

# LONG TERM CARE RESTRUCTURING IN NEW YORK STATE: A CONSUMER PERSPECTIVE



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## **EXECUTIVE SUMMARY:**

The long term care system in New York State serves a population that is diverse in terms of health care needs as well as personal needs and desires. In addition, it provides a wide range of services in different settings, from around the clock care in nursing homes to personal care and assistance in an individual's private home or community. From a consumer perspective, however, though the system serves many people, it does not serve many of them well.

While there are many good nursing homes in New York, generally speaking they are understaffed and outmoded, providing substandard care and a quality of life that is institutional and dehumanizing for both the residents and direct care workers. In addition, despite the long-acknowledged fact that consumers strongly prefer to receive long term care (LTC) services outside of nursing homes (and have the legal right to receive care in the least restrictive setting possible for them as individuals), nursing homes continue to be over-used and over-populated by residents who don't want to be there and who could safely be cared for elsewhere if such an opportunity was available to them.

Home and community-based services are an attractive idea for most consumers but systemic complexity and problems with access are basic issues that prevent many consumers from availing themselves of these options. In addition to these basic, threshold issues, there are crucial issues relating to: (1) monitoring and oversight (e.g., how can the state ensure good care and consumer safety behind the closed doors of an individual's home?), (2) programmatic efficiency (is a particular program a good use of government funding?) and (3) the extent to which a program is successful in achieving its stated goals and the fundamental goals of most consumer: to receive the care, assistance and environment necessary to enable one to achieve his or her highest practicable physical, social and emotional well-being (including the ability to retain and maintain autonomy and self-direction). The third issue area is the central focus of this report.

The report endeavors to provide a context for assessing the LTC system as a whole from a consumer perspective and present ideas and recommendations on how restructuring should be tailored to best meet the needs of consumers. Two resources are used as a basis for identifying major consumer priorities and preferences and for assessing LTC programs and restructuring proposals: (1) the Long Term Care Community Coalition's white paper on the future of long term care in New York, which identified a number of fundamental principles for the long term care system and (2) the results of a survey of long term care ombudsmen and consumers across New York State, conducted for this report. While financing is, of course, a crucial issue, the report does not focus on financial issues *per se*; the relative "efficiency" of home and community based vs. institutional services continues to be debated and will, undoubtedly, be an area of further study by scholars and economists for many years to come. The goal of this paper is to present a consumer perspective on programs and options that are plausible within the present financing context.

Based on the principals identified in LTCCC's earlier white paper – which center on the need to focus on and empower the three people at the heart of the LTC system, the consumer, the formal caregiver and the informal caregiver – survey participants were asked to evaluate whether the LTC programs that they are familiar with are meeting the white paper principals. Their responses are discussed in terms of the different residential and community based programs and their overall thoughts about the challenges facing the system. While many of the responses confirmed well-acknowledged issues, like the systems overreliance on a "medical model" and lack of sufficient trained direct care workers, a number of participants made "out-of-the-box" recommendations such as "making nursing homes without walls the norm instead of institutionalizing a population we should revere" and "[Governor] Patterson appoints a NYS Contractor/Builder with a heart for the needy. No politics."

Understanding the consumer as a whole and tailoring care to each individual's needs and preferences is one of the principles from LTCCC's white paper on the future of long term care and, as the survey results revealed, consumer

representatives from across the state believe this to be one of the most important principles. Thus, the discussion on LTC program evaluation is premised on the idea that the government should assess whether or not all of consumer needs (medical as well as emotional and social) are being met.

However, because the monitoring and evaluations currently being done may not be sufficient or reliable in this respect, it is difficult to determine the extent to which long term care programs are achieving their goals or standards, particularly the goals and standards that relate to issues concerning consumer self-direction, psycho-social well-being or access to committed and skilled care givers. While the state is responsible, under the auspices of the federal government, for monitoring and oversight of programs that are funded through Medicaid and/or Medicare, the focus of these efforts tends to deemphasize non-medical issues. Though it varies somewhat from state to state, our findings indicate that, on a national basis, there seems to be little evaluation of outcomes for most programs, particularly for home and community based services (HCBS). While the ultimate goals for community based programs are to provide care in a setting that maximizes the individual's level of functioning and quality of life, little is known about how well these goals are being met.

The final section looks at the experience of New York State in terms of the principal priorities for consumers (and the challenges to achieving them): the need to appropriately and accurately assess the consumer's needs and desires; the need to overcome access issues; the need for sufficient direct care workers who have the appropriate training and supports to do their jobs well; and the need for meaningful consumer direction and control. Selected initiatives undertaken by other states that could be instructive for New York are discussed for each issue and recommendations for the state as it moves forward are presented.

The full report, with links to reports and websites of interest, as well as other relevant information can be accessed from our website, [www.ltccc.org](http://www.ltccc.org) (directly at <http://www.ltccc.org/key/AccessToLongTermCare.shtml>).

