

# Consumer Assessment of Senior Services in the Portland Community

## A Focus Group Project

Spring, 2002

**A project by the Greater Portland Senior Service Coordination Committee:**

Community Health Services  
Maine Alzheimer's Association  
Office of Elder Affairs, Health and Human Services Department, City of Portland  
Partnership for Healthy Aging  
People's Regional Opportunity Program (PROP)  
Social Security Administration  
Southern Maine Agency on Aging

Report submitted by:

Linda Weare, Elder Advocate  
City of Portland, Health and Human Services Department

Office of Elder Affairs  
1145 Brighton Ave., Portland, ME 4102  
207-541-6620

[lsw@ci.portland.me.us](mailto:lsw@ci.portland.me.us)

---

## Introduction

The first Portland Senior Summit took place on April 25, 2001. Participants at this one-day conference were senior services providers from the Portland community. This group worked together to identify some problem areas and "gaps" in the senior service system. Service providers were concerned specifically with the perceived lack of service coordination within a complex and fragmented service delivery system.

A Service Coordination Committee was formed and charged with the task of assessing the extent to which service coordination issues affect the accessibility and quality of services available to Portland seniors. The committee was made up of representatives from a number of senior service organizations in the Portland community. They include Community Health Services; Southern Maine Agency on Aging; Social Security Administration; Partnership for Healthy Aging; Maine Alzheimer's Association; PROP; and City of Portland, Health and Human Services Department, Office of Elder Affairs.

This group decided to implement a focus group project, in which Portland senior citizens and family caregivers would be interviewed about their experiences using the senior service system during the past two years. Four focus groups were held in various neighborhoods around the city. A total of twelve (12) participants were asked the following six (6) questions:

1. What was your first step in seeking information and/or assistance?
2. Please explain and evaluate the way in which information was presented to you. (Easy to understand? Easily accessible? Complete? Fragmented? Confusing?)
3. What questions do you wish you had asked sooner?
4. Is there a difference between what you thought you needed and what you discovered you really needed?
5. Are there some needs that have gone unmet? What seems to be missing?
6. Please describe the most frustrating, as well as the most helpful aspect of your experience working within the "system".

Focus group meetings were conducted by impartial facilitators, who were not associated with a senior service agency. Two USM nursing students were present to record participants' verbal responses, as well body language and word emphasis. Responses ranged from very specific stories and examples, to some broader themes that carried through from each of the separate groups. This report will

cite some specific comments from participants that help to capture the spirit of the discussion. The identification of particular agencies will not be included, however, specific comments will be passed along to agencies that were mentioned by name, to allow for internal processing of the information. Focus group participants were assured that their names and affiliations would be kept confidential.

---

### **Experiences Seeking Information/Access to Information**

Many caregivers and seniors spoke about having had a **sudden or unexpected need to access elder services**. Some caregivers received initial information from primary care providers, as well as hospital staff. However, others had no "contact person" and **found it difficult to begin their search**. One elderly woman said, "You don't know where to start. How do you know who to go to for help?"

A common complaint voiced by caregivers was that the **information they received was fragmented and incomplete**. There were many numbers to call, applications to fill out, and figurative hoops to go through. Caregivers maintained that the seniors they care for, if left on their own, would not have been able to navigate the system at all or would have given up long before they received the assistance they needed. **It was suggested that a central hotline, acting as a service coordinator would be helpful** for caregivers as well as seniors. Caregivers wished they had had access to one person who was informed about various types of services, eligibility requirements and terms of service.

It was the opinion of many of the focus group members that **some service providers are not well informed or educated about services that are available through other agencies**. Several caregivers stated that they were given wrong or incomplete information regarding services available to them in the community. One person said she called an agency requesting information about a service she knew existed and was told that it did not! This woman, a caregiver for her mother, eventually had to disclose that she worked for another service agency and asked to speak to a supervisor after being questioned as to how she knew about the service. One elderly participant talked about a friend of hers who was having her blood pressure taken by a nurse each week. She said, "I didn't even know this service existed. I think her neighbor set it up for her." **These stories seemed to emphasize the haphazard and unstructured way information and services may be obtained, and points to the challenges a consumer might face if he or she did not know a person on the "inside"**. One consumer offered sound customer service advice for service providers, as she relayed this experience: "Every person

I called said to call someone else. Well, someone did call me back and told me there was no one to help. I think one service should have referred me to another agency without just dropping me if they couldn't help."

Another issue discussed by participants was the **methods by which senior service information could be shared** in order for it to be most beneficial to them. Many thought that making sure literature is presented in easy-to-understand everyday language was key. Others said that information presented verbally was better than written material, as informational brochures may get lost or pushed aside. It was suggested that the use of television for informing seniors about available services would be very helpful.

---

### **Availability of Services**

Focus group discussions revealed some instances where after a long and tedious search and many referrals, **the needed service was never obtained**. Seniors and family caregivers were left to deal with the problem situation on their own, often without a strong informal support system in place. One caregiver reported that she moved her mother to the Portland area from northern Maine, because of her housing and care needs. She then began to look for a mental health practitioner and other programs for her mother who suffered from a long-standing mental illness. Her search uncovered two potential mental health providers, but she learned that there was a long waiting list for one service and that the other was no longer accepting new patients. She stated, "**So we really did not find any elderly psychiatric care for her. We went in circles and ended up without care.**"

Some focus group participants stressed **a need for more transportation options in Portland**, especially for those in wheelchairs. They felt that there was one affordable transportation service available, but that this service is slow, inconvenient, and requires a lot of waiting. One woman said that she had been "forgotten" after getting a ride to her medical appointment and had to wait three hours before someone picked her up to take her home. There is also a need for transportation on "short notice". Currently riders have to arrange for pick-up a day or two in advance. Participants knew of a private transportation agency in the area, but did not think it was affordable for many people living on low fixed incomes.

It was also articulated that even though a service system is in place, and a person finally makes through the application process and is accepted for assistance, **there is not always enough staff to provide the service**. Several caregivers said that their loved ones were found eligible for funding and accepted for PCA or nursing

services, only to find that there was no one available to come and help. One daughter explained, " There was an instance when we had nursing care and home services and I got a phone call at work from someone saying 'we are not going to be able to cover your mother at one o'clock today'. So all of a sudden my mother was going to be by herself. In that case I was going to have to leave work and go home, so she wouldn't be alone." Another person said, "Even if you are willing to pay, there are no personnel for home health care, especially in the area of homemakers and personal care attendants."

Elderly consumers felt that **eligibility requirements for different types of senior housing are too restrictive**. They thought that there was plenty of housing for those with little or no money, and enough for people with lots of money, but few options for those in the middle-income category. In telling her story, one woman said, "My first step was to find a place for my mother to live in Maine. The process of looking for housing took three years. The other problem is that there was all this housing for people with no money and fancy luxurious housing for those with lots of money. Then in the middle are all the working people who had a little extra, but didn't know it would be this expensive to live." All agreed that this is a serious problem for Portland seniors.

---

### **Accessibility of Services**

Accessibility of services was a hot topic in all four focus groups, as this seems to be one of the most frustrating aspects of care for seniors and caregivers. The areas discussed within this category included difficulty contacting people at agency offices, overly complex application process, repetitive screening, and a referral system that does not necessarily lead to needed services. **Participants clearly experienced the "system" as a maze of paperwork and often futile telephoning that many caregivers felt was impossible for them to navigate, and certainly a roadblock for an elderly person trying to arrange for services on their own.** One woman said, " It took three weeks to get answers about different services because people were on vacation. We always got voice mail and when we called we would play phone tag. There was only one person who was familiar with our case and nobody else was able to find information to help us at all."

Participants also pointed out that each agency has it's own application/intake process, required interviews, and eligibility guidelines. People often end up filling out the same or very similar paperwork over and over again. **Services were fragmented**, with various services coming in from several unrelated agencies and little communication happening between these providers. This was confusing for care recipients as well as caregivers. It was suggested that the **tedious**

**application process and the involvement of too many agencies are major obstacles to accessibility.** Another noted frustration is that most agencies have office hours that make it difficult for caregivers who work to arrange services. Some employers prohibit workers from making personal calls or handling family business on the job. At least some days with extended hours would be helpful.

---

### **Challenges of Service Coordination for Family Caregivers**

Of the 12 participants in these focus groups, **the majority were caregivers.** Most had had the experience of trying to access services for elderly parents, while two had been caregivers for their spouse. The challenges they described are not only that of providing care, but this role coupled with the other responsibilities in their lives, and the emotional stress of caring for an aging loved one. The reported challenges range from accomplishing daily tasks, to dealing with finances, to their own emotional needs.

The overriding sentiment from participating seniors and caregivers was the **frustration and difficulty of coordinating services.** Accomplishing tasks such as making phone calls, waiting to receive information, and acquiring needed supplies consumed more energy than they expected. It was everyone's experience that more than one service provider was needed to obtain all the necessary services. This is where much of the frustration began. As mentioned previously, caregivers lamented the lack of coordination among providers. Time and energy was needed for a separate application and evaluation for each provider. Caregivers tired of repeatedly giving the same

information. As the care needs increased, caregivers were less and less tolerant of this process. In some cases, participation in one program deemed the senior ineligible for services under another program, even though the service was still needed.

Caregivers found it **difficult and stressful to keep up with changes in the service delivery system.** One caregiver described the experience of receiving a phone call at work telling her that her mother's home health services would expire at noon that day, and her mother was going to be left alone. Another caregiver found weekend and summer in-home care to be unreliable. One senior was delighted to be informed that her insurance would pay for a wheelchair designed just for her. After waiting an extended period of time, she discovered upon delivery that the wrong chair had been sent to her. She expressed frustration at having to start the approval process all over again.

The financial aspect of being a caregiver was consistently mentioned as an unexpected burden, and one without much support or guidance. **Caregivers asked for more assistance in understanding the financial requirements of various programs.** They reported difficulty in discovering exactly what services their loved ones were eligible for, as this sometimes required extensive research and the search did not always yield correct information. They were often frustrated to find that the senior had too much money to qualify for financial assistance, but did not have enough resources to pay for the services they really needed. Financial restrictions and other program guidelines limited the consumer's ability to choose the support services that they wanted. As one senior noted, "People want what they want, not just what they need. I want both." Caregivers expressed anxiety over being responsible for someone else's financial well-being. In trying to make long-range plans, caregivers found themselves asking questions they never thought they would have to confront: How long will my parent live? How far does this money need to stretch? Is this service worth it? Am I doing what is best for my parent/spouse? If they could make a sound decision for themselves, what would they want?

**The emotional needs of caregivers** were expressed in each of these groups as an unanticipated, and unmet need. The caregivers who participated in these focus groups did not directly mention this as a need, but these sentiments were indicated in their responses to other questions. Many caregivers struggled with the role reversal experienced in caring for a parent. They were challenged by differences in perception of the situation between the caregiver and the elder, and the need to constantly reassess the situation. Caregivers remarked that they "did not know what it took to be a caregiver" and felt "emotionally worn out from this process." Through their responses, it appears that their own needs take the lowest priority, as their efforts and energy are mainly focused on someone else. Those who had assumed the role of primary caregiver found themselves in charge without knowing exactly what needed to be done or how to respond to offers of help. Many had children, spouses, and careers of their own to manage. They constantly questioned whether or not they were doing the right thing, if they had found the best service, or if they had all the information they needed. Many caregivers reported that it took them a long time to realize that they needed respite, and then found that setting up respite services was yet another chore. Very few had achieved a sense of peace about how to meet this personal need and some had trouble justifying taking a break from care giving duties or spending money on respite care.

---

## Recommendations and Things That Work Well

Much attention has been devoted so far to documenting the negative experiences of working within the senior service system. Though much can be learned from tales of what went wrong, why it was frustrating, and what needs are still unmet, it should be noted that the **focus group participants were quite articulate in praising the services that worked for them**, and in trying to come up with solutions to their problems. Most participants wanted to address systematic pitfalls more than to air complaints about particular services. Perhaps these voices of experience can best guide any process for improving services to seniors.

The recommendation was made at several focus groups for **the creation of a central agency that makes connections for you and puts services together**. The expressed hope was that connections to multiple services could be accessed with one phone call and that one intake process would be sufficient. Through this one entry point, a caregiver or senior would be able to speak with someone who is knowledgeable about an array of services, coordination of services would be improved, and fewer individuals would fall through the cracks.

Other suggestions were made regarding the **availability of information**. These included the development of a current and accurate list of resources written in understandable language, and advertisements on television informing people where this information could be found. Caregivers and seniors in these groups would prefer printed material over an Internet resource, but would ideally like to talk with a knowledgeable person about their needs. Verbal information was perceived as best, as it's "so nice to sit down and talk with someone," it "ensures understanding," and "written literature sometimes gets put aside." Along this same line, caregivers greatly appreciated the visit when someone came into the home to see where the senior is living. One caregiver was especially pleased when an occupational therapist visited the home, and made helpful, concrete suggestions on how adaptations could be made.

**Caregivers felt strongly that seniors need advocates**. Some participants perceived that they had received better services because they were employed within the system of providers. They particularly felt that they were at an advantage, and everyone should have access to an informed advocate. These caregivers seemed most strongly concerned for seniors who do not have an able-bodied and able-minded family member or friend to navigate the system with them. Persistence was mentioned most frequently as a helpful trait in an advocate or caregiver. It was also noted that **many of today's seniors are not comfortable asking for help** and that staff should be particularly tuned in to this phenomenon.

Just because they are not asking for something, does not mean that they do not need it.

**One caregiver praised her employer for the support she received through allowing relocation and a change in hours to accommodate her new role as a caregiver.** She hopes that this will become the norm and not the exception, and acknowledges that advocacy is probably needed here.

Many people found it helpful to stay connected to their primary care physician, relying on a specialist only when necessary. Other suggestions for service providers include offering more advice around financial issues, how to handle prescription costs, how to help an incontinent senior, and trying not make a crisis situation unnecessarily more stressful. **Other creative ideas were suggested** which would bring people together and ease some of the loneliness and burden for seniors and caregivers. These included Friendly Visitors and an Adopt-A-Grandparent program, respectively.

---

### **In Summary**

The information garnered through this focus group project supports many assumptions made by providers at the Portland Senior Summit 2001, about the difficulties consumers may experience when seeking information, arranging for, and/or coordinating services for senior citizens in our community. The Service Coordination Committee views this project a first step in the process of identifying specific problems and service delivery "gaps" from the consumers' point of view. This information may be used in a variety of ways by individuals, service organizations, policy makers, and by the senior service community at large in our efforts to improve the way in which we serve Portland seniors and those who care for them. We would like to thank the 12 individuals who took time out of their busy schedules to answer our questions with great clarity and wisdom. It is our hope that many positive changes will result from your willingness to share your stories with us.