

**Translating Evidence-Based Practices to Community Settings for People Aging with Disabilities and their Caregivers: Gaps and Opportunities, Administration for Community Living Webinar, February 4, 2016, 1:00pm - 2:30pm (ET).** Please stand by for real time captions. >> Today's conference is being recorded. If you should have any objection you may disconnect at this time. It is my pleasure to turn the call over to Doctor Margaret Campbell. Welcome everyone. Welcome to the ACL webinar on translating evidence -based practices to community settings for people aging with disabilities and caregivers, gaps in opportunities. I will be serving as the moderator for this event along with my colleague Doctor Elena Fazio. We will be taking turns as we go through this event. I want to begin by saying how thrilled we are at the turnout. There were 500 people registered for this event with another 100 on the waiting list. That is rewarding. I want to begin by thanking all of the ACL staff who made this webinar possible. In addition to Elena Fazio, Lan Marshall and Michele France and other colleagues.

This event is being recorded and will be recorded with captioning. That will be available at a later time. We are going to hold all questions till the end. I would like to turn to the agenda. >> It is up on the screen. I will make some preliminary remarks regarding the objectives of the webinar and we will hear an explanation of the context of the webinar. First it will be Elena Fazio. She will give the ACL perspective and Ruth Brannon Director of the office of research sciences. She will give the NIDILRR perspective. We will turn it back over to Elena Fazio to introduce our keynote presenters.

We will look at the overall objectives for the webinar.

This webinar is designed as a breeding event to increase awareness among the fields of both gerontology and disability regarding recent efforts to use translational research strategies to increase the availability of evidence-based programs for and was those aging with disabilities and caregivers for older adults with dementia. While the pace of progress differs between gerontology and disability researchers administrators practitioners and funding agencies from both fields face similar challenges in meeting the growing demand for evidence-based programming for older adults and people with disabilities and community settings.

The investment in evidence -based programming to promote the health and well-being of older adults and adults with disabilities is a priority throughout ACL in the administration on aging grant programs. For example. AOA awards competitive grants to states tribes universities in various amenity-based organizations to implement evidence-based chronic disease self-management education and fall prevention programs. The Older Americans Act also invest in evidence-based programs through disease prevention and health for motion funding through Title 3-D. >> Hello everyone. I am really happy to be able to take a few moments to speak to you about this initiative and how it relates to NIDILRR approach to research and development. It is a wonderful opportunity to reach out to a broader ACL stakeholder community. Many of you may not know much about NIDILRR. I will start and talk about our research focus. Our research focus has always been on generating new knowledge and promoting its use to change policy practice and programs to improve the short and long-term

outcomes of the chewables -- of individuals with disabilities for all ages. To reach this goal NIDILRR funds discretionary research projects and programs in major life domains of employment health and function and community living and participation.

For many years NIDILRR research focused on knowledge creation because rehabilitation and disability research was in its infancy. For the last decade, knowledge translation defined in the NIDILRR context as a multi-dimensional active process of ensuring that new knowledge and products gained via research and development are relevant to the user's needs, reach intended users, are understood by these users, and are used to improve participation of individuals with disabilities in society. This has been a 4 requirement of all of our grants for at least a decade. In recent years NIDILRR has adopted a field initiated approach for grants and several grantees have been successful. One of them is Doctor Ivan Molton in adding translation research products to our portfolio. We have learned a lot. We are actively seeking now to learn more from ACL experience so that we can formally incorporate translational research into a continuum of interventions development targeted at real-world environments. The ecological framework of translational research makes it a powerful tool that blends well with NIDILRR commitment to community living and participation. Operator, can you confirm that all participants are muted? Other than presenters. We are hearing there is a lot of ground noise. As a second protocol if everyone on the line to make sure their line is muted, it would help. Thank you. The participants are muted. It is the speakers that have open minds at this point. Thank you. >> We are also told that WebEx audio may be interfering with participant sound quality. Please turn off WebEx audio and only listen to the conference call number that you have been provided. Only use your telephone not WebEx or your computer for calling in. Thank you. Now I would like to introduce our speakers today. Ivan Molton is an associate professor in the Department of rehabilitation medicine at the University of Washington. A rehabilitation site -- psychologist by training his clinical and research interest lie in ways to promote health and well-being and results with early acquired physical disability conditions including MS, spinal cord injury and neuromuscular disease. He is currently the Director of a NIDILRR funded rehabilitation research and training Center on aging and physical disabilities. Which includes a program of longitudinal research to identify and ameliorate chronic medical comorbidities in people with disability as they age. Our second keynote speaker, Doctor Laura Gitlin is an applied research sociologist and a professor in the Department of community public health school of nursing with joint appointments in the Department of psychiatry and division of geriatric medicine at Johns Hopkins University. She is also the founding Director of the Center for innovative care and aging at Hopkins which is transforming healthcare delivery in the health and well-being of older adults and their families through rigorous research training and health and human service professionals and evidence-based programs and models of care. And translation and implementation of proven interventions and service delivery settings. Now I would like to turn things over to Ivan Molton. Thank you. This is Ivan Molton. I am at the University of Washington. I hope everyone can hear me okay. I will talk about a case study in translational research that we are contacting. Attempting to adapt an existing intervention developed in gerontology for

people younger adults especially, younger and middle-age adults with long-term physical disabilities.

Can we advance to the next slide? >> Operator, can you hear me?

I do not have control of your presentation. One of the other speakers will need to advance the slides. >> The slide is on the screen. You are not seeing it?

I am not. I am seeing my title slide. Next slide. Do you see it now? I am not. Sorry. >> Can you switch to your slide deck?

I will do that. The only challenge -- are you seeing a graph labeled aging into disability? Yes. >> For those who may be low vision this is a slide that shows a graph documenting the percentage of the U.S. population over 65 across time. As we know we are living in a time of demographic changes in the U.S. and elsewhere. About 12.5% of the population is over 65. By 2030, that should be about 20%. By 2030 we expect one in five individuals in the U.S. will be over the age of 65. That means a lot of positive things I would argue for our society through a longevity dividend. But it also means greater incidence of disabilities. Here we are talking about disabilities like osteoarthritis, coronary heart disease, is that progressively lead to impairment. Although -- also with impairment disabilities. In both cases what we talk about our formally able-bodied adults who age into impairments. That group is described as those aging into disability. That is the group I think that has received the most attention in gerontology research. I believe there is a second group I want to make sure we enter into the conversation.

Those are individuals who have an early acquired disability. A disability typically acquired and 20s or 30s. Those are living into older age as well. I sometimes hear that has to be a small percentage of the population. Why is it important? It is not. In 2010 almost 30,000,000 working age Americans reported some significant physical disability. That is one in eight in the American workforce. We're talking about hundreds of thousands of people. 260,000 individuals with spinal cord injury. 350,000 individuals with multiple sclerosis. More than 100,000 people with CMT. And every year we have millions of traumatic brain injuries which could lead to physical impairments. >> This is a population that is living longer and growing older as well. That is due to a number of reasons. In some cases we have become better at promoting early survivorship. For spinal cord injury in 1945 if you had a spinal cord injury your life expectancy was 18 months. Now most are expected to live up to 85% of the normal lifespan. The average age of people is increasing. 40% of that population are over the age of 45. We see similar effects with things like multiple sclerosis with a mean age is 65 years and half are over 65. That is a population who due to medical advances are living longer and into older age. There are special conditions like post-polio syndrome. Polio was effectively eradicated in the 1950s. To have post-polio syndrome you are almost by definition an older adult. In issues with cerebral palsy, if a child can survive cerebral palsy, most of those individuals will live past the age of 50. We are seeing an increasingly graying population of adults with these acquired his

abilities. This is a population we describe as aging with disability. I am making an argument that we have two groups of older adults. Those aging into disabilities. In those aging with long-standing disabilities. >> This should show shared needs. Despite those different diagnoses, these are groups that really have shared requirements. We are talking about problems with balance, chronic pain, need for caregiver support. You would think that the research policy and service networks serving these groups would be in tight collaboration. Historically that has not been the case. Historically the groups serving older adults and those serving those with disabilities have been disorganized from one another. Disconnected. Different priorities and different funding streams. Those aging with disabilities were in a gray zone between those networks. >> The way that I have heard this point best, we have different philosophies between these networks. For the disability system aging is seen as a success and for the aging network disability is seen as a failure. That summarizes the historical disconnection. >> Fortunately I think the tide is turning. We are living in an age where there is an increased awareness of mutual opportunity to serve both those aging with disability and those into disability. That is evidenced by the recent federal expansion of the [Indiscernible] model, the inclusion of the NIDILRR. And I am hearing from community agencies their estate pressure for them to serve both older adults and those with early acquired his abilities. >> Along with that comes a need for translational research to promote evidence-based health promotion practices for those aging with disability. If you look at the data on this you will see that individuals with these long-term physical disabilities they describe a need for community-based programs for exercise and wellness. They perceive there are barriers to the participation. >> How do we do this? There are two roads by which we can increase the availability of evidence-based community wellness programs for people aging with disability. You can take existing interventions -- we have interventions developed specifically for people with spinal cord injury or MS and disseminate them and adapt them as necessary to include older adults. And/or we could go the other way and take existing older adult interventions developed in the gerontology literature that are out in the community and adapt them to serve younger people with disability. I will make the argument that the second road is the one to take. Let's start with the first road. The rehab-based intervention. Thanks to funding from organizations like NIDILRR we have a promising and developing evidence base. It is behind the evidence base in gerontology and public health. To give you a sense, in spinal cord injury we have 28 unique exercise trials of community exercise programs. There is a peer navigator program. In MS we see lots of trials of fall reductions, trials to increase exercise and recently some collaborative care trials to manage pain and fatigue. We have a promising evidence base. >> But I argue we lack translation. These interventions from the rehab world tend to be based in hospitals and clinics. Most of them are diagnosis specific. You may have an intervention to improve exercise in muscular dystrophy. These conditions when taken individually have a low prevalence relative to the disability associated with aging. They are impractical to be disseminated in a small town of 30,000 people. Most of these are research trials. The funding model is not sustainable. There is not a built-in model for translation. Most of the interventions tend to emphasize the recently diagnosed and not adults who have lived for 20 or 30 years. >> What if we go the other way? What if we take interventions

that are designed in the gerontology world and adapt them for people with disabilities? I am showing a slide that shows a screenshot from the [Indiscernible] webpage where they keep a list of title 3-D evidence-based interventions for older adults. At the outset, they are not endorsing these interventions but they are saying these interventions that meet the criteria. We are grateful that they keep this list. >> Next slide. >> I am having a problem with the slides. I will go back to my deck. The slide I am looking at now should be a table that says title 3-D higher tier evidence-based health promotion programs.

One example is a matter of balance. Fall prevention programs. Who delivers it and what is the target audience.

When it comes to disabilities there is a limited evidence-based for these interventions that are developed for older adults. To give you a sense, as part of our group we are doing a scoping review of those interventions that happen to be on the NCOA list. It is not comprehensive but it includes 39 interventions. Those are based on more than 150 randomized trials. Of those randomized trials only two studies specifically include people with early acquired his ability conditions. >> Sometimes people say we included adults with disabilities but we did not specifically target them. Actually when we look at the criteria the inclusion criteria, we see language that would have excluded most people who are wheelchair-bound as they describe in the studies or who had a physical disability. Here is an example. It excluded people who have disabilities that required higher levels of supervision. Excluded those who were wheelchair-bound or experienced loss of balance while standing. Excluded those who were just too disabled based on the judgment of study staff. There is a lot of evidence that these interventions which were designed to be scientifically controlled trials of older adults excluded those with disabilities that were long-standing. >> These interventions themselves may not be appropriate to those with disabilities. Some required sustained walking balancing or aerobic exercise. Sometimes key outcome measures were not suitable. You may look at timed sit and stand test. Measures of date speed. Self-report measures of physical activity. These are ways that people with disability have unfortunately and inadvertently been left out of the gerontology evidence base. >> This gives us a translational research challenge. We need a greater reach of community innovation for those with disabilities. I believe that the most efficient way to do that is to take the existing evidence base of why these disseminated programs for older adults and test them and adapt them for younger and older people with disabilities and test for efficacy. There are some structured approaches. You may have heard of the [Indiscernible] protocol. In our particular case study we are using in -- an event -- Called intervention mapping.

It is a theoretical approach we used to guide our adaptation trial. It is a stepwise approach where you take an intervention that has been developed in one population and adapt for another. These steps are reciprocal. The first step is to perform a needs assessment. The question is how does this new population compare in terms of demographics context for the development population? Step to you define a logic model of your change. What changes in behavior or environment am I seeking? What am I target outcomes? In step three you will try to

match the practical methods to the desired outcomes. What is the essential active ingredient in the original intervention program? How can I maintain that? >> Step for you will consider the existing treatment components and delivery channels. You are asking do I need to change these materials in any way to meet the needs of target populations? To the materials need to be translated? Then you will implement the program and ask yourself what changes are necessary to maintain fidelity across the adaptation? It may involve a fidelity check. And an evaluation of the program in terms of feasibility and effectiveness. We wanted to try this. Our study we wanted to identify an existing evidence based program designed for older adults. To partner with a community agency that was delivering the intervention and to engage in a structured adaptation process. We wanted to test the efficacy. The test is ongoing. I have some preliminary data that we are in the middle of the trial. Is efficacious we want to design materials that can be used by the people providing this intervention to extended to people with long-term disabilities. >> Here is the case study. We used an intervention that is already out widely disseminated for older adults. It is called enhanced wellness. It is owned and maintained by a nonprofit called sound generations in Washington state. The way that enhance wellness works is it is a one-on-one health coaching model. It is based in this question, has your doctor ever told you to do something you knew would be good for you but you did not do it? I am sure no one can relate to this question. I ask myself this question every six months and I have my physical. It is a common problem. >> The way that enhance wellness works is an individual wellness coach who can be a nurse or a social worker meets with individuals who want to be in the program. In its current form the meeting places can be anywhere in the community. It can be at a coffee shop or a skilled nursing facility. Most trials have taken place in senior centers. You may with the individual and you identify a goal that is related to health or participation or personal goal. It can be variable. It could be about weight loss or increased socialization or maintaining your health or managing a secondary condition. It is an active program that involves physician involvement and there is a computerized system for outcomes monitoring. The individual coach will work with the participant to develop an action plan based on strengths and to meet personal goals. I want to make sure we are on the same slide. The slide should read our adapt -- adaptation process. >> We really divided the mapping approach into three phases. The first was pre-implementation adaptations. They are changes you make with stakeholders prior to rolling out the intervention. Then we had ongoing allocations. Which involved making iterative adaptations during the trial. In the third phase we wanted to document the final changes to the adaptation and disseminate treatment.

The slide should read select a structured method for considering proposed adaptations. This is a piece of advice. It is important that you select a structured method for adaptations. For us we pick the adaptation traffic light. It is a model designed by the CDC. And that model what we did is we assembled a committee of five individuals that include some stakeholders in the community, the intervention developer, the PI on the research study. Anytime there was a proposed adaptation we talk about do we want to make this. We use these anchors to guide us. A red light is an adaptation that removes or alters key aspects of

the program that will weaken the effectiveness. We do not want to do that. I am trying to think of an example. Hypothetically it could be what if we only met once every six months? In enhanced wellness you meet in person and you will meet on a weekly basis to monitor your progress. >> A yellow light adaptation is one you might make but you want to be cautious. You want to make sure it is not altering the components of the intervention. You want to consult with the model developer to make sure it is in line with the model of change. A green light adaptation is appropriate and encouraged. It can better fit the age culture and context of the population. >> You want to maintain a manual of procedures and an adaptation log. So at the end of a trial you can document carefully what you did and look back to make sure that it is still meeting the scope and intention of the original trial. >> Here is a screenshot of our manual of procedures. This is an example of our adaptation log. We logged the date that a proposed adaptation came along in the results of the committee using the traffic light model. -- Like model. >> Here are some examples of phase 1. Pre-implementation. Stakeholder engagement is key. We had some initial conversations with community partners and established an advisory board. We did some focus groups with our participants. We asked of them, this is the enhanced wellness approach what do you think? Do you have any concerns or questions? We also made a plan for follow-up interviews.

Here are a few examples of adaptations. Our community providers said they were not as comfortable as they want to be in serving people with long-term disabilities. They requested some training material. We provided a two-day training to our wellness coach and others on various aspects of disability. Some additional adaptations -- we made our wellness coach mobile. We supported her ability to go to homes. Many of our participants were not connected to community senior centers. And felt a meeting at home would be useful. We had a physical therapist available to consult with our wellness coach if needed. If the participant identified an exercise goal in the coach wanted to make sure the exercise goal was reasonable and safe. We use outcome measures that were validated for adults with disabilities.

Phase 2 the ongoing adaptation. This is based on clinician experience participant feedback or outcome data. We used a formal system for making ongoing adaptations. >> In the existing enhanced wellness protocol, if a participant indicates on a screening there is a problem area like depression it generates a flag. The interventionist follows up on that and make sure it is addressed in the action plan. Many participants who had conditions like neuromuscular disease or MS who identified fatigue as a great problem but it was not creating a flag, the interventionist what only know to check on that based on their clinical expertise. We generated a procedure by which a high score on a baseline measure of fatigue generates a flag for the interventionist. These are a few other examples along the way. How comfortable do you feel in controlling your chronic condition? Many found that wording objectionable. I cannot control my neuromuscular disease. All I can do is manage it. We corrected the wording. Those are some examples of phase 2 adaptations. >> I know this is not a research talk. I have to move quickly. I want to give you a sense of what we are doing. We have a goal of 120 individuals with spinal cord injury, MS, or neuromuscular

disease. We have 108 enrolled so far. 54 have completed the six months of the trial. We have had a waitlist in place since the beginning and interest in the program. I want to go through some preliminary results. Our mean age is 64. Primarily female. We had good reports of the treatment being helpful and the benefits outweigh the effort in participating. We are seeing statistically significant decrease in pain interference. Which is consistent with the evidence-based for this intervention and older adults.

Similarly we are seeing reductions in fear of falling. And we are seeing incidental positive findings. These are based on pilot data. We see increases in leisure physical activity. Increases and satisfaction with social roles, decrease in fatigue and anxiety.

Phase 3 what we hope to do is disseminate the adapted intervention materials. After demonstrating the efficacy of the intervention, we design a module that will be an accompaniment to the enhanced wellness manual. There is a training manual now and we would like to develop a new module for doing enhanced wellness with our disciplines who have long-standing physical disabilities. That will include the information we provided to our wellness coach suggested adaptations suggested resources and some data from the evidence base we are collecting. Our plan is to disseminate that. Potentially to offer as needed remote training or supervision our existing interventionist as they use this in adults with disabilities. In the future we would like to test for feasibility and acceptability in the existing sites. This was just a report of a pilot trial to use a structured adaptation process to increase translation of evidence-based practices that are already out in the gerontology world to include those with physical disabilities. The program we are using is owned and administered by sound generations in King County.

This is a slide with key references. Thank you. I would like to take a moment to remind everyone on the call that you should be dialed in by the telephone number you received in the invitation. Please use your telephone and do not call into the WebEx number that you may see. Use it the audio number provided to you in your invitation. As a reminder, this session is recorded and you will be notified when it is available. Now I would like to invite our next speaker. Doctor Laura Gitlin to share on her work, translating evidence-based dementia caregiving interventions into practice.

Thank you. Good afternoon. I would like to thank ACL and NIDILRR for their leadership in thinking through and beginning this very important dialogue and how do we move translational -- how do we move evidence-based programs from efficacy into the community. What I would like to do is give you a summary and an aerial perspective as to what is going on in translating evidence-based programs for families who are caring for people with dementia and who are primarily living at home. This will serve as a contrast from some of the remarks in the case study that Doctor Ivan Molton presented. We can collectively derive some lessons learned to push all evidence-based type programs forward. >> I would like to begin by setting the stage by presenting a very brief case. Mister Smith cares for his wife at home in West Virginia. She was

diagnosed with dementia about four years ago. Mister Smith is one of 15 million family caregivers in the United States caring for the over close to 5.3,000,000 people with dementia. When he was -- she was first diagnosed with dementia, Mister Smith said what do we do? He was told there was nothing you could do. He learned about the Alzheimer's Association by chance from a neighbor and he did receive from -- helpful information. Was not interested at the time in their support group efforts. Mister Smith had to stop working to care for his wife. He is feeling isolated. His children live far and have difficulty participating in care and helping. He is becoming clinically depressed and he is also feeling strained financially. He also has increasing difficulty managing Mrs. Smith's increasing physical dependence and behavioral symptoms. He has no help in the home. Mrs. Smith's position provided medications that were not only ineffective but also had some negative side effects. Mister Smith discussed those medications. This is the picture of families. What is important about this case -- for those of you who do work with families, it is safe to say that you have many families that you are familiar with. This is the profile. What is important is that this is the first family that ever enrolled in any of my trials over 30 years ago. And they look exactly the same as the caregivers who we are enrolling now in several trials. That is a very powerful.. Because it has to do with what do we know about ways to help Mister Smith and Mrs. Smith. And why are they getting what we know is helpful? That is the premise of many of my points. >> There is good news -- you have to go back to the good news slide. There is good news because there has been over 30 years of excellent research. Evidence-based programs that have been tested in randomized clinical trials. That have shown many different ways that we can support the Mister and Mrs. Smith. In the United States. We recently conducted a comprehensive review of this literature. It has such depth that we ended up reviewing reviews of about 20 reviews. Reflecting over 200 randomized trials that had been published between 1966 and 2010 with over 1000 caregivers. Recently we have been trying to update this. There are 20 other interventions that have been published. The good news is that we have great depth of knowledge and evidence that really is ripe for knowledge transfer or moving along a pipeline from the efficacy trials to implementation into clinic and community and aging services.

We also completed a review of home-based interventions that targeted persons with dementia. Using more nonpharmacologic approaches. We also found 49 trials as of last year and updated that to find another 10 making it 59 randomized trials showing a range of benefits for persons with dementia. Some of the positive outcomes that have been included in these studies have shown that we have ways of working with families that can improve their knowledge burden self-efficacy their depression their health behaviors and their skills in managing many of the complexities with dementia. We also have 59 randomized trials all of which report at least some benefit to the person with dementia in terms of improvements in quality of life function reducing behavioral symptoms or reducing time to institutionalization. >> We have a pretty rich body of evidence. Do we need more research? Yes. I will return to that. The slide shows the very long road that has been portrayed by many others from the research to the introduction of such varied practices in the real world study. We see this final effect of a lot of studies like I

just reported. But very few making it into practice. For a variety of reasons. Some I will highlight. I hope that we can also get into a discussion about this. From my own work and having done randomized trials for the past 30 years, I can say first-hand experience that it can take anywhere from 17-25 years to get any particular program into practice and where you get placed into practice is very limited in terms of geographic region. We have a lot of work. I want to go back to the good news. We had a rich body of evidence that we can move forward.

Let me tell you where we are with the translation. Most of these trials whether they are focusing on family caregivers or people with dementia or both, they are tested outside of any service delivery. There is a need to go through some kind of translation or adaptation. >> Here we can show some really nice progress. I have to say spearheaded by the administration on aging and ACL. This is a map. It reflects the different places in the country in which a proven evidence-based program for family caregivers has been translated. This is data from 2012. There could be increases. I want to say that the state Mister and Mrs. Smith has come from has not had the benefit of this effort. We can be very proud that a total of 37,000 family caregivers have participated in one of the funded ADSSP grants. When you take a look at 15 million people that represent a very small percent. I will come back to what some of the challenges our. >> The translation -- the translation of these programs is slow but is also occurring. We should be very happy about that. This shows a map in which the resources for enhancing alzheimers caregiver health interventions have been translated. You can see that it is pretty impressive in terms of all the states in which this kind of 12 session intense caregivers supportive program has been translated. This is data from 2011. This is large-scale translational efforts supported by the Veterans Administration with regard to the project. 127 caregivers were served. In each of these states it could be misleading in the sense that the funding occurred in one very small location. The triangle in California represents just one small location in California. Even since 2011, in four years we have had really great progress specifically with the reach through the VA in which there has been over 238 sites trained. The group has received funding to train 35 sites in Indian country and nine sites in community Indian country with an estimated number of caregivers being involved over 800.

I want you to see we're making great progress. It is very slow. The outreach, if you think of 15 million -- it is small. This is another example of an intervention. This is from the NIH REACH Philadelphia site skills care. This involved six occupational therapy visits in the home of a family caregiver to improve skills and communication. Addressing functional disability. And addressing multiple behavioral symptoms and helping families take care of themselves. We have been very successful in integrating this skills to care approach. In a funded mechanism. Through home health care agencies, area agencies on aging and home-based agencies. We have trained about 20 agencies. We trained individual occupational therapists in private practice. Through these programs we have reached out to about 800 caregivers. If you think about why we have been successful with REACH through the VA, we have been able to embed these evidence-based programs into specific funding and reimbursement mechanisms or social services. This is an important

point when we think about what makes translation successful or not. And also affords a potential for a program to be sustained. >> I want to say that -- I will return to this again. You can see from the previous talk and what I am saying the tremendous effort involved in translation and funding is needed. Very few sources of funding has been available to the community at large. ACL, VA and also Rosalynn Carter had at one point translated four interventions. In the Rosalynn Carter caregiver Institute, they are introducing the REACH intervention throughout the state of Georgia. I want to point out that we have over 200 interventions all tested in a randomized trial. We had 16-18 or let's just say 20 translational efforts with only six or so of the proven interventions being translated.

On this slide you see the number of other kinds of interventions that ACL has identified and other funders have identified. We are moving forward. With translation and each of these are in varying stages of being tested and translated and adopted. One of the challenges is that there is no central depository. I cannot tell you what the REACH is in any one of these programs is unless we contact the developers.

When you think about the state of translation, what we see is depth of evidence, we have a burgeoning record of translation. And we see that we have really made some very good progress. But more is needed. Of 2015 only 16 studies have been published. About six -- things are changing rapidly. Today I saw several publications. I will change the number 29. -- To nine. That is less than 3% of programs available to families. In dementia and dementia caregiving it is such a complex field. Dementia is a progressive deteriorating terminal condition and caregiver needs change over time. There is no magic bullet. We really have to be invested and moving forward a whole range of interventions to address the multiple needs the families have. >> 15 million caregivers -- if you look at the total number of people that have been served, it is very exciting at some level. We have to recognize that it is actually .003% of people who may potentially need something. Education about the disease. >> Why is it challenging to integrate evidence into practice? While my remarks reflect the experience with dementia caregiving, I think it is relevant to aging with an aging and disability.

There are some limitations to the existing evidence. Most of the programs have been tested outside of existing payment systems. Therefore we do not know how they operate in real context in service delivery. They have been tested in ideal situations. The REACH intervention started with a technology component, 12 face-to-face sessions and a telephone support. In its translation, those components had not been able to be retained. 12 sessions are way too much for any social agency to commit to. And it has been recently published in which these 12 sessions have been reduced to four sessions. Technology is changing. It is not been able to be retained in the intervention. The support group component has been pulled up completely. Interventions have typically addressed family needs at one point in time. We have to be very clear which intervention we need to translate and for which point in time in the disease trajectory in the caregiving trajectory. There is a poor link of the interventions to the person with dementia. Poor characterization of who

caregivers are, so that medical and health and human service professionals are unclear. What intervention should they look for for any one person who has dementia. There is a lot of limitations in the data itself. We have limited outcomes on cost, cost saving, health care utilization and limited evidence for various subgroups that really signaled the need to adapt these interventions for an increasingly extremely diverse group of caregivers. Diverse and socioeconomic status, health literacy, language and geographics accessibility. It is unclear to use which intervention and when. The other major limitation or challenge to integrating evidence into practice is the limitation and funds for translation. This shows the various funders. I want to applaud the administration on aging for taking the lead in the veteran administration for taking the lead. There is one program announcement that represents a joint adventure between the national Institute on aging and the administration on aging. That is called the translational research to help older adults maintain health and independence in the community. This has been re-issued. It is the only program announcement focused on taking evidence not specific to dementia, and systematically making adaptations for it to fit into the aging services. >> It should say, with a community-based agency or clinic to do? Another limitation of our translational efforts and challenges is that it is very unclear what an agency should do. What intervention could be adopted? How do you go about finding out about it? Agencies are left on their own to identify the literature, contact the developer, determine if the developer is interested in partnering, determine what kind of training is necessary and the developer may or may not have the training program. There may be fees attached. The other point is also that it is difficult to access families. Our randomized trials recruit people who self identify as family caregivers and there is a virgin in body of literature indicating that that group who volunteers for efficacy trials are quite different than families at large. Quite different than Mister and Mrs. Smith who I introduced you to initially. >> Other significant barriers -- funding reimbursement. There is no CMS code for the reimbursement of a health or human service provider to provide caregiver training that is independent of the Medicare benefit -- beneficiary. This is a significant limitation. We are finding that in our translational efforts we have to do an inordinate amount of training because the workforce is underprepared to work with a person with dementia or a family caregiver. That happens to be a significant barrier. There are other issues that may be specific to researchers. Why does one intervention get pushed along? What are the factors that influence the adoption? Who owns these programs? Who owns the training? Where should the programs reside? If they only reside with the developer have we invested research so when the investigator or developer -- what happens to the program? I would like to conclude by offering some various strategies which we can accelerate translation, implementation and the goal is to change practice in such a way that these programs can be sustained. We are not up to sustainability. One is an effort I want to alert you to. It is sponsored by the Hartford change initiative. A group of us are looking at this body of over 200 interventions. We are developing a classification system and order to help agencies identify what interventions are available, which have been translated, what are the outcomes they yield, where'd you get training. This we help eventually will be a web based tool for agencies, community-based

agencies and clinics to use to identify the community they are serving and match them to the intervention. The other strategy is there are not many publications of translational efforts. Particularly when transitional efforts those translational efforts are not -- these kinds of endeavors even though there may be very systematic approaches that were used. We really need to understand what works and what does not. That is another strategy. >> When you take a look at these many interventions for family caregivers, they share many common elements. One of the initiatives that we are trying to move forward is to begin to disaggregate these common elements of interventions so they can be disseminated. Many interventions use a protocol that came from the psychology literature and was adopted by REACH for stress reduction. That technique and its protocol could be widely disseminated so that in working with a family the situational stressors that present could be addressed. A provider could easily use that stress reduction technique. Problem-solving -- coming from psychology and modified through these different interventions for families. It is a standalone approach. We have been trying to disaggregate these common elements and protocols and see if we can also begin to disseminate them. We have done some of that in terms of developing a caregivers guide to dementia it is a checklist of some of the key strategies that family can use for managing behavioral symptoms without having a full-blown evidence-based program. Families find this helpful. We are taking over 1000 of these strategies and we have created a web-based program that we are testing. This is another strategy. >> The next strategy is for the research community. We need to begin to develop the evidence in a different way. One our goal is to integrate -- to have an impact on practice and policy. The new way of doing research -- I should say specifically behavioral intervention research is we must involve stakeholders, agencies, payers, early on in the way we think about what we are doing and how we can construct the intervention. When I say and user I mean the people who were benefit.

We need to integrate different sets of methodologies that need to be supported by funders. The hybrid approaches are published. They can combined efficacy with the effectiveness. We cannot wait five years after efficacy to evaluate the cost of an intervention. Another strategy is the big question -- we don't have a pharmaceutical industry for all of these nonpharmacologic approaches, behavioral approaches. Where can they reside? Should there be the development of nonprofit organizations? We are beginning to think through an idea of having a dissemination that begins to link various agencies, government agencies and industry to help agencies learn about training programs and link them in meaningful ways. I want to conclude by saying when you look at the field of translation and family caregiving and dementia, we have good news. We need more research in many ways that we have a robust body of evidence. We also have good news and that the level of understanding of the importance of using evidence-based programs by healthcare providers and aging services is high. I no longer have to go to a meeting and convince anyone we need that. Agencies come to me and say show me the evidence. Our scaling up -- there is good news but it is really slow. It is occurring in existing healthcare systems. Such as BA, CMS, Medicare and Medicaid. Reimbursement systems, the Medicaid waiver program and state programs. We have challenges ahead in terms of

really moving forward and more rapidly which we have to be committed to a more rapid scaling up in terms of evolving payment models and retraining and retooling our health professionals in the area of dementia care. With that I will conclude. I look forward to a dialogue and questions. >> This is Margaret Campbell . I assume I am online. Thank you very much. They were outstanding presentations representing what is going on and emerging in the field of disability research particularly focused on people aging with physical disability in terms of translational research efforts in the need that exist. And in the world of Geritol logical research particularly caregiving for people with dementia. The challenges in terms of adapting the evidence to real world settings and adapting it to the diversity of subpopulations as well as all the challenges of dissemination and scale up and funding. Together they were a tour de force. Thank you very much.

The timing came in close. We have about 18 minutes. For questions and discussion. We are eager to hear from you on the telephone. I will turn it over to Emily. She will give you some instructions for how you express your question in terms of through the audio. I think we can still take questions through the chat box. >> At this time anyone wishing to ask a question or make a comment, press \* one . Be sure that your phone is unmuted and clearly record your name so your question may be introduced. It is \* one to ask a question. Our first question -- >> I am sorry I did not mean to raise my hand.

Thank you. >> If we have anyone wishing to ask a question press \*1 and record your name at the prompt. That includes the keynote presenters. You can ask questions if you have any. It would be interesting to hear -- any questions that came to your mind. Don't be shy. I am sure we could come up with some questions. We want to give the audience a chance. At this time we have a question. >> Can you hear me? This is Linda.

Go ahead. I think with exercise and people with disabilities -- I personally have a disability. I think that the biggest problem is motivation. Life is already hard. -- Life is already hard. The answer is socialization and exercise. You need those. We are very isolated often times. There for if you are going to give us socialization with exercise -- it will be more fun and it will meet another need. >> This is Ivan Molton . If I can address that, it is a fantastic observation. It is consistent with what we heard from our focus groups of people with conditions like MS when we talk about community exercise. They talk about having a community garden. That idea of merging socialization and social for and participation with physical activity is the way to go. The model I think people who are able-bodied , when they think of exercise they think of going to a gym. Aside from the fact it does not improve your socialization and has cost limitations there are accessibility barriers. I agree completely and I think that any exercise program for people with long-term physical disabilities really should work to include group -based activities and socializing. This is Margaret. That is built into your adaptation of enhanced wellness because it takes place in community settings.

It takes place in community settings but it would depend entirely on the participants goals in the enhanced wellness context. The participants that I want to exercise more and I want to increase socialization, the coach may say what is a strategy to achieve those goals. They may refer them to a group-based exercise program like enhanced fitness. Or two other socialization activities. It would depend on the goals. The coach is aware of this issue and tries to hit two boards with one stone. Margaret this is Laura. Can I say one thing about this. This is a great example of how when we look at these evidence-based programs across all areas, one of the key features is that we are helping people change behavior. And motivation interviewing is key to - - not every program but many programs. This is a good example of how trying to move the evidence for word, if we train people in motivation interviewing there is less of a translational -- health and human service professionals -- than learning would be that much faster. >> Are you making the case for motivational interviewing being one of the components that you could disaggregate from all of the randomized clinical trials? And try to disseminate for agencies to incorporate into their regular services? Correct. That underlies it. It underlies any approach where we are teaching new skills. In which there has to be some kind of change in a person's behavior in order to realize the benefit of what we are delivering. Thank you. Interesting discussion. Does anyone want to add to that? Is there another question? >> This is from the chat box. Is there anything in place to help a senior connect with the resources that have been discussed? That is a good question and a broad question. Lara, do you want to take this. >> If there is computer literacy , there are various briefings from most funders that explain these programs. And the lessons learned. [ Indiscernible ] was one of the slides that Doctor Ivan Molton indicated in the area of dementia the deer website has many excellent resources for families that have been vetted and that also have knowledge from these different proven interventions or evidence-based programs. I think doing a search on the government websites can be very helpful. The public health service in the area of dementia caregiving has a devoted website with helpful information for people with dementia and family caregivers. That comes out of the national Alzheimer's plan act that President Obama initiated in 2011.

Thank you. We have another question. We are a disability agency that is seeing a lot of our clients who are aging. We are really interested in how to bring dementia care best practices. We are happy to see the website that would aggregate good programs. Can you supply the email addresses for Ivan Molton and Laura Gitlin ? We would have to ask them. It is on their slides. Email addresses are available on their slides. Everyone has access to downloading the slides. After the recording.

You will be notified and you will be able to download the slides. You will get email addresses.

We have contact information on our final slide that lets you give us comments and questions and feedback. You should send an email message if you have questions. I want to comment. It is to the point of why we designed this webinar as a bridging event between aging and disability.

The lines between disability and aging start to blur as people are aging. Even though it is a disability agency they are starting to get older adults with disabilities who also have age-related chronic conditions and including dementia and mild cognitive impairment. It reflects a crossover . We decided to focus on the the need for translation research because there are so many needs to be addressed. In the case of the aging with disability world in the disability world in general not only how do we build the evidence-based, what is common to both aging and disability is how do we take the evidence base we have that has been developed in research settings under research control and translate that into real-world settings including community-based organizations, service delivery programs, senior citizen centers etc. So people who participate in this programs get the best possible evidence-based interventions and service delivered to them. These programs have to be adapted in all cases because what works under a clinical setting or research control setting is not necessarily going to work in a real-life situation. Frequently it has to be adapted to the sub population served by the center. That is one problem . It reflects the crossover in who is aging with a disability includes people who are over 65 who are aging with a disability acquired over the age of 65. Thank you for the comment. It is at the heart of the purpose of this webinar. >> If I can make one additional comment. I think that question really is a rich descriptor of the intersection of aging and disability. It is people with disability conditions age what looks like dementia may be a combination of what we think of dementia in gerontology -- stroke -- but might also be the kind of cognitive impairment that comes along with other disabilities. The dementia you see an older adults with long-term physical conditions, can have both flavors. The approach may need to be tailored with information about what the disability is and how it manifests with cognitive impairments. That information is available but not widely disseminated. Emily, is anyone on the phone? >> We have questions. >> I wanted to know about individuals with cerebral palsy. Who are not yet 65. What kind of exercise programs or health and wellness programs exist for those individuals so when they turn 60 they don't have contractures and significant disabilities. Do you have information on that? >> If you are willing to send me an email I could try to connect you with resources. That would depend on your area. That is an example of where we do see in the literature there are evidence-based practices for exercise for people with cerebral palsy. We have this dissemination problem. I do think there are some available exercise programs through places like the YMCA that will work with people with cerebral palsy. It would depend on your location. Follow-up with me with an email. Thank you. Second question, there was a caregiver guide to dementia. Where can I obtain that? This is a booklet that represents the best strategies from our research and best evidence. You can go on Amazon.com and look it up. It is also in a the reader version. Thank you.

We have a question. >> Thank you for taking my call. The question is regarding -- I did not hear much about some of the evidence-based practice that was mentioned in minority groups. Especially information in adaptation to Hispanic and African-American groups. I was wondering if you have any comment. >> I will direct back to you, Laura.

This is an important point. If you look at the body of studies that currently exist, they are most represented by a sample of varying levels of socioeconomic status some geographic diversity mostly Caucasian. Then African-American. And then Latino. The NIH funded reach caregiver intervention study, that focused on three race minority groups. Race ethnic groups. Latino, African-American and occasion. Within the Latino group we had representation from Puerto Rico Mexico Cuban-Americans and Central American. There is a tremendous -- some of the other studies there are some emerging evidence with Asian communities and different groups within the Asian communities. There is tremendous room for the need to adapt the existing programs for different groups and also in different geographic locations as well as new evidence that needs to occur. Again, there are evidence-based programs specific for those three groups I mentioned. Caucasian African-American and Latino. >> Ivan, you have any comment? I could not agree more. If you look at the literature on people with physical disabilities have not done an adequate job of reaching minority groups. Various reasons for that. It is funding that is not come down to translating interventions and making sure they are culturally appropriate. I think it is a growth area.

How are we on time?

Is there anyone else online, Emily?

Yes. >> I have a question. Could you talk about the role of technology in increasing the dissemination of our research? >> I think that technology will have to play a very big role in several ways. First, it can play a very important role in the implementation of different kinds of interventions. Having said that there are issues because technology is very rapidly changing all the time. And it is not accessible to all people. We have issues of cost. Nevertheless, I think it is going to play a big role particularly as we adopt some of the evidence-based programs for delivery and evaluate their effectiveness or delivery through smart phones. I think we need to keep on top of the technology. It is not going to solve all things. We are trying to evaluate in the area of dementia care the role of technology for assessment. Can someone take a video of some of the challenges they are having and send it to a provider? Does it give clues that are important? It is important for assessment and potentially important for measurement. It is important for the delivery of education. The question is in what way could it help families who are really struggling with learning very specific skills of how to manage medications and comorbidities and how to make their homes safe. Thank you. I think that will be over last question because we are at 2:30. This has been a wonderfully rich experience. I wish we could continue. The last slide says comments and questions. We encourage you to send any comments you have about this webinar. Any suggestions for how to make it better for questions for the presenters. Or for anyone at ACL. Please send them to this email address on the last slide. We thank you for your participation. We thank Ivan Molton and Laura Gitlin for devoting time to this and preparing and for being so willing to help advance understanding of what is going on in terms of trying to close the gap and evidence-based programming for people with disabilities and for caregivers of older adults with dementia. Thank

you. Thank you ACL and all our technical support. It is time to close. Thank you. >> This concludes today's conference. Thank you for joining. You may disconnect at this time. >> [Event concluded]