Averting the Caregiving Crisis: Why We Must Act Now
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PROLOGUE

The Rosalynn Carter Institute for Caregiving (RCI) held its annual National Summit, “Averting the Caregiving Crisis: Why We Must Act Now”, on October 20-22, 2010 at Georgia Southwestern State University (GSW) in Americus, Georgia.

The 2010 RCI National Summit was designed around a comprehensive report published in October of 2010 by RCI, based on a culmination of more than three years of intensive study of the caregiving process, evidence-based programs to help family caregivers, and current translational strategies for making effective programs widely available to caregivers. The summit proceedings followed the 12 recommendations outlined in this report, and experts were tasked with fleshing out these recommendations in detail.

In addition to the summit presentations, RCI facilitated an invitation-only pre-summit workgroup, whose purpose was to identify common barriers and challenges to implementing evidence-based caregiver programs in local community settings. Experts on evidence-based programming outside of the caregiving realm were included in this discussion in an attempt to learn from the work others have already successfully realized.

Believing strongly in the need to develop a National Caregiving Initiative to provide an umbrella for disparate caregiving efforts across the Department of Health and Human Services, the Veterans Administration, the private sector, voluntary health organizations, corporations, and private philanthropy, RCI invited representatives from all of these areas to the table. This document contains the important discussions and information gleaned from the summit.

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OCTOBER 20, 2010
PRE-SUMMIT WORKGROUP
(Summary)

Led by Dr. Laura Gitlin, Director of the Center for Applied Research on Aging and Health at Thomas Jefferson University, this workgroup was titled “Plotting the Course for Going to Scale with Evidence-Based Programs for Caregivers”. The workgroup included individuals from several disciplines who were working on varying kinds of projects, in terms of taking evidence-based programs and bringing them to scale in different types of settings. The workgroup objectives were to learn about different models for implementing and sustaining proven caregiver programs; to identify barriers and supportive structures for implementing and sustaining caregiver programs; delineation of research questions specific to implementation of evidence-based caregiver programs, and the role of RCI in disseminating evidence-based programs to service and clinical settings.

Director of National Initiatives for the RCI, Laura Bauer Granberry acknowledged the wealth of experience and knowledge in the room, and shared RCI’s vision to help move the translational process forward to more quickly bring evidence-based programs for caregivers into community settings across the country.
Brief presentations were made on different models for diffusion of proven programs:

1. National SafeCare Training & Research Center (Dr. John Lutzker, Georgia State University)
2. Chronic Disease Self-Management Program (Dr. Kate Lorig, Stanford University)
3. Role of the National Council on Aging in building upon the CDSMP (Dr. Nancy Whitelaw)
4. FOCUS intervention (Dr. Laurel Northouse, University of Michigan)
5. Skills2Care Program through Medicare A and B (Dr. Laura Gitlin, Thomas Jefferson University)

Common themes and challenges emerged during the presentations and ensuing discussions. Topics addressed included licensure and certification, readiness issues related to adoption, reimbursement and policy implications. Issues related to sustaining programs were identified: impact of agency staff and mission changes; need for ongoing training, coaching, and supervision; reimbursement and changes in funding streams; and monitoring to insure fidelity.

Financial considerations identified included marketing tools, staffing, quality assurance, and the role of universities, federal agencies, and foundations in supporting the work of translation and implementation. Legal considerations touched on were the issue of who owns what, how to sustain programs through agency personnel changes, and intellectual property rights. How to integrate changes or refinements in evidence during the implementation phase of programs was also discussed.

Dr. Gitlin concluded the workgroup by suggesting that the conversation begun by the workgroup be continued in a meaningful way, perhaps by moving towards a concept paper specific to the issues identified. Laura Bauer Granberry pledged RCI's support for such an effort, looking at lessons learned across all evidence-based caregiver programs, leading to development of a toolkit that would walk agencies through the process of translation and implementation to ensure their success in bringing effective programs for caregivers into the community.
careers developing effective interventions to help family caregivers. Georgia CARE-NET Coalition members and members of the RCI-Korea team were also recognized.

Mrs. Carter introduced Joanne Fillweber, Corporate Contributions Manager from Johnson & Johnson, and thanked her for her years of support and friendship to the RCI. Joanne stated that the J&J executives hold the RCI program near and dear to their heart, as the philanthropic work they are supporting here sets the tone for who J&J is as a corporation. She shared that J&J believes it is now time to move community-based adoption of research closer to the national stage. The accumulated knowledge and experience of the past and present grantees must be shared with other donors, policy makers, and thought leaders to bring about systems change. She said that the field must prepare clear communication strategies – refined and focused messages to capture the attention of those who can help move this work forward.

Laura Bauer Granberry, Director of National Initiatives for the RCI, gave a brief overview of the day’s proceedings, stating that the RCI position paper contained in the attendee materials would serve as the agenda for the next day and a half. She said that we have to recognize that the confluence of our overburdened health care system, along with a rapidly aging population, has created both a moral and an economic imperative to fix the broken pipeline between caregiving research and practice in this country. She stressed that by addressing the most pressing unmet needs of family caregivers, including a lack of adequate training, additional respite care, and greater access to support programs, the caregiving crisis could be successfully averted. Modeling the summit presentations on the RCI’s 12 recommendations, care was taken to match each recommendation to an expert in the field who could address their recommendation in detail.

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RCI NATIONAL SUMMIT KEYNOTE ADDRESS
(Summary)
Kathy Greenlee, Assistant Secretary for Aging, HHS

Good morning to you all. What an honor to be introduced by Mrs. Carter, whose leadership in the fields of mental health and caregiving is truly extraordinary. All of us here would do well to do half of what you have been able to do for this country. I also want to thank you on behalf of the Obama administration for what you are doing with regard to caregivers. Clearly this has become a signature issue. It's the reason I wanted to come here today, to demonstrate, not just my commitment, but this administration's commitment to working with you. And I know you came to town and met with Secretary Sebelius to talk specifically about the recommendations that we're covering today, and I've had a chance to meet with RCI staff at my office in Washington.

Sometimes when I meet with caregivers, it's the little things that stay with me. After a site visit to an adult day program last year, I met with two family caregivers whose loved ones attended this program. A woman who was caring full-time for her sister talked dramatically about the value of adult day programming, but she also talked about the burden of caregiving. The other caregiver agreed that the services were wonderful, but she talked about how hard it is to get up in the morning to take her mother to the program - the magnitude of the impact on caregiving ranges from the small to the enormous. At another conference, I sat and listened as caregivers one after another talked about the devastating impact of isolation.
In Chicago in March I met informally with a group of caregivers and again heard their stories of how they got into the caregiving role - I remember these people. These are the same people that you have met.

So I came today to lend my support and to tell you that I did understand and to demonstrate my commitment to working on this issue at a national level. I have read and met with you about the National Quality Caregiving Initiative outlined in your report. You document the need that I have seen with my own eyes. You document the scope and I understand that 80% of long-term care in this country is provided by families. Families don't first look to government for their support. The families provide family care on their own – it is unseen and often not talked about and invisible, but this is not a largely government funded program. Families have not abandoned each other in terms of the government for help. Instead they are now the core of the system. They always have been. They are both the center and the soul of the system. We need family caregivers - we need them because there is no replacement. You can't make this a commodity. But we also need them economically as a nation, because we can't afford to buy this care from strangers.

You also document the future in your report. We know that in the next 20 years, we will have twice the number of people who need family care or long-term care, most of that provided by family members. So the scope of your report is very comprehensive, in terms of the need. I am often the person who doesn't need to be convinced of need. I'm with you, I agree, now what do we do? I want to help.

The Administration on Aging needs to know what piece of the work is ours. What should I fund and support so I can do that well?

When I look at any topic, because I am the Assistant Secretary for Aging, not the Assistant Secretary for Caregiving - I have a broad perspective. And what I need to do for you, for myself, is to frame this in a larger context. I will talk specifically about caregiving, but I don't want to start there. I want to talk to you about where I think we are in history - the forces that are in play and why I think we have a unique opportunity right now, especially with the Affordable Care Act, to get the nation's attention in a way that we have not been able to before.

There were four distinct social movements for the last 45 or 50 years that have all been pointing us in the direction of community living. And those are all converging. In the field of aging we have needed to move from institutionalizing people in skilled nursing homes, to providing services in the community. The work for people with physical disabilities has also been much the same; independence at home, the community living and independent living center movement, as well as the long history of people with developmental disabilities, their families and their advocates. The history of treatment of people with developmental disabilities in this country is appalling. And this has taken centuries to move forward so that we have a humane and civil approach to people with developmental disabilities.

We passed Medicare in 1965, providing health systems and health support for seniors in this country. We also passed Medicaid, a system to provide support for the poor, which of course has become the primary source of funding for long-term care in the country. We also passed the Older Americans Act. It is important to know that President Johnson signed into law all three of those at the same time. And they were meant to complement each other, to be the full array of services for seniors.
The Older Americans Act, not being an entitlement, was designed differently than Medicare and Medicaid; it was designed to meet the unique needs of the person who needs the services. But what we didn't figure out in 1965 is the relativity of the investment that we make in an individual. How much should go to Medicare and how much should go to social support? What is the right blend in the relationship between these two systems? I think the Affordable Care Act now gives us some opportunities.

In 1970, the Developmental Disabilities Services and Facilities Construction Amendments were passed - they mandated states to develop DD programs and pay more attention to the needs of individuals with DD and their families. And they required the establishment of Developmental Disability Councils in each state.

The Area Agencies on Aging were not created when the Older Americans act was passed in 1965; they were amended in 1973 and added to the law. So the structure with the Older Americans Act of focusing specifically on the community really started to take shape in the '70s; we got the congregate meal program, the home delivered meal program as well as the Ombudsman Program. Now think about where we were in the late '70s - the institutional bias of Medicaid was in place from the very beginning. It wasn't until 1981 that CMS was put in place -- they would have been called HCFA at this time, the Medicaid waivers. So there was no possibility of this conversation about long-term care balancing or rebalancing prior to 1981. The only option for Medicaid coverage if you were impoverished and needed long-term care, was nursing home placement.

So in 1981 CMS moved forward with support for the Medicaid waivers to cover the physically disabled, developmentally disabled and senior populations. So all of this conversation we have, which is now 20-30 years old, has been about how do we shift from where we started and now support community living. And for those of us in the aging network, the Medicaid waiver system has become one of the largest funders of our programs, because we are so integral on the ground of providing these particular services.

In 1990, the Americans with Disabilities Act was passed. The goal of the ADA was to provide further community integration for individuals with disabilities in a combination of public housing and employment. We need to make sure people with DD have access to these resources so they can live independently in the community. And of course, it was the ADA that became the foundation for the Olmstead decision, which was decided in 1999.

This is the first time I have ever come to Georgia to talk about Olmstead. And because I have very capable staff, I read the press reports from Tuesday, with the settlement of what it's taken, 11 years later, to really be able to move forward in this state to implement Olmstead to the degree that you, as advocates, have been wanting. Around the rest of the country, other states have moved more quickly. And certainly other states have a desire and the direction from the Supreme Court that we focus on state resources so that people who can live in the community are provided state support to do so. Now, I'm a lawyer. I've read the case. I understand the caveats, with regard to budget. But the goal was clear from the Supreme Court, based on the ADA, people have a right to live in the community in the least restrictive setting. So Olmstead was critical in 1999. And Olmstead dealt primarily with people with developmental disabilities, but it impacts all populations. It will impact a senior as well as someone with physical disabilities. It is a comprehensive interpretation of the ADA.
A year later, in 2000, the Older Americans Act was amended with the National Family Caregiver Support Program. We have planned a party next month in Washington to celebrate the 10-year anniversary during National Family Caregiver month. And we will recognize my predecessor, Former Assistant Secretary Jeanette Takamura. It was really her mission to get implementation and support for the National Family Caregiver Support Program. The goal of this program is to provide information and assistance, counseling, support groups, in-home respite and other services.

In 2005 the Deficit Reduction Act was passed, which gave federal support for Money Follows the Person. Increased federal matching rates for states to work in their institutional settings, whether they are seniors or DD or VD, to look for individuals who wanted to return home, who could return home successfully with supports and creates a financial incentive for states to do this work, to help people return to the community. The support for Money Follows the Person has been reconfirmed in the recent passage this year of the Affordable Care Act.

I believe the Affordable Care Act, if you look at it, really codifies the history I have been talking about. For support for the Aging & Disability Resource Centers, $50 million will be received over the next five years, specifically for the Administration on Aging to send out to the network for increased support; something as basic as information and referral and integration of community services between systems.

There is additional money for Medicare beneficiaries and Medicare outreach. There is expanded funding for Money Follows the Person. And there are entire conversations about care transitions – this doesn’t say caregiver in the title, but that's you. Care transitions are something we need to focus on. There is a huge new investment in innovation at CMS, with who we have wonderful partnerships, looking for innovations and opportunities. And also the Class Act was passed – I believe that this Act represents for us a unique and historic opportunity to find a different way to fund long-term care. The goal is for people to voluntarily put aside their own money, so that they can get cash assistance to remain independent at home.

The Older Americans Act programs have never significantly changed in terms of funding, and because of differences in federal budgets, this is not an entitlement program. The Older Americans Act is funded as a discretionary budget item. What I think we will need is the ability to go back and innovate and look for more holistic approaches to care and that those are the opportunities that health reform will provide us. I need to know the social supports. I need to talk to my patient. And they have got a caregiver. And I think we can use the leadership of the geriatricians and the people who have done this more holistically to look at where we need to go to knit these systems together. Chime in for caregivers! Don’t assume they are included in the language; they are usually not thought of but need to be.

I need to shift now and talk specifically about AoA; I want to be responsive to your report. You state emphatically that the AoA and the aging network should integrate evidence-based programs into our core work and make them widely available. I agree with you! The dilemma is how to get there. This is a law that's 45 year old. How do we make this transformation so that we can do sustainable systems change? I think it takes vision, but I also think it will take some time and it will take a variety of approaches. So let me start off by talking about the budget. I think that the purpose of grants is to build a base; we have discretionary grant programs at AoA. I think that we should try things and test them, and when they work, we should incorporate them into the core services that we provide. And free up that money
and find new things to innovate. It must be a cycle. Unfortunately, this process does not
guarantee that you will ever have any additional resources. But certainly, we can take the
evidence-based programs that we have and move them into the core. We want to make them
widely available, as well.

I think we have an opportunity to begin down this path with the 2011 reauthorization of
the Older Americans Act. I have done extensive public listening on the reauthorization and it
covers the gambit. But with regard to this topic and specifics, I would like to talk to you about
Title IIID - where we spend money on health and disease prevention activities. It’s my vision,
with support, that we could start taking the demonstration work we have been doing and
embed this in the law by saying that states and AAA’s cannot receive any Title IIID money,
unless they implement evidence-based practices.

Regardless of who is in office, this is your work. If you want to start down this path and
do what you are saying in the report, this is the first opportunity, because this is where we have
the most experience. This is not long standing for us, evidence-based. But with regard to Title
IIID, we have the most expertise and support to say let’s embed this. And we could put this
into law. So have you to pay attention to reauthorization.

Often the caregiver issues are not going to be named that, but there will be structural
markers in place to help you move along the way. I think that will be critically important. But I
don’t think we are quite ready to do this with the National Family Caregiver Support Program.
I think we should start with Title IIID - health prevention, because we have more expertise in
this and more support for this.

The reauthorization comes up every 5 years. I would be sincerely interested in working
with you to look at what it would take to come up with a 5-year plan, if we wanted to figure out
a way to require that AoA only fund evidence-based programs in the National Family
Caregiver Support Program. We need a strategy to get there. If we want to be successful in
amending the Older Americans Act to say fund only evidence-based programs with Title IIID,
we must support the network with technical assistance on how to get there. The first type of
guidance we must give are on regulations. If we want a national network to rise to equal level
and standard so that we have more uniformity and consistency among any of our programs, we
must have comprehensive regulations for the Older Americans Act.

Any regulations are fraught with controversy. But I think on the heels of
reauthorization, we must look at regulations. And it would be critical that you participate in
this. If you ever want to go down this same path, it must be important that we look at what
regulatory guidance we need to give on a program the size of $21 million before we ever tackle
the Family Caregiver Support Program, which is much, much bigger. There are people who are
eager to learn more and this is certainly an opportunity for us.

If we are going to do this with the National Family Caregiver Program, we need much
more information about displacement - what happens to the programs that we’re already
funding? What are we funding now that is not evidence-based? What are we funding that
would be displaced? And are we being comprehensive? Maybe what we need is a split – not
everything we do has to be evidence-based, such as for something as basic as a phone call and
where to call. So this is complicated. But I am willing to be involved in this work with you,
because what you are talking about comes back to my philosophy of budget, which is how you
demonstrate and innovate and incorporate it. But it doesn't become the whole. It becomes a significant piece. And I'm willing to work with you on that.

One of the other things that you point out in your report is the critical relationship between the AoA, CMS and the National Institutes of Health, specifically the National Institute on Aging. We are participating in an advisory counsel at the NIA - we talked a lot about elder abuse. We also talked about this dynamic that I have a laboratory that they can use, that there are things that their bench researchers can try that I would like to fund. And so in this nice world that we would all like to create where we innovate and we incorporate into the core and then we get a little more money for innovation, NIA should be the pipeline. We should go to them and say what do you have for stroke victims or stroke survivors that we can use in our network; or we should say to them we don't have anything for traumatic brain injury for seniors. Can you research something for us? It needs to be a fluid conversation and I'm aware of that and so are they. But these are not necessarily new relationships, but they are certainly revamped.

We made a terrible mistake when we divided the world into the medical model and the social model because we assumed that the only people who needed to do research were the medical people. So now we have to catch up - we need research on fundamentals and science for social services, as well. And in this way, I think we have a great opportunity to work more closely with the NIA.

There is a quote from the NCQI summary that says that NIH, AoA and CMS have no collaborative planning process to develop and disseminate caregiver interventions. That's a little hard to hear, but we are working on that. But there are some facts that you need to understand to have success. NIH has around 18,000 employees; CMS has 4,500; and AoA has 109. So there are differences, because of the nature of the programs. You need to know and certainly understand that our ability to act depends on resources, and I have no shortage of people who come to AoA looking for help, for resources. But AoA doesn't belong to this administration. It belongs to the country. And we need to decide, as a country, what the role is.

I have great support with this administration, but we also didn't create AoA, we inherited it. What are the ways structurally to provide a solid base so we can grow? Many of the states are reorganizing so that aging and disability programs are combined. I am certainly open to and have been discussing at the federal level whether that would be wise. If we would have more strength in a collective voice, the common denominator is independent living and the ability just to provide community supports. I think that disability advocates need to be with us.

Caregiving issues, as you know, are lifespan issues - they are not just for seniors. The end of the last administration, AoA developed wonderful partnerships with the VA. The VA has a strong system of health care, focused on medical centers and nursing homes and the veterans, the younger veterans, in particular, coming back from the two wars want to stay at home and be independent. We have a national network of expertise on community resources. So AoA was able to broker an arrangement that doesn't benefit us, it benefits the network and the VA, which says, we have experts you should talk to. So now the VA contracts directly with AAAs as a provider network to provide assessment. And the VA being the progressive entity that it is, sees that if we are going to provide comprehensive home and community-based services, we must deal with caregivers.
We have another opportunity with the Elder Justice Act, which was passed as a part of health reform. I was most encouraged and enlightened that you called out in your report, specifically, the issue of elder abuse. And if we are going to competently serve both, the people receiving services and the caregiver, we need to address the issue of elder abuse. But although the Elder Justice Act was passed with appropriation authority, you need to know that there is no money appropriated for it. There are tremendous gaps in data with regard to Adult Protective Services and even though we talk a lot about APS and seniors, it covers the lifespan as well. So there are some great opportunities here, but it must be funded quickly.

I would encourage you to pay attention to the reauthorization of the Older American’s Act next year, not just the piece about Title IIID, because due to the economic downturn, many states are cutting their supplemental services for all of our programs. We have seniors in need and at risk for poverty and nursing home placement more than ever before. Supporting us in the reauthorization is a way to make sure this the law is written in a way that we need, that it is progressive in the way that we will need it to be in the next few years.

I think we do have the opportunity to work with volunteer organizations, faith organizations, and the philanthropic community. These funders are also interested in evidence-based practice and good outcomes - they want to spend their money as wisely as we do with tax payer money.

Another opportunity that we have coming up, specifically, is a budget recommendation sitting in front of Congress right now. As a result of the Vice President’s Middle Class Task Force, the President announced a Caregiver Initiative that would increase the Older Americans Act budget by $102.5 million; the largest recommended increase for AoA programs in over a decade. We were excited to get this recommendation, now we need your help to make sure we get the funding. It will help us so much, because the need is so great.

The other thing that you wanted me to address briefly this morning was leadership. I think leadership requires advocacy at every level. And one of the best things about the Older Americans Act is that a requirement that all of us advocate is written into the law. We have to spot issues. You have to look at the Affordable Care Act and see where caregivers fit in; you have to build a case. You have to have the evidence to do it whether we are talking about these programs or just a budget request. You have to understand the complexities because this is tricky and it's federal. The implications are national, but every state is different. You have to be committed to systems change, which takes years. It's about laying a foundation 2 and 3 years down the road or telling you, here, I already have a short list for the next reauthorization. We haven't done this one yet. It's about having a vision. I am so pleased to be a part of the administration and to work with Secretary Sebelius. I have seen her talking to people and having a genuine interest in health policy in this country and what we can do to promote health and long-term care. She certainly will be there as we call upon her for her leadership, but we must support her as well.

I started out talking about the caregivers that I have talked to. And I want to return to Chicago. We went around the table. There was a man who sitting there and we were talking about caregiving. He said of his partner of 25 years, “he is my sweetie, not my patient”. Oh, that was one of those moments. It's like, yes. I get it. I really seriously value caregiving. I do. I am also eager to learn as much as I can about serving the care recipient. We live in a society that's ageist, where seniors become invisible, as do people with disabilities. So we need to
support those interventions and programs that ensure that the care recipient doesn't get lost. We can’t design programs for caregivers without care recipients. I am charged with the responsibility of covering both. I am quite committed to this, to both ends. This man in Chicago is a loving partner. The people who are engaged in caregiving are loved ones and friends. How do we best embed science in a relationship that's built on love? And how do our loved ones remain our loved ones and not patients? After all they are the sweeties in our lives! Thank you, all.

NATIONAL PERSPECTIVES ON TARGETED INVESTMENTS FOR CAREGIVER SUPPORTS
(Summary)
Heather Mahoney-Gleason, LCSW, Caregiver Support Program Manager, VA

I would like to thank Mrs. Carter and everyone at the Rosalynn Carter Institute for inviting me here today to speak with you about some very exciting initiatives around caregiving going on at the VA. Like other health care systems across the country, VA has moved to a more managed care approach where a lot of services are being provided on an out-patient basis versus an in-patient basis. So, we really come to rely on family caregivers, neighbors, friends to support people at home for a variety of things. VA has tried to incorporate the family caregivers and their health care system since it started. We are a really unique system of care because when a veteran comes in for primary care, they are not just coming in to see their doctor, there is a whole inter-disciplinary team assigned to the treatment of that veteran. We have nurses, social workers, dietitians, physical therapists, and pharmacists, right there in the primary care clinic. We provide skilled home care, home based primary care, Veteran directed home and community based care, and respite care.

VA has a comprehensive Prosthetics Department for providing equipment at home. We have programs to modify homes and vehicles. We provide transportation to the veterans to and from appointments. We allow their attendants to come with them if they need the assistance of an attendant. Through our Veterans Benefits Administration we also have a program called Aid & Attendance, which provides additional financial benefits to veterans to help them get additional care at home. We have been providing caregiver education and training, rolling out family psycho-educational programs. We have brochures on different caregiving topics, and do family support groups and family counseling. Through the Fisher Foundation, we have 13 Fisher Houses located on VA properties where families can stay in a home setting while they are visiting their veteran in the hospital.

We developed caregiver assistance pilot programs that were conducted from 2006 to 2009. VA allocated $5 million and we selected 8 pilot programs covering over 39 VA medical centers to provide services to veterans and caregivers. We served over 1400 veterans and caregivers during this time. We have learned that supportive services provided to the caregiver really does improve the quality of life for both the caregiver and the veteran. We found that there was a reduction of health care utilization by supporting the caregivers. They are better educated to handle difficult behaviors. They are better educated on what the needs of the veteran are. And by empowering them with this education and knowledge and supporting themselves as well, the ER visits decreased. In-patient stays decreased. And in one program
the pharmacy orders for particular veterans decreased. We learned that multi-component approaches work best. We need to have a variety of different programs available that they can continue to go to and interact in. Focused intervention and technology-based interventions worked well.

So I just wanted to highlight a couple of the pilot programs that we have moved forward with. In 2008, the VA won the Rosalynn Carter Leadership in Caregiving Award for the REACH VA program. We have now partnered with RCI to roll this program out through the Area Agencies on Aging in Georgia. Originally developed for Alzheimer’s caregivers, we are now modifying the program for use with other populations, such as spinal cord injury and traumatic brain injury.

We also have the Transition Assistance Program. This intervention targets stroke caregivers from the point of diagnosis to preparing to take their loved one home. We are also rolling out Powerful Tools for Caregivers in 2 states. Working with Stanford and Kate Lorig, we also completed a pilot Self-Management Course for Caregivers.

All our VA medical centers now have a caregiver support point of contact. And in the VA world, this is kind of like your first start to getting movement to an initiative. They are responsible for making sure that the caregiver is integrated into all program areas. They serve as resource experts for all of our clinical teams at the medical center. And they organize focused activities such as those for national family caregiver month that's coming up.

I'm very excited to share with you about the recently enacted Caregivers and Veterans Omnibus Health Services Act of 2010. This law is really ground-breaking legislation. A significant part of the law is going to serve our Iraq and Afghanistan veterans. Veterans will designate their primary family caregiver, who will get instruction on training and caring for their disabled loved one. They will get travel, lodging, and per diem when they attend training. We are also going to provide additional respite care while the caregiver is going to training. The most exciting part of this legislation is that the designated family caregiver will be paid a monthly stipend and be provided health care coverage if they currently lack coverage.

Another component will serve caregivers and veterans of all eras. VA now has authority to provide in-person education, a comprehensive interactive website for caregivers, tele-health training, focused teaching and training on skills for disabled veterans, counseling services, respite care, and information on available VA and community resources. Although we already teach caregivers how to care for veterans when they come home, we know we can do a better job.

We want a caregiver support program that focuses on both veteran and caregiver well-being. We know that there needs to be a clear assessment of eligibility that's clinically based, that we need to have national criteria for eligibility, based on veteran's deficits and functional capacities and needs for assistance. We need to have standardized caregiver curriculum and core training. Consistent monitoring will ensure that caregivers are receiving psychological protection in their role.
THE IMPORTANCE OF MONITORING CAREGIVER HEALTH
(Summary)
Elena Andresen, PhD, University of Florida

This important recommendation speaks to the public health importance of caregiving in America. In order to have an impact on policy and programs that can help caregivers and their families, we need to be able to answer questions about the population of caregivers and describe their special health problems. In 2003, the CDC sponsored a call for proposals asking for research that was about the public health of caregiving. As a public health scientist, the first thing that I did was look for where the data and information would come from to foster public health attention to caregiving. There were no regularly occurring data that could be used in our traditional public health methods that would support “data driven” public health. That was really the impetus for creating a method to measure the impact of caregiving that can be used to support this RCI recommendation.

First, let’s review how public health is organized, so that the context is clear for how we can acquire data on caregivers and caregiving. Public health operates at local (e.g., county), state, and national levels. For many public health policies and programs, but especially for collecting data, the state level is the most important. At the same time, much funding comes from the national level, so that if data are available for all states, the importance of any particular public health issues can also be raised to federal funding agencies. At all these levels, information (data) is a key element in promoting policies and programs, and for evaluation. States generally have the primary operations of surveillance and data collection in their health departments.

In public health, what we mean by surveillance is “regular ongoing data collection about health or health related issues.” The periodic assessment that RCI asks for in this recommendation asks for collecting caregiving data every two years at the state level and this would fall into the definition of a surveillance activity. Fortunately for us, for issues of disability, aging, and caregiving, there is a public health service plan for health in the United States, called the Healthy People agenda. Healthy People 2020 proposed national objectives that have to do with caregivers. In order to do so, we will need regularly occurring data. The caregiving surveillance data that we have been talking about come from the Behavioral Risk Factor Surveillance System (BRFSS). This is a surveillance system that is used in the entire United States, in our territories, and in Washington, DC. The BRFSS is a telephone survey of randomly selected community living adults that represent each state. It includes broad health topics, like health behaviors and health care access. It is done on an annual basis in all of these jurisdictions. The main issue to take away is that if we identify caregivers in a regularly occurring question on the BRFSS, then we could track caregiver health. And we could compare them to others; compare their health and their outcomes and their behaviors and their income and their education and some things on social opportunities, based on caregiving status.

We now have a 10-question module on caregiving that’s available to the BRFSS that can be used as a whole, or with a selection of questions that focus on identifying caregivers. It has gone through several iterations and is now acceptable to the BRFSS, and a number of states have used the module, and have state-based reports about caregivers and their health (see reports on the website [http://fodh.phhp.ufl.edu/](http://fodh.phhp.ufl.edu/)).
Excitingly, in 2009 there was one question asked universally in all states that identified caregivers on the BRFSS. The second message for today is that you can go back to your states and advocate for a caregiving report in your state: every single state, territory and Washington, DC used the question: “people may provide regular care or assistance to a friend or family member who has a health problem, long term illness or disability; during the past month, did you provide any such care or assistance to a friend or family member?” As an example of monitoring caregiver health, there is a question on the BRFSS asked every year of everyone who answers these questions about days in the last 30 where your mental health was not good; so you could monitor differences in caregiver mental health compared to people who were not caregivers.

So, how do you get this full caregiving module into your state BRFSS? The person that you need to get to know is your Behavioral Risk Factor Surveillance System coordinator; they are very responsive to the interests and needs of their state. You may need to develop a coalition of interested agencies and groups to advocate for (and fund) the addition of the caregiver questions to the state BRFSS. You can locate your state BRFSS coordinator at this website (http://apps.nccd.cdc.gov/BRFSSCoordinators/coordinator.asp). States charged between about $2,000 and $4,000 per question to add to the BRFSS. You need to contact your BRFSS coordinator by early summer to make sure that you have space for questions on the BRFSS in an agreement for the following year. In addition, there is an annual BRFSS coordinators meeting each year, and this is an important national venue to garner the attention and support of these important state people to ask for, and garner support, for national-level changes to the BRFSS “Core” for all states. The RCI recommends a periodic use, every other year, of caregiving questions on the BRFSS to monitor caregiver health.

OUTREACH & PUBLIC EDUCATION OF CAREGIVERS: CHALLENGES & RECOMMENDATIONS
(Summary)

David M. Bass, PhD, Margaret Blenker Research Institute, Benjamin Rose Institute

Marketing is one of the most difficult challenges for large-scale, successful, and sustained implementations of evidence-based caregiver programs. This same difficulty plagues most caregiving research, which usually struggles to get the desired number of caregiving subjects. Projected numbers of enrollees are nearly always overestimates.

There are multiple causes of marketing difficulties, with no single explanation and, correspondingly, no one remedy. Marketing difficulties are caused by: characteristics of the evidence-based program itself; characteristics of caregivers and care receivers who are the consumers; characteristics of the organization delivering the program; and characteristics of the community where the program is being implemented.

Our implementation research at the Margaret Blenker Research Institute of the Benjamin Rose Institute on Aging is studying the myriad of factors that impact marketing, with the goal of developing a conceptual framework for successful and sustainable implementation (Bass and Judge, 2010). Much of this research is based on experiences implementing an evidence-based program called “BRI Care Consultation.”
This presentation focuses on one category of factors that impact the success of a marketing plan; characteristics of consumers. The presentation is based on a well-established body of research on why people do and do not use services. This body of research can be used to design marketing plans that maximize the likelihood of successful and sustained implementation.

**Existing Conceptual Models**

Several existing conceptual models can be helpful guides for devising a marketing plan, including the behavioral health model (Andersen, 1995), the health-belief model (Becker, 1974), and the trans-theoretical model (Prochaska and DiClemente, 1984). Our approaches to marketing evidence-based programs most often use the behavioral health model because it includes a diverse and comprehensive range of consumer characteristics. Additionally, this model incorporates characteristics of both caregivers and care receivers, highlighting that caregivers are more likely to accept and use evidence-based programs (hereafter referred to as caregiver services), when there is simultaneous attention to the needs of care receivers (Bass and Noelker, 1987). The behavioral health model also suggests the use of different types of services may be explained by different consumer characteristics. For example, characteristics that determine the use of support groups may differ from characteristics that determine use of a telephone coaching service.

The behavioral health model posits three categories of consumer characteristics as influencing caregiver service use: presupposing, enabling, and need. Presupposing characteristics are: health-related attitudes, past service use experiences; and socio-demographics. Enabling characteristics are economic resources, informal and formal support, and informational resources. Need characteristics for care receivers are health problems, impairments, and general well-being. Need characteristics for caregivers are care-related strains and general well-being.

These three categories of characteristics impact caregivers’ decisions about whether to use services. Correspondingly, they can guide the content of marketing approaches for caregiver services. Marketing strategies should incorporate strategies for overcoming the characteristics that are barriers to service use (e.g., negative predisposing attitudes about services); capitalize on characteristics that facilitate service use (e.g., enabling resources to encourage service use); and identify the characteristics of persons targeted by services (e.g., certain types and levels of need).

**Predisposing Characteristics**

Examples of predisposing attitudes that are barriers to caregiver service use include: a belief that family members should be the sole care providers; lack of trust of service providers who come to the home; services are poor in quality; services used in the past did not help; services are too costly and inconvenient. While these examples are negative, positive attitudes and positive past service experiences can be facilitators of service use.

There are many socio-demographic predisposing factors; four are especially relevant to marketing: 1) race/ethnicity; 2) caregiver gender; 3) whether caregivers and care receivers reside
in the same or separate households; and 4) whether caregivers are care receivers’ spouse. Minority caregivers and care receivers, male caregivers, caregivers residing in separate households from care receivers, and spouse caregivers are less likely to use caregiver services due to cultural beliefs, values and preferences, perceptions of filial obligation, and the extent of caregiving tasks. Three other important predisposing characteristics are macro-level factors reflecting the context where caregivers reside: number of caregivers with the characteristics targeted by a service; number of competing caregiver services; and whether there is a third-party payment source.

**Enabling Characteristics**

Having knowledge of available caregiver services is essential for service use. Providers of other services and members of the informal network of family and friends can increase caregivers’ knowledge of services, and the likelihood that services are used. These formal and informal supports also can legitimate and encourage caregivers to use services. For example, physicians, clergy, nurses, or social workers are important resources for informing caregivers about services and educating caregivers about the potential benefits. Marketing strategies should consider partnering with formal providers in order to inform caregivers about services. It also may be effective for marketing activities to be directed to family members and friends of caregivers, knowing these individuals influence caregiver behaviors.

Another important enabling characteristic is financial resources of caregivers. Caregivers with more financial resources are more likely to use services, particularly when third-party reimbursement is not available.

**Need Characteristics**

Need characteristics include a diverse set of characteristics including both objective measures and subjective perceptions of symptoms and health conditions; care-related strains; and deterioration in general well-being. The 20 to 30% of caregivers who report high care-related strain, or symptoms of depression or anxiety that place them at clinical risk, are primary targets for marketing caregiver services. Caregivers assisting more impaired care receivers also are primary targets, particularly those caring for persons with memory and behavioral symptoms of dementia, and/or dependencies in personal care tasks. Examples of other relevant need characteristics are multiple caretaking responsibilities (e.g., care for children and parents); experiencing multiple major life events; being worried about or believing symptoms or strain are getting worse, and multiple serious chronic conditions.

**Conclusion**

The Behavioral Health Model outlines the wide range of consumer characteristics that influence service use decisions by caregivers. Marketing strategies for caregiver evidence-based programs can increase the likelihood of success by building on existing research on the impact of predisposing, enabling, and need characteristics.
REACHING CAREGIVERS WHERE THEY ARE
(Summary)
Alan B. Stevens, PhD, Scott & White Healthcare

Reaching Caregivers: A Framework for Reaching Caregiver with Evidence-based Interventions in the Community

The existing infrastructure for reaching caregivers includes various organizations, agencies, groups and healthcare providers. On a federal level, such as the Administration of Aging (AoA), and state level, such as the Alzheimer’s Association Leadership of State Government Alzheimer’s Disease Plans, several initiatives have been implemented to improve the well-being of caregivers. For example, more than 25 states currently are involved in developing their own state government Alzheimer’s disease plans.

Another group aimed at reaching caregivers includes advocacy groups. Organizations such as the Alzheimer’s Foundation of America, including national and local chapters, the Family Caregiver Alliance, the National Alliance for Caregiving, are just a few of these examples. In addition to these organizations whose primary purpose is to help caregivers, other organizations find themselves helping caregivers to better achieve another mission primarily non-related to caregiving. For example, various social and faith-based groups assist caregivers where they are at as part of their overall vision of their specific groups. These groups find themselves serving caregivers through their respective missions of helping people in general.

Reaching Caregivers: An Example of a Healthcare System Approach

Healthcare and service providers are another example that serves family caregivers through their own missions of providing healthcare and supportive services to their patients. An example of this type of program includes the Scott & White Family Caregiver Program, begun in 2007 with a grant from the Rosalynn Carter Institute for Caregiving and Johnson & Johnson. The Scott & White Family Caregiver Program (FCP) is based on the Resources for Enhancing Alzheimer’s Caregiver Health II (REACH II) intervention, which is one of the leading evidence-based approaches to support family caregivers of persons with Alzheimer’s or dementia disease. Implementation research methods were utilized to embed the evidence-based intervention for family caregivers.

The FCP provides the unique service of embedding caregiver supports within an integrated healthcare delivery system. Integration of the FCP into existing structures and systems within Scott and White was critical to the successful adoption and implementation of the program as it allowed program staff to screen a large number of potentially eligible Alzheimer’s or dementia patients admitted into Scott and White. Created in collaboration with technology specialists from the Scott and White Seimens Information Technology team and the nursing staff, two key questions were embedded into the hospital admissions electronic medical record (EMR) infrastructure across the entire hospital. Leveraging the characteristics of an integrated healthcare system enabled the FCP staff to target, identify, and enroll family caregivers in needs of support. Critical to the organization buy-in from the leadership and
management was ensuring that our program was designed to align with the existing mission and vision of Scott and White. Recognizing that the program could add value to the system, particularly to the caregivers and thus affecting their respective care recipients (ie. the patient), in a unique, needed, and compensatory way, allowed our program to be implemented in a non-competitive, complementary manner.

Major accomplishments of the FCP to date include the translation of the REACH II Intervention materials into a user-friendly format (e.g., A Caregiver's Notebook). The “Caregiver Notebook”, created in collaboration with the Scott and White Development Marketing and Strategy team, contains the customized plan of care for each enrolled caregiver. The “Caregiver Notebook” serves not only as a vital resource to our individual caregivers but also as a branding tool on an organizational level, supporting the mission and vision of Scott and White. A second major accomplishment was identifying champions within the healthcare system and throughout the community to foster identification of family caregivers. Learning the important characteristics of the care delivery system required identifying persons across all levels of the healthcare system and support staff who could provide vital information and feedback pertaining to embedding, implementing, and sustaining the program. Likewise, members of the Central Texas Aging and Disability Resource Center (ADRC), the community partner for the FCP, were needed to design the most efficient and effective method for community referrals to our caregivers. Lastly, the third major accomplishment of the FCP to date is implementing the program in a systematic manner through the main hospital system and group practice primary care clinic. This systematic dissemination allowed adequate nursing staff training on each floor and provided each floor the ability to customize the location of the Caregiver Packets. Similar to the hospital, strategic dissemination of the FCP throughout the main Scott & White primary care clinic, the Center for Diagnostic Medicine (CDM), occurred in phases.

In FY2011, Scott & White Healthcare invested $150,000 in the FCP. The program will be expanded into two new service regions, including two additional hospitals and multiple primary care clinics. The FCP staff expects to enroll an additional 485 family caregivers throughout the two new service areas. Additional outcome measures, including the REACH II Quality of Life outcome, healthcare utilization outcomes, and impact on primary care provider outcomes, will be used in the expanded program.

**Reaching Caregivers: An Example of an Integrative Model Approach**

Integrative models which align service approaches to address needs and serve the mission of multiple stakeholders exist to reach family caregivers in the community. The Central Texas Community Living Program serves as an example of such a model.

The goal of the Central Texas Community Living Program (CLP) is to establish a nursing facility diversion program for individuals at imminent risk for nursing home placement and Medicaid spend-down using more flexible administrative processes and funding mechanisms. The CLP is a partnership among the Texas Dept. of Aging and Disability Services
(DADS), Central Texas Area Agency on Aging, Scott & White Healthcare, and Central Texas VA. A risk assessment is used to enhance Person/Family Centered Planning.

Eligibility criterion includes persons age 60 or over, residents of Bell, Coryell, Hamilton, Lampasas or Milam County, and those not eligible for Medicaid or not currently enrolled in Medicaid. Furthermore, persons who need help completing at least 2 ADL’s, has memory problems that make it difficult to live alone, has a family caregiver that provides assistance with routine care needs, and meets certain income and assets limits are targeted for enrollment. Once enrolled, persons receive Transitional coaching from hospital to the home, support and skills training for the family caregivers via the REACH II intervention, and direct access to community-based services available through the AAA and other partner agencies of the Central Texas Aging and Disability Resource Center (ADRC).

National evaluation strategies were implemented that used standard cross-site assessment items. A full logic model, assessing implementation methods and outcomes (short and long-term), was measured based upon the RE-AIM Framework. The RE-AIM framework is designed to guide evaluation of health promotion interventions to be translated into public use and to impact public health and has recently applied in the translation of community-based caregiver interventions.

To date, 156 persons were assessed for CLP, with 104 completing the full 10-month intervention. Preliminary data analysis indicates the program may positively impact caregiver well-being. Furthermore, families are satisfied with the services received and are requesting these services. Lastly, most consumers remain in the community for 10 months.

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**EVIDENCE-BASED PROFESSIONAL ASSESSMENT OF CAREGIVERS**

*(Summary)*

Rhonda J. V. Montgomery, PhD, Helen Bader School of Social Welfare

This presentation focuses on the importance of and value of conducting caregiver assessment and draws on our experience with the Tailored Caregiver Assessment and Referral Protocol to illustrate the way in which caregiver assessment can serve as the engine for changing the way in which we support caregivers.

First I identify several reasons for supporting families and focus on the importance of caregiver assessment as a cornerstone for effectively and efficiently supporting caregivers. I will illustrate the benefits of caregiver assessment by sharing findings from our studies of the Tailored Caregiver Assessment and Referral Process (TCARE®) which is a care management protocol designed to support family caregivers. Finally, I will use the TCARE® experience to illustrate the way in which caregiver assessment can be an engine for change because it has the capability to alter current practice and programs to more effectively support family caregivers.

**The Importance of Caregiver Assessment**

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It is important to support family caregivers because they are the lynch pin in the long term care system. For large numbers of older adults, it is assistance provided by family members that enables them to continue to live in the community. Family members provide and foster quality care, which can help prevent premature placement of older adults in institutional settings. Through their efforts, family members who act as caregivers also reduce costs of health care. Their presence is associated with shorter hospital stays and fewer readmissions. It has been estimated that the value of the direct care they provide is more than $375 billion dollars.

There is great diversity among caregivers as to how they came into the role, how they perform their care activities, and how they experience their role. An assessment process is essential if we are to fully support family caregivers. The vast variation in the way in which caregivers experience the role translates into variation in the types and levels of need that they have and, consequently, in the types of resources and services that will effectively meet their needs. It is also the case that the caregiving experience changes over time as do their needs for support. The variation in the caregiving experience requires systematic approach to serving family caregivers which includes an assessment of their needs. Past research has taught us that support programs are most effective for reducing burden when appropriately “timed and dosed”. We have also learned that multiple-component, comprehensive support services have had most impact. Unfortunately, in the past we have often treated the label “caregiver” as if it is a diagnosis and offered a very limited array of support services. What has been missing in most programs is an assessment process that can be used to effectively target services to the specific circumstances of the caregivers we serve.

**Characteristics of an Effective Assessment Process**

An ideal assessment process would use a valid and reliable assessment tool and a structured process that would foster client choice and provide guidance for understanding caregiver’s needs and strengths to help select and recommend services. A good assessment process parallels the process that a tailor would follow to construct a well-fitting garment. This would include taking measurements, inquiring about preferences of style and materials, constructing a pattern or a preliminary plan, consulting with the client to gain approval, firming up the plan (e.g. sewing the garment) and then adjusting the fit. Our goal was to provide caregivers with relevant options, i.e., services that are available, consistent with their preferences, and for which they are eligible.

With this goal in mind, our research team worked in collaboration to create an assessment process would be easy to implement and understandable, transparent and instructive to both the caregiver and the care manager or the assessor.

**Lessons from TCARE®**

**The Development of TCARE®**

TCARE®, which stands for Tailored Caregiver Assessment and Referral, is a systematic triaging process for serving caregivers. It is not a substitute for other services; it is the beginning point for directing caregivers to other evidence based interventions that will meet their needs. The development of TCARE® has been an iterative process that began with literature reviews,
focus groups and measurement development and included collaborations with local and state level provider organizations in six states. It was designed to offer structure by providing flexibility that would allow it to be used in many different types of organizations.

**Caregiver Identity Change Theory**

TCARE® is a systematic approach to serving caregivers that is an evidence-based process grounded in caregiver identity change theory. The core idea of caregiver identity change theory is that caregiving is a dynamic journey that entails three types of changes. Caregivers experience change in their tasks and responsibilities, their relationship with the care receiver, and their own sense of identity. The core idea that underlies the TCARE® process is that caregivers’ personal expectations and rules regarding their care responsibilities often lag behind and are inconsistent with the care responsibilities that they are forced to assume. This leads to identity discrepancy and is a source of stress. This idea can be illustrated by placing a rubber band around your two pointer fingers. If the finger on your right hand represents your rules or expectations and the finger on your left hand represents your actions, the tension is created when the behaviors move away from the rules. This is a major source of stress. As caregivers embark on their journey initially in a familial role, such as a wife or daughter, they interact with the person they are caring for that way. But as the care needs of the care receiver grow, they find themselves taking on all kinds of tasks, many of which they are not comfortable with. And that’s why we often see the sons leave the role early on. From a son’s perspective it is okay to help mom with her lawn. But, when mom needs a bath, that is uncomfortable. This idea of identity discrepancy as a source of distress is important because most of our resources for supporting family caregivers have historically been focused on providing respite or addressing the physical care tasks, but much of the stress that caregivers experiences stems not from the tasks, but how they feel about the tasks. This understanding of a major source of caregiver stress undergirds the TCARE® process.

**The TCARE® protocol**

TCARE® is a tool that enables care managers to obtain relevant information about the caregiving situation, interpret the information, and then triage caregivers to the specific type of service they can most benefit from at that time. TCARE® helps identify: (1) the presence of depression, (2) types and levels of stress, (3) appropriate goals for supporting caregivers, (4) strategies to meet goals, and (5) an array of services consistent with goals and strategies. It is a six step process that starts with a screening protocol to identify caregivers who could most benefit from a full assessment. A full assessment is conducted with individuals with high scores on depression or one of the burden measures. Using the information gained from the assessment and a set of decision algorithms, care managers create a care consultation worksheet that includes several service options identified as appropriate and available to the caregiver. Using this worksheet as a tool, care managers consult with the caregiver and provide detailed information about the caregivers’ scores on key measures in the assessment tool and the way in which the recommended services might benefit the caregiver. Decisions made during the consultation process are then translated into a care plan for the caregiver. A follow-up assessment is conducted every 3 to 6 months. This protocol helps care managers engage
caregivers in the care management process as well as assess caregivers’ strengths and needs. The goal of this process is not to “do for” but to “collaborate with” caregivers and teach them how to manage their own situation to the extent that they are able to do so.

Benefits of TCARE®

Over the past three years our research team has conducted two randomized controlled trials to assess the merits of TCARE®. The findings from these studies indicate that caregivers served with this protocol had higher levels of uplifts and lower levels of identity discrepancy, stress burden, relationship burden, and depression. Caregivers served with the protocol expressed less intent to place the care receiver in a long-term care setting. We believe these positive outcomes in part stem from differences in the care plans that were observed between the treatment and control groups. Our review of care plans indicated that more services and a wider variety of services were included on care plans for caregivers in the treatment group. Most notable were the inclusion of services to address physical and mental health needs of the caregivers.

Although we have not yet conducted a study to examine the impact on the TCARE® organizations, anecdotal reports suggest that its adoption can lead to significant savings for organizations. These savings stem from reduced staff time spent in crisis management, and the reduction of costs associated with inappropriate allocation of services, delays in delivery of support services, and unnecessary or premature placement. In short, we believe that TCARE® helps organizations more efficiently use their resources.

Caregiver Assessment as an Engine of Systems Change

The minute you put an assessment tool in place, it creates a systematic process to identify your caregivers. The first thing we teach organizations is to use an initial inquiry from caregivers about services for the older adult as an opportunity for early identification of family caregivers. Front door staff should ask callers are you the person that is doing the most care for them. And if the answer is yes; can we follow up by gaining permission to ask a few more questions. This process enables providers to more quickly work with caregivers who initially do not self-identify.

The assessment process leads to the creation of a care plan, informs the client, fosters the client's participation, and it values and formalizes follow-up. If you institute a process like this, you automatically are changing the philosophy to recognize that caregivers are our key partners. They are not visitors or servants in our world. They are our team members and they are our partners in decision-making, and we embrace them. We also acknowledge the diversity of caregivers and the complexity of their situations.

Changes in policy also follow when this philosophy is embraced. Policy can be established that supports the health of caregivers. The assessment process also provides data that allows examination of outcomes for clients and for organizations. This evidence can provide support for changes in the allocation of resources, staff training programs and technology. The policy changes can ultimately lead to greater efficiency and an expanded array of support services. Our experience has been that adoption of a well-designed assessment process can create change in the system, the philosophy, the policies and the resources.
TYING EVIDENCE-BASED CAREGIVER SERVICES TO RISK

(Summary)

Steven H. Zarit, PhD, Human Development and Family Studies, Penn State University

Let me begin by thanking Mrs. Carter for her long-standing leadership and commitment. I think we can see the fruition of the long and hard work that she and the Institute have made over the years. It is really remarkable. And I am so pleased to be here and be part of it. The theme of my talk is that we need to recognize what the strengths are in the available research, but also what the weaknesses are, because if we look at it that way, we can build more carefully and move forward in expanding that database, expanding what we know to improve empirically validated treatments and in the end, do a better job with helping caregivers and the people they are caring for.

Let me start with the positives - we know a lot about what works. First, you can compare interventions on different dimensions. The first dimension is psychological versus educational. Psychological interventions, where people engage actively in learning new skills, are more effective than educational approaches. In psychological interventions, people role-play, try out things, get feedback, behaviors are shaped and reinforced. Where there is an active process of change, that's more successful than simply giving people information and assuming they'll run with it. Information alone does not make a difference. People need to engage actively to make changes in behavior and beliefs.

Multi-dimensional interventions work better than uni-dimensional. The stressors that caregivers experience are multi-dimensional, stress is not a single entity. Flexible, rather than rigidly manualized studies work better. One example is family focused, where interventions go beyond the primary caregiver, bringing family members, friends, or a natural helper into treatment.

Finally, treatment has to be targeted at an appropriate dosage. I like to use the example of penicillin. If we dosed penicillin in trials at the kind of dosage we do many human services, we wouldn't have antibiotics today, because they would not have been shown to be effective. Yet we often assume that a small amount of a psychosocial intervention will be able to treat a complex caregiving situation.

There are many programs where the results are minimal or disappointing - we need to understand what some of the factors are that may have led to those findings and how we can both design programs and design the research to evaluate programs more effectively.

The starting point is to talk about goals. Surprisingly we haven't talked a lot in the field about what the goals of our intervention should be and we haven't talked to caregivers about what their goals should be. Instead, what we have done, especially in research trials, is to adopt public health outcomes as our goals - that we are going to lower depression, improve health, prevent or delay institutionalization. These are the goals that NIH and its study sections and other funders want to see addressed.

But this is a problem. A typical study is designed like this: You start by recruiting a group of caregivers, you randomly assign people into a treatment or a control condition. Then you take some outcome measure from the set of public health indicators that NIH will fund. You can see the problem - people are selected into these trials because of incumbency in the
caregiving role. The outcome then is depression.

However, caregiving is not a disease. Depression is very common among caregivers - 40 or 45 percent of caregivers may have significant elevated symptoms of depression. But that also means that in a given sample, you may have 50 percent of your sample or more who don't have the problem that you are trying to change. There are two things that are wrong with that. The first is that from a research point of view, you lose statistical power to demonstrate change. Second, there is increasing evidence from prevention studies with children and families that show when you treat people for a problem they don't have, they get worse.

Tailoring is very important. One strategy would be if you want to treat depression, you want to select caregivers with that problem into the program. You don't want to select caregivers just because they're caregivers. You want to select caregivers who are depressed and then make sure to use treatments that are specific, not just to caregiving stress, but to the problems associated with depression or whatever problem you might have focused on.

The same thing holds with health as a target of an intervention. We talked a lot yesterday in the preconference meeting and there was a lot of talk today about health outcomes. We would all love to show that an intervention has affected caregiver health. But things like depression and health have multiple determinants. Caregiving is one of them. So the notion that a caregiving intervention, even the best one that we have available, will make long term effects on depression or health may potentially be a naive assumption. We may, if we are really serious about dealing with depression, need caregiver specific interventions and something else focused on treatment of depression-related issues. If we are serious about affecting health, we need some way of identifying what kind of health problems we are really trying to change. Who is at risk of the problem we want to prevent? Who is in the population that we have, where we can show a change? Then we can use procedures that include caregiver issues, but also go beyond them to address health.

We could also look at this mismatch between our samples and the outcomes we use in another way. Those of us who have been in the field a while know that this issue of caregivers who seek treatment but do not report much distress goes back to the beginning of caregiver research. Why do caregivers seek treatment if they don't have the problems that we're measuring, like depression and burden and poor health? Why are they coming to us? We need to really ask ourselves what they are seeking. Assessment can help get us there, or at least partway.

One of the things they may be seeking is they want help before things get overwhelming. Our goal, then, isn't treating depression. It's preventing depression or burden or whatever it might be that they are seeking help for. And it means we approach our evaluation and our design of treatments differently. It means we have to get sample sizes that will allow us to test a hypothesis about prevention, rather than going in with power estimates based on changing depression or changing subjective health or changing something else in the short run. It also means that we need to rethink the goals, because some of the things that caregivers may be interested in may not be captured by the public health outcomes that have dominated the literature. We need to go back to caregivers and learn from them what they believe are really the things that are important. Caregivers may say that getting help with the very immediate practical things will make a difference. It may also be that we have not yet identified what types of interventions will, in the long run, be the most important for caregivers.
The next thing I want to talk about is addressing risk factors. We have been looking at outcomes. Now let's look at the content of interventions. Interventions are designed to produce some beneficial outcome by treating a specific risk factor. I have organized caregiver stressors into three types of risk factors: (1) care-related stressors like behavioral problems or helping the person with activities of daily living; (2) secondary stressors; the spillover of caregiving into other roles in the person's life; and (3) lack of resources.

As with outcomes, we need to begin by recognizing that people don't necessarily have the same risk factors. We need to determine which risk factors they have. As with outcomes, there are two ways we could approach this issue. One way would be to say we really do want to do something about behavior problems, so let's identify a sample that has behavior problems and we will give them an intervention.

Another thing we can do when caregivers vary in risk factors is to tailor treatments. Taking a clinical approach would be one way of tailoring treatment. An experienced clinician makes decisions about what a particular caregiver-patient dyad needs. It can be a very effective strategy when the clinician is experienced, but the drawback with clinical decision-making is that it is very hard to replicate. It's also very hard to train how to make complex decisions. A clinician with 20 or 30 years of experience makes decisions based on cues that the novice clinician doesn't see.

An approach that can incorporate setting flexible goals in a more systematic manner is called an adaptive intervention or a tailored intervention. We assess need, and then we provide treatment that addresses the specific risks or needs. We also need to evaluate if the treatment module achieved its proximal goals, what we expected it to accomplish. If we are trying to improve management of behavior, did the caregiver implement it? And does the caregiver report less stress due to behavior problems?

Again that's a research issue, but it's also the kind of thing in a service setting that can be done to evaluate how well services are delivered. One of the most important things we can all do to market programs is to demonstrate success. While a service program in the community isn't a randomized trial, it is possible to collect the kind of data that will both help you improve and refine your own delivery of services as well as help you demonstrate to the larger community that your program is effective.

What is our model? We need to be very specific about it, and make sure that change processes are embedded in all the modules that we might use in a treatment. It’s important to understand what the caregiver wants, and also to help them understand the range of issues that can be addressed in treatment.

Most programs do give information, which is very important, but it's not enough by itself. We need to follow up with more things. For dementia care, behavioral management and problem solving are particularly important. But I think you see behavior management in lots of other situations. There are a lot of problems that arise, between siblings caring for parents, between spouses helping one another that reflect a lot of old stuff in the relationships. These issues may get labeled as behavior problems or stubbornness or getting the person to do what you want them to do. There needs to be attention to how to work out these relationship issues and tensions.
We also need to deal with the emotional issues that the caregiver has; feelings of loss about the relationship, feelings of despair, feelings of anger, feelings that nothing will make a difference. All of these are important pathways to helping them choose the things that they want to do and to be more effective at them. If we don’t address these emotional levels in our treatment, we may not be able to help them make changes.

Another goal is to increase use of informal and paid services, such as case management and respite programs. Providing respite does make a difference in stress exposures. Caregivers want that. And we need to listen to them and find ways of doing it.

We also want to look at possible synergies between treatment modules. We want to consider prevention and not just treatment. We want to identify what problems caregivers want to prevent and see if we can help them.

With these research strategies, we may be able to, in time, devise more flexible and well-designed multidimensional interventions to address some of the bigger issues like health.

The fact remains that despite all the good things everyone in this room has done; most family caregivers don’t get help at all. And a particularly vulnerable group is people with no family support. So we have a lot of work to do. There is much that we can do to improve and streamline and target caregiver interventions and develop new strategies that will help deal with the real problems that caregivers are experiencing. My last point is that we also need to concentrate on the process of dissemination. I know this is something that RCI is very interested in. How do we get information about caregiver interventions more widely accepted? We don't have drug reps, but maybe we need something like that to get this information across to the masses.

OCTOBER 22, 2010

PROFESSIONAL DEVELOPMENT NEEDS & OPPORTUNITIES IN SERVING CAREGIVERS
(Summary)

Susan C. Reinhard, RN, PhD, Senior Vice President for Public Policy, AARP

My interest in caregiving has been literally for decades. The one thing I want to share with you has to do with how we can have nurses and social workers better support family caregivers. I am addressing the recommendation for professional development. You all know that family caregivers are the backbone for all long-term services and support, but there are things that professionals just take for granted. Helping with ADL’s; bathing, dressing. This is difficult for family caregivers - giving your mother a bath is a big deal. From basic things as well as more sophisticated things, like managing difficult medication schedules and using technology in the home. We’ve now asked family caregivers to do things that make nursing students tremble. But we expect this all the time – go home and do these injections or do this or do that. Even oxygen, it seems like no big deal; but the hum of the machine and how do you manage this and keep it away from flames and all of this kind of stuff, ventilator care, wound
care – it is a big deal. This is very much social work, this idea of navigating the systems of care. We know that the economic value of family caregivers exceeds everything that Medicaid is paying for. It’s a very powerful way of looking at this asset that we cannot afford to let erode. It’s not that professionals don’t want to be respectful of family caregivers, they just need to understand more about the issues families are dealing with. Eight out of ten family caregivers say they need help, and they don’t get everything they need from healthcare providers. They say that getting information from professionals is particularly difficult because there’s more than one that they’re working with, and they may get conflicting information. So we do believe that caregivers need more support starting with better communication. You all know that the law is to protect people. We have found that some professionals stand behind HIPPA and say, I can’t talk to you because of privacy laws, but that’s not true. So HIPPA information is important, as well as assessment of caregiver needs, preparation for transitions, and recognition as a team member. These are the kinds of things that health professionals need to be focusing on.

In 2008, AARP conducted a very complicated project that involved multiple funders, multiple partners, and multiple components. It was the first time AARP ever did anything around professionals. The goal was to find out what we already knew about what nurses and social workers were doing to support family caregivers. We started off identifying existing evidence and really looking at the competencies that professionals need to have. We had over 50 nurses, social workers, and family caregiver researchers involved. It was issued as a report in the American Journal of Nursing. So, in addition to disseminating this information, how do we make it happen? What do we do next?

Let me talk about the competencies because this became a focal point of our work going forward. I’m going to talk about communication. So the idea of active listening, empathy, and respect came forward as a competence. You would think that nurses and social workers have active listening, empathy, and respect. But we get pretty busy and sometimes we’re not listening too well and just feeling pretty uptight ourselves; so really getting these skills down and embracing them is vital. The translation information the system has provided to that competency is something that is not typically done. In fact, nurses we’ve talked with absolutely feel like it is not their job; that that’s someone else’s job. So this unique goal, unique strengths, the idea of developing and evaluating care plans in collaboration with family caregivers, this actually in many ways was against what some professionals feel. Bringing other people into this feels uncomfortable sometimes and maybe not right. So this is the competency that needs to be discussed, explored, and embraced. Assisting family caregivers in identifying and accessing services is a little more comfortable for social workers than it is for nurses. We need an interdisciplinary team approach.

The good news is that interdisciplinary collaboration is now the buzzword with our new healthcare reform. But it’s not easy. In fact, there are very, very few programs in the country that really get to interdisciplinary collaboration at the undergraduate and graduate level. This is easier said than done, and we have to do more.
Leadership, knowing best practices, this gets into how do you change the organizational culture? Leading an interdisciplinary team and advocating is really not part of your professional license as a nurse, but I think it’s actually part of what we should be doing. One method for developing these competencies is inclusion of case studies in all programs that include family caregivers. That makes it normative, what you’re supposed to do.

Training for doctors includes one hour on family caregiving – that’s just not going to do it. It’s got to be part of everything that you’re thinking about. In the social work field, we’ve been working with the National Social Work Leadership Institute in New York on a Train-the-Trainer Program. Teaching strategies include role playing and including family caregivers as mentors. Kathy Kelly at the Family Caregiving Alliance has been also working with our New York colleagues to bring family caregivers into the classroom and work with social workers who are getting their master’s degree as part of their clinical experience.

Some of the practices we’ve talked about, like, caregiver assessment and referral, are very tricky because people don’t like to be assessed, the word is too clinical. I wish that we could find a better word for that because it should be more like a conversation. When you say assessment to a nurse, it has a whole other meaning, it’s like checking things off and the caregiver can feel very evaluated. So assessment cannot be the end, it’s got to be more about what you do with that assessment.

I want to talk about the public awareness component of our work. We are doing that through our website, where we have a way for family caregivers to interact. We’re going to create a whole component so that nurses and social workers can interact through the AARP portal and connect them to information to help them in their practice. So the next step is bringing in new stakeholders and partners. We’ve been working with CMS particularly on reimbursement or payment policies. We are interested in Medicare B policies. We’ve been talking to some people here about that. How can we make sure that those Codes are actually used? And when you use them, that you don’t get audited, which is what has been happening. We are now looking at data from CMS to determine who are using these Codes, and how do they vary around the country.

I want to share part of what we learned from focus groups on family caregivers and professionals to see what was the perception of family caregivers’ needs and the perception of both nurses and social workers on what those needs are. The number one priority for a caregiver is information about available services, while nurses rated this as priority six. Some of the other priorities were even more skewed. Social workers were slightly better aligned with family caregivers. What we’re going to do now is have similar kinds of focus groups; perhaps different questions with diverse social workers and nurses to see if we can better understand the needs of family caregivers and different kinds of cultures around the country.

We want to take everything we’ve learned and see if we can embed it in existing networks. We’re starting with the Aging and Disability Resource Centers working with the AoA to see if that can be one of their next grant proposals. We’ve now established standards of practice for social workers, to be released next month by the National Association of Social
Workers. A lot of work has gone into this; expert panels; voting. Now, my next step is to get standards for nurses. We’re also working on assessment because it’s my belief that if the care plan that Medicaid is paying for depends on a family caregiver to be there, then there should be a responsibility to do a caregiver assessment and that it should be paid for and acted upon.

We’re currently developing a survey to look at what are the health tasks that family caregivers are doing. What are we expecting them to do? What help are they looking for? We do believe that this constant drive for family caregivers to be doing health-related tasks is very understudied.

I want to talk about NICHE, our NYU partner. It’s Nurses Improving Care for Healthsystem Elders. It’s been around for about ten years. We know that nurses in hospitals care mostly for older adults. But very few nursing students are prepared; they don’t receive much geriatric training. We are working with them to add family caregiving as a module, and that those hospitals incorporating this training can become certified as NICHE hospitals.

Our newest initiative is a State Long-Term Services Support Score Card, this is an addition to the Commonwealth Scorecard for States, which ranks states on certain characteristics of a high performing healthcare system. The most exciting thing is that there are five characteristics of a high performance system that have been identified, and support for family caregivers was number one!

All of our work is geared towards changing the organizational mind-set and culture of how professionals are working with family caregivers. We need the data, and maybe all of you could help us with this. In conclusion, I leave you with this quote from Deborah Stone: “It will take a movement to join the three quarters of the care triangle – people who need care, families to care for, and people who give care for a living.” So that’s our journey. Thank you so much.

ROLE OF A NATIONAL RESOURCE CENTER FOR EVIDENCE-BASED PROGRAMS
(Summary)

Nancy Whitelaw, PhD, Center for Healthy Aging, National Council on Aging

I currently run the National Resource Center for the National Council on Aging (NCOA). NCOA is not a federal agency; we are a national non-profit organization. We focus on having a large national impact improving the health and economic security of older people. Our core competencies focus on innovation, collaboration, and advocacy. Within NCOA resides the Center for Healthy Aging, our health division dedicated to improving health and reducing disability among older Americans.

I’m here to talk about developing a resource center. So the first question is - what is a resource center? It’s a variant on a library, but without people sitting at desks surrounded by books. The heart of both the opportunity and the challenge of a resource center is the notion of scanning and filtering and interpreting masses of information so that others can be assisted in
their work. It’s not just stored information - what people need is somebody to have filtered what’s out there and made some judgment about its quality and converted it into something that is easy for you to find and to put into practice.

You have to detail out what the resource center’s mission and scope will be. Models that fit bringing evidence-based caregiver programs into community settings should be identified. Having a model opens up people’s minds to what it is you want to say about community resources and caregiving - influencing an informed and activated caregiver and helping to get them into appropriate community supports. You need active engagement around the nature of the evidence-based programs and what their underlying and theoretical change mechanisms are and how they work; that they fully engage and support caregivers in the community; that they are built into organizational networks and collaborative systems and that every sector of the community in the nation sees itself as being able to play an important role in the effort to improve quality of life for caregivers and those they provide care for. It’s a big picture, but we don’t do everything ourselves - we try to help frame the vision so that everyone can see how they participate.

We work with the RE-AIM framework to create a conversation across all the states in the U. S., all the service providers in that state, all the academics and researchers that are involved, all the health policy people about what are the essential elements that we have to pay attention to for the effective translation of research practice and to scale this work across the nation. One of the challenges when you’re doing this and you’re working with multiple evidence-based programs in multiple organizations is they all have their own language. So, when we are doing technical assistance and providing resources, we organize all of this diversity around common themes. One of our jobs is to create a language out in the communities so we can effectively reach out to diverse populations and people at risk.

A collaborative and integrated approach across disciplines focused on evidence-based programs helps you identify key system level changes that will ensure success and help drive technical assistance, build sustainable distribution and delivery systems with these programs in convenient successful local sites, appropriate implementation, fidelity, and reaching diverse vulnerable high risk populations who can most benefit from these programs and then demonstrating the ability to replicate the results of the original studies so you can actually get a national level impact.

One of the important roles of a resource center is the mandate to help everybody see that they have something to offer. You have to decide who your users will be; the researchers or the practitioners? Each has different, distinct needs. Much of our technical assistance is hands-on; it’s hugging, it’s re-enforcing, it’s supportive, and it’s tailored. There are grantee calls, webinars, annual grantee meetings, as well as individual consultations via e-mail, phone, etc. We develop tools, resources, do training sessions, conduct site visits. People learn by doing. People in the field share in the development of the tools - after all, it’s to support them in their work.
What are the specific tools? Videos, lessons learned, an on-line learning community where we’re trying to stimulate more interaction - people in the field posing questions to one another and getting more active engagement around the work that they’re interested in and some of our more specialized tools. Our partners are helping develop national marketing tools to assist community organizations with recruitment issues. For sustainability purposes, agencies need to know how much these programs cost them, so we are developing a cost calculator to assist in this process.

I will leave you with a few key questions. As you are trying to think about shaping a national resource center for the work you want to do, first, just start out with the end in mind. What roles need to be filled? What activities and what impact are you trying to achieve? What is the national ten-year difference in something? What’s the role of a resource center in helping that difference to happen? What type of organization should house a resource center? How will you engage and coordinate all sectors so that everyone could make a contribution on making a change? What are the expectations of everybody that feels that they have a stake in this resource center? How do you try to make sure that you’re managing all of those expectations? How does the resource center relate to the specific developers and researchers who created the evidence-based interventions but are generally neither the targets of the resource center nor where the resource center is located? How does the resource center manage the debate and disagreement about what is evidence-based? This will give you a starting point.

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TECHNICAL ASSISTANCE FOR IMPLEMENTING EVIDENCE-BASED PROGRAMS
(Summary)
Kate Lorig, RN, DrPH, Stanford University

As an academic, I’ve had the great fortune in my life of having created several evidence-based programs and successfully brought them to scale in both the U.S. and overseas. The first thing you have to do in translation is to build a program that’s translatable. Is this something that can be done by large numbers of people without large amounts of training, without using huge amounts of resources? How can we do this in the most cost-effective way possible? Who’s doing it? What is the training going to cost and what is the mode of delivery? Then I have to look at the individual agencies where this program is going to be implemented. Does the agency have personnel that can do this? Does it have the resources? Does it fit culturally? I would suggest that the person doing the translating doesn’t make this decision. Be open to opportunities that you didn’t initially envision. A survey conducted by NCOA revealed that most agencies feel that recruiting and retaining are the most difficult pieces of implementation. So that tells me that, from a technical assistance point of view, I have to devote a significant amount of resources to marketing. I need to be able to show that the program helps to achieve the organization’s mission and helps establish new partnerships.

It’s critical to discuss legal issues. As a program developer, you have to develop a licensure/certification progress. One reason is to ensure the program is delivered with fidelity. Indemnification is important as no organization wants to risk its endowment. You have to protect your intellectual property so that you don’t see somebody else publishing it.
Infrastructural sustainability means that by collecting small licensure fees, I can continue to give technical assistance and support to people and track program usage. Another piece of technical assistance is establishing guidelines for implementation. These guidelines need to be documented into detailed implementation manuals. It’s important to realize that just because you have documented implementation does not ensure that everyone will follow your guidelines. You cannot be the implementation police. But you can make lawful decisions and help people think through changes and when changes should be made. Your training materials need to be very clearly written and leave nothing to chance. In our programs, we actually have checklists that we use to watch people do their second practice teach. If they don’t make the grade on the second practice teach, they are not certified.

So what is fidelity and why bother? Fidelity is how closely an agency or staff member delivers something in the manner it was originally intended. As far as time, as far as cost, it’s all kinds of levels. We developed a very detailed fidelity manual. It goes all the way from hiring staff to figuring out why people dropped out. It’s there to set a standard.

Another technical assistance issue is sustainability. If a program is really sustainable in an agency, it has to have a line item in the budget. So agencies have to be taught how to get things into a line item in the budget. We should look more towards industry for funding streams – caregiving is an immense problem for industry; lost work days, lost productivity, etc.

Another concern is program evaluation. A good evaluation costs around 20% of your budget. Most agencies only devote 2-5% of their budget for evaluation, so they get what they pay for – a really poor evaluation. For a decent evaluation you have to evaluate 70 or 80 percent of the participants; this is very hard to do since people drop out, etc. So my feeling is that we probably should do less very localized evaluations and do more centralized evaluations. There are so many problems around collecting data that I believe evaluation may not be necessary. If you’re to evaluate, evaluate something new. Don’t evaluate something somebody has already done. If you’re going to evaluate, do it right. The major evaluation problems are that sometimes the samples are too small; the data collection is not complete; people want to ask 150 questions. They use really good measures, but the measurements are things that won’t change much over time. The biggest problem is it’s just not properly budgeted. My closing thought on technical assistance is that it needs to be centralized. It should focus on learning in the field. It should be documented so that, when we learn something, we document it.

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CAREGIVING IN KOREA AND THE RCI-KOREA INITIATIVE

(Summary)

Kyungjin Cho, Ph.D., RCI-K & Dept. of Applied Culture, The Cyber Univ. of Korea

Dr. Cho thanked the RCI for the opportunity to present the work that they have been doing this past year. She stated that some of the RCI-Korea team have siblings fighting cancer, a parent fighting cancer, and she revealed that she is the mother of a son with Asperger Syndrome; making their interest in caregiving both personal and academic.

RCI-Korea represents a collaboration between the Cyber University of Korea and the RCI to develop a caregiving curriculum at the undergraduate level. They are also in the process of implementing the RCI’s “Caring for You, Caring for Me” intervention program for caregivers.
as the first support program for caregivers ever introduced in Korea. Dr. Cho shared the following about caregiving in Korea; Korea is a rapidly aging society and 10.9% of the population is over age 65. Combined with the lowest birth rate in the world (1.08), this will result in a massive shortage of family caregivers. Although caregivers in Korea have traditionally been women, mostly daughters-in-law, more and more women are entering the workforce. By the year 2015, Korea’s over 65 population will more than double. Some services have been provided by the local government for low-income elderly who live alone, but Korea now has a national long-term care insurance policy that provides for paraprofessional care for the elderly. Only 3.9% of the target population receives care services through this insurance policy program as of June 2009, and care needs are still mostly met by family caregivers or private services which can be uneven in quality and very costly. Dr. Cho stated there is a definite threat of an impending caregiving crisis, along with a moral as well as a practical imperative to provide long-term quality care on a consistent basis.

A big problem in Korea is that the concept of “caregiver” is not present in their language or their mental map. So there is a lot of work to be done – identifying caregivers, training and supporting them, creating partnerships between family and professional caregivers, and the need to connect them with community services.

The Cyber University of Korea (CUK) is the first university in Korea to provide 100% of its classes on-line. Korea has always been a very education driven nation, with life-long learning being extremely popular. Korea is also a very wired nation, so the Internet represents a good vehicle to disseminate information about caregiving. CUK has about 8,000 students whose ages range from people in their 20’s to people in their 80’s. They have a very strong undergraduate program in social welfare and counseling, making it amenable to the creation of the country’s first caregiving curriculum.

The first course offered, “Introduction to Caregiving”, had an enrollment of 458 students. The second course, “The Caregiver’s Journey”, is currently in session. “Best practices in Supporting Caregivers” will be offered in March 2011, and a schedule for development of the final three courses is in process. RCI-Korea is also planning to host an international conference in 2011 that will bring together caregiving specialists from different nations in Asia.

Dr. Cho then shared information on translation of the RCI’s “Caring for You, Caring for Me” intervention program into usage in Korea. The translated materials will be published by the end of the year. When the program was first tested, it had a high satisfaction rate, with everyone saying that they would recommend the program to others. Dr. Cho feels the program has vast potential because it is a source of social support and healing which is practically nonexistent for caregivers in Korea where people are known for being stoic at performing their job, their work, and their tasks as a caregiver. It’s significant also because participants see that there is a possibility of collaboration between family and professional caregivers, where in the Korean culture, they tend to distrust and dislike each other. Participants from the first trial workshop bonded so well that they continue to meet every month. Currently CUK and RCI are working on necessary modifications to the program to see what kind of models work best for the Korean situation.

Dr. Cho stated that it was very exciting to meet Dr. Kate Lorig at the summit as they are an on-line university and plan to look at her materials for guidance in how to offer future RCI-Korea programs on-line. Dr. Cho thanked all of their American hosts, and the RCI-Korea team
was introduced to Dr. David Haigler, original author of “Caring for You, Caring for Me”, who was present in the audience.

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**TEACHING CAREGIVING ONLINE: THE CASE OF “INTRODUCTION TO CAREGIVING”**

*(Summary)*

Kee Yeon Bang, Ph.D., RCI-K & Dept. of Counseling, The Cyber Univ. of Korea

This presentation covered current progress on course development for RCI-Korea’s caregiving curriculum. The plan is to develop six courses in three years. The first course, “Introduction to Caregiving”, opened in spring of 2010. It’s 15 weeks long, so it’s a whole one-semester course. It was taught as a team; two professors are in psychology, two are in social work, and one is in anthropology. RCI-Korea’s process for developing an on-line class is this: the professor provides the original lecture notes, the media team videotapes the professor’s lecture, then the on-line class is put on the system. Each weekly class has four parts – introduction, main lecture, application, and review. The introduction is called “warming up”; here short interviews are provided; there are readings from books and poems, anything to motivate the student. By clicking the link “understanding” you go straight to the main lecture. Each weekly class takes 75 minutes; the Government of Education regulates this. A personal case study is provided in each class, students find this especially moving. After the main lecture, students are asked to apply what they learned to their own situation. They keep their answers on their own computers, and have access to seeing what the professor thinks and what the other students are thinking so that they can compare and see the similarities and different perspectives. There is a lot of interaction, and professors are bound by a 24-hour rule for answering student’s questions. There is a bulletin board feature that allows classmates to talk to one another and a discussion room where they share their personal experience, as well as learning experiences.

Responses to the class have been very positive – students like the focus of the class and are eager to learn more about caregiving. They really apply what they learn from the course to their own personal caregiving situation.

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**WRAP-UP, NEXT STEPS, CAREGIVER MONTH PROCLAMATION**

*(Summary)*

Laura Bauer Granberry, MPA, Rosalynn Carter Institute for Caregiving
Former First Lady Rosalynn Carter
Barry Blount, Mayor, Americus, Georgia

Mrs. Granberry commented that a lot of ground work towards averting the caregiving crisis has begun here. She stressed the need to keep the momentum moving forward around the issues, and asked all participants to continue to be part of the national dialogue. She mentioned some upcoming briefings with CMS and the Office of Disability in Washington, DC and pledged RCI’s ongoing support to getting effective caregiver programs into communities giving concrete information and strategies of how to do this successfully. She stated that the RCI will be hosting a full-day session at the 2011 Aging in America Conference in San Francisco on April
26, and urged everyone to attend for an update on the progress made on the 12 recommendations.

Mrs. Carter thanked everyone for attending and actively participating, and reminded everyone that National Family Caregivers Month is just around the corner, in November. With that, she introduced the Mayor of Americus, Barry Blount, who read a Caregiver Month Proclamation on behalf of the office of the Mayor and the City Council of the City of Americus.

“Whereas, during this season of thanksgiving, as we pause to reflect on the many blessings bestowed upon us as individuals and as a city, we are especially grateful for the love of our family and friends.

Whereas, one of the most profound ways which that love is expressed is through the generous support provided by family caregivers to loved ones who are chronically ill, elderly, or disabled;

Whereas, caregivers reflect family and community lives at its best and among the City of Americus’ most important natural resources;

Whereas, the need for family caregivers is growing, and we are blessed to live in times where medicine and technology have helped us live longer. As a result, persons with disabilities are living longer and people over the age of 85 are the fastest growing segment of our population.

Whereas, family caregivers can be found in every city and town in America. In this life, we will all know at least one family caregiver, and family caregivers deserve our lasting gratitude and respect.

Whereas, this month, as we honor the many contributions that family caregivers make to the quality of our national life, let us resolve to work through our community religious, social, business, and other organizations to offer programs and services that will provide caregivers the support and the encouragement that they need to carry out their vital responsibilities.”

Therefore, I, Barry Blount, Mayor of the City of Americus, do hereby proclaim November 2010 as the National Family Caregivers Month in Americus, Georgia, self-proclaimed this 22nd day of October 2010. Thank you all.

SUMMIT CONCLUDES