
**A REPORT TO THE SECRETARY OF THE
EXECUTIVE OFFICE OF ELDER AFFAIRS**

**Caring for the Caregivers:
Improving Resources for Elder Caregivers
In Massachusetts**

By

**The MIT Workplace Center
Sloan School of Management**

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EXECUTIVE SUMMARY

November 2007 marks the 14th annual celebration of National Family Caregiver Support Month. The month provides a wonderful opportunity to thank, support and celebrate the invaluable contributions of caregivers across the country – now over 50 million strong. But it is also a time to reflect back and assess whether the community resources and public policies we have as a state, and as a nation, are adequate to supporting family caregivers all twelve months of the year.

This report from the MIT Workplace Center is based on its own research on family caregivers of elders, as well as the views of a wide variety of eldercare and geriatric health care professionals. It is intended to stimulate greater awareness of the needs and challenges that family caregivers of elders face, and to provide some ideas on how the Commonwealth of Massachusetts can expand its support for the important work that families do for each other. Here follows a summary of recommendations to expand caregiver support.

- **Make Elder Care and Caregiver Support a Public Priority** by launching a public education campaign on existing agencies and services, and requiring interagency planning and coordination at the highest levels of state government.
- **Build Stronger Connections between Health Care Institutions, Elder Care Services and Families** to create a seamless system so that elders and their families can move safely and easily across diverse care settings.
- **Expand Caregiver Support Resources**, including information and referral services, respite care, and affordable geriatric care management services.
- **Emphasize Wellness for Caregivers** by teaching caregivers self-assessment techniques and by making PCPs and other health care providers more aware of, and proactive about, caregiver health issues.
- **Train and Certify a Geriatric Care Workforce** by expanding continuing education courses for doctors, nurses and social workers, and expanding the number of medical schools and nursing schools with a geriatric care focus.
- **Create More Effective Transportation for Elders** through a combination of public resources, affordable fee for service programs, and community volunteer programs.

- **Encourage Employers to Expand Workplace Supports** such as leave programs, flexible work arrangements and elder care information.
- **Improve Conditions of Support for Paid Caregivers**, including a livable wage, health insurance and adequate benefits for those in the Personal Care Attendant Program, and the Adult Foster Care Program, and expand the definition of “eligible family” members to include spouses as well as other family members.
- **Utilize Information Technology to Help Elders and Caregivers**, including expanded computer access to elder care services and resources, as well as in-home monitoring devices and other types of assistive technology.
- **Make Massachusetts a Model for Supporting Caregivers at Work** by providing elder care resource and referral services, flexible work arrangements, and adequate leave.

The ten-point plan above is offered as a starting point for a statewide conversation on change – but it’s not just about changing line items in the state budget or changing the benefit plans of private sector employees. It’s about the need for a cultural shift, a change in attitudes and social values.

As the elder care experts convened in an MIT Caregiver Forum in 2007 made clear, the extent of caregiver support is closely tied to the way we in our society view aging and the elderly. If we see old age a normal part of human development, and elders as an asset, then we will enhance the ability of caregivers to plan ahead for elder care and provide the appropriate resources for each stage of aging.

Part I. Public Awareness and Helping Families Care for Elders

The “aging of the population” – this phrase has almost become a cliché, but what does it really mean for the quality of life in Massachusetts? It means that over the next 25 years, there will be increasing numbers of elders living longer, working longer, contributing to our society longer, and needing care longer. While these demographic trends and the aging “baby boomer” generation get considerable media attention, the increasing numbers of families who will be providing elder care, and the strains on families who are already struggling to provide that care, do not.

This report aims to put a spotlight on the almost 700,000 residents of the Commonwealth who are now involved in caring for elders and disabled family members. It has been estimated that they spend 697 million hours a year providing care, at an annual market value of \$6,914,000.¹ These figures of course cannot measure the social value of what it means to an elderly person to receive good care, or the social and economic cost to elders and their families

¹ These statistics are based on data collected in 2004 and prepared in August 2006 by the National Family Caregiver Alliance and Family Caregiver Alliance’s National Center on Caregiving in conjunction with Dr. Peter Arno, Department of Epidemiology and Population Health, Montefiore Medical Center, Albert Einstein College of Medicine.

who are struggling to find and pay for that care. If the work of family caregivers is to become fully visible and fully valued, then a significant shift in cultural attitudes toward both aging and elder care work is needed.

Three issues that require broad public education in Massachusetts:

First, is the need to recognize old age as a normal part of life, a normal phase of human development, not a disease.

Second, and directly related to this cultural shift in attitudes toward aging, is the need to recognize that caring for our elders is also a normal part of life, not something to be denied or feared. Families need to see the importance of planning for care before a crisis arises. This includes financial, healthcare and legal planning, and learning where to find good elder care information in their community. It means accepting the changes that aging brings, both for elders and for their families.

And third is the need for innovation in the financing of eldercare. Moderate-income families – that is the majority of families – are in a particular bind when it comes to buying the services and equipment they need for elder care. They do not qualify for most subsidized services, but they also cannot pay for long term, private home care and geriatric case management services. New financial models are needed to help accommodate elder care requirements for all, not just the wealthy and the poor.

Part II. Recommendations for Improving Caregiver Resources

On January 31, 2007, the MIT Workplace Center at the Sloan School of Management convened a public forum on elder care and caregiver issues, “Who is Caring for the Caregivers?” Over 160 leaders from a broad cross-section of organizations that work with the elderly and their families in Massachusetts attended the forum. A panel of elder care experts was asked to consider two questions: what are the dimensions of unmet caregiver needs? And what can a variety of state and community organizations do to expand caregiver supports?

The following recommendations are based on both the ideas of forum participants and the findings from a multi-year MIT research project on elder caregivers (detailed in Part III).

1. Make elder care and caregiver support a public priority

The overwhelming consensus of families and experts alike is that the residents of Massachusetts do not know about the important resources that state government and community-based organizations provide for elders and the families who care for them. Information and referral services, such as 1-800-AGE INFO, and the help lines provided by the Area Agencies on Aging (AAAs) and the Aging Service Access Points (ASAPs) are not well known. The additional resources available through Councils on Aging (COAs) in 348 cities and towns of the Commonwealth are also not widely known. A public education campaign about how state government and local organizations help families of all ages, incomes, and abilities would help

elevate the issues surrounding aging, and encourage the public to connect to resources before a crisis develops.

In terms of the Executive branch of state government, Massachusetts was the first state in the country to have a cabinet-level position for elder affairs. In order to maximize the effectiveness of the Secretary of Elder Affairs and the Executive Office of Elder Affairs, Governor Patrick should require interagency planning and coordination at the highest levels of state government. In this way, Massachusetts will be able to address the major demographic shift that is just starting – the aging of the population – and plan for appropriate changes in areas such as home care, health care, housing and transportation.

2. Build stronger connections between healthcare institutions, elder care services and families

An issue that affects all caregivers – and one that requires broad systemic change – is the need to create better connections and collaboration between health care practitioners, community-based elder care agencies and families. Both health care providers and social service providers are counting on families to take charge and frequently to take over the care of an elder, but they do not communicate this clearly. They often provide too little information or too much information, leaving caregivers feeling isolated and overwhelmed.

Better coordination of services at the point of hospital and rehab discharge is particularly needed. This means insuring that all medical records, prescription drug information and dietary needs are transferred with the elder, as well as culturally sensitive information about their physical and mental health status at the time of discharge. However this improved coordination is accomplished, it is a change that would profoundly benefit family caregivers who now spend so much of their time and energy trying to connect the pieces of a fragmented geriatric care delivery system.

3. Expand caregiver support resources

The agencies providing caregiver support programs need additional funding and resources to build the reach and effectiveness of their programs. A comprehensive, well-coordinated and culturally sensitive set of programs and resources for caregivers would include:

- Improved Information and Referral Services:
 - * Centralized and accessible sources of information and referrals;
 - * Referral services for long distance caregivers who need help identifying agencies and resources in other states;
 - * Translation services and multi-language materials for non-English speaking caregivers and elders;
- Increased access to affordable geriatric case management services;
- Increased respite care programs that cover evenings and weekends;
- Changes in the HIPPA law to expand access to needed medical information; and
- More available and affordable legal information services

4. Emphasize wellness for caregivers

We need greater awareness by health care institutions and practitioners that caregiving is stressful and can lead to its own set of physical and mental health issues. Caregivers themselves need to be educated about the importance of not compromising or ignoring their own health issues.

Broad dissemination of caregiver self-assessment tools – by health care practitioners, discharge planners, and community-based elder care agencies – could be a useful part of this process. For example, having primary care physicians ask patients about their caregiving responsibilities when they go for annual physicals or other appointments, and promoting exercise and nutrition programs targeted at elder caregivers.

5. Train and certify a geriatric care workforce

Addressing caregiver health issues, as described above, requires a workforce of health care professionals trained in geriatric assessment and geriatric care - including physicians, physician assistants, nurses, social workers, case managers and others. We also need health care personnel trained in palliative care and an expanded public understanding that palliative care does not mean death is near but rather that pain can be controlled and comfort can be enhanced when curative measures are no longer possible. However, at this time very few health care professionals have expertise in either geriatric or palliative care.

Given the aging of the population and increasing numbers of elders and caregivers, this need will only intensify in the years to come. We need a concerted effort in the present to change and develop new curricula in medical schools and nursing schools that focus on the special needs and issues of aging. We need also need continuing medical education courses and other opportunities for geriatric training in the post-professional school years.

6. Create more transportation options for elders

While some caregivers can provide transportation for the elders in their care who do not drive, many cannot for a variety of reasons: they may be working, they may not physically be able to transfer an elder into a car or van, or they may not have access to a car or van that can safely transport an elder whose mobility is compromised. Accessible and affordable transportation can decrease pressure on caregivers and enable elders to do daily errands, get to doctor's appointments, and participate in social and cultural events independently.

Good transportation options are not only about getting from one place to another, but also about decreasing the kind of social isolation that can affect both elders and their caregivers. Given the importance of this service, we should find ways to expand the number of solutions beyond the regional transportation authorities. Suggestions for expansion include having grassroots groups organize volunteer drivers in their own local communities, or having hospitals cluster appointments of elderly patients so that it is cost effective for them to transport groups of elders in a given city or town to and from their appointments.

7. Encourage employers to expand workplace supports

There are many things that employers can do to expand their support of employees with elder care responsibilities. These include strengthening Employee Assistance Programs and

support groups, offering geriatric case management services to employees, providing flexible work arrangements to allow caregivers to take time off during the workday to accompany elders to doctor's appointments or respond to emergencies, and ensuring that all employees have paid sick days so they can care for their own health issues.

In addition, caregivers who are self-employed have particular needs. While they may have considerable flexibility in their schedules, they do not have access to paid sick days or other kinds of standard employee benefits, and they are not covered under the Family and Medical Leave Act (FMLA), so support programs recognizing their situation are needed.

8. Improve conditions of employment for paid caregivers

Keeping elders healthy and in their own homes for as long as possible is acknowledged as the most desirable, and also the most cost efficient plan. Caregivers are essential to the home care strategy. There are several programs that allow low-income caregivers to care for their elderly relatives, most notably the Personal Care Attendant Program and the Adult Foster Care Program, which pays family members and others to provide care for elders who are Medicaid eligible and need help with their activities of daily living.

Both programs are in need of expansion in concept and resources. For example, the definition of eligible family members does not include spouses, and a spouse is often the person an elder would prefer as a caregiver.

Foremost, these programs need to provide caregivers with health insurance and an hourly rate of pay that constitutes a living wage. In addition, caregivers need training opportunities in basic CPR and safety skills, as well as knowledge about the chronic illness that are common among the elderly such as diabetes, dementia and congestive heart failure.

9. Utilize information technology to help elders and caregivers

As more and more caregivers gain access and experience using computers and other high-tech devices, technology can help to advance many of the caregiver support programs being delivered through health care institutions and elder care service providers. While there is no substitute for personal contact with a well-trained elder care professional, or a close family member, technologies can be particularly useful in several areas;

- Computers can give caregivers access to important resources, services, and information.
- In-home monitoring devices can allow frail elders to remain safely in their own homes with some degree of oversight. These kinds of devices can assist with nutrition, medications, and other daily routines, and may be particularly important to employed caregivers who cannot be present with an elder during the day.
- Computers can also connect caregivers with other caregivers for both support and information sharing. Some organizations provide caregiver "chat rooms" for caregiver support; others offer calendaring and networking programs to connect caregivers to family and friends who want to share caregiving responsibilities.

10. Make Massachusetts a model for supporting caregivers at work

State government has a special role to play in making Massachusetts a model for supporting caregivers who are employed. First, as an employer, the state can model support for elder caregivers in their own policies and practices. Whether it is a good referral program for state employees looking for elder care services, or the availability of part-time positions and job sharing arrangements, the Commonwealth can show other employers the benefits of these policies to productivity, recruitment and retention.

Second, the Governor could recognize private sector employers who do have model caregiver support programs. This could be done through tax incentives, or by publicizing the best practices of employers who have shown leadership in this area and encouraging other employers to follow suit. A statewide conference that would showcase what “elder-friendly” employers are doing – including small, medium and large firms from a variety of industries – could be a catalyst for other employers to follow suit, and give employed caregivers ideas to take back to their own Human Resource Departments.

These recommendations grew out of a three-year research project and the expertise of many elder care and health care professionals. The development of this research project and the key findings of the study are summarized below.

Part III. Background: The MIT Research Project

In 2003, the MIT Workplace Center launched a two-part study of the geriatric health care system in the Greater Boston area. The first phase of the research focused on the lives of health care professionals who provide geriatric and palliative care. Observing the work of two mobile teams from Harvard Vanguard Medical Associates (HVMA),² their clinical practice was traced as they moved from hospitals to rehabilitation facilities to patients’ homes, and back and forth. These observations provided evidence that the mobile team model is particularly suited to geriatric care because it allows for a high degree of continuity of care that is beneficial both to elders and their families.

These work observations also revealed that the families were playing an important role in caring for elderly patients in all settings, both inpatient and outpatient. To better understand their roles, phase two of the study focused on the families of the elders the HVMA teams were caring for, and in-depth interviews were conducted with a diverse group of fifty family caregivers of elders. An article detailing the findings is available from the MIT Workplace Center.³

This research project generated a number of findings. First, the study documented persistent problems with the current system of geriatric care. Although many of these are well-known, what is not fully known or understood is how they impact the lives of caregivers *and* how caregivers respond. Four key issues were identified by caregivers as particularly

² Access to the HVMA teams was made possible through collaboration with a team member, Dr. Robert Buxbaum. He was co-principal investigator of the research project and crucial in drawing our attention to the often unrecognized issues facing families caring for elders.

³ A. Bookman and M. Harrington, “Family Caregivers: A ‘Shadow Workforce’ in the Geriatric Health Care System?” *Journal of Health Politics, Policy and Law*, 32:6, 2007 (forthcoming).

challenging: a lack of basic information about how to find elder care services and resources; a lack of coordination and communication between the health care institutions and the community-based services on which elders rely; significant gaps in the provision of elder care due to understaffing in hospital/rehabs and high staff turnover in community-based service agencies; and a lack of access to health care professionals with expertise in geriatric medicine.

The study further documented how caregivers respond to these deficiencies in the system of geriatric care. First, they act as *unofficial geriatric care managers*, lending some degree of coordination to an otherwise fragmented system. Second, they are like *walking medical records* often providing health care professionals with the only comprehensive picture of an elder's health history and current status. Third, they often act as *paramedics*, providing a type of care in the home that goes well beyond personal care and includes critical jobs that are usually done by trained health care providers. And finally, they acted as *patient advocates*, insisting on quality care standards and stepping into the breach themselves when adequate care was not available.

The study co-authors, Ann Bookman and Mona Harrington, challenged the common assumption that family caregivers provide care only in private homes, that is, their own homes or the homes of the elders that they care for. What they observed is that families are playing an important caregiving role in hospitals, in rehabilitation facilities, in nursing homes and in outpatient settings— not only in homes. They also found that the work families are doing outside of the home is largely invisible to most people, and so they call family caregivers a “*shadow workforce*” in the geriatric health care system.

Based on these research findings, Bookman and Harrington offer a number of recommendations of interest to both public policy makers and employers. One set of recommendations focus on increased support for family caregivers, such as expanding respite care programs, expanding training opportunities, and increasing flexible work arrangements for employed caregivers. Another set focus on what health care institutions and community-based agencies can do to build a better integrated, better quality geriatric care system.

Following the MIT Workplace Center's commitment to translate research findings into action plans, the Center developed the *Family Caregiver Handbook: Finding Elder Care Resources in Massachusetts*⁴ to address caregivers' need for accessible information. It is designed to give caregivers a tool that will help them navigate the geriatric care system and become knowledgeable, pro-active consumers of elder care services and geriatric health care.

While the Handbook is a useful tool for providing accessible information about the elder care delivery system and available resources, information is clearly just one of a myriad of supports that caregivers need. In the pages that follow, a detailed picture of those needs and how to address them is provided by a diverse group of elder care experts with literally decades of experience to share.

⁴ A. Bookman, M. Harrington, L. Pass and E. Reisner, *The Family Caregiver Handbook: Finding Elder Care Resources in Massachusetts*. Cambridge, MA, MIT Workplace Center, January, 2007. The content of the Handbook is also available on the web at: www.familycaregiverhandbook.org

Part IV. The Panel: Framing Elder Care Challenges and Opportunities

In order to understand the depth and breadth of issues facing family caregivers of elders in Massachusetts, in January 2007, the MIT Workplace Center convened a panel of distinguished geriatric health care and elder care experts and provided a public forum to address the question, “Who Is Caring for the Caregivers?” The panelists – and eventually all of the forum attendees, over 160 strong – were asked to describe the challenges that family caregivers face, and most importantly to frame ideas on how we can improve supports for caregivers.

The panelists are briefly introduced here:

- **Joan Butler** is Executive Director of Minuteman Senior Services, an agency that runs 22 different programs and services for communities north and west of Boston. Previously the president of Mass Home Care, Joan has over 25 years of experience in developing and managing programs for seniors and their caregivers at both the state and regional levels.
- **Dr. Robert Buxbaum** is an Associate Clinical Professor of Medicine at the Harvard Medical School. Since 1964 he has been practicing internal medicine with the subspecialty in hospice and palliative care. As a physician at Harvard Vanguard Medical Associates, he practices principally at geriatric and end-of-life centers and consults on palliative care issues at the Brigham and Women’s Hospital and Faulkner Hospital.
- **Andrea Cohen** is CEO and co-founder of HouseWorks, an award-winning, private pay home care agency. For the past 20 years Andrea has been a leader in elder care business development and innovative partnerships for home care. She is also the co-founder of the Family Caregiver Coalition of New England.
- **Rebecca Gutman** is the Community Coalition Coordinator for 1199SEIU United Health Care Workers East. She has worked in the labor movement for 10 years organizing low wage health and human service workers. Most recently, she organized a broad coalition of senior, disability, and other social justice organizations to support a Massachusetts law making improvements to the MassHealth PCA program and giving Personal Care Attendants the right to form a union.
- **Barbara Moscovitz** is Coordinator of Geriatric Social Work at the Massachusetts General Hospital and Director of a community-based program, MGH Senior HealthWise. She has over 27 years of experience working with elders and families. Barbara is also the executive producer of a new film, *Family Matters*, designed to introduce newly diagnosed and early stage patients and families to the world of Alzheimer’s.

MODERATOR: I am going pose two questions and ask each of our panelists to answer in turn. First, thinking about your own professional experiences over the years, and we have hundreds of years of experience here on this panel, what do you see as the key unmet needs of family caregivers of elders?

BUTLER: To start with, in my experience, one of the key unmet needs is the need for a different language. Just the word caregiver itself is a problem because most people don't self-identify as caregivers until the situation is so stressful and so overwhelming that they are often at a crisis point. I think that's a challenge before all of us to figure out how we let people know that you don't need to be living with someone and caring for them to be considered a caregiver. You don't need to be doing physical, hands-on care to be called a caregiver. You don't need to have 24/7 kind of involvement to be considered a caregiver. In fact, if there's any older person in your life that you're at all concerned about, and you're starting to ratchet up your contact with them and your concern, then you're a caregiver. And there's lots of support out there. I think the MIT Workplace Center is really to be commended, and I think the Family Caregiver Handbook is a tremendous contribution to our field and can go a long way in helping raise awareness and be a tool for caregivers. The challenge is to try and get it into people's hands before they need it, or at the early stages when they're just anticipating caring for an older relative or themselves.

I think very often people feel that if they're a daughter or a spouse, then they should be doing this. This is just part of daily life and again, the label caregiver doesn't seem to fit until the extreme takes place. I'm hoping that we can work to change those attitudes and the Handbook can help us do that. The lack of information – obviously where to turn – is a big challenge.

We at Minuteman hear this over and over again, even though agencies like mine—we feel like we've been beating the bushes for 30 years telling people, "we're here, we're out there." And I know the Councils on Aging are a very strong presence in their communities and they've been out there for a long time too. Again, I think it's the lack of a consciousness - until you're faced with a critical problem, you don't necessarily pay attention to what's out there and available to you.

We live in such a busy society; we're all so busy with our own work and family lives, that when things are going well we tend not to take in that kind of information. I think there is a lot of information out there, [although] it can be scattered. There are structures and you'll hear of agencies like mine – which is an Area Agency on Aging and an Aging Service Access Point – that were set up to be a centralized first step source of information, one-stop shopping if you will, to try to answer people's questions and then refer out or provide services to meet a wide variety of needs.

I think also the public awareness issue is particularly relevant in the area of home and community-based care. When we were all growing up, at least in my experience, when my grandmother needed help, the family was there to a degree, and a nursing home was the only other option. Nowadays there's a rich mix of home and community-based services out there, but

“Just the word ‘caregiver’ itself is a problem, because most people don’t self-identify as caregivers until the situation is so stressful and so overwhelming that they are often at a crisis point.”

*–Joan Butler,
Minuteman Senior Services*

most people are just not familiar with the lingo or the levels and different models of care, whether it's "adult day health," "personal care attendant," all the various models that are now available weren't available when we were younger. I'm hoping maybe our children's generation will have a different understanding of the range of options available to keep an older person at home, which is where they want to be, and where family members – who, as Ann said, do most of the care – want to keep them. And the down side: I think the Internet is a fabulous resource, but I think it can almost be overwhelming, giving too much information and unreliable information, even misinformation, and too much, too fast.

“Nowadays there’s a rich mix of home and community-based services out there, but most people are just not familiar with the lingo or how to access these services.”

–Joan Butler

The other thing that follows is that when people get all this information they really need a one-on-one relationship with someone to help them sort it out and validate them emotionally. My staff who work with caregivers on a daily basis - and we serve over 2,000 people a year in this situation - will tell you that caregivers very often break down in tears and just say, “Thank God somebody is here listening to me and can empathize with what I’m going through and help me sort through the maze of all the programs, benefits, eligibility, the stresses, help me decide exactly what is the right path for me to take at this point in time.”

Obviously families need support with tasks and with respite care. While some people have medical needs for ongoing skilled nursing support, the vast majority of needs that older people have to remain independent at home is in non-medical services, the tasks of daily living: shopping, laundry, transportation, personal care—and caregivers really need respite. You never want to supplant what family members do, but we want to complement it. So respite care, a break from caregiving, and just allowing caregivers to care for themselves. We did a focus group when we started our family caregiver program and I’ll never forget this one woman who said, “I just want a good night’s sleep. I can do everything for my mother. I just need a good night’s sleep.” So we help family members zero in what they need to keep going – and give them the validation and the support they need – that is really what we’re all about.

BUXBAUM: First of all, I just want to thank you for the collaboration that we’ve enjoyed all through these last three years. I do want to correct one thing: I was not involved in this work until about 12 years ago when my friend and colleague Dr. Mark Yurkofsky drafted me; like most physicians I knew nothing about pain control, geriatrics, or the other issues that I’m now dealing with daily. So it’s been a learning experience, a transformative experience for me; I think that it’s fair to say that most physicians don’t have this background or interest. Most patients will never meet a palliative care physician or nurse, or experience hospice, unless they ask or if the institutions they encounter offer this alternative.

There are a lot of social policy implications related to this topic, and I just want to say this as we set out: I think most of you in this room are professionals, as I understand it, but

you're also family members. And I think if you turn yourself around for a minute and say, "How is this affecting me? How has life with an elder relative been? What has happened?" You will have learned more from that experience than from any of the professional education you've had.

Geriatrics is a little bit like pediatrics: there is almost never a patient that I've seen who doesn't have family involved. And the family meeting, the least-studied part of our work, is the most important mechanism we have for achieving change, in my view.

I also want to emphasize this: the death rate is 100%. Not the age-adjusted death rate, not the disease-specific death rate. There is a final, absolute, immutable death rate of 100%. The reason I mention this is because in this Boston urban community in particular, we have a problem. Here is the problem: If you look at today's paper you'll see that the Dana Farber Cancer Institute is proposing a billion dollar expansion, not a million dollars, not ten million dollars, a *billion* dollar expansion to cure cancer and to use the new advances in cancer care that are coming on line. My comments are not to be taken as diminishing the need for this. It's simply that the public relations side of medicine is a bit out of balance with the reality of eventual death and dying. Thus geriatrics and palliative care must compete with the universal expectation of cure.

It's perhaps a little different in other parts of the country. It's certainly different in less developed countries, but this is our unique Boston problem -- "cure" is the gold standard.

From family meetings and talking with families and patients as my colleagues and I do, what we've learned is that families have no idea how to approach the inevitability of dying. They are in the wilderness. It is the opposite of what happens around birth. Conception, birth, pregnancy, child education, child rearing, for example: these are well-supported areas of life in which everybody knows where to turn to find help. There are other moms and dads, there's the web, there are magazines and books, and of course there are obstetricians, pediatricians, and abundant other professional resources. There are whole hospitals devoted to the challenges.

But with elder care and dying, nobody knows where to turn to find help. As has been pointed out very nicely, there are many helping agencies around. The MIT Family Caregiver Handbook is going to be very helpful. When you're dealing with the problems of an elder loved one, and you're part of the sandwich generation -- it's actually now the "club sandwich generation," -- you're going to have to deal with complexity of a new order. The challenge is clear. But I don't think we're really prepared to do what needs to be done, nor do I think the public has begun to understand the political and social dimensions of this astounding problem.

**"In geriatric medicine, the family meeting – the least-studied part of our work – is the most important mechanism we have for achieving change, in my view...families have no idea how to approach the inevitability of dying. They are in the wilderness."
–Bob Buxbaum, M.D.
Harvard Medical School**

Let me give you the typical situation as it exists in our hospitals. A typical patient on the medical service—the internal medicine service is the main one I deal with—is probably 84 years old and presents a list of 8-10 problems: cardiovascular, pulmonary, endocrine (diabetes, for instance), depression, delirium, neurological, functional decline, and so forth. But the training of the hospital staff caring for the patient is to *cure everything*. How can we square that with the inevitable decline that patients suffer at that age? How can we maintain function? And how can we improve the quality of life? Those are the issues, not exclusively cure.

One more thing. In our family meetings, I find it's best to rest on an ethical, biological framework. There are four elements, with the overlying standard that says: tell the truth, even though it may be upsetting, anger producing, and frightening. Almost universally, families and patients can learn to accept this.

The four principles are:

- 1) *Patient Autonomy*. The patient decides. I don't want to go into this in detail because we all know what the legal issues around this issue are, proxies, living wills, and the like, but nonetheless, the patient is the decider. Politicians are not the deciders, doctors are not the deciders. The patient is the decider. Unless he or she is cognitively or otherwise unable to express a wish, in which case, the proxy acts for the patient. Does everyone have a proxy? No. Should everyone have a proxy? Yes.
- 2) The second principle is the *Principle of Beneficence*. Is this action that we are going to take - whether it's a test, or a procedure, or a move to another place - will it do good? What are the chances that it will be beneficial? Sometimes we can quantify those based upon medical research, sometimes not.
- 3) The third principle is just the opposite - it's Do No Harm, or the *Principle of Non-Maleficence*. Are we about to do something that's potentially harmful to this patient? Taking this patient into an operation, or doing a test that might be painful, or even moving them to another facility may do harm.
- 4) And the fourth principle is the *Principle of Distributive Justice*. Are we doing as much for this person as we would do for anybody else under similar circumstances and given the disease that we're facing?

Those principles have been around for a long time, but most families and many professionals have never heard of them. The principles are tools that we can use, patients and families can use, and society can use to help make decisions in complex situations. If we have to face such dilemmas, we all can use ethical decision making. Life isn't perfect, death is inevitable, decisions have to be made, and ethics can assist us in coming to some kind of common ground. Thank you.

“Life isn't perfect, death is inevitable, decisions have to be made, and ethics can assist us in coming to some kind of common ground.”

—Bob Buxbaum, M.D.

COHEN: When I was asked to talk about the unmet needs of caregivers, what I decided to do - because it's such a vast topic - is to throw out a vision to you. I want to talk about what the world would look like if family caregivers were fully supported and felt on top of their game, so when they go into this caregiving responsibility, they do it well and feel great. So remember, this is the vision. I think that pieces of this exist, but we still clearly have a lot of work to do.

So, first of all, in this vision, family caregivers would be confident that they're making informed decisions about their parents' health care and living arrangements. They would know what their parents want, know their preferences, know what they fear. They've had the conversation.

They're aware of all the services and living options that exist, and they know there are certain trade-offs with each one of them. They're realistic about that. These folks are developing confidence in their informed decisions because they have access to a medical team who spends time with them, answering their questions and explaining their treatment options in a way that they understand and feel supported. They also have easy access to information about health, housing and other kinds of services. Currently, as Joan says - there is so much caregivers don't know—they seek out people like us and say, “Am I doing this right?” We need to supply them with the tools to help them feel empowered to make informed decisions.

“We need to supply caregivers with the tools to help them feel empowered to make informed decisions.”

*—Andrea Cohen,
Houseworks*

Second of all, in this vision, caregivers would feel confident that their parents have the supports they need during all their health care transitions. An example of a health care transition is when they move from one part of the continuum to the next. When they are discharged from a rehab and all of a sudden they can't drive and they need a little help around the house. Families would know that during all of these times, their parents have what they need.

What would they have? They would have a team of compassionate caregivers who treat them and their parents respectfully, whether they're using private pay or subsidized services. The families would be connected to a reliable service network that “owns” the problem. That's the big difference. If there's a problem with the services, that service provider will fix it. The responsibility does not only fall on family. And the service provider will show up, be professional and make communication easy.

They would know that their parents' health care information is stored in one place and easily accessible. Again, in talking with families now, most don't know where the information is, and when their parent goes to the emergency room, they have to find and collect it all. So that's point two.

Point three is that these families, in this visionary world, would have enough money to pay for what their loved one wants and needs. That they would understand what is and what is not covered by insurance. They would know how much money they have and how long their money will last. And finally, they would have had a frank discussion with their parents about the

realities of what they can and cannot afford. This would reassure them that their parents will be well cared for.

The fourth point is that these families will be able to manage all that they're currently doing, and also have time to take care of their parents. They know and accept their limits before they exceed them, and they're kind to themselves because they know that they can't do it all. This would especially pertain to working caregivers or those with young children. They have thought about and begun to answer the hard questions that are fraught with a great deal of emotion. Things like—what does it mean for them and their own families if they move their parent closer? Everybody automatically defaults to “I need to move my parent closer” but we must think about what it actually means for ourselves and our families? And if they've never had a great relationship with their parent and they all of a sudden have to take care of their mother, what does that mean?

“Personal care attendants in Massachusetts make \$10.84 an hour. They get no health insurance benefits at all.”

–Rebecca Gutman, 1199SEIU

Two final points: family members in this visionary world would feel supported. They would have emotional and social networks to depend on and a sense of connection and community as they meander through what is often uncharted territory. And finally, in this world, as these caregivers age themselves, they are confident that they have the flexibility and choices to do what they want as they grow older. They have assurance that they can take an active role to influence where they live and who they live with. They know that they will have more control than their parents if they start thinking about what they want NOW. Clearly we have a lot of work to do and this Handbook will help guide us.

GUTMAN: I have a little bit of a different perspective in that I work most directly with the low wage healthcare workers who provide care to elders and people with disabilities. 1199SEIU United Healthcare Workers East is a health care workers union devoted to improving and expanding quality patient care and protecting and improving the lives of healthcare workers.

So the folks I'm going to be talking about are actually paid caregivers - some of whom are also family caregivers - under the MassHealth Personal Care Attendant Program. This Medicaid funded program allows elders and people with disabilities to hire personal care attendants to support them in their homes. The costs of the program and wages paid to PCAs are funded by MassHealth.

I'm going to start by telling you a little bit about the people who are providing this care to elders, and to younger folks with disabilities. The MassHealth Personal Care Attendant program is a great program, but there are issues in the program that make it challenging for both the healthcare providers – the personal care attendants – and the people receiving care – the consumers. First of all, there is very high turnover among these paid caregivers.

Nor do they get any paid days off. When they work at night between the hours of midnight and 7 am, they often only get paid for two of those hours, between those times. So when you think about other jobs, it's pretty rare that you would only get paid two hours for potentially working during a 7 hour period. This situation means that elders are not being assigned enough care hours and the Personal Care Attendants are not paid for the full time they are at their consumers' homes and obviously makes it difficult both for the people receiving care and the people providing the care.

The majority of folks who are providing this care are women between the ages of 35 and 50. Because they are not given any paid days off including no paid sick days, they are often forced to go to work sick because they cannot afford to take an unpaid day off. Meanwhile Personal care attendants care for elders and people with disabilities, people who often already have compromised immune systems. We have heard too many stories of PCAs being forced to go to work sick and infecting the very people they are there to support. PCAs also have no health insurance through their jobs and often can't afford to go to the doctor. So while they are helping elders and people with disabilities live more independent lives, their own lives are often falling apart.

“Sometimes I lose a good PCA (Personal Care Attendant) because they need to go somewhere that provides better benefits. Without reliable, competent personal care attendants my life falls apart fairly quickly.”

–Home care recipient

I want to give you an example of a couple of specific people who are doing this work and a sense of their working and personal conditions. One person is Cliff Whalen from Lowell, Massachusetts. He provides personal care services for his brother. He's been doing it for 20 years. Cliff has no health insurance. He has a chronic heart condition. Because of the low wages and no insurance, Cliff actually can't afford to get the medication he needs to control his own heart condition. He has two kids. He's a single father and he's trying to support them all on \$10.84 an hour. Meanwhile, three people in his life are totally relying on him.

Miurka Morales is from Worcester. She cares for her elderly mother. She quit her job when her mother went into the hospital so that she could care for her mother at home and now gets paid for this work. But when she quit her job, she gave up her health benefits. She now has no health insurance and she's making \$10.84 an hour, raising two children.

And I want to end with a quote. This is a quote from somebody who actually receives PCA services in her home, from personal care attendants.

“Wonderful people have come into my life over the last 20 years. They have been my arms and legs, my administrative assistants, my personal groomers and my physical therapy aides, just to mention a few of the many things they do. PCAs have worked very hard for me at a job that can be demanding, isolating and at times even demoralizing. Sometimes I lose a good PCA because they need to go somewhere that provides better

benefits. Without reliable, competent personal care attendants my life falls apart fairly quickly. I see people who put off going to the doctor because they are not covered. They show up to work with bad colds and even the flu because they cannot afford to miss work. From asthma to skin conditions to family counseling, I see the downward spiral that happens when one has a job with no benefits.”

So just to wrap up, until the paid caregivers actually can afford to live doing the work they do, it’s always going to end up impacting both the seniors and the family caregivers who are basically left to pick up those pieces.

MOSCOWITZ: When you are the last person on a panel such as this you get to say, “I agree,” and I’m happy to tell you that.

I honestly think, and I do not say this lightly, I think we have an enormous sociological problem; it’s the fact that we really do view age as a disease. Our vision of age, and what happens when you get old, is that age just means illness. In fact, age or old age can be as long as a 45-year period of life, it is not so unusual if you retire at 65 and live to be 105. Isn’t it time that we acknowledge that old age is a developmental phase of life? For some reason we acknowledge childhood, adolescence, young adulthood, middle age, but not old age, death.

I don’t like jargon, and I don’t want to be glib about this, but if we could really understand, and if all of us at a certain age really understood that – I’m going to go to college, I’m going to get married, I hope to have babies, I hope to have a career, I expect to spend about 25 years possibly caring for my husband’s parents or my own. Caregiving has to be part of your life plan, because it is. And I think it’s quite stunning that when it happens, somehow we’re surprised – and please yell at me later if you think I’m wrong – I think fundamentally somehow we’re still surprised by old age. I think what we really need to do is acknowledge a whole process, and stop being so surprised that someone is going to get old and someone is going to need care. We actually have to normalize aging instead of thinking of it as only a disease.

So having said that, now the question is just what do we do about it? And even if it’s as simple as – when I think of retiring to Arizona, I buy a first floor apartment instead of a third floor walk-up – then I’ve thought about aging, and that’s how you think about it as a time of life, not a disease.

I think a lot of the time we think aging starts at the point of contact with the health care system which is illness during crisis, when you’re eligible for ASAP services and when you hit the hospital. And I think therefore in many ways, all of us, caregivers, children, family, patients, older adults, think of the issue of aging and the need to be a caregiver as a point of crisis. I’ll

“Caregiving has to be part of your life plan, because it is. And the caregiving experience - which can be a tragedy in the family’s life - can be poignant and rich if you have resources.”

**–Barbara Moscovitz, LICSW,
Mass General Hospital**

hold my breath for three weeks. I can be on leave from work for three weeks. I can let my bills go for three weeks. I can go over to Connecticut and be with Mom, and then it's over and I can go back.

We have to start educating all of ourselves in thinking about aging. It would be wonderful if at 85 we ran a marathon, but that is as likely as whatever, my being on the Patriots. If we normalize and understand old age - understand that there is a physiology of aging, just as there's a physiology of being a child - and that things do happen and that there are illnesses that happen. They're not necessarily normal consequences of aging, but there are functional issues that are consequences of illness.

If we think of the challenges of aging more as functional issues, then we can understand that when there's a crisis, when my mother has a stroke, it's not just the two weeks that I have to take care of her, and it will probably be the next eight years of her life. I think it is our job to educate the caregivers, as hard as that is for them to bear. [We need to tell them] that basically you could hold your breath for two weeks, but you can't hold your breath for eight years. And the caregiving experience - which can be a tragedy in the family's life - can be poignant and rich if you have resources, and it's a long-term experience. We're all afraid of that I bet. I am. But we have to make that adjustment.

“The real failure of our system now is that there are fewer points of contact for both patient and family to have a relationship with someone who will educate them.”

–Barbara Moscovitz, LICSW,

Here's how I'll blame the hospital system, and I mean this with all due respect. We're all part of a new system where essentially you can be in the hospital maybe until you wake up, but maybe not. I am so old and started working so long ago that when I started at MGH people would come in for two weeks for a lung biopsy. Now you have that on the way to the subway. And so think about the average patient stay. The average patient stay for an 85-year-old person who has a hip fracture is less than a week - a good, clean hip, you can be out in 48 hours. The patient is discharged very quickly before they and the family can adapt to the changes and new expectations. Once at the skilled nursing facility, the SNF social worker or discharge planner has his or her own favorite agencies, and by the time a person gets home, they may have the cards of four case managers and they may have the cards of three social workers. And then they get home, and who knows what, and they're on entirely new medicines.

So one of the problems I think is very profound and very serious for the caregiver - which is where this MIT Handbook is so important and other things are important - is that there are now fewer points of contact for both patient and family to have a relationship with someone who will educate them. It used to be when I was a discharge planner that I had a couple of weeks with the family and the patient. I could get to know them and say, “So you broke your hip, now what about thinking ahead to years from now.” I hope I was that smart. But that's what I think is the real failure in our system now. We are all under such pressure not to be talking to anybody for a minute that can't be perfectly accounted for on our database. What is missing is the relationship,

the single relationship, or the ongoing relationship, where that caregiver and patient have ongoing support through this long period of time. So we simply deal with crises. We're not all dealing with one person over what could be a 10 to 15-year period of time.

MODERATOR: Thank you. Here is my second and final question to all of the panelists. Given these problems that have been so well articulated, what do you think your organization, or organizations like yours, can do to expand supports for caregivers? Let's go back to Joan Butler.

BUTLER: I'm here representing the network that's called Mass Home Care which is a network of 30 non-profit organizations that are Area Agencies on Aging and Aging Service Access Points. And to give a 2-second history lesson, in the 60s and early 70s, when there was a whole movement towards deinstitutionalization and care in the least restricted environment, there were advocates at the federal and state levels that were pressuring Congress and our governor at the time to create home care alternatives, community-based alternatives for seniors. And out of that grew this whole national network of Area Agencies on Aging and there are 670 covering every city and town in the United States and on the state level.

"As an Area Agency on Aging, we're there to create a coordinated and comprehensive system of care for people of all incomes and all ability levels in our community. There's a misconception that ASAP or AAA services are for low-income people only, and that's a myth."

*—Joan Butler,
Minuteman Senior Services*

Under the advocacy of a man named Frank Manning, who many of you may know, the state under Governor Sargent created the nation's first state-funded home care program. It created 27 home care agencies which are now called Aging Service Access Points that have a range of services, largely non-medical. These agencies look at functional needs and provide seniors and families with an alternative to institutional care when family members can no longer be available to do all that is needed, given the trends of women in the workforce and a more mobile society and so forth. We have both federal and state mandates to do information and referral, and we are a source of information, often a first stop. We like to say that there's no wrong door. No matter where or who a family contacted – whether it was at the hospital level, the Council on Aging level, whether it was a neighbor – they should be directed eventually to all of us. We are paid by your tax dollars to be here as a source of information and referral as well as support.

There's a common misconception that many of the ASAPs or Area Agency on Aging services are for low-income people only, and that's a myth. Information and referral, and many of our other services, are available to people regardless of income. As an Area Agency on Aging—we're there to create a coordinated and comprehensive system of care in our communities, again, for people of all incomes and all ability levels. And we do a state wide needs assessment and local needs assessments. We're really here to understand the needs of local seniors and caregivers and develop extensive resource databases and support.

Under our home care hat, under the state hat, there's a network of case managers statewide. This is a subsidized program where the case manager can come into the home, sit with the family, sit with the senior, and identify what the needs are. They can identify what seniors can do for themselves, what the families can do, where there are gaps in services, and how we can subsidize and help fill those gaps so people can remain independent. And again, we do what we can to help the caregiver, and any services we provide for the senior will often help free up the caregiver.

We do a whole range of services, too many to list here today, including information and referral, as I said, case management, homemaking, laundry, grocery shopping, adult day care, respite care for families, elderly nutrition programs, meals on wheels, access to assisted technology and home modification, really a wide range of services. Again, under the state program, if they are eligible, we can link people up with whatever they need. And we can also do referrals for people who are not eligible under the state set guidelines—we wish we could do a sliding fee up to full cost. That would be ideal because there's always that middle class that kind of gets stuck, but many of us offer private pay, geriatric case management, as well as continuous referrals to all providers in the community. We're often the hub and the glue where people can come to get access to a range of services.

In the year 2000, Congress passed an amendment to the Older Americans Act called the National Family Caregiver Program and that created a really wonderful sort of service at the ASAP agency level. Before when someone called and they were looking for home care services, if they were eligible under the state guidelines, we could send a case manager out to do the full assessment and subsidize the services. If they were not eligible, then we were basically limited to telephone referrals. Now under the National Family Caregiver Program, we can actually send someone out into the home, regardless of income, regardless of ability, and sit down and have a face to face conversation on a limited basis. We can provide maybe one or two visits, a real face-to-face meeting with the "care adviser" who again can get the family started. What's my situation? What kind of education do I need? Is there a dementia situation involved? Is it a physical dependence, and how can I get started? Sometimes that's all families require is that direction. The Handbook is going to be very valuable as a tool for that person. But sometimes they need more one-on-one help and then they can be directed to care managers or other agencies out in the community.

One thing I'd like to add is that last year we were successful in having a new law passed in Massachusetts called the Equal Choice law. This is something that came out of a Supreme Court decision in 1999 that said all disabled people are entitled to care in the least restrictive environment. And it mandated that states look at their delivery systems and make sure that there was no a bias towards institutional care. As other speakers have said, we need a full continuum of care, and clearly there are people who need 24-hour skilled care. But many people don't, and there are new models of care being developed around the country and we are looking at them here in Massachusetts, different residential options for smaller home-based settings for people living in their communities who need 24 hour care, as well as a range of home care services. And I'd like to thank Senator Jehlen – she was an advocate for that program [Equal Choice], and I understand she's the new chair of the Joint Elder Services Committee.

I think as Andrea and Barbara and many speakers said, it's all about choice. We all want control over our lives. How we're aging, where we live. And hopefully by all working together, looking at what we have now, looking at what the new models are, we can all have choice over where we live and how we age. Thank you.

BUXBAUM: A person who goes to the hospital is likely to be discharged within two or three and days winds up in a rehab setting like one of facilities where I do my work. Now those rehab settings increasingly used are skilled nursing facilities, and in our particular group at Harvard Vanguard Medical Associates, that's actually where we function. A question was asked about what could be done in the future and I want to make a plea for a change in our thinking here. It isn't just about going to rehab. The word "rehab" implies a certain optimism about the outcome, and as we can all imagine there are different trajectories that can take place, not all of them successful in terms of rehabilitating people who come into those kind of settings. It sets up an expectation - that the families almost universally believe - that the outcome will be positive.

“Geriatric assessment can give us a much richer opportunity to impact families and patients in terms of what to expect in the future... we should be discussing what’s ahead and what the natural trajectory of a disease is.”

**–Bob Buxbaum, M.D.
Harvard Medical School**

In doing some research for an article I published recently, I came across the fact that the case mix in other countries is not the same as ours. For instance, in Australia, sub-acute care, which is really what I'm talking about here, consists of rehab, yes, but it also consists of geriatric assessment, including geriatric psychiatric assessment and palliative care. If those were included in the case mix of the patients that we take care of in settings like that, we would have a much richer opportunity to impact the families and the patients in terms of what to expect in the future.

Consider what a geriatric assessment really would involve. And we do have the time to do this, by the way. The patients who come to our settings—it's a fractured hip, or it might be for pneumonia, congestive heart failure, or any number of other issues—for instance - spend days to weeks with us.

We know how to prognosticate. I should mention that it's not a mystery to figure out that somebody who has his or her first episode of congestive heart failure will probably live about six years. With Alzheimer's disease it's approximately the same. End stage renal disease on dialysis: about five years maximum. Those numbers are known. We can talk about these diseases to some extent the way we talk about cancer prognostication. So with families, we should be discussing what's ahead and what the natural trajectory of a disease is.

Consider what geriatric assessment would be in an ideal setting. It would not only be medical and nursing evaluation, social work would be involved. A very important member of the team would be the pharmacist because these people are often on many drugs, and the

implications of that are huge. Not only in terms of side effects and interactions, but also the huge costs involved. Every time a patient goes in the hospital he or she likely will wind up on two or three more of these medications. And usually they are the drug *de jour*. We have the opportunity to discuss housing. We could talk about financial planning. We could talk about aging in place. We can talk about palliative care. We can talk about the legal and financial implications of aging. It is an opportunity which is now being missed. There are other opportunities. Patients who come to rehab watch Judge Judy on their television sets, but they don't get education about their disease or anything else. Yet we have all the mechanisms to do that. There may be examples of where that takes place, but it's certainly not happening in most nursing homes.

We're missing a huge opportunity. The experience in rehab, if you will, currently, whether it's a rehab hospital or in a skilled nursing facility is like a compressed period of time in which patients and their families can be brought together with professionals with the appropriate skills and degree of expertise in order to really learn what's ahead and to develop a plan. That is not being done. But that could be done. If you in this room have elderly parents and they're functioning - or they're living in Florida or they're around here - you have an opportunity to bring them together with professionals, or you would if you had your geriatric assessment available. To sit down and talk about what's ahead. To plan for the future.

“When Bill Clinton enters his nursing home we will probably hear about palliative care in greater detail.”

–Bob Buxbaum, M.D.

As has been mentioned, there are all kinds of alternatives to housing. There's aging in place with lots of service, like the PACE programs. There's assisted living. We haven't even touched on that today. A booming industry, really. There are adult day care programs. There are all kinds of new opportunities available. There is long-term insurance. How many people here have long-term insurance? [Few hands are raised.] Lots more of you could. The opportunity is there to do something for the future. I think we're missing the chance. Hospitals could start the process. Skilled nursing facilities and rehabs could implement it. The community could be involved. But as usual, and is true in palliative care too, the demand is not there. The public has not heard this message. I have to say that when Bill Clinton enters his nursing home we will probably hear about this in greater detail. We have to hear about it because he's never going to stop talking about it.

We're on the cusp of this movement, and it is an urgent time in terms of demographics. We cannot ignore it. It's here. We might as well deal with it, and we might as well deal with it up front. Thanks very much.

COHEN: Just to be clear about what I do and what my business does, HouseWorks provides private pay home care. When a senior can't get any or all of their home care needs through an ASAP or their insurance, we provide the care. As a result, we're familiar with all the different parts of the long-term care continuum. We primarily provide service in private homes, but we see people in skilled nursing facilities, rehabs and senior housing. So, we see it all.

In terms of what we can do better, the private home care industry is fairly young, although it's getting more sophisticated. We have been told that HouseWorks is quite innovative in regards to how we provide the service. Frankly, as an industry, the solutions start by offering people flexibility and choice, and giving adult children control. They want to know that they are asking the right questions, getting answers, getting the services they need WITHOUT worrying.

In terms of the bigger picture, we ran focus groups where we brought all the people that are part of a long-term care continuum -- the rehab, the nursing home, the assisted living, and the home care -- all in one room together and said, "how can we all work together collectively for the greater good?" Long-term care, for lots of reasons, has segmented into "we do this, we do that." This needs to change. Everyone in the long-term care industry must work together and help each other out at these different points of transition. We must think of what's best for that senior and how collectively we can work together to get there.

"Our innovation is simply about providing a great service. It's about being responsive. It's about listening to what our clients want *versus* telling them what to do. It's about flexibility and choice."

**–Andrea Cohen
Houseworks**

An important component to help someone age in place at home is a great service provider. Technology is going to have a big role in how we communicate and how we can provide service at home. The design of the home, which we haven't talked about as well, is also important to support aging in place. Again, we have to be thinking about what *collectively* we can do in each setting to help. That's the big paradigm shift now. If all of us in this room think that alone we can make it happen, we are fooling ourselves.

GUTMAN: Again, I'm going to be coming at this largely from the perspective of paid caregivers. I want to tell you about a campaign that we, 1199SEIU, have been involved in for the last couple of years. We have been working in coalition with senior advocacy and disability organizations, including Mass Home Care. Last July we passed a Personal Care Attendant Workforce law. I think in a lot of ways it goes right alongside the Equal Choice bill that Joan mentioned. The Equal Choice law gives seniors the option to live in whatever setting they choose, and the Personal Care Attendant Workforce bill ensures that there are caregivers available when seniors do choose to live at home.

The Personal Care Attendant Workforce bill, which passed last July, creates a Workforce Council to oversee and make improvements to the MassHealth Personal Care Attendant program. The Council is a 9-member board that's made up of people who receive personal care attendant services, surrogates or family members, and a couple of representatives from the state. The goal of this council is: 1) to create a registry of personal care attendants, to make it easier for family members and seniors themselves to find help in their homes through the Personal Care Attendant program; and 2), to make sure that there are real training opportunities for those people who are providing that care. Right now in the MassHealth Personal Care Attendant

Program there is no official training offered at all to those people who are providing the care. So the Workforce Council is charged with creating these training opportunities.

The other thing that the Workforce Council is charged with is looking at the wages and benefits of the PCAs and trying to figure out a way to really stabilize this workforce so that people can afford to continue to do this work. Right now there is not only very high turnover among PCAs, there is also a growing shortage as more and more elders need care at home. One way to address wages and benefits is through a union and so this law also gives personal care attendants the right to form a union. This will be a different type of union in that it's really much more a political coalition of PCAs, and senior and disability advocates and the premise is that we all need to work together to make the necessary improvements in the program.

Working with this model, the union and the advocates together will lobby the legislature to increase the funding for the MassHealth Personal Care Attendant Program. The union will negotiate for raises and for benefits for the personal care attendants with the Workforce Council. Again, this will be a different union model. Rather than being adversarial, the goal of this union is to join caregivers and the people who receive care together to make necessary political change. In this union, strikes are prohibited and caregivers cannot file grievances; consumers maintain all rights in hiring, firing and scheduling their PCAs. This model has been successful in four other states throughout the country. Based on those examples, the only way that we're going to figure out how to solve all of the issues facing our long term care system in Massachusetts is if we can figure out a way to work together and bring together the interests of the family members, the seniors, the people who are getting paid to provide this care and do it all together.

“The Workforce Council is charged with looking at the wages and benefits of the PCAs and trying to figure out a way to really stabilize this workforce so that people can afford to continue to do this work.”

**–Rebecca Gutman
1199SEIU**

Just a couple of other points about the supports we're offering the personal care attendants while they are still in the process of organizing their union. As I mentioned before, many PCAs are very low income and therefore are eligible for the earned income tax credit but don't know it. So the union joined a coalition of organizations to offer free earned income tax credit and tax preparation services. We are starting to provide CPR training to the paid caregivers. And finally, the process of forming a union is creating opportunities for these paid caregivers to come together and to talk. It's incredibly isolating work. PCAs go into people's homes and don't have a common workplace to share. They don't have an opportunity to talk with each other about what they're facing emotionally and how they can learn from each other, especially when they're caring for people who are dying and are sick. Coming together provides PCAs a chance to feel empowered and to feel like they actually can take some control over improving the quality of their own lives and the lives of the people they care for.

MOSCOWITZ: I'd like to mention two initiatives, one ongoing and one about to start, I hope. By way of the first – just earlier at my table I met a family care specialist from HESSCO Elder Services and she was mentioning that under the family caregiver alliance bill you're able to meet the caregiver wherever the caregiver wants to meet you and we started joking—Starbucks! You come in with a little red hat and the caregiver sneaks in and confesses that life is too hard. I think that idea is relevant to the point that I want to make. It's meeting the caregiver where the caregiver is.

At Mass General Hospital, we have an astonishingly exquisite, robust employee assistance program. And as all of you know, many of the caregivers are at work. I think one of the great issues we have to pay more attention to is finding those caregivers at work. You all know, or someone knows, how many billions of dollars it costs the employer when I spend four hours a day talking to my mother's PCA in Florida and/or I don't have the attention to give to a project, and on and on.

“One of the great issues we have to pay more attention to is finding – and helping -- those caregivers at work.”

*– Barbara Moscowitz
LISCW, Mass. General Hospital*

I'm very honored to introduce Andrea Stidsen, the head of the Employee Assistance Program at MGH and her colleague, Janet Loughlin. On a monthly basis I co-lead with Janet a caregiver support group for employees. It has been one of the most astonishing and poignant experiences I have had. We're on our third year and yesterday we just had someone come back for her third year. When she came three years ago she said, “My father didn't recognize me last night,” but didn't know what that meant. She came yesterday to tell us her father is in a dementia assisted living facility, and so we've grown with her. Lots of anecdotes. But the point is we've got to find the caregivers where the caregivers live. They live everywhere. As Bob said, we're in the room and we're everywhere, and we have to acknowledge and find them. They don't necessarily, even with this magnificent Handbook, find us. We have to find them.

At Mass General, at the Beth Israel Deaconess, all of the hospitals, social workers are present, and we're present for the purpose of providing caregiver support. But again, given what we've acknowledged, which is that hospital visits are short, they're focused on crisis. Even doctor visits are short, focused on what is your pain today. Social workers are being robbed of that which we crave – which is an opportunity to help people grow through and live through an entire process of a condition.

I know the Alzheimer's Association is represented here. We all know that when you are diagnosed as being in the early stage of Alzheimer's, what you need today is not what you need a year from now, or three months from now. It is long-term. So the second thing I am proud to say is that, with my colleague Shelley Amira, we are in the early stages at the General of planning and creating a family caregiver center. It's not rocket science, but what we're telling you is that people no longer have someone to work with, or when they meet you, they meet you at the point of crisis, you can only deal with that broken hip. We are hoping that a center – which will be open to all in the community and the hospital employees who can use it as a benefit – will have social workers, education groups, support groups. The point is, again, it is an ongoing, open

facility. It will help create somewhat of a bridge between all of this fragmentation. So I'm proud to announce we're working on that.

Part V. Summary: Building Consensus and Collective Action

By bringing together a community of people who are the front line of elder care and caregiving, the MIT forum "Who Is Caring for the Caregivers?" held in January 2007 was successful in building the kind of cross-sector communication that many of the panelists and others called for. But the creation of the *Family Caregiver Handbook* and the discussion of expanding supports for caregivers are only part of a long process – with a great deal of work that preceded them, and a great deal more work to do. The issue before us all is how to move from here, not only to have family caregivers and elder care professionals communicate with leaders in key health and elder care agencies and state government, but also to have families and providers communicate with each other.

As this report suggests, the problems facing family caregivers of elders are fairly well understood, however, many of the solutions are unrecognized or under-funded. The themes of this report lay the groundwork for common action and coalesce around four key points of consensus:

There is significant consensus around the need for families to plan for the full cycle of elder care, not just the crisis of the moment. If we plan better for aging as a normal part of life, if we think about elder care in advance, and if we face the fact that elder care becomes end of life care at some stage, then families can manage much more effectively. They can be better caregivers when the time comes. This suggests that a key task for elder care professionals – whether they work in health care settings or community service settings – is educating families about this cycle, how it begins, how it progresses, and how it ends.

The second point is that public education around existing elder care resources and services is critically important. Whether it is a hard copy book like the *MIT Family Caregiver Handbook*, or any other elder care pamphlets, websites or training workshops, these materials will only become a widely known and used resource if we create a cross-agency, cross-sector distribution network and promote them in a coordinated way. We need to reach professionals in the field about the best information available, get it out to the people who have first hand contact with caregivers, and learn to customize information so that it is appropriate for the needs of the particular group of caregivers they serve. If part of caregiver support is empowering caregivers, and knowledge is power, then getting caregivers the best possible information will empower them to seek the resources they need.

The third point of consensus relates to the process of implementing a new health care policy in Massachusetts. Inevitably there will be pressure to reduce costs and/or keep costs low in order to make the new insurance plans affordable. The work of elder care professionals – to develop first class home care and community-based services and to make them widely available – is an incredibly important part of cost control, of efficient cost effective health care. If we can get home-based resources and services out to the elders who need them, we can help prevent

many of the crises that send elders in an ambulance to the emergency room, into rehab after discharge, and into nursing homes. If we can better utilize and expand home and community services, this can be part of the way in which we provide a sustainable model of health care access to the people who need it the most. We should present this to the Governor as part of his initiative to address the cost issue of insuring the uninsured.

Finally, we need to profile the tens of thousands of people who are caring for elders across Massachusetts – be they volunteers, family members, or home health aides. Some of these individuals are the “shadow workforce” that Ann Bookman and Mona Harrington have written about, others are the low-wage workers, often immigrants and often people with their own elderly relatives to care for. If we start to put a human face on the people who are providing elder care, perhaps this will increase recognition that this work is a high stress, highly personal, very difficult set of tasks. If we can put a human face on family caregivers, perhaps we can provide the support and resources they need to get the job done. Those providing elder care – whether it is health care, personal care, transportation or housing – are an incredibly important part of the workforce of our society, whether they are paid or unpaid. We need to know who these people are, know exactly what they do, and value them for their efforts to help elders age with dignity.

About the MIT Workplace Center ***Redesigning Work-Family-Community Connections***

The MIT Workplace Center was founded in 2001 and is funded by the Alfred P. Sloan Foundation to address the current mismatch between existing workplace policies and practices and the changing work force. The Center’s goal is to stimulate change both on the level of private sector workplaces, community-based family care agencies and public policy. The Center is part of the Massachusetts Institute of Technology’s MIT Sloan School of Management. For more information, see the MIT website: <http://web.mit.edu/workplacecenter>.

The Workplace Center has two recent publications on elder care: a consumer publication entitled “*The Family Caregiver Handbook: Finding Eldercare Resources in Massachusetts*” and “*Family Caregivers: A Shadow Workforce in the Healthcare Industry?*” by Ann Bookman and Mona Harrington, forthcoming in the Fall 2007 issue, *Journal of Health Politics, Policy and Law* (Vol.32, No.6) by Duke University Press. To visit the Family Caregiver Handbook website, go to: www.familycaregiverhandbook.org.
