



How to Create Your Own Caregiver *Handbook*: Thinking Nationally, Acting Locally

Why Create a Caregiver *Handbook*?

Anyone who has been through a crisis with an elderly relative or friend can tell you how difficult it is to find services, or even to grasp the range of services that exist. Eldercare professionals will tell you that an emergency situation is the worst time to try to learn about the complex subject of eldercare, but that's what most people do—they wait for a crisis and are then unprepared to make decisions or act.

The Caregiver's Handbook: A Companion Resource to Caring for Your Parents (pbs.org/caringforyourparents/community/index.html), created by the WGBH Educational Foundation and the Massachusetts Institute of Technology, is a comprehensive compendium of advice, tips, and helpful organizations to contact. Developing a localized *Handbook* for your state or region, city, or town can make an enormous contribution to the lives of caregivers, and the need is growing. MIT Workplace Center, author of the original *Massachusetts Family Caregiver Handbook* (from which *The Caregiver's Handbook* was adapted), documented this need in a study of the geriatric health care system in the Greater Boston area. It concluded that families are carrying an increasing degree of responsibility for the care of elders.¹ As health care institutions attempt to control escalating health care costs, there is increased reliance on families to provide safe, high-quality care for elders.

Through in-depth interviews with caregivers, MIT researchers found that many families struggle to find the services they need because basic information is difficult to find and hard to understand. Caregivers reported that information exists, but it is unclear where to begin: there is no navigation to guide them through the maze of 800 numbers, unlinked Web sites, and eldercare service providers.

Goals

The overall goal in creating a localized *Handbook* is to make information on eldercare issues easily accessible to elders, their families, and friends in language they can easily understand. *Handbooks* may vary in their scope and specifics, but these are general goals for a successful *Handbook* project:

- The *Handbook* directs caregivers to a starting point in their community—"gateway organizations"—so that caregivers can find knowledgeable professionals who can orient them to the eldercare system.
- The *Handbook* demystifies the eldercare system by explaining how services are organized and how to navigate them.
- The *Handbook* helps caregivers frame the questions they need to ask about specific needs, such as how to find home care, health care, housing options, and transportation in their community.
- The *Handbook* helps caregivers to find local support services for themselves, accept help from others, and take care of their own health and well-being.

¹ Ann Bookman and Mona Harrington, "Family Caregivers: A 'Shadow Workforce' in the Geriatric Health Care System?," in *Journal of Health Politics, Policy and Law*, 32:6, 2007.

The Planning Phase

There are several questions to consider before starting the process of creating a Handbook. These “go/no go” issues can help an individual or organization decide about whether to do a Handbook project for their state or community.

Q: What is the scope of the *Handbook*?

Handbooks can be developed for an entire state, for a region, or for a particular city or town. The scope obviously affects the amount of time it will take and the cost, so it is best to consider how broad an audience you intend to reach and how in-depth the coverage of key eldercare issues and organizations will be.

Q: Is there anything like *The Caregiver Handbook* that already exists for your state or locality?

It is important not to reinvent the wheel! A good publication or Web site may already exist for your area, so ask around. Contact your local Area Agency on Aging (AAA) or senior center to learn what directories, publications, and Web sites they use as references. Perhaps you can build on existing information or partner with other organizations that develop references in your area.

You may find publications or Web sites that offer very detailed information, but not enough of an introduction to the eldercare delivery system to demystify the process in your area. Or there may be a good model for a *Handbook* that is limited in scope: in Massachusetts, MIT found an excellent *Handbook* produced by a regional AAA, but the *Handbook* did not cover the metropolitan Boston area or other regions of the state. Sometimes there are good lists of agencies, but the way the information is presented makes it almost unusable. Assessing the quality of what exists is an important part of the planning process.

Q: Who will write the *Handbook*?

An individual researcher/writer, or a small team of individuals, can create a *Handbook*. Prior experience in eldercare is helpful, but it is not advisable to have someone who is involved in the day-to-day delivery of eldercare services as the lead author. The project will take too much time to be completed by someone with a full-time job, either as a caregiver or an eldercare professional. There is some advantage to having a writer who has been a family caregiver, rather than a professional who works in social services and may be too close to the system to understand what a newcomer needs to learn. Another candidate might be someone who has worked in the Information & Referral or Educational Outreach department of an eldercare agency, or someone who is recently retired from a job in the eldercare field.

Professional researchers were involved in creating the *Massachusetts Family Caregiver Handbook*, but this is not necessary. Ultimately, finding a person(s) with research and writing experience and good organizational skills is best.

Q: Do you want to create a printed version of the *Handbook* or a Web-based version, or both?

Printing and mailing copies adds significantly to the cost. However, the MIT authors found that many caregivers, particularly those who are elders themselves, preferred the printed book to read and to use as a reference.

You may choose to create only a Web site. One of your local gateway organizations may be able to host a site, and the *Handbook* can be designed so that each section can be downloaded and printed. Inexpensive copies can be printed for local libraries, senior centers, and other organizations—such as your Area Agency on Aging (AAA) or Council on Aging (COA). The Web site can provide public access to the information, as well as an inexpensive way to update content.

Q: How much will it cost?

The greatest expense in creating a *Handbook* is the time committed by the writer/researcher(s). The next largest expense is printing and mailing, if you decide to produce printed copies. Both of these expenses depend on the scope of your *Handbook*: one can research and design a *Handbook* for a small town or region in a matter of months, while a statewide *Handbook* could take more than a year.

The scope of the *Handbook* is, in part, determined by the ability of the lead author(s) to build resources by partnering with other individuals and organizations.

Q. Where can we find partners to help create a *Handbook*?

There are a number of potential partners in your state and in your local community that can help to make a *Handbook* affordable and feasible. For the MIT Workplace Center, two different kinds of partners were important: funding partners and distribution partners.

Funding partners can offer financial assistance for all or part of the expenses (such as printing). Potential partners for your project may include:

- Large employers in your area
- Private and nonprofit philanthropic foundations
- Local home care agencies, medical centers, and/or health insurance companies
- Professional associations and trade associations affiliated with eldercare issues

Finally, although the government eldercare agencies, such as the AAAs, operate under tight budget constraints and have little funding that is not already committed, it is worth checking with them, because they are required to provide information and referral (I&R) as part of their mandate from the federal Older Americans Act. A *Handbook* may help fulfill their mission to deliver information and referral services.

Distribution partners are critical because a *Handbook* is only effective if it is disseminated widely. You should consider how you will distribute the *Handbook* throughout your community and identify organizations that can help. Public libraries, hospitals, health clinics and doctors' offices, senior centers, social workers and therapists, churches and interfaith organizations, and the many not-for-profit agencies who work with elders are all likely to help in distributing your *Handbook*.

The Process

The following steps are drawn from the experience of writing the Massachusetts *Handbook* and are meant as guidelines, not requirements.

- 1 Identify the “gateway organizations” in your state** such as the Area Agencies on Aging (AAAs), the local Councils on Aging (COAs) or senior centers, and the State Units on Aging (SUAs), and learn how these agencies work together in your state. This will allow you to describe the big picture—how “the system” works in your area—and how to navigate it.
- 2 Form relationships with key people** in these gateway organizations, send them the material you've written, and ask for comments on accuracy and clarity. This initial review will verify that you have an accurate starting point for your research.
- 3 Define the content for your *Handbook*.** For example, you could do a *Handbook* just on home care resources in your state, or you could do a *Handbook* on all the topics covered in *The Caregiver's Handbook: A Companion Resource to Caring for Your Parents* (pbs.org/caringforyourparents) for your town. Your decision should reflect what you learned about information gaps and needs in your locality.
- 4 Identify key organizations that work on the key content areas you have chosen.** The Web is ideal for starting to research a *Handbook*. The goal is not to create an exhaustive list of organizations, but rather to *select* organizations that give families a good place to start in their own searches. You will begin to notice multiple references to certain agencies or groups as you research a particular issue; this is a good indicator that you will probably want to include them in your *Handbook*.
- 5 Capture and organize the list of organizations.** Your list will grow quickly! A spreadsheet or database will allow you to gather information on organizations and re-sort the information as needed. Keep track of your contact names and their titles, phone numbers, e-mail addresses, and mailing addresses, as well as the name of the organization, its phone numbers, and Web address.
- 6 Create brief descriptions of what each organization does.** This can often be done by modifying and rewriting what is available on its Web site and/or reviewing its recent publications.
- 7 Identify issue experts in each topic or issue that you want to cover,** and ask them to review your manuscript. For example, if you are preparing a section on legal issues for caregivers, find one or two eldercare attorneys who can review what you have written. If possible, offer them a small honorarium for their time.

8 Revise the manuscript. Take what the reviewers have sent you, synthesize their suggestions, and make appropriate revisions. If the issue is particularly complicated—and if the reviewer is particularly generous with her or his time—you may want to send the revisions back to him or her for a second review.

Piloting the *Handbook*

Once you have a fairly complete draft of your *Handbook*, it is time to “take it on the road” and get feedback, especially from caregivers themselves. If you have the time and resources, discussing your *Handbook* with caregiver support groups can be very useful. You might reach out to:

- An eldercare agency such as an AAA, that has a support group for caregivers
- An organization that deals with a specific disease that affects elders, such as Alzheimer’s, that has support groups for caregivers
- An eldercare consumer or advocacy organization

Once you have some feedback, it will be the lead author or authors’ responsibility to make decisions about what suggestions and changes to incorporate. Not all suggestions are created equal!

Permissions and Fact Checking

There are two types of “due diligence” that are needed before publishing the *Handbook* or going live on a Web site.

- If you want to use information, photographs, artwork, or forms created by another organization or individual, you must contact them and ask permission to include them in your *Handbook*. Usually organizations are happy to get wider distribution of their material, but it is important to formally request permission to reprint. Include the title of your *Handbook* and the number of copies you intend to distribute in your request. Some organizations may require a written request and will answer with a written permission or denial.
- E-mail or write to every organization that you include in the *Handbook* and ask them to review the description of their organization as listed in your manuscript. This is not only a courtesy to let them know you will be publicizing their services—an opportunity that most organizations welcome—but it also serves two important additional functions: it allows you to verify that all the URLs and contact information you have in their listing are correct; and it lays the groundwork for enlisting their help in distributing copies and updating information.

Publication and Distribution

Distributing your *Handbook* begins when you start talking to organizations during your research. Ask how they might help distribute the book. Whether you are printing copies or launching a Web site—or both—decide on a publication date and get the word out. Send a mailing or an e-mail “blast” to the organizations you’ve included in your *Handbook*, and encourage them to spread the word about your publication. Offer a simple form that outlines the features of the *Handbook* and how to obtain a copy.

Your local AAA, senior center, or your other partners (especially funders) can plan events to publicize and distribute the *Handbook*. Determine who will be responsible for responding to requests and funding the supplies and postage needed to send copies. Mailings are expensive, and it is better to have your printer ship cartons to the organizations who can distribute copies on-site, rather than mailing all the books to individual addresses.

Ongoing Issues

The key ongoing issue is keeping the information in your *Handbook* up to date. This is obviously done more easily and less expensively with Web-based *Handbooks*, because updating a printed *Handbook* requires additional print runs and other production costs. In any case, consider the resources you will need to update content on a regular basis during the planning phase of your project and determine how long you can support a *Handbook*.

The information in your *Handbook* should not go out of date quickly unless there are major policy changes that affect health care or social services delivery systems, but plan to revisit the Web sites and telephone numbers at least once a year to see if the information or the navigation has changed. Your readers are your best source of identifying content that needs updating. You may want to include a phone number and e-mail address so that readers can let you know what’s working or what’s not working in the *Handbook*.

Finally, if resources allow, it is very helpful to do some kind of evaluation of the *Handbook* with three important audiences: elders, caregivers of elders, and professionals who work in the field. Here again, your funding partners and distribution partners may be able to help. For example, in Massachusetts, one of the key distribution partners—the geriatric medicine department of a large hospital—distributed brief questionnaires to elders who are patients and their caregivers. This provided useful information about how successfully the *Handbook* met their needs, as well as ideas for future editions.

We wish you the best of luck in your endeavor!

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