



Disability, Long-Term Care, and Health Care in the 21st Century

Michael Morris, Johnette Hartnett

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Some people say that a picture is worth a thousand words. The field of management often uses a "rich picture" systems methodology, "an innovative tool that encapsulates knowledge relevant to strategic reform". It is often described in the management literature as a "soft systems methodology" for linking hard and soft facts in a cartoon-like representation to illustrate a complex problem simply and clearly. The following research is presented using the rich picture methodology to capture the current long-term care and long-term services and supports (LTSS) crisis. The picture and narrative rely on expert research from the past and present, as well as on one-on-one open-ended interviews with key stakeholders in the fields of disability, long-term care, and health care. The setting for the rich picture is the ocean, with the current LTSS ship heading toward an iceberg that represents the barriers and challenges to systems reform. The "cast" for this rich picture will provide the substantive descriptions and body of research and analysis about the barriers and challenges of navigating through the current system of LTSS. The presentation of the research is purposeful, so that the reader and the researcher can begin the voyage together with a snapshot of the problem. The purpose of this research is to produce new knowledge and understanding of current experience with and future need for affordable LTSS for people with disabilities. This research on the State of LTSS Financing and Systems Reform is the first part in a five-part series that will tell the story of the current LTSS system to set the stage for the exploration of future market demands and current gaps in supply; to explore promising state practices and challenges; and to picture what the 21st century's comprehensive, consumer-responsive system might look like and make policy recommendations. The research is based on five assumptions. First, people with disabilities, whether young or old, desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Second, the current financing mechanisms (public and private) will become unsustainable in the near future without significant reform. The system must be affordable to all Americans regardless of income levels and must consider opportunities to leverage public and private support in new ways without impoverishing beneficiaries. Third, there is an opportunity with the changing demographic picture of the United States to explore the possibilities of a universal approach to the design and financing of services and supports that is responsive to individuals under the age of 65, as well as seniors with disabilities, without sacrificing individual choice and flexibility. Fourth, formal and informal caregiving must be sustained, examining family needs and workforce recruitment and retention challenges. Fifth, the approach to quality must examine consumer direction and control of resources in addition to traditional external quality assurance mechanisms.

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