamin et al., 1999, used the same composite measure of empowerment to examine differences between individuals who hired family members and those who hired nonfamily members. In multivariate analysis, they found that individuals who hired nonrelatives were more empowered, in that they were more likely to supervise their workers and direct their own care.

### *Unmet Needs*

Three studies examined this important outcome: Benjamin and Matthias, 2001, Benjamin et al., 2000, and Foster et al., 2003. Benjamin and Matthias, 2001, also examined differences in unmet needs among those receiving consumer-directed services based on age. The two areas of unmet needs that were examined in these studies were assistance with ADLs and assistance with IADLs.

In multivariate analysis, Benjamin et al., 2000, found that individuals receiving consumer-directed services had significantly fewer unmet IADL needs than individuals receiving agency-directed services, but had more unmet ADL needs. However, it is important to note that the consumer-directed group had significantly higher impairment, as measured by baseline ADL needs, than the agency-directed group. Foster et al., 2003, found that individuals receiving consumer-directed services had significantly fewer unmet ADL, IADL, and transportation needs than those receiving agency services. In the study that compared older and younger consumer-

directed care recipients, Benjamin and Matthias, 2001, found that younger people reported higher unmet IADL needs than older people, but there was no difference in unmet ADL needs.

### ***Change in Health Status***

Only one study examined this outcome. Foster et al., 2003, found no significant difference in changes in overall health status between those who received consumer-directed services and those who received agency-directed services. However, over a nine-month period, there were some small improvements in important health outcomes for individuals in the consumer-directed program. Younger people reported fewer bedsores and less shortness of breath than people in the agency-directed program, and older people reported fewer muscle contractures. Although these improvements were not statistically significant, they were very important clinically.

### ***Safety***

Three studies examined differences in the safety of individuals who received consumer-directed services and individuals who received agency-directed services. Two of the studies, Beatty et al., 1998, and Foster et al., 2003, found no difference in safety. Foster et al., 2003, looked at reports of adverse events, accidents, falls, or health problems that might indicate inferior treatment. The Benjamin et al., 2000, study defined safety in terms of provider behaviors (yelling, threatening, stealing, or alcohol use on the job), consumer reports of being hurt or neglected, and how safe the consumer felt. They found that individuals who received consumer-directed care reported significantly higher safety indicators than those who received agency-directed care.

### ***Quality of Life***

Only Foster et al., 2003, explicitly examined this issue, and they found that people receiving consumer-directed services were nearly 20 percent more likely to be very satisfied with their lives than people receiving agency-directed services. This was true for individuals over and under the age of 65.

The table below summarizes the outcomes found to be associated with consumer direction across the studies.

## Outcomes Associated with Consumer Direction

Study	Year	Satisfaction	Empowerment/ Control	Unmet Need	Health	Safety	Quality of Life
Beatty et al.	1998	Y	Y			N	
Benjamin and Matthias	2001	Y	Y	Y			
Benjamin et al.	2000	Y		Y		Y	
Benjamin et al.	1999	Y	Y			Y	
Doty et al.	1996	Y	Y				Y
Feinberg and Whitlatch	1998	Y	Y				
Foster et al.	2003	Y		Y	N	N	Y

Note: Y = Statistically significant association

N = No statistically significant association

Blank cell = Not studied or reported

### *Other Relevant Outcomes Research*

As noted above, there were three other studies that did not conform to our criteria for inclusion, but provided outcome information about an important group of individuals with disabilities not included in the studies reported above, and a promising model of consumer direction, referred to as “Self-Determination.”

Conroy et al., 2002, conducted a study of pilot Self-Determination projects at three Regional Developmental Centers in California for people with developmental disabilities. The evaluation was conducted over approximately one and a half years, during which time 63 program participants and their families (out of a total of approximately 90) were interviewed three times, once before the project began, once at midpoint, and once at the end of the pilot. In addition, 14 clients of the Regional Center who did not participate in the Self-Determination pilots completed interviews. Demographics of pilot program members and comparison group differed significantly by race/ethnicity, with the 14-person comparison group having fewer Caucasians and more Latinos and Asians. All of those interviewed for this study were individuals with developmental disabilities or their surrogates.

Conroy et al., 2002 (December), conducted an evaluation of the Robert Wood Johnson Foundation-funded Self-Determination projects in six states. In a final report to the Foundation,

this study included data on 441 program participants from the six states. We included results from the two state studies with sample sizes over 75—Wisconsin and Michigan. Initial interviews with individuals with developmental disabilities and/or their surrogates were conducted pre-enrollment in this demonstration, and again one, two, or three, years post-enrollment.

Conroy et al., 2002 (November), issued an evaluation report to the New Jersey Developmental Disabilities Council on the implementation of Self-Determination in that state. More than 300 people with developmental disabilities enrolled in the New Jersey Self-Determination project. The report, based on 2002 interview data with 138 people, indicated that some individuals were interviewed at two points in time, before enrollment in the project and after enrollment in the project, but it was not clear about how many of the 138 responses were reflected in reported results or what the time period was between the initial and follow-up visits.

Despite their limitations, it is instructive to review the findings from the studies of the Self-Determination programs, as they address consumer direction for people with developmental disabilities. The table below summarizes study sample sizes and demographics. Most of the samples were small compared with other studies of consumer direction. In all the states except California, the study participants were mostly white. In contrast with the other consumer direction studies, the majority of enrollees in the Self-Determination studies were male.

**Study Size and Demographics of the Self-Determination Studies**

<b>Study</b>	<b>Year</b>	<b>Sample Size</b>	<b>Location</b>	<b>Female</b>	<b>White</b>	<b>Black</b>	<b>Latino/a</b>	<b>Asian</b>
Conroy et al.	2002	77	CA	29%	54%	2%	33%	8%
Conroy et al.	Dec-02	135	MI	45%	86%			
		89	WI	42%	93%			
Conroy et al.	Nov-02	138	NJ	49%	91%			

In all four states, people with developmental disabilities experienced greater empowerment and control during the time they participated in the Self-Determination projects. This was measured through an instrument called the Decision Control Inventory that asked 35 questions about the extent to which life decisions, both major and minor, were made by paid staff or by the consumer



and their unpaid friends or relatives. The areas of most significant change were different in each state, but the overall score was significantly higher from pre to post-enrollment. For example, in Michigan, the greatest gains were in options to hire and fire support personnel, choice of agency support personnel, choice of people to live with, choice of case manager, and choice of house or apartment. In Wisconsin, the gains were in how consumers spent their funds, choice of case manager, and choice of service agency.

Three of the studies found significant improvements in quality of life during the course of the demonstration projects, and three of the studies found significant increases in community integration. Quality of life was measured by asking people with developmental disabilities or their surrogates to rate 14 items before and after enrollment in the project. Sampled items included “health,” “what I do all day,” “seeing friends,” “safety,” “treatment by staff,” “food,” and “privacy.” Community integration measures included the number of times individuals did any of a set of 16 activities in the past month (visit with friends, go to a movie, bank, shopping, and sports event) and access to transportation. In three of the four states, participants in the Self-Determination project reported significantly more community integration over time, while in the fourth state community integration declined, although not significantly.

Two of the studies examined health status and found no change in health over time. One study looked at safety and found a significant improvement over time. The Michigan and Wisconsin studies examined the impact of the demonstration on caregivers through a survey on the quality of their work lives. In Wisconsin, direct care staff experienced a significant positive change in the quality of their work lives, while in Michigan, staff experienced no significant change.

In summary, as with the consumer preference studies, it is difficult to come to definitive conclusions about outcomes because the research covers such diverse populations and asks different questions, in different ways. On the other hand, the evidence does point to the fact that people who receive consumer-directed services are more satisfied with their care, feel more empowered, and experience a higher quality of life than individuals who receive agency-directed services. The satisfaction outcomes, however, should be viewed with some caution, as satisfaction with community-based services tends to be very high, regardless of the model. Furthermore, in two of the studies—Foster et al. and Beatty et al., the sample who used agency-

directed services were individuals who had already expressed an interest in consumer direction, by virtue of enrolling in the Cash and Counseling Demonstration or being placed on a waiting list for consumer-directed care. Perhaps it was no surprise that they were less satisfied with their care since they were not yet directing it.

### **C. Is Consumer-Directed Health Care Cost-Effective or Cost Neutral?**

Examination of the cost-effectiveness of consumer-directed health care raises complex issues. Different results can emerge depending on the methods that are used to determine costs. For example, in examining different models of personal assistance, some researchers look simply at the direct cost of providing each mode of service while others look at the impact each model has on utilization of the full range of long-term care and supports. A few researchers have looked even more broadly at total costs of health and long-term care for people with disabilities given different models of care. The broader the approach, of course, the more difficult it becomes to access and analyze the different funding streams that pay for the different components of care. Thus, much of the research focuses on the cost of the intervention itself.

Another issue in determining cost-effectiveness in the short term is how to predict what might ultimately happen to an individual in the absence of community-based services. Would the individual actually be institutionalized? If it were possible to be sure that an individual would be institutionalized absent community care, one could easily document the cost-effectiveness of community-based services. Absent knowledge of the probability of averted institutional cost, it is difficult to document the cost-effectiveness of enhanced community-based care to the system.

We identified nine studies that met our criteria for inclusion that measured cost outcomes.

The nine studies examined the following aspects of cost:

- Four studies examined the cost-effectiveness of home- and community-based services compared with nursing home care, primarily for elders and people with physical disabilities.

- Two studies examined the cost-effectiveness of community-based care compared with institutional care for people with developmental disabilities.
- Two studies documented the differences in expenditures under consumer-directed models compared with agency-directed models.
- One study examined the substitution effects of paid services provided by long-term care insurance on the provision of unpaid care.

### *Comparing Home- and Community-Based Service Costs to Nursing Home Costs*

One of the requirements of the Medicaid HCBS Waiver Program is cost neutrality. Home- and community-based services can be covered only if they cost no more than institutional care. Four studies examined the cost-effectiveness of home- and community-based services on a systems level, including in their analyses the likelihood that Waiver participants would enter a nursing home.

The Kemper et al., 1986, study was a meta-analysis of the federally funded National Long-Term Care Demonstration, known as Channeling, which served as a prototype for Home- and Community-Based Waiver Programs. Ten programs tested one of two models for financing and delivery of services. The first model was an informal, referral, and case management model, with very limited funding to purchase direct services. The second model expanded services and established a pool of funds to allocate these services based on consumer needs. In this model, the role of the case manager was expanded to include authorization of services for specific individuals. Evaluations were conducted at each site, using a randomized control group who received no intervention. Costs included in the analysis included expenditures by Medicaid, Medicare, and the demonstration projects themselves.

The Kemper et al., 1987, study was another meta-analysis of home- and community-based demonstration projects funded through Medicaid or Medicare. Kemper et al., 1987, began by looking at evaluations of 16 demonstrations that offered case-managed community care to elders with disabilities from the early 1970s through mid-1980s. From this group, they selected six evaluations that used randomized control designs and included fairly complete cost data. These demonstration projects provided different combinations of nonmedical services such as

homemakers, personal care, transportation, and home-delivered meals. Some served all ages of adults with disabilities, rather than restricting services to older people. Sample sizes ranged from 139 to 6,326, the largest being the Channeling Project, which was one of the six demonstration projects included in this meta-analysis.

Vertrees et al., 1989, compared home- and community-based Waiver services costs with nursing home costs for Medicaid participants in the aged and disabled HCBS Waiver Programs in Georgia and California. The samples consisted of everyone enrolled in the Waiver Programs (1,241 people in Georgia and 2,107 people in California) as well as comparison groups of people living in the community who were not enrolled in the Waiver. The populations were stratified into five groups based on ADL and IADL impairment levels, whether or not they lived alone, and enrollment in Waiver or comparison group. Vertrees et al., 1989, conducted a life table analysis to determine the likelihood that people would enter a nursing home or hospital in a given length of time in each of the groups. The analysis relied on data from Medicaid claims for both nursing homes and Waiver services, as well as information about hospital admissions.

Weissert et al., 1997, also compared costs of home- and community based Waiver services with nursing home costs, but for a very different program model. They analyzed the Arizona Long-Term Care System, a statewide capitated long-term care program funded by Medicaid. All of Arizona's elderly and disabled Medicaid HCBS Waiver Program participants and nursing home residents were enrolled in this managed long-term care program. Data on the universal sample of Waiver participants (N = 20,361) were then compared with two national data sets, one a random sample of elderly nursing home residents and the other a random sample of elderly community residents, because of the absence of any control or comparison group in the state. Weissert et al., 1997, used logistic regression to identify risk factors for nursing home placement by merging the national data on community and nursing home residents and then applied this analysis to the Arizona Waiver population.

The table below summarizes the different research studies.

### Results of the Research Studies on Cost

Study	Year	Location	Sample Size	Study Population	Disabilities			Sampling Method
					Phy<65	Phy>65	Cog.	
Kemper et al.	1986	10 states	6326	Participants in Channeling demonstrations		x		Random
Kemper et al.	1987	6 programs	varied	Participants in community demonstrations	X	x		Random
Vertrees et al.	1989	CA	2107	Home- and Community-Based Waiver participants	X	x		Universe with comparison group
		GA	1241	Home- and Community-Based Waiver participants	X	x		Universe with comparison group
Weissert et al.	1997	AZ	20361	Participants in capitated Medicaid long-term care program	X	x		Compare universe to national data

Three of the four studies found that Home- and Community-Based Waiver Programs did not, for the most part, prevent or delay nursing home admission for program participants compared with comparison or control groups. The programs did not, therefore, reduce system costs. Using multivariate regression analysis, Kemper et al., 1986, found that control group members entered nursing homes at the same rate as members of each of the two treatment groups. Kemper et al., 1987, found that in five of the six demonstration programs, participants entered nursing homes at the same rate or less often than the control groups, but those differences were not significant. However, in South Carolina, participants in the demonstration program entered nursing homes at a significantly lower rate than controls. To see if this trend was sustained, researchers conducted the same analysis three years later, and found significantly lower nursing home use at this time as well. In terms of cost, most of the programs increased costs to the system overall, while the South Carolina program broke even. Alone of all the programs, the South Carolina program required program participants to complete a nursing home preadmission screen and qualify for admission. Thus, it appeared that strict targeting of services to individuals with significant likelihood of nursing home placement might explain the difference. Similarly, Vertrees et al., 1989, found that while the costs per participant in both California and Georgia were significantly lower than the costs per nursing home resident, neither of the programs prevented nursing home admission for some of their participants. Thus, from a systems perspective, neither program was cost neutral.

Weissert et al., 1997, by contrast, estimated that Arizona saved over \$4.6 million by substituting home- and community-based services for nursing home care, or more than 35 percent of nursing home costs. In the Arizona Waiver Program, eligibility for home- and community-based services was very tightly controlled, with approximately 15 to 20 percent of applicants denied entry into the program each year owing to insufficient medical or functional need. In addition, the cost of the first three months of nursing home care was covered by the acute care managed care system, and thus Home- and Community-Based Waiver applicants had to demonstrate the need for at least three months of nursing home care to be eligible for participation in the Waiver. This meant that participants in this program would have been highly likely to enter nursing homes without home- and community-based services. This probability changed the cost-effectiveness ratio for this particular study.

In summary, it appears that while the Waiver Programs all cost less per participant than nursing home care, the impact of home- and community-based services on the prevention of nursing home admissions was negligible unless Waiver services were highly targeted to individuals most likely to enter nursing homes. On the other hand, most of these studies also examined the impact of home- and community-based services on quality of life and satisfaction outcomes, and found significant differences between treatment and control or comparison groups, with treatment groups experiencing better outcomes.

### **Comparing Home- and Community-Based Service Costs to ICFs/MR or Institutional Costs for People with Mental Retardation and Developmental Disabilities**

Two studies in Minnesota examined differences in cost between home- and community-based care and institutional care for people with mental retardation, developmental disabilities, and related conditions. In contrast to the programs described above, these were evaluations of programs that were implemented to move people out of (rather than avert or substitute for entry into) institutions. Therefore, there was no need to estimate which of these individuals would be likely to move into an institution—the nature of the program itself meant that the individuals met the criteria for institutional care.

Stancliffe and Lakin, 1998, conducted a study of 116 people with mental retardation and related disorders who moved from institutions to the community through the Minnesota Home- and Community-Based Waiver Program. The experience of this group was compared with that of 71 individuals who remained institutionalized. The institutionalized sample lived in large state-operated ICFs/MR, while the Waiver sample lived in smaller ICFs/MR or households/group homes financed by the Waiver Program. There was no significant difference in demographic or functional characteristics between the community sample and the institutionalized sample. Data for the cost analysis were derived from state-funded residential and day program expenditures and individual contributions made from personal income, SSI, SSDI, and state-administered room and board supplements.

Hewitt et al., 2000, also conducted a study of the Minnesota Home- and Community-Based Waiver Program, using data from Medicaid cost reports on institutional and Waiver services, as well as Medicaid state plan services. Data were analyzed for 6,548 individuals with mental retardation and/or developmental disabilities, a universal sample of both institutional and community-based program participants.

Study	Year	Loc.	Sample size	Study Population	Disabilities			Sampling Method
					Phy<65	Phy>65	Cog.	
Hewitt et al.	2000	MN	6548	Institutionalized and HCBS Waiver community residents			x	Universe
Stancliffe and Lakin	1998	MN	116	Institutionalized and community residents			x	Comparison Group

Both studies found that the costs of serving people in the community were significantly lower than the costs of serving people in institutions. Stancliffe and Lakin, 1998, found that institutional costs were 36.4 percent higher than community residence costs. Through regression analysis, they found that individual characteristics, including the level of impairment, predicted neither staffing patterns nor expenditures. This was important because staff wages and benefits typically constitute 82 percent of expenditures in institutions or community settings for people with mental retardation (Stancliffe and Lakin, 1998). In this study, the direct care staff-to-client ratios in the community were higher than in the institutions, suggesting that the community programs were less expensive without sacrificing client care.

Hewitt et al., 2000, found that Home- and Community-Based Waiver Program costs/person/year were 78 percent of institutional costs/person/year, but rose in proportion to the individual's level of disability. The study report also noted that as the number of people living in large state institutions declined from 1,022 to 72 between 1992 and 1999, residents remaining in the ICFs/MR tended to have more serious health-related needs than others.

***Comparing the Costs of Consumer-Directed Health Care with Agency-Directed Health Care***

Two studies examined difference in costs between consumer-directed and agency-directed health care services. The first was a small study of family caregivers of individuals with cognitive disabilities who used a direct-pay system for obtaining in-home respite in California, while the second was a large-scale study of the Cash and Counseling Demonstration project in Arkansas. The Feinberg and Whitlatch, 1998, study used cost data from the respite program to conduct the cost analysis, and did not look at expenditures for other health care services. The expenses of in-home respite care for the families who used the consumer-directed model were compared with expenses for in-home respite for families who used an agency-directed model.

Dale et al., 2003, conducted a comprehensive cost analysis of the Cash and Counseling program in Arkansas, based on Medicaid claims data. Expenditures for the treatment group, who received Cash and Counseling services, were compared with expenditures for a control group over a 12-month period. A second 12-month period was examined for approximately half the sample who were “early enrollers” in the demonstration.

Study	Year	Loc.	Sample size	Study Population	Disabilities			Sampling Method
					Phy<65	Phy>65	Cog.	
Feinberg and Whitlatch	1998	CA	168	Caregivers of adults with disabilities			x	Universe
Dale et al.	2003	AK	2008	Participants in Cash and Counseling demonstration	x	x		Universe

Feinberg and Whitlatch, 1998, found that there was no significant difference between the consumer-directed group and the agency-directed group in expenditures for in-home respite. The consumer-directed group received significantly more respite hours per month than the



agency-directed group, but this was offset by lower costs per hour for the consumer-directed group.

Dale et al., 2003, found that the expenses for personal assistance were twice as high for Cash and Counseling participants as for the control group, largely because the control group did not get the services they were authorized to receive. Among control group members who were new to the program, 50 percent did not receive any of the personal assistance that they were authorized to receive, compared with only 8 percent of the newly enrolled Cash and Counseling participants. In the first 12 months of the program, the increased costs for personal assistance among demonstration participants was partially offset by reduced costs for nursing homes, home health, and inpatient hospital care. After two years, however, the difference in cost between the treatment and control groups was insignificant. By reducing institutional and acute medical care, the Cash and Counseling demonstration managed to increase the availability of personal assistance services for both older and younger adults with disabilities without changing the overall cost of care.

### *Substitution of Formal Care for Informal Care*

Despite research documenting the distress and hardship that informal care creates for the many, mostly female, family members who provide this care,<sup>3</sup> one policy concern about providing financial assistance for community-based long-term supports is that the individuals who provide free care will reduce their services once paid care is available. This concern is raised most frequently in regard to programs that allow family members to serve as paid caregivers. We identified two studies that addressed this issue. The 1986 study by Kemper et al, described above, examined the role of informal caregivers among two treatment groups—those who received case management services and those who received case management and additional long-term support services—compared with control groups.

The second study, Cohen et al., 2000, examined the experiences of informal caregivers of adults with private long-term care insurance once the long-term care insurance took effect. Samples

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<sup>3</sup>Cohen, Feinberg, and Whitlatch (2002) found the prevalence of depressive symptoms among family caregivers was very high in both the agency- and consumer-directed models.

were derived from eight of the largest long-term care insurance companies in the country, and interviews were conducted with both consumers and caregivers. Consumers had to be at least 65 years old, live in the community, and have a policy that covered both home care and nursing home care. The table below summarizes key features of these studies.

Study	Year	Loc.	Sample size	Study Population	Disabilities			Sampling Method
					Phy<65	Phy>65	Cog.	
Kemper et al.	1986	10 states	6326	Participants in Channeling demonstrations		x		Random
Cohen et al.	2000	National	424	Informal caregivers, privately insured		x	x	Sample*

\*Did not say how the insurance companies selected their samples.

Both studies found that people who lived in the same household as the consumer provided most informal care. Kemper et al., 1986, found that the amount of informal care provided to individuals in the two treatment groups did not differ significantly from the amount of care provided to individuals in the control group. The treatment group that received both case management and enhanced community-based services received slightly less assistance from nonhousehold members than control group members, but the difference was not significant.

Cohen et al., 2000, found that the majority of informal caregivers of privately insured individuals were spouses of the consumer, and that while two-thirds of caregivers reported no reduction in the level of informal care provided once paid care was available, this was less true of adult children who were caregivers. Formal care did not substitute for informal care based on severity of disability. Cohen et al. also found that the burden on caregivers was significant. Nearly two-thirds of caregivers reported that their caregiving affected their ability to work. However, the presence of paid care reduced the level of stress for 66 percent of caregivers.

### ***Summary***

While satisfaction and quality of life were markedly improved for individuals with disabilities who moved from institution to community care and from agency-directed services to consumer-directed services, findings concerning other outcomes were more mixed. Cost-effectiveness of

consumer direction was particularly hard to document, except in cases where it is easy to demonstrate that the alternative would be institutionalization.

It is important for policymakers to consider cost-effectiveness in the context of quality of life and the ability of a program to meet client needs. If the Arkansas Cash and Counseling demonstration cost more than the alternative because more than half of the control group did not receive the agency-directed services for which they were authorized, does that make agency-direction the better model because it costs less? This question is posed rhetorically here, but the same issue emerges in other cost studies. A parallel question emerges from studies that looked at supplementation of unpaid by paid care. While paid care may create a minor substitution of paid for unpaid care, the research shows that the substitution effect is insignificant where it appears at all, and the quality of life benefits are substantial. Thus, here too, minor differences in cost may be balanced by differences in effectiveness, if the latter is defined to include areas in which quality improvements were seen.

## VI.

### **Lessons Learned About Implementing Effective Reforms and Strategies**

#### **A. Barriers to Implementation**

Most of the information discussed below came from key informant interviews conducted in the winter of 2003–04 and from the policy research literature. Not surprisingly, informants had a wide range of insights to share on barriers to implementation of health reforms.

##### *The Institutional Bias of Medicaid*

Key informants repeatedly cited a bias in favor of institutional care in Medicaid regulations and program implementation. In fact, individuals with long-term care needs could receive Medicaid benefits only by entering an institution until the 1980s, when states were first permitted to develop HCBS Waiver Programs for people at risk of institutional placement or offer personal care as a state plan service. From 1990 through 2002, the percentage of total Medicaid long-term care expenditures allocated to community-based services nationally grew from 13 percent to 30 percent (Crisp et al., 2003). That means the allocation of Medicaid funds for community-based services and supports is still less than one-third of the allocation for institutional care.

In fact, as informants pointed out, the underlying assumption of institutional care as the baseline model still survives in the requirement that states demonstrate cost neutrality before they can receive CMS approval for HCBS Waiver Programs that allow for community-based long-term care. States must also demonstrate cost neutrality to obtain the 1115 Waivers that allow people with disabilities to receive cash allowances or budgets to manage their own care or hire relatives as caregivers. Key informants cited the complexity of measuring cost-effectiveness, noting (1) limits on the availability and flaws in the reliability of cost data, (2) hidden and hard-to-measure costs of the current system related to unfilled service needs, (3) the inconsistent application of measures across programs and states, and (4) the overall expectation of immediate cost savings. On the other hand, no state has to demonstrate cost neutrality in order to cover care in a nursing home, developmental center, or ICF-MR. As one informant said, “It’s hard to

operate programs as flexible as Cash and Counseling and Self-Determination in an environment as rigid as Medicaid. In fact, everything we do in these programs is a trick to get around the fundamental nature of Medicaid.”

Finally, the nature of HCBS Waiver Programs is that they are generally age- or disability-specific. For example, HCBS Waiver Programs may be targeted to older adults, younger adults with physical disabilities, people with developmental disabilities or traumatic brain injury, or people with AIDS. Thus, the possibility of offering consumer-directed personal care services to people across the lifespan and spectrum of disability requires either a whole series of Waivers, or a state plan amendment that offers a model of personal assistance that can accommodate varying levels of interest and capacity to self-direct. Several key informants acknowledged that CMS has taken some steps to address this institutional bias through a variety of initiatives.

### ***Labor Supply and Quality***

The shortage of direct care personnel in the long-term care system is a major issue across the spectrum of services: institutional, agency-based, and self-directed. Consumer informants related many stories of difficulties encountered in their efforts to find dependable personnel. In part, this shortage reflects the economics of the long-term care marketplace. Wages for direct care workers are among the lowest in any industry. Different sectors of the long-term care delivery system find themselves in stiff competition for a limited supply of labor, and payment rates for consumer-directed workers are often at the low end of the spectrum. When qualified staff is available (aside from consumers’ own family or friends), it is often difficult to retain them given the lack of advancement opportunities and persistently low wages. Many direct care workers are employed without health insurance or other benefits that most American workers need and expect.

With the supply of direct care workers clearly documented as inadequate to meet current demands, demographic trends as the baby boom generation ages will only exacerbate this shortage. A number of informants expressed the opinion that the sheer demand for personnel and the inadequacy of traditional supply to meet this demand will promote consumer direction,

with its capacity to draw consumers' families and friends into the workforce, as a response based on expediency, if not principle.

### *Fiscal Issues*

Fiscal issues that impede implementation of consumer-directed or -oriented health care include the following:

- State budget constraints and the imperative felt by state governments to reduce service costs immediately;
- The front-end expenses involved in the design and implementation of new programs;
- Concerns about the “woodwork” effect when new services are offered; and
- Gaps in the community long-term care infrastructure that inhibit consumer-directed care.

### *Fiscal Uncertainty*

A number of key informants cited the uncertainty of federal budget priorities, the general economic climate, and stresses on state Medicaid budgets as major barriers to advancing-consumer oriented reforms and consumer-directed services. Consumer informants illustrated this concern by telling personal stories. For example, a mother of a child insured by Medicaid and enrolled in a Waiver Program related that the personal budget determined for her child was originally set at an amount that was less than the cost of caring for her child in an institutional setting, but allowed her to obtain the personal assistance she needed to augment the care she and other family members could provide. At the time of the interview, she had just been advised that the total budget for the care of her daughter was about to be cut in half due to a state initiative to “rein in” Medicaid spending.

Medicaid, in addition to being the primary payer for health care services for low-income people with disabilities, serves as a safety net for adults and children with disabilities who buy in to Medicaid for supplemental coverage of services and supports not available through other

insurance. Consumer key informants related the serious psychological impact that any threat or actual reduction of Medicaid coverage has on people for whom alternative options do not exist.

### *Start-up Costs*

Many key informants, particularly researchers and program administrators, discussed the need to invest resources to design, implement, and evaluate consumer-directed programs and services, and the challenge that this presents. At a minimum, programs for people with long-term care needs require the same investment of resources as program initiatives for the general population. More often, they require higher levels of staffing and other resources, owing to the inherently complex needs of the populations.

The prevailing approach of public and private agencies is to serve the greatest number of people at the lowest possible cost. When state and federal administrators are faced with setting priorities in the context of fiscal realities, the relative rate of return for populations that may benefit from the initiatives at issue here is small compared with initiatives targeting the broader population without long-term care needs. In addition, one informant suggested that many states view experimentation with alternative programs as too burdensome an undertaking and feel they do better to stand by and learn from other states' initiatives.

### *Unmet Needs—Expected Woodwork Effect*

An often-cited barrier to the development of consumer-directed programs is the concern that they will open up a floodgate of demand for services, thus increasing overall cost to the system. There is an underlying assumption that the current system does not meet the community-based long-term care needs of people who require these services. Many individuals rely on families and friends to remain in their homes and communities when the more formal, provider-driven support structure is insufficient or fails them. It is a widely held belief that the promotion of consumer-directed care will force provider and payer systems to acknowledge the role of unpaid family and friends in the provision of care and to provide reimbursement and other supports for that role. As one informant said, "States offset costs by maintaining the status quo of unmet need."

### *Infrastructure Inadequacies*

Reliable and fully accessible support services such as transportation, meal preparation and delivery, and housing are essential to individuals with disabilities who want to live in the community but have significant ADL or IADL needs. These services are part of the community infrastructure that makes consumer-directed care feasible. Many informants relayed instances in which the lack of support services minimized or completely prevented their participation in consumer-directed options. The promotion of consumer direction undoubtedly adds to the demands on already stressed and inadequate support systems.

### *Provider Resistance*

Consumer direction represents a divergence from the traditional strategies for safeguarding the health and safety of consumers, handing responsibility that used to belong to professional providers over to the consumer and nontraditional caregivers, including family members and friends. Some institutional providers and home care agencies argue that independent caregivers pose significant safety risks that must be addressed in consumer-directed models. In addition, some provider organizations argue that the consumer-directed movement is taking patients away from traditional care settings, such as home health agencies, and thus threatening their viability. Overall, there is significant resistance and distrust within many traditional provider organizations toward consumer-directed models of care for individuals with disabilities.

Institutional opposition to consumer direction often emerges in terms of presumed health and safety risks of consumer-directed care for all consumers, especially consumers with cognitive disabilities. One key informant expressed concern about who would be held responsible and what actions would be taken if a consumer employed a personal care assistant more often to accompany him/her to the movies than to assist with health-related ADLs. In an agency-directed model of care, this choice would not arise. Other informants argued that simply having a choice might in fact contribute to higher overall quality of life.

### *Consumer and Caregiver Education and Skill Building*

All models of consumer-directed care assume a transfer of responsibility and risk from provider organizations to the consumer and his/her caregiver. Consumer understanding of the options



available within consumer direction and the associated responsibilities are critical to the advancement of responsible consumer-directed care. Consumers must be able to understand their options and be aware of support available to assist them in managing their choices. The absence of education and skills training can be a significant barrier to consumer-directed care.

While many individuals with disabilities have a strong interest in gaining more control over their health care services and engaging in consumer-directed care, many do not have the information, experience, or skills needed to set goals, develop care plans, and take responsibility for hiring, training, supervising, and monitoring staff. Cash and Counseling programs, for example, require consumers to hire and fire, supervise, develop schedules, manage budgets, and determine the delivery of care. Many consumers have no previous experience with such tasks and need basic skills training before they can effectively assume responsibility and fully participate in consumer-directed care programs. In addition, consumers need to be apprised of the full range of their options for care before they can be expected to make optimal choices. One informant commented, “Individualization should not be limited to what a person says they want; they need to know what is possible.”

Caregivers, often family and friends of consumers who provide care independent of any formal arrangements, assume different levels of responsibility across the many manifestations of consumer-directed care models. They, too, need orientation and skills training to care for an individual with a disability through a consumer-directed model of care.

Key informants identified the general lack of orientation and awareness among long-term care providers as a barrier to consumer direction and home- and community-based alternatives. One key informant described an experience that is common among people with disabilities, who often learn about management and self-care *after* an adverse event occurs. For example, consumers and their caregivers may learn self-management and prevention for pressure sores or urinary tract infections after acute care episodes rather than as part of their orientation and training for consumer-directed care.

### *Lack of Common Definitions*

According to many of the key informants, the absence of good outcome or cost data is a barrier to the expansion of consumer-directed care. The inconsistency with which terms are used and concepts defined across disability groups and service systems contributes to this situation. Although consumer-directed care is applicable across the spectrum of disabilities, the language used to capture the concept of consumer direction varies among disability groups.

First, the term “consumer-directed care” is defined and understood in various ways. As a result, programs are designed and implemented differently with different objectives. In reviewing the literature and conducting key informant interviews, the terms “consumer-centered care,” “person-centered services,” “self-direction,” “personal care assistance,” and others were sometimes used as synonyms for consumer-directed care, and sometimes as distinct terms. People using these terms assume their applicability to certain groups of disability or age categories.

There is also lack of clarity and, in some cases, outright debate among key stakeholders, including policymakers, program directors, and consumers, about which segments of the population should be defined as having a disability. Even within disability groups there is disagreement about the specific conditions that should be included. Some consumers feel stigmatized by being labeled “disabled” and reject services targeted for people with disabilities. Many individuals with arthritis, for example, resist identifying themselves as people with disabilities and accepting specialized services even if their functional needs are similar to those of individuals whom they would identify as disabled.

As a result of variation among programs in their definitions and disability inclusion criteria, research comparing program outcomes is particularly challenging. Policymakers and researchers struggle to find commonalities between programs that allow for meaningful analysis. A key informant stated, “The poor definitions, notions, and organization of consumer direction and the implicit assumption that the notions are antithetical to one another impede intelligent discussion and research on the matter.”

### *The Need for Reliable and Meaningful Outcome Measures*

Several key informants stressed that measuring outcomes for those enrolled in consumer-directed programs is both challenging and highly subject to interpretation. First, there is debate about the outcomes that are most important to measure through such research. Second, enormous variation in design of programs, populations served, level of consumer interest, and outcomes measured makes it difficult to identify best practices in consumer-directed care. Very specific challenges arise in relation to measurement of consumer satisfaction, the most frequently assessed outcome of care. Consumers may be fearful that if they complain about the services they are receiving their services will be “taken away” or negatively influenced in retribution. One informant stated, “In so many instances, people have such limited life experience and such low expectations, they are satisfied with programs that can really stink.” It is difficult for programs to identify areas for improvement or gauge if the services are actually meeting enrollees’ needs under such circumstances.

## **B. Facilitators of Implementation**

It was easy to elicit information about barriers to implementation. Key informants, many of whom struggle consistently with challenges in this field, were less prompt to identify facilitators. However, several factors were mentioned that have facilitated or are expected to promote consumer-directed care.

### *Federal Initiatives*

Several new federal initiatives may spur the implementation of consumer-directed and -oriented care:

- Streamlining of the Waiver process and improved communication with states through Independence Plus;
- Real Choice Systems Change and Medicaid Infrastructure Grants; and
- The proposed Money Follows the Person Rebalancing Initiative.

CMS has implemented the Real Systems Change Grant Initiative to help states implement community-based care systems through partnership with community organizations. These grants support the development of programs that enable individuals to move out of institutions into the most integrated community setting appropriate to their individual needs and preferences. Real Systems Change programs also offer consumers choice in regard to living environments, care providers, the types of services they use, and the way these services are delivered (CMS Web site, 2004). This is the first major federal initiative to support consumer-oriented and -directed care across the spectrum of disability and across the lifespan, and as such facilitates the implementation of new community-based care systems.

The joint support of CMS and the Administration on Aging of Aging and Disability Resource Centers in 16 states is intended to help those states develop “one-stop shopping” programs. These programs, which work at the community level to help people make informed decisions about their service and support options, serve as the entry point to the long-term care system. Eligible populations for these programs include people over 65 and at least one additional population (such as people with serious mental illness, developmental disabilities, or physical disabilities). Funds can be used to coordinate or redesign information systems, to provide consumer education, or to facilitate access to care across multiple federal, state, and local programs (CMS Web site, 2004). This program has the potential to address some of the consumer education barriers to community-based care, and it also begins to break down some of the age-related barriers to care.

#### ***Foundation Support for Pilots, Demonstrations, Start-up Costs, and Evaluation***

As mentioned previously, foundations have provided significant financial support for pilot projects, multistate demonstration projects, start-up costs for new initiatives, and program evaluation. Of particular note is the role of the Robert Wood Johnson Foundation (RWJF). RWJF funded the pilot Self-Determination program in New Hampshire, and then expanded the pilot to create demonstration initiatives in more than two dozen states. RWJF was also instrumental in working with CMS and contributing financial support to the Cash and Counseling Demonstration. Other consumer-directed and -oriented initiatives have received

start-up funding with foundation grants, and foundations play an important role in funding program evaluations.

### ***Advocacy and Policy Leadership***

Systems change requires leadership, and leadership has been an important factor in promoting consumer-directed and -oriented care. Often the leadership has come from disability advocates working in partnership with policymakers in a particular state. These partnerships have been important in overcoming the many barriers to implementation mentioned above. Less frequently, policymakers are the leaders and work to develop partnership with consumer advocates. While not the norm, this is, in fact, what happened in at least one of the Cash and Counseling Demonstration states.

### ***Research and Evaluation Results***

The results of research and program evaluations such as those described earlier in this report are invaluable in promoting consumer-directed and -oriented care. Faced with financial barriers, provider resistance, and widely held concerns about safety and quality, proponents of consumer-directed and -oriented care need all the evidence they can muster to address the myriad issues that arise in efforts to change delivery systems. Satisfaction, quality of life, and consumer empowerment outcomes are a very important foundation for these efforts. But perhaps more important, research documenting the comparative safety of consumer-directed care, the maintenance or improvement of health status and function, and the lack of substitution effects can be powerful facilitators and agents of systems change able to confront the prevailing interest groups or public impressions that impede change.

## VII.

### **The Role of Federal Agencies in Promoting Research**

Federal agencies play an important role in promoting research on consumer-directed and consumer-oriented health care. The Centers for Medicare and Medicaid Services, the Office of the Assistant Secretary for Planning and Evaluation, and the National Institute on Disability and Rehabilitation Research play leading roles in this area. What follows is an account of federally sponsored outcomes research, as well as some of the major current policy research initiatives. Please note that this is not an exhaustive list of all research in this area, as some research activities are not publicized until the results are final.

#### *National Institute on Disability and Rehabilitation Research (NIDRR)*

NIDRR, a branch of the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education, sponsors demonstration projects and research related to disability (NIDRR Web site, 2004). NIDRR recently funded a study on the availability and quality of personal assistance services for people with disabilities provided by formal and informal caregivers (Rey, 2003). In January 1999, NIDRR also committed \$1.6 million to a four-year project to support the National Resource Center on Supported Living and Choice for People with Mental Retardation and Developmental Disabilities at Syracuse University in New York. The resource center will document innovative policies and practices in the areas of self-directed support services, self-determination, self-advocacy, ownership of a home, and participation in the community (NIDRR Web site, 2004). NIDRR has sponsored several small studies of consumer-directed care (sample sizes under 120), including the following:

- A study that explored satisfaction among individuals with physical disabilities who were receiving consumer-directed personal assistance services (Beatty et al., 1998);
- A study that examined choice of health plan by people with mobility impairments (O'Day et al., 2002); and

- An evaluation of level of empowerment, consumer contacts with family, cost, and degree of community integration among deinstitutionalized individuals with disabilities (Stancliffe and Lakin, 1998).

### *U.S. Department of Health and Human Services*

DHHS has broad national responsibility for promoting and protecting the health of American citizens, with a particular focus on vulnerable populations (DHHS Web site, 2004). DHHS subdivisions have funded most of the federally sponsored studies of consumer-directed health care. One was a major study that examined differences in outcomes between people who received agency-directed long-term care and people who directed their own in their levels of consumer control, satisfaction, and unmet needs. Subdivisions of DHHS that are active in this field are listed below, with a description of their research activities in consumer-directed health care for people with disabilities.

*Centers for Medicare and Medicaid Services* oversees the Medicare and Medicaid programs, SCHIP, the Health Insurance Portability and Accountability Act (HIPAA), and many of the New Freedom Initiative programs (CMS Web site, 2004). CMS has supported the following evaluations of consumer-oriented care:

- The National Evaluation of the Medicaid Home- and Community-Based Services Waiver Program, which measures the impact of Waiver Programs on quality of life, quality of care, utilization, and cost (DHHS Report 100-97-0019, 2001);
- The evaluation of the Medicare Coordinated Care Demonstration, which implements disease management and case management strategies in an effort to improve outcomes for individuals with chronic conditions (CMS Web site, 2004);
- Evaluations of utilization of outpatient services, level of control or empowerment, satisfaction, change in health status, unmet needs, and caregiver burden in health care programs for individuals who are dually eligible for Medicaid and Medicare (Kane et al., 2001, 2003);
- An evaluation of the level of control or empowerment, satisfaction, and unmet needs in Medicare managed care nursing home residents (Kane et al., 2002);

- An evaluation of utilization, satisfaction, cost, quality of life, changes in health status, and feasibility of CMS’s End State Renal Disease managed care demonstration (Dykstra et al., 2002); and
- An evaluation of PACE that measured utilization of outpatient services, hospitalizations and nursing home admissions, satisfaction, consumer and caregiver quality of life, and changes in health status, functional status, and mortality of PACE enrollees (Chatterji et al., 1998).

CMS also maintains a repository of Promising Practices in Home- and Community-Based Services in order to help states improve services for people with disabilities (CMS Web site, 2004).

*The Office of the Assistant Secretary for Planning and Evaluation (ASPE)* is the principal advisor to the Secretary of DHHS and “is responsible for major activities in the areas of policy coordination, legislation development, strategic planning, policy research and evaluation, and economic analysis” (ASPE Web site, 2004). The Office of Disability, Aging and Long-Term Care Policy (DALTCP) within ASPE evaluates many of the DHHS programs that serve individuals with disabilities. ASPE- and DALTCP-supported outcomes studies include the following:

- An evaluation of the Channeling Demonstration (Kemper et al., 1988) that measured the comparative costs of community versus nursing home care, quality of life, and burden experienced by caregivers of individuals who received community-based care;
- A study of choice of plan, caregiver burden, and caregiver characteristics among informal caregivers of elders with disabilities and long-term care insurance (Cohen et al., 2000);
- A study that measured quality of life and ability to “age in place” at an assisted living facility (Phillips et al., 2000);



- An evaluation of the California in-home supported services program, the largest consumer-directed personal assistance program in the country (Benjamin et al., 1999, 2000);
- A study comparing the outcomes of consumer-directed and agency-directed care in three states (Doty et al., 1996); and
- Studies to evaluate process and outcomes of different aspects of the Cash and Counseling demonstration project (Foster et al., 2003; Mahoney et al., 1998; Phillips et al., 2003).

*Administration on Aging (AoA)* is one of the largest providers of home- and community-based care to the elderly in the United States (AoA Web site, 2004). AoA jointly funds the Cash and Counseling program and evaluation along with the Office of the Assistant Secretary for Planning and Evaluation and the Robert Wood Johnson Foundation (Cash and Counseling Web site, 2004). The Cash and Counseling Demonstration has been implemented in three states (Arkansas, New Jersey, and Florida), and an additional \$7 million grant has recently been approved that will expand the program into as many as ten more states (Cash and Counseling Web site, 2004). AoA is currently collaborating with CMS on a grant program that promotes consumer-oriented, coordinated, long-term care (see Collaborative Efforts section below).

*Administration on Developmental Disabilities (ADD)* is the federal agency accountable for implementing the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), which calls for ADD to involve individuals with developmental disabilities in the planning and design of health services and to ensure that these individuals receive the necessary services and supports (ADD Web site, 2004). To our knowledge, ADD has not sponsored research on outcomes of consumer direction.

*Agency for Healthcare Research and Quality (AHRQ)* is the health services research arm of DHHS. AHRQ describes its mission as improving, “the quality, safety, efficiency, and effectiveness of health care for all Americans” (AHRQ Web site, 2004). AHRQ has sponsored conferences at which experts from different disciplines have explored patient-centered teams and models of care that are sensitive to consumer preferences and expansion of consumer choice

(TRIP Web site, 2004; AHRQ Web site, 2004). AHRQ also funded an outcomes study that examined the impact of Consumer Assessment of Health Plans (CAHP) performance information on choice of health plan by Medicaid beneficiaries (Farley et al., 2002). However, this research was not focused on the health care of people with disabilities.

*Substance Abuse and Mental Health Services Administration (SAMHSA)* is responsible for improving the quality and availability of services for individuals with mental illness or substance abuse (SAMHSA Web site, 2004). The Center for Mental Health Services (CMHS), which operates within SAMHSA, funded the Consumer-Operated Services Program Multi-Site Research Initiative, which examined the outcomes of consumer-operated services for people with mental illness. These services included “drop-in centers, peer counseling, advocacy, training, peer support groups, and vocational and housing programs” (BU (Boston University) Web site, 2004). This study measured “the level of empowerment, housing, employment, social inclusion, satisfaction with services, costs, and cost-offsets” (BU Web site, 2004). This project has not yet produced published results.

*Health Resources and Services Administration (HRSA)* has as its mission the improvement of access to quality health care for all Americans (HRSA Web site, 2004). Within HRSA, the Maternal and Child Health Bureau sponsors demonstration and evaluation projects to improve care for children with special health care needs. Some of the major areas of interest include care coordination, development of medical homes, and managed care for children with special health care needs. Although we found many policy reports and case studies related to these topics, there were few published outcome studies.

### ***Congressional Budget Office (CBO)***

The CBO supports the U.S. Congress by providing analyses needed for economic and budget decisions (CBO Web site, 2004). While CBO conducts cost analyses in various areas of health care, including mental health parity and expanded access to health services (CBO Web site, 2004), the agency does not have a major presence in research around health care.

### ***Congressional Research Service (CRS)***

CRS is another support agency to Congress that provides research and analyses on all legislative issues (CRS Web site, 2004). CRS has looked at long-term care policies in ten states to provide background information and analyses of the different systems to help Congress make informed decisions regarding long-term care policies (Walters et al., 2003). CRS also examined trends in institutional care and home- and community-based care for individuals with disabilities, as well as consumer-directed care under Medicaid and mental health parity (Penny Hill Press Web site, 2004). These studies are reports of trends in the field rather than outcome studies.

### ***Government Accountability Office (GAO)***

GAO is the audit, evaluation, and investigative branch of Congress (GAO Web site, 2004). GAO has produced several reports that provide background and trend information on consumer-directed care and look at several key features of these models, such as case management and cost. GAO research in this field has focused more on policy issues than outcomes.

### ***National Institute of Mental Health (NIMH)***

NIMH is an arm of the National Institutes of Health that funds research on mental health and behavioral disorders (NIMH Web site, 2004). NIMH has funded one outcome study that examined access, satisfaction, and quality of life among adults with different levels of insurance coverage who had substance abuse and mental health problems (Wells et al., 2002).

### ***Collaborative Federal Groups***

The table below lists interagency research collaborations and provides information about which federal agencies *are* or *were* involved, the outcomes they have measured, and the context in which the outcomes were measured.

<b>Federal Agencies</b>	<b>Outcomes Measured</b>	<b>Context</b>	<b>Study</b>
DHHS; ASPE; CMS	Access to health care; access to preventative care; satisfaction of enrollees	Medicaid managed care	Hill and Wooldridge, 2002
DHHS; NIH; NIMH	Cost, access, and quality of mental health and substance abuse services	Managed care	Varmus, 1998
DHHS; CMS; ASPE;	Access to care; utilization of services; medical/behavioral/cognitive and social outcomes	Specialty managed care program for children with special health care needs	Coulam et al., 2000
DHHS; SAMHSA; CMHS; CSAT*	Service utilization; access to mental health and substance abuse services; cost to consumers and health plans	Vermont Mental Health and Substance Abuse Parity Law	Rosenbach et al., 2003

\*CSAT = Center for Substance Abuse Treatment.

Federal agencies also collaborate on other efforts to evaluate consumer-directed health care. The Interagency Committee on Disability Research, coordinated by NIDRR, was created to promote collaboration across federal agencies engaged in disability and rehabilitative research programs. Membership on this committee includes the Rehabilitation Services Administration, the departments of Education, Veterans Affairs, and Transportation, the National Institutes of Health and Mental Health, the Indian Health Services, and the National Science Foundation. CMS, AoA, SAMSHA, ASPE (and RWJF) funded a Consumer-Directed Care Conference in June 2001. This conference gave experts in the field of consumer-directed care an opportunity to share experiences and lessons learned in the implementation of different models of consumer-directed care. AoA and CMS are also collaborating on a grant program to fund state efforts to develop “one-stop shopping” for the elderly and at least one other population with significant health care needs who use long-term care services in the community (AoA Web site, 2004). The programs must provide education and counseling on care options, care coordination, and services to help clients plan ahead for their long-term service and supports needs” (AoA Web site, 2004). As part of this initiative, states are required to evaluate their programs.



## VIII.

### **Recommendations to Policymakers**

The recommendations are divided into two parts: recommendations related to policy and program design and implementation and recommendations related to research. In addition, we offer one core recommendation, applicable to both research and program implementation.

The policy and programmatic recommendations encourage the expansion or replication of strategies that are supported by current research or that are consistent with current research and supported by experts in the field. Few strategies in the area of consumer-directed or consumer-oriented care for individuals with disabilities have been subjected to sufficiently rigorous research to be characterized as “best practices” or “standards of care.” We present this set of recommendations nonetheless, because policymakers and other stakeholders are faced with decisions every day and need to know which of the options available are most likely to be optimal, even when definitive research is lacking.

Recommendations related to research identify strategies to enhance the quality of information available to policymakers, program designers and managers, funders, and the general public as they consider options for consumer-oriented care for individuals with disabilities. In addition to our research recommendations, we have included key informant responses to the question, “If you could fund one research project concerning long-term care for people with disabilities, what is the topic you would look at?” Please see Appendix M for their responses.

The main audience for these recommendations is government at both federal and state levels. Research recommendations may also be relevant to foundations and other research organizations. Program recommendations are relevant to government agencies, private agencies, foundations, policymakers, and program managers.

## **A. Core Recommendation**

Consumers, including both individuals with a full range of disabilities and those who provide their care, have the most direct and immediate stake in recommendations for both research and programs. Informed consumers will most often and most consistently advance the cause of adequate research in this area and demand programs that are shaped by the best available research findings.

One overarching recommendation, aimed at consumer groups, foundations that support consumer advocacy, and government agencies, is the inclusion of consumers representing a wide range of disability perspectives in decisionmaking at every step in the process that ultimately shapes programs: from development and implementation of a research agenda through policymaking to program design, oversight, and evaluation. To make this recommendation meaningful, it is critical that the issue of diversity be understood in its full breadth. Research suggests that options and outcomes vary widely depending on the nature of an individual's disability and on demographic factors such as age, gender, race/ethnicity, and language. An inclusive approach would reflect this broad understanding of diversity and ensure inclusion of a correspondingly broad range of consumer perspectives. It would also include youth with disabilities and parents or caregivers of children with special health care needs in decisionmaking not only about child-focused programs, but also about programs that serve adults and will serve their children in future years. Government agencies to which this recommendation is most directly addressed are those within the Office of Special Education and Rehabilitative Services in the Department of Education; and the Social Security Administration, the Centers for Medicaid and Medicare Services, the Substance Abuse and Mental Health Services Administration, and the Health Resources and Services Administration within the Department of Health and Human Services.

## **B. Policy and Program Recommendations**

### **Establish a locus of responsibility for programs and services related to health and well-being of individuals with disabilities within the federal government.**

The need for such an entity emerged from both the literature review and key informant interviews. The intent here is not a new clearinghouse or interagency council, but rather a focal point for programmatic responsibility in the area of health and well-being of individuals across the spectrum of disability.

Most immediately, this could be the entity to take on the recommendations made above: to convene and staff consensus groups, to provide language related to consumer participation for other agencies to incorporate into their funding announcements, to identify unmet needs and reshape programs to fill those needs. Such an entity does exist in relation to children with special health care needs (the Title V Children with Special Health Care Needs Program in the Maternal and Child Health Bureau of the Health Resources and Services Administration), but it does not exist for adults or elders.

Here again, a reasonable case could be made for adding this central coordinating role to any number of existing federal agencies. After considering different options, we would assign the role to HRSA. In part, this choice reflects the agency's experience with evaluation and focus on vulnerable populations (HIV-infected individuals, low-income families, mothers and infants at risk, and children with special health care needs). Additionally, the agency is responsible for the impact of health programs and policies on the well-being of the overall population. We note that although the agency plays a central role in health care improvement efforts, it does not administer major entitlement programs. From our viewpoint, this is an advantage, since it reduces any real or perceived conflict of interest on issues, which might draw on the resources of an entitlement program to reduce overall systems costs.

In part, this call for a proactive government role in shaping services reflects the finding that the market has not, on its own, created the continuum of services required to meet consumer needs. Shortages of trained personnel, inadequacy of accessible housing, and inadequacy of



health care options in the community may all make community-based services functionally unavailable even to individuals who want them and are theoretically eligible to receive them. A dedicated unit of government could take on these challenges, serving as both a focal point for identification of gaps in services and responsive planning and as a voice for creative thinking in these areas.

**Make response to critical personnel shortages a first order of business for this newly identified unit of government.**

Without competent, affordable community-based caregivers, consumer orientation and direction are meaningless. Widespread shortages already place programs at risk; an aging population will widen the gap between need and supply. Federal agencies should convene a work group to address quantity and quality of available personnel. This group should identify models for recruitment, training, and supervision of personnel, including models that offer consumers a range of roles in each of those tasks.

**Ensure broad consumer representation in program planning and implementation.**

Here again, goals are both to ensure that programs reflect the needs and preferences of consumers with a range of disabilities and to ensure that the process of designing or implementing a new program does not offend consumers to the extent that evaluation is compromised.

**Incorporate opportunities for choice wherever possible, even in institutional settings and certainly in programs that are not explicitly defined as consumer oriented or directed.**

The single finding that emerged most firmly across studies was that consumers feel best about programs and have the most positive outcomes generally when they have real options and can choose the degree or type of self-direction that matches their preferences. Given the variability among models of consumer direction that produced equal levels of satisfaction among those who wanted consumer direction (even the Cash and Counseling programs differed substantially in terms of the nature and extent of self-direction permitted), it may well be that the fact of having choices and having one's choices listened to is an important variable in and of itself.

This recommendation has implications well beyond programs that are explicitly defined as consumer-directed or -oriented health care. Even institutional sites such as nursing homes may offer consumers more or less choice about daily activities, social interactions, living arrangements, food, and exercise. Findings suggest that degree of choice should be considered an important measure of quality in any program model.

**While choice is critical, it should not be advanced at the expense of quality or accountability.**

Flexibility is elevated to a principle here, but with consumers, rather than states or agencies, as the intended beneficiaries. The option to participate in a consumer-directed program should not be traded off against accountability for entitlement programs. If, for example, unnecessary bureaucracy slows the Medicaid Waiver process, that issue can and should be addressed without removing critical safeguards that make coverage available to a broad population of individuals with disabilities.

**Do not build expectations of cost savings into start-up of consumer-directed or -oriented health care.**

While cost saving is always a relevant issue in publicly funded programs, study data suggest fluctuation in the early years of program implementation. In some cases, costs are incurred in retooling programs, retraining staff, recruiting new staff, and recruiting program participants. In other cases, there is an early increase in costs when new models lead to identification and treatment of long-hidden problems. It is logical to expect these start-up and transition costs; new programs should be designed to accommodate them.

One additional point about program costs is that it is important to look not just at savings, but also at allocation of costs as new models are set up. Findings in relation to mental health parity suggest increases in the overall cost of care in start-up years in some cases, but shifts in the allocation of costs from inpatient to outpatient settings. It is also important to note that where total increases were seen in these models, they also reflected increased program penetration rates. In other words, parity permitted treatment of a greater number of patients on an outpatient basis as opposed to a smaller number of patients on an inpatient basis. The values placed on this

trade-off are a matter of public policy; from a technical perspective, the important issue is that the full picture of shifting costs be taken into account.

**Break down barriers and create opportunities for cross-fertilization between narrow and arbitrarily defined disability sectors.**

The apparent failure to study consumer-directed models among individuals with mental health diagnoses, the existence of Title V for children with no equivalent program for adults, the development of the medical home concept for children with no equivalent development in care for adults, and the implementation of PACE models for elders long before equivalents were thought of for younger people with disabilities all reflect the historical impact of narrow, categorical funding streams. Narrow funding streams have often led to the development of discrete industries that provide services to narrowly defined population groups. While some target groups may differ in the nature and extent of services needed, there is much similarity across groups and much to be learned across categories. One role of the government entity suggested above should be the integration of systems of care based on functional needs, so that service needs, rather than diagnosis or age group, drive service options, and lessons learned from the experience of one population group are available to others. But in general, thinking about new programs should start from the premise that programs should be available to people across the disability spectrum and designed with the flexibility to accommodate diverse needs.

**C. Research Recommendations**

There are inherent challenges in researching consumer-directed and -oriented care. The concepts themselves are abstract and relative: there is no such thing in the real world as absolute consumer direction, and there are few care models in which the consumer exerts no control. The programs that seek to operationalize these concepts may have limited funding for evaluation and are often under political or consumer pressure to put new models in place in less time than it takes to conduct good baseline measurement or ensure a good evaluation design. And even with good design, elimination of bias is challenging. It is clearly impossible to randomly assign those who do not wish to control their own services to a program that requires them to control their

services, and equally difficult to eliminate all consumer control over services provided to those who seek autonomy.

The practical impact of research in this field has been limited by these challenges. Furthermore, the field suffers from inconsistent definitions of predictors and outcomes across studies, vague explanation of variables in reports on specific projects, and in many cases, study designs that do not support credible generalization. This makes it difficult to compare findings across studies or to generalize based on specific studies. Recommendations concerning research address these limitations.

The recommendations that follow require the designation and authority of a federal entity responsible for coordinating disability research across the public and private sectors—those that have an explicit role in policy, program administration, and evaluation and those that affect the lives of individuals with disabilities indirectly. A reasonable case can be made for any one of several existing federal agencies to serve as the central entity responsible for coordinating research on disability and health. Our recommendation, based on a review of current missions and research capability, is for this role to be served by the Office of the Assistant Secretary for Planning and Evaluation within the Department of Health and Human Services. The broad mandate of this office, its interest and efforts to date in shaping and conducting research and data policy in this arena make it an appropriate locus for the proposed role—to shape and guide all of the disparate efforts into a coherent research agenda and effort, and apply the knowledge base gained from the research to develop and design policy and the allocation of funds for maximum benefit.

**Create a national stakeholder group to define critical terms in research on consumer-directed and -oriented care, at least for purposes of federally funded research.**

Informants told us forcefully that research would be much more useful, despite inherent challenges, if consensus were achieved around key terms related to consumer-directed care. They called for establishment of a coherent taxonomy that could form the basis for the evaluation of diverse programs serving the broad spectrum of disability.

To that end, a small national work group made up of consumers, researchers, service providers, and government officials should be convened to grapple with terms used to characterize predictors and outcomes in this field. Such terms as “consumer-oriented,” “consumer-directed,” “disability,” “satisfaction,” “personal care assistance,” and “choice” could be addressed, making it possible for researchers to tailor studies to particular interventions while promoting comparability across and clarity within individual studies.

The intent of this recommendation is the development of a set of definitions for use by all federal agencies and federally funded contractors and grantees. It is important to note that the definition of disability crafted through this process is not meant to imply that *all* federal programs must have the same eligibility criteria. Some programs (for example, Supplemental Security Income) may seek to define eligibility narrowly in order to target scarce or costly benefits. What this recommendation does imply is that rather than choose completely unrelated criteria, benefit programs set their eligibility criteria to include a subset of those fitting the broad research definition.

**As a second step, this group or a follow-up group should go on to identify a menu of indicators for each term defined.**

**Develop protocols for federally funded evaluation studies.**

Given clear definitions and meaningful indicators, the next step is to develop guidelines for the design of research in this field. Such issues as the collection of baseline data, the identification of target populations, options for avoiding use of proxy informants, strategies for analysis of data when proxies are unavoidable, and the identification and use of comparison groups could be addressed. Here again, this could be the same or a new group (perhaps with greater research expertise).

Consumer advisors to this project and key informants were both concerned about studies of cost-effectiveness. Protocols guiding the evaluation of federally funded programs should require that costs to consumers, as well as costs to government and other institutional payers, be taken into account in measuring cost or cost-effectiveness of different program models. The overwhelming role of families and individuals in paying for long-term care and the risk of cost-shifting to

families as care moves out of institutional and into community settings makes it particularly critical that research in this area follow well-defined guidelines.

**Cross-disability consumer involvement should be an integral component of program evaluation from the very start.**

The definition of relevant outcomes is not solely a technical matter. It is also a matter of what is subjectively important to different stakeholder groups. Consumers may place different weight on outcomes in different domains, and their priorities may differ from those of other stakeholders. Different consumer groups (e.g., parents of children with special needs as compared with adult consumers) may weight outcomes differently. Therefore, when developing protocols, diverse consumer representation should be part of all stages of program design, including identification of goals and objectives and design of evaluation studies.

Consumer inclusion in research may also minimize adversarial situations that have arisen in cases when consumers who were invited to participate in pilots of consumer direction were then assigned to comparison groups. Several key informants commented on evaluation studies that they felt had limited validity because consumers who found themselves disappointed in this fashion were too angry to fairly assess the services they did receive. Informants suggested that involvement of consumers in the design and implementation of evaluations, while challenging from both logistical and scientific perspectives, could ultimately improve the validity of study findings and outcomes.

**Include measures of quality of life among outcomes studied in program evaluation.**

Consistent with including a consumer voice in the design of research, key informants suggested that funders encourage or require evaluation studies to address quality of life as a key outcome of consumer direction. Several pointed out that satisfaction with services might not capture the full impact of consumer direction. If, they noted, agency-directed services are the only alternative to institutionalization in one community or population studied, there could be a ceiling effect making it impossible to distinguish between satisfaction with *any* community-living option (as compared with institutionalization) and further satisfaction due to a greater degree of control over those services. The solution proposed was that consumers be involved in a process to define

quality of life indicators, and that those indicators be included in research to permit more refined comparison of different models of community-based service.

Further support for this recommendation comes from the observation that health outcomes, which are closely linked to quality of life conceptually and may be of high salience to both consumers and providers, may be so influenced by other factors that outweigh the impact of services (age, disability status, income, long-term work and life experiences, family and social relationships) that they do not reflect important differences that can influence health in the long run. Measuring quality of life may be a way to understand how the individual experiences his or her current environment, which in turn may influence health in the long term.

**Include measures of mental health in evaluation studies on consumer-directed care.**

The literature review revealed no studies that reported data related to the mental health of clients as an outcome of consumer-directed care. Given the important relationship of depression to overall health and well-being (found in the National Health Interview Survey and other health studies) and the significance of depression treatment as a cost to systems, this constitutes a critical gap in current knowledge. Measures of depression and other negative and positive mental health outcomes (ideally defined via a process with consumer input, as discussed above) should be incorporated into future studies across the field.

**Include individuals with primary mental health diagnoses in evaluation studies.**

Here again our findings were absolute: not a single study looked at the impact of consumer-directed care on individuals with mental illness. While this omission primarily reflects the lack of health care interventions targeted to individuals with mental health diagnoses, it is likely that some of those included in studies we reviewed had identified or unidentified mental health conditions. Studies may well have missed an opportunity not only, as noted above, to look at mental health status as an outcome of consumer direction or orientation, but also to look at mental health status as a predictor of the impact of innovative models of care by failing to screen evaluation respondents on mental health status. Given the fragility of deinstitutionalization for mentally ill individuals and the inherent relevance of psychosocial factors to outcomes for this population, it seems appropriate for impact-of-service models to promote new kinds of

psychosocial interaction between caregivers and care recipients with mental health needs to be documented carefully.

**Include children with health care needs and their families in evaluation studies.**

None of the studies identified for this report looked at outcomes of consumer-directed or consumer-oriented long-term care for children, despite intense interest in the implementation of a medical home approach to pediatric care that shares many of the values and some of the strategies of consumer direction. A research taxonomy and protocols for evaluation are needed; ideally, what is done around medical home would be fully integrated with research on efforts to improve care for adults.

**Strengthen the nation's consumer-directed research effort's to include a stronger focus on family.**

Federal agencies' research efforts should recognize America's families, not only in the role of caregivers, but also in the planning, management, and delivery of services and supports sustaining the consumer-directed efforts to empower individuals with disabilities to achieve their potential and enjoy the fruits of their civil rights like other able-bodied citizens.

## **D. Conclusions**

While each of these recommendations may be understood in isolation, there are clearly themes that run through them and have important implications for research and practice in consumer-oriented services for people with disabilities. The themes may be summed up as follows:

1. Services need to be individualized, with consumers offered as much flexibility and choice as is feasible in relation to a given type of care.
2. Services should, wherever possible, be designed to serve individuals with a broad range of disabilities. This flexibility will yield more individualized and therefore better services for individuals within as well as across disability groups.



3. To achieve flexibility and accommodate diversity, consumers with different experiences and perspectives must be included at all stages of program design, implementation, and evaluation.
4. The achievement of these goals requires the designation or establishment of an oversight agency within government, responsible for identifying needs, convening planning groups, and ensuring the broadest possible continuum of service options.

Taken as a whole, these themes and the recommendations they encompass imply a major shift in the way government, private agencies, and even to some extent consumer organizations think about disability. It implies a shift from a narrow diagnosis-focused approach, with a one-size-fits-all (or at best a limited) range of service options to a cross-disability, lifespan approach in which funds are available to meet individualized needs. It implies a shift in the role of government from focused oversight of tightly defined program options to a broader responsibility for ensuring that a set of definitions, protocols, and strategies is available to support the development of a knowledge base in this area, that those tools are used to assess consumer needs on an ongoing basis across disability groups and age categories, that resources are directed to fill gaps in the service continuum, and that the programs meet rigorous evaluation standards for consumer-defined outcomes in domains that include not only direct satisfaction with services, but also quality of life, health, mental health, and function.

## IX.

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## Appendix A.

### Consumer-Oriented Health Care Advisory Board

<b>Name</b>	<b>Disability Type</b>
Charles Carr, Executive Director Northeast Independent Living Center	Physical
Linda Horton St. Hubert AIDS Alliance for Children, Youth and Families	Physical/Chronic Illness
Polly Arango, Parent and Advocate Algodones Associates	Multiple
Owen McCusker, Director Community Living Alliance, ILC	Sensory
Marilyn Rohn, Consumer and Advocate	Mental Health
Denise Payne, Consumer and Advocate	Physical (CP)
Lou Brothers,* Consumer and Advocate	Cancer Survivor
Joe Flores,* State Administrator	Physical
Patricia Osborne Shafer, Parent and Clinician Beth Israel Deaconness Medical Center	Developmental
Peter Thomas, Esq. Powers, Pyles, Sutter and Verville	Physical
Kay Tucker, Consumer and Advocate Crossroads Employment Services	Mental Health

\* Resigned for health reasons



## **Appendix B.**

### **Roles and Responsibilities of the Consumer Advisory Board on Consumer-Oriented Health Care**

- Add value to the process, products, quality, and validity of research offered to the National Council on Disability;
- Offer guidance and relevance to the research process, design, problem-solving, priorities, and direction taken;
- Ensure the integrity of the approach undertaken throughout the engagement;
- Assist with linkages to local and national contacts, networks, organizations, literature, and research;
- Engage in a collaborative partnership at critical intervals of the project during scheduled conference calls and individually as needed;
- Promote co-learning and capacity building among staff and members; and
- Actively participate in the knowledge gained to inform the recommendations to the National Council on Disability to improve the health and well-being of consumers with disabilities.





**Appendix C.1.**  
**NCD National Consumer Advisory Board**  
**Meeting Minutes**  
**June 30, 2003**

**I. Introductions of Members and Staff**

Joe Flores, from Texas, an MSW of 28 years, person with a physical disability, working at the Texas Department of Health.

Denise Payne, wheelchair user, born with CP, a self-advocate from Florida, very involved with Medicare bureaucracy and access to needed equipment.

Charlie Carr, from Massachusetts, founder and Executive Director of independent living center, person with physical disability, involved in access to primary health care for persons with disabilities in managed care systems.

Linda Horton, woman living with HIV in DC, works at the AIDS Alliance for Children, Youth and Families, with a focus on Medicaid.

Marilyn Rohn, person with mental illness from New Mexico, involved in issues of Medicaid and Medicare and Housing, on State Council for Consumer Affairs.

Kay Tucker, from California, a woman with bipolar disorder, very involved with passage of Parity Bill in state and cultural competence, recently attended a conference on evidence-based practices at the California Institute for Mental Health.

Polly Arango, Lou Brothers and Owen McCusker did not participate in the conference call.

The HDWG project team of Carol Tobias, Debby Allen, Kate Brown, Regina Murphy, and Sarah DuRei participated in the call.

**II. Joint Review of Roles and Responsibilities**

Kate Brown read the roles and responsibilities as provided in the package of materials sent to the membership in advance. All members accepted roles and responsibilities as read. An invitation was extended to all members to be in touch with the project team.

### III. Overview of the Project Goals

Carol Tobias provided an overview of the ten-month engagement, explaining the primary focus as the identification of best-evidence practices and to contribute to the knowledge about the factors that facilitate or impede the implementation of these practices. Carol reported on the focus of our research in this phase of the project:

- Laws and regulations that promote consumer-oriented reforms and practices; and
- Current programs and practices that are documented to be effective or show promise, without the benefit of evidence-based evaluation.

Carol provided an inventory of the **reform areas** identified to date and invited the board to add to the list and/or critique those identified. Board members offered the following additional areas:

- Medicaid Buy-In Programs—protection of benefits when returning/maintaining work/income;
- Provider Education on disability and cultural competence (including Dentists);
- Inpatient mental health treatment practices of restraints, medications and seclusion—research on the least restrictive practices;
- The New Freedom Initiative, incorporating *Olmstead*;
- Barriers to health care created by HIPPA;
- Benefits Counseling;
- PCA Payment Reforms;
- Jail Diversion Programs—dual diagnosis;
- Minority Sensitive Programs;
- Micro-Entrepreneurship for self-employed; and
- Mental Health Parity.

Carol then explained our research efforts to identify those reform efforts that have been evaluated with outcome measures identifying those reforms that work or don't work. Carol read a list of identified **reform outcomes (intermediate and long-term)** that “work” and asked the membership to comment on the value of them and once again, offer input. The membership offered the following additional outcomes:

- Improved Self-Esteem;
- Work and Continuity of Work;
- Family and Child Satisfaction and Function;
- Transitional Programs for Adolescents;
- Reduction in Homelessness;
- Healthy Lifestyles;
- Cultural Competence;
- Prison Diversion; and
- Reduced ER/Hospitalizations.

## IV. Review of Preliminary Research Findings

Carol appraised the membership of our findings to date—lots of articles and reports in four general categories: opinion pieces, program descriptions, policy studies (usually qualitative case studies, lessons learned), and outcomes research. Our emphasis and concentration will be focused on the policy studies and outcomes research. Carol listed off the outcomes evidence research directly related to consumer-directed or -oriented care identified to date. She invited the membership to assist with identification of evidence for HIFA, *Olmstead*, Respite, Care Coordination, and medical home—areas the project team has yet to find.

Debby Allen summarized the reforms identified specific to children and families as Home- and Community-Based Waivers (Katie Beckett), Family-Centered Care and Medical Home concepts, and Parent Empowerment/Partnering legislative initiatives.

In the interest of time, the group was advised of the next scheduled call date for December and asked about their interest in meeting sooner. It was unanimously agreed that an interim meeting would prove useful. An October date will be scheduled.

### Follow-up

- Cultural Competence Keynotes, Sergio, UC Fresno and Stanley, UC Davis; Kay Tucker
- UMASS Medical Provider Education Project, Charlie Carr
- National Empowerment Center, Lawrence, MA
- “Double Trouble in Recovery” in Vermont—dual diagnosis, Marilyn Rohn
- New Hampshire Follow-Along Program, Kay Tucker
- San Francisco Peer Counseling and Support Program, Kay Tucker (Pat Deegan)
- Women’s Wisdom Project, Sacramento, Kay Tucker
- Michigan Program for Dual Diagnosis, Linda Horton
- Commonhealth Evaluation, Velvet Miller
- WRAP Program, Marilyn Rohn



## **Appendix C.2.**

### **NCD National Consumer Advisory Board Meeting Minutes November 14, 2003**

#### **I. Introductions of Project and Membership**

In light of new members joining the board since the first meeting, a general overview of the project and brief introductions were made. In explaining the scope of work, it was explained that the HDWG was engaged by the NCD to conduct a study of the research to identify best-practice outcomes or emerging evidence practices regarding consumer direction and consumer orientation; essentially, what is known to be effective, ineffective, why, and how. The distinction between consumer direction (long-term care and supports) and consumer orientation (broad initiatives to expand access such as TWWIA) was offered. In the initial phase of work undertaken since the first board call, the HDWG has conducted a massive literature search to discover the body of evidence-based outcomes, resulting in a limited number. At this time, the HDWG has identified the knowledge, gaps, and conflicting evidence. The primary purpose of the call today is to gain input from the membership on the findings to date and direction of future qualitative research to inform the final product due to NCD.

Two new members, Peter Thomas and Patty Osborne Shafer, began the introductions followed by Polly Arango, Owen McCusker, and the HDWG project team of Carol Tobias, Debby Allen, Kate Brown, and Kate Tierney. Other members who joined the call later included Charlie Carr, Denise Payne, and Kay Tucker. It was noted that Lou Brothers had resigned due to failing health. Also, Marilyn Rohn and Joe Flores were unable to participate in the call.

#### **II. Summary Review of Outcomes Literature**

Carol led a summary review of the outcomes literature and findings in the two major topic areas: long-term care and managed care (See documents). For long-term care, while satisfaction and quality of life are markedly improved for those individuals with disabilities who move from institution to community and from agency-directed services to consumer-directed services, other outcomes are more mixed. However, consumer choice and control improved in all of the consumer direction models, and safety and perceived quality of care never declined. All other outcomes—cost, impact on caregivers, community integration, unmet needs, health status, and access to health care services—met with mixed results.

Owen asked about the defining characteristics of consumer-directed versus agency-directed and suggested that it is important to describe the importance of viewing these distinctions along a continuum. He further noted that one's needs and desires are dependent on an array of variables at any given point in time and explained the ethical and safety concerns and conundrums when advocating for persons desiring consumer-directed services. Patty echoed Owen's point regarding language and terminology and noted the parallels of like concepts and issues when reviewing the medical literature. Patty further enumerated that treating persons with disabilities as a whole group contributed to the lexicon challenges, in that it doesn't allow for distinctions and differences in choices, control, shared decision-making, etc. It was acknowledged that there is a large degree of shared decision-making within self direction. Charlie acknowledged that the "real" differences are between being institutionalized and in the community and having services such as personal assistance versus none.

The discussion turned to discrepancies in defining "good" outcomes—between the researchers and the consumers, in addition to the variability and individuality of consumer interest in/ability with control. In all instances of consumer direction, consumers need to assess what they are being asked to do. The membership concurred with a fundamental principle that consumer involvement in defining the research outcomes is critical.

Peter commented on the inadequate budgets in the Cash and Counseling programs and the lack of incentives for provider participation.

Carol then directed the discussion to the findings of the literature on managed care.

She reported that persons with disabilities have similar experiences in problems accessing care and in delays to getting care with Medicaid and Medicare managed care as experienced in fee-for-services systems of care. In some studies, managed care enrollees had better access to specialists and prescriptions, although other study results indicated better access to care in fee-for-service arrangements. Results were also mixed when reviewing enrollee relationships with providers in managed care.

Regarding consumer choice of health plan and the impact of information provided influencing the choice of plan, the literature indicates that none of the information provided was particularly helpful or useful. In one article, it was not read by over half of the sample. In several studies, cost and prescription coverage influenced choice of enrollment into Medicare HMOs.

Lastly, managed care enrollees in voluntary managed care programs (SSI and dually eligible) were generally more satisfied with managed care, used more outpatient services, and were more likely to report improvements in health status than their fee-for-service counterparts.

In response to the findings reported, a reference to the dismal effect of consumer education was made and the influence of the regulatory environment on this effect—the ongoing tension between regulation and implementation of programs. Charlie commented on the Massachusetts experience involving consumers in the design and implementation of its managed care program

as being critical and successful. Owen cited Family Care of Wisconsin as an example of consumer involvement in the evaluation outcomes of the program. Polly offered the Title V program in Florida as another example of consumer investment.

Carol inquired of Owen whether any evaluations had been conducted on the Partnership. Owen suggested contact with Steve Landkamer of the Department of Health and Family Services in Madison. Carol mentioned the modification of CAHPS for disability populations. Peter asked, “Who are the researchers?” Primary researchers identified include Medstat, Abt Associates, Robert Wood Johnson, ASPE, Urban Institute, Triangle Research, Rand, Kaiser, Mathematica, etc. It was suggested that THE HDWG look at DeJong and Freiden for possible outcomes literature.

### **III. Long-Term Care Initiatives—State-by-State Matrix**

Kate solicited feedback on the usefulness and applicability of the sample LTC matrix provided. Members were interested in receiving more information on the nature of the program initiatives listed. It was also suggested that this kind of information is useful to consumers.

### **IV. Key Informant Interviews**

Debby reviewed the strategy and general approach proposed by the HDWG for the next major phase of the project, key informant interviews. She summarized the purpose as seeking input to confirm the discovery of outcomes, affirm the controversial and ambiguous findings, and seek interpretation regarding the topic of study and emerging practices such as mental health parity, the medical home concept, and the Ticket-to-Work reform effort.

The membership was unanimous in their support of the most meaningful and critical input to come from consumers themselves—those who had first-hand experience with the services, programs, and reform initiatives. Polly recommended the Family Voices model of researchers working directly with consumers to develop and interpret the research.

In response to a request for explanation of the medical home concept, Debby explained the concept as a “hub”—one endorsed by the AAP, emphasizing comprehensive, coordinated, continuous, and consistent services on an individualized basis involving partnership on the parts of parents and providers of children with special health care needs. Polly indicated that the practice is actually working in places across the country and may indeed be transferable to other populations. She also noted the distinction from disease management. Kay cited a model, the Invisible Children’s Project in Sacramento, as another family-centered care model.

Debby introduced the notion of “managed parity”—a coined phrase to acknowledge that in every article studied on the topic of mental health parity, the advent of parity was associated with either



the simultaneous introduction or intensification of managed care. No evidence of parity causing more than a short-term and small increase was found in the literature. Some plans experienced rapid and dramatic reductions in cost.

No studies reviewed indicated that cost containment resulted in decreased access or quality. A shift in location of care away from inpatient to outpatient settings and increased “treatment prevalence” (percentage of persons receiving care) is shown. Quality was addressed in a limited way (mostly administrative) and generally scored well as a measure. More substantive patient outcomes are needed. It was noted that cost increases have been cited as a reason for resistance to parity; yet evidence shows it is cost neutral.

Kay shared her observation of consumers receiving employment support services from the agency where she is employed as a group clearly in need of mental health support and estimates that ninety-five percent are not receiving it. She remarked on the significance of the increased treatment prevalence as important.

Another example of an emerging practice for further pursuit with key informants is the Ticket-to-Work program. Following a brief explanation of the program, Charlie indicated that the state of New York is offering ILCs incentives to enroll their clients into the program and the importance of Medicaid Buy-In provisions for the program to work. Peter suggested that the program is in dire need of enriched incentives for provider participation. Owen made note of the limited number of states using the Medicaid Buy-In provision with program implementation. Charlie suggested that the HDWG contact Connie Garner in Senator Kennedy’s office for more information on the Ticket-to-Work implementation.

The HDWG requested members to identify the stakeholders for the key informant interviews. Peter suggested that the HDWG provide the membership with a grid to organize the contacts into categories of Capitol Hill Staff, Policymakers, Provider and Consumer Representatives, Researchers and Administrators. In response to the HDWG’s request for specific questions to be posed and answered in the key informant interviews, members offered the following:

- How cultural competence fits with these initiatives;
- Direct care workforce shortage;
- Lack of standards for personal care assistance;
- Individual competencies to managed care;
- What the findings/accomplishments are in the early implementation of Real Choices;
- Don’t forget the kids; and
- Talk with CMS about initiatives underway and planned direction of agency.

In closing, Polly remarked and it resonated among the group—ultimately, these questions need to be asked of the consumers. The next board teleconference will take place in January/February of 2004 and the primary focus of input from the board will be framing the recommendations for the NCD report. A number of board members commented on the complexity and challenge of the project.

## **Appendix C.3.**

### **NCD National Consumer Advisory Board Meeting Minutes March 17, 2004**

#### **I. Introductions**

Brief re-introductions were made by those members present on the teleconference including Marilyn Rohn, Charlie Carr, Polly Arango, Linda Horton St. Hubert, Kay Tucker, and Peter Thomas. Also present were Carol Novak from the NCD, and the HDWG project team of Carol Tobias, Debby Allen, Kate Brown, and Kate Tierney. Owen McCusker, Patty Osborne Shafer, and Denise Payne were not able to join the call.

The HDWG briefly reviewed the purpose and content of the three draft documents sent in advance of the meeting and encouraged the membership to actively comment on them.

#### **II. Literature Review—Consumer-Directed Long-Term Care**

It was explained that the first draft document, Literature Review—Consumer-Directed Long-Term Care, was a summary version of a literature review section conducted by the HDWG—a synopsis of the approach undertaken and resultant findings. The membership was invited to comment on the document, particularly the findings. The following comments and suggestions were made on the Literature Review document:

- The paucity of research and the general lack of interest is noteworthy.
- Researchers engage where funding is directed and the lack of research in this area is reflective of the apathy of funding agencies and the consumers not making it a more pressing issue.
- The NCD could be most useful by drawing attention to the lack of research in this area.
- Carol Novak introduced herself as an NCD Board member and indicated that the NCD had been successful in getting some research generated using census data. She encouraged the group to propose areas of need and specific funding levels.
- The NCD was complimented for its efforts in advancing the New Freedom Initiative grants as the best opportunity to shift institutional biases.
- Policymakers should focus evaluation efforts on quality of life measures and the need for a universal taxonomy as opposed to the traditional cost-effectiveness emphasis.

- The more subjective the outcomes (e.g., quality of life), the larger a sample size is needed.
- It was noted that unpaid care makes community living possible, and that not enough attention has been given to it.
- It was suggested that program evaluations look at caregiver quality of life and the cost factor of unpaid care.
- Look to the National Association of Family Caregivers for study of unpaid care.
- Long-term care insurance is a possible model for study in the area of consumer-directed care.
- The findings of consumer-directed care being as safe as or safer than traditional agency-directed care were conclusive and should be highlighted since lack of safety is one of the biggest arguments against consumer-directed care.
- Note the focus of studies on adult populations, over the age of 65, and the lack of studies on children and youth as a prominent finding.
- Evaluations that measured cost-effectiveness had different findings, depending on the community studied. In the DD community, where HCBS programs deinstitutionalize people with disabilities, HCBS programs were generally cost-effective because community care is cheaper than institutional care. In other communities (e.g., elders, children with special health care needs), where HCBS programs seek to prevent or delay institutionalization, they are generally not cost-effective, because it is very difficult to prove who would or would not be forced into institutionalization lacking such programs. For these populations, programs are cost-effective *only if* they target participants very selectively (e.g., require applicants to be screened for nursing home admission).

### III. Key Informant Cited Barriers to Consumer-Directed Care

The following comments and suggestions were made in reference to the second draft document, Key Informant Cited Barriers to the Adoption of CD.

- Caution for citing the Medicaid bureaucracy as a barrier; may play into the current climate of passing all Medicaid risk onto states as a means of flexibility.
- Medicaid institutional bias is real; “money should follow the person, not the facility” should be the focus verses inflexibility. Frame the argument as more choice/flexibility with community-based services. The spending data is persuasive.
- Although Independence Plus streamlines the waiver process for states that access personal care under 1915(c) and 1115 waivers, it doesn’t help the generally more progressive states that offer personal care services as a state plan benefit.
- There is a false assumption that states that cover PCS under the state plan have all-encompassing PCS. Yet, people with psychiatric disabilities in Massachusetts cannot get a personal care assistant to assist with cuing.

- The Independence Plus templates are too broad and give too little direction to the states on how to provide consumer-direction and what determines consumer direction. Direct the research to assess the existing models and use the results to inform the policy for states and adjust the template parameters accordingly (setting individualized budgets, administering funds, etc.).
- Factors of cost-neutrality; further complicated by in-kind care estimates are volatile, debatable, and contentious. Caution on emphasis in report.
- Lack of common definitions is important.
- Provider resistance is important. Educating the providers is critical and should be conducted simultaneously with other stakeholders.
- The lack of standards and responsibility for licensing and training of caregivers are important barriers, needing address.
- Consider a recommendation to “professionalize” the caregivers as a response to the labor shortage issues. The shortage needs to be publicized along with choice as an important parameter. The nursing shortage is well known; the direct care worker shortage is not known.

#### **IV. DRAFT Recommendations to NCD**

The following comments and suggestions were made in reference to the DRAFT Recommendations document:

- To ensure the inclusion of consumers across the span of disability, modify the word consumer by adding “with a variety of disabilities” in the second paragraph of the first recommendation.
- With respect to the programmatic recommendation to establish a locus of responsibility within the federal government, it was noted that a history already existed. The Coordinating Council on Rehabilitation and Research (which collaborated with AHRQ and NIDRR), housed within the Department of Education, was established to focus on rehabilitation and disability research, with an emphasis on physical disabilities. There was a report in 1997 calling for this merger.
- It was clarified that the recommendation was for a group more HRSA-like than NIDRR-like, that it is meant to be programmatic, and would be a place to address concerns where the market fails—the locus that currently resides at CMS by default.
- The earlier suggestion to make the waiver templates more directive (and informed by the research) should be included under Research Recommendation #3.
- Emphasize the cross disability and cross generational nature of initiatives as important—elders and persons < the age of 65 are of the combined desire and demand for community-based alternatives.
- Demographics—size, breath, depth, should be included in recommendations to provide context.

Prior to adjourning the meeting, the HDWG commented on the lack of research with mental health outcomes. Several members referred to different pilot projects of wellness models replacing medical models across the country as just beginning for which evaluation will be forthcoming. Caution for adoption of the PACT model, describing it as regressive was expressed.

The HDWG will be sending drafts of the report to all the CAB members with the understanding that not everyone will be able to read the long report and critique it before the HDWG submits it to the NCD. All members were thanked for their participation on the CAB.

# **Appendix D.1.**

## **Outcomes Literature Review Protocol**

**Name of Reviewer:**

**Date Reviewed:**

**Article Citation:**

**Type of Source**

(Peer Review Journal, Government Report, Newsletter, Foundation Report, Web site/Self-Published, In-house study (HDWG))

**Funding Source for Analysis (different from intervention?)**

**Affiliation of Authors:**

**Study Purpose**

- Pilot/Feasibility
- Process Evaluation
- Outcome Evaluation
- Cost-Benefit Analysis
- Cost-Effectiveness Analysis
- Other:\_\_\_\_\_

**Study Design**

(RCT, Quasi-experimental, Cohort—retrospective, Cohort—prospective, Cohort—ambi-directional, Case Control, Pre-experiment (before/after), Cross-sectional, Case study, Ecological, Qualitative)

## **Study Duration**

## **Geographic Location**

## **Target Population Demographics**

Describe Inclusion and Exclusion criteria related to demographics. For example: race, age, gender, SES (proxies can be income, insurance status, education), language

## **Disability Profile**

- Diagnoses/conditions—(physical, psychiatric, developmental, CSHCN, SED, chronic illness, sensory)
- Functional Limitations (IADL, ADL)

## **Sample Size and Unit**

For example: individual, clinic, community

## **Observation unit**

For example: individual, clinic, community

**Sampling Methods**—(Random—systematic, Random—simple, Random—stratified, Random—Cluster, Nonrandom—convenience, Nonrandom—purposive, Nonrandom—quota, Census)

## **Intervention/Program**

- Category of intervention (summary), e.g., Expanding eligibility, Outreach, Personal Assistance, Consumer-directed long-term care; Creating a multidisciplinary care team, etc.
- Description of Intervention/Program (Location, target population, duration, activities)

**Intermediate Outcomes Studied**

For example (Access to health care services, Access to mental health and substance abuse treatment services, Access to long-term support services and community living, Access to preventative care/risk reduction services, Change in health behavior, Reduced utilization of inpatient, emergency or institutional services)

**Long-Term Outcomes Studied** (health-related QOL, Health Outcomes, Consumer Satisfaction, Age and culturally appropriate consumer participation in decisions about life, Cost Effectiveness)

**Analysis Measure(s) of association (Strength and Statistical Significance) if applicable**  
(For example, RR, OR, Chi-square, and p-value or confidence interval)

- Type(s) of analysis (how analyzed)

**Findings/Outcomes****Conclusions/Recommendations****Follow-up notes****Other notes**





## **Appendix D.2.**

### **Policy Study Protocol**

**Name of Reviewer:**

**Date Reviewed:**

**Article Citation:**

**Type of Source:**

**Funding source for Study (different from intervention?):**

**Affiliation of Author:**

**Purpose of the Study:**

**Study Design:**

**Geographic Location(s):**

**Study Subjects (e.g., state officials, health plans, ILCs):**

**Number of interviews/case studies:**

**Summary of Analytic Methods (including logic for selection):**

**Disability Population Demographics:**

**Policy/Program:**

**Findings/Recommendations:**

**Follow-up notes:**

**Contact information:**

**Other notes (type in):**

# **Appendix E.**

## **Consumer-Oriented Managed Care Outcomes**

### **Managed Care Outcomes**

Managed care has been a major trend in the financing and delivery of health care over the past two decades, and disability advocates have raised concerns about how this trend affects people with disabilities. The managed care incentives to control or reduce costs, and the traditional mechanisms to achieve cost savings, such as restricted provider networks, utilization controls, and service authorization requirements, could have an adverse impact on the health of people with disabilities. At the same time, managed care systems claim to emphasize care coordination and preventive care, services that could benefit people with disabilities but are often missing in fee-for-service health care systems.

Results in this area parallel those in relation to other findings: studies are inconsistent and/or seem to reflect complex interactions between consumer and program attributes and contextual factors that are not fully elucidated in study reports. There is no basis, therefore, for drawing general conclusions about either the sorts of individuals who may be better cared for in managed or fee-for-service systems, or the models of managed care that are likely to work best for specific consumer groups. The specialty program described in Appendix J do suggest that some managed care models can work well for some consumers, but research does not yet offer us a science for matching system attributes to client needs to optimize outcomes.

The search of published and unpublished literature revealed few studies that examined the impact of managed care on people with disabilities. There were dozens of descriptive studies, but few contained outcomes evidence. We identified 13 studies with sample sizes over 75, covering eight significantly different topics, that addressed the service or satisfaction outcomes among people with disabilities enrolled in managed care plans.

These 13 studies included the following:

- Two studies that compared the experiences of Medicare managed care enrollees with Medicare fee-for-service enrollees;
- One study that compared the experiences of older and younger Medicare managed care enrollees;
- Four studies that compared the experiences of people dually eligible for Medicaid and Medicare who were enrolled in managed care plans with those who received services in the fee-for-service systems;
- One study that compared the experiences of Medicaid managed care enrollees with disabilities before and after their enrollment in managed care;

- One study that compared the satisfaction of Medicaid managed care enrollees with disabilities with Medicaid managed care enrollees who received benefits based on Transitional Assistance for Needy Families status;
- One study that looked at the difference in the experience of Medicaid managed care enrollees based on the characteristics of the managed care plan model;
- Two studies that compared the experiences of employed individuals with chronic illnesses who were enrolled in managed care plans with the experience of similar individuals who received care in indemnity plans; and
- One study that compared the experiences of dually eligible managed care enrollees who were enrolled in two different models of managed care.

Below we provide an overview chart of the 13 studies and eight different topic areas considered in this review. It is important to note that four of these studies, conducted of three different programs, were studies of specialty managed care programs designed to serve people who were dually eligible for Medicaid and Medicare. These programs all operated under risk-adjusted payment systems for relatively limited populations.

Populations Covered	Number of Studies	Authors			
Medicare MC vs. FFS	2	lezzoni et al.	Stafford et al.		
Medicare MC older vs. younger	1	Gold et al.			
Medicaid MC vs. FFS before and after	2	Schaller-Anderson, Inc.	Minot et al.		
Dual eligible MC vs. FFS	4	Burton et al.	Kane et al., 2001	Kane et al., 2003	Chatterji et al.
Medicaid MC plan type differences	1	Hill and Wooldridge			
Medicaid MC for disabled vs. TANF	1	ORC Macro			
Employed MC with chronic illness vs. FFS	2	Stafford et al.	Druss et al.		
Dual eligible plans—model differences	1	Kane et al., 2002			
Studies of specialty managed care programs for dual eligibles	4	Kane et al., 2001	Kane et al., 2002	Kane et al., 2003	Chatterji et al.

The diversity of these studies makes it difficult to draw any general conclusions about the impact of managed care on people with disabilities. The research conducted was among different study populations (Medicare, Medicaid, dually eligible, and privately insured) and different managed care program models, and different outcomes were measured. Below, we provide an overview of the 13 studies, sample sizes, populations studied, and basic research methods.

Author	Year	Sample Size	Loc.	Pop.	Sample	Response Rate	Topic
Gold et al.	1997	3080	Nat.	Medicare HMO enrollees and disenrollees	Nationally representative sample	64%	Medicare MC older and younger members, disenrollees
Hill and Wooldridge	2002	1293	TN	MA SSI enrollees in TennCare (mandatory)	Unclear if random. Stratified sample.		How characteristics of MCOs affect access and quality of care
ORC Macro	2002	2742	CA	MA ABD enrollees, voluntary	Random		Satisfaction

Author	Year	Sample Size	Loc.	Pop.	Sample	Response Rate	Topic
Schaller Anderson, Inc.	2002	538 cost	OK	MA SSI high cost managed care enrollees(mandatory)	Universe	92%	Satisfaction and cost
		194 sat			Unk	66%	
Iezzoni et al.	2002	16403	Nat	Medicare beneficiaries in community	Nationally representative sample		Mostly FFS <->65 comparison, some Medicare MC vs FFS
Burton et al.	2001	200	MD	Plan members as compared to local FFS and Nat'l FFS	Random sample	81%	Voluntary MC for Dual Eligibles, comp to FFS
Minot et al.	1996	143	NJ	MA managed care, all ages		94%	Medicaid MC satisfaction compared to FFS experience of same group. Voluntary program
Stafford et al.	2003	44281	NE	Employed and Medicare populations with diabetes, CHF or asthma	Universe	NA	Employed and Medicare MC vs FFS—Rx access for people with chronic illness
Druss et al.	2000	DK	NE	Privately insured	Random sample	72%	MC vs FFS—chronic illness
Kane et al.	2001	~400	MN	Dual eligible elders and two comparison groups	Random sample	78%–90%	MC Specialty Plan—MSHO
Kane et al.	2002	629	WI	Dual eligible over age 55	Universe		PACE compared to Partnership
Kane et al.	2003	1273	MN	Dual eligible elders and two comparison groups	Random sample	83%	MC Specialty Plan—MSHO
Chatterji et al.	1998	1098	Nat.	Frail dual eligible elders and a comparison group	PACE members and applicants who did not enroll		MC Specialty Plan—PACE, longitudinal survey

The main outcomes examined in these studies were satisfaction with care (11 studies) and access to care (7 studies). Three studies also examined change in health status and service utilization; and one study looked at consumer participation and costs. The table below provides an overview of the outcomes measured in each of the studies.

### Managed Care Outcomes Summary

Author	Year	N	Pop.	Access	Satisfaction	Utilization	Consumer Participation	Change in Health Status	Cost
Gold et al.	1997	3080	Medicare HMO enrollees and disenrollees	1	1				
Hill and Wooldridge	2002	1293	MA SSI enrollees in TennCare (mandatory)	1	1				
ORC Macro	2002	2742	MA ABD enrollees, voluntary	1	1				
Schaller Anderson, Inc.	2002	538 cost	MA SSI high cost managed care enrollees (mand)		1			1	1
		194 sat							

Iezzoni et al.	2002	16403	Medicare beneficiaries in community	1	1				
Burton et al.	2001	200	Plan members as compared to local FFS and Nat'l FFS	1	1				
Minot et al.	1996	143	MA managed care, all ages	1	1				
Stafford et al.	2003	44281	Employed and Medicare populations with diabetes, CHF or asthma	1					
Druss et al.	2000	DK	Privately insured		1				
Kane et al.	2001	~400	Dual eligible elders and two comparison groups		1	1		1	
Kane et al.	2002	629	Dual eligibles over age 55						
Kane et al.	2003	426	Dual eligible elders and two comparison groups		1	1	1		
Chatterji et al.	1998	1098	Frail dual eligible elders and a comparison group		1	1		1	
<b>TOTAL</b>	<b>13</b>			<b>7</b>	<b>11</b>	<b>3</b>	<b>1</b>	<b>3</b>	<b>1</b>

## Satisfaction

Eleven of the studies examined satisfaction with care among people with disabilities enrolled in managed care plans, usually in comparison with populations that were not enrolled in managed care, or with another population enrolled in managed care.

Gold et al., 1997, conducted a study of Medicare managed care enrollees and disenrollees, oversampling enrollees under the age of 65 and over the age of 85, African Americans, and disenrollees. Samples were then weighted to ensure that estimates were representative of the national population. The study compared the experiences of people over and under the age of 65 within Medicare managed care. Gold found that managed care enrollees generally rated their health status higher than those in the fee-for-service program. People under the age of 65 were more likely to disenroll than older people, and were also more likely to report poor or fair health. Eighty-nine percent of enrollees with disabilities said they would recommend their health plan to family or friends.

Iezzoni et al., 2002, looked at a nationally representative sample of community-dwelling Medicare beneficiaries, primarily to examine health care access for older and younger Medicare beneficiaries with disabilities. The authors found that people with disabilities were less satisfied with care than other Medicare beneficiaries, but this varied by the type of care needed and the age of the enrollee, and was not related to managed care enrollment. Iezzoni et al. also examined satisfaction with care for Medicare beneficiaries enrolled in managed care organizations

compared with people who received Medicare fee-for-service benefits. They found that managed care enrollment made no significant difference in satisfaction with care. Older members were slightly more dissatisfied with access to specialists under managed care, but both older and younger beneficiaries with disabilities were significantly more satisfied with the costs of their managed care services.

Hill and Wooldridge, 2002, conducted a study of Medicaid SSI managed care enrollees in four different health plans in Tennessee. Study participants were under the age of 65, lived in the community, and received neither Medicare benefits nor Home- and Community-Based Waiver Services. Approximately 80 percent of the sample was African American. The study looked at managed care organization, age, and type of disability using regression analysis to compare access to and quality of care, controlling for enrollee characteristics. The plan ranked most highly by Medicaid members in the areas of provider knowledge of disability, how disability affected day-to-day life, and the information the members received about managing their condition was the plan with the largest provider network. The plan that was based among university-affiliated physicians and safety net providers was not ranked as high.

The next three studies included in this report were self-published or foundation-published studies. The Minot et al., 1996, study was a member satisfaction survey conducted in Spanish and English of 143 SSI Medicaid managed care enrollees in New Jersey. Enrollment in this managed care program was voluntary. Slightly over half the sample was African American. Sixty percent of the respondents rated their health as fair or poor. Managed care enrollees preferred the managed care plans to fee-for-service in their choice of doctors, the ability to get advice by telephone, and the ability to get specialty care. People preferred fee-for-service to managed care in the convenience of office hours, waiting times for appointments and in the doctor's office, and the ability to get dental care. Respondents whose health status was good or excellent were more likely to prefer managed care than respondents whose health status was fair or poor.

ORC Macro, 2002, conducted a patient satisfaction survey of Medicaid aged, blind, and disabled (ABD) members enrolled in Caloptima, a county-operated health system in Orange County, California, that contracts with 11 health networks to provide capitated acute medical care. The random sample of 2,742 members received surveys in English, Spanish, and Vietnamese. The satisfaction survey included many of the questions contained in the widely used Consumer Assessment of Health Plan Satisfaction (CAHPS) survey in order to allow comparison between Caloptima's members with disabilities and their previously surveyed Temporary Assistance to Needy Families (TANF) members. TANF members were more likely to rate their health as excellent (63 percent) than ABD members (7 percent). TANF families were significantly more likely than ABD members to report that their doctors explained things well and showed respect for what they had to say. TANF families also reported fewer problems getting specialty referrals, or getting care right away for an injury or illness.

Schaller Anderson, Inc., 2002, conducted a satisfaction and cost study of Medicaid managed care enrollees in Oklahoma who had been identified by the state as being among the 10 percent highest cost SSI members. The satisfaction survey was conducted among 194 managed care



enrollees with disabilities. Eighty percent of these individuals reported that their managed care experience was good or very good, and 83 percent reported that they received the care they needed all the time or most of the time. Managed care enrollees also reported greater satisfaction with the ease of obtaining prescriptions, health care services received in general, and the ease of seeing a doctor after enrollment in managed care as compared with prior experiences in the fee-for-service system; however, authors did not report if this difference was significant. It should also be noted that this was a foundation-published report, and the report authors were involved in the management of the managed care plan assessed in the study.

Druss et al., 2000, conducted a study of employees of three major corporations who were enrolled in three types of health insurance plans: fee-for-service plans, independent practice associations (IPAs), and prepaid group practices. The purpose of the study was to examine if people with chronic illnesses were more satisfied with their health care services under one type of plan than the others. In general, the managed care enrollees (members of IPAs or prepaid group practices) were younger, higher functioning, and less likely to have a medical illness or chronic illness than fee-for-service enrollees. However, individuals with chronic illnesses in both groups reported the same level of dissatisfaction with their services. The overall conclusion drawn by this study was that chronic illness predicted many aspects of dissatisfaction with managed care, but did not predict dissatisfaction with fee-for-service care.

The next five studies reported satisfaction outcomes for dually eligible Medicaid/Medicare managed care enrollees in specialty managed care plans. The Burton et al., 2001, study compared the experience of 200 enrollees in Elder Health, a for-profit managed care plan in Baltimore for dually eligible elders, with 201 local fee-for-service dual eligibles and a national sample of 531 fee-for-service dual eligibles. Elder Health provided transportation to all medical visits and a team approach to care by nurse practitioners and physicians. Differences in the three samples included race (Elder Health serviced primarily an African-American population), age, and self-reported health status. Self-reported health status of the two Baltimore cohorts was lower than the national sample, and the national sample was older and had more ADL needs. Dual-eligible members enrolled in Elder Health were significantly more satisfied with care in general than both fee-for-service cohorts, especially in access to care and the technical skills of their providers. However, they were significantly less satisfied with the interpersonal manners of their providers.

Kane et al., 2001, and Kane et al., 2003, conducted two studies of the Minnesota Senior Health Options Program (MSHO), a managed care plan for people over the age of 64 who were dually eligible for Medicaid and Medicare. The MSHO benefit package included most Medicaid services, including a portion of nursing home care, and the program was operated by three managed care organizations. Capitation payments could be used to cover services that were outside the traditional benefit package, and providers were required to offer care coordination. The majority of MSHO members lived in nursing homes. In both studies, the authors compared MSHO members with two comparison groups: dual-eligible elders in the same community who did not enroll in MSHO, and dual eligibles living in other counties where MSHO was not available, who thus could not enroll in the program. All three groups were stratified according to the location of residence (community or nursing home). Interviews were administered in only English, although proxy responses were allowed.

Kane et al., 2001, found that MSHO and comparison groups were similar in demographics, illness patterns, and function. There were no significant differences in satisfaction among the three community samples, but MSHO nursing home residents and families expressed more satisfaction with several aspects of care. In summary, Kane et al. concluded that the minor differences in satisfaction that did exist among samples were probably attributable to geographic differences and the availability of resources in different communities.

Kane et al., 2003, used the same model for the research but was able to look at changes over time. Again, there were few differences in satisfaction among the three samples, but MSHO clients were more satisfied with their involvement in decisionmaking about medical care, and MSHO families reported significantly lower burden in five areas than controls. Thus, Kane et al. concluded that although MSHO did not seem to differ significantly in terms of members' experiences, families of members experienced relief under the program.

Kane et al., 2002, conducted a study of the Wisconsin Partnership Program, a program for dual eligible adults and elders in Wisconsin. The Partnership program was similar to the Program of All Inclusive Care for the Elderly (PACE—see below) except that it allowed people to keep their own physicians and did not require them to participate in adult day care. Health care services were provided by an interdisciplinary team that included a nurse, social worker, and nurse practitioner. Kane et al. examined differences in the experiences of elder Partnership enrollees with PACE enrollees living in the community to explore whether people were more satisfied with either of the two models. In-person interviews were conducted and proxies were permitted. The PACE sample was older, less likely to be married, and included more racial/ethnic minorities. PACE enrollees were more likely to have dementia but less likely to have heart disease or chronic pulmonary disease. The authors found no significant difference in satisfaction after adjusting for age, race, education, function, and number of medical conditions.

The Chatterji et al., 1998, study compared the experiences of people enrolled in PACE with the experiences of people who inquired about the program but did not enroll. PACE was a Medicaid/Medicare managed care option for Medicaid recipients over the age of 55 who were eligible for nursing home admission. The PACE model included comprehensive medical and social services through an interdisciplinary team of providers who operated out of an adult day center. The center served as a social venue for PACE enrollees as well as the main location for medical and social service care. The Chatterji et al., 1998, study was conducted over a two-year period, with interviews administered every six months. PACE enrollees were more likely than comparison group members to be female and widowed, and were less educated and less cognitively impaired. There were no differences between the two groups in terms of race or ethnicity. PACE enrollees reported better health status. In regression analysis, the authors found that PACE enrollees were significantly more likely than comparison group members to be very satisfied with their care arrangements, had more confidence in dealing with life's problems, were more likely to report having at least some choice in how they spent their time, and had a higher probability of finding life to be satisfying.

To summarize the results of all of these studies:

- Health status of managed care enrollees compared with fee-for-service enrollees was higher in three of the studies (Gold et al., 1997; Druss et al., 2000; Chatterji et al., 1998) and lower in one (Burton et al., 2001).
- Three of the studies found no significant difference in satisfaction between fee-for-service and managed care enrollees (Iezzoni et al., 2002; Kane et al., 2001; Kane et al., 2003).
- Two of the studies found more satisfaction in some areas and less in others (Minot et al., 1996; Druss et al., 2000).
- Four of the studies found increased satisfaction with managed care overall compared with fee-for-service (Druss et al., 2000; Burton et al., 2001; Schaller Anderson, Inc., 2002; Chatterji et al., 1998).

## Access

Seven of the studies, including six of those mentioned above, examined access to care for individuals with disabilities or chronic illness who were enrolled in managed care. The seventh study, Stafford et al., 2003, examined the health care experiences of adults with diabetes, congestive heart failure, and asthma to determine whether people who received managed care services through three health plans were more or less likely to use chronic disease medications than people who received care through two fee-for-service plans. Although the majority of individuals in this study were privately insured, each category of plan offered at least one Medicare product. Using multiple logistic regression to adjust for case mix and the number of primary care visits, the authors found that managed care enrollees were more likely to use chronic disease medications than fee-for-service enrollees in most cases. This held true for both expensive and inexpensive medications. It should be noted, however, that while the fee-for-service patients faced high deductibles and coinsurance for prescription drugs, the managed care enrollees had no deductibles and only modest co-payments for prescription drugs. This suggests that the differences in utilization might be associated with the cost of medications under each service delivery model.

Iezzoni et al., 2002, found that older Medicare health maintenance organization (HMO) beneficiaries were significantly less satisfied with access to specialists than Medicare fee-for-service beneficiaries. HMO beneficiaries also were less satisfied with the availability of medical care at night and on weekends, but the difference was not statistically significant. Gold et al., 1997, also looked at access to care for Medicare HMO enrollees, and found that younger Medicare enrollees with disabilities experienced more access barriers with adverse consequences than elderly HMO enrollees. Statistically significant barriers included difficulty making appointments, delays while waiting for plan approval of services, inadequate home health care, and lack of referral to a specialist or admission to a hospital when the enrollee thought it was needed. Gold et al. also found that younger fee-for-service enrollees with disabilities, like their HMO counterparts, were more likely to experience barriers to access than elderly fee-for-service enrollees—this access gap was actually greater under fee-for-service systems than it was under

managed care. In their one comparison between HMO and fee-for-service enrollees, Gold et al. found that HMO enrollees with disabilities were more likely than fee-for-service enrollees with disabilities to experience access problems, although HMOs did better than fee-for-service systems in providing preventive care.

Hill and Wooldridge, 2002, found that nearly all of the Medicaid managed care enrollees with disabilities in Tennessee felt they had good access to providers, a usual source of care, and the ability to schedule appointments within one week of contacting their providers, regardless of the specific health plan model. Enrollees in the fee-for-service health plan, however, reported greater access to preventive care and more visits to manage their chronic conditions than enrollees under the three capitated health plans. They also reported better access to services, fewer delays in receiving approval for care, and better access to emergency services.

In comparing the Medicaid managed care experiences of the ABD population with the TANF population, ORC Macro, 2002, found that ABD members were less likely than TANF members to get a referral to a specialist or to get care right away for an illness or injury, and were more likely to experience delays in health care while waiting for approvals from their health network.

Burton et al., 2001, compared the experience of dual eligibles in a managed care specialty program with the experience of enrollees in fee-for-service programs. The authors found that dually eligible enrollees in managed care were significantly more likely to report that they were “highly satisfied” with access to care than those in fee-for-service. Managed care enrollees also had better access to preventive care than those in both the local and national fee-for-service programs.

To summarize the results of these studies:

- Working-age adults with disabilities routinely reported more access barriers than elders or TANF beneficiaries, regardless of whether they were enrolled in an HMO or in a fee-for-service program (Gold et al., 1997; ORC Macro, 2002).
- Some HMO enrollees experienced more access problems (especially access to specialists) than fee-for-service enrollees (Iezzoni et al., 2002; Gold et al., 1997).
- There was some evidence that HMOs provided better access to preventive care and prescription drugs (Gold et al., 1997; Burton et al., 2001; Stafford et al., 2003).
- The one study of a managed care specialty program for dually eligible participants demonstrated better access on all fronts than comparable fee-for-service programs (Burton et al., 2001).

## **Changes in Health or Functional Status**

Three studies examined changes in health status under managed care, the first looking at general managed care, and the other two looking at specialty managed care programs. Schaller

Anderson, Inc., 2002, found that health status improved among the Medicaid ABD population from the time of enrollment in managed care to a follow-up period after enrollment. Kane et al., 2003, found no significant differences in function over time for dually eligible enrollees in MSHO or for two fee-for-service comparison groups.

Chatterji et al., 1998, found that PACE enrollees reported better health status and quality of life over time than a fee-for-service comparison group. This effect was most dramatic six months after the baseline survey. In some areas, PACE enrollees also experienced less deterioration in physical function than the comparison group during the first six months of enrollment. Holding other factors constant, participation in PACE was associated with a lower mortality rate and an increased number of days living in the community than the comparison group. Chatterji et al., 1998, also found that the percentage of PACE enrollees reporting good or excellent health was very stable over time, while the percentage of comparison group members originally fluctuated, and ultimately dipped in the second year.

In summary, two studies (Chatterji et al., 1998; Schaller Anderson, Inc., 2002) found that managed care enrollees experienced positive changes in health status over time or less deterioration than a fee-for-service comparison group, while the third study found no significant differences in functional status change between managed care enrollees and comparison groups (Kane et al., 2003).

## **Changes in Utilization**

Three studies of two specialty programs for dually eligible enrollees examined changes in service utilization over time. Kane et al., 2001, found that MSHO enrollees were more likely to use special transportation than both sets of controls and were more likely to have had a nurse visit than one set of controls. Two years later, Kane et al., 2003, found a significant increase in MSHO enrollees' use of homemaker services, meals on wheels, and outpatient rehabilitation over the use of these services by the comparison groups. MSHO enrollees also received significantly less help from family with household tasks than one of the control groups. Chatterji et al., 1998, found that PACE enrollees had much lower rates of nursing home utilization and in-patient hospitalization than did comparison group members. PACE enrollees showed higher utilization of ambulatory services. These differences between PACE enrollees and comparison group members were still evident two years after enrollment in PACE, although the magnitude of the difference did appear to diminish over time.

## **Consumer Participation**

Although only one of the studies examined consumer participation as an outcome, it is worth mentioning here because it links studies of managed care to studies of consumer-directed and -oriented long-term care, which place consumer participation squarely in focus. Kane et al., 2003, looked at enrollees' self-rated involvement in making decisions about medical care,

finding that MSHO enrollees were more likely to be involved with decisionmaking than non-enrollees. Family satisfaction in this respect with input into decisionmaking was also greater among MSHO families than among fee-for-service comparison group families, although the difference was not significant.

## **Cost**

Only one study, Schaller Anderson, Inc., 2002, looked directly at the claims data to examine cost as an outcome. Per member per month costs dropped 4 percent for Medicaid SSI beneficiaries as a result of switching from fee-for-service to managed care. This figure took into account the additional administrative cost under managed care.

## **Conclusion**

The research described here is far too diverse in terms of program models, study populations, study questions, and findings to generate conclusive findings. A few trends are worth noting, however. In general, younger people with disabilities seemed to experience more barriers to care than older people who receive Medicare benefits, regardless of enrollment in managed versus fee-for-service care. Medicare beneficiaries enrolled in managed care had better access to preventive care and prescription drugs, but experienced more difficulty gaining access to specialists and other components of care. On the other hand, at least two of the studies of specialized managed care programs for people dually eligible for Medicare and Medicaid found that people in the managed care programs had better access to a wide spectrum of outpatient care.

Several studies documented that managed care enrollees had better health status than fee-for-service counterparts; one study, however, found the reverse to be true. Satisfaction outcomes varied greatly across the studies, and these results are confounded by the fact that some studies compared managed care enrollees with fee-for-service enrollees, while others compared the satisfaction of younger and older Medicare beneficiaries, or TANF and SSI members in one or the other financing system. In fact, differences in satisfaction may be linked to program model, health status, or other factors that were not fully explored. In addition, it is important to note that most of the managed care programs studied were voluntary enrollment programs, and thus people's health status may have been a factor in their choice of program model.

It is clear that there is a need for further research that goes beyond one program in one state, or limited questions posed of national samples, in order to understand if outcomes really differ for people with disabilities who enroll in managed care plans. In addition, research is needed to clarify how differences in outcomes may be associated with specific program models. The studies discussed here provide a baseline and a framework for considering the implementation of broader research initiatives. Findings from these studies confirm some speculations (healthier people tend to enroll in managed care programs), while they defy others (in a voluntary plan or specialty plan, people with disabilities may be more satisfied with their managed care plans than they were with their fee-for-service programs).



## Appendix F.

### Key Informant List

<b>Name</b>	<b>Perspective</b>	<b>Area of Expertise</b>	<b>Organization</b>	<b>Location</b>
Polly Arango	Consumer	CSHCN	Algodones Associates	Algodones, NM
Julie Beckett	Secondary Consumer	Healthcare financing for children with disabilities, esp. Medicaid waivers and private coverage	Family Voices	Iowa
A.E. (Ted) Benjamin	Researcher	Consumer Direction/Self-Determination	UCLA	Los Angeles, CA
Randy Brown	Researcher	Medicaid, LTC, Managed Care	Mathematica	Princeton, NJ
Cheryl Bushnell	State Administrator	Health and Disability	MA Department of Public Health	Boston, MA
Charlie Carr	Consumer	Persons with Disabilities/Independent Living	Northeast Independent Living Program, Inc.	Lawrence, MA
Henry Claypool	Consumer/Policy/Advocacy	Disabilities	Advancing Independence Modernizing Medicare and Medicaid	Washington, DC
James Conroy, PhD	Policymaker/Researcher	Disability Program Outcomes	Center for Outcome Analysis	Narbeth, PA
Suzanne Crisp	Researcher	LTC	Medstat	Cambridge, MA
William Ditto	Program Administrator	Consumer Direction/Self-Determination	NJ Office on Disability Services	Trenton, NJ
Virginia Dize	Policymaker/Program Administrator	LTC, Directed "Independent Choices"	Center for Advancement of State Comm Services	Washington, DC
Pamela Doty, PhD	Policymaker/Researcher	LTC, assisted living, community care	ASPE	Washington, DC
Sue Flanagan	Researcher/Consultant	Cons. Directed LTC, state programs	Westchester Consulting Group	Washington, DC
Donna Folkemer	Program Manager	Medicaid Buy-In; Aging and disabilities; LTC and managed care	National Conference of State Legislatures	Washington, DC
Wendy Fox-Grange	Policy Specialist	Long-Term Care	National Conference of State Legislatures	Washington, DC
Lex Frieden	Researcher	Disability/Independent Living	NIDRR	Houston, TX
Rick Greene			U.S. Administration on Aging	Washington, DC
Bob Griss		Systems and program/legislative and political impact of health		Washington, DC



<b>Name</b>	<b>Perspective</b>	<b>Area of Expertise</b>	<b>Organization</b>	<b>Location</b>
		care		
Patti Hackett	Secondary Consumer	Youth and adults into transition— health coverage issues	Self-employed	FL
Michelle Herman	Policy Associate	Mental Health	National Conference of State Legislatures	Washington, DC
Chris Hess	Program Administrator	Self-Direction for Elderly	Community Care for the Elderly	Milwaukee, WI
Diane Hovey, PhD	Professional artist/consumer	Families with special health care needs	Family Institute for Creative Well-Being	Maple-wood, MN
Henry Ireys, PhD	Researcher	Children with Special Health Care Needs/Managed Care	Mathematica	Princeton, NJ
Steve Landkamer	Program Administrator	Community Based/Integrated Care	Wisconsin Partnership Program	Wisconsin, MN
Kevin Mahoney, PhD	Program Administrator/ Researcher	Cash and Counseling	Professor, Boston College	Chestnut Hill, MA
Owen McCusker	Consumer		Community Living Alliance	Madison, WI
Mark Meiners, PhD	Researcher, Program Administrator	Medicaid and Medicare Integration, Professor	University of Maryland Center on Aging	College Park, MD
Bob Michaels	Researcher	Independent Living		AZ
Charles Moseley, EdD	Program Administrator, Policymaker	Self-Determination	NPO on Self Determination; Prof at UNH; National Association of State Directors of DD Services	Durham, NH; Alexandria, VA
Patricia Neuman	Policy	Health Policy	Kaiser Family Foundation	Washington, DC
Jim Perrin		Children with Special Health Care Needs	MGH/Harvard Med School	Boston, MA
Mike Radu	Senior VP of Business Development	Managed Care	United Health Care	Phoenix, AZ
Marilyn Rohn	Consumer	Mental Health		Los Alamos, NM
Sara Rosenbaum	Research/Policy/ Law	Health Services Policy and Management	George Washington University	Washington, DC
Marcie Roth	Policy Advocate	Independent Living	National Spinal Cord Injury Association (NSCIA)	Bethesda, MD
John Rother	Legislation/Public Policy	Seniors/LTC	AARP	Washington, DC

<b>Name</b>	<b>Perspective</b>	<b>Area of Expertise</b>	<b>Organization</b>	<b>Location</b>
Mark Sciegaj	Researcher, Professor	Racial differences in consumer-directed preferences	Lasell College Center for Research on Aging and Intergenerational Studies	Newton, MA
Peter Thomas	Federal law and legislative practice (lawyer)	Health care and disability policy, Medicare coverage and reimbursement policy, medical rehabilitation research, and vocational and community supports	Powers Pyles Sutter and Verville PC	Washington, DC
Jane Tilly	Researcher	Medicaid, HCBS, LTC, and Cons Direction	The Urban Institute	Washington, DC
Karen Tritz	Researcher	Consumer-directed health care	Congressional Research Service	Washington, DC
Kay Tucker	Consumer		Crossroads Employment Services	Sacramento, CA
Conni Wells		Children with special health care needs and mental health	ED of FIFI (Florida Institute for Family Involvement—parent organization in FL)	FL
Anita Yuskauskas		Disabled and Elderly	Center for Medicare and Medicaid Services	MD



## Appendix G.1.

### **Consumer-Directed and Consumer-Oriented Health Care for People with Disabilities**

#### *Key Informant Interview Guide—Long-Term Care*

The Health and Disability Working Group at the Boston University School of Public Health has sent this interview guide to you as part of a project for the National Council on Disability (NCD) to assess the state-of-the-art in relation to consumer-directed and consumer-oriented services.

We are contacting you about reforms related to the implementation of long-term care for people with disabilities, which we have identified as one of the topics on which there are outcome studies. Our focus within the broad topic of long-term care is to look at innovative and responsive models aimed at enhancing care for individuals with disabilities—spanning the spectrum of children to elders and all types of disability.

1. The findings of our literature review in relation to long-term care services and supports for people with disabilities are contradictory, ambiguous, and subject to more than one interpretation within individual studies. For instance,
  - In some studies, interest in consumer-directed models like Cash and Counseling varied by age, disability level of functioning, and race/ethnicity. In other studies, there was no difference.
  - In some studies, consumer direction resulted in fewer unmet needs; in other studies, there was no change.
  - Consumer direction could be cost-effective, but in many studies, cost-neutrality was not achieved.
  - Also, there were mixed results on health status and access measures.
- a. First, we would like to explore your perception of the rationale(s) for implementing long-term care options for people with disabilities. What are your views about home- and community-based alternatives to institutional care as a means to improve outcomes?

- b. Consumer involvement in the planning, design, implementation, or evaluation of long-term care systems is not well reported in the literature. What is your sense of the extent of consumer involvement?
  
- c. In terms of research findings, our review suggests that consumers with disabilities are generally satisfied with community-based supports, whether or not they are consumer-directed. We have noted some apparent advantages to consumer-directed care for those who choose consumer direction. In general, research findings indicate that younger persons with disabilities and those with relatives providing care are particularly favorable to the consumer-directed models. Do these findings resonate with you?

Are there other relevant evidence-based outcomes known to you?

- d. What factors do you associate with these outcomes?
  
- e. Do you know of research that suggests that these findings are particularly applicable, or inapplicable in relation to particular disability categories, or to the age, sex, or race/ethnicity of consumers or to particular geographic regions?
  
- f. Do you find those data persuasive?
  - Are there particular findings or experiences in related fields that you feel confirm or challenge these studies?
  
  - Are there methodological or measurement issues we should be aware of in assessing the validity of these findings?
  
- g. Do you think there are important gaps in practice and/or research that have not been and are still not being addressed, in terms of understanding how reforms in this area affect particular populations?





## Appendix G.2.

### **Consumer-Directed and Consumer-Oriented Health Care for People with Disabilities**

#### *Key Informant Interview Guide—Managed Care*

The Health and Disability Working Group at the Boston University School of Public Health has sent this interview guide to you as part of a project for the National Council on Disability (NCD) to assess the state-of-the-art in relation to consumer-directed and consumer-oriented services.

We are contacting you about reforms related to the implementation of managed care for people with disabilities, which we have identified as one of the topics on which there are outcome studies. Our focus within the broad topic of managed care is to look at innovative and responsive models aimed at enhancing care for individuals with disabilities—spanning the spectrum of children to elders and all types of disability.

1. The findings of our literature review in relation to managed care for people with disabilities are contradictory, ambiguous, and subject to more than one interpretation within individual studies. For instance,
  - In some studies, managed care enrollees had better access to specialists and medications, and in other studies, fee-for-service enrollees had better access to care.
  - Satisfaction was likewise, mixed.
    - a. First, we would like to explore your perception of the rationale(s) for implementing managed care for people with disabilities. What are your views about managed care as a means to improve outcomes?
    - b. Consumer involvement in the planning, design, implementation, or evaluation of managed care systems is not well reported in the literature. What is your sense of the extent of consumer involvement?



- c. In terms of research findings, our review suggests that consumers with disabilities are no less satisfied in managed care than in fee-for-service systems. We did, however, find that younger people and people with mental health conditions were less satisfied than elder persons with disabilities. We also found evidence of dissatisfaction with the level of home care available to younger consumers with disabilities. Finally, we found that overall satisfaction with a given system was closely associated with the level of choice available to consumers. Do these findings resonate with you?

Are there other relevant evidence-based outcomes known to you?

- d. What factors do you associate with these outcomes?
- e. Do you know of research that suggests that these findings are particularly applicable, or inapplicable in relation to particular disability categories, or to the age, sex, or race/ethnicity of consumers or to particular geographic regions?
- f. Do you find those data persuasive?
- Are there particular findings or experiences in related fields that you feel confirm or challenge these studies?
  - Are there methodological or measurement issues we should be aware of in assessing the validity of these findings?
- g. Do you think there are important gaps in practice and/or research that have not been and are still not being addressed in terms of understanding how reforms in this area affect particular populations?





## Appendix H.

### Federal Legislation Intended to Serve Persons with Disabilities

YR Enact	Title	Intent/Purpose/ Brief Description	Target Population(s)	Intervention(s)
1935	<b>Social Security Act</b> P. L. 74-271	Established federal old age benefits and grants to states for assistance to aged and blind individuals, dependent and crippled children. Extended first permanent authorization for the federal Vocational Rehabilitation Program, emphasizing vocational rehabilitation of persons with disabilities as a social responsibility. Title V of SSA created a centrally administered fund to train personnel who work with children with disabilities.	Elderly, Blind, Dependent, and Crippled Children	Employment and Economic Independence
1950	<b>Social Security Amendments</b> P. L. 81-734	Extended federal/state public assistance programs to the permanently and totally disabled.	Permanently and Totally Disabled	Economic Independence
1954	<b>Social Security Amendments</b> P. L. 83-761	Established the first operating Social Security disability program under Title II provisions for SSDI monthly disability insurance payments to workers with disabilities and their eligible dependents.	Workers with Disabilities/ Dependents	Employment and Economic Independence
1956	<b>Social Security Amendments</b> P. L. 84-880	Created the Social Security Disability Insurance Program (SSDI) for workers with disabilities aged 50–64.	Workers with Disabilities/ 50+ years	Acute Medical Care and Economic Independence
1960	<b>Social Security Amendments</b> P. L. 86-778	Eliminated the restriction that workers with disabilities receiving SSDI benefits had to be aged 50+.	Workers with Disabilities/ All Ages	Equality of Opportunity Employment and Economic Ind.
1963	<b>Maternal and Child Health and Mental Retardation Planning Amendments</b> P. L. 88-156	Expanded Title V eligibility to include young persons with/at risk of chronic and disabling conditions	Children w/ Chronic/ Disabling Conditions	Acute Medical Care
1965	<b>Social Security Amendments</b> P. L. 89-97	Established Title XVIII (Medicare) and Title XIX (Medicaid) providing hospital and medical insurance protection to workers with disabilities and funding to states for medical assistance programs for the poor, including persons with disabilities.	Workers with Disabilities Persons of Low Income Persons with Disabilities	Acute Medical Care Community-Based LTC
	P. L. 101-508	Medicaid-eligible persons to receive equal care to that available to the general population.	Medicaid eligible	Equality of Opportunity
1965	<b>Older Americans Act</b> P. L. 106-501	Established Administration on Aging (AoA) at DHHS, responsible for funding and coordination of community-based services for elders, their families and caregivers via Area Agencies on Aging (AAA).	Elders; 60 yrs.+	Community-Based LTC

<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
1967	<b>Social Security Amendments of 1967</b> P. L. 90-248	Medicaid/EPSTDT mandate for Children under the age of 21 years. States given option to provide services under EPSTDT not covered in state plan. Effective 1970: mandatory coverage of home health services to those entitled to SNF level services. Permitted Medicaid beneficiaries to use providers of choice.	Children <21 years Persons with Disabilities Elders	Equality of Opportunity Acute Medical Care Community-Based LTC
1970	<b>Developmental Disabilities Services and Construction Amendments of 1970</b> P. L. 91-517	Provided first legal definition of developmental disabilities. Established broad responsibilities for state planning and advisory councils to plan and implement comprehensive services for persons with developmental disabilities. Also authorized grants to support interdisciplinary training of personnel involved in providing services to persons with developmental disabilities.	Persons with Developmental Disabilities	Equality of Opportunity
1971	<b>Amendments to Title XIX of the Social Security Act</b> P. L. 92-223	Authorized public mental retardation programs to be certified as intermediate care facilities, requiring active treatment, funded by Medicaid. (Optional State Coverage)	Persons with Mental Retardation	Equality of Opportunity
1972	<b>Social Security Amendments of 1972</b> P. L. 92-603	Repealed existing public assistance programs and replaced them with a new Title XVI program— Supplemental Security Income (SSI)—authorizing national cash benefits for aged, blind, and disabled individuals. Also authorized a new assistance program for children with disabilities or blindness under the age of 18, comparable to adult populations. Auto extension of Medicaid to SSI eligible. Optional coverage of Children < 21 years in psychiatric hospitals. 209(b) option established on 1972 eligibility criteria.	Children and Adults with Disabilities	Acute Medical Care Community-Based LTC Economic Independence
1973	<b>Rehabilitation Act of 1973</b> P. L. 93-112	Revamp of state formulas for grant support of vocational rehabilitation programs. Established priority of serving persons w/ severe disabilities. Changed Vocation Rehabilitation Act to Rehabilitation Act. Established Title VI civil rights protection for persons with disabilities, including Section 504, prohibiting discrimination of persons with disabilities when granted federal funds. Enhanced involvement of consumer in development of the Individual Written Rehabilitation Program (IWRP). Allowed SSI eligibles to return to work at state option—Section 1619.	Persons with Disabilities	Equality of Opportunity Employment and Economic Independence
1975	<b>Developmental Disabilities Assistance and Bill of Rights Act</b> P. L. 94-103	Created a “bill of rights” for persons with developmental disabilities; funded services and added new funding authority for university affiliated facilities; and established state protection and advocacy organizations.	Persons with Developmental Disabilities	Equality of Opportunity

<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
<b>1978</b>	<b>Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments</b> P. L. 95-602	Established the national Independent Living (IL) program by adding Title VII to the Rehabilitation Act. Established the National Institute of Handicapped Research, the National Council of the Handicapped, and new programs of recreation and employment. Updated the term of developmental disability in terms of function and clarified the functions of university affiliated programs. Mandate for persons with developmental disabilities right to appropriate treatment, services, and habilitation in the least restrictive environment.	Persons with Disabilities Persons with Developmental Disabilities	Equality of Opportunity Community-Based LTC Employment and Economic Independence
<b>1980</b>	<b>Social Security Act Amendments</b> P. L. 96-265	Authorized cash payments (Section 1619 (a)) and continued Medicaid eligibility (Section 1619 (b)) for SSI recipients engaged in substantial gainful activity for three-year period. Medicare home health broadened.	Workers with Disabilities Persons with Disabilities	Community-Based LTC Employment and Economic Independence
	<b>Omnibus Reconciliation Act</b> P. L. 96-499			
<b>1981</b>	<b>Omnibus Budget Reconciliation Act</b> P. L. 97-35	Consolidated six Title V programs into single block authority—Maternal and Child Health, including needs of children with special health care needs. Also converted the existing Title XX program into Social Services Block Grant, authorizing the Sec'y of HHS to grant "home and community-based" waivers, including personal care assistance.	Low Income Children with Special Health Care Needs Persons with Disabilities	Community-Based LTC
<b>1982</b>	<b>Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982</b> P. L. 97-248	Permitted states to cover home care services for certain children with disabilities whose family income and resources exceeded eligibility criteria under Medicaid. (Katie Beckett) Allowed states to impose cost-sharing.	Families of Children with Disabilities with Income	Community-Based LTC Acute Medical Care
<b>1984</b>	<b>Rehabilitation Act Amendments of 1984</b> P. L. 98-221	National Council on Disability became an independent federal agency within the DOE. Also required states to establish a Client Assistance Project (CAP). Helen Keller National Center for Deaf-Blind Youth and Adults established.	Persons with Disabilities	Equality of Opportunity
<b>1984</b>	<b>Deficit Reduction Act of 1984</b> P. L. 98-369	Mandated a demonstration of the S/HMO concept, including evaluation results.	Medicare Beneficiaries	Acute Medical Care Community-Based LTC

<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
<b>1985</b>	<b>Consolidated Omnibus Budget Reconciliation Act of 1985</b> P. L. 99-272	Authorized states to cover case management services on less than statewide or comparable basis to target populations under Medicaid. Expanded the definition of habilitation for HCBS to persons with developmental disabilities to allow for pre-vocational and supported employment for previously institutionalized individuals and authorized states to cover ventilator-dependent children under the waiver program if they would otherwise require continued inpatient level care.	Persons with Disabilities Ventilator-Dependent Children	Community-Based LTC
<b>1986</b>	<b>Education of the Handicapped Act Amendments</b> P. L. 99-457	Established new grant program for states to develop an early intervention system for infants and toddlers with disabilities and their families. Offered states incentives for provision of preschool programs for children with disabilities, aged 3–5 years.	Children with Disabilities (0–5 years) and their Families	Community-Based LTC
<b>1986</b>	<b>Rehabilitation Act Amendments of 1986</b> P. L. 99-506	Broadened the purposes of the Act including supported employment services and rehabilitation, particularly for persons with severe disabilities. Required consumer controlled boards in Centers for Independent Living (CILs) and states to establish State Independent Living Councils to provide for the development and expansion of IL programs and concepts on a state-wide basis through five-year plans. Specified states responsibility to plan for individuals transitioning from school to work. Extended habilitation services expanded beyond MR/DD populations.	Persons with Disabilities (inc. Severe)	Community-Based LTC Employment and Economic Independence
<b>1986</b>	<b>Employment Opportunities for Disabled Americans Act</b> P. L. 99-643	Made Sections 1619 (a) and (b) permanent in the Social Security Act. Also added provisions for individuals to move between regular SSI, Section 1619 (a) and Section 1619 (b) eligibility status.	Workers with Disabilities	Employment and Economic Independence
<b>1987</b>	<b>Omnibus Reconciliation Act of 1987</b> P. L. 100-203	Provided for nursing home reforms, including requirements to eliminate inappropriate placement of people with mental illness, mental retardation, and other related conditions.	Persons with Disabilities In/At Risk of Nursing Home Placement	
<b>1988</b>	<b>Medicare Catastrophic Act of 1988</b> P. L. 100-360	Expanded Medicare coverage and extended financial protections to spouses of persons living in institutions and receiving HCBS to prevent spousal impoverishment.	Medicare Beneficiaries and Spouses	Acute Medical Care Community-Based LTC
<b>1989</b>	<b>Omnibus Budget Reconciliation Act of 1989</b> P. L. 101-239	Major expansion in required services of Medicaid EPSDT and specified at least 30 percent of Title V funds to be used to improve services for children with special health care needs.	Children with Special Health Care Needs	Acute Medical Care Community-Based LTC

<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
1990	<b>Americans with Disabilities Act (ADA)</b> P. L. 101-336	National mandate for the elimination of discrimination against individuals with disabilities in employment, public services, public accommodation, and services operated by private entities.	Persons with Disabilities	Equality of Opportunity
1990	<b>Individuals with Disabilities Education Act Amendments (IDEA)</b> P. L. 101-476	Renamed the EHA to Individuals with Disabilities Education Act (IDEA) and reauthorized programs to improve support services to students with disabilities, most notably in areas of transition and assistive technology. Least restrictive language was emphasized.	Students with Disabilities	Equality of Opportunity
1990	<b>Omnibus Budget Reconciliation Act of 1990</b> P. L. 101-508	Allowed "access credit" to small businesses for half of eligible costs for compliance with ADA. Also established optional state coverage of community supported living arrangements for persons with mental retardation and related conditions. Authorized second generation model—S/HMO II	Persons with Mental Retardation and Other Related Conditions Elders	Equality of Opportunity Community-Based LTC
1991	<b>Civil Rights Act of 1991</b> P. L. 102-166	Reversed numerous U.S. Supreme Court decisions restricting protections in employment discrimination; authorized compensatory and punitive damages under Title V of the Rehabilitation Act and Title I of the ADA.	Persons with Disabilities	Employment and Economic Independence
1992	<b>Rehabilitation Act Amendments of 1992</b> P. L. 102-569	Comprehensive revisions to the legislation with explicit national findings, public policy commitments, statutory purpose: access to state vocational rehabilitation for most severely disabled individuals, consumer choice and control in rehabilitative process, opportunities for career advancement. Established State Rehabilitation Advisory Councils (SRACs) and Statewide Independent Living Councils (SILCs); responsible for the development, submission, and implementation of State Plans for Independent Living (SPILs).	Persons with Disabilities (inc. Severe)	Equality of Opportunity Community-Based LTC Employment and Economic Independence
1993	<b>Family and Medical Leave Act of 1993</b> P. L. 103-3	Granted employees leave under certain circumstances for medical reasons including birth or adoption of a child and for the care of a child, spouse, or parent with serious health conditions.	Employed Persons of 12+ duration	Acute Medical Care Community-Based LTC
1996	<b>Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996</b> P. L. 104-183	Extended funding authority of Developmental Disabilities Councils, Protection and Advocacy Systems, University-Affiliated Programs and Projects of National Significance.	Persons with Developmental Disabilities	Equality of Opportunity
1996	<b>Health Insurance Portability and Accountability Act of 1996</b> P. L. 104-191	Among other provisions to ensure access, limits applied to pre-existing condition exclusions.	All Insureds; inc. Persons with Disabilities/ Pre-Existing Conditions	Acute Medical Care



<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
1996	<b>Personal Responsibility and Work Opportunity Act of 1996</b> P. L. 104-193	Established more restrictive definition of disability for children in the SSI program; mandated changes in the evaluation process for claims and continuing disability reviews. Also required predeterminations for children prior to the age of 18 years.	Children with Disabilities Receiving SSI	
1996	<b>Mental Health Parity Act of 1996</b> P. L. 104-204	Prohibited certain insurance companies from lifetime cap differences between mental health and medical treatment allowances.	Persons with Mental Illness	Equality of Opportunity
1996	<b>Balanced Budget Act of 1996</b> P. L. 105-33	Section 4913 restored Medicaid to the children who had lost SSI to a definitional change (Sullivan v. Zebley, 1990)	Children with Disabilities	Acute Medical Care
1997	<b>Balanced Budget Act of 1997</b> P.L. 105-133	Established the State Children's Health Insurance Plan (SCHIP) to expand coverage to low-income children not then eligible for Medicaid. In addition, authorized the SSA to use adult criteria for childhood SSI recipients turning 18 years; continued Medicaid coverage for children not meeting the revised disability criteria; permitted states to allow workers with disabilities with family income less than 250 percent of poverty to buy-in to Medicaid paying premiums on a sliding scale of income; eliminated the requirement of prior institutionalization for rehabilitation services provided for in Medicaid HCBS waivers; directed a study of EPSDT; and permitted states to mandate adult populations into Managed Care by amendment to state plans (as opposed to waivers). Exempted populations included SSI eligible children, certain foster care and adopted children, and certain Native Americans. Called for a study of special challenges to serving children with special health care needs and chronic conditions in Medicaid Managed Care. Required a report on the integration and transition of S/HMO into Medicare. Significant amendments to Medicare.	Low Income Children and Adults/Families Persons with Disabilities Children with Special Health Care Needs/ Chronic Conditions. Certain Foster Care, Adopted, and Native Americans Workers with Disabilities	Equality of Opportunity Acute Medical Care Community-Based LTC Employment and Economic Independence
1998	<b>Workforce Investment Act (WIA)</b> P. L. 105-220	Consolidated several employment and training programs into statewide systems of workforce development partnerships, including the Rehabilitation Act. Consumer choice is emphasized and the SRACs are renamed to the State Rehabilitation Council with expanded responsibilities to work with the state agency in joint development of and collaboration of state goals and priorities.	Persons with Developmental Disabilities	Equality of Opportunity Employment and Economic Independence
1999	<b>Ticket to Work and Work Incentives Improvement Act (TWWIIA)</b> P. L. 106-170	Established to provide SSDI and SSI beneficiaries with a "ticket" for vocational rehabilitation services, employment services, and other support services from an employment network of their choice. Also included provisions to eliminate disincentives to employment in Social Security and Medicaid law.	Persons with Disabilities Receiving SSI and SSDI	Employment and Economic Independence

<b>YR Enact</b>	<b>Title</b>	<b>Intent/Purpose/ Brief Description</b>	<b>Target Population(s)</b>	<b>Intervention(s)</b>
<b>1999</b>	<b>Supreme Court <i>Olmstead</i> Decision</b>	Interpreted Title II of the ADA as a mandate for public entities to provide services to persons with disabilities in the most integrated setting appropriate to their circumstances. The Administration announced New Freedom Initiative in response to decision. Interagency identification of barriers and funding to states.	Persons with Disabilities	
<b>2000</b>	<b>Older American Act Amendments of 2000</b> P. L. 106-501	Reauthorization of the Older Americans Act (OAA), including R&D programs and the National Family Caregiver Support Act, designed to provide respite and support services to families caring for ill and disabled relatives. White House Conference on Aging to be held by 2005.	Elders/Families Persons with Disabilities/ Families	Community- Based LTC
<b>2003</b>	<b>Medicare Prescription Drug, Improvement Modernization Act</b> P. L. 108-173	Amended the Social Security Act to provide for a voluntary program of prescription drug coverage and other Medicare related amendments.	Medicare eligibles	Acute Medical Care Community- Based LTC
Refer- ences:	www.findlaw.com www.ppsv.com www.thomas.loc.gov www.gpoaccess.gov www.cms.gov www.ssa.gov			



## Appendix I.

### Overview of Laws and Legislative Initiatives

Americans, including those with disabilities, hold equality and independence as core national values. These values are reflected in the laws, policies, regulations, and programs enacted by the executive, judicial, and legislative branches of government. Below is a brief summary of the laws and policies that provide the underpinning for consumer oriented practices reviewed in this study. Legislative and regulatory reforms are categorized based on whether they address

- A. Equality of opportunity;
- B. Acute medical care;
- C. Community-based long-term care; or
- D. Employment and economic independence.

#### A. Equality of Opportunity

##### *The Rehabilitation Act of 1973*

The Rehabilitation Act (Public Law 93-112) was a major piece of legislation designed to protect the rights of people with disabilities. Section 504 of the Rehabilitation Act states that “No otherwise qualified individual with a disability in the United States, as defined in section 706(8) of this title, shall, solely by reason of his or her disability, be excluded from participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance” (EEOC Web site, 2003).

The Rehabilitation Act of 1973 was amended in 1992 to charge the National Institute on Disability and Rehabilitation Research (NIDRR) with the responsibility to provide a comprehensive and coordinated program of research and related activities to maximize the full inclusion and social integration, employment and independent living of individuals of all ages with disabilities. The Interagency Committee on Disability Research at the Office of Special Education and Rehabilitative Services was created to foster coordination across federal agencies engaged in disability and rehabilitative research programs (National Rehab Web site, 2004; ICDR Web site, 2004).

##### *Americans with Disabilities Act*

The Americans with Disabilities Act (ADA), signed into law in July 1990, was designed to fully integrate people with disabilities into the mainstream of American life, to provide equal opportunity for individuals with disabilities commensurate with the prohibition of discrimination on the basis of age, race, religion, or natural origin, for

- Individuals with a current disability;
- Individuals with a history of disability;
- Individuals who may be regarded as having a disability by others, whether or not they actually have a disability; and
- Individuals who encounter discrimination on the basis of their association or relationship with an individual with a disability (e.g., parents).

The Title II provision of the ADA, which concerns the obligation of state and local government agencies to provide equal access for individuals with disabilities, was challenged in the United States Supreme Court’s historic *Olmstead v. L. C.* decision (1999). Language in the ADA requiring that people receive the “most integrated” services, in contrast with language calling for the “least restrictive environment,” which characterized the Rehabilitation Act, was the central issue in this decision (ADA Web site, 2003).

### ***Supreme Court Olmstead Decision (Olmstead v. L.C. 527 U.S. 581 [1999])***

In June 1999, the Supreme Court interpreted Title II of the ADA as an obligation for all public entities to provide services to people with disabilities in the most integrated setting appropriate for their circumstances. Under *Olmstead*, public entities are responsible for making reasonable modifications to achieve that end. An agency seeking to comply with the ruling must

- Develop and implement comprehensive plans to provide services for people in less restrictive settings; and
- Ensure that waiting lists for services in community-based settings move at a reasonable pace (CMS Web site, 2003).

The Court ruled that it is a violation of Title II of the ADA to institutionalize an individual when health professionals have determined that community-based services would be appropriate and when the individual desires such services. In response to the decision, the Bush Administration announced the New Freedom Initiative.

### ***New Freedom Initiative***

The New Freedom Initiative is a broad federal interagency initiative to assist states and localities with the implementation of the *Olmstead* ruling. The New Freedom Initiative establishes and funds activities that respond to the *Olmstead* decision. DHHS is responsible for leading this effort, but all federal agencies are mandated to identify barriers and solutions to support community living for Americans living with disabilities. Last year, the President created the New Freedom Commission on Mental Health, charging it to conduct a comprehensive study of the nation’s mental health delivery system (public and private) and make recommendations to improve the system.

### ***Mental Health Parity Act of 1996***

The Mental Health Parity Act of 1996, an extension of the Health Insurance Portability and Accountability Act (HIPPA), amended the Employee Retirement Income Security Act (ERISA) and the Public Health Service Act to require health insurance plans with any mental health coverage to provide the same lifetime and annual maximum dollar limits for mental health benefits as they do for medical benefits. Thus, if plans do not impose dollar limits on medical or surgical services, they may not place them on mental health services. Plans without mental health coverage are not subject to this law.

This legislation applies to groups of 50 or more employees and to individuals covered by self-insured ERISA plans, as well as fully indemnified plans and plans that operate under the Federal Employee Health Benefits Act (FEHBA). Parity does not apply to individual policies, Medicare risk contracts, Medicare Select, or subsidized versions of Medicaid. Employers who can demonstrate that provisions of the Act would result in a 1 percent or greater increase in the cost of their group health plan can claim exemption from the Act.

The national parity requirements went into effect in January 1998, although states have enacted their own mental health and substance abuse parity provisions since 1991, and many states have passed parity laws more far-reaching than the federal mandate (FMHI Web site, 2003; DOL Web site, 2003).

## **B. Acute Medical Care**

### ***Title XIX of the Social Security Act—Medicaid***

Title XIX of the Social Security Act established the Medicaid program in 1965. Medicaid is the primary source of federal funding for acute and long-term care for low-income individuals with disabilities. Eligibility for Medicaid benefits is based on both categorical and financial criteria. As an overall rule, people with disabilities must meet the Social Security criteria for disability or be determined medically needy, and must meet the income and asset requirements for SSI. However, there is great variability in implementation from state to state, with some states being far more restrictive within the framework of federal guidelines, while others are more lenient.

Two particularly important categories of Medicaid coverage for people with disabilities are the Medically Needy and Medicaid Buy-In programs. Medically Needy programs are discretionary on the part of states: states have the option to offer Medicaid eligibility to individuals with high medical costs who are otherwise ineligible because they have income or assets above the financial eligibility criteria. These individuals are allowed to “spend down” this excess income and then obtain Medicaid coverage for their health care expenditures. Medicaid Buy-In programs are also discretionary on the part of states, and allow individuals with high health care expenditures to pay a fee to “buy in” to Medicaid as primary or supplemental insurance.

Title XIX of the Social Security Act stipulates that in order for states to receive federal Medicaid funds, certain mandated services must be provided to Medicaid recipients. Currently, there are nearly 30 mandated Medicaid services, including hospital inpatient, outpatient and emergency services, physician services, rural and federally qualified health center services, laboratory and x-ray services, home health care, nursing home care, and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services for all children. States may also provide optional services, such as rehabilitative and physical therapies, prescription drugs, transportation, dental care, and vision services. In addition, states may provide Home- and Community-Based Care Waiver Services, including case management, personal care services, respite care services, adult day health services, homemaker/home health aide, habilitation and other services, further described under Community-Based Long-Term Care.

### ***Managed Care—1915(b) Waiver (Freedom of Choice) Program***

1915(b) Waivers allow the Secretary of Health and Human Services the authority to waive “statewideness,” comparability of services among beneficiaries, and freedom of choice requirements for Medicaid beneficiaries. The most common use of 1915(b) Waivers is to mandate enrollment of Medicaid beneficiaries into managed care. States also use 1915(b) Waivers to allow for the management of behavioral health services separately from medical health services. A few states have used 1915(b) Waivers to provide long-term mental health services to persons with severe and persistent mental illness. States are responsible for ensuring that Waiver Programs do not negatively affect access or quality of services, and that they are cost neutral. 1915(b) Waivers require states to conduct an independent assessment of the program.

### ***Balanced Budget Act of 1997***

The Balanced Budget Act (BBA) of 1997 included several provisions relevant to people with disabilities. First, the BBA gave states the option to implement mandatory Medicaid managed care programs without a Waiver from the federal government. This option applies to adults with disabilities, but exempts children with special health care needs—thus, mandatory managed care programs for children with special health care needs still require a Waiver application and approval from the federal government. The BBA managed care provision required states to develop and implement quality assessment and improvement strategies and external independent reviews of managed care organizations with which the state contracted for coverage of Medicaid enrollees.

Second, the BBA created the State Children’s Health Insurance Program (SCHIP) to expand coverage to uninsured children, including children with disabilities. Third, the BBA gave states the option to establish Program of All-Inclusive Care for the Elderly (PACE) programs to provide community-based care and integrate Medicare and Medicaid funds for beneficiaries over the age of 55 with disabilities sufficiently serious to meet nursing home eligibility standards.

Fourth, the BBA permitted states to offer “habilitation services” in either residential or day settings, without the previous requirement that the recipient be institutionalized. Residential habilitation combines therapies, personal care, and clinical assistance into a single service, usually serving persons with mental retardation or other developmental disabilities residing in

group homes or like arrangements. Day habilitation services are generally provided outside of the individual's living place and may include transportation, adult day health, mental health services, extended education, or prevocational or supported employment services.

### ***Title XVIII of the Social Security Act—Medicare***

The Medicare program was established along with Medicaid in 1965 as Title XVIII of the Social Security Act. Medicare provides health insurance for people over the age of 64. In 1972, amendments to the Social Security Act expanded coverage to adults of all ages whose disabilities prevented them from earning income.

While the Medicare program covers acute medical care, it is not as comprehensive in coverage as the Medicaid program. For example, Medicare does not pay for prescription drugs, personal care assistance, extended nursing home care, and Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Durable medical equipment (DME) is covered only when prescribed by a physician for use in the home, and respite is covered only as part of hospice care. Inpatient care, outpatient care, and partial hospitalization for mental health care is covered only when furnished by a doctor or health care professional who is a Medicare provider. Substance abuse treatment is covered only as an outpatient service. Medicare does not cover non-ambulance transportation.

The Medicare Catastrophic Coverage Act of 1988 included significant changes to Medicaid financial eligibility rules to allow spouses of individuals who were institutionalized to retain more assets and income than had been previously allowed. States can also extend these allowances to spouses of persons receiving services under Medicaid Home and Community-Based Waivers.

A notable expansion of the Medicare program was the Medicare Prescription Drug, Improvement and Modernization Act of 2003. This Act provides an optional prescription drug benefit for Medicare beneficiaries with incomes below 150 percent of the federal poverty level, and catastrophic drug protection for all beneficiaries once established premiums and deductibles are paid. The legislation established a series of interim demonstration plans until the year 2006, when the prescription drug coverage benefit is scheduled to be fully implemented (SSA Web site, 2003; CMS Web site, 2003).

## **C. Community-Based Long-Term Care**

### ***Medicaid***

Medicaid pays for long-term services provided in the community in one of three ways:

- Within the mandatory home health state plan benefit;
- Within the optional personal care services state plan benefit; or
- Within 1915(c) Home- and Community-Based Waiver Services.



Home health services are a mandatory benefit for individuals eligible for nursing facility services. As the primary payer for community-based long-term care and a major payer for acute medical and behavioral health care for people with disabilities, the Medicaid program is the major financial resource for the reforms and studies described in the previous sections of this report (SSA Web site, 2003; CMS Web site, 2003).

Medicaid is also the leading national payer for personal care services, also referred to as personal attendant services, personal assistance services, and attendant care services. States can define the amount, duration, and the scope of their covered personal care benefits, as long as they comply with federal requirements that the services be

- Authorized by a physician in accordance with a plan of treatment or, at the state's option, otherwise authorized in accordance with a service plan approved by the state;
- Provided by a qualified individual as defined by the state who is not one of the individual's "legally responsible relatives"; and
- Furnished in a home or in the community.

The Health Care Financing Administration (HCFA, which is the former name of the Center for Medicare and Medicaid Services) issued a communication to the states to update their guidelines concerning coverage of personal care in 1999. Significant provisions included the following:

- Services can be used to support IADLs, such as assistance with shopping, housekeeping, and transportation, in addition to ADLs, such as bathing and feeding.
- Relatives other than "legally responsible relatives" can be paid for providing personal care services.
- Covered services for people with cognitive impairments can include coaching to achieve cognitive tasks.
- Consumers can direct, supervise, and train their personal care attendants.

### ***Omnibus Budget Reconciliation Act 1981—Home and Community-Based Services Waiver Programs***

The Medicaid Home- and Community-Based (HCBS) Waiver Program was established in Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. This legislation created Section 1915c of the Social Security Act and provided an option for states to offer community-based services to a limited group of individuals in lieu of institutional care. States are responsible for demonstrating that the federal funding for Waiver Services does not exceed the cost of institutional placement for the target population, and for ensuring the health and safety of the affected population. Passage of this statute acknowledged the use of community alternatives for persons at risk of institutionalization. Prior to passage of the legislation, Medicaid long-term care benefits were restricted to home health, personal care, and institutional facilities.

Home and Community-Based Waivers allow states to

- Provide services in the home or community as a cost-effective alternative to institutional care;
- Divert or prevent extended institutionalization of individuals;
- Target services to a specific group of people;
- Limit services to a specific geographic area by waiving Section 1902(a) (1) of the Act about the statewideness requirement;
- Request coverage for services not otherwise covered under the state’s Medicaid plan; and
- Expand income and asset eligibility for this benefit to people who would not ordinarily meet Medicaid eligibility guidelines, but would soon meet them if institutionalized and required to pay for nursing home care.

States typically define their Waiver populations as aged or disabled people, physically disabled people, people with developmental disabilities, people with traumatic brain injuries, and/or people with AIDS. Services often included in Waiver Programs include respite care, environmental modification, personal assistance, expanded medical equipment and supplies, expanded personal care and personal emergency response systems, transportation, homemaker services, adult day care, assisted living, and habilitation services. Case management is a required service in all HCBS programs.

Although every state operates Home- and Community-Based Waiver Services (with the exception of Arizona, which operates the equivalent of an HCBS Waiver under a different Medicaid Waiver provision), the services offered vary in scope and eligibility requirements. States differ greatly in their use of HCBS Waivers and the uptake of Waivers as substitutes for institutional care.

Although consumer direction is not required in any HCBS programs, most states allow consumers some degree of control over the delivery of care in at least some of their HCBS Waiver Programs. A recent report published by the National Council on Disabilities states, “Title XIX Waivers have significantly expanded available funding for home- and community-based services but have not leveled the playing field; because state governments do not recognize Home- and Community-Based Waiver Services as entitlements, waiting lists for Waiver services are long in most states” (Gran et al., 2003; Smith et al., 2000; CMS Web site, 2003/2004).

### ***Section 1115 of the Social Security Act—Research and Demonstration Programs***

Section 1115 of the Social Security Act authorizes the Secretary of Health and Human Services to authorize experimental, pilot, or demonstration projects to further the objectives of the Medicaid statute. 1115 Waiver Research and Demonstration projects allow states the flexibility to test ideas of policy merit, as long as a commitment is made to evaluate the project and prove budget neutrality over the life of the project. Section 1115 Waivers allow for the expansion of eligibility to individuals not otherwise eligible for Medicaid as long as it can be demonstrated that this expense is covered by savings in the program model.

Some states have used this Waiver authority to expand Medicaid eligibility for people with disabilities or develop managed care programs. Initiatives of particular relevance to people with disabilities authorized under 1115 Waivers include two specialized managed care programs for people with disabilities and the Cash and Counseling demonstration programs.

### ***Independence Plus***

Independence Plus is an initiative of CMS to assist states with implementation of self-directed programs for people with disabilities and their families. CMS revised and made available two tools in the form of templates for states to expedite the Waiver process. The standardized, Web-based 1115 Demonstration Application allows states to extend cash allowances to eligible individuals and families. The 1915(c) Waiver Application permits states to allow eligible beneficiaries an individual budget to arrange for and purchase their own personal assistance services and related supports. States are required to indicate the number of unduplicated beneficiaries to receive Waiver and demonstration services. Amendments to the Waivers are required for changes to enrollment limits and must include the results of an independent evaluation, demonstrating budget and cost neutrality along with the ability to adequately address the health, welfare, and satisfaction of the participants.

### ***Section 1915(b)/(c) Waiver Programs***

Some states have combined 1915(b) authority to waive consumer freedom of choice with 1915(c) authority to provide home- and community-based services to individuals with disabilities and people over the age of 64. States that choose this approach must request and comply with the two different Waiver requirements. For example, states must demonstrate cost neutrality to meet requirements of the 1915(c) Waiver and cost-effectiveness to meet requirements of the 1915(b) Waiver. Although the separate requirements and timelines can be cumbersome, the opportunity to develop innovative managed care systems that include home- and community-based care has appeal. Three examples of these combination Waivers are the Texas STAR + PLUS program, Michigan's Medicaid Prepaid Specialty Services (a specialized mental health and substance use treatment program), and Supports for Persons with Developmental Disabilities.

### ***Older Americans Act—National Family Caregiver Support Program***

The Older Americans Act, enacted in 1965, established the Administration on Aging within DHHS with the responsibility to organize, coordinate, and fund community-based services (nutrition programs, in-home services, long-term care ombudsman programs, and health promotion) for elder Americans to remain at home and live independently in their communities. Over time, Area Agencies of Aging were established at the state level to promote local identification and provision of needed services.

The Older Americans Act Amendments of 2000 authorized continuation of the Area Agencies on Aging through 2005 and established the National Family Caregiver Support Program (NFCSP). NFCSP provides a range of support services to family caregivers through formula grant funding to states and Area Agencies on Aging. Populations particularly targeted for services include

grandparents who are caring for their grandchildren, older persons caring for adult children with disabilities, and minority elders. Services funded by this program include respite care, caregiver education, assistance to caregivers in accessing services, individual and group counseling for caregivers, and supplemental services, such as home modifications. Many of the recently awarded NFCSP grants include innovative demonstrations for people with disabilities.

### ***Lifespan Respite Care Act of 2003***

The Lifespan Respite Act of 2003 was proposed as an amendment to the Public Health Service Act to provide information and fund respite care for unpaid family caregivers of individuals of all ages (children and adults) with special needs or disabling and chronic conditions. The Senate version (S. 538) was passed unanimously and joined the House version (HR 1083) for referral to the House Energy and Commerce Committee for consideration.

### ***Family and Medical Leave Act***

The Family and Medical Leave Act (FMLA), enacted in 1993, is the first federal policy intended to directly benefit family caregivers, although not specifically caregivers of people with disabilities. It allows for employees to have up to 12 weeks per year of unpaid leave in the event of a birth or adoption of a child or to care for a relative. This law applies only to employees in companies of more than 50 people, employees who work 1,250 hours or more per year, and employees who have been with current employers for a year or more. However, it can be and is used to care for family members with disabilities.

## **D. Employment and Economic Independence**

### ***Ticket-to-Work and Work Incentives Improvement Act (TWWIA)***

Enacted in December 1999, TWWIA was designed to provide states with the tools to allow people with disabilities to seek employment without fear of losing Medicare and/or Medicaid coverage. On the premise that employment will reduce or eliminate dependency on two cash benefit programs (Social Security Income and Social Security Disability Insurance), “tickets” are provided to people with disabilities, who can redeem them at Employment Network (EN) providers for services to find, enter, and retain self-supporting employment. EN providers are responsible for the coordination and delivery of employment services, vocational rehabilitation, and other support services.

Over a five-year period, the Social Security Administration intends to award cooperative agreements to Benefits Planning, Assistance and Outreach projects, to offer beneficiaries with disabilities, aged 18 to 65, and their families (including transition-to-work aged youth) access to benefits planning and assistance services for participation in TWWIA and other work incentive programs on a voluntary basis.

### ***TWWIIA and the Balanced Budget Act of 1997—Medicaid Buy-In Programs***

Two pieces of federal legislation, the Balanced Budget Act of 1997 (BBA) and TWWIIA of 1999 provide the statutory authority for states to implement Medicaid Buy-In programs for people with disabilities who work or want to work. The statutes also allow states to expand income thresholds and waive asset limits as well as encourage workers to accrue modest savings for the future from their earned income. The goals of the Medicaid Buy-In option for workers with disabilities include the following:

- To ensure access to comprehensive health benefits for individuals with significant disabilities who would otherwise lose or not be eligible for Medicaid because of earned income or accumulated assets;
- To provide wraparound coverage (such as prescription drugs, durable medical equipment, and personal assistance services) for workers with disabilities who are enrolled in Medicare or have other private health insurance coverage; and
- To promote economic security and self-sufficiency among individuals with disabilities who are primarily dependent on disability cash benefits.

These laws give states flexibility in the design of their programs. Most states have targeted their Buy-In programs to the SSDI population to address the inadequacy of the Medicare benefit, particularly for prescription drugs and durable medical equipment. Medicaid Buy-In programs complement the 1619b program for SSI recipients. They permit beneficiaries to earn and save money they would otherwise be unable to save due to Medicaid eligibility restrictions. The 1619b Program allows SSI recipients to supplement earnings with cash benefits and maintain their eligibility for Medicaid as earnings increase (University of Iowa Web site, 2003).

## **Appendix J.**

### **Medicaid Managed Care Policy Trends and Program Descriptions**

The Balanced Budget Act of 1997 allowed states more freedom in designing managed care programs for Medicaid beneficiaries with and without disabilities. Specifically, states no longer have to request a federal waiver to require most adults with disabilities to receive care through managed care systems. Thirty-six states now enroll at least some of their Medicaid beneficiaries with disabilities in managed care programs, and it is estimated that 27 percent of non-elderly people with disabilities are enrolled in Medicaid managed care (Regenstein and Schroer, 1998).

States use a variety of contracting and financing models in their managed care programs for people with disabilities. In terms of finance strategies, some states use capitation, others use gatekeeper models without capitation, while others use a combination of the two methods. A few states use health-risk-adjusted payments to compensate plans for enrolling individuals with above-average health care needs, but this practice is not widespread. States also vary in terms of whether programs are mandatory or voluntary for individuals with disabilities and the scope of benefits included in the managed care package (Regenstein and Schroer, 1998). Behavioral health services, in particular, are handled very differently from state to state. Some include behavioral health in the managed care benefit, while others keep behavioral health as a fee-for-service benefit. Still other states “carve out” behavioral health from the MCOs and contract with separate behavioral health managed care entities to manage this benefit.

The majority of states keep people with disabilities in their Medicaid fee-for-service systems, enroll them in primary care gatekeeper programs, or enroll them in mainstream MCO organizations. People who are dually eligible for Medicaid and Medicare, including most Medicaid beneficiaries over the age of 65, are less likely to be required to enroll in managed care. A few states, however, have developed specialized managed care programs for people with disabilities and people who are dually eligible for Medicaid and Medicare. A comprehensive national summary of state Medicaid managed care programs (as of June 30, 2002) can be found on the CMS Web site.

#### **Specialty Managed Care Programs**

Although managed care, in general, emphasizes centralized control of acute medical care, some specialized managed care structures have been developed for people with disabilities. These specialized managed care programs cover less than 1 percent of all non-elderly beneficiaries with disabilities in managed care (Regenstein and Schroer, 1998), and they tend to target a specific group of people with disabilities, such as dually eligible older people, adults with physical disabilities, or children with special health care needs. Examples of specialized managed care programs targeting specific populations are provided below.

### ***Program of All-Inclusive Care for the Elderly (PACE)***

PACE is a national voluntary managed care program for people over the age of 54 who are certified to need nursing home care and who receive their health care coverage through some combination of Medicaid and Medicare. CMS pays PACE programs special capitation rates that recognize the individual's risk of nursing home placement, with formulas for the contribution of both Medicare and Medicaid payments based on the person's eligibility status with those programs. PACE programs coordinate the medical and support services of enrollees with the goal of sustaining their autonomy as long as possible (NPA Web site, 2004). They provide a full continuum of primary, acute, behavioral, and long-term care services, usually coordinated around an adult day health program that participants are required to attend. Participants receive their care from a multidisciplinary PACE clinical team or contracted providers, and are generally required to switch their primary care to a PACE physician. Thus, although there are 43 PACE sites in 21 states, total enrollment in the PACE programs is much smaller than the eligible population. At the end of 2001, only 7,335 individuals were enrolled in PACE programs nationwide (NPA Web site, 2004).

### ***Wisconsin Partnership Program***

The Wisconsin Partnership Program is a voluntary managed care program that serves adults with physical disabilities, modeled after the PACE program, but available to younger as well as older adults. Enrollees must be eligible for Medicaid, may also have Medicare coverage, and must be certified by their state as eligible for nursing home care (WI DHFS Web site, 2004). The Partnership Program uses a capitated payment structure and integrates medical and long-term care services through the use of team-based care management. The team includes the enrollee, physician, nurses, and social workers who work together to create a care plan for the enrollee (WI DHFS Web site, 2004). Partnership enrollees are not required to participate in an adult day health program and may keep their existing primary care provider. Of note, two of the MCOs that operate the Partnership program evolved out of Independent Living Centers. As of January 2003, 1,384 individuals were enrolled in the Partnership Program in two different areas of Wisconsin (WI DHFS Web site, 2004).

### ***Minnesota Senior Health Options (MSHO)***

MSHO is a specialty managed care program offered by the Minnesota Department of Human Services that serves people over the age of 64 who are eligible for Medicaid and Medicare (MN DHS Web site, 2004). Both Medicaid and Medicare contribute funding for this voluntary program, which is administered by the state to participating MCOs. MSHO provides access to preventive, medical, long-term care, and support services. The program is operated by MCOs that provide each enrollee with a care coordinator who assists with paperwork, arranging services, and answering questions (MN DHS Web site, 2004). A report released by the state in September 2003 showed that just over 5,000 individuals were enrolled in MSHO (MN DHS Web site, 2004).

### ***Minnesota Disability Health Options (MnDHO)***

MnDHO is a voluntary managed care program for working-age adults with physical disabilities who are either eligible for Medicaid or dually eligible for Medicaid and Medicare. It is modeled to some extent after MSHO (MN DHS Web site, 2004). However, MnDHO is operated by a partnership between a commercial managed care organization (UCare) and an organization formed by a partnership of disability advocates and providers (Axis). Axis is responsible for the coordination and authorization of care and played a major role in the development of the provider network and preventive primary care protocols for members. Axis uses a consumer advisory committee to assist in developing and reviewing the managed care organization's policies, procedures, and operations. MnDHO currently has 320 members in the Twin Cities area of Minnesota and is growing rapidly.

### ***Community Medical Alliance (CMA)***

CMA is a voluntary Medicaid managed care program operated by the Neighborhood Health Plan in Massachusetts. CMA has several different clinical programs for specific groups of people with disabilities, including working-age adults with severe physical disabilities, people with AIDS, medically fragile foster children, children with physical disabilities, and children with serious emotional disturbances. The health plan receives special capitation payments for each of these programs; each program offers clients a special network of providers knowledgeable about the needs associated with their particular condition and home-based care provided by nurse practitioners or in some cases physicians or mental health providers. Approximately 500 individuals are enrolled in the CMA programs.

### ***MassHealth Senior Care Options (SCO)***

SCO is a managed care program for people over the age of 64 who live in Massachusetts and are eligible for Medicaid or Medicaid and Medicare. SCO is designed as a coordinated health plan to provide comprehensive coverage for all services covered by Medicaid and Medicare. Enrollees will have a primary care physician in the SCO network who, along with the enrollee, a team of nurses, specialists, and a geriatric support services coordinator, will create a plan of care tailored to the enrollee's specific health care needs (MA DMA Web site, 2004). This new program began enrollment in the spring of 2004.

### ***Health Services for Children with Special Needs (HSCSN)***

HSCSN is a voluntary managed care program for SSI-eligible children in the District of Columbia. All Medicaid benefits, including acute medical care, behavioral health care, and residential care, are covered in this program, as well as care coordination, outreach services, respite care, home modifications, and behavioral and developmental wraparound services. HSCSN began as an 1115 waiver demonstration project in 1995, and currently serves 2,800 of the children who receive SSI benefits in the District of Columbia, more than 80 percent of the eligible population (HSCSN Web site, 2004). The program operates under a risk-sharing agreement between Medicaid and the managed care organization. A central feature of the program is a care management team that works with each family and the child's primary care



provider. An independent evaluation found that access to care was equal to or better than previous fee-for-service arrangements; however, the demonstration program experienced financial losses and difficulty coordinating with other agencies serving the same children (Coulam et al., 2000).

### ***Children's Choice***

Children's Choice in Michigan is a specialized Medicaid managed care program for children who are dually eligible for services provided by the state's Maternal and Child Health Block Grant (Title V) program and Medicaid. These children are eligible to enroll in the program up to age 21 or older if they have cystic fibrosis or hemophilia (CCOM Web site, 2004). Children's Choice involves the enrollee and his or her family in decisionmaking around the child's health care and in the development of an Individualized Health Care Plan that serves as the basis for coordinated efforts on the part of enrollee, family, a principle physician, and a care coordinator (CCOM Web site, 2004).

### ***Medically Fragile Children's Program (MFCP)***

MFCP is a voluntary managed care program that began as a program for medically fragile children in Columbia, South Carolina, in 1996. The founders of MFCP modeled it after the PACE programs, using a multidisciplinary team to provide care. However, the setting for care is a daycare center rather than an adult day health program, and none of the children have Medicare insurance coverage. The program began as a partnership between the state's child welfare system and Medicaid for foster children, but is now available to any Medicaid-eligible child who meets clinical criteria and has expanded to other parts of South Carolina. The team approach to care includes parents, a pediatrician, a pediatric nurse practitioner, nurses, social workers, pharmacists, physical therapists, occupational therapists, speech therapists, a dietitian, psychologists, and home care technicians. One of the challenges MFCP faced is that children whose health improved had to be discharged from the program because they no longer met program eligibility criteria. However, some of these children's health deteriorated after discharge because they no longer received the services that helped to keep them healthy. MFCP recently introduced a Step-Down program for graduates in order to continue providing support services.

## **Summary**

In general, managed care has changed the structure of service provision by incorporating some form of centralized oversight into the care of each individual. While fee-for-service health care offers consumers relative freedom to choose their providers (if the service is reimbursable and available in their area), it offers almost no assistance to those in need of coordinated or comprehensive care. Although specialty managed care programs differ from one another in many ways, the premise of comprehensive, coordinated care with consumer autonomy or involvement is often present. Specialty Medicaid managed care programs, by virtue of their planning capabilities, are designed to provide the support for coordinated and comprehensive care. These benefits of managed care have the potential to make an especially good marriage with long-term care because long-term care needs are relatively predictable and lend themselves to planning.

## Appendix K.

### Summary of Preference Study Similarities and Differences

Six of the preference studies were conducted in one state or large city, and one was conducted nationally. Sample sizes ranges from 168 (a universal sample) to 1,102 (a nationally representative sample). Four of the studies were random samples, one was a universal sample, and one was a convenience sample. We included the convenience sample in this review because it was the main source of information about racial and ethnic differences in consumer preferences for consumer-directed care. Four of the studies restricted their sample to Medicaid recipients of Home- and Community-Based Waiver Services or personal assistance services; the respite caregiver study sample consisted of moderate- or low-income families who did not qualify for Medicaid, and the other two studies included a more heterogeneous population in terms of income or health coverage.

Study	Year	Sample Size	Location	Recruitment Base	Sampling Method	Research Design	Response Rate	Actual Choice
Gibson et al.	2003	1102	Nat'l.	DK	DK	Cross sectional	32%	N
Desmond et al.	2001	743	Florida	Personal care clients	Random	Cross sectional	48%	N
Feinberg and Whittlatch	1998	168	CA	Family caregivers who used in-home respite care	Universe	Cross sectional	81%	Y
Mahoney et al.	1998	493	New York	Personal care clients	Random	Cross sectional	23%	N
Sciegaj et al.	2004	731	Boston	Clients of CBO using services to assist with ADL	Convenience	Cross sectional	N/A	N
Simon-Rusinowitz et al.	1997	491	Arkansas	Medicaid personal care clients	Random	Cross sectional	34%	N
Simon-Rusinowitz et al.	2001	378	Florida	HCBS waiver clients	Random	Cross sectional	53%	N

All of the studies included individuals over the age of 65, and most included individuals with disabilities under the age of 65. However, the Sciegaj et al., 2004, study that looked at ethnic and racial factors included only individuals over the age of 65. Most of the studies also included individuals with physical disabilities. One study was conducted exclusively among individuals with developmental disabilities, and one study explicitly mentioned the inclusion of individuals with cognitive disabilities. Five of the studies permitted surrogate responders, and the family caregiver study targeted families caring for people with cognitive disabilities. None of the studies mentioned the inclusion of individuals with psychiatric disabilities.

Study	Year	Sample Size	Age		Disabilities				Surrogates	Care-giver	Languages	
			>65	<65	Physical	Develop.	Cog.	Psych			Span.	Chin.
Gibson et al.	2003	1102	x	x	x		x		x			
Desmond et al.	2001	743	x	x	x				x		x	
Feinberg and Whitlatch	1998	168	x	x			x			x		
Sciegaj et al.	2004	731	x								x	
Mahoney et al.	1998	493	x	x	x				x		x	
Simon-Rusinowitz et al.	1997	491	x	x	x				x			
Simon-Rusinowitz et al.	2001	378					x		x		x	

In most of the studies, the vast majority of respondents were female. The two exceptions were the national sample of elders with disabilities living in the community (Gibson et al., 2003) and the Simon-Rusinowitz et al., 2001, study of adults with developmental disabilities in Florida. Although the Gibson et al., 2003, study respondents were diverse in gender, they were predominantly white. Three of the studies included sizable samples of racial/ethnic minorities: the Simon-Rusinowitz et al., 1997, study in Arkansas; the Sciegaj et al., 2004, study in Boston; and the Mahoney et al., 1998, study in New York. Just as there was wide variation in the demographic characteristics of the populations studied, there was also diversity in peoples' living situations and health status. The respondents in the Florida study of individuals with disabilities, for example, reported much better health status than the community-dwelling elders in Boston.

It is important to note that in the Feinberg and Whitlatch, 1998, study of caregivers, the care receivers were majority male (53 percent), had an average age of 67.5, and had seriously debilitating chronic illnesses, such as stroke, Alzheimer's, dementia, brain tumors, or traumatic brain injuries.

Study	Year	Female	>65	White	Black	Latino	Asian	Other	Lived Alone	Health Status Fair/Poor
Desmond et al.	2001	80%	66%	58%	24%	12%		3%	50%	74%
Gibson	2003	54%		81%	10%	5%	1%	6%	28%	
Mahoney et al.	1998	77%	63%	47%	31%	12%			61%	70%
Simon-Rusinowitz et al.	1997	89%	85%	50%	48%				57%	67%
Simon-Rusinowitz et al.	2001	54%	DK	73%	22%	3%			7%	17%
Sciegaj et al.	2004	72%	100%	27%	27%	18%	27%		74%	82%
Feinberg and Whitlatch	1998	74%	DK	77%					N/A	

## Appendix L.

### Summary of Long-Term Care Outcome Study Similarities and Differences

None of the studies were national, but rather were concentrated in individual states: including California, Maryland, Michigan, Texas, Virginia, and Arkansas. Samples ranged from 92 to 1,739, with the larger studies permitting stratification by both age (over and under 65) as well as program model (consumer direction vs. agency direction). Those studies that used random or universal samples achieved fairly high response rates.

Study	Year	Sample Size	Location	Recruitment Base	Sampling Method	Research Design	Response Rate	Response Bias
Beatty et al.	1998	92	VA	People receiving paid personal assistance through the state	Quasi-experimental	Longitudinal with comparison group	DK	
Benjamin and Matthias	2001	511	CA	Recipients of CD in-home supportive services	Random	Cross Sectional with Comparison Group	78%	Younger, minorities more likely to respond
Benjamin et al.	2000	1,095	CA	Recipients of CD in-home supportive services	Random	Cross Sectional with Comparison Group	78%	Younger, minorities more likely to respond
Benjamin et al.	1999	511	CA	Recipients of CD in-home supportive services	Random	Cross Sectional with Comparison Group	78%	Younger, minorities more likely to respond
Doty et al.	1996	879	MD, MI and TX	Older Medicaid recipients of personal care services	DK	Cross Sectional with Comparison Groups	88%	DK
Feinberg and Whitlatch	1998	168	CA	Family caregivers who used in-home respite care	Universe	Cross Sectional	81%	DK
Foster et al.	2003	1,739	AK	People enrolled in AK C&C Program, 9 mos. after enrollment	Universe	Randomized, Control Study, pre and post	89% tx grp, 85% control group	DK

Six of the studies included people over the age of 65 (Beatty et al., 1998, being the exception), and six also included adults with disabilities under the age of 65 (Doty et al., 1996, being the exception). Six of the studies focused primarily on individuals with physical disabilities and chronic illnesses. Of these, one permitted proxy respondents, four excluded individuals with cognitive impairments who could not participate in an interview, and one did not mention the use of proxies. The sixth study was conducted of family caregivers, who cared primarily for individuals with cognitive disabilities. None of the studies addressed consumer-directed care for individuals with psychiatric disabilities.

Study	Year	Sample Size	Age		Disabilities		Exclusions	Surrogates	Care-giver	Languages		
			>65	<65	Physical	Cog.				Span.	Chin.	Viet.
Beatty et al.	1998	92		x	x							
Benjamin and Matthias	2001	511	x	x	x		Cog*			x	x	x
Benjamin et al.	2000	1,095	x	x	x		Cog*			x	x	x
Benjamin et al.	1999	511	x	x	x		Cog*			x	x	x
Doty et al.	1996	879	x		x		x					
Feinberg and Whitlatch	1998	168	x	x		x			X			
Foster et al.	2003	1,739						x				
Conroy et al.	2002	77*		x		x		x		x	x	
Conroy et al.	Dec-02	13,589		x		x		x				
Conroy et al.	Nov-02	138		x		x		x				

With the exception of the Beatty et al., 1998, study of individuals with physical disabilities in Virginia, the majority of study participants were female. Several studies included a sample large enough to divide into two age groups for comparative purposes, those age 65 and older, and those under age of 65. With the exception of the Benjamin et al., studies in California, all of the research was conducted among individuals who were predominantly Caucasian. This is particularly interesting in the Foster et al., 2003, study of Cash and Counseling demonstration in Arkansas, because in the Simon-Rusinowitz et al., 1997, study described above, being black/African American was a predictor of consumer interest in self-direction prior to implementation of the Cash and Counseling demonstration. The Benjamin et al., studies, on the other hand, had strong participation rates on the part of racial/ethnic minorities. The education level of study participants spanned a wide range, with the general trend of younger adults being more likely to have at least a high school education than older adults.

Study	Year		Female	>65	White	Black	Latino	Asian	Other	Lived Alone	Percent High School Ed. Or +
Beatty et al.	1998		46%	avg. = 42	82%						
Benjamin and Matthias	2001	>65	81%	N/A	30%	24%	22%	17%	17%		36%
		<65	57%		47%	22%	17%	6%	8%		66%
Benjamin et al.	2000	AD	77%	50%	70%	11%	9%	2%	8%	70%	64%
		CD	70%	54%	38%	23%	20%	12%	8%	43%	51%
Benjamin et al.	1999	Fmem	74%	59%	30%	24%	24%	16%	6%	31%	43%
		Other	67%	49%	46%	22%	25%	8%	9%	53%	57%
Doty et al.	1996			100%							
Feinberg and Whitlatch	1998		74%	N/A	77%					N/A	
Foster et al.	2003	>65	82%	N/A	60%	34%			6%		16%
		<65	68%	N/A	65%	30%			6%		46%

## Appendix M.

### Key Informants' Responses to Research Priorities

**In the course of key informant interviews, we asked each informant, “If you could fund one research project concerning long-term care for people with disabilities, what is the topic you would look at?” The following responses are grouped by the informants’ area of expertise.**

#### Long-Term Care

I would fund a project that aimed to find an equitable way to determine the cash allowance adequate to meet the consumer’s needs.

I would fund something around service coordination that helps people across the board (not just children, or people in vocational rehabilitation).

I would like to know how different disability advocacy groups perceive the definition and application of consumer direction and how this differs by group (MR/DD, physically disabled, parents of CSHCN, and persons with mental health care issues).

I’d like a massive, intensive evaluation of what happens with Florida’s System of the Future initiative.

I’d like to study empowerment. Does Self-Direction really empower people? How? When? Is it a good thing or not?

I’d like to understand why people enter long-term care facilities as opposed to remaining in the community. What is the unique set of circumstances that prompts people to make that move?

I would like to look at liability issues. There are many small programs operating without fiscal intermediaries. As these programs grow, this will become a bigger deal, potentially squashing growth. I’d also like rigorous studies of broader models of consumer direction, not just Cash and Counseling. And I’d like to look at risk management: what risks do consumers naturally take on, even in status quo (e.g., under Medicaid, they regularly have no backup, but Independence Plus requires it).

I would like to find out how many consumer-directed programs are actually out there, working. There are so many programs at various levels that we really do not have a handle on the number and types of programs out there.

I'd look at the role of case manager/service brokers in self-direction.

I want to know what would it really cost to get it really right for everyone with a disability, and what is it costing getting it wrong (e.g., lost wages, lost opportunities, etc.). Also, regarding the woodwork effect—who are the people that are not costing anything now but would come out of the woodwork if resources were available?

I would like to tap in to these different groups (younger adults with disabilities, the elderly, CSHCN, people with DD, people with mental health issues).

I would like to answer the questions: What is the appropriate role for institutions in this country? Is there a role? Who should they be serving? Can deinstitutionalization go too far?

We need to define and measure consumer involvement. An interesting study would be to look at consumer governance versus some predefined level of consumer involvement versus nothing.

I've been pushing for a meta-analysis. Also, Florida and Iowa are consolidating lots of their long-term care programs; eligibility—we should keep our eyes on those states.

I'd like to see this idea expanded further in terms of feasible ways—especially nursing home transitions.

I'd like to somehow identify the factors that make life satisfying/bearable for people with disabilities and translate them into public policy. People with disabilities piece together their lives and services in such different ways. If we could create a hierarchy of what is needed, that would be excellent. Also, in the world of policy, there is cash payment, vouchers, training programs, transportation—what of this is useful and to what extent? Also, we should look at the ridiculous rules of Medicare, etc., that don't really work for people with disabilities.

I'd like a study of what the world is going to look like in 20 years.

I actually think we know enough to know what works. I don't want to get into the business of suggesting we need a lot more research before moving forward. We should move forward and maybe evaluate what we do.

We should look at what, if any, are the adverse effects of Cash and Counseling.

I would love to know where most young people with disabilities (i.e., graduates of special ed. programs) are living now. With whom? Why? How satisfactory is this life? What financial supports are there? I think the answer will be that 19- to 35-year-olds are living with family members. Until we know the living circumstances, we will not know the extent of the costs.

I would like to study what individualization means to people with disabilities in a whole variety of areas and find ways that the general population can see that individualization for people with disabilities is parallel to how they view individualization. I would also like to work with the disability community to find ways to use their protected status as a countervailing force to market pressures...strategies for social change.

I'd like to study uses of the Internet—how information can be sent to older adults and people with disabilities, and how it can be used to train them, link them to services. We'd also have to study how people judge the validity of information on the Internet and how they make informed decisions.

I'd like to have funded a demonstration that allows for the development of a full continuum of services to meet all the chronic needs of persons residing in a community. We could show the OMB [Office of Management and Budget] and the policymakers a system that is cost-effective, safe, of quality, independence-oriented; one that is equal if not better than the existing system. We need to show them it is possible.

I'd like to determine how great the unmet needs are and how you can better manage the way people begin to receive services if this consensus is in place.

## **Managed Care**

I'd find out what really works and what doesn't by finding a way to compare various CMS projects with one another. Then, we could develop better measures of quality of life.

I'd like to know whether, if all basic needs were met and supported (housing, transportation, etc.), the overall medical costs would decrease (we must also account for lost days of work, productivity, etc.).

I'd love to have a study that would tap into the various groups of people with disabilities. We naturally assume that younger adults with disability embrace consumer-directed care, but we haven't seen large-scale studies. Is this a huge advance for them, or an additional burden?

I would look at the efficacy of diversion. I would also look heavily at satisfaction. At the end of the day, everyone is trying to provide consumer choice in a safe and cost-effective way. We need to be able to say, with control groups, that these programs are effective.

I'd like to get health care users (who run the disability/age spectrum) together to say what they need to get decent health care, what they believe would happen in their lives if they got decent health care, and to give personal examples of the barriers they've faced and the results of these barriers. I'd also have at the table people with successful experiences in health care to talk about



what it took for them to get good health care. From this discussion, we'd derive good interventions that lead to empowerment and action.

## **Children with Special Health Care Needs/Medical Homes**

I'd like something on the communication between physicians and families and their partnership. I'd like to see documentation that good communication leads to a successful child with health, self-esteem, and view-of-the-future outcomes.

I'd like to look at quality of life and health care status. We look at the Band-Aid part of health care, but we don't look at how we can really support the kids in inclusion in the community, etc.

I would like to study the connection between the medical home and the family home.

We should be measuring and monitoring medical homes. We've done a lot of research on implementation. Now, we must develop a consistent definition and measurable outcomes, and tools to do this measuring.

It's not that simple, and not just one topic—the medical home model entails changes in many elements. I'd want to see a multistate, multisite, infant follow-up model, studying developmental outcomes of high-risk newborns, systemizing the methodology, funding, and enhanced home visiting. Must have multisite trials, enroll tons of kids, vary treatments slightly with different doses. I'd also like to know whether developing a parental advisory council is really helpful.

I would develop a three-group project with random assignments that varied critical dimensions of the medical home model: (a) with different level of funding for pediatrician medical home services and (b) with improved communication. This would get to the heart of whether it is the money or the change of behavior that will be most successful in creating a medical home.

I would assess how and why medical homes work within a variety of settings, funding schemes, demographics, and diagnoses. I would also be tempted to do a medical home transition project for youth with special health care needs, including kids with mental health diagnoses.

## **Mental Health**

First, we need to see if communities are ready to accept parity. We also should research the disparities in the U.S. government between mental health and DD policy and funding (e.g., how much people are paid, our expectations of them, etc.).

We should do a project on economic issues. Realistically to change the system, policymakers need to look at money; the more research there is showing that implementing parity costs little money and will have cost-saving long-term benefits, the more likely legislation for parity will pass. The project should also address that mental illness accounts for 4 of the top 10 causes of disability in the Global Burden of Disease.

In the places where parity exists, we need to better study access and outcomes.



## **Appendix N.**

### **Mission of the National Council on Disability**

#### **Overview and Purpose**

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

#### **Specific Duties**

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

### ***International***

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

### ***Consumers Served and Current Activities***

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of

people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

### ***Statutory History***

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

