

**SANDWICH GENERATION SQUEEZE:  
CONFRONTING THE MIDDLE CLASS  
STRUGGLE TO RAISE KIDS, CARE FOR  
AGING PARENTS, AND SCRAPE  
TOGETHER ENOUGH FOR RETIREMENT  
IN TODAY'S ECONOMY**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED THIRTEENTH CONGRESS

SECOND SESSION

PITTSBURGH, PENNSYLVANIA

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**MONDAY, JUNE 30, 2014**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The Committee met, pursuant to notice, at 1 p.m., in the Allegheny County Courthouse Gold Room, Pittsburgh, Pennsylvania, Hon. Bob Casey, presiding.

Present: Senator Casey.

**OPENING STATEMENT OF SENATOR  
ROBERT P. CASEY, JR., COMMITTEE MEMBER**

Senator CASEY. The hearing of the U.S. Senate Special Committee on Aging will come to order.

I am grateful for everyone being here today. I wanted to do some opening comments and then we will turn to the introduction of our first panel of witnesses.

We gather today to talk about an issue that is too infrequently examined, and that is the pressure or the stress that is created and the implications for our health care system, family life, and so many other concerns that we have, when an individual, in many instances maybe in their 40's or 50's, has kind of a dual responsibility in addition to going to work every day or doing other—conducting their own affairs and having their own responsibilities, where they have to care for an aging parent, sometimes directly and sometimes less directly, and at the same time care for the generation behind them, a son or daughter who requires some degree of help, financial or otherwise. We refer to this phenomenon and those who live in that age, or who are in that age category, as the so-called “Sandwich Generation,” that they are between two generations and they have responsibilities for both, in addition, as I said before, to their own responsibilities and their own jobs.

We know that this affects a lot of middle-class families in the United States of America who are often working more and earning less, and, at the same time they are doing that, they have these responsibilities of caring for aging parents or raising children and scrambling—in many cases, this is a daily scramble, a daily chal-

lenge—to save for retirement. These families are those who drive the consumer spending, and we know that that ultimately drives the economy. As much as three-quarters of the economy is tied up in consumer spending, so, maintaining a middle-class lifestyle or anything close to that is becoming more and more of a challenge.

We know that in the 20-year timeframe between just 1989 and 2010, for example, the median household income increased 70 percent. That sounds like it is good news. Not until you compare it to the college tuition going up in those same 20, 21 years, increasing over 300 percent, health care costs going up over 200 percent in that same time period.

We know that even since—in the more recent past, even since the end of the recession, the wages of many middle-class jobs have continued to decline. The auto industry, for example, those wages are down ten percent, even though we had a great rescue, really, of the auto industry, but, wages are not where they need to be. Manufacturing job wages are down less, but still down 2.4 percent. Construction wages are down almost two percent, so, that is just the most recent numbers in terms of what has happened to the middle-class because of these major job sectors.

If you look back further, further than the last couple of years, further than the last 20 years, if you go back 45 years, since 1968, for example, the value of the minimum wage lost one-third of its value, so, for example, when we are debating in Washington—and we are going to have another debate, thankfully, in the next couple weeks—of raising the minimum wage to \$10.10 over three years, even getting to \$10.10 over three years would not catch up to where we were, or where we would have been, I should say, if we kept pace from 1968 to the present. If we had kept pace up to the present, the minimum wage today would be about \$10.50 or \$10.60, roughly, so, we are way behind in keeping up with the minimum wage itself. All the more reason why we need to raise it.

Compounding all of these economic concerns and challenges are the challenges of those in the Sandwich Generation. A recent study found that almost 50 percent of middle-aged Americans are in the so-called Sandwich Generation. As I was preparing for this hearing, I realized I, too, am a member of the Sandwich Generation, maybe not having as many stresses and challenges that a lot of families have, but I am certainly in that age category and have some sense of what it is like to have responsibility for at least one generation, my children, and those—we have two out of college now, and in one case, we have some responsibility, and I have a mother who is over the age of 65 and I have, other than making sure that I stay in touch with her, I do not have any direct financial responsibilities like so many people that are my age and the stress that comes with that.

The typical caregiver is a—and these are broad categories, but this is about the average—the typical caregiver is a working woman, 49 years old, who spends up to 20 hours a week caring for a family member, usually her mother. She has much greater stress and responsibility for her family than I do, than I am sure some others in the room, as well.

In Pennsylvania, there are an estimated 1.85 million caregivers, so almost two million caregivers, providing 1.77 billion—not million, billion—hours of care just in one year, 2009.

There are financial challenges associated with providing care. As we know, many families access their personal savings to pay for care. Actual out-of-pocket costs by caregivers reveals that 42 percent of caregivers spend more than \$5,000 a year on caregiving expenses.

Some caregivers even cut back on work or leave the workforce. This allows them to provide care, but there are lost wages and less retirement savings as a result, so, they make a very conscious choice to take care of a family member, knowing that, or experiencing the fact that that will have an adverse impact on their own job, their own career, their own wages, their own retirement, and you can add to that from there.

Wage and retirement losses due to caregiving range from over \$283,000 for men to almost \$325,000 for women. That is the wage and retirement loss that women experience, on average, because of those caregiving responsibilities if they are in that category of being in the Sandwich Generation and having those substantial responsibilities, \$325,000 in the life of that woman.

We have to ask some fundamental questions. One question is, where is the time for these families? How do they do it? How do they make ends meet and still provide the kind of care and support that they want to provide? How do they do that is a question that this hearing will not answer, but it is an important question for us to keep asking because it, I think, increases our vigilance to do something about this challenge.

Do these families have access to the programs and services which can make their lives easier? I think the answer to that is a resounding no, not in every instance, but in a lot of instances, because if the answer to that was yes, we probably would not be here. I believe, and I think the data shows, that far too many people with these challenges do not have access to programs and services to make their life just a little bit easier when they are doing these—providing this service, doing this work.

How do families in our society handle the financial ripple effects of the Sandwich Generation? If someone is losing wages, they are obviously not going to be as productive in the economy. They will purchase less. They will be less of an economic factor if they are having to provide that kind of care without some kind of relief.

There are just a handful of questions, but, I think this gets back to, for so many families, and I know this is true of so many women, they have a basic sense of obligation, an enduring sense of obligation to their mother, their father, and to their children. Men do it, as well, there is no question, but, I think if we add it up, probably more women are in these stressful circumstances.

It is not just kind of a general value. It is the value they have to care for their families no matter what the circumstances, no matter what the financial implication, no matter what the stress, no matter what the challenge is, and, in many cases, their health as they are trying to provide support for, say, an older parent, their own health is compromised. That, too, has an economic impact.

I think this, in some ways, is as fundamental as the scriptures. In the scriptures, there is a line that tells us that we should, "Honor thy father and thy mother," and so many families take that scriptural admonition, or scriptural inspiration, to heart, and they work very hard to provide a better life for those who come after them and those who were ahead of them, and, so, they are squeezed in that sandwich.

We have to make sure that we are taking constructive steps to help. The solutions are not easy to devise. The resources are limited, and, the challenges are substantial, but, I have no doubt, I have no doubt at all, that as a result of hearings like this and engagement, listening to people that are living this life and/or have some expertise in these challenges, either personally or by way of study and scholarship and work, that we can come up with solutions that will provide a measure of relief to those who are trying to keep that commandment, in a sense, trying to be that loving family member, but also know that they have other responsibilities that they have to balance.

We have a tough challenge ahead of us, but I have no doubt it is a challenge that is worthy of our country, worthy of our Commonwealth, and for today's purposes, worthy of this great city and this County of Allegheny.

I wanted to first introduce our first panel of witnesses. Our first witness is Tom Moore. Tom recently retired as President and Assistant Business Manager for the International Union of Operating Engineers, Local 95, in Pittsburgh. Tom Moore and his wife, Becky, have four children ages 18 to 23, and I am looking at those ages and I have almost exactly the same ages and same number of children, in my case four daughters with my wife, Terese.

In addition to helping their children into adulthood, Tom and Becky are helping to care for Becky's mother, who has dementia, so, Tom, I will be asking you in a couple of minutes to provide your testimony, but we are grateful you are here and grateful you can offer a personal witness to this based upon not just your own family's experience, but your own work, as well.

Our second witness is Judy Mills, although she is not going to be with us in person today. Judy is unable to join us today because she is accompanying a family member to a medical procedure. She is out doing the kinds of things that we are talking about today, but, this is a story we have heard often in approaching families to speak today. They are eager to participate, but could not because of scheduling conflicts with appointments and events for different family members.

Although she cannot be with us today, I would like to mention that Judy Mills is the Director of the Saint Valentine's Preschool and has been in the position for 25 years. She has two sons who are now in their 20's, but when her sons were in middle school and high school, Judy Mills' father also lived with the family. He now lives in an assisted living facility, and Judy was going to share her experience of supporting both generations under one roof, so, we will make sure that we submit Judy Mills' written statement for the record of this hearing.

Our third witness is Sister Barbara Ann Boss. Sister Barbara Ann is President of Elizabeth Seton Center, which has a location



in the Brookline section of Pittsburgh. The Elizabeth Seton Center offers intergenerational programming with adult day care services, and it is a center for older adults. It is also a child care center for children up to age 12 and a senior center where older citizens can socialize, learn, and engage in healthful activities, and, I want to thank you, Sister, for being here and bringing your own personal experience to this important topic.

I would ask these witnesses, as well as all of our witnesses, to keep their testimony to about five minutes. There is not going to be a curtain that comes down on you if you hit five, but try to keep it as close to five as possible. We will hear from, starting with Tom, we will do your testimony, and, Sister, then you, and then I will do some questions, and then we will move to our next panel.

Tom, why do you not get us started and provide your testimony.

**STATEMENT OF TOM MOORE,  
MEMBER OF THE SANDWICH GENERATION**

Mr. MOORE. Good afternoon, Senator. My name is Tom Moore. Prior to my retirement in 2012, I was President of the International Union of Operating Engineers, Local 95. I live in Ross Township with my wife, four children, and grandson. Three of my children have special needs, two with autism.

Ten years ago, my mother-in-law was widowed and moved from her home in Monroeville to the house on my street. Slowly, as her age increased and her health decreased, we assumed more and more responsibilities for her home and her daily needs. For the past five years, as her physical health deteriorated rapidly and her mind succumbed to advancing Alzheimer's disease, my wife and I became her caregivers. All household chores, both inside and outside, had to be done by us. We provided all her meals, did all her shopping, scheduled and drove her to all her appointments, administered all her medicines multiple times a day, took care of her finances, and saw to all of her daily needs.

At the same time, we were fulfilling all those responsibilities for our children plus the added commitment of their individual school, social, and leisure activities and the appointments related to their special needs, all while providing child care for our grandson so that his mother could work.

The physical demands of taking care of two families is tiring—two yards to cut, drives to shovel, houses to clean, extra meals, extra laundry, extra appointments. The extras are never ending. The emotional demands and time restraints are harder. If a child has a therapy appointment and Gram has a doctor's appointment, which is more important? Neither can attend an appointment alone.

If you want to go to dinner with a friend, you have to find someone to take medicine and dinner to Gram, to check to make sure she got into bed. If you are out and she accidentally pushes her safety alarm, you have to go home. There are rarely long evenings out as a couple. There are never vacations as a couple or even as a family. Taking care of your needs becomes the lowest priority because you are too busy seeing to everyone else's needs.

My wife and I are very committed to each other and our family. We both have close-knit extended families that give us support. We

also each have a large group of friends that allow us an opportunity to individually spend time away from our daily commitments.

Unfortunately, there are not enough reliable, affordable services for the elderly. What services are out there is not widely known and often only discovered when commiserating with someone else in the same situation. Medical professionals tell you to take your insurance to see what is available. Insurance tells you to ask your medical professionals. In the end, you just keep doing what needs to be done, hoping that not much falls through the cracks.

That is my statement.

Senator CASEY. Tom, thank you very much.

Sister.

**STATEMENT OF SISTER BARBARA ANN BOSS,  
PRESIDENT, SETON CENTER**

Sister BOSS. Good afternoon. My name is Sister Barbara Ann Boss, a Sister of Charity of Seton Hill from Greensburg, Pennsylvania. At the present time, I am the CEO of Elizabeth Seton Center, located in the South Hills of Pittsburgh.

Seton Center is an intergenerational center dedicated to the belief that no matter what age we are, growing and learning are lifetime activities, and that people of all ages are bound together by what they share, not separated by age or interest. Our programs include care for children age six weeks through 12 years of age, enrichment programs for seniors, arts programs such as instrumental music instruction and theater activities for all ages, and care for the frail elderly.

Today, I am not here to give you facts, numbers, or statistics about what each of these programs need to survive. I come to talk about the struggles, stress, and strain that people caught in the middle, better known as the Sandwich Generation, are experiencing.

Just last week, we were interviewing for a position at Seton Center, so this story is very fresh in my memory. First, picture this, a grandmother, now not one old in age, but one in her late 50's or early 60's, young looking and willing, able, and out of necessity has to work. All of a sudden, she finds herself faced with the custody of a four-year-old grandson. The grandson attends Seton Center during the weekdays and she receives subsidized care. However, she is employed at a fast food restaurant that schedules her to work evenings and weekends. How does she choose between the safety and security of the child and her job? Her only choice is to find a nine-to-five job or go on welfare. Believe it or not, there are some people out there who feel that their self-worth is measured by their ability to provide for themselves and their families. Maybe we need to think outside the box. A sandwich has a top, middle, and bottom. What if the top is the grandparent, taking the responsibility of the child and grandchild.

Seton Center has expanded its adult day care hours to 6 a.m. to 9 p.m., and on Saturdays from nine to five, to accommodate the needs of the Sandwich Generation. One reason is to enable the adult child of the frail elderly person to attend the sports games, rehearsals, or other events that are a growing part of their own

child's life. Many times, we hear, "Can Mom or Dad stay at the Center longer today so that I can go to my child's game?" or, "Can Mom or Dad come on Saturday so that we can spend some quality time with our children?"

We all know that family is the core of our society. Many times, the Sandwich Generation find themselves caught in the middle between parents and child. This generation needs respite time or they become overwhelmed and stressed. An overwhelmed and stressed caretaker is not able to give quality care to parent or child.

Most clients we care for at Seton Center are victims of Parkinson's disease, dementia, or Alzheimer's. People with these diseases often do not sleep at night. My father was a victim of Parkinson's. Being an independent person all his life, he would wake up at night and try to get out of bed, causing many falls. If my mother was to get any rest, it meant that the children had to take turns doing night duty. This became very stressful, knowing that you had to go to work the next day with little or no sleep.

Financially, the strain on the Sandwich Generation is huge. If the parent has any retirement funds set aside, the adult child tries to make the funds stretch as long as possible. Before placing the loved one in a nursing home, they will try to juggle their own job schedule to care for them, or find someone to come into the home, or place them in an adult day care facility.

There needs to be more education on funding sources that are available and the services that adult day care can provide. In most cases, this kind of information is given when the adult child comes to inquire about the services at the center. However, most centers do not have the funds for a marketing budget. How do those in need even know where to go for assistance?

Child care can be expensive. If the adult child qualifies for subsidized care, there is usually a long waiting list for the funding. Transportation is an issue. Families often need help getting their parents to the adult day care site. Transportation rules prohibit families from choosing the best center for their loved one, because multiple companies service areas in the county and do not cross into another's area, clients often cannot go between their homes and the center of their choice.

Thank you for this opportunity to speak on behalf of our clients who find themselves caught in the middle.

Senator CASEY. Sister, thank you very much for your testimony.

I will begin a round of questioning for both of our witnesses in panel number one.

I was struck, as well, by a couple of things you said, Tom. You said at one point, and I am quoting—I want to make sure I get your words right here—you said in the end of the fourth paragraph, "There are rarely long evenings out as a couple. There are never vacations as a couple or even as a family. Taking care of your own needs becomes your lowest priority because you are too busy seeing to everyone else's needs." Never a vacation. Your needs become your lowest priority. That probably encapsulates as well as anything I could say the challenge that you and so many others face.

I guess one of the questions I have is when you have these responsibilities and the challenge that comes with that, describe, if you can, kind of your typical day. What is your—if you can walk through kind of a typical day for you or for your family in terms of all the things you have to juggle. Or, maybe there is not a typical day, but as best you can—

Mr. MOORE. There is not a typical day, but—my mother-in-law, we put her in the Kane Nursing Home about three months ago, but, before that, the typical day was get up in the morning at 5:30 and take a walk, clear your head, and start. Now, I would have to make sure that she had breakfast and was out of bed and got her in the living room, and then go home and cut the grass or whatever you are going to do and get the kids out to school earlier than that, and then at lunchtime, go back again, make sure she ate and took her medicine, which she said she would, but never would, and then just, every once in a while, I would sneak a round of golf in, of course, and then at dinnertime, the same thing. Go down and make sure she had dinner and her second dose of medicine and come home and do your housework or whatever at the house, and then go down at night and make sure she was back in bed and comfortable, and hopefully, everything would be okay, but that would be your typical day.

My wife was, the same thing. She was caring for the grandchild at home and the kids with the special needs, so it is hectic, but you just do it. That is what you do.

Senator CASEY. I know it is hard to—there are a lot of ways to measure this challenge. One is time. One is the stress and the strain. As Sister said, she described it as struggle, stress and strain, and that is a pretty good summary of what people are up against every day.

I know this is one way to measure it, but it is not the only way, but it is one measure that at some point you have to assess, the financial impact and what that means. Any way to give us an example of how this caring for two generations, or having responsibility for two generations, has a financial impact?

Mr. MOORE. Well, sure. I mean, my mother-in-law got Social Security. That was her income, but, you know, outside of that, we bought all the food. We bought all her medicine. We provided all her needs, took care of her house. You know, everything that she needed financially, we supported. Fortunately, you know, my former position, I had a pretty decent pension, which helped pay for it, but you still go in the hole. You know, I bought my house twenty-five years ago for a fifteen-year mortgage and I still owe seven years on it because I have had to refinance. That is how you do it. You have got no choice.

Senator CASEY. Well, even as we analyze the financial impact, the other ways we measure, or the other ways we assess this are almost incalculable. There is no way to put a number or a metric on it.

I wanted to ask you, as well, we are just beginning, I think, to begin to wrestle, at least in terms of the work that will get done in the House and the Senate on issues like this, just beginning to wrestle with some of the answers to these questions, or the solutions that would provide a measure of relief, but, do you have any

ideas about things you hope we would pursue or any policy you would hope we would have enacted so that it would provide some relief?

Mr. MOORE. I think the main thing, even with the kids with the special needs and the elderly, my mother-in-law, is the services are out there. You have got to go find them. You know, you have got to talk to people and find them. There is no direct route to try to find out what they are, so, you have to talk to people and talk to agencies. There is help out there. It is, you know, you are inventing the wheel every time. That is the big problem that we found.

Senator CASEY. Not necessarily a resource toward which you can turn.

Mr. MOORE. Yes.

Senator CASEY. A resource of services or help you can get to provide some relief.

Sister, I know you shared a story of the young woman that you recently encountered that came to Seton Center seeking work and described kind of her challenges and her dilemmas. Any other way to describe that from your own experience? You have seen a lot of these circumstances, and you provided one example. Any others that you wanted to highlight?

Sister BOSS. Well, I think there are a lot of single parents out there—

Senator CASEY. Right.

Sister BOSS.—who have jobs, but they are minimum-wage jobs. I believe if there was some way that they could have flexibility in the hours that they work, but, when an organization schedules you at night or on weekends and you are responsible for a young grandchild or something, you have to make the difficult choice of do I continue to work here or do I find someplace that will fit my schedule, so, I think it is important that there is some kind of flexibility—businesses allow some kind of flexibility in their hours of employment.

Senator CASEY. At one point, I know, you described that lack of flexibility, or at least a question about it, when you said, “How does she choose between the safety and security of the child and her job? Her only choices are to find a nine-to-five job or go on welfare.” Then you talk about the self-worth.

It is an important note in your testimony where you say, quote, “Their self-worth is measured by their ability to provide for themselves and their families.” In other words, that is the standard against which they measure their own worth.

Sister BOSS. That is right.

Senator CASEY. In a world where sometimes we measure it by other metrics—fame, fortune, and other measurements—that is a good description of what they are up against.

Sister, in your experience, is this—I guess you would agree with me, the problem is worse now than it was 15 years ago or 20—

Sister BOSS. Oh, yes. I think—well, we are living longer, let us face it.

Senator CASEY. Right.

Sister BOSS. I think that in many cases, the child of an elderly person, with children of their own, feel, my mom or dad raised me, so now it is my responsibility to take care of them, and, they

stretch their budgets as much as they can, their own, and, like I said, if the parents do have retirement, they try to stretch that as much as they can before placing them, because placing a parent into a nursing home can give the individual a guilt trip, let us face it. They took care of me when I was young. I should be able to take care of them in their old age. It is like a family responsibility.

Senator CASEY. If you had to, and I guess I would address this to both Tom and Sister, but I will start with you, Sister, if you could recommend one policy, or if you could recommend a menu of things we could take a look at, what do you think would be the most meaningful, that would have the most positive impact?

Sister BOSS. Well, I kind of agree with what Tom had to say.

Senator CASEY. Mm-hmm.

Sister BOSS. There needs to be more education in what is out there—

Senator CASEY. Right.

Sister BOSS.—for the Sandwich Generation. There are places where they can get a—and they can get help, but they do not know where to go. There is not enough, do I want to say, marketing on what is out there for the people. The only way they find that is, like, to talk to someone who can give them that information, so, I think, education is a big part of it.

Senator CASEY. Mm-hmm. Tom, anything you wanted to add to that?

Mr. MOORE. When I was [inaudible] just the other day, we met with hospice, and, you know, to me, hospice is an end-of-life thing and die with dignity, but, we found out that they do a lot more than that, that they come into the Kane and they bathe her, they make sure the medicine is right, they take care of all her needs. You know, they will do that for years, if needed to be. I did not know that. Nobody knew that. Once you come in and meet with them, they explain it to you and you say, well, how come somebody did not tell us that?

Senator CASEY. I guess part of what undergirds that sense or that measurement that you had talked about, Sister, that your own sense of what you are worth is what you are contributing, I guess part of what motivates people is not just love and obligation, but also the sense that, as a journalist said about 15, a little more than 15 years ago, now maybe 16 years ago, a series that I read in a newspaper in Pennsylvania had a series about long-term care, and one line I will never forget, he said, advocates for the elderly, experts in the field, say that life can have quality and meaning even until the very last breath, and, so, I think there is a sense that people have both love and obligation in addition to the commitment they have or the belief they have that every life is precious and has meaning and value, even until the very last breath.

I cannot say that my experience in any way matches yours in having seen this up close, either personally or professionally, and we are grateful for your willingness to help us.

I think that is all, the only questions I have. If either of you has to go, feel free to go. If you could stay, you can certainly be a part of the discussion, and, I may think of some other questions as we go, so if you are still here, I might ask you a few more.

Let me move for now to our second panel and then we can open it up for questions for both panels.

Our first witness of our second panel is Mildred Morrison. Mildred is the Administrator of the Allegheny County Department of Human Services, the Area Agency on Aging. The Area Agency on Aging plans and coordinates services for 43,000 older adults annually. We know that before joining the Area Agency on Aging in 2000, Mildred Morrison served as the Executive Director for a community agency serving older adults, so, Mildred, we are grateful you are here, and I will have you give your testimony first in a few moments.

Our second witness is Dr. Charles Reynolds III. Dr. Reynolds directs the Aging Institute at the University of Pittsburgh School of Medicine. He is the UPMC Endowed Professor in Geriatric Psychiatry at the University of Pittsburgh School of Medicine and Professor of Behavioral and Community Health Sciences at the Graduate School of Public Health. Doctor, thank you for being with us.

Mildred, we will start with you. As my early admonition suggests, try to keep it as close as you can to five minutes. Thank you.

**STATEMENT OF MILDRED E. MORRISON,  
ADMINISTRATOR, ALLEGHENY COUNTY DEPARTMENT  
OF HUMAN SERVICES, AREA AGENCY ON AGING**

Ms. MORRISON. I will do my best, but when you are caught between Sister and psychiatry—Senator Casey, the Allegheny County Department of Human Services espouses to deliver a comprehensive human service system that ensures holistic services to Allegheny County residents, in particular, vulnerable populations.

Annually, our Area Agency on Aging serves 8,000 older adults with social work services, developing plans of care and delivering hands-on direct care in partnership with family members and friends who provide essential care at home. While we serve an additional 35,000 seniors with a variety of senior center, advocacy, transportation, and informational services, I wish to take this opportunity to address the growing challenges of caregivers that assist the 8,000 older adults at home that we are aware of.

As the Administrator of an urban Area Agency on Aging with one of the country's highest density of seniors, let me begin by thanking you for holding this field hearing to share with the Special Committee on Aging our deep concerns and some of the solutions we have found. I must also voice our appreciation for the Older Americans Act and other Federal funds, which, when combined with the considerable State resources of Pennsylvania, make providing services possible, and, I make that distinction knowing that Pennsylvania contributes far more resources than virtually any other State in the Union.

With the growing number of seniors, especially the rising rates of those living to advanced years, those experiencing dementia, and the increasing frequency of complex late life, or life limiting medical conditions, we have seen a 24 percent increase over the last 10 years in the number of families we assist in caring for a frail elder.

This has been a complete reversal of circumstances from 50 years ago, when an adult woman in her 40's or 50's provided care at home, usually for just the last two years of a parent's life. Typi-

cally, she was married. She was a full-time homemaker. Her children were grown, and, she had the assistance of siblings.

Today, her life is very different in Southwestern Pennsylvania. She works full time and that income is essential for her household. Her children may have been born later, and, therefore, are more likely to still be at home. Furthermore, those beloved parents are far older and frailer, but wishing to remain in their own homes. This caregiving family is, indeed, the Sandwich Generation, if not what I call the Double Decker, that is caring for children and for grandchildren in the same household.

National studies indicate that 20 percent of adults continue to provide more than 75 percent of the care for elders that allow that frail population to remain at home. It is essential that public services enhance families' capacity to maintain this commitment, as it is unimaginable that government should or even could assume that degree of responsibility, but, many of those caregivers are caught trying to understand the medical and cognitive changes they are seeing in this elder, of access those invisible resources Mr. Moore referred to, of maneuvering in an unfamiliar but complex long-term care system, as well as coping emotionally, physically, and indeed, financially.

The normal scenarios we witness, the major thing is they happen at a point of crisis, when the family has exhausted their abilities and they really are no longer able to manage. Then, in desperation, there is the memory of what that hospital discharge worker or somebody said about call the AAA, not the motor club, but the other ones.

These families often are living with very modest incomes or through very difficult times that might have been caused because of low wages or because of a job loss. They were trying to save for retirement and trying to educate young adult children, but, they often also are experiencing in their own right a major health incident or a major home repair. Note our recent flooding of the last few days. Nobody planned to spend thousands of dollars suddenly to do a repair, and, the strain is even greater when it is a single parent household.

In the past few years, we have witnessed situations with the four generations of a family that are being cared for by adults raising grandparents. Yes, there is the sort of the stereotypical drug abuse or incarceration reasons, but, more frequently, we are also seeing it is because someone has to travel out of the area to find a well-paying job and, therefore, relying on grandparents to help with raising the children. Or, they are serving in the military. Again, a family needs to kick in.

When the call comes to us, they ask us for help with bathing a parent, respite, or oversight so the caregiver can handle their personal business, that they can go to work, that they can just attend to family matters. Other requests are for meals, housecleaning, transportation, and escort to medical appointments, and sometimes an electric stairglide or an expansion of a bathroom doorway.

We have found that whether the circumstances are best met by a Medicaid-funded service or a program using a combination of Federal and State dollars, there is almost always a need for additional support and a creative response, so, this AAA and many of



our peers have figured out ways to use program resources as given in ways that may or may not have been a part of what they were originally imagined to be.

Yes, we reimburse in low-income households family members who provide some direct care, but even that has a limit of only a few hundred dollars per month. We also work with many families who are then able to hire a relative to be the caregiver and provide for that caregiver all of the full benefits and protections of any employee, but, it is only available in certain restricted circumstances. We routinely do extraordinary counseling on benefits, be it everything from LIHEAP to the ability to claim a VA disability if a person had served in combat, as well as SNAP, and as well as how to find low-cost medical equipment, et cetera, et cetera, how to find a subsidized apartment.

We provide advice, sometimes, it is just common sense that makes a life possible. If you have an elder with dementia who wanders, we can tell you where to go buy the shoes that have the built-in GPS device so you can find them more quickly.

We are strong advocates for adult day care because it is simply cheaper to spend \$70 a day for the wonderful care of adult day care than to have an individual person coming into your home at an hourly rate.

We recommend little changes. If you love your mother-in-law, change the shower head from fixed to hand-held because it is going to be easier to bathe her with dignity, et cetera, so, the recommendations are small, they are little, or they are large.

What we cannot do as a AAA is we cannot cause or force families to purchase long-term care, if it were affordable, early enough. We cannot help them claim an income tax deduction for caring for an elder because the elder resides in a separate household. We cannot create the massive awareness campaigns that both members of the first panel spoke to that would help many families know when and what to ask for help.

Be it measures great or small as a country, we must face the aging tsunami so that family caregivers do not suffer financial hardship along with the other burdens of caring for their loved ones. Thank you.

Senator CASEY. Thanks very much.

Dr. Reynolds.

**STATEMENT OF CHARLES F. REYNOLDS III, M.D.,  
DIRECTOR OF THE AGING INSTITUTE, UNIVERSITY  
OF PITTSBURGH, SCHOOL OF MEDICINE**

Dr. REYNOLDS. Thank you very much, Senator Casey. Good to be here.

I would also like to convey to you thanks from my colleagues on the Pennsylvania Long-Term Care Commission, on which I am currently serving.

What I would like to do for just a few minutes is focus on some of the themes that have been coming up at the Long-Term Care Commission and try to offer some thoughts that we have that might be policy relevant at this point. I have captured some of this in my written testimony and will focus primarily on that in my remarks to you today.

You have heard Mildred Morrison talk about how the lives of caregivers have changed so dramatically here in Western Pennsylvania, and that is very typical for what we see nationally. I think a good point here is that Mildred's comments really highlight the caregivers who are at particular risk for the adverse consequences of caregiving. We need to disseminate that information more broadly so that clinicians like me and agencies can recognize people at particular risk and go the extra mile to be of particular service for those folks.

As Mildred has emphasized, these are people who provide high levels of care. They may have low income. They live with the care recipient. They may have less education. Often, they had no choice in assuming caregiving roles, and, as both Tom and Sister Barbara have emphasized, their own self-care is diminished and they may neglect their own health. They have low levels of support, and very often, they experience very difficult problem behaviors on the part of the loved one for whom they are caring, so, I think the importance there is disseminating information about caregivers at particularly high risk.

Tom's testimony emphasized how long the journey of caregiving can be. It covers a lot of territory, and, so, part of what we need to do, and I think, Mildred, you spoke to this very well, is to incentivize clinicians and agencies to tailor interventions to the journey of caregiving, intervening earlier, if possible, to help protect people from the adverse health effects of caregiving, so, that is going to include things like addressing safety issues with home assessments and alterations, the little things that Mildred Morrison referred to that are so important, patient monitoring devices, removing access to guns, addressing self-care and preventive health behaviors so that caregivers learn to take better care of themselves.

As all three of us have emphasized so far, providing a range of support—informational, instrumental, and emotional, to help navigate to needed resources, so often, the resources are there. Agencies like the Area Agency on Aging help to put caregivers in touch with those resources, and we need greater emphasis, I think, on that.

Finally, again, as both Tom and Sister Barbara emphasized, help with depression and distress because this is part of the burden of caregiving. Over time, as people become heavy duty caregivers, their health declines more rapidly than non-caregivers. Indeed, we have learned that caregiving can be a risk for mortality in its own right.

I would like to focus a couple of remarks now on recommendations that came out of the Institute of Medicine's panel which dealt with the aging of America, retooling for an aging of America. There were two key recommendations from that panel that pertain to caregivers.

One is the need for public, private, and community organizations to provide funding to ensure that caregivers have adequate training for the roles that they are now being asked to undertake. Tom has emphasized, for example, how much he had to learn the hard way, and would it not be better if we could provide some basic training, and there are good examples of this that can be cited.

The other recommendation from the Institute of Medicine was that Federal agencies, including Labor and including Health and Human Services, provide support for the development and promulgation of technological advances that could enhance an individual's capacity to provide care for older adults. These include technologies to assist with the activities of daily living and health information technologies, as well.

Finally, to come back to a point that Mildred Morrison made, having greater flexibility with home health care-based services as we move toward managed long-term care or move toward the integration of Medicare and Medicaid services, having greater flexibility in these programs would be more responsive to the needs of caregivers. The current experiment in California, the MediConnect pilot experiment, may be something that we can learn from.

I will stop there. Thank you.

Senator CASEY. Doctor, thank you very much.

I will start with Mildred Morrison, and thanks for your own service, how many years now with the county?

Ms. MORRISON. Fourteen.

Senator CASEY. Fourteen. We are grateful for that.

I wanted to ask you about—one point that you made is one that bears repeating. Sometimes, when we think of a Sandwich Generation, we think of one generation in the middle in between two others, but you are pointing out, because of a number of factors, that sometimes we are talking about four generations. We are talking about an individual who has a son or daughter, and then a granddaughter or grandson or sons, plural, or granddaughters, plural, and then sometimes great-grandchildren, as well, so, that is a new phenomenon, and, the description that you gave of a woman in Allegheny County facing these challenges, I think, is an update for a lot of us in terms of what is happening today.

I guess one of the questions I had is, from your own experience, how do people make ends meet? That becomes a big part of the challenge. I mean, one of the basic problems we have now is that, in my judgment, if you do not have a minimum wage that keeps up, obviously, that is going to be a stress on the whole family, and we have an economy where, too often, one income, even a good income, is not enough, so, that alone has created the kind of "how do you make ends meet" challenge ever more difficult, but, tell us about what your sense of this is.

Ms. MORRISON. Right, and, we see the question at two levels. When it is a low-income family, it is possible to counsel, to recommend, to really bring hands on to what are other public resources, be they governmental or they be charitably provided, so, when you have got the food banks and the food pantries.

To help a family recognize that they are allowed to tap into that, not only for the younger part of the family, but it is also on behalf of the older person, perfectly acceptable, to try to make sure every kind of—a utility benefit, every—that is involved.

What we often see with very low-income families, that economics is a reason for why households have become blended, that it changes. When we move to a more middle-income family, it becomes blended for convenience and for safety, but, the factor of being able to—how many people can we put into a household, and

it is usually a matter of, physically, which facility is larger determines where they go.

Does the younger family—when a low-income family often does not own a home and, therefore, their ability to move in with an elder, then we have issues of convincing the elder that it really is time to purge some of the things in the house so that there is room for them to come in. One of the major problems families have when they do that is if it requires a change of school district, because virtually no one wants to disrupt the children's education school district.

How do they make do? We see a lot of filling in, and by that, I mean we are fortunate that, even before Medicare Part D, because of the drug prescription subsidies that this Commonwealth provides, that is a huge relief, so, for families who have not had the senior utilize that, that is an enormous game changer, to say you can literally save thousands of dollars a year by taking advantage of this public benefit.

Senator CASEY. I guess some are unaware that they are out there.

Ms. MORRISON. It did not occur, and then you say, well, with that, you also have a right to tax rebates, even if you are a renter, or a property owner, so, you are putting together—it is not one solution, it is the menu, and, the list just goes on and on.

What I do find for families in that circumstance, and because they have to annually reapply or redo or go back, that that becomes a mixed blessing. They want the benefit, because it helps all, but the effort to claim it is sometimes awkward.

I was very impressed last year when the United Way locally worked with county government and others and really opened the doors wider for people to do tax returns at a non-commercial setting and to take full advantage of the Earned Income Tax Credits in ways they had not before.

Here, it was just a matter of, often, for the families that survive, it is to tap into the benefits that exist is what is the difference between drowning and making it.

In preparing my remarks, I had asked our social workers, tell me the stories, and one of the ones that I heard about was a man who was working two jobs. They had two small children who were literally eight and six as his divorce was finalized, because his father's income put him out of eligibility for medical assistance services, the family covered it and that was why the two jobs and paying for the bills, whatever, and that there was this desperate wish not to use the nursing home facility, and so the care, but, upon his father's death, shortly thereafter, that man filed for bankruptcy, and, it was not his health care, it was a family member's. It has taken him five years and he is coming out of that. I am not saying most situations are that desperate, but for a very low-income, that is a possibility.

For middle-income families, how do they survive? That is where the willingness to offer your employer, can I work extra hours? Can I take the second job? And that works when a family almost works off of a calendar. Okay, you are doing what, when, you are doing what, whatever. When you have the opportunity to extend your work in balance with a family member who is able to extend the

care, that is when the families literally are hardly seeing each other because they are just so busy at it, my observation.

Senator CASEY. Making the ends meet becomes an almost 24-hour challenge.

Ms. MORRISON. Yes.

Senator CASEY. Doctor, I wanted to ask you about—you talked about, and others have either talked directly or referenced the emotional and physical strain it has, this challenge of caring for, or having responsibility for two generations causes, and, if the caregivers are providing some measure, some level of care to the older relative at the same time they are raising children, can you speak to the effects on the children?

Dr. REYNOLDS. I think your theme, Senator Casey, of making ends meet is pertinent not only to the financial issues that, Mildred, you discussed, but also to issues of time resources, emotional resources, and otherwise. I think children feel the strain that you are talking about. We think of stress and depression, in a sense, as contagious illnesses, and if one member of a family is becoming depressed, it is not unlikely that another one will, as well.

Recognizing that, then, becomes very important, because there are many ways that you can be of help. You often hear the word “respite” used, the need for time to recharge emotionally. Tom Moore talked about that in his eloquent testimony, and, that can go a long way toward restoring someone’s morale, recharging them to enable them to continue trucking, to continue tackling the very difficult tasks that are with them, and, I think that can repay benefits to the kids, as well, but, certainly, the kids feel that stress and strain no less than other members of the family.

I thought that Mildred’s response to your question is really a great example of the kind of navigational assistance that so many caregivers need. The resources are there, but helping them navigate, to find those resources, to pull them together to meet the needs is a key issue.

In our report to Governor Corbett on Pennsylvania’s Alzheimer’s Planning Committee, we underscored the existence of the resources. We talked about the great help that the Area Agencies on Aging can provide, and, hopefully, more people will learn about these.

Senator CASEY. Just a brief followup on that question as it relates to the effects on children. If you have a particularly stressful—not that everyone fits this category, but if you have a particularly stressful, burdensome situation where the individual in her, say, her 40’s or 50’s, is caring for an older parent, and in a situation where there is an impact on his or her—I will use “her” for the example—her children, I guess one of the concerns is that it is gradual and it is almost imperceptible so that it is not as if the child stands up one day and declares, “Mom, you are not giving me enough attention. You need to spend more time with me.” It is just, little by little, it is having an impact, and you may not have a full sense of it until somewhere down the road. Is that accurate?

Dr. REYNOLDS. Yes, it is. A child who is experiencing stress and strain, and perhaps developing some type of depression, may, for example, experience changes in the way they behave with members of the family. They may withdraw. They may become irritable.

They may withdraw from peers, or their work at school may suffer. There are any number of ways in which child or adolescent stress and strain can manifest itself, and it is a signal that help is needed.

Senator CASEY. I guess in those circumstances, part of the tragic irony is that even when there is an adverse impact on the child, that child is being presented with a great example of how to care for a family member, so, they are seeing an example that is very positive, but they are also having to bear some of the impact of it in ways that they cannot always manage.

Dr. REYNOLDS. Or quite understand at the point where they are in the life cycle. You know, at the same time, I think many kids and adolescents come to love their grandparents deeply and have very positive experiences and the memory of their grandparents becomes a blessing for them the balance of their lives.

Senator CASEY. Mildred, I wanted to ask you about the—you talked about programs through the Area Agency on Aging here where you provide the option for the elder to hire a relative as a trusted care provider. Tell us how that works, to the extent that you can use it as a model for other areas.

Ms. MORRISON. Yes. Around the country, there are slightly different versions, the mechanics of it, but, we have seen in a number of programs, particularly some of the Medicaid programs, where a family member is deciding, do I need to stop work in order to physically continue to care for my mother, to care for my uncle, whomever that person is, if, as an alternative, we can say to them, you can do both, you can quit your other job and let your relative hire you, that brings the joy of being an employee of a relative, which may or may not have its own stresses, but so be it.

It allows that person to earn \$10 an hour or \$15 an hour, depending upon the nature of the work. We do it, and we always recommend it be done under a formal structure. There is an agreement. There is a third party who handles the payroll and makes sure there is Workers Compensation, because if you lift someone the wrong way, you have a job site injury and you need to be protected and recover from that. It is then reported for tax purposes and income, and it is very much above the board.

What it allows is that that senior—and we often see this particularly in cases of dementia, where somebody may be anxious about having a stranger or someone they do not know care for them—but if it is someone they know, then it also helps the rest of the family relax a little bit. We can trust that we know it is Joey, and Joey is very responsible.

In some parts of the country, we are seeing this is a particularly positive model, and, one of the unexpected resources is with young Hispanic men as an employer. Low-income, difficult to find work sometimes, but, the tradition, the cultural tradition of caring for an older relative, it works both ways. It is a formal agreement, but it works. We have seen it work for years and years when we have this kind of a structure.

With families with greater resources, we say, formalize it. Go to an attorney. Have this documented. This is economic value. It is important. It is a contribution to the care of the elder.

For the senior, it is a validation of their role as a senior in the family, in terms of having some control, having some say so, but done in partnership, and, we are able to arrange that a person could have a couple of different relatives. It does not have to be just one. That person is put through full criminal history clearance, and if there is anything that is a blemish or a concern, we are able to have the discreet discussion with the elder about what is their judgment, what is their wish, and, if they say, "Oh, he did that 23 years ago. I know it. It is over. I am fine." When we are in doubt, we will pull in a psychologist who will do a home visitation just to make sure that the person is competent and able to make a reasonable judgment, so, you are trying to protect everyone's interest.

What we find is with families that are wanting to do this, they are perfectly willing to go through the machinations and the paperwork because it is a win-win for everyone.

Then the other thing, what we have seen in that case is that beyond the scheduled time that person is supposed to work, when something else goes wrong, that elder is far more likely to call them and say—and it is everything from, "My oxygen tank is not working," and they will come running, literally come running in terms of providing the care, and often, we get to avoid a hospitalization or a whole another incident. The trust is there. They will call the relative, and the relative, if they cannot come, they know who else in the family to get over to that house ASAP. It really works.

Senator CASEY. I guess if it is working well, it has a lot of positive features. It is almost wholly intra-family—

Ms. MORRISON. Mm-hmm.

Senator CASEY [continuing] so, there is a level of trust in most instances. Maybe, in some instances, there would not be and it will not work. There is an agreement that is binding. There is background work that is done and all of that to ensure, and, there is a degree of kind of buy-in by both sides, so, I guess, in a sense, it affirms the person's dignity, as well—

Ms. MORRISON. Right.

Senator CASEY [continuing] that their care plan is something they are participating in with a family member, and, it does have the obvious benefit of relieving some of the stress. Ten dollars an hour may not be the be all and the end all for someone, but it does provide—

Ms. MORRISON. Something.

Senator CASEY [continuing] some of that. That is good.

Ms. MORRISON. If you will excuse me, the one thing I failed to say is that when we do that, what we clearly do is define what are the primary tasks that person is supposed to do, so that you are still able to complement the other things the family does. The family member will fill—somebody else will still cook. Somebody else will still cut the grass, so, it really does blend, and, therefore, it keeps some degree of peace within the family, that they are all pulling together to support that elder. Excuse me.

Senator CASEY. We will wrap up in a minute or two and I will open it up for one broader question, but, Doctor, you also spoke about the need for education and training. Any ideas on how best to meet some of those objectives?

Dr. REYNOLDS. Yes. I think there are some very good examples of that both here in the U.S., Senator Casey, and also abroad. I think the types of programs that Mildred is describing through the AOA offers a very flexible, responsive approach to education and training to caregivers and it would be hard to overstate their value, but, that is an extremely important, I think, area of policy going forward.

In the United Kingdom, there are programs that have trained family members of older relatives that have been hospitalized with stroke on the basic care of family members when they come home from a hospital, and these have been shown to save considerably in health care costs, so, we need that kind of training program.

The other comment I would make, and it connects with something Mildred said in your reference, Mildred, to Latino families, and that is, Senator Casey, as you know, not only are we living longer, but the racial and ethnic diversity of the Nation's seniors is steadily increasing, and, to Mildred's point about the need for flexible, responsive approaches to the use of Medicaid waivers, this becomes particularly key, I think, for families of different racial and ethnic origins, where there are different cultural norms, if you will, for caring for older adults.

Senator CASEY. I know there was the Pew study that we have looked at. I will not go into the details of it, but there are some pretty significant demographic data. This was a study that I know several people here are familiar with, January 30, 2013, "The Sandwich Generation: Rising Financial Burdens for Middle-Age Americans," by the Pew Research Center. Among lots and lots of—probably hundreds of individual findings, they did mention—they mention on page three here, in terms of different groups that are more directly impacted by this challenge, a very high number of Hispanics are more likely to be in this situation, so, you would hope that the prevalence would match the commitment that a particular family or particular group would want to provide.

I know there is a lot more that we can cover, but I wanted to get to kind of the—oh, I did want to mention one thing, Doctor. Some of the data that you provided here at the beginning of your testimony, your written testimony, you say, and I am quoting, in talking about the Sandwich Generation, "Twelve-point-nine million have provided care to both adult and child recipients," just an incredibly high number, and, again, I am quoting, "The market value of 'free' services provided by family members is \$350 billion annually." That is a staggering number, and, what we do not want to do is diminish that. We want to keep those hours—we want to be racking up those hours and that value, but give people who are doing that hard work some relief.

Maybe we can just go from left to right. We will start with Tom and go down. We do not usually keep the first panel here, but since you are here, we will include you again in terms of our questions. If there was a one, two—one or two policy changes, or even just one, that you would recommend that we make, what would they be?

I say it for this reason. I believe that when you look at a problem like this, there are two things that are in existence at the same time. A lot of good programs and policies that are available and



folks just do not know about them, so making people more aware is one part of the solution, but, I also think we have got some gaps, some things we are not doing, or some regions are and others are not, or some communities are and others are not, so, to the extent that you can make specific recommendations, sometimes it is just repeating what you have already said in one way or another, repeating what might be in your testimony, but it is a good way to kind of summarize kind of next steps that we can take, but, anything in particular, Tom, that you would hope that we would do?

Mr. MOORE. I think, as I said before, that somehow——

Senator CASEY. Maybe you could just move that microphone so——

Mr. MOORE. Somehow where people can get the information and find out what programs are there and how they are used and who they can talk to. Like I said, right now, it is a guessing game. To me, that is the most important thing——

Senator CASEY. Yes.

Mr. MOORE [continuing] that we are facing, trying to find out what programs are there and how to use them and who to talk to, but, that is the biggest challenge we have right now.

Senator CASEY. Thank you.

Sister.

Sister BOSS. I would have to agree with that, and I think there are a lot of choices out there, but, the families have to know what those choices are and then select the one that fits their needs and their wants for their loved one. I think that would be it.

Senator CASEY. Thank you.

Mildred.

Ms. MORRISON. Wow, there are many. I would very much agree, but I would almost like to say, take one service and let it be really well known, and if were to pick one, I would pick adult day care——

Senator CASEY. Mm-hmm.

Ms. MORRISON [continuing]. having run an agency that offered it, because people might be able to see it as a gateway, as a door to open up. Oh, there are other possibilities. I can ask. I can find out. Sometimes, I think when we try to go so broadly, we still miss it, but I might target there as a beginning point.

Senator CASEY. Doctor.

Dr. REYNOLDS. Maybe the key words here, Senator Casey, are things like training caregivers to do a better job, and to Mildred's point about day care services, that is one really good way to do that.

Another is navigation, helping people find the services, and, again, the gateway concept here is one that appeals to me immensely as a clinician.

I think, flexibility. One of the themes that you have heard today has to do with the flexibility of financial support. Models like Cash and Counseling, like we see in Florida, for example, and, I think, Pennsylvania has a program like this, can do a great deal of good.

There is a lot that we can do, and I would like to end this on a hopeful note by underscoring that there are many good things that we can do, and we would like to stay in touch with you from the Pennsylvania Long-Term Care Commission and continue to

communicate with your good office about the things that we are doing there.

Senator CASEY. We will do that.

Dr. REYNOLDS. Thank you.

Senator CASEY. That goes for all of our witnesses and anyone else who wants to help on this challenge.

There are certainly, I am sure, a lot of families who say, I am providing care and support to more than one generation, and some days it is tough, but I am okay and we are all set, and then there are others who have a more difficult challenge.

This hearing is very helpful for us, to be able to speak to people that are, either by way of their own personal stories, your own personal experiences, or your professional work, can give us both information and inspiration about how to confront this challenge.

You know, we sometimes turn to the Bible for inspiration. Once in a while, you run across a politician who can inspire you, too. Hubert Humphrey was one of those people who often would talk about the moral test of government. He used to say that the moral test of government is how we treat those in the dawn of life, those in the shadows of life, and those in the twilight of life. Of course, he was talking about, all three of those categories, he was talking about some of the people we are concerned about here.

I think there are some things we can do in the near term which will have a, not just a positive impact on the economy overall, but an impact, a positive impact on these families that have these particular challenges and burdens. Raise the minimum wage, I mentioned before. Worker training can be very important. We know that the Workforce Investment Act legislation we just passed in the Senate the other day is an attempt to narrow the gap between the skilled jobs of the future we need to fill and the systems or the programs that support the skill levels that need to be achieved to fill those high-wage and high-skilled jobs of the future.

Many of you talk about flexibility, giving workers the kind of flexibility they need to have time off and to adjust to family circumstances. We could be here a long time talking about that.

Time is a big factor here for a lot of people, time to take a break, time to get a little relief, and, sometimes, there are people who only ask for that. They do not ask for any kind of new initiative. They do not ask for any new or substantial help. They just say, give me a little time. Give me a little break.

I know that—I will brag about my father a little bit here. When he was Governor—I am not sure, I think it was his first term—his team developed the Family Caregiver Support Program, and, like a lot of things, it started in the State and became a national model and then a national program. That was a very singular attempt to provide a little bit of time off, as Doctor and others said, respite care.

I also think, to support families and members of the so-called Sandwich Generation, we have got to initiate new answers, new strategies, new approaches. One of them is a bill that we are working on now—we have not introduced it yet, but we are working on it—to have a Caregiver Corps, folks that—a lot of people have such a commitment to volunteerism, volunteering to help strangers, volunteering to help family members and others, and we need to em-

power them, to assist them. We do not need to motivate them. They are already motivated, by love or by obligation or some other impetus, but, we are going to be working on that, and as we finely tune that legislation, we will be seeking your continued help and your assistance on that.

If you have another idea for another bill, even if it is a—it does not have to be a broad and comprehensive bill, even if it is something very specific to deal with some of these challenges, we welcome that.

Let me just conclude with this thought. A long time ago, like a lot of families in Allegheny County and Southwestern Pennsylvania who have loved ones who worked in coal mines or steel mills or factories, their lives are the source of great example and inspiration to us. Even more than one generation after a lot of those jobs are gone, those individuals, those families provide inspiration.

My father was always inspired by his own father's life. He was in the coal mines at the age of 11, and that was not uncommon. He was not some unique Horatio Alger story, but, he always drew inspiration from that, always said his life was made easier by his father's work, and, he talked about, you know, his father worked in the mines as a young guy, young boy, really, then became an adult, held all kinds of jobs, became a lawyer, I guess, in his mid-to late-30's, many, many years later, but, he did not have a life that was up in the headlines, but my father said his own father's life was a life that could be described as quietly triumphant, and, he used to use that phrase describing the lives of a lot of other people in Pennsylvania.

Everyone in this courtroom today could point to some member of your own family whose lives have been quietly triumphant, that they have overcome, they have surmounted barriers in a way that really is triumphant, even though it was not in a headline or was not the subject of some movie or documentary or acclaim.

Many of these millions, literally, tens of millions of people doing this work, and all those billions of hours, I think, are a testament to lives that are led and that achieve a measure of triumph, that they overcome so much, are able to work so hard just to make ends meet, but in addition to that, they are caring for or having some positive impact on more than one generation, or at least one other generation in their family, so, they lead quietly triumphant lives. All of you have met those people. Many of you have lived those same quietly triumphant lives.

What we have got to do is to align the policy with the commitment, to align the policy with the fervor that people have to volunteer and to help either their own family or some other families, and, some of that is just letting people know it is out there and guiding them better, or giving them information and empowering them, but, some of it is filling in those gaps.

That is an inspiration for me to keep going and keep trying to find these answers, and, your testimony, your witness, and your work is also an inspiration and I thank you for that today.

I appreciate your time, everyone, and our hearing is adjourned.  
[Whereupon, at 2:30 p.m., the Committee was adjourned.]



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## **APPENDIX**

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**Prepared Witness Statements**

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Testimony of Tom Moore  
June 30, 2014

My name is Tom Moore. Prior to my retirement in 2012 I was President of the International Union of Operating Engineers, Local 95. I live in Ross Township with my wife, four children and grandson. Three of my children have special needs.

Ten years ago my mother-in-law was widowed and moved from her home in Monroeville to a house on my street. Slowly as her age increased and her health decreased we assumed more and more responsibilities for her home and her daily needs. For the past five years as her physical health deteriorated rapidly and her mind succumbed to advancing alzheimers disease my wife and I became her caregivers. All household chores both inside and out had to be done by us. We provided all her meals, did all her shopping, scheduled and drove her to all her appointments, administered all her medicines multiple times a day, took care of her finances and saw to all her other day to day needs.

At the same time we were still fulfilling all those same responsibilities for our children plus the added commitment of their individual school, social and leisure activities and the appointments related to their special needs. All while providing childcare for our grandson so that his mother can work.

The physical demands of taking care of two families is tiring. Two yards to cut, drives to shovel, houses to clean, extra meals, extra laundry, extra appointments. The extras are neverending. The emotional demands and time constraints are harder. If a child has a therapy appointment and gram has a doctors appointment which is more important? Neither can attend an appointment alone. If you want to go to dinner with a friend you have to find someone to take medicine and dinner to gram or check to make sure she got into bed. If you're out and she accidentally pushed her safety alarm you have to go home. There are rarely long evenings out as a couple. There are never vacation as a couple or even as a family. Taking care of your own needs becomes your lowest priority because you're too busy seeing to everyone elses needs.

My wife and I are very committed to each other and our family. We both have a close knit extended family that gives us emotional support. We also each have a large group of friends that allows us an opportunity to individually spend time away from our daily commitments.

Unfortunately there aren't enough reliable, affordable services for the elderly. What services are out there are not widely known and often only discovered when comiserating with someone else in the same situation. Medical professionals tell you to call your insurance to see what is available. Insurance tells you to ask your medical professionals. In the end you just keep doing what needs done and hoping not to much falls thru the cracks.

Testimony of Sister Barbara Ann Boss  
June 30, 2014

Good Afternoon, my name is Sister Barbara Ann Boss, a Sister of Charity from Seton Hill in Greensburg, PA. At the present time I am the CEO at Elizabeth Seton Center located in the South Hills of Pittsburgh. Seton Center is an Intergenerational Center dedicated to the belief that, no matter what age we are, growing and learning are lifetime activities and that people of all ages are bound together by what they share, not separated by age or interest. Our programs include care for children age 6 week through 12 years of age, enrichment programs for seniors, arts programs such as instrumental music instruction and theater activities for all ages and care for the frail elderly.

Today I am not here to give you facts, numbers or statistics about what each of these programs need to survive I come to talk about the struggles, stress and strain that people caught in the middle, better known as the "sandwich generation" are experiencing. Just last week we were interviewing for a position at Seton Center so this story is very fresh in my memory. First, picture this, a grandmother, now not one old in age, but one in her 50's or early 60's, young looking and willing, able and out of necessity has to work. All of the sudden she finds herself faced with custody of a four year old grandson. The grandson attends Seton Center during week day and she receives subsidized care. However, she is employed at a fast food restaurant that schedules her to work evenings and week-ends. How does she choose between the safety and security of the child and her job? Her only choices are find a 9 to 5 job or go on welfare. Believe it or not there are some people out there who feel that their self-worth is measured by their ability to provide for themselves and their family. Maybe we need to think outside the box. A sandwich has a top, middle and bottom. What if the top is a grandparent taking on the responsibility of the child and grandchild.

At Seton Center we have expanded our Adult Day Services hours to 6:00 am to 9:00 pm and on Saturdays from 9:00 am to 5:00 pm to accommodate the needs of the "Sandwich Generation" One of the reasons is to enable the adult child of a frail elderly person to attend the sport's games, rehearsals, or other events that are a growing part of their own children's life. Many times we hear "Can mom/dad stay at the Center longer today so I can go to my child's game." Or can mom/dad come on Saturday so that we can spend quality time with our children." We all know that the Family is the core of our society. Many times the Sandwich Generation find themselves caught in the middle between parents and child. This generation needs respite time or they become overwhelmed and stressed. Having an overwhelmed and stressed caregiver is not able to give quality care to parent or child.

Most of the clients we care for at Seton Center are victims of Parkinson's disease, Dementia or Alzheimer's. People with these diseases often do not sleep at night. My father was a victim of

Parkinson's. Being an independent person all his life he would wake up at night and try to get out of bed causing many falls. If my mother was to get any rest, it meant that the children had to take turns doing night duty. This became very stressful knowing that you had to go to work the next day with little sleep.

Financially, the strain on the "Sandwich Generation" is huge.

1. If the parent has any retirement funds set aside the adult child tries to make the funds stretch as long as possible. Before placing the loved one in a nursing home they will try juggle their own work schedule to care for them, find someone to come into the home or place them in an Adult Day Service facility. There needs to be more education on funding sources that are available and the services that Adult Day Care can offer. In most cases this kind of information is given when the adult child comes to inquire about services at the Center. However, most centers do not have the funds for marketing budgets. How do those in need even know where to go for assistance.
2. Child Care can be expensive. If the adult child qualifies for subsidized care there is usually a long waiting list for the funding.
3. Transportation issues. Families often need help getting their parents to the Adult Day Care site. Transportation rules prohibit families from choosing the best center for their loved one. Because multiple companies service areas of the county and will not cross into another's area, clients often cannot go between their homes and the Center of their choice.

Thank you for this opportunity to share my experience and the experiences of the families we see at the Seton Center.



US Senate Special Committee on Aging  
Senator Robert Casey Field Hearing

Monday, June 30, 2014

Testimony of Mildred Morrison, Administrator of the Allegheny County Area Agency on Aging

Senator Casey:

The Allegheny County Department of Human Services espouses a vision *to create an accessible, culturally competent, integrated and comprehensive human services system that ensures individually tailored, seamless and holistic services to Allegheny County residents, in particular, the county's vulnerable populations.* Annually, our Area Agency on Aging serves 8,000+ older adults with social work services, developing plans of care and delivering hands on direct care in partnership with family members and friends who provide essential care at home. While we serve an additional 35,000 seniors with a variety of senior center, advocacy, transportation, and informational services, I wish to take this opportunity to address the growing challenges of Caregivers that assist the 8,000+ older adults in the home. As the Administrator of an urban AAA with one of the country's highest densities of seniors, let me begin by thanking you for holding this Field Hearing to share with the Special Committee on Aging my deeply felt concerns and some of the solutions we have found. I must also voice our great appreciation for the Older Americans Act and other federal funds which combined with considerable state resources that make providing any service possible.

With the growing number of seniors, especially the rising rate of those living to advanced years, experiencing dementia and complex life-limiting medical conditions, we have seen a 24% increase over ten years in the number of families we have assisted in caring for a frail elder. This is a complete reversal of circumstances from fifty years ago when an adult woman in her 40-50s provided at home care for usually the last two years of a parent's life. Typically, she was a married, full time homemaker whose children were grown and she was assisted by her siblings. Today her life in southwestern Pennsylvania is radically changed – her full time work is essential to the household, and her children were born later and far more likely to be at home and/or require child care for their own children while they are at work. Further, those beloved parents are older and frailer with multiple health issues but wishing to remain in their own homes. This caregiving family is the sandwich generation if not the double-decker that is also caring for grandchildren.

National studies<sup>1</sup> indicate that 20% of adults continue to provide more than 75% of the care for dependent elders that allow this frail population to remain at home. It is essential that public services enhance families' capacity to maintain this commitment as it is unimaginable that

government services should or could assume such a responsibility. But many of those caregivers are caught trying to understand the medical and cognitive changes, accessing resources, maneuvering in an unfamiliar but complex long term care system, as well as coping emotionally, physically and financially.

The normal scenarios we witness, often at a point of crisis as the family can no longer manage on their own and reach out for assistance, are:

- living with modest household incomes or through difficult economic times re no overtime, low wages, or job loss,
- saving for retirement,
- educating young adult children,
- major health or home repair event.

And the strain is even greater when it is a single parent household. In the past few years, we have witnessed situations of four generations of family members that were being cared for by adults who were raising grandchildren and caring for elderly relatives. These situations were a result of drug abuse and incarceration, but also travel out of the area to find work or to serve in the military.

When the call comes to us the ask is for help with bathing a parent, respite or oversight so the caregiver can handle personal business, go to work, attend to family matters, etc. Other requests are for meals, house cleaning, transportation and escort to medical appointments, and sometimes an electric stair glide or expansion of a bathroom doorway. We have found that whether the circumstance are best met by a Medicaid funded service or a program using federal and state dollars, there is almost always a need for additional support and a creative response. So this AAA and many of our peers have implemented services to help address the financial pressures of caregivers taking care of their parents. For example, we:

1. Reimburse low-moderate income households for direct costs to care for elders through the Family Caregiver Support Program
2. Provide ability for elder to hire a relative to provide care so elder can have person trusted and allowing provider to maintain employment
3. Support benefits counseling that provides and links elders to supplemental resources like LIHEAP utility assistance, re VA disability for those who served in combat, SNAP, free or very low cost used medical equipment, social-nutritional services of senior centers, subsidized apartments and access to para-transit especially for frequent dialysis or chemotherapy treatments, etc.
4. Provide advice that is sometimes lower cost, enhances the older person's safety and thus the caregiver's piece of mind. Such as:
  - Encourage out of town relatives to pay for the sneakers/shoes with a built in GPS device so if the senior with dementia wanders away, they can be more easily tracked
  - Build adult day care into the plan as cheaper to spend \$70 per day for 10 hours of care than to have someone come into the home at double or triple the cost. And the elder is with trained staff who are able to feed, toilet and, if needed, shower the person while providing activities, meals, nurse oversight and engagement to send them home to sleep through the night.

- Replace the fixed shower head with a hand held device so bathing someone is quicker, is more agile, and thus engenders dignity with compassion.

What the AAA cannot do is: have families consider purchasing long term care insurance (if it were affordable), help them claim an income tax deduction for caring for an elder who resides at a separate locale, or create the massive awareness campaigns that would help many families ask for help. Be it measures great or small, as a country we must face the often labeled "aging tsunami" so that family caregivers do not suffer financial hardship along with the other burdens of caring for loved ones.

<sup>1</sup>[The MetLife Study of Caregiving Costs to Working Caregivers – Double Jeopardy for Baby Boomers Caring for Their Parents – Full Report \(2011\)](#)

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Caring for the Caregiver: Testimony of [Charles F. Reynolds III, MD](#); UPMC Endowed Professor in Geriatric Psychiatry and Director, UPMC/Pitt Aging Institute ([www.aging.upmc.com](http://www.aging.upmc.com)) - Sandwich Generation Caregivers, 6/30/14

Senator Casey: Thank you for the work you do on behalf of seniors and their caregivers, both in Pennsylvania and in the Nation as a whole, through your work on the US Senate Aging Committee.

In the United States, more than 65 million people have provided care to a chronically ill, disabled, or aged family member or friend in the past year. Of these, about 20% or 12.9 million have provided care to both adult and child recipients (the "sandwich" generation caregiver). (National Alliance for Caregiving and AARP, 2009) The market value of "free" services provided by family members is \$350 billion annually. With respect to Alzheimer's disease and related disorders, 15 million people provided 17.4 billion hours of unpaid care, and of those, 60% rate the emotional stress of caregiving as high or very high, and 1/3 to 1/2 reporting high levels of depression.

Family caregivers are the backbone of the long-term care system, providing millions of hours of care every year for no compensation and frequently at great cost to their own emotional health. They're burned out and exhausted from juggling work, family responsibilities, and care giving. In addition, many caregivers have to reduce their work hours or quit their jobs to care for a loved one. Additionally, American businesses lose \$11 billion - \$29 billion each year due to employees' need to care for loved ones age 50 and older. We need policies supporting care givers, enabling them to cope with the burden of care giving and relieving the stressors associated with their role.

At the same time, and for a variety of reasons, the overall availability of "informal" caregivers (especially those in the sandwich generation) is decreasing. The factors behind this trend include: (1) the entry of more women into the workforce (increasing the number of other obligations they face); (2) decreased birthrates (resulting in fewer children to provide care); and (3) the geographic dispersion of families (stemming from job migration and increased divorce and marriage rates).

AgingCare.com explains some of the particular issues faced by "sandwiched" caregivers as illustrated by Mary and her daughter: Mary, a 74-year old Florida woman, suffered a stroke, then required assistance with all the basics of daily life: bathing, dressing, food shopping, meal preparation, laundry and housekeeping. Her daughter took time off work to care for Mary—time that, from a financial perspective, she could ill-afford. Part of the dilemma Mary and her daughter faced was that while their state Medicaid plan covered the cost of a home health care worker to provide

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Page Two

those services, local agencies were short-staffed and couldn't send aides on the schedule Mary needed. Mary and her daughter required a more flexible approach that would allow them to use the Medicaid-provided personal assistance budgets to hire their own personal care aides as well as purchase items or services, including home modifications that would help Mary live independently. I'd like now to place this case example within a broader public health and policy framework, and then return to Mary and her "sandwiched" daughter a bit later, in the context of recommending specific policies.

As you know, the journey of care giving is long and arduous, often spanning a decade or longer. The journey covers the "territory" of occasional sporadic care (appointments to physicians, light errands, checking in and monitoring), progresses to care in the instrumental activities of daily living (cooking, cleaning, shopping, managing finances and household tasks, coordinating care, monitoring symptoms and meds, and providing emotional support), and expands to care in the highly personal activities of daily living (bathing, dressing, toileting, monitoring behavior and location, dealing with insurance issues, providing acute care and managing symptoms). As the burden of heavy-duty caregiving increases on this journey, additional issues of long-term care placement (advance care planning, personal care, emotional support) are confronted, and may or may not end in death (depending upon the duration and complexity of grief). Becoming a heavy-duty caregiver is associated with increased depression, poor health, poor self-care, loss of weight, and increased chronic illness. Over time, heavy-duty caregivers decline more rapidly than non-caregivers. Care giving is a risk factor for mortality.

We understand the problem, but what can we do about it?

**Recommendation:** disseminate information about the 10 characteristics of caregivers (especially in the sandwich generation) at highest risk. They (1) provide high levels of care, (2) have lower income (< \$30K), (3) live with the care recipients (adult and child), (4) have less education (HS or less), (5) are female, (6) had no choice in taking on caregiving duties, (7) show impaired self-care and health behaviors, (8) have low levels of social support, (9) experience care recipient problem behaviors, and (10) endorse high levels of depression/anxiety.

**Recommendation:** incentivize clinicians and health care agencies to tailor interventions to the journey of caregiving, intervening early if possible to prevent the adverse health effects of caregiving: (1) address safety issues with home assessments and alterations, patient monitoring devices, and removing access to guns; (2) address self-care and preventive health behaviors via "health passports", education, monitoring, and facilitating access; (3) provide informational, instrumental, and emotional support through assistance in navigating to needed resources and to support groups; (4) help with depression and distress by facilitating relaxation/pleasant events training/respite, assistance with care coordination, counseling, treatment for prolonged grief, and coaching to resume previous and new roles.

Since, informal caregivers have a profound effect on long-term care processes and outcomes, what policies will support the engagement of families in patient care to improve outcomes, especially in dementia, and to postpone institutionalization? The Institute of Medicine of the National Academies of Science has made two recommendations (Retooling for an Aging America: Building the Healthcare



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Workforce, 2008):

**Recommendation:** "Federal agencies (including the Department of Labor and the Department of Health and Human Services) should provide support for the development and promulgation of technological advancements that could enhance an individual's capacity to provide care for older adults. This includes the use of ADL technologies and health information technologies, including remote technologies that increase the efficiency and safety of care and caregiving." (Recommendation 6-1, "Retooling for an Aging America")

**Recommendation:** "Public, private, and community organizations should provide funding and ensure that adequate training opportunities are available in the community for informal caregivers." (Recommendation 6-2, "Retooling for an Aging America")

These initiatives may be modeled after those provided by the Area Agency on Aging, which has established programs to assist caregivers in making decisions and solving problems related to their roles. Other potential models include those developed by CMS, HRSA, Geriatric Education Centers, a UK program that trained informal caregivers of hospitalized stroke patients in basic nursing and personal-care tasks, resulting in reductions of annual health care costs by more than 4,000 pounds (roughly \$8K), and the NIH sponsored REACH study (Resources for Enhancing Alzheimer's Caregiver Health), whose intervention yielded improvements in caregiver burden, quality of life, and depression after 6 months.

Some states, including Pennsylvania, allow for the payment of family members as caregivers, and some Medicaid waiver programs allow for respite support. If we return to the case of Mary and her daughter, they were able to access Florida's *Cash and Counseling*, a non-traditional Medicaid program that allows people to hire privately someone to provide care, deciding if they would rather hire a home health aide to cook for them, or pay a friend or relative to do it. The difference with *Cash and Counseling* is that family members and friends chosen by the elder are providing those services instead of an agency worker.

More general flexibility in HCBS waivers as we move toward managed long-term care and the integration of Medicare and Medicaid funding will produce better value for families and greater responsiveness, as well. Models like *Cash and Counseling*, exhibit more flexibility in approaching the needs of caregivers. But recall that even with *Cash and Counseling*, family caregivers are typically paid lower than average wages and, in most cases, are paid only a fraction of the hours of service they provide.

In summary, these policy recommendations recognize that family members and other unpaid caregivers provide the backbone for much of the care that is received by older adults in the US. And, although informal caregivers are vital members of the healthcare team, little has been done to impart the necessary knowledge or skills to these team members. The type of education and training needed is not currently reimbursable under most insurance plans, including Medicare and Medicaid. If caregivers (and patients) are able to manage their conditions more effectively, they are likely to use fewer healthcare resources and reduce the strain on the healthcare workforce.



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**Statements for the Record**

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Testimony of Judy Mills  
June 30, 2014

Hello everyone. My name is Judy Mills. I am the wife of 33 years to Deacon Thom Mills, and the mother of Nick and Tim Mills, ages 29 and 27 respectively. I am the full-time director and teacher at St. Valentine Preschool, in Bethel Park, PA. My husband and I have been residents of Bethel Park for 28 years.

Thom and I officially became "Empty Nesters" 2 months ago. This was postponed by 8 years after our youngest son left home, when we moved my father into an assisted living facility 15 minutes from our home. Let me share with you a little history of our family dynamics over the past 29 years.

When my sons were young teenagers, my mother passed away, leaving my father in an apartment in Bethel Park not 5 minutes from our home. They had moved there 8 years before her passing, so that they could be closer to our family. So we have technically been members of "The Sandwich Generation" for 22 years, since my mother's health went downhill quickly after the move to Bethel Park. Dad lost his life-line, my mom, in 2001, and I knew that I would be running 2 households for quite some time. When he was age 70, we moved my father in with our family. He had his own bedroom and full bathroom on the first floor of our home, complete with TV and a recliner. Quite comfortable arrangements!

Dad's first years with our family blessed us by his helpfulness in household responsibilities. (For ex. – picking up some items at the store for dinner, cleaning his own bathroom and bedroom, dropping our sons off at sports practices or jobs.) Unfortunately, he also tended to add to the drama of raising 2 teenage boys! We began to see, as time went on, that our social life was starting to suffer – no time, no money, no space to invite friends over to our home, without feeling that Dad was the authoritative figure and we had become the teenagers with a curfew!

As the years went by, family members' roles began to change quite dramatically, and the parent who helped us now became the one who needed our help. Many days we felt as if there were not enough hours in the day to juggle our responsibilities of caring for 3 generations of family. (For ex. – homework and school projects, family events, meal preparations, laundry, chores, etc.)

As my father's health and mind began to fail, more of our parenting was directed towards Dad than our sons. Again we saw major role reversals in our family. Now our sons began to help care for Dad, including driving him places after we had to take his car keys away for safety reasons.

Living as an extended family has presented unique blessings and challenges for all of us. During the difficult times, we have prayed together, laughed together, and cried together. This experience has drawn our family closer together, and made our sons realize how much we have sacrificed for them and for Dad.

We were met with financial challenges, even after our sons moved out. We faced higher food bills (Dad's appetite never declined!) , higher cable bills (too many sports channels!), and even higher utility bills since Dad was home most of the day. Needless to say, these are the things that we have seen decrease over the past 2 months since we have moved dad to assisted living. But we are not responsibility-free yet! We still visit Dad at his assisted-living home, clean all of his laundry, pay all of his bills, manage his affairs with his new dwelling, and take him to all doctor appointments, at least 4 a month. And the biggest blessing for Thom and I is that we realize that moving Dad out of our home was the best arrangement for him, as his health and mind continue to deteriorate, and really don't feel guilty or selfish, and haven't lost our sense of humor! We realize that assisted living can provide more than we could give him at this point in our lives. (For ex. - social interaction with peers, meals on time, supervised care 24/7 for safety reasons.)

Over these "Sandwich Generation" years, Thom was often one step ahead of the latest corporate takeover, employer bankruptcy, or merger, none of which helped us prepare for retirement, and Dad's ongoing medical and housing requirements pretty much guarantee that we won't be seeing any inheritance. The dream of carefree retirement, for us, seems very distant.

We have learned a few ways to help other caregivers like ourselves to balance more than one generation of family at a time. Some of these ways include pulling together as extended family to help with care and morale, attending caregiver support groups, sharing with and asking for help from our Church family, and picking up the slack for each other when we have reached our breaking point. We have been on the learning and teaching ends of the importance of family unity and love. We would not change anything that we have done, nor do we regret the decisions that we have made. We hope that we have shown to our sons through role-modeling that "charity begins at home." In today's individualistic culture we cannot think of a more importance lesson to leave to our sons and their future families.

In closing, I thank you for this opportunity to share my story. It is my hope to be of some help to others about to embark on this journey.

Mrs. Judy Mills

June 25, 2014

Hi, my name is Christine. I have lived in Lackawanna County my entire life. I have been married for almost 25 years and have 6 children. Prior to getting married, I was diagnosed with Cancer. The first two years of my marriage I was undergoing Cancer treatment and was unable to work very much. Therefore, we were unable to save very much prior to having children. I have 2 children in college and one entering. All three living at home due to the fact that dorming is not financially beneficial. I have one child in 11th grade, one in eighth, and one in sixth. My youngest child was diagnosed with Asperger's syndrome at the age of 4. While in headstart and early intervention he received more help than in the public system. Due to the fact that both me and my husband work full-time and have health insurance he does not qualify for any programs and the only help he receives is thru the public school system under his IEP.

I have been a health professional for 30 years. I am an x-ray technician working in a doctor's office but have not taken x-rays for over three years due to employment opportunities. At this time, 3 of my children are working and my oldest daughter who is 22 makes almost as much as I do. She carries a full schedule at school and works 30 hrs a week. She will owe probably \$45,000 after school and we will not be able to help her. She is in her fifth year because she changed her major sophomore year. She needed one semester to graduate but opted to go full-time another year just so she can still receive financial aid. She is already 22 and will only be covered on our insurance until she is 26. If she is not working, then what? Fortunately, my son who is now entering his junior year has a full academic scholarship but will still need money for graduate school. My third child, who is entering college this upcoming fall did not do as well in high school and will need to borrow much more money. My husband has a bachelor's degree in health policy and administration and is unable to work in his field. He is working at a job that pays enough to cover our expenses but most of all health insurance for our family.

Between mortgage, utilities, food for 8, home owners, credit cards (which wouldn't be used if we had enough to live on), and car insurance for 4 (soon to be five and six), we barely have enough to survive.

My mother-in-law is a widow, in her eighties, who lives close by. She still works a bit because she worries about her future. Due to the fact that my brother-in-law lives in Philadelphia, we are the only ones close enough to help. As time passes by, she needs more and more help and we worry what the future will bring. Me, my husband, and my children help as much as possible between school, work, and other responsibilities. My husband and boys take care of yard work, and car problems, plumbing, snow removal, and overall home maintenance. They do so for two households. There have been incidences where she has been ill and my girls and I needed to help with the house and to help take care of her. We help with Dr.'s appointments and other medical care, as well. When she gets to an age where she needs full-time help, we know there will be no one to afford her to live in a nice aging community so she will need to live with us. No one will be able to financially afford an assisted living community.

The physical demands, as well as mental anguish, are very overwhelming. We worry about what the future brings for all of us. Will we be able to survive?

There is no money left to cut back on expenses and save. We don't go out very often or take vacations. Me and my husband have not had a weekend away in 22 years. We don't go out to eat

very often (occasional take-out) and we don't go to movies. We work, we eat, and we sleep, when we are not kept awake all night worrying about the financial strain on our family and, again, what lies ahead for us.

Will our children be able to find work and pay off all of their student debt or will they still be at home, needing our help (which would never be denied)? What type of care will our family need and will we be able to provide it? How long until my mother-in-law needs support full-time and needs to live with us?

We dream of the day that we can provide our family with everything they need to be successful and happy and fear that day will never come.

Christine Chylak  
Lackawanna County, PA



#### Our Sandwich Experiences

My husband was a teacher who retired a few years ago and I have worked for a large insurance company for the past 34 years, 6 of those years I worked 2nd shift so we could care for our daughter ourselves. I was very lucky to have an employer that supported my family responsibilities.

Our first sandwich experience was before our daughter was born. My mother in law was in the hospital for 9 months prior to her death and we visited her every day at the hospital.

Our only child was born with an intellectual disability.

Our second sandwich experience was with my husband's aunt and uncle who lived locally but never had any children. As they advance in to their 80's they requested with any activity that took place outside of their apartment. I carry a lot of guilt for not being able to be there for the Aunt after the Uncle's death. The Aunt died 3 years after the Uncle. Those last 3 years were very lonely for her and I don't think she ate very well after the Uncle's death. This is when I started to feel, time is the enemy. I just didn't have enough time to care for her and everyone else in my life that needed attention.

Our third sandwich experience was with my mother. While my father was able to provide most of the care for my mother during the last year of her life, there was one crisis after another. All of the crises wear on you emotionally. I took my parents to the sea shore 6 months prior to my mother's death. During this vacation I witnessed how worn down and impatient my father had become, he was also having difficulties walking and my mother was in a wheel chair. My father was so exhausted that he could no longer prepare meals. I had taken steps to take a leave of absence from my job but then my mother died.

Our current sandwich experience is with my father. It's been 5 years since my mother's death. There are daily phone calls, the weekly cleaning of the litter box and many dinners together. I constantly worry about his diabetes, falling and not being able to get up and being in a car accident. I can see that the driving will probably soon come to an end and he constantly tells me that he wants someone to care for him at his home, not in a nursing home. I dread the day that he can no longer drive because a lot of responsibility will be shifted back to me.

I recall 2 situations where some assistance could have improved our lives. The first, prior to my daughter leaving the public school system we could have greatly benefited from some type of companion service for her. Our county offers little assistance while our kids are in school. As she got older all of our non-paid help resources were exhausted and my husband and I had to rely on each other 100%. The second is, my husband was hospitalized for 8 days for burns that he received in a gasoline fire. Our non-paid supports were exhausted so I had to take my daughter to the hospital with me and she refused to enter my husband's room. During that visit I had a cousin with me but that was the only time I had support at the hospital. I was only able to visit my husband 1 other time because a neighbor offered to keep our daughter for the day.

I was lucky to have a husband and parents that fully participated in the raising of our daughter and caring for relatives. I know that if I had to raise my child by myself, and help my relatives, I could not have worked outside the home, especially as we all got older.

While taking my daughter to therapies at United Cerebral Palsy I attended a parents group that urged us to take 15 minutes a day for ourselves. At the time I was enraged thinking that 15 minutes was not enough. Later on in life I realized that my 15 minutes was really the 8 hours that I was at work each day. Time is the enemy.

It's not like social services knocks on your door and asks you what you need. You have to take the time to educate yourself and establish relationships to maximize any help that you get.

Laurene Kohler  
Mechanicsburg, PA

I am a 48 year old mother of two teen age daughters and daughter to my 89 year old mother. This past February we lost my dad. He and my mom were married for 65 years. My mom took care of my dad until he died, still living in my childhood home. Now that my dad has died my mom remains in this home. She does not drive and is very lonely without him. One month and a day to my father's death, my mom had a seizure. This has required many visits to doctors and time helping her to recuperate. My siblings and I take turns visiting my mother daily, driving her to many doctor appointments, church and weekly bingo. It takes all three of my siblings and I to take care of her needs, of which she has many more since my dad died. We do not allow her to drive, so I must fit visits to my mom's doctor appointments in with my full time job and driving my children to their activities and helping them with school work. Both of my girls are very active, taking voice lessons, playing volleyball, performing in band and chorus, and require rides several times a day. Some days are tough. Last Tuesday I had meetings at work but had to take my mom for blood work so that she can have cataract surgery in a few weeks. I also had to simultaneously juggle rides for my daughters to volleyball and voice lessons. It's not always easy to find someone to share rides, particularly when there's an emergency with my mom. We constantly worry about mom's health and safety but, like many people her age, she refuses to move, even to a location closer to her children. One of the reasons my mom does not want to leave her home is because she worries about the high cost of housing for people her age. She owns her home and is able to afford to keep it. She and we worry that if she moves into even a moderately priced facility, she will quickly exhaust her savings and be forced to move into the county run facility, which is severely under funded. At this point, even though I'm exhausted, I'd rather keep her where she is because we worry that she can not afford the quality of care that she needs and deserves. I don't have the means to help pay her costs at a retirement facility as I am saving for college for my girls. I just don't have enough money to give my mom the quality of care that she needs and deserves and help my daughter's pay for college. So, mom will stay in her half-double, we will continue to care for her as best as we can, and I will continue to do the best job I can as daughter and mom.

There is only one place in the Lehigh Valley that will let you stay and lived after you've exhausted your savings, beyond the county run facility.

Michele Deegan  
Bethlehem PA – Lehigh Valley

My name is Tanya Regli. My husband and I both have full time jobs with benefits. We live in Cheltenham Township with our two children, one of which has a diagnosis on the Autism spectrum.

Four years ago we moved my parents from Kentucky to an apartment near our house because of developing health conditions. My parents had been running a parish church there but my mother's kidneys were beginning to fail and my father had a back condition that was making it more difficult to work a full time job. All of us knew we needed to get them set up near better long term medical services while also having them nearby so we could help with any supports they might need both in the short and long term.

While my parents work at part time jobs when they can the last year has been especially difficult as my mother went through chemotherapy and radiation for breast cancer and my father got a debilitating case of Shingles. On the parenting front; providing homework support, trying to overcome the barriers to a good education for our son, supplementing everything with time and money, all takes a toll. Between the additional costs of having a child with autism and helping to defray the expenses associated with my parents' medical care we find ourselves stretched economically. We find it difficult to take care of our own needs, finding that we do not always get to the doctor for routine medical visits, struggle to find the time to exercise or do other self-care activities. The stress related to these issues also certainly weighs on us.

My parents are a great joy to me, as are both our children, but as we look to the near future, as my parents lose more of their ability to live independently, we know that even more of this care will fall on us. Meanwhile we will continue to have to work to also create opportunities and supports for our son with Autism even after he ages out of the public school system. There are days when the task is daunting, especially trying to find the supports my parents will increasingly need. Accessible services for my parents will be the key.

Tanya Regli  
Wyncote, PA