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## **Executive Summary**

Over the period of May 12, 2008 to July 22, 2008, the Bureau of Elderly and Adult Services in collaboration with the State Committee on Aging and the Institute on Disability at UNH, conducted seventeen community listening sessions throughout the State to hear what seniors and local service providers thought about the transformation efforts taking place in the long term care services system. The listening sessions were held as part of the Systems Transformation Grant work plan as a means of public outreach and comment. BEAS also plans to use the findings from these sessions as a documentation of need for the upcoming State Plan on Aging.

Sessions were held in Nashua, Laconia, Keene, Manchester, Claremont, Concord, Dover, Plymouth, North Conway, Wolfeboro, Berlin, Salem, Portsmouth, and Littleton at a variety of venues: senior centers, community meeting spaces, public buildings, and educational facilities. A total of twelve consumer/community and five provider listening sessions were held, with over 355 people attending these sessions, including community members, consumers, advocates, legislators, and community service providers. Consumer/community and provider listening sessions were held separately in order to assure that the voice of consumer/ community members were clearly heard. Kathleen Otte, BEAS Administrator, facilitated the discussion. She was accompanied at each session by key BEAS program management staff and local District Office staff in order to answer questions and assist consumers experiencing problems in accessing needed services.

Feedback from these community sessions was thoughtful, direct, and indicative of the issues seniors currently face. Throughout the sessions, a number of recurring concerns became evident:

- Overwhelmingly, New Hampshire's seniors prefer home care, but the current economic situation is making it difficult for them to stay at home. Home care workers and home-delivered meals drivers cannot afford the price of gas. Providers are anticipating they will have to cut back on the areas they serve and the frequency of home visits because they are losing workers to jobs that do not require travel.
- New Hampshire seniors are very worried about high energy costs. Many spoke of the difficulty people on fixed incomes will face this winter. Some will have to make difficult choices between paying for needed medications and heating their homes. At each session, people asked for State government to develop more programs and funding for energy assistance.
- Along these same lines, seniors requested long term care programs to help people who do not qualify for Medicaid but who cannot afford to pay privately for home health, homemaker, and other services.
- The need for additional supports for family caregivers, who provide 80% of long term care services, was heard at several sessions.

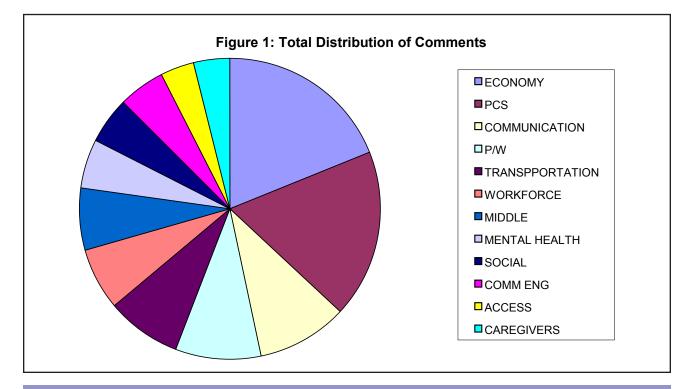
- Transportation still remains a major problem throughout the State. Many seniors rely on volunteers to take them to medical appointments, in particular chemotherapy and dialysis, and necessary shopping. The high price of fuel is limiting the ability of volunteers to continue driving because many volunteers are also on a fixed income.
- Many seniors raised other issues related to transportation such as fear of losing their driver's license, lack of adequate parking near senior centers and other services, public transportation that does not truly meet their needs (routes, schedules, accessibility, etc.), and lack of well marked crosswalks.
- Dental care was consistently brought up as a serious lack in the State's health care system.
- Seniors also noted the need for mental health services for older adults, particularly those who are isolated.
- People advocated for more programs that encourage socialization and keep seniors connected with the community. The State's senior centers were recognized as outstanding resources for socialization and wellness programs, but not every community has a senior center.
- A number of seniors advocated for more support for food pantries. Many of them volunteer at these programs and are seeing a growing incidence of working families with children who rely on these resources. Food pantries are running out of food.
- Significant concern was raised about the adequacy of the direct care workforce to provide home and community based care. Many participants talked about the loss of home care workers and volunteers due to rising gas prices, particularly in the more rural areas of the state. Consumer directed services which allows for the hiring of family, friends, and neighbors was cited as one solution to this problem.
- The lack of program literature and brochures that are easily understandable was noted as a barrier to accessing various programs and services. Materials need to be clearly and simply written and available in other languages.
- The State's interest and dividends tax and the school portion of local property taxes were identified as significant economic barriers for older people on fixed incomes. Many older people who do not have a pension rely on their investments to support their retirement and feel that taxing interest and dividends is in reality an income tax.

Comments from participants at the community listening sessions were transcribed by a CART reporter and carefully coded and analyzed for recurrent themes across the state. This report provides a more extensive analysis of the themes identified through these listening sessions as well as a summary of findings from the provider forums.

## **Consumer & Community Findings**

Kathleen Otte, Administrator for the Bureau of Elderly and Adult Services opened each session with a brief presentation on the transformation efforts underway at the Bureau. She commented that the Bureau is working with all of their partners who help them provide support in the community to assure that services are person-centered and that all providers understand this philosophy. She noted that this is a paradigm shift and the Bureau wants to make sure that services are customized so that they are provided for the person and directed by the person. In a person-centered system, the focus is on the individual, the strengths they possess, and their network of family and friends. The Bureau is working with its partners to create a system that is flexible and cost effective and allows maximum choice over services and supports as people age. She emphasized that one of the core values of the system is "respect". We want a system that respects the individual and responds to individual needs.

This section of the report documents the findings from the consumer/community forums which were held in Nashua, Keene, Plymouth, Conway, Wolfeboro, Concord, Manchester, Salem, Laconia, Dover, Berlin, and Claremont. In addition, comments from the Conference on Aging NH Speaks forum held on May 29, 2008 are included. In total, over 300 consumers and community members provided input for this report. A number of key themes emerged through these sessions. The following are the key themes in order of the frequency mentioned during these forums: the economy and funding for services, person-centered services, communication, prevention and wellness, transportation, workforce, "caught in the middle," mental health, social connections and relationships, community engagement, access to services, and caregivers. In addition, the need for ongoing education and outreach to professionals, service providers, caregivers, and individuals was identified. Figure 1 illustrates the distribution of comments across each of these theme areas.



## The Economy and Funding for Services

"What about the people just above Medicaid? They don't have a lot of money. What happens if they don't get services? They end up on Medicaid or in nursing homes. Personal care and homemaking services are not well funded. And nowadays everything is going up, these poor folks are even less able, between the gas and fuel, and heating and stuff like that." **Berlin** 

Throughout the state, the current economic situation is a grave concern and issues related to the economy and rising energy costs dominated the discussion in many of the forums. Concerns about the economy were raised in all forums a total 396 times. People expressed fear about staying warm this winter and being able to afford basic needs while paying rising heating costs. The economic pressures caused by increasing costs for gas, heating fuel, food, and medication are forcing many people to make untenable choices between basic necessities. The following comment from the forum in Conway exemplifies the concerns raised throughout the state:

"They need to do more for the seniors and other people because this is a fixed income area, unfortunately. The cost of living is getting extremely expensive. Home heating oil, electricity, gas, groceries, and there is no relief, and they are saying now it doesn't look like we will bounce back from this the day after tomorrow. This could take two or three years, and the damage is done. What will be done to fix it?"

The cost of health care services was also raised as a major issue in most forums. For many, the increasing costs of medical care are becoming unaffordable. The "donut hole" in the Medicare system is forcing some seniors to forego needed medications. Medical and dental co-pays and premiums are often too high to afford, and many doctors want payments up front instead of offering payment plans.

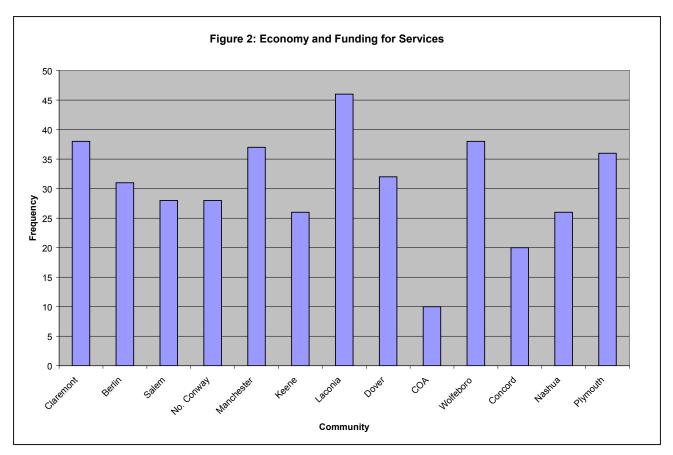
It was noted in many forums that most people prefer to remain at home as they age and home care is typically more cost effective than institutional care. However, the economic strains of paying the increasing costs of heat, food, prescription drugs, medical care, dental care, and property taxes; make it very difficult for many people to remain at home. As one participant in Plymouth remarked:

"My biggest concern is this upcoming winter. And people who are struggling to stay in their homes. I hear stories about moving themselves into one room in their homes last year, and this year will be really brutal."

The cost of housing is an issue across the state. There is a need for more affordable housing and more housing subsidies for low-income seniors. Concern was also raised about landlords who do not provide adequate services (heat, electricity, etc) and who take advantage of renters, especially vulnerable seniors.

Long term care insurance was raised at several forums as an option for paying for home care services. However, many participants noted that it is not an affordable option for many seniors.

Figure 2 reflects how comments about the economy were raised in each community forum.



## **Person-Centered Services**

"We have different complications and different challenges and a person-centered system identifies that, what services you may require, and not only what services you require but how they are delivered." **Claremont** 

New Hampshire's systems transformation efforts support people to remain living in their home and community, if they choose to remain there, for as long as possible. In-home services are cost-effective, and are generally preferred over nursing home care. Forum participants commented that most people want to remain living at home and want to have more control over their care. Comments related to consumer directed, home and community based services were made in all forums a total of 378 times. Consumer-directed services give more control to the individual regarding who provides their care and where and how that care is delivered. However, participants expressed concern about the availability of safe and affordable options throughout the state. Particularly in the more rural regions of the state, comments were made about the lack of options for home care services.

The lack of a wide range of options in home and community based services was raised as an issue throughout the state. Participants noted that there needs to be more options for community living such as adult family care and assisted living and that funding needs to be increased for home and community based services. In addition to a wider range of options, participants also felt that current programs and services need to be more responsive to the needs of both participants and caregivers. Programs need to be of interest to seniors, hours need to be flexible for working caregivers, and rates need to be affordable. There needs to be more flexibility from the agencies regarding times services are provided and how long service is provided. Often services are scheduled at the convenience of the provider and many agencies set a minimum number of hours that they will provide home care services, regardless of the amount of care needed by the individual. A person-centered system would provide greater flexibility in meeting individual needs.

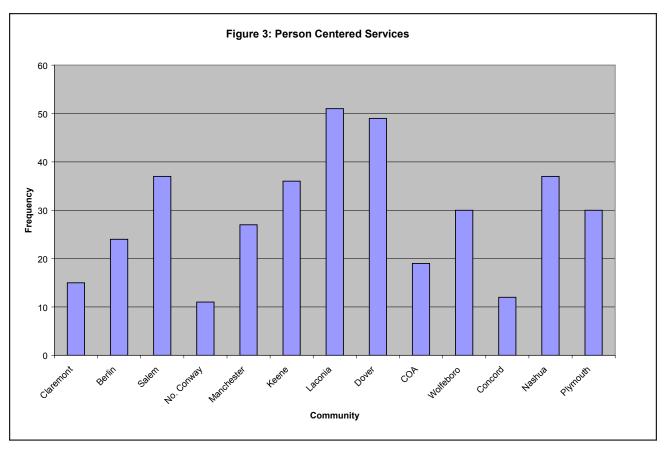
Forum participants remarked that community agencies need more training on consumer directed, person centered services. People need to be asked what they need, not be presented with a set agenda or service package. Consumers should have more control over how their service dollars are spent, who provides their care, and how and when this care is delivered. Participants also commented that services need to be sensitive and flexible to different cultures and address the needs of the varied communities. As one participant from Conway observed, "Quality of life is very different at each stage of our life. Services need to be flexible with our needs."

While forum participants were supportive of home and community based care, many were also concerned about the safety of people living at home, particularly those living alone. It was noted that many people do not have family nearby and become isolated. As one participant from Dover noted:

"I like the idea of person-centered and at home care, but that isn't the answer for everybody. If someone is living in their own home and they're two miles out of town, their family lives on the other side of the country and they don't have anyone to visit them or see them, having someone come in and provide services for half an hour a day isn't going to do it."

Concern was also raised about the increase in cases of self neglect among older adults. Ideas to address issues of isolation and safety included: using volunteers or emergency personnel to check in on older residents, building informal support networks of neighbors and friends to check in on older residents, and working with local emergency response systems to assure that they know who needs help in an emergency.

Figure 3 presents the frequency of comments related to person centered services in each forum.



#### Communication

"I would not have known about all these services if I wasn't involved with the community." Berlin

Communication was raised 200 times across all of the community forums. Many people expressed that they want information but they don't know where to get it. Word of mouth is often how people get the information they need and those who are not well connected have less knowledge about available services. Other sources of communication that people noted are newsletters from agencies and community newspapers. Many people requested that more information be placed on the front page of newspapers and on public radio, commercial radio, and TV. The use of varied communication avenues was stressed as many seniors do not have access to computers and other modes of communication. As one participant in Wolfeboro reported:

# *"I don't have a computer. I have a cell phone, I don't have a land line so I can't stay on the phone forever. I didn't know about all these services, and God knows I need them."*

Whatever medium is used, forum participants noted that communications must be culturally sensitive and easy to understand. For example, there are many areas of the state that are bilingual, and there is a language barrier for many to get the info they need and want. Information needs to be presented in multiple languages, depending on the demographics of the specific community. It was noted that there may be people in the community who would volunteer to translate materials. Sometimes information is presented in a way that is difficult

to understand. Information needs to be presented simply and clearly so that people can understand what they need to do to access help.

People are often unaware of the resources and services available and, therefore, don't use them. Information needs to be distributed through multiple venues including doctor's offices, service agencies, businesses, and community centers. Media outlets such as newspapers, radio, and TV should be utilized to educate the public. This was emphasized by a woman at the Berlin forum:

*"If the local attending physicians had said to me, to my dad, to anybody, 'Hey, you need to give these people a call because this is what is available'. With my mom, honestly we had no clue that there were any services available."* 

Many participants spoke positively about the listening sessions and suggested that they should be held more often. They also recommended that other bureaus within DHHS hold similar public meetings. The need for more sharing of information among state agencies, communities and service organizations was noted in several forums.

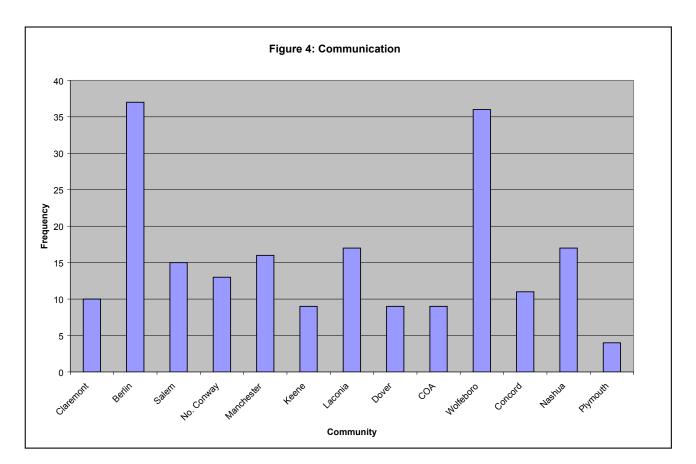


Figure 4 presents the distribution of comments related to communication across the communities.

## **Prevention and Wellness**

*"Know your neighbors. Check on people who are living alone. Do that on a daily basis. Promote wellness. Focus on things that help us stay vital."* **Manchester** 

Issues related to prevention and wellness were mentioned 190 times across all community forums. Comments related to prevention focused on both physical health as well as advanced planning for financial and medical needs. Many participants encouraged the state to promote and support wellness programs in order to encourage healthy behaviors and prevent the need for more costly services later. It was suggested that a legislative effort to fund prevention and wellness programs would be beneficial.

The role of communities in promoting health and wellness was stressed. Opening community centers and recreation facilities in the winter months for walking groups was cited as an example of using existing community resources to promote health and wellness. Participants conveyed that information needs to be made easily accessible to the public. Community centers, senior centers, and other places of congregation are a great place to distribute information about services that can contribute to health and well-being. A participant from Claremont summed up the importance of getting information to seniors:

*"If we can get the information out about services, as well as initiatives for wellness, I think that helps. If we can get that information to seniors that will help potentially lower the need for services."* 

The ServiceLinks were consistently commended for their services in all regions of the state. It was noted that they are a great resource for user-friendly information, educational materials, and referral to services. The ServiceLinks are seen as an invaluable resource for families and individuals to help them connect to needed services. A participant in Keene stressed the importance of accessing the ServiceLinks for information early on:

"I would tell anyone here if you have questions, even if you don't need the services now, check out Service Link. It is a resource. I think it's a smart thing to do, while I still have my head on straight. I don't want to wait until the need arises."

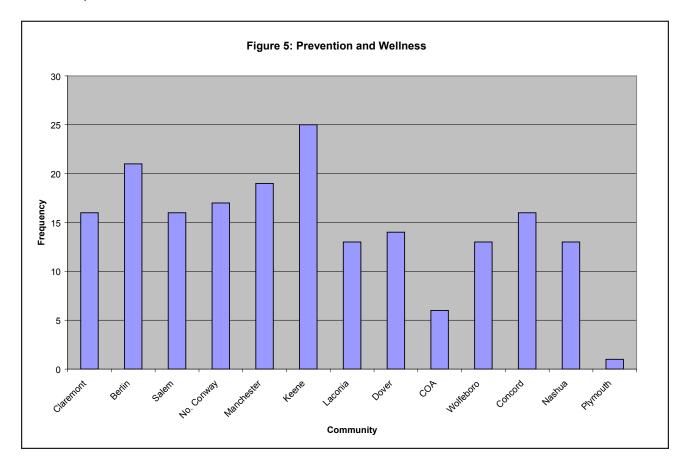
The importance of preventative health care and screenings was stressed. Information about Medicare and other coverage for these services is critical. Many people put off screenings because they are unsure if procedures are covered and they don't have the funds to cover the costs. Dental coverage was noted as an important service in preventing other, more costly medically related issues. Lack of good dental care was also raised as an issue for preventing many physical problems as good dental care is linked to overall good health.

Barriers to participating in wellness programs included lack of transportation, bad weather, and lack of money. Many participants noted that small steps to stay healthy regarding nutrition, physical wellness, dental care, mental health and spiritual wellness can prevent more serious illness and possible nursing home placement. The need to fund wellness and prevention activities was stressed in several forums.

Recommendations for prevention activities included:

- 1. Wellness programs need to be provided in community and senior centers.
- 2. More nutrition programs and nutrition education is needed.
- 3. Incentives should be made available for the purchase of long term care insurance to make it more affordable.
- 4. Provide support services to assist in long range financial planning.
- 5. Education on the need for advance planning documents such as end of life care and durable powers of attorney needs to be provided.

Figure 5 represents the frequency of comments related to prevention and wellness across the community forums.



#### Transportation

"Transportation is a trouble. A lot don't want to take the bus. A lot can't walk. It's a big problem. But if churches can do it and get money from donations, why can't we? We have to go through a bureaucracy in order to do that." **Nashua** 

Transportation was raised as in issue in every forum, but was of particular concern in rural areas such as Berlin, Conway, and Claremont. The issue of public transportation is complex

and challenging. There have been numerous efforts to better coordinate transportation services across the state with varying degrees of success. While forum participants did not provide specific solutions, their input helps to illustrate the complexity of the issue. The urgency to address transportation issues will become even greater issue as more people remain in their homes and communities as they age. Participants stressed that the state needs to address this issue now. As one participant from Berlin stressed, *"Transportation is critical for everything."* 

There is a need for better transportation services in all parts of the state, but it is more pronounced in rural areas where there is less public transportation available. Even in areas that have good public transportation systems, they are often not responsive to the needs of seniors. For example, many seniors are unable to stand for long periods of time waiting for a bus or are unable to carry items home from shopping trips. Often bus stops are not close to where people live, especially those who live in remote areas or off the main roads. Many consumers at the sessions mentioned that they would like transportation available in the evenings for social events like movies and going out to dinner. Some people require the use of wheelchairs and other medical equipment that has to accompany them, and the vehicles used must be able to accommodate them. In short, even where transportation services are available, they are often not convenient for the people who need them. As one participant from Dover noted:

"There is a bus that is available at the end of a street, but it's too far for the elderly to walk there. And we have asked that they please consider changing their routes because most of the seniors are at the other end of that street. We've had no success."

The lack of transportation presents significant barriers to access to services, particularly for services such as specialty medical care which is not available locally. Some programs provide transportation to allow participants to attend and others do not. Another issue is that many seniors are unable to drive themselves and rely on caregivers and/or volunteers to drive them where they need to go. It was reported that many of the volunteer drivers were not consistent, and the cost of gas has forced volunteers to either cut back on the amount of help they can provide or stop driving others completely. Program and funding rules also serve as a barrier to accessing transportation. For example, several transportation programs are not allowed to assist a rider from their house to the vehicle. For someone with mobility issues, this can prevent them from accessing that ride. A participant at the Manchester forum remarked:

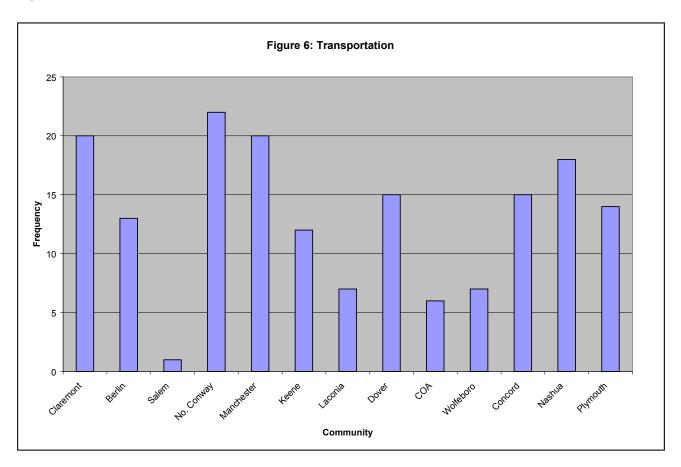
"I'm an entry level senior, what I'm finding is that there are a lot of activities out there for seniors but transportation is a very, very big issue. They would participate but can't get there because they don't have a license or can't afford transportation."

Participants related that the myriad of transportation contracts, funding mechanisms and programs could be better coordinated to utilize these resources more effectively to meet the needs of NH residents. It was commented that the brokerage model that is being discussed and piloted in several areas appears to be a promising idea.

A number of suggestions to provide relief for the current high gas prices were elicited. These included: the state purchasing gas in bulk for agencies and direct care providers, paying incentives to agencies that reimbursed direct care providers for mileage, adjusting rates to account for the higher transportation costs, and consolidating trips and sharing vehicles among

different organizations. Video conferencing was also raised as a way to reduce travel costs by to limit the need to travel to doctor or agency offices for appointments, meetings, and workshops.

Figure 6 reflects the frequency of comments related to transportation across the communities.



## Work Force

The quality of life for people who require care is directly tied to the quality of the workers who support them. In New Hampshire and nationally, the ability to recruit and retain a quality direct care workforce is becoming increasingly difficult. Unable to earn a livable wage and with no health insurance or other benefits, direct care workers frequently leave for better jobs. The situation is only expected to get worse. By 2030 the number of people over 65 will nearly triple and the number of those over 85 will nearly double, at the same time the workforce available to meet the needs of an aging population is constricting.

Issues related to the workforce were raised 144 times in all forums. Workforce issues range from the lack of specialized medical professional to the lack of quality direct care workers. There is concern that we do not have an adequate direct care workforce to support the State's efforts to shift care for older adults from nursing facilities to home and community-based settings. With a population that is older than the national average, there are an increasing number of New Hampshire residents who require direct care. At the same time, there is a shrinking number of qualified workers available to meet this need. In addition to the paid workforce, the home care work force is made up of many volunteers, and the number of available volunteers is also shrinking. Lastly, many spouses and adult children are providing personal care for their parents, and these informal caregivers need support in order to continue to provide this care.

Participants reflected that wages and benefits for New Hampshire's direct care workforce are inadequate. Most front line workers are not paid a livable wage and few workers receive benefits of any kind. An assessment of staffing patterns and community needs should be done in order to make an informed, coherent and powerful argument for additional funding for direct care wages and benefits.

More ways need to be found to utilize volunteers who are able and willing to share their experience, talents and passions. Retraining those who have retired or been laid off from other professions to be caregivers could open the door for many workers. As one participant in Plymouth stated:

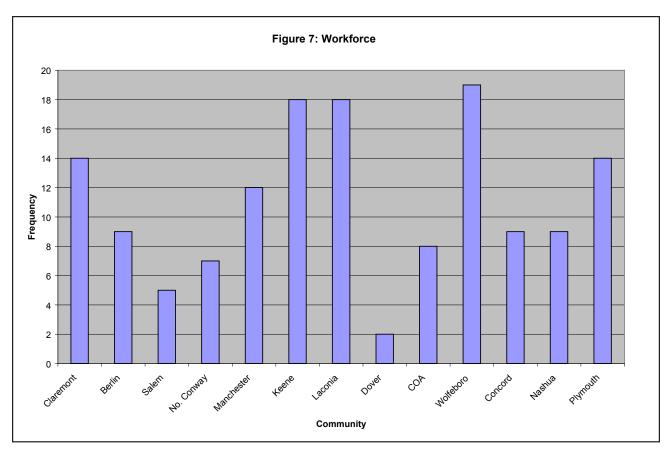
"We should encourage older citizens to come back into the workforce, people who are 55 years of age to come back in and provide care for people."

There is a need for more physicians, nurses, social workers and volunteers, and an incentive needs to be created to encourage people to pursue and remain in the field. More effort and creativity are needed to promote direct support as a viable career option. Students enrolled in high schools and New Hampshire's Community Technical Colleges should be informed about direct support career opportunities. It was also suggested that the state could provide incentives for medical students to specialize in gerontology and to stay in the area, such as loan forgiveness for a certain number years of service.

"The state ought to think a little out of the box on how to have incentives for young people to pursue careers in the occupations that will help address these needs." Plymouth

> A number of issues related to the direct care workforce were raised. The lack of an adequate number of direct care workers was mentioned in many forums and the shortage is predicted to get worse. Many participants argued that the state needs to address the shortage for personal care, respite care, and other direct service needs if it hopes to increase access to home and community based services. It was also noted that there needs to be better training, staff development, and quality assurance for New Hampshire's direct care workforce. Some participants noted that direct care services are not well coordinated and that better communication is needed among provider organizations, direct care workers, and those receiving services.

Figure 7 reflects the distribution of comments related to workforce issues across the state.



## Caught in the Middle

"Our concern is for that group that falls through the cracks, who are not poor enough to qualify for public programs but don't have enough income to pay privately for services." **Claremont** 

"We have people that are growing older caught in the middle. They are not eligible for services because of their income and so forth and they begin to have needs and cannot afford to pay privately for some of the services because they are caught in the middle like that." **Claremont** 

"Something has to be done for that person that needs a little help so they don't spend down everything and outlive their money." **Manchester** 

These were common refrains across all of the forums. Participants were concerned about those who do not qualify for publicly funded services, but who do not have adequate resources to pay for services themselves. Those who planned well financially their whole lives feel "punished" because they don't qualify for services and programs such as heating assistance even though they cannot handle current costs for these services.

Long-term care insurance was noted as a useful product but many cannot afford to purchase it and the benefit package is often limited. In its current form, long term care insurance is not adequately meeting the identified need. The following comment from a participant in Plymouth articulates the issue well:

"I'm one of the people in the gap. I work, get a pension, and get social security. I make too much for any of the program, and so I have had to spend lately, I have spent up to \$500 over what I

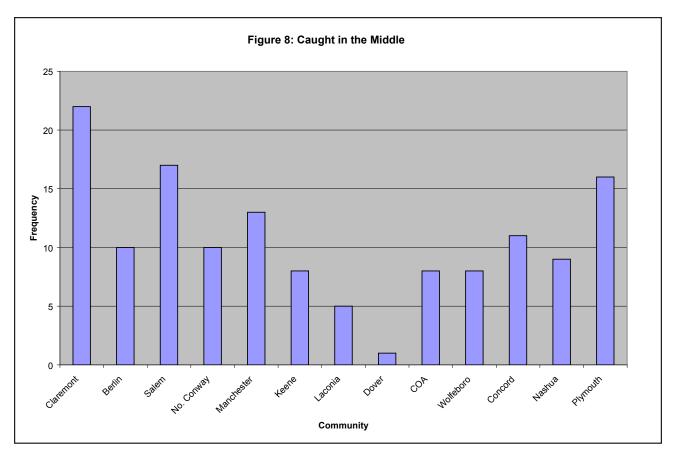
make a month for medical and try to stay even. I have been in a rut. But there aren't any services for the people in the gaps. It totally frustrates me."

Some participants noted that there is a lack of awareness and information about what services people may be eligible for. Income limits vary across programs and some services are available to all residents of the state. Better communication about what is available and who is eligible is needed. It was also noted that the paperwork for applying for services needs to be streamlined and made more manageable for consumers and agencies alike. Better sharing of information across agencies would make it easier for people to access needed services.

Participants at several forums raised concerns that the rising cost of health care services will limit the number of people receiving services. While it is extremely difficult for individuals who do have insurance to afford care, concern was expressed that even those on Medicaid and Medicare are finding it hard to access care as many providers are unwilling to accept Medicaid's and Medicare's low reimbursement rates. A common complaint at almost every forum concerned the issue of the "donut hole" in Medicare services where prescriptions are no longer covered. Many participants noted that the program is confusing and that they pay more for prescriptions now than before Medicare Part D. Participants expressed concern that people are having to make a choice between prescriptions and other basic needs like heat or food. As one participant in Dover lamented:

"I get so angry sometimes when I think about some of the things that seniors, and I'm counting me in that, aren't covered for. When I worked full time, it was wonderful. I had all the care I needed. When I've gotten old, now my teeth, my hearing is shot, my eyes, I can't see as well, and yet none of that is covered under Medicare. Not one bloody cent of that is covered. Yet that affects so many seniors. And the cost of that is just outrageous. I'm very frustrated about it because I think there needs to be something done. There are other things this can cause with depression when people can't communicate or they can't hear."

Figure 8 represents the frequency of comments related to concerns about people who cannot afford to pay for services, yet are not eligible for publicly funded services.



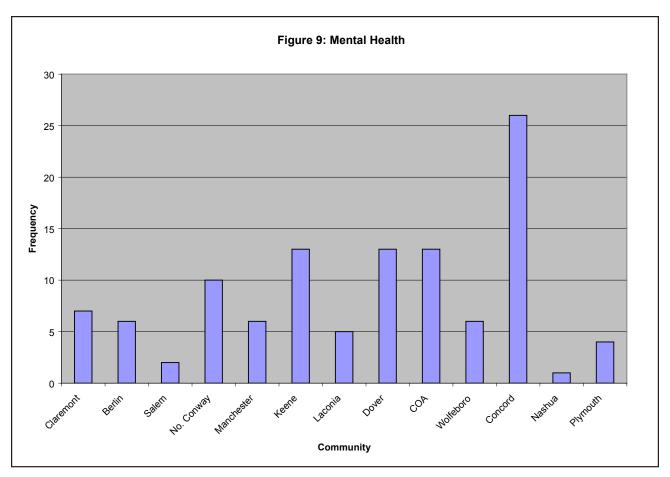
#### **Mental Health**

# *"Encouraging people and providing services for people to remain in their home is great, but we see self-neglect reports rise and isolation and depression increase."* **Wolfeboro**

The need for mental health services for older adults in New Hampshire was raised a total of 112 times across all of the consumer forums. The lack of access to mental health services was raised as a concern throughout the state. Many noted that they have seen an increase in self-neglect, and it was felt that this is partly because people are too proud to ask for assistance from family and strangers alike. There is a high incidence of depression among older adults. It was recommended that community based mental health and substance abuse services need to be increased.

The increasing number of people with Alzheimer's and related dementias was specifically raised as a growing concern. Caregiving for someone with Alzheimer's is particularly challenging and mental health services for caregivers needs to be addressed. It was suggested that there needs to be more education about Alzheimer's disease and related dementias for both doctors and families that is culturally sensitive.

Figure 9 illustrates the frequency of comments related to mental health services across the state.



## Social Connections and Relationships

*"How important it is for all of us to be connected with one another. That leads to a quality life, a healthy and happy life."* **Conway** 

"I get energized by people, and I think that each one here has a gift, and we can help each other but we don't have a common place." **Concord** 

At sessions throughout the state, people commented on the importance of participation in senior programs and attending social and spiritual events. Senior Centers were praised as excellent community resources that provide low-cost programs, nutrition, social connections, physical activity, and medical support. Senior Centers are an untapped resource in many areas and it was suggested that they should be supported in every community. A Conway participant stressed how important the local Senior Center is:

"Most of us are so grateful for the Gibson Center and not just the quality of the meals, but for the people, association and friendships and to learn to get along with people.... We depend on other people for socializing, for talking, or telling jokes."

Social relationships can improve the quality of life and keeping people engaged in the community is important for their overall health and well-being. Unfortunately, many people who are staying at home, especially in rural areas, are isolated from such activities and social

connections. Family and friends are a tremendous resource but many seniors do not have family nearby.

One thing that is overlooked is socialization. There are not the Halloween parties and availability to get people out of their apartments socializing with one another, which helps to develop friendships and also mental alertness. Socialization is key, it is one of the predominant needs that anyone has, to be with people." Manchester

Social interaction and psycho-social needs have to be considered when planning services. In many forums it was noted that an increase in the number of social programs available to seniors that provide transportation is needed. Many comments specifically supported the need for more social opportunities on weekends. Services such as Meals on Wheels are important, but for many, the sharing of time with the person who delivers the meal can be more important than the meal itself. As one participant from Concord noted about the Meals on Wheels program, *"I think that being together and talking was just as important as the meal."* 

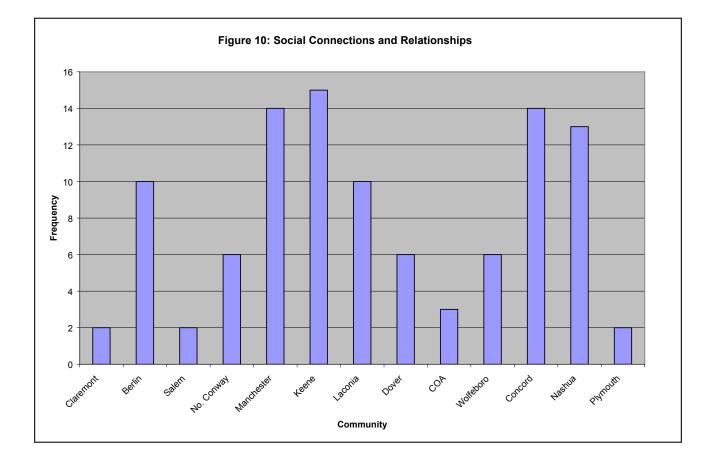


Figure 10 reflects the frequency of comments related to social connections across the state.

"These are our neighbors and families, people that we have known probably most of our lives. So, it isn't the stranger down the street that just moved in. It's our neighbors. So, it is about helping our neighbors and they need help." Littleton

"In my mind, it's really about the community system. What can we be doing as friends, as neighbors, to change to make things more livable for all of us? Do we need to have community associations, neighborhood associations, more involvement with some of our civic clubs and organizations so that we are all helping each other?" **Nashua** 

The importance of working together with local communities was stressed in all of the forums. It was noted that partnerships among community organizations can improve services by sharing resources and expertise. Collaborative efforts at fundraising could help to address the varied needs of all residents and to better manage available funds. Many participants commented that agencies need to share resources more with each other to better serve their clients. Transportation and transportation funding were raised as an example as one of the most important areas where collaborative efforts would better utilize existing resources and improve service.

Forum participants commented that local groups such as churches, Chambers of Commerce and Rotary Clubs need to be engaged to support seniors in the community as well as to share information about services and social activities. Individuals in the community could be tapped to share more of their personal and professional talents in order to make the community better for all. There needs to be more creative thinking for solutions and more thinking outside the box rather than relying on publicly funded services. One Keene participant described an innovative idea they are working on:

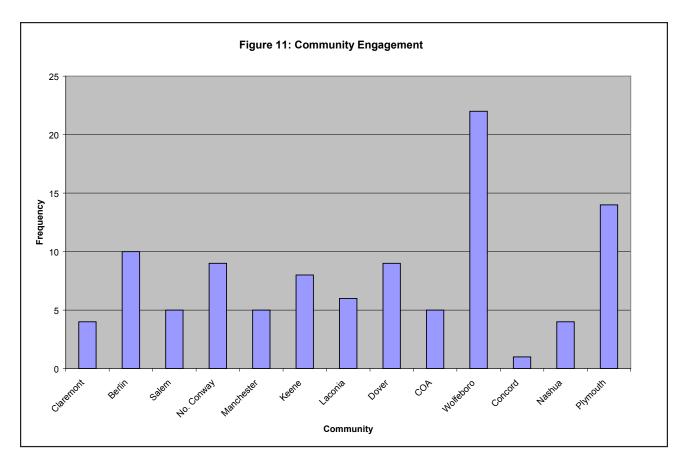
"We are trying to get five or six rural communities to get together, starting at an earlier age. We know the boomer are about to hit us, and that will make a lot of difference in the long run. The state can't handle it. We have to do it ourselves. A lot of this is live free or die. And maybe live free with other people. Independence and choice, respect, those are the things that people talk about."

There needs to be more inter-agency and inter-departmental collaboration not only with resources, but with ideas and sharing information. There should be more collaboration with colleges, universities and other educational establishments. For example, creating or utilizing programs where students in the Human Services Program become involved with the agencies and are included in the work force through internships and program requirements can reduce costs to the system, increase the work force and provide training needed for those entering the field.

It was also noted that seniors can benefit from stronger partnerships with professionals. For example, having a good relationship with a physician can provide the connection needed to feel comfortable asking questions about one's health and available services. A strong

relationship with one's health care providers is critical to empower seniors and foster informed decision making.

Figure 11 represents the frequency of comments related to community engagement across the communities.



## Access to a Range of Service Options

"One of the things that I'm seeing for myself is that there isn't anything in between independent living, whether it be in an apartment or house or whatever, and assisted living. And a lot of people who live here, including me, either have help from friends and relatives, or they don't. And I inquired about services from VNA and I was told that I couldn't get a home maker companion unless I also needed nursing services, which I don't need." **Concord** 

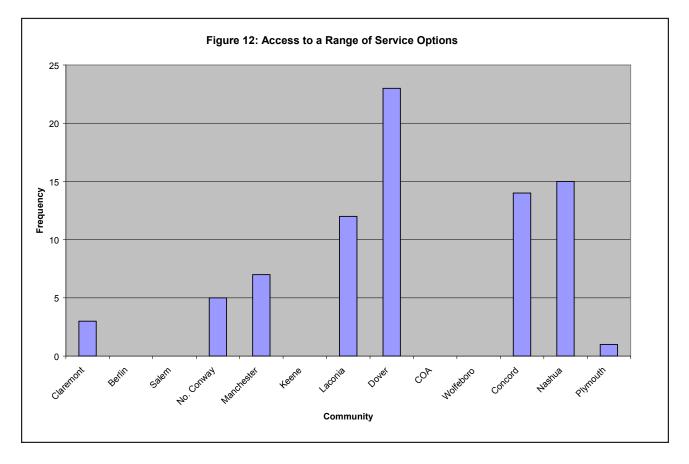
The need for a range of service options that are easily accessible in every community was raised at eight of the community forums a total of 80 times. Comments reflected on the lack of options for home and community based care, and the need for a broader range of services between independent living and nursing home care. The following comments reflect the sentiment heard throughout the state:

"People trying to avoid becoming ill or declining so they have to go into a nursing home, is a common theme that I have seen with people that I speak with on the phone. They worry about asking for help, because they think the only option -- like this old way of thinking -- is nursing

home. And I'm not going there. Whereas if we can address their needs in the home successfully and appropriately, they can stay at home. But because that's such a new way of thinking, a lot of the elders don't even realize that that's available. Then they don't ask for help, then they decline, then they do have to go in a nursing home. Somehow we need to let people know that there is this option. **Nashua** 

"I just need somebody to come in and help me with cooking and cleaning. And I think being a Boomer, as we age, is going to be more people needing this to stay in their homes. And we all know that that's best for mental and physical health and it's less expensive." **Concord** 

Figure 12 presents the frequency of comments related to access to a range of service options across the state.



## Caregivers

"... we owe a lot to family caregivers. They are the unsung heroes, providing 80% of the care that is given to older adults in this country. Not through nursing homes and not through the VNA, but family taking care of family." **Berlin** 

"I would have killed for a haircut. I didn't have one in over a year." Berlin

Family caregivers provide the vast majority of all long-term care, and NH relies on this informal network of support as a primary source of care for older adults. That care is frequently complex, demanding, and may extend over a long period of time. Often, a caregiver is a spouse, adult child, or other relative. These family caregivers need support in order to continue to provide care for their family member. There needs to be greater attention paid to the needs of caregivers. As a Salem participant observed:

"I have to tell you people who have loved ones that are ill and they are frail and they are still married, the spouse that is providing the care, they are wearing out, but they are wearing out because they are scared. They are scared that their finances are dwindling and they are frightened. We have to start where we can help to support the people, so they don't have the fear and can focus on the care giving."

Adult day care is a great resource for both the individual and their caregiver. Alzheimer's is a family issue and needs family care. Family caregivers need emotional respite; not all needs are financial.

People complained about being on a waiting list for respite care. Many people do the best they can until they just can't do it anymore. When they finally ask for assistance, they need help immediately and can't be on a waiting list. In addition to services such as respite care, many caregivers noted how helpful support groups have been for them. The need for more caregiver support programs is reflected in the following remarks:

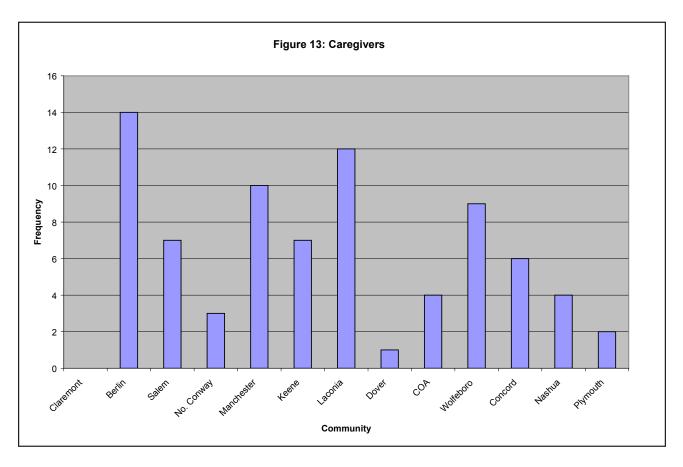
"There is really not a lot of money out there to help the care giver who is providing that 80% of the care to their parents. We would ask additional support if that is possible in the future, to get more support for them. And also a support group." **Berlin** 

"We don't have enough help. There is no money available for house cleaning and all that. When you call for that there is nothing available. They pass you around to different places. I have a husband and I can take care of him. I don't want him in a nursing home. But how long can I care for him without certain services?" **Manchester** 

"I hear families coming in to the support group that are caring for loved ones at home. The caregiver grants are excellent, they need that respite care, and I see that need increasing. More older people are being cared for by their spouses or children, or are trying to take care of grandchildren. There does need to be more attention to caregivers and taking care of themselves." **Conway** 

It was recommended at several forums that support groups for caregivers be made available throughout the state and be advertised widely. In addition, the need for more respite care providers and a backup system in the event that a worker does not show up were noted.

It was noted at a number of forums that the caregiver support grant is vitally important and funding for this program should be increased. In particular, comments indicated that the Transitions in Caregiving program is a huge help and should be expanded statewide. Transitions in Caregiving is a nursing home diversion program funded by the Administration on Aging that is transforming the state's caregiver support system to a community-based, consumer-directed caregiver program.



#### Figure 13 depicts the distribution of comments related to caregivers across the state.

#### **Education and Outreach**

"I don't know what we can do to target those people that need these services but are isolated in their homes. Those are probably the voices we need to keep in mind at these meetings because those are the people that can benefit the most and don't have access to health care. They don't have a close family situation or anybody they can count on." **Laconia** 

In order to make informed choices about long term care, people need good information about the options available. Education is power and it should be an ongoing process for professionals and consumers alike so that both are informed about available services. The areas that were expressed as being most important during the sessions were: learning about rights regarding exploitation and abuse; information about what services are available; nutrition education; money management; information on various mental and physical conditions; and caregiver education. In particular, many people asked for information about Dementia and Alzheimer's to better understand how to assist their loved ones and what to expect down the road.

Many participants noted that education is an ongoing issue as individual circumstances change and people don't always 'hear' the information until they need it. As one participant from Wolfeboro observed, "We never think about the services until you are there and it is one of those 'Oh My God' moments, and you needed it almost yesterday." **Wolfeboro** 

## **Other Concerns**

A common refrain in many forums was that some people may be afraid to ask for help, thinking that they may be forced into a nursing home. It was also noted that some seniors may be afraid to attend a community meeting, or to speak freely, for fear of having others find out their personal business. Other concerns that were expressed indicated that many seniors don't want to talk about getting older and fear being a burden on their family.

"It might be uncomfortable, what nobody wants to talk about, but I think we all worry we're going to be a burden to our kids. And you know things happen. I wish the state would just be a little bit more concerned." **Concord** 

"Many times people don't want to recognize that they are aging or getting older. We don't want to talk about being old. Our state needs to have an initiative that recognizes and values growing older and there is a lot to do and a lot of things for people to experience. Seniors are the forgotten people" **Manchester** 

Other participants reflected on the aging of the baby boomer generation and how the increasing number of seniors will change the face of aging.

"And one of the things that's really frightening for me standing here is that I'm realizing that the issues of the generation ahead of me haven't really been addressed or met, and here I come as a boomer -- there are more of us. It's going to get worse, and I'm scared half to death." **Concord** 

"This generation is not willing to lay back and accept what was. They're going to challenge. And they're going to push. And they're going to shift the paradigm into being proactive." **Concord** 

## **Provider Findings**

This section of the report documents the findings from the provider forums which were held in Nashua, Littleton, Berlin, Claremont, and Portsmouth. In total, almost 100 providers attended these sessions and provided input. A number of key themes emerged through these sessions. They include: the economy and funding for services, consumer-directed personal care services, workforce, communication, transportation, community partnerships, mental health, social connections/relationships, mental health, and prevention. In addition, a number of barriers to community services were identified.

## The Economy and Funding for Services

"... the character of an individual is always tested with adversity and right now we as a system and organization are being tested mightily." **Conway** 

Issues related to the economy were paramount in all five provider forums. In total, 59 specific comments were raised, the largest number for any theme area. The downturn in the economy and the rising costs of fuel have increased the level of anxiety around funding at both the individual and agency level.

Forum participants remarked that the economy is unstable and it affects the state budget, county budgets, local funding, and fundraising. This will have a serious impact on the availability of services in the community. At the same time, it is anticipated that the number of people seeking services will increase as the economy worsens.

The increases in fuel costs is affecting agency budgets for both heating and travel expenses. The increasing cost of driving is an issue for agencies, workers, and volunteers. Agencies cannot afford to pay the increased mileage reimbursement, workers are not paid adequately to cover basic fuel costs, and volunteers are cutting back on driving as their fuel costs increase. Participants in the more rural areas commented that they are particularly hard hit as workers have much further distances to drive to make home visits. It was strongly recommended that the state consider differential rates between urban and rural areas to account for the increased travel costs in rural areas.

The need for more funding for dental services was also raised as an issue in the provider forums. Providers also anticipated that the number of seniors who will be exploited could increase as the economy worsens. Increased efforts should be made to educate seniors about financial and emotional exploitation.

## **Consumer-Directed Personal Care Services**

"So we want to get to that point in a person-centered system where not only are the services determined by the clients but also the service dollars and how they're spent by the individuals and their families, their support. I should say and also add that managing these services is a very important part of the process, not only in designing the services but managing them, and we think that is best served by the person who is receiving the care." **Claremont** 

Issues related to consumer-directed personal care services were raised in all five provider forums with a total of 45 comments. Comments ranged from concern about the lack of choice and availability of home care workers to strong support for a more consumer-directed system. Participants noted that one size doesn't fit all situations and that the system needs to be more person-centered, individualized, and flexible.

The lack of access to a wide range of supportive services in the community was raised as a concern. Services areas that were noted as needing additional funding include: residential care, caregiver support, respite beds, assisted living, denture program and dental needs in general, emergency placement, assistance for the homeless, veteran's services, transportation, adult day, and more. With the downturn in the economy, referrals for services are increasing, especially for personal care assistance, home making, and personal errands. Many areas reported the need to establish waiting lists for services.

It was noted that in a person-centered system all of the person's existing support networks are assessed. Existing supports are augmented with agency supports. This results in a more cost-effective and higher quality service. Participants commented that procedures for determining eligibility for services and the provision of services needs to be streamlined in order to get assistance to people more efficiently and timely.

## Work Force

*"We have the "perfect storm" situation. We're encouraging people to stay at home but we won't have the workforce to support them."* **Claremont** 

Issues related to the workforce were raised in all five provider forums. Concern was expressed about the lack of an adequate home care workforce and how this affects access to care and the quality of care provided. Concern was raised that there are not enough workers and recent cutbacks have made the situation worse. As the population ages and younger workers leave the state, it is anticipated that issues related to the workforce will be heightened. As one participant noted:

*"We have a workforce problem in NH, we have many people from the ages of 24 -54, women especially, who are leaving the state, seeking higher paying wages, and this is the population that has typically provided the care giving."* **Wolfeboro** 

In addition to the lack of a paid workforce, concern was also raised about the loss of volunteers as the cost of gas increases and volunteer cut back on travel. It was also noted that most volunteers are older and as they age they may need services themselves, rather than be providing services. On a positive note, it was suggested that consumer-directed personal care services may have appeal to workers who would not typically work for a home care agency, such as friends, family, and neighbors, and this will bring a new and atypical workforce into the field.

Participants also noted the need for more professional services for geriatric care. They observed that it is currently very hard to find doctors, nurses and social workers trained in geriatrics that are willing to come to and stay in NH, especially in the more rural areas. It was

suggested that the state consider programs to encourage professionals to work in NH, such as loan forgiveness, educational benefits, and other career enhancements.

## Communication

#### "The biggest problem is getting information out there to the common person." Nashua

Issues related to communication between the state and providers, among providers, and with community members were raised at four of the five provider forums. Participants remarked that the Department's cross-bureau team could help with the lack of communication. It was felt that better communication between the managers of the various waiver programs would benefit community providers who struggle to find appropriate services and funding for their clients.

The need to have materials written in simple language that everyone can understand was stressed. It was noted that many people don't know what services are available or how to access them. Often the written material they receive is confusing, particularly if it includes legal, bureaucratic language. Comments also indicated that people often don't look for information or pay attention to what is available until they need it. As one participant observed:

"We've been here 30 years as a senior center and they don't know there is one. On the other side of that, we have people who come to the state from another area, to be close to children, they immediately seek out a senior center because they were active in one back at home and they find us right away. To me it's a selective process. If you don't want or you don't -- you just don't see it. It's invisible unless that's what you're specifically looking for. So there are a lot of things slipping by people simply because it may not be that one thing you need now." **Nashua** 

Issues related to outreach and education were raised at three of the provider sessions and focused on the need for more education on the Community Passport program, emergency planning, and guardianships. It was suggested that both Service Links and Senior Centers are great places to distribute information. It was remarkable how often people at the forums indicated that they did not know that Service Link existed. It was suggested that continued efforts be made to get the word out about Service Link. As noted at the Claremont forum, *"ServiceLink is helpful because it is a one-stop shop where people can come in and get information about services."* **Claremont** 

#### Transportation

"So people that are going to remain in their homes are going to need support for transportation, not just for groceries, but for a myriad of things, to get to the care that they need, etc." **Concord** 

Transportation was identified as an issue in four of the five provider forums. Issues related to transportation varied by community, based on the availability of public transportation and the rural nature of the area. Transportation issues were intertwined with the economic issues related to the increase in fuel costs.

It was noted that there is no public transportation in many areas and where there is, it often doesn't work for seniors because of lack of proximity to bus stops, inconvenient schedules,

medical issues that prevent access, lack of places to wait for the bus in bad weather, and difficulty carrying personal items such as groceries. Transportation for people who need ongoing treatment at specialized facilities such as dialysis or chemotherapy, is particularly difficult as they often require one-on-one attention and regularly scheduled transport. For those living in rural areas, the distance to travel to these appointments is particularly challenging.

Mileage reimbursement and fuel costs are a grave concern and affect the level of service provided; particularly for services such as home-delivered meals and home health. This theme was heard widely in all communities and providers are very concerned about being able to continue to provide services in the most rural areas. Many people, especially those who live in rural areas who have to travel long distances for medical care, haven't been able to get to medical appointments which can compromise their health. As one participant in Claremont noted:

*"I'm very concerned about the lack of transportation for a lot of these folks. There is a real shortage of transportation for folks to get to life saving medical appointments. This is a rural state and public transportation is really minimal, unless you live in Manchester or Concord where there is regular transportation."* 

Recent efforts to develop transportation brokerages across the state were praised as a promising practice. As one participant summarized:

"We are trying to set up what we call a transportation brokerage. The reality is that there are a number of agencies that have transportation assets in our respective communities, but they are not coordinated." **Conway** 

## **Community Partnerships**

"Working together as a community and relationship building is key and paramount to just about anything that we do. Being able to establish rapport and trust is how we will weather the storm." *Littleton* 

Partnerships at the state and community level were raised at three of the five provider session. Participants talked about successes as well as problems with partnerships. Participants commented that there needs to be more communication, planning and cooperation among community agencies, especially in respect to sharing resources. Several communities are working to create community partnerships to help address needs at a local level. As one participant from Keene remarked:

*"We are looking at ways to work with existing volunteer organizations and the business community to help people who are looking for concrete ways to volunteer."* **Keene** 

## **Mental Health**

"There is a real need for our seniors and also for the other folks in the community for mental health and substance abuse services. That is something on the back burner or swept under the

rug. Mental health issues will not go away without care and there are not enough health care providers who are actually facing the issues." **Conway** 

Concern about the availability of mental health services was raised at three of the five provider forums. Comments indicated that many regions are seeing an increase in depression and isolation among older residents. Several participants expressed concern about the increased numbers of reports of neglect and self-neglect. The need for more community based mental health services was stressed. As one participant stated:

*"Mental illness is probably one of the most vexing issues that we have in the state. The root issue is inadequate services and bed capacity and substance abuse services in the community."* **Conway** 

#### **Social Connections and Relationships**

"We are concerned about folks who are remaining at home and don't have the social networks they need. So they are isolating themselves and not getting out and that doesn't promote healthy living." **Keene** 

Issues related to social connections and personal relationships were raised at four of the five provider sessions. Participants remarked that the lack of socialization increases the likelihood of depression and has a negative effect on overall quality of life. Personal connections often result in better care and more access to services and supports. Those who do not have family and friends nearby often need more formal services as they lack an informal support network. On the flip side, concern was also raised about family members moving back in with their older parents during these difficult economic times and taking advantage of them.

#### Prevention

*"We need to focus on prevention. I think it does keep people well longer. It keeps people from getting into the system before they really need to."* **Nashua** 

Issues related to prevention were noted in four of the five provider forums. Issues were raised across a range of areas including: the need for places for seniors to congregate and socialize, particularly on weekends; the need for better preventative dental care; and the need for emergency planning at an individual and community level. Many participants noted the value of the contact made with individuals through programs such as Meals of Wheels which provide an extra set of eyes to check on people who live alone. Concern was raised that many agencies have had to cut back on the frequency of these visits due to fuel costs. Concern about the lack of funding for preventative services was illustrated by the following refrain:

"So there needs to be a balance. But it's difficult to have that balance when those types of preventative services we used to have available evaporated as funding dried up and we were no longer able to do that. Our concentration became on the neediest, the most frail, and that also makes sense. When you don't have a lot of money, you put your money where it really is going to go the furthest." **Nashua** 

The following table indicates the frequency with which each topic was raised at each provider listening session.

	Claremont	Berlin	Nashua	Littleton	Portsmouth	Totals
ECONOMY	10	10	9	24	6	59
CDS	7	7	14	23	8	59
WORKFORCE	4	6	1	16	2	29
COMMUNICATION	2		6	12	1	21
TRANSPORTATION	2	8	5	3		18
PARTNERSHIPS		4	3	10		17
MENTAL HEALTH	1	7	4	7		13
SOCIALIZATION	1	3	5	1		10
PREVENTION		3	1	4	1	9

#### **Barriers**

Barriers to accessing home and community based services were raised at four of the five provider forums.

Barriers identified include:

- 1. The process of accessing services is confusing and disjointed;
- 2. Many people fall between the cracks and don't qualify for Medicaid or other public services, yet cannot afford to pay for services on their own;
- 3. Some people are reluctant to ask for or accept services;
- 4. The availability of services varies across the state;
- 5. The various eligibility criteria for programs is confusing;
- 6. Liability concerns sometime prevent agencies from providing services people need;
- 7. Lack of transportation makes it difficult for people to access services, medical care, and social events; and
- 8. The lack of affordable, safe housing in many areas of the state makes community living difficult.

## Recommendations

A number of recommendations emerged from the vast array of comments collected through these forums. The following summarizes these recommendations.

- 1. Increase the assistance that can be provided for home and community based services to help people stay in a home setting and delay nursing home placement. Utilize some of the savings realized through nursing home diversion to increase funding for home and community based services.
- 2. Continue the State's efforts to create a more person-centered, consumer-directed system. This means providing greater choice over where and how services are delivered and tailoring services to meet the needs of individuals.
- 3. Increase the resources available to support family caregivers. Implement the consumer directed family caregiver model statewide.
- 4. Increase education and outreach to better educate families, individuals, and professionals about available services. Assure that information is provided through multiple venues and that written information is easy to understand.
- 5. Support prevention and wellness programs in every community. Define prevention and wellness broadly to include all aspects of healthy aging to include dental care, nutrition education, physical activity, financial planning, advanced planning for health care, socialization, etc.
- 6. Partner with existing community resources to enhance services for seniors. Develop strong community partnerships in each community to support seniors. Work with local Senior Centers to provide programs to engage seniors.
- 7. Develop a comprehensive strategy to address the workforce shortage that considers the lack of geriatric medical specialties, nurses and other health care providers, and personal care workers.
- 8. Increase access to geriatric, community based mental health services.
- 9. Continue the work to coordinate transportation services statewide through regional brokerage systems.

## Other

A number of ideas were generated that were not within the purview of the Department of Health and Human Services. However, the issues were important to community members and are included here for consideration.

- 1. Many towns and the state could follow the lead of one area that permitted citizens to go into forests to cut down previously marked and approved dead trees for firewood to offset oil costs.
- 2. The state could provide a credit card like those that doctors and dentists offer to pay for services. It would have a relatively low interest rate, and the interest paid could go back to the state to pay for services.
- 3. Provide financial relief to certain seniors through property tax relief and interest and dividends tax exemptions.
- 4. It would be helpful if the Department of Motor Vehicles provided handicap stickers at their locations so they could be obtained quickly when needed.
- 5. It would be helpful to have all medical and social services in one place, like a Senior Super Center. This would assist with transportation issues as well as make communication and collaboration between professionals easier.

Appendix



## The State Committee on Aging and The New Hampshire Department of Health and Human Services Bureau of Elderly and Adult Services



## Community Listening Forums Helping Each Other Through the Ages

Schedule 2008

It really is about you. For so many years you may have been focusing on your job or career, raising a family, or giving unselfishly of your time and talents to your community. Now it's time to concentrate on how you want to spend this time in your life. What do you need to stay engaged and active? How can the State and communities support you in living life on your terms? Please join us for a discussion on this topic at any of the sessions listed below. Representatives from the State will attend these sessions to hear your ideas firsthand.

Date Monday, May 12 1:30 p.m.	<i>Location</i> Nashua Senior Center 70 Temple St., Nashua	<i>Contact</i> 889-6155
<u>Monday, May 19</u> 10:00 a.m.	Laconia Public Library 695 Main St., Laconia	524-4775
3:00 p.m.	Monadnock ServiceLink 105 Castle St., Keene	352-9354
Wednesday, May 28 10:00 a.m.	William B. Cashin Senior Activity Center 151 Douglas St., Manchester	624-6536
<u>Monday, June 9</u> 10:00 a.m.	River Valley Community College (formerly NHCTC–Claremont) 1 College Drive, Claremont	542-7744
<u>Monday, June 16</u> 9:30 a.m.	Horseshoe Pond Community Resource Room 26 Commercial St., Concord	228-4704
1:30 p.m.	St. John's United Methodist Church 28 Cataract Ave., Dover	742-3046
<u>Tuesday, June 17</u> 2:00 p.m.	Plymouth Senior Center 8 Depot St., Plymouth	536-1204
<u>Monday, June 23</u> 12:30 p.m.	Gibson Center 14 Grove St., North Conway	356-3231
<u>Monday, June 30</u> 12:30 p.m.	Wolfeboro Public Library 259 South Main St., Wolfeboro	569-2428
<u>Tuesday, July 15</u> 10:00 a.m.	White Mountains Community College 2020 Riverside Dr., Berlin	445-4525
<u>Thursday, July 17</u> 1:00 p.m.	Salem Senior Services Center 1 Sally Sweet's Way, Salem	890-2190
<u>Tuesday, July 22</u> 1:30 p.m.	Littleton Area Senior Center 77 Riverglen Lane, Littleton	444-6050

To view this report online, visit: http://www.dhhs.state.nh.us/DHHS/BEAS/