

Thank you Teresa for your kind introduction and to all of you for being here today; to AARP SC, the SC Public Health Institute, and office on aging for inviting me.

We've all heard that "the journey of a thousand miles begins with a single step," and this inspirational quotation can reassure us when we are beginning a daunting task. How many times have each of us, either individually, professionally, or as a part of our community, state, or nation, been faced with what appears to be an impossible task? Whether it's writing a paper, cleaning out the garage, organizing a major meeting – like this one today – or trying to pass legislation at the local, state, or national level – we often have that 1st reaction to procrastinate – to turn our attention to an easier task and hope that somehow our problem will either just go away; or that someone else will do it for us; or maybe that some Divine intervention will take care of it for us. But let's face it – how often do any of these "solutions" ever materialize? Oftentimes (and I speak from personal experience) it takes the agony of a looming deadline to spur us into action. But it feels so much better once we've taken that 1st step toward completing our task that moving on to the next steps gets easier, and once we start to build positive momentum, completing that task can start to feel more achievable.

It often helps to break a task down into its component parts and start by tackling one thing at a time, gradually progressing toward a solution. And that is what I'm here to talk about today: how can South Carolina build a plan to achieve the kind of long-term care system that its residents deserve?

The fact of the matter is that South Carolina today – like *most* of the states in the nation – has a long-term care system that puts the majority of its resources into paying for nursing home care. And while nursing homes are an important part of providing essential services for people who are too sick to remain at home, or who don't have family supports that can help them remain at home...survey after survey has already told us that nursing homes are not the residence of choice for most people when they think about how they want to spend their elder years.

One of the people from whom I've learned the most about reforming LTC is an AARP board member: Charley Reed. He has characterized the problem with the LTC systems in most states as this: they have been designed by bureaucrats (and he speaks as a former state bureaucrat) who are putting together a system for someone else – usually they're thinking about designing a program for poor people. They should, instead, think about designing a program that **THEY** would want to use themselves. Any of us can imagine the sort of system we would want (or not want) for our own parent or child or even, perhaps, for ourselves.

Now a minute ago I mentioned that sometimes it takes a looming deadline to spur us into action. Well – our nation, and this state, are facing one in not too many years – and that is the aging of the population. I'm sure that everyone in this room is well aware that the population age 85 and older is growing rapidly and this is the age group most likely to need LTC services. In South Carolina the older population is growing faster than the national average and by 2030 22% of your residents will be age 65+. Looking at data about LTC programs in SC, the growth in demand has, indeed, been fastest

among the older population. Now the good news is that people are, on average, living to older ages with lower levels of disability than was true in the past. Another piece of good news is that more people are maintaining their independence with assistive technology and may need less in the way of human supports. But the bad news is that the sheer number of people who will need help to remain independent is growing.

So back to this idea of taking the 1st step in a journey of 1,000 miles, it's important to have a vision about where you want to go. Otherwise, you might find you've gone about 500 miles in the wrong direction! I want to mention a few guiding principles that are critical to achieving real progress. The first is that a state absolutely needs to embrace a philosophy that supports the right of individuals to have choice and control over things like where they live, what services they receive, who provides those services, and how they are delivered. The right of people to live in the "least restrictive" environment was affirmed by the Supreme Court in the Olmstead decision...but it's not just a matter of legal rights. It's a matter of thinking about what *you* would want. What kind of system would you design if you had no idea how you were going to come out in the lottery of life: would you be born rich or poor, would your children be able bodied or born with a developmental disability? What kind of system would you design without knowing how would you age – would you succumb to a sudden heart attack, or live for many years with Alzheimer's disease? And when it comes to needing LTC – the fact is that disability can strike any one of us at any time in life. So let's think about what sort of system we would want for ourselves or for the people we love.

I think that there is really a general agreement that our systems need to move more toward the home and community-based services that people want. Many industries find that they have to change with the times and often they can benefit by diversifying. In many areas, folks in the nursing home industry have seen the writing on the wall and already have begun to diversify, branching out into community-based alternative modes of service delivery. But part of the problem in achieving system reform has been finding an answer to the \$64,000 question: will HCBS save money? As with many questions, the short answer is: “It depends.” But let me tell you what we do know.

First of all – the cost to the Medicaid program of maintaining an older person in a nursing home is, on average, about \$26,000 per year. By contrast, the Medicaid cost of providing home care services is a little over \$9,000 per year – just about a third of the cost. Looking at data for South Carolina: the Community Choices program spends, on average, just \$23 per day per person receiving HCBS – compared to an average expenditure of \$112 per day for a nursing home resident: nearly 5 times as much!! But, of course, it’s a bit like comparing apples and oranges – since the cost of keeping someone in a nursing home includes the expenses for room and board...services that Medicaid does not pay for outside of an institution. Also – the classic concern of legislators is what’s often called the “woodwork effect.” What this means is that most people are so averse to going into a nursing home that they will do whatever they can to avoid it. The argument goes that, if public programs make HCBS available, people will “come out of the woodwork” to use these services and the state will end up paying for services for people who might not have used nursing homes.

Aside from the rather ugly image of older people with disabilities being compared to something like termites – fortunately there is new research to combat this perception.

The AARP Public Policy Institute recently published a paper called “Taking the Long View: Investing in Medicaid Home and Community-Based Services is Cost-Effective.”

http://www.aarp.org/research/assistance/medicaid/i26_hcbs.html

What we did was pull together all the best and most recent research that’s been done on the question and here’s the bottom line: over time – **states that have invested in HCBS have a lower rate of overall spending growth compared to states that continue to rely on nursing homes.** But don’t just take my word for it – I have here a quote from Thomas Hamilton, from the Centers for Medicare & Medicaid Services (CMS), who said recently to the Senate Aging Committee: “Despite the fears of critics that it would expand Federal spending, the HCBS program actually contained institutional costs and helped States moderate the growth of Medicaid spending overall.”

Now – of course there are some caveats. The first one is that there is generally an increase in spending when a state is expanding its HCBS programs. Once these programs mature and states begin to reduce their reliance on nursing homes they start to see real savings. It’s important for me to note that, in the major research we drew on for preparing this report, when the researchers compared the spending trends for HCBS with nursing homes, they factored in the cost of room and board in the community, so that they wouldn’t be comparing “apples and oranges.”

So this is really a “win-win” situation for people who need services and the states that administer those services. More people get the services they want and states can provide services to more people in a cost-effective manner.

According to a report that your Dept. of LTC and Behavioral Health shared with me: 1 in 5 South Carolina nursing home residents – 3,200 people – have expressed a desire to move back into the community but, in 2006 there were already 2,600 people on a waiting list for HCBS. Not everyone in a nursing home HAS to be there. Just looking at the disability levels of the folks that SC currently is serving: while 98% of the nursing home residents need help with 3+ activities of daily living – such as eating, bathing, dressing, and so forth – some 90% of the people being served in the Community Choices program have this level of disability. So it really is possible to cost-effectively serve people with pretty high levels of impairment in home and community-based settings.

So how do you get there? What are the steps that will help more people stay in their homes and communities and reduce the state’s reliance on expensive nursing homes? Well I can’t help promoting the work of the AARP Public Policy Institute – so I am going to draw from a report that we released last year called “A Balancing Act: State Long-Term Care Reform.”

http://www.aarp.org/research/longtermcare/programfunding/2008_10_ltc.html

We addressed a series of questions in this report and I’m going to lay some of them out here and discuss how you might begin to think about them in SC. And let me start by saying that the fact that all of you have come here

today to participate in this meeting is a good sign that you're ready to start rolling up your sleeves and getting to work.

So the first question is: what constitutes a reasonable balance between institutional services and HCBS? When we prepared this report, what we did was separate out the spending for older people and adults with physical disabilities from the spending for people with mental retardation and developmental disabilities – not because we think that it's more important to provide services to older people, but because virtually every state has made better progress in getting people with developmental disabilities out of institutions, but has made less progress for older people. Now, in SC, according to our most recent estimates, you were right smack in the middle of the pack in the US – ranked number 25 in the nation in terms of the percent of Medicaid LTC spending going to HCBS. Right now that is about 24%.

http://www.aarp.org/research/longtermcare/trends/d19105_2008_atc.html

By contrast, the states with the most developed systems are spending more than half their Medicaid LTC dollars for HCBS. And while that is currently just a handful of states, it proves that it can be done. South Carolina already has made a lot of progress in getting people with developmental disabilities out of institutions – your Medicaid program for this population is spending 58% of its Medicaid LTC dollars on HCBS. So the good news is that you've already proven that you know how to turn things around for one part of the population with disabilities.

The next question is: What is a reasonable pace of change? According to our national data – if the states continue reforming their LTC systems at

historical rates, it will take 10 more years to reach a 50-50 balance between spending on HCBS and spending on nursing homes. We'd not only like to see that pace accelerate, but we think that we can do better than 50-50!

So we asked also: Why have some states made more progress than others? And there actually is a body of literature that has analyzed this question. It's not only a question of dollars and cents, but there are a host of factors that characterize an ideal system of long-term services and supports. I already mentioned what may be the single most important factor – embracing a philosophy that looks at the quality of life for people with disabilities and the importance of having choices. This describes AARP's overall message on LTC – **people should have choices**. Our overall goal for the nation is to have an affordable, consumer and caregiver-focused system providing coverage for, and access to, high quality long-term services and supports for independent living. Another factor is that there need to be an array of services available, since everyone's needs are individual – a “one size fits all” approach simply won't work. The needs of someone with a physical disability are very different from the needs of someone with mental health issues or someone with a developmental disability. So, for example, innovative alternatives like small group homes can really be a good answer for some people who need a lot of assistance but want to live in a home-like environment.

How does the state organize responsibility for overseeing LTC programs? Some of the most successful states have reorganized their systems so that a single administrator oversees the entire system. Similarly, coordination of

multiple funding sources can maximize a state's ability to meet the needs of people with disabilities. But – it's not only about the money.

Another important factor is timely eligibility. What often happens is that someone is being discharged from a hospital with a need for continuing services. Too often these people end up in a nursing home and never leaving because the way the Medicaid program is set up it takes too long to qualify them for HCBS. The nursing homes are more willing to admit these people and have enough overhead to take on the risk if they are not eventually found eligible for Medicaid. In SC, on average, it took only 14 days to qualify someone for Medicaid nursing homes services whereas it took, on average, 73 days to qualify for HCBS. Developing a fast-track eligibility process for HCBS can prevent people from unnecessarily going into nursing homes. Another step to help avoid unnecessary nursing home use is to develop a standardized assessment tool to minimize differences among care managers and to ensure that assessment for nursing home and HCB services are on a level playing field.

My next point is to develop a single point of entry so that all people who need help – whether they are going into the Medicaid system or whether they can afford to pay for services out of pocket – have a place to turn to get answers to their questions about what services are available. I know that I have a second informal job – and many of you in this room probably have the same thing – I get asked a host of questions from friends who are caring for a spouse or parent and haven't got a clue where to turn or what programs can help them. Finding the services needed to care for someone shouldn't require a complex roadmap or an advanced degree.

Consumer direction is a growing trend and virtually every state provides at least some opportunities for people with disabilities to direct their own services and hire the workers of their choice. These programs have proven to be not only popular with consumers, but they can help to expand the supply of home care workers, as many people hire someone who is known to them, often a family member. These programs also can be less expensive, since people are not paying the overhead of a home care agency, so the result is that they often are able to receive more hours of care.

Another area is to actively initiate nursing home transition and diversion programs. The best thing is if you can keep people from entering a nursing home in the first place – since we know that the longer one stays in a nursing home, the harder it is to get them back into the community. Especially once someone has given up their home – finding accessible and affordable housing is one of the biggest problems across the entire country in terms of helping people with disabilities remain in the community. But even so – it is worth the effort to build programs to help people get out of nursing homes, since the cost of keeping them there is so high.

Quality improvement is an area in which SC has been a leader. The Care Call system that you have developed has been highlighted as a “promising practice” for other states to emulate and AARP highlighted it in a PPI report a couple of years ago.

http://www.aarp.org/research/longtermcare/quality/2006_07_hcc.html

So I definitely want to applaud your leading efforts in this area. Last but not least is to take steps toward integrating health and LTC services through

programs like PACE which I understand SC has implemented. So there are many areas in which SC has already taken action.

Now our PPI report also asked, How does federal Medicaid law affect state LTC reform?, because we understand that there are some inherent barriers that hold states back, and we think that these, also, need to be addressed. Among these is the institutional bias which entitles people to nursing home services, but not to HCBS. And when Congress passed the DRA in 2005 it tried to make things better by authorizing an HCBS option under the Medicaid state plan – but there are some kinks in that program that have not made it very appealing to states, and we are hoping that in health care reform this year Congress will fix some of those problems – particularly in regard to the income eligibility under that new provision. We also think that the Medicaid asset test is not very realistic for people who are trying to stay in their own homes. In general, Medicaid only allows you to keep \$2,000 in assets – which is hardly enough of a safety net if you need a new roof or a furnace. What’s more – speaking for AARP – we tell people that saving for retirement is the responsible thing to do, but then we make them spend down their life savings if they need LTC. That just puts people into a no-win situation and forces them to make impossible decisions. We also think that Medicaid needs to let the spouses of people who get home care services keep enough of their income and assets to prevent poverty – just like they can if their spouse goes into a nursing home.

Now you might ask, why am I only talking about government programs? Don’t individuals have a responsibility to help plan and pay for their own LTC needs? And my response is yes indeed – government can’t do it all.

But I also need to emphasize that our current LTC system depends heavily on the efforts of family caregivers who still provide the majority of all LTC services. Another PPI report estimated the economic value of family caregiving and found that it came to some \$375 billion – more than the entire Medicaid program spends on both LTC and acute care services.

http://www.aarp.org/research/housing-mobility/caregiving/i13_caregiving.html

In SC you have more than half a million family caregivers and the economic value of their contributions is nearly 6 times as great as all Medicaid LTC spending in the state. But of course, as the advertisements for those credit card companies say – the real value of what family caregivers provide is priceless. There needs to be more support and help for caregivers, who are subject to very high levels of depression and stress so that they don't burn out.

So I know I have thrown out a lot of things to think about, but I need to get back around to why this is such a critical and timely issue right now. Our nation is facing its deepest economic crisis since the Great Depression and just as each of us has to figure out from our own personal budgets where the money is going to come from, every state in the nation is searching its pockets to see where the money is going to come from to fund essential services and to decide what hard choices will be made for cutting back on spending. And that's why I think today's message is imperative. Don't allow the progress that you've begun to make in expanding HCBS begin to backslide. As leaders and active participants in this area it is important to take the long view and recognize that if HCBS are cut back now, the inevitable result will be more reliance on nursing homes which ultimately

are more expensive and they're not what people want. If you can't take the long view and hold on to the progress you've made – even during tough times, no one else is going to do it for you.

It reminds me of the discussions I've had to have with my teenage daughter (and she would kill me if she knew I was saying this) – but when she brings home a C on her report card I tell her she's got to get to work pretty fast to try to bring it up, because if you let it slip to a D, you've dug a hole from which it is nearly impossible to recover. So – as I said before – looking at SC's Medicaid spending for older people – you're right in the middle of the pack...which means things aren't so bleak that the task is insurmountable, but it's also not where you want to stay. Just like when my daughter tries to argue that a C is average and why do I expect more of her – I say, it's because you're capable of doing better. And I know that SC is capable of doing better, and you've already demonstrated it through some of the innovative programs that you've put into place.

I want to encourage you to look at that journey of 1,000 miles, realize that you've already taken the 1st steps in the right direction, and build some momentum to go the rest of the distance. I want, also, to bring this down to a human level. We're not just talking about programs and spending and budgets; we're talking about the lives of real people – maybe they are in your own family, but if not, the people who need services might turn out to be your favorite teacher or friendly bus driver, or that childhood neighbor who always gave out your favorite Halloween candy. It is in your power to help make sure that people have the ability to live out their lives with dignity and independence. AARP wants to work with you to build a better future

for all Americans and I thank you again for giving me the opportunity to share our vision with you.