

## **National Council on Disability: Consumer Directed Health Reports**

*Non-government and government-wide reform should expand consumer-directed health care options/choices available for people with disabilities and/or who are aging. Consumers need cross-disability involvement from the planning to evaluation phases.*

### **Lead Agency:**

National Council on Disability

### **Agency Mission:**

The mission of the National Council on Disability is to promote the full inclusion, independent living, and economic self-sufficiency of people with disabilities of all ages and backgrounds by providing advice, analysis, and recommendations on disability policy to the President, Congress, and other federal agencies.

### **Principal Investigator:**

Martin Gould, Ed.D,  
Director of Research  
National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, DC 20004 -1138  
Telephone (Voice): (202) 272-2004; (TTY): (202) 272-2074

### **Partner Agency:**

Health and Disability Working Group  
School of Public Health  
Boston University

### **General Description:**

NCD reviewed the literature on consumer-directed care, obtained guidance from a key informants and a Consumer Advisory Board, evaluated relevant policies, identified practices in consumer-directed health care for people with disabilities. The agency also made recommendations for improving how health care planning, services and outcomes are established, implemented, and/or evaluated.

In the health and supportive services arena, people's desire for independence and control is more likely to be satisfied when health care systems have several factors in place. First, such systems are consumer directed and provide care coordination. Second, they seek to eliminate barriers to care and give consumers choice about the location and type

of services provided. Third, the favored health care systems provide high-quality, seamless, consumer-centered, and continuous care across settings and providers. Fourth, these systems provide support services linked to housing to increase the availability and efficiency of service provision. A fifth factor is that people with disabilities and their caregivers need and want access to timely, understandable, and culturally appropriate information. Combined, the factors help people navigate the maze of services and make informed choices.

The report informs policy discussions among policymakers, practitioners, researchers, consumers, and advocates for health reform. The report also examines current laws; program and policy trends in financing; outcomes; implementation of models; barriers to and facilitators of consumer-direction; the role of federal agencies; and includes recommendations for improvements.

Key NCD recommendations imply that shifts are needed in government and non-government strategies for organizing, locating, and managing health care for people with disabilities. The recommendations include replacing a narrow diagnosis-focused approach and limited service options with a cross-disability, lifespan approach that: (a) considers consumer input and (b) includes funding to meet individual needs. The role of government should change from the oversight of tightly defined program options. Broader responsibility of government should include ongoing assessments of consumer needs and a continuum of choices, provision of resources directed to fill gaps in the service continuum, and incorporation of programs and practices that meet rigorous evaluation standards for clear consumer-defined outcomes.

*Excellence:*                   What makes this project exceptional?

This report is based on a one-of-a-kind systematic analysis of federal policy, program, and research initiatives regarding the interaction of consumer-directed health care and the needs of individuals with disabilities including people who are elderly. Taken as a whole, the methodology, findings and recommendations in this report 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 and people who are elderly.

*Significance:*               How is this research relevant to older persons, populations and/or an aging society?

The systematic analysis relied on in this report included evidenced-based federal and state level research available regarding people who are elderly and people with disabilities. The evidence-based research captured for analysis involved seminal demonstration projects (e.g., Cash and Counseling), traditional federal initiatives (e.g., Medicaid Waivers), and programs that provide a continuum of community-based care (e.g., Programs of All-Inclusive Care for the Elderly (PACE)).

**Effectiveness:** What is the impact and/or application of this research to older persons?

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. This report's findings support federal initiatives needed to expand the implementation of consumer-directed and -oriented care, as demonstrated through:

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 was the first major federal initiative to support consumer-oriented and -directed care across the spectrum of disability and across the lifespan, and as such has facilitated the implementation of community-based care systems.

The joint support of CMS and the Administration on Aging of Aging and Disability Resource Centers in 40 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 are 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.

**Innovativeness:** Why is this research exciting or newsworthy?

The report, *Consumer-Directed Health Care: How Well Does It Work?*, offers a clear picture of the strengths and limitations 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. It also provides a basis for policymakers who use health research evidence to make informed policy decisions in keeping with the intent of the New Freedom Initiative.