The Ethical and Empirical Basis for Consumer-Directed Care for the Frail Elderly

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In recent years many members of the baby boom generation have become involved with the U.S. long-term-care system as they helped their parents and grandparents receive the care they need. This experience and the growing awareness of what they may face themselves in 20 to 30 years is likely to make long-term-care a highly visible public policy issue over the next 10 years and to increase public dissatisfaction with the existing system of long-term-care services. Dissatisfaction is already pervasive among those who have some knowledge of the current publicly supported long-term-care system, which is dominated by institutional care (nursing homes).

A growing number of critics of the U.S. long-term-care system are advocating a qualitative change in the methods and kinds of care now provided rather than incremental changes involving a "little more of this and a little less of that." One of the major qualitative changes many of these critics now support is to move the control of long-term-care resources from provider agencies to those who need and use the resources—the consumer. This long-term-care strategy is usually called consumer-directed care (CDC) and is defined by the National Institute on Consumer-Directed Long-Term Care as:

... a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choice about the services they receive. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. Choice and control are both key elements of any consumer-directed system (National Council on the Aging 1996, p. 1).

The cash and counseling version of CDC could theoretically be incorporated into any state or federally funded long-term or chronic care program servicing persons of all ages and many disabilities. Generally, disabled persons would have a choice of a case-managed service benefit or a monthly cash allowance of a monetary value lower than the service benefit. To be eligible for the monthly income supplement, an individual with a disability would have to show in some predeter-mined way that she could effectively use the extra income to meet her long-term support needs. Consumers would be able to spend the money in ways they best see fit. They might choose to purchase services from a home care agency or referral service at current rates, pay a friend or a relative to provide personal assistance services, make needed home modifications, move to an assisted living facility or other new housing arrangement.

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The counseling component would involve an assessment of need, consumer information and advice about the various services, financing, and housing options available. Centers for independent living, area agencies on aging, other public or private organizations, or individuals that do not have a vested financial interest in the decisions made by the consumers would provide the counseling service. The purpose would be to provide consumers and their families with the information and assistance they need to make their own decisions and manage their own care.

The philosophical and empirical case for consumer-directed long-term-care may be summarized as follows:
1. Human identity in western societies is substantially based on a strong sense of autonomy and personal agency.

There is substantial evidence, in fact, that the value of autonomy to identity and life satisfaction among Americans is growing and sustaining. Maximum autonomy will be the major concern of the baby boom. Physical and cognitive impairments may limit an individual's capacity to act autonomously, but they do not diminish the significance of autonomy as a pillar of identity—as an organizing principle of sense of self.

2. The limited research done on the importance of choice and control (autonomy) to recipients of long-term-care services indicates that a substantial percentage want greater control over the delivery of care and that the ability to exercise choice and control greatly affects the recipients perceived quality of life.

In my experience, this fact (the value of autonomy) has been largely ignored in the development of a long-term-care policy for the frail elderly which is one of the major reasons our publicly supported long-term-care system is dominated by nursing homes. I think this is a far more flagrant case of neglect of the frail elderly than would occur under any system of CDC, which is designed to nurture the autonomy of the frail elderly and respond to the realities of dependency. Many nonaffluent frail elderly persons who need and qualify for publicly supported long-term-care services avoid them for fear of losing their autonomy and ending up on a slippery slope into a nursing home. They also fear getting caught up in a bureaucratic environment that may erode their privacy and the intimate arrangements of their daily lives. I think this is why many frail elderly persons struggle with their impairments to the point where they have no choice but to surrender virtually all of their autonomy and enter a nursing home.

3. Currently available evaluation findings indicate that consumer-directed programs are exceptionally popular with recipients and caregivers and are a cost-effective alternative to institutional and agency-directed care for many seriously impaired elderly persons.

These findings provide clear evidence that CDC is as appropriate a form of long-term-care for many frail elderly persons as it is for younger, disabled persons.

Consumer-directed care is not for every frail elderly person in need of long-term-care services but it could be for far more consumers.

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than are currently provided this option. The available empirical findings suggest that CDC is the most flexible form of long-term-care in that it can be designed to permit not only the paying of individual caregivers, but also allow consumers to pay for community-residential care and, if necessary, nursing home care. In short, CDC could be designed to empower the consumer across the spectrum of long-term-care services and have dollars follow consumers rather than going directly to providers. For those not in a position to benefit from CDC, it is reassuring to know that the aging network has developed a broad array of home- and community-based services over the last 20 years. Most of these programs, however, are underfunded with long waiting lists which reflect only a fraction of the numbers of people in need of some assistance.

Some aging policy experts and advocates have taken the position that CDC may be appropriate for cognitively intact frail elderly persons, but not for the cognitively impaired. There is clearly a difference between these groups in terms of their capacity to benefit from CDC, but the difference should not be made absolute by drawing a bright line between them and blocking access to consumer direction for the cognitively impaired. As long as the cognitively impaired have the capacity to form and express values and have competent caregivers, they should be considered legitimate candidates for CDC. From this perspective, CDC is not just a means of empowering the consumer, it is also a program to empower the caregiver consumer unit and enhance the capacity of the informal system to provide high quality care for much longer periods of time than many unsupported caregivers can sustain. A CDC design that incorporates family caregivers is likely to be not only more effective than a design that excludes them, it can also be argued that it is more compatible with a broad commitment to the value of public policies that strengthen the family and support its capacity to care for impaired relatives.

As the states and federal government sort through the implications of the Supreme Court's 1999 Olmstead decision for long-term-
care of the frail elderly, advocates for the elderly should make every effort to convince the public and policy makers that CDC and paying family caregivers are the best alternative to institutional care for a large percentage of frail elderly persons in nursing homes or at risk of admission to a nursing home. Our objective should be to make CDC a principal vehicle for in-home care for the frail elderly by persuading the federal government to implement powerful incentives to move states toward the CDC model and by working at the state and federal levels to gain acceptance of CDC programs that include paying family caregivers an adequate amount so good care is sustained. More specifically, we should work to convince Congress and the Health Care Financing Administration (HCFA) that states should be permitted to include CDC programs, including those designed to pay family caregivers, in their Medicaid state plans as either revisions to their personal care programs or as new programs. HCFA could be allowed to require that states meet criteria designed to limit the “woodwork effect” and maintain “budget neutrality” through clearly formulated and well-managed eligibility requirements.

Finally, aging network providers should not be alarmed by the prospect of CDC programs. As the frail elderly population grows over the next several decades, it will be pressed to meet the needs of those who cannot benefit from a CDC approach to community-based long-term-care. Furthermore, providers themselves may benefit from the development of CDC programs whose popularity with the general public could create a more favorable atmosphere for increased funding of home and community care, including agency-directed programs. Growth in funding for these programs has been slow or nonexistent in many states for several years and CDC initiatives could help move home- and community-based care to the top of the policy agenda over the next decade.

The CDC approach to community-based long-term-care will certainly require a change in the way agencies provide case management. As consumers are empowered, case managers will have to relinquish the kind of control characteristic of conventional case management strategies and take on the role of adviser, counselor, and advocate for the consumer. The increased satisfaction this change in roles is likely to bring the consumer and caregiver should be gratifying for the case manager as she witnesses lives being enlarged by the exercise of autonomy under conditions of physical and mental impairment.

Providers must be prepared to adapt to the emergence of CDC because, with the aging of the baby boom generation, the odds are it will become the preferred long-term-care service of a growing number of impaired persons and their caregivers.

NOTE

This decision has been interpreted by many court observers as establishing a judicial framework for claiming that states have a responsibility to care for and provide persons with disabilities in-home and community-based alternatives to institutional settings whenever appropriate.

REFERENCES


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