Short report on Elder and Caregiver Focus Groups

Held July – August 2014

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As part of its new priority to support the dignity and health of Elders in New Hampshire, the Endowment for Health decided to take the step of listening to Elders and their Caregivers directly about their issues and concerns. Eight focus group – engaging 84 people - were held in different parts of the state, with an attempt made to include people living independently in the community, in a supported living situations such as a nursing home and those with memory loss who regularly attend day programming. A staff member of the Endowment attended almost everyone in order to assist with note taking and hear the conversation directly.

The schedule looked like this:

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th># attendees</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 25</td>
<td>Keene Senior Center, Keene NH</td>
<td>14</td>
<td>6 men and 8 women</td>
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<tr>
<td>Aug 6</td>
<td>Grafton County Nursing Home, Haverhill NH</td>
<td>11</td>
<td>6 women, 5 men – all were residents of the nursing home</td>
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<tr>
<td>Aug 7</td>
<td>Nashua Senior Center, Nashua NH</td>
<td>10</td>
<td>8 women, two men</td>
</tr>
<tr>
<td>Aug 12</td>
<td>Bishop Gendron Assisted Living, Dover NH</td>
<td>9</td>
<td>8 women, 1 man</td>
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<tr>
<td>Aug 13</td>
<td>Ossipee Concerned Citizens, Ossipee NH</td>
<td>19</td>
<td>17 men and 12 women</td>
</tr>
<tr>
<td>Aug 28</td>
<td>Easter Seals, Manchester, NH</td>
<td>7</td>
<td>All women and all attendees self-reported issues with memory loss</td>
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</table>

In addition, the Endowment wanted to hear from Caregivers directly as well, and two focus groups specifically for Caregivers were scheduled:

<table>
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<tbody>
<tr>
<td>Aug 13</td>
<td>Horseshoe Pond Senior Resource Center, Concord NH</td>
<td>7</td>
<td>4 men, 3 women – group had past and current caregivers</td>
</tr>
<tr>
<td>Aug 27</td>
<td>Family Resource Center, Gorham NH</td>
<td>7</td>
<td>All women – group had past and current caregivers</td>
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Focus group participants were asked two basic questions: What is working well in your life? And what is not working well? The broad nature of the questions allowed for a lot of latitude with the discussion, yet many of the themes were similar.

Themes from Elder Focus Groups:

**Housing:** Those who were living in a supported living arrangement – either the nursing home or assisted living reported that they were generally pleased with the place they lived. The high caliber of the staff was mentioned frequently as being a factor in enjoying where they lived. Those living in their own homes or with relatives were generally satisfied with the arrangements, although a few reported that they felt their communities did not have enough housing options available for seniors.

- “I need to move because there isn’t enough housing stock in the area. There is some, but not nearly enough.”

**Perception of Older Adults**

- “I have a mother-in-law who is 102 and she would not want to be associated with being a senior!”
- Kept her convertible mustang. Her kids drive her around in it. Put that roof down.
- “Enjoy yourself it's later than you think.”

**Health care:** While a handful of people reported a shortage of Primary Care Physicians in their area (especially in the Keene area), most reported that they get the health care they need. A larger issue was needing assistance in navigating the health care system, especially insurance coverage.

- “Everyone here (nursing home) is paralyzed with fear that someone is going to fall. I am fortunate enough to take care of myself, I don’t need appliances or drugs. I see some of those things that go on and why can’t people be taught to do more for themselves but people are afraid that they are going to fall”
- “To get out and take a walk and get my exercise. No therapy available that is useful to us. Spend a whole lot of time doing nothing. “
- I would like to have a support group for the mentally ill. I was diagnosed with bipolar. I keep it quiet I don’t know how people are going to react.
- “In my case I am very emotional and I have ups and downs – and I go to my room until I am able to get along all right.”
- “It’s just easier and quicker to get an appointment with a specialist at Maine Medical vs. waiting for a doctor to come to the area.........that doctors are leaving the state in droves, which means having to change primary care physicians frequently.(from attendee in a rural area)”
- “The county nursing home (in that person’s area) is not taking any more Medicaid clients.”

**Policy:** Deep concern about regulations/definition of “homebound.” If you take someone out for a ride they lose their services because they are not “homebound.” People have to choose between having nursing care at home (for example, wound care) and attending a congregate meal at the senior center – so they stay away and risk social isolation. Something is wrong with this!!

**Transportation:** In the cities, most reported having access to public transportation, especially a senior transit which will transport door to door with prior notice. In the rural areas, transportation was cited as a major issue which affected the ability to access services, do errands and stay in touch with family and friends.

- “We had Nashua Transit come in to the Senior Center and talk to the seniors—they brought a bus and showed people how to use it. Some people are not comfortable with buses.”

**Staying connected:** Almost everyone gave high praise to the organization which had recruited them – typically a senior center or nursing home – as the “hub” which kept them connected to people, services and the community. More than once, these organizations were described as a “life line” and one person went so far as to say that he felt the organization saved his life. Clearly the combination of a friendly face, information and resources, companionship and often a noon time meal meant a great deal to those in the groups, and was extremely effective in keeping these older adults functioning well.

- “I have lived all my life in Nashua and I began helping in the kitchen. I was not doing anything and I did not like that. Now I am in the kitchen and meeting people—I like it. (from a 90 + year old attendee)”
- “The Senior Center is working—it is getting people together. It does make you think maybe you can do more to volunteer. There are a variety of things—if you don’t like one, you can always do another.”
- “We also have outside agencies here at the Center—ServiceLink for example. It is a many-faceted place. Physical therapy, meals, blood pressure clinics, screenings, tax help, footcare. The Senior Center is a focal point for services and it works.”
- “A lot of people out there have a preconceived notion about what we are—see this as all about old people. So people hesitate to come in. We need to let the public know about this place.”
- “People get closer when they help each other out.”
- “Living alone works for some people but not for me. Have been coming by bus five days a week. Instructors and helpers are a1. Everybody says good things about the helpers.”
• “Folks who don’t have support.....wish there was a centralized place to call for resources. Get back into the world.”
• “I relocated to Ossipee after living in Massachusetts for 67 years. Then I lost my husband. I showed up at the Senior Center alone and raw....and was immediately welcomed. I’ve lived in the community for 12 ½ years and could not stay “without this place.”

Navigating the system: Over and over again, the need for assistance in navigating the system was mentioned. Some had received individual support navigating Medicare and other services, and some mentioned that they still had questions about where to turn. Service Link was mentioned quite frequently as being a helpful resource, and those in the group who didn’t know about it, often took information on their local Service Link office and planned to take advantage of the services.

Themes from Caregivers Groups:

Frustration with the system – almost every caregiver reported that navigating the system was complex, frustrating and often futile. Needed services were often unavailable – such as respite care – due to lack of funding and strict regulations.

• “Everyone needs a caregiver specialist. Good listener, empathetic, good boundaries, can help you navigate the system.”
• “We need a schematic diagram to help us better understand the services offered through Choices for Independence, etc. What do the in-home care services for Medicaid look like? We need a diagram that lays out various situations and what services would be available in those situations. We need to better understand case management approaches.”

Financial Impact of becoming a Caregiver:

• “I was wiped out financially, but I don’t look “poor.” State employees act as if I am trying to “get too many cookies from the cookie jar.”
• “When you are reduced to a certain economic level, you are treated differently by the system.”
• “I applied for Medicaid and HCBC. Given the growing demographic, I’m worried about pace of applications. It takes 4 to 6 months to get in-home care on Medicaid (unless you’ve been discharged from a three-day hospital episode). “
• “My choice was to put my wife in a nursing home or become a full-time caregiver. I gave up my job. Became caregiver. Lost all financially. Lived on less than $739 per mo. I made more than that in a week. We were living below the federal poverty level. We went on food stamps. “
• “We had to sell our farm and house. It was so hard to watch my husband’s decline.”
• “There is no financial compensation for spousal caregivers. We oftentimes have quit our job and are wiped out financially. Sibling caregivers get compensation. Agencies are compensated. Shy not spouses?? Spouses need help. Not to get rich. To survive.”

• “I do not understand why spousal caregiving is considered a conflict of interest. I had two case managers who both quietly suggested I divorce my wife in order to get compensation. I showed them both the door. “

Fatigue – understandably, the constant need for caregivers to be available to their loved ones was exhausting, and little support – such as through respite care – was available to relieve the Caregiver

  o “Takes a big family to support you. My mother cannot live w other adults in an assisted living environment because of her mental health issues.”
  o “Everyone needs a caregiver specialist. Good listener, empathetic, good boundaries, can help you navigate the system.”
  o “When caregiving gets intense, you are isolated. Friends avoid my home. Psychologically you are stepping into a world that is different.....we become mother and mother becomes child.”

Guilt – Many mentioned that as they watch their loved one’s abilities decline, deciding whether to allow him or her to do something they previously had done was fraught with guilt. If they allow it, the person might be hurt; if they don’t allow it, it robs their loved ones of their dignity. Even though these Caregivers were giving their all, they suffered from significant amount of guilt and doubt about whether they were doing enough.

  o “Life as a caregiver.....we go on guilt trip when we resent our situation. It is a new way of life. Suddenly you are not the most important person in your own life”

Simple suggestions

• “Where I live, a bench to wait for the bus would be helpful. A covered bench to provide shade.”
• “There is a Senior Relations Officer (police department?) in both Manchester and Nashua. They are very effective. Jane was the person in Nashua but she is retiring. But perhaps she is still doing something with seniors. Concord may have someone also. They reach out to senior centers and senior housing.”
• “How about bringing kids into the Senior Center? There are children out there who could come to the Senior Center. “
• “You could take seniors to a day care center to read to the kids. Kids could go to the senior center and play chess, etc.”
• “(Sr. Center staff) We just finished a pilot program with nursing students. Nursing students were happy to deal with seniors who are active. It was great for them to see seniors who are in a healthy, active state. They are used to seeing seniors in nursing homes. “
• “More therapy dogs. People benefit greatly from visits of therapy dogs. We have a friend who brings in a puppy. They are wonderful. Oh gosh yes! (BIG SMILES).”

Closing Thoughts: Staying connected to people and to support services is vital for successful aging. Over and over again, focus group participants mentioned organizations or individuals they have come to rely on who have played critical roles in keeping things on an even keel.

Generally speaking, there was an upbeat tone to the focus groups of participants with older adults. This makes sense, since they were ones we were able to find, and invite to these discussions. Likely those who are not connected with senior centers or other resources would have a far less positive spin on their lives.

The focus groups with Caregivers, though, was in sharp contrast to the relative optimism of the older adults themselves. The discussions with caregivers was brutally honest, often tear-filled, sometimes angry, but almost always tinged with guilt and frustration. Given that family caregivers are a critical link in the overall picture of successful aging, more attention is warranted to the many concerns they raise.