

# Introduction

The MIT Workplace Center's research on the geriatric health care system in the Greater Boston area began with a focus on the crucial work of the professionals who provide health care to elders. As we traced their daily routines, we were struck by the presence and involvement of family members in all settings – be it hospitals, rehab facilities, out-patient clinics, or homes. This prompted us to shift the focus of our project to family caregivers in order to document in detail the role that families are playing in elder care.

Two major findings emerged from this research on elder caregivers.

First, families are carrying an increasing degree of responsibility for the care of elders in our society. As health care costs continue to escalate, and fee for service home care is increasingly out of reach, elderly patients often face the need for significant medical and personal care with only minimal institutional support. This produces considerable pressure on families to organize and monitor both in-patient and out-patient care for elderly relatives and often to provide care themselves in their homes – which they are doing in great numbers.

In fact, we call family caregivers a "shadow workforce" in the geriatric health care system because on the one hand, their work is essential to the functioning of the current system, but on the other, it operates in the shadows, usually invisible and often undervalued.

Second, we found that when families try to put services and supports in place, they often have difficulty finding the basic information they need, or even knowing where to look. Although a wealth of information is provided by health care and social service agencies for the elderly, when caregivers try

to find it they get easily lost in a maze of 800 numbers and unlinked websites, with no mechanism for coordination.

This Handbook is written with the caregiver in mind, both those anticipating the need to provide care and those already actively involved in elder care. It provides in a single source both the basic information and tools needed to navigate the elder care system in Massachusetts. It explains how the service delivery system is organized, and contains a glossary to define unfamiliar elder care terms. It provides an introduction to the major components of elder care by framing the questions caregivers need to ask and the key issues they need to consider. It is a gateway to eldercare resources and organizations across the Commonwealth.

Although it is a small step in addressing the unmet needs of family caregivers, we hope the Handbook will be part of a growing movement to recognize the important work that caregivers do, and expand the resources they need to do that work well. With the number of elders growing and living longer lives, ensuring the wellbeing of elders and caregivers alike should become a priority for Massachusetts.

**Ann Bookman, Executive Director**  
**Mona Harrington, Program Director**  
**MIT Workplace Center**

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