>> GOOD AFTERNOON LESSON. WELCOME TO THIS WEBINAR. MY NAME IS GREG LINK I'M AGING SERVICES PROGRAM SPECIALIST WITH THE ADMINISTRATION ON AGING WHICH IS NOW PART OF THE U.S. ADMINISTRATION FOR COMMUNITY LIVING. I'M THE FEDERAL PROGRAM OFFICER FOR BOTH THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM AND I'M PLEASED TO WELCOME YOU THROUGH THIS WEBINAR. THIS WEBINAR IS PART OF THE OLDER AMERICANS BEHAVORIAL HEALTH TECHNICAL ASSISTANCE CENTER. THE CENTER SUPPORTS AN IMPORTANT PARTNERSHIP BETWEEN THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION AND THE ADMINISTRATION ON AGING TO PROVIDE ISSUE, WEBINARS AND REGIONAL POLICY ACADEMIES FOR STATES FOCUSED ON ALCOHOL AND PRESCRIPTION DRUG. MISUSE AND ABUSE, ANXIETY AND DEPRESSION AS WELL AS THE IMPORTANT TOPIC THAT WILL BE DISCUSSED TODAY. THE BEHAVORIAL HEALTH ISSUES RELATED TO FAMILY CAREGIVING. WE HAVE A NUMBER OF OBJECTIVES THAT WE WANT TO ACHIEVE AS A RESULT OF THIS WEBINAR. WE WANT TO GO OVER SOME OF WHAT WE KNOW ABOUT CAREGIVING IN THE U.S. THE NUMBER OF WHO CAREGIVERS ARE, WHAT THEY KNOW AND WHAT IS KNOWN ABOUT CAREGIVERS CARING WITH PERSONS WITH MENTAL ILLNESS. WE ALSO WANT TO EXPLORE SOME OF THE STRATEGIES FOR REACHING AND ENGAGING CAREGIVERS AS WELL AS ASSESSING AND REFERRING THEM TO MENTAL HEALTH SERVICES. WE'RE ALSO GOING TO BE DISCUSSING SOME OF THE EVIDENCE BASED INTERVENTION THAT IMPACT CAREGIVER ISSUES SUCH AS DEPRESSION, ANXIETY, ANGRIER AND PROBLEM SOLVING. WE'RE ALSO GOING TO BE PRESENTING YOU WITH SOME PRACTICAL APPROACHES FOR WORKING WITH CAREGIVERS. AT THE END WE'LL EXPLORE SOME RESOURCES, THE AMERICAN PSYCHOLOGICAL ASSOCIATION CAREGIVER BRIEFCASE AND OTHER PARTNERSHIPS OPPORTUNITIES THAT YOU MAY WISH TO EXPLORE. THIS WEBINAR WILL BE RECORDED. THE RECORDING IN THE SLIDES AND A LIST OF THE RESOURCES ON CAREGIVING WILL BE PROVIDED ALL WHO REGISTERED FOR THIS WEBINAR. CONTINUING EDUCATION CREDITS ARE NOT BEING OFFERED FOR THIS WEBINAR.

AT THE END, WE HOPE TO HAVE APPROXIMATELY 15 MINUTES FOR Q&A SESSION. WE WILL ADDRESS QUESTIONS AS THEY COME IN. IF YOU HAVE QUESTIONS, PLEASE TYPE THEM INTO THE CHAT BOX AT THE UPPER PART OF YOUR SCREEN. BEFORE WE GET INTO THE MEAT OF TODAY'S DISCUSSION, I WANT TO INTRODUCE OUR SPEAKERS FOR TODAY'S WEBINAR. IN ADDITION TO MYSELF, WE'RE GOING TO FEATURE THREE ADDITIONAL SPEAKERS. AFTER MY PRESENTATION, WE'LL HEAR FROM BARRY JACOBS, DR. JACOBS IS A CLINICAL PSYCHOLOGIST, FAMILY THERAPIST, AUTHOR OF THE BOOK" THE EMOTIONAL SURVIVOR GUIDE OF CAREGIVERS." AS A CLINICIAN, HE SPECIALIZES IN HELPING FAMILIES COPE WITH SERIOUS AND CHRONIC ILLNESS. AS A EDUCATOR, WE WORK AS DIRECTOR OF BEHAVORIAL HEALTH SCIENCE FOR THE CROZER-KEYSTONE CENTER. HAS HAD ADJUNCT FACULTY POSITIONS WITH THE TEMPLE UNIVERSITY SCHOOL OF MEDICINE, AND INSTITUTE OF PSYCHOLOGY. DR. JACOBS HAS DOCTORATE IN CLINICAL PSYCHOLOGY. DR. JACOBS WILL BE FOLLOWED BY DAVID COUN. DR. COUN IS THE ASSOCIATED VICE PROVOST AND PROFESSOR IN THE COLLEGE OF NURSING AND HEALTH INNOVATION AT ARIZONA STATE UNIVERSITY. HIS RESEARCH INTEREST INCLUDE THE DESIGN, EVALUATION AND TRANSLATION OF EFFECTIVE PSYCHOSOCIAL INTERVENTIONS FOR MIDLIFE AND OLDER ADULTS FACING CHRONIC ILLNESS, SUCH AS ALZHEIMER'S SUICIDE, AND HIV AIDS. OUR THIRD SPEAKER IS SARA HONN QUALLS. SHE'S THE KRAEMER FAMILY STUDY OF FAMILY. SHE'S PRACTICING CLINICAL PSYCHOLOGIST WHO HELPED ESTABLISH THE AGING CENTER IN COLORADO SPRINGS WHICH PROVIDE MENTAL HEALTH SERVICES FOR OLDER ADULTS. SHE'S PUBLISHED SIX BOOKS ON MENTAL HEALTH. FOR RESEARCH ON FAMILY DEVELOPMENT FOR CLINICAL INTERVENTIONS FOR FAMILY, INNOVATIVE APPROACHES TO SENIOR HOUSING AND APPLIED TECHNOLOGY, INTERVENTIONS TO IMPROVE THE WELL BEING OF OLDER ADULTS. SHE HAS SERVED ON DR. GOODHART 2011 TASK FORCE FOR ONLINE TOOL FOR PSYCHOLOGIST CALLED APA CAREGIVER BRIEFCASE. BEFORE WE BEGIN I WANT TO THANK THE AMERICAN PSYCHOLOGICAL ASSOCIATION FOR THEIR ASSISTANCE IN DEVELOPING THIS WEBINAR. BEFORE WE DELVE INTO SPECIFICS OF TODAY'S TOPICS, I WANT TO SPEND A FEW MINUTES GETTING EVERYONE ON THE SAME PAGE AND SOME OF THE UNIQUE NEEDS AND CONCERNS OF FAMILY CAREGIVERS WHO PROVIDE CARE FOR PERSONS OF MENTAL ILLNESS. WE KNOW

FAMILY CAREGIVING IS A PREVALENT ISSUE IN THIS COUNTRY. NATIONAL ALLIANCE FOR CAREGIVING STUDIES THE FAMILY OF CAREGIVING WITH INDIVIDUALS. WHEN WE CONSIDER THE TOTALITY OF FAMILY CAREGIVING IN THE U.S., THE NATIONAL ALLIANCE FOUND THAT THERE WERE APPROXIMATELY 65.7 MILLION PEOPLE IN THE U.S. WHO REPORTED BEING A FAMILY CAREGIVER IN 2009 TO ADULT AND CHILDREN WITH SPECIAL NEEDS. WE ALSO KNOW THAT FAMILY CAREGIVING IS AN IMPORTANT PART OF OUR LONG TERM SERVICE HERE IN THE U.S. IT'S ESTIMATED FAMILY CAREGIVERS PROVIDE 80% OF LOCK TIME SERVICES IN THE U.S. THE WORK THEY DO AND WHAT THEY CONTRIBUTE HAS TREMENDOUS MONETARY VALUE AND THAT HAS BEEN ESTIMATED AT ANYWHERE AROUND \$450 BILLION. WHEN WE BEGIN BREAKING DOWN THE CAREGIVERS INTO CERTAIN DEMOGRAPHIC GROUPS, WE ALSO KNOW THERE ARE APPROXIMATELY 43.5 MILLION CAREGIVERS CARING FOR SOMEONE 50 YEARS OF AGE AND OLDER. THERE'S APPROXIMATELY 14.9 MILLION OF THEM WHO CARE FOR SOMEONE WITH ALZHEIMER'S DISEASE OR ANOTHER DEMENTIA. WHAT'S PROBABLY VERY OBVIOUS IS THE TREND THAT'S LIKELY TO CONTINUE IN FAMILY CAREGIVING AS OUR POPULATION AGES, IT'S LIKELY THAT WE'RE GOING TO SEE INCREASE IN NUMBERS OF FAMILY CAREGIVERS AND FAMILY CAREGIVING SITUATIONS. WHILE THESE NUMBERS ARE STAGGERING, THEY DEMONSTRATE THE BREADTH OF THE ISSUE WE'RE FACING. AS OUR POPULATION AGES WE'RE GOING TO SEE, I BELIEVE, A GREAT NUMBER OF FAMILY CAREGIVERS. WE KNOW THAT THERE ARE A LOT OF CAREGIVERS BUT WHO ARE THEY? WE KNOW ALSO THAT FAMILY CAREGIVING IS NOT STRICTLY AN AGING ISSUE. QUITE THE CONTRARY. IT'S A LIFE SPAN ISSUE. WE ALSO KNOW THAT IT ISN'T NECESSARILY JUST A MALE OR FEMALE ISSUE. WE DO KNOW THERE'S A FAIRLY TYPICAL PROFILE OF WHO THE FAMILY CAREGIVER IS. WE KNOW FROM THE RESEARCH THAT'S BECOME DONE BY THE NATIONAL ALLIANCE, THAT CAREGIVERS ARE PREDOMINANTLY FEMALE. WHAT WE'RE SEEING INCREASING NUMBERS OF MEN BECOMING FAMILY CAREGIVERS STEPPING INTO THAT ROLE. WE'RE ALSO SEEING THERE ARE SANDWICH GENERATIONS WHERE YOU HAVE INDIVIDUALS WHO ARE CARING FOR AGING PARENTS AS WELL AS CHILDREN. WE'RE ALSO SEEING INCREASING NUMBERS OF GRANDPARENT AND KINSHIP CAREGIVERS. GRANDPARENTS AND OTHER RELATIVES WHO STEP IN TO RAISE YOUNG CHILDREN. OF COURSE WE'RE SEEING INCREASE IN THE NUMBER OF

FAMILIES PARENT WHO BECOME CAREGIVERS TO OTHER CHILDREN OR OTHER WOUNDED WARRIORS WHO COME BACK FROM THE CONFLICTS OVERSEAS. WE KNOW THERE ARE A LOT OF CAREGIVERS AND WE KNOW OUITE A BIT ABOUT WHO THEY ARE AND WHAT THEY DO. I THINK IT'S FAIRLY EASY TO SAY THAT MOST CAREGIVERS WILL AGREE THEY'LL DO WHATEVER IT TAKES TO CARE FOR THEIR LOVED ONE AT HOME. WE KNOW FAMILY CAREGIVERS COME FROM ALL WALKS OF LIVES. WE ALSO KNOW THAT THE CAREGIVING TASKS THAT THEY DO VARY A GREAT DEAL IN TERMS OF COMPLEXITY AND THE LEVELS OF SKILL REQUIRED. THE TYPES OF THE THINGS THAT FAMILY CAREGIVERS DO FOR THEIR CARE RECIPIENT CAN RANGE FROM BASIC TRANSPORTATION, DOCTORS, GROCERY SHOPPING, BILL PAYING TO THE MORE COMPLEX TASK LIKE MEDICATION MANAGEMENT. ALSO KNOW THAT FAMILY CAREGIVERS SPEND A GREAT DEAL OF TIME DOING WHAT THEY DO BUT ON AVERAGE, IT'S BEEN FOUND THEY SPEND ABOUT 20.4 HOURS PER WEEK PROVIDING THAT CARE. WHILE MOST FAMILIES CAREGIVERS REPORT GETTING A GOOD DEAL OF SATISFACTION OUT OF THE WORK THEY DO, THAT SATISFACTION ALSO COMES WITH A PRICE. THAT PRICE OFTEN THE CAREGIVERS OWN PHYSICAL, EMOTIONAL, AND FINAL WELL BEING. THE IMPACT ON THE PHYSICAL AND EMOTIONAL HEALTH TO FAMILY CAREGIVERS CAN VARY GREATLY FROM INDIVIDUAL TO INDIVIDUAL AND TO SITUATION TO SITUATION. FAMILY CAREGIVERS CAN EXPERIENCE DIFFERENT TYPES OF IMPACT AND VARYING DEGREES. WHAT IS INTERESTING TO NOTE STUDIES HAVE SHOWN FAMILY CAREGIVERS PROVIDING CARE FOR FIVE YEARS OR LONGER, TYPICALLY REPORT THEIR HEALTH TO EITHER FAIR TO POOR. WHILE NOT SPECIFICALLY A FOCUS OF OUR DISCUSSION TODAY. CAREGIVERS IN HIGH BURDEN AND SOCIAL AND EMOTIONAL SITUATION ARE ALSO AT RISK THEMSELVES FOR PROBLEMATIC ALCOHOL AND USE AND ABUSE. FAMILY CAREGIVING WE KNOW CAN BE HIGHLY STRESSFUL. IT'S INTERESTING BUT NOT ALL TOGETHER SURPRISING TO KNOW THAT WOMEN ARE MORE LIKELY THAN MEN TO REPORT EYE STRESS DUE TO CAREGIVING. PROBABLY BECAUSE THERE ARE TYPICALLY ARE MORE WOMEN AND THEY TYPICALLY TEND TO TAKE ON THE MORE COMPLEX TASK IN CAREGIVING SITUATIONS. THE PURPOSE OF OUR DISCUSSION TODAY IT'S INTERESTING TO NOTE THAT CAREGIVING OF THOSE WITH EMOTIONAL AND MENTAL HEALTH PROBLEMS ARE MORE LIKELY THAN THEIR COUNTERPARTS DEALING WITH OTHER ISSUES TO REPORT A DECLINE IN THEIR

HEALTH. AS WE BEGIN TO FOCUS OUR DISCUSSION TODAY ON FAMILY CAREGIVERS AS PARTNERS AND CLIENTS I WANT TO SPEND A MOMENT TALKING ABOUT THE MAGNITUDE THE ISSUE OF MENTAL HEALTH IN U.S. IT'S BEEN ESTIMATED THERE ARE APPROXIMATELY 23.6% OF ADULTS HAVE BEEN DIAGNOSED WITH A MENTAL HEALTH DISABILITY. MENTAL ILLNESS IS KNOWN TO BE A LEADING CAUSE OF DISABILITY AMONG THOSE AGES 15 TO 44. WE ALSO KNOW THAT MENTAL ILLNESS IMPACT MANY AREAS OF INDIVIDUALS AND FAMILY LIFE. IT IMPACTS HEALTH INTERPERSONAL RELATIONSHIPS, MARRIAGES, EMPLOYMENT AND FAMILY LIFE IN GENERAL. IF WE HAD TO PUT A DOLLAR AMOUNT ON IT, STUDIES HAVE SHOWN THAT MENTAL ILLNESS CAN COST ABOUT APPROXIMATELY \$193 BILLION IN LOST WAGES. AS WE LIKELY TO SEE A CONTINUE TREND UPWARDS IT'S PROBABLY NOT TOO FARFETCHED TO ASSUME THAT WE WILL LIKELY SEE THE NUMBER OF SITUATIONS IN WHICH FAMILY CAREGIVING ARE CARING FOR SOMEONE WITH MENTAL ILLNESS INCREASE AS WELL. SOME OF IT MAY HAVE TO DO WITH A POSITIVE REALITY AS WE MOVE FURTHER AWAY FROM INSTITUTIONAL SETTINGS OF THE NORM AND PROMOTING MORE COMMUNITY BASED OPTIONS FOR PERSONS. INDEED, THAT HAS BEEN THE CASE FOR MORE THAN 60S. WE CAN ALL AGREE THAT'S BEEN A VERY POSITIVE TREND. HOWEVER, AS WE EMBRACE THE CONCEPTS OF COMMUNITY BASED LONG TERM CARE AND STRIVE FOR GREATER INTEGRATION, A PERSON OF ALL AGES WILL DISABILITY INTO OUR COMMUNITY, WE MUST ACKNOWLEDGE THAT IN ORDER TO DO THIS EFFECTIVELY, MORE AND MORE FAMILIES WILL BE LIKELY STEPPING IN TO FILL IN THE GAPS. THE NATIONAL ALLIANCE FOR CAREGIVING ALMOST RECENT 2009 STUDY OF FAMILY CAREGIVERS FOUND APPROXIMATELY 32% OF FAMILY CAREGIVERS PROVIDE CARE TO SOMEONE WITH EMOTIONAL OR MENTAL HEALTH CONCERNS. IT'S LIKELY THAT MANY OF YOU THESE INDIVIDUALS WILL REQUIRE MULTIPLE FAMILY MEMBERS TO BECOME INVOLVED IN THEIR CARE. DEPENDING ON THAT RELATIONSHIP, THE DIFFERENT FAMILY MEMBERS WILL LIKELY HAVE DIFFERENT SUPPORT NEEDS AS FAMILY CAREGIVERS. FOR EXAMPLE, HOW THE SPOUSE OF SOMEONE WITH A MENTAL HEALTH INTERACT AND IS IMPACTED BY THE SITUATION MAYBE DIFFERENT FROM HOW A CHILD OR FRIEND OR ANOTHER RELATIVE IS IMPACTED OR DEALS WITH THE SITUATION AT HAND. CAREGIVER BURDEN. I WANT TO TALK ABOUT THAT FOR A MOMENT. THAT'S TYPICALLY THE TERM YOU HEAR MOST FREQUENTLY AS A WAY TO

DESCRIBE THE LEVEL OF DISRUPTION THAT'S CAUSED IN THE LIVES OF FAMILY MEMBERS BY CARE RECIPIENT CONDITION. RESEARCH HAS SHOWN THAT BURDEN CAN BE BOTH OBJECTIVE AND SUBJECTIVE. HOW WE EFFECTIVELY SUPPORT CAREGIVERS AND THOSE INTERVENTIONS THAT WE EMPLOYED CAN OFTEN BECOME DETERMINED BY WHETHER A CAREGIVER BURDEN IS MORE OBJECTIVE OR SUBJECTIVE OR PERHAPS A COMBINATION OF BOTH. WHEN WE TALK ABOUT OBJECTIVE BURDEN, IT'S MORE ABOUT THE EXTERNAL INFLUENCES, THE ECONOMIC ISSUES, THE CAREGIVER HEALTH IMPACTS. WHEN WE TALK ABOUT THE SUBJECTIVE, IT REFERS TO THE AMOUNT OF STRESS, EMOTIONAL, PSYCHOLOGICAL IMPACTS ON THE FAMILY CAREGIVER. THERE IS INDIVIDUALS WITH MENTAL ILLNESS AND SUBSTANCE ABUSE ISSUES DO HAVE SPECIFIC NEEDS AND CONCERNS AS THEY GRAPPLE WITH THE CHALLENGE. MOST NOTABLE IS TYPICALLY ACCESSING SPECIALTY SERVICES OR FINDING AND MAKING USE OF OTHER HOME AND COMMUNITY BASED SERVICES LIKE RESPITE CARE. MOST FAMILY ARE NOT PREPARED TO DEAL WITH THE ILLNESS. THE STRESS ALONE CAN MAKE IT ESPECIALLY DIFFICULT TO MANAGE THE CARE RECIPIENT SYMPTOM OR FOLLOW THEIR TREATMENT PLAN IF THERE IS ONE. ONE STUDY SHOW IN A CAREGIVER IS STRESSED, OTHER CARE RECIPIENT HAS A GREATER DIFFICULTY FOLLOWING THEIR OWN TREATMENT PLAN. BEING A FAMILY CAREGIVER IS DIFFICULT EVEN IN THE BEST OF CIRCUMSTANCES. GIVEN THE FACT THAT MENTAL -- ILLNESS CAN BE UNPREDICTABLE AND ENABLE THEM TO BETTER MANAGE THEIR SITUATION. OUR NEXT SEVERAL PRESENTERS WILL WALK US THROUGH HOW TO ENGAGE FAMILY CAREGIVERS THROUGH THEIR EXPERIENCE. I WILL TURN IT OVER TO DR. JACOBS. >> WHAT I WILL BE TALKING ABOUT IS NUMBER ONE, HOW DO WE GET CAREGIVERS TO USE THE SERVICES THAT WE HAVE TO OFFER THEM. HOW DO WE GET THEM IN THE DOOR. AS YOU LIKELY KNOW, THERE ARE MANY FOLKS PROVIDING CAREGIVING WHO DO NOT IDENTIFY THEMSELVES AS CARE GIVING. ONCE WE GET THEM IN THE DOOR, WE NEED TO FIGURE OUT HOW TO ASSESS THEM HOW WELL THOSE CAREGIVING ARE COPING. WE NEED TO HELP THEM GET HELP FOR THEMSELVES. IN MY EXPERIENCE, MANY CAREGIVERS ARE RELUCTANT TO REACH OUT FOR OR ACCEPT SUPPORT WHEN IT'S OFFERED. FINALLY, I LIKE TO TALK A LITTLE BIT ABOUT WHEN AND HOW TO REFER A FAMILY CAREGIVER TO A MENTAL HEALTH SPECIALIST. I WANT TO TELL YOU A LITTLE BIT ABOUT PSYCHOTHERAPY PATIENT WHO

CAME TO ME NOT LONG AGO. HE'S A 56-YEAR-OLD AFRICAN-AMERICAN MAN WHO'S DOCTOR SENT HIM TO SEE ME FOR ANXIETY AND CAREER BURNOUT. DON INITIAL COMPLAINT TO ME WAS I'M AN ANXIOUS WRECK AT WORK. THE STORY THAT DON TOLD HE'S WORKED IN THE SAME JOB IN A BANK IN A HIGH PRESSURED POSITION FOR OVER TWO DECADES. IN TALKING WITH HIM, I GOT THE IMPRESSION THAT HE HADN'T BEEN STRESSED OUT OVER THE YEARS HE'S BEEN WORKING UNTIL RECENTLY. AT THAT POINT, HE TELL ME, HE FINDS HIMSELF THINKING, WHILE AT WORK, ABOUT HIS MOTHER WHO HAS SEVERE COPD AS WELL AS DEPRESSION AND SPENDS MOST OF THE DAY AT HOME. DON IS PREOCCUPIED WITH HIS MOTHER, HE WOULD BE CALLING HER FIVE TIMES DAY. AS SOON AS HE LEFT WORK, WOULD RUSH TO HER HOUSE AND SPEND TIME WITH HER. WHAT I FOUND WITH DON, HE WAS VERY EMBLEMATIC OF A LOT OF FOLKS OUT THERE DOING CAREGIVING WHO MIGHT BE SO ACCEPTING OF THE HELP THAT WE HAVE TO OFFER. HE SAID HE WAS EMBARRASSED HE FELT TO ANXIOUS WHEN IT WAS HIS MOTHER SUFFERING BECAUSE OF HER MEDICAL CONDITION. WHEN WE TALKED MORE ABOUT HIS SITUATION AS A FAMILY CAREGIVER, HE SAID I DON'T KNOW WHAT A FAMILY CAREGIVER IS. I'M NOT A CAREGIVER, I'M A SON. WHEN I TALKED TO HIM POSSIBLY CALLING AREA AGENCY IN THE COUNTY, HE NEVER HEARD OF A AAA AND, DO MAKE THIS MORE COMPLICATED, HIS MOTHER WAS RELUCTANT TO ACCEPT SERVICES, SHE DIDN'T LIKE THE IDEA OF HOME HEALTH AIDS IN HER MIND STRANGERS COMING INTO HER HOME. SHE DIDN'T WANT TO BE TREATED FOR DEPRESSION. IN HER MIND, THE IDEA OF BEING DEPRESSED WAS STIGMATIZING, AND A FLAW IN HER CHARACTER AND WEAKNESS IN SENSE OF FAITH. DON WAS IN MY OFFICE. DURING THAT INITIAL VISIT, I HAD SIMPLY GIVEN HIM THE PHONE NUMBER TO AAA. THE LIKELIHOOD, HE WOULD NOT HAVE GONE. THE QUESTION IS, HOW DO WE ENGAGE FOLKS LIKE DON IN THE PROCESS OF IDENTIFYING THEMSELVES AS CAREGIVERS AND THEN SEEKING SUPPORT FOR THEMSELVES FOR THE FOLKS THAT THEY ARE CARING FOR. I HAD TO IDEAS LONG THIS LINE. THESE IDEAS I HELP PUT INTO PLACE IN THE FAMILY CAREGIVER SUPPORT PROGRAM IN MY OWN COUNTY IN PHILADELPHIA WHERE I'M ON THE ADVISORY BOARD FOR FAMILY CAREGIVER SUPPORT PROGRAM. ONE IS I DON'T RECOMMEND ADVERTISING CAREGIVER SERVICES. I DON'T RECOMMEND HAVING COMMUNITY EVENTS WHICH TALK ABOUT CAREGIVERS SUPPORT OR

CAREGIVER BURNOUT. INSTEAD, TO HAVE EDUCATIONAL SESSIONS WHICH ARE A LITTLE BIT MORE NEUTRAL IN TONE. TALKING ABOUT TAKING CARE OF AN AGING PARENT OR SPECIFIC DISEASES LIKE DEMENTIA OR DEPRESSION. ONCE YOU GET THEM THROUGH THAT DOOR, YOU CAN BEGIN TO TALK TO THEM ABOUT FAMILY CAREGIVER STRESSES. THE OTHER IDEA I'VE HAD, I COME TO THIS IDEA BECAUSE I WORK IN A LARGE FAMILY MEDICAL PRACTICE OUTSIDE OF PHILADELPHIA. IN SOME WAY USING THE POWER, THE PRESTIGE OF PHYSICIAN TO HELP GIVE A BLESSING TO THE SERVICES THAT WE HAVE TO OFFER IN THE SOCIAL SERVICES AND MENTAL HEALTH FIELD. THE NATIONAL ASSOCIATION OF AGENCY ON AGING, SOME YEARS AGO HAD PUT TOGETHER A PROGRAM CALLED MAKING THE LINK. WHICH WAS ABOUT HOW AAA CAN DEVELOP A RELATIONSHIP WITH PRIMARY CARE PHYSICIANS WITHIN THEIR COMMUNITY. THAT PROGRAM IS STILL AROUND BUT EVEN WITHOUT THAT PROGRAM, I THINK IT'S VERY IMPORTANT FOR ALL OF US TO LET THE PRIMARY CARE PHYSICIANS KNOW WHO WE ARE AND WHAT THE SERVICES ARE. THOSE PRIMARY CARE PHYSICIANS ARE IN AN IDEAL PLACE IN OUR SOCIAL SERVICES AND HEALTHCARE SYSTEM TO GET PEOPLE INTO OUR DOORS. ONCE WE HAVE THEM IN THE DOOR, FIRST THING WE DO IS SO ASSESS THEM. I LIKE TO JUST SHARE A NUMBER OF DIFFERENT RESOURCES WITH YOU ALONG THESE LINES. THE FIRST IS THERE WAS A TASK FORCE PUT TOGETHER BY THE FAMILY CAREGIVER ALLIANCE IN 2006. IT WAS CHAIRED BY MY FRIEND LYNN WHO NOW IS AARP. THAT TASK FORCE THAT SHE CHAIRED GAME UP WITH SEVEN DOMAINS THAT WE NEEDED TO ATTEND TO IN ASSESSING CAREGIVERS. NUMBER ONE OF THE CONTACTS OF CAREGIVERS. WHAT IS GOING ON. NUMBER TWO WHAT THE CAREGIVERS PERCEPTION OF RECIPIENTS NEED. THREE, WHAT THE CAREGIVER VALUES AND MANY OF THOSE ARE SHAPED BY THE SPIRITUAL OF THE CAREGIVER. FOUR, WHAT THE WELL BEING OF THE CAREGIVER. BECAUSE WE WILL TALK MORE ABOUT THIS AFTERNOON, MANY CAREGIVERS ARE SUFFERING BECAUSE IT'S THE CAREGIVING THEIR DOING. NUMBER SIX, WHAT ARE THE CAREGIVERS SPECIFIC SKILLS, ABILITIES AND KNOWLEDGE AND WHAT ARE THE GAPS WE NEED TO ADDRESS. NUMBER SEVEN, WHAT ARE POTENTIAL RESOURCES TO HELP CAREGIVERS. OTHER APPROACH TO ASSESSMENT, MY CO-PRESENTER TODAY, SARA HONN QUALLS HAS A LIST OF QUESTIONS. I LIKE TO SELECT A FEW OF THEM. A GOOD QUESTION BEGIN TO UNDERSTANDING THE EXPERIENCE OF

CAREGIVERS WERE ASSESSING. ASK THEM HOW WILL YOU DESCRIBE YOUR CAREGIVING EXPERIENCE. DO YOU SPEND TIME WITH YOUR FRIENDS AND SOCIAL ACTIVITIES. IT REALLY GIVES US A BEST HANDLE -- DEGREE TO WHICH THEY ARE FEELING BURDENED BY THOSE ROLES. AS YOU MAY KNOW, THERE ARE ALSO A NUMBER OF FORMAL PAPER AND PENCIL INSTRUMENTS FOR CAREGIVERS ASSESSMENT. THESE ARE AVAILABLE, BY THE WAY, IN THE APA CAREGIVER BRIEFCASE. THE MOST WELL USED ONE IS THE CAREGIVING QUESTIONNAIRE AND THE PROCEDURE TO BENEFITS OF CAREGIVING. I JUST WANTED TO SHOW YOU A PAGE FROM THE CAREGIVING BRIEFCASE. THIS IS A PAGE WHICH THERE ARE LINKS TO DIFFERENT ASSESSMENT TOOLS WITH INFORMATION ABOUT THE INDIVIDUAL TOOLS, HOW THEY CAN BE USED. I THINK HAVING A FORMAL ASSESSMENT TOOL IS A VERY GOOD IDEA PART OF YOUR ASSESSMENT PROTOCOL. NOW WE'VE GOT THEM IN THE DOOR, WE'VE ASSESSED THEM. ONE OF THE THINGS WE NEED TO ASSESS IS HOW LIKELY ARE THEY TO TAKE CARE OF THEMSELVES. BECAUSE AS YOU PROBABLY KNOW, CAREGIVERS ARE NOTORIOUSLY KNOWN FOR NEGLECTING THEIR OWN NEEDS. TO THAT POINT, MY PATIENT DON WOULD NEVER HAVE COME TO SEE ME AS A PSYCHOLOGIST. HIS PHYSICIAN HASN'T TWISTED HIS ARM TO DO SO. FOR ME TO SIMPLY TELL DON OR ANY CAREGIVER THAT TAKING OF HIMSELF WILL BETTER ENABLE HIM TO CARE FOR HIS LOVE ONE. IT DOESN'T DO THE TRICK OF HELPING THAT CAREGIVER TO BETTER TAKE CARE OF THEMSELVES. I'VE COME UP WITH THREE IDEAS THAT I WORKED WITH OVER THE YEARS. I WANT TO SHARE THEM WITH YOU VERY BRIEFLY. THERE IS NOT ROCKET SCIENCE. IT'S REALLY MORE OF HOW DO WE GRAB PEOPLE'S ATTENTION AND GET OUR POINT ACROSS TO HELP THEM CARE FOR THEMSELVES. ONE IDEA IS THE METAPHOR. I TALK WITH FOLKS ABOUT HOW PROVIDING CARE FOR A LOVED ONE WITH A CHRONIC ILLNESS, LIKE A MENTAL HEALTH ISSUE, IS LIKE RUNNING A MARATHON. TOO OFTEN CAREGIVERS GO AFTER IT AS IF THEY'RE RUNNING A SPRINT. WHAT THEY NEED TO DO IS LEARN TO PACE THEMSELVES AND SOMETIMES THEY HAVE TO REALLY -- IT'S A TRAINING PROCESS TO LEARN HOW TO PACE THEM. THEY HAVE TO LEARN THE UPHILLS AND DOWNHILLS TO LAY OF THE LAND. THEY HAVE TO LEARN HOW TO REPLENISH THEMSELVES ALONG THE WAY. CAREGIVERS NEED TO GRAB EVERY WATER BOTTLE AND NOT SAY NO THANK YOU I'M NOT THIRSTY AND KEEP RUNNING. ALL OF THESE

SUPPORTS, ALL OF THESE DIFFERENT STRATEGIES FOR RUNNING A MARATHON ARE THE SAME STRATEGIES CAREGIVERS NEED TO USE IN ORDER TO RUN THE VERY BEST RACE THAT THEY CAN. ANOTHER IDEA I'VE USED IN WORKING WITH CAREGIVERS TO ACCEPT HELP IS TO NOT OFFER THEM ADVICE PREMATURELY. IN OTHER WORDS, IF SOMEONE COMES INTO MY OFFICE AND THEY LOOK TERRIBLE AND THEY'RE A CAREGIVER AND CHANCES ARE THEY WILL NEVER USE THEM. BEFORE I DO ANYTHING, I NEED TO INQUIRE WHAT DOES CAREGIVING MEAN TO THEM. WHAT IS THE EXPERIENCE OF BEING CAREGIVER MEANT TO THEM IN THEIR LIVES. OFTEN TIMES PEOPLE SHARE WITH ME THAT THEY FEEL LIKE THEY'RE GIVING BACK TO THEIR LOVED ONE FOR ALL THE THINGS THEIR LOVED ONE DID FOR THEM. SOMETIMES PEOPLE WILL TELL YOU THEY FEEL LIKE THEY'RE DOING GOD'S WORK. SOMETIMES FEEL LIKE THEY WILL TELL YOU NEGATIVE MEANINGS. I THINK THAT WHEN WE -- ESPECIALLY WHEN PEOPLE HAVE POSITIVE MEANING FOR THE CAREGIVING THEIR DOING, WHAT WE WANT TO DO IS HELP SAY TO THEM, THINK WHAT YOU'RE DOING IS A WONDERFUL THING. I WANT TO HONOR THAT SENSE OF MISSION WHAT YOU'RE DOING. THEN I WANT TO HELP YOU DO MORE OF IT AS LONG AS YOU CHOOSE TO DO IT. THEN, I WOULD BRING UP THE ISSUE OF SUSTAINABILITY. I WOULD SAY TO THEM, YOU'RE RUNNING A MARATHON. HOW IS IT YOU'RE GOING TO RUN THIS MARATHON IN A SUSTAIN ALL WAY POSSIBLE SO YOU REALLY DO GET FROM THE BEGINNING TO THE END WHERE YOU LIKE TO. IT'S ONLY AT THAT POINT VERY OFTEN CAREGIVERS THEMSELVES BEGIN TO TALK ABOUT WHAT ARE THE SOURCE OF SUBSTANCE IN THEIR LIVES. AT THAT POINT, THEY REALLY AMENABLE TO ACCEPTABLE SUGGESTIONS FOR THINGS LIKE CAREGIVER SUPPORT GROUPS, ETCETERA. A THIRD IDEA, WHICH I HAVE FOUND HELPFUL, IS TO REALLY TALK WITH CAREGIVERS ABOUT HOW RECEIVING CARE FROM OTHERS IS IN FACT, SOMETIMES A WAY OF GIVING TO OTHERS. I THINK ABOUT THIS ESPECIALLY WHEN I WORK WITH OLDER AMERICANS WHO MAY NOT WANT TO INVOLVE THEIR CHILDREN IN THE CARE OF SOMEONE WHO'S ILL. LET'S SAY A HUSBAND IS TAKING CARE OF A WIFE WITH SEVERE DEPRESSION, THE HUSBAND SAYS, I'M NOT GOING TO ASK MY ADULT CHILDREN TO GET INVOLVED, THEY HAVE THEIR OWN LIVES. I'M QUICK TO SAY TO THEM, IF YOU ASK YOUR CHILDREN TO GET INVOLVED, IN FACT, SURGIERING THEM THE OPPORTUNITY -- YOU'RE GIVING THEM THE OPPORTUNITY TO STEP INTO A ADULT ROLE.

YOU ARE IN FACT, GIVING THEM AN OPPORTUNITY TO MATURE. WITH THAT ARGUMENT, SOMETIMES THOSE CAREGIVERS ARE MORE READILY ACCEPT HELP FROM OTHER FAMILY MEMBERS. I WANT TO TURN SPECIFICALLY TO TALKING ABOUT CAREGIVERS WHO MAY NEED MENTAL HEALTHCARE. PATIENT TO ADD, THE MAJORITY OF CAREGIVERS WILL NEVER NEED FORMAL MENTAL HEALTH SERVICES. THE QUESTION IS WHO DOES? IF THE CAREGIVER IS DEPRESSED, SO ANXIOUS AND SO ANGRY AND GUILTY THAT IT'S AFFECTING THEIR CAPACITY TO FUNCTION, MAYBE FUNCTION EFFECTIVELY IN LIFE. SHORT ANSWER IS THE ISSUE OF SEVERITY. THOSE WHO ARE MOST SEVERELY AFFECTED GET THE MENTAL HEALTH REFERRALS. A TERM YOU WILL PROBABLY HEAR A LOT IS CAREGIVER BURNOUT. I WANT TO DEFINE THAT BRIEFLY. TO ME IT'S A SENSE OF DREAD, IRITABILITY, PEOPLE WHO WAKE UP JUST FEELING LIKE, MY GOD, I DON'T WANT TO DO THIS TODAY. OFTEN HAVE DISTURBED SLEEP AND CONCENTRATION DIFFICULTIES. CAREGIVER BURNOUT IS PRECURSOR TO CLINICAL DEPRESSION. IN MY CASE OF DON, HE CAME IN ANXIOUS AND DISTRACTION AND JUMPY. HE WOULD BE THE PERSON I WOULD BE THINK ABOUT DOES HE NEED THE CRITERIA OF MAJOR DEPRESSION DISORDER. WHEN WE TALK ABOUT MAJOR DEPRESSIVE DISORDERS, THERE ARE SPECIFIC CRITERIAS. THEY INVOLVE THINGS LIKE SADNESS, SLEEP AND APPETITE DISTURBANCES. IT WITH THOSE CRITERIAS THAT WE MAKE THE DIAGNOSIS. WHAT WE SAY ABOUT DEPRESSION, IT'S A DISABLING CONDITION. IT'S AN ILLNESS FOR WHICH PEOPLE NEED TREATMENT. THE BEST TREATMENT WE HAVE ARE PSYCHOTHERAPY AS WELL AS MEDICATION. THE OTHER VERY COMMON DISORDER WHICH WE SEE SOME CAREGIVER SUFFERING IS SEVERE ANXIETY. WHERE THE PERSON -- THE CAREGIVER IS WORRYING PERSISTENTLY AND IT DOESN'T HAVE THE ABILITY TO CONTROL THEIR WORRYING. THEY MAYBE VERY TENSE AND HAVING SLEEP DISTURBANCE, AGAIN THE PRIME TREATMENTS ARE PSYCHOTHERAPY AND MEDICATIONS. WHO DO WE REFER THESE FOLKS TO? WHEN WE IDENTIFY THEM, I THINK IT WOULD BE VERY IMPORTANT TO REFER TO FOLKS WHO UNDERSTAND A LITTLE BIT ABOUT THE STRESSES THAT FAMILY CAREGIVERS ENDURE AS WELL AS THERAPIST WHO ARE MEDICALLY KNOWLEDGEABLE. WE WANT SOMEBODY WHO UNDERSTANDS SOME OF THE CARE RECIPIENT CONDITION, NOT SIMPLY WHAT THE CAREGIVERS MENTAL STATE IS. A GOOD RESOURCE TO THAT IS THE APA LOCATER. IF CAREGIVER IS

RELUCTANT TO GO TO A MENTAL CARE PROVIDER, I SUGGEST THEM GO TO A DOCTOR. THE DOCTOR IS QUALIFIED TO DIAGNOSE THEM AND PRESCRIBE MED CAKE. THE MOST IMPORTANT POINT HERE. WE WANT TO HELP PEOPLE SEE -- ACCEPT MENTAL HEALTHCARE AS A WAY OF RUNNING A BETTER RACE SO THEY CAN PROVIDE THE CARE TO THEIR LOVED ONE THEY WANT TO PROVIDE AND NOT BURN OUT THE PROCESS. THAT IS THE END OF MY PRESENTATION. I LIKE TO TURN IT OVER TO DR. DAVID COUN.

>> THANK YOU BARRY AND GREG. I REALLY APPRECIATE THE OPPORTUNITY TO SPEAK TODAY A LITTLE BIT ABOUT WHAT WE KNOW IN TERMS OF CAREGIVER INTERVENTION FOR OLDER ADULTS. ON THE NEXT SLIDE BEFORE I REALLY DIVE INTO INTERVENTIONS, I WOULD LIKE TO REINFORCE THE CASE FOR CAREGIVING AS A NATIONAL PUBLIC HEALTH PRIORITY. CLEARLY, CAREGIVING AND CAREGIVERS TAKE A UNIOUE AND VALUABLE ROLE IN OUR SOCIETY. WE KNOW THAT THE NUMBER OF CAREGIVERS ARE GOING TO CONTINUE TO GROW. AS ITS GROWN, IT'S GAINED NATIONAL ATTENTION. THE NATIONAL ADOPTION OF PUBLIC HEALTH PRIORITY IS REALLY GUIDED BY SPECIFIC PRINCIPLES AND THOSE PRINCIPLES INCLUDE LARGE BURDEN, MAJOR IMPACT WITH RESPECT TO HEALTHCARE COST OR CONSEQUENCES AND BOTH OF THESE HAVE REALLY BEEN REINFORCED BY GREG AND BARRY'S PRESENTATION. THERE'S ALSO THE POTENTIAL FOR PREVENTION. WHEN PEOPLE SHOW UP AT OUR DOOR, THEY'RE OFTEN ALREADY DISTRESSED, ALREADY UPSET AND MAY BE WE CAN'T HAVE AN ALREADY PREVENTED THAT. DEFINITELY WE KNOW THERE ARE WAYS TO HELP ALLEVIATE AND KEEP IT FROM GETTING WORSE. ON THE NEXT SLIDE, I THINK IT'S ALSO IMPORTANT TO RAISE THE CAREGIVING REALLY IS A HEALTH DISPARITY. THESE FOLKS ARE HIDDEN PATIENT. THEY REALLY ASSESSED FOR THEIR OWN ISSUE AND NEEDS. THEY OFTEN COME WITH MULTIPLE ROLES. IT'S NOT AS IF PEOPLE SHOW UP TO BE A CAREGIVER. THEY ARE WORKERS. THEY ARE GRANDPARENTS. THEY ARE ALL DIFFERENT TYPES OF PEOPLE. THEY LACK ENERGY OR TIME FOR HELP PROMOTING STRATEGIES FOR THEMSELVES. WHEN WE LOOK AT COMPARISONS BETWEEN CAREGIVERS AND NONCAREGIVERS, WE SEE SIGNIFICANT GAPS IN TERMS OF QUALITY OF AIR CAREGIVERS HEALTH. IT'S IMPORTANT TO RECOGNIZE THE DISPARITY EXIST ACROSS GROUPS OF CAREGIVERS AS WELL. THERE ARE DIFFERENCES IN TERMS OF HOW PEOPLE EXPERIENCE CAREGIVING BY RACE AND ETHNICITY

AND IN DIFFERENCE IN SPOUSAL AND ADULT CHILD. ALL OF THIS I THINK REALLY HIGHLIGHTS THE NEED FOR CAREGIVER INTERVENTIONS AND ONGOING WORK AND THE DEVELOPMENT AND TESTING AND TRANSLATION OF CAREGIVING INTERVENTION WORK. WITH REGARD TO INFORMAL CAREGIVING FOR FAMILY AND FRIENDS OLDER ADULTS FACING BEHAVORIAL HEALTH ISSUES, UNFORTUNATELY THE VAST MAJORITY OF INTERVENTION WORK TODAY REALLY HAS FOCUSED ON ALZHEIMER'S DISEASE AND RELATED DEMENTIA. I'M GOING TO USE THAT AS A BACKDROP. CLEARLY WE NEED MORE WORK WITH MENTAL HEALTH ISSUES. I HOPE YOU CAN TAKE WHAT I'M GOING TO TALK ABOUT TODAY AND BEGIN TO THINK ABOUT HOW THAT MIGHT ALSO BE APPLIED INTO OTHER BEHAVORIAL HEALTH CONCERNS. AS WE LOOK AT THE NEXT SLIDE IN TERMS OF THE CHRONIC STRESS TRAJECTORY OF CAREGIVING, IF YOU LOOK ACROSS THE TOP AND WE LOOK AT THE CAREGIVER TRAJECTORY. WE KNOW THERE IS A PERIOD WHERE PEOPLE BEGIN TO INITIATE IDL, S OR MEDICAL APPOINTMENTS AND EXPANDING ROLES WHERE THOSE ACTIVITIES MAY GROW AS WELL AS ACTIVITIES OF DAILY LIVING AND MAKING SURE PEOPLE ARE FED AND CLOTHING PROPERLY ETCETERA. THEN THERE IS A TRAJECTORY WHERE SOME PEOPLE MAYBE PLACED SOME POINT TO AN INSTITUTION OR ASSISTED LIVING FACILITY OR GROUP HOME. THEN THERE IS THE DEATH OF THE CARE RECIPIENT AND THAT TRAJECTORY PLACEMENT MAY NOT ALWAYS OCCUR IN ALL FAMILY SITUATIONS. WHEN WE BEGIN TO MOVE BACK IN TERMS OF LOOKING AND INITIATING IADL AND CAREGIVING ACTIVITY, WE KNOW VERY LITTLE ABOUT THE BEGINNING IN TERMS OF THE IMPACT OF INTERVENTION. THE VAST MAJORITY OF INTERVENTIONS REALLY HAVEN'T FOCUSED HERE AND IT'S THAT PSYCHOLOGICAL APPRAISAL BENIGN. WE DO KNOW WITH SOME OF THE WORK THAT'S BEEN DONE THAT'S REALLY TARGETING THESE KIND OF DYADS OR FAMILIES, MOST OF THE REALLY LOOKED AT IMPACT OF INTERVENTION OF CARE RECIPIENTS. THERE ARE SOME US WHO BEGUN TO LOOK AND SEE THIS AS AN OPPORTUNITY AND FIGURE OUT HOW WE ENGAGE WITH FAMILIES TOGETHER EARLY IN THE PROCESS TO HELP PREVENT STRESS IN THE FUTURE. MY NEXT PART OF MY TALK IS REALLY GOING TO FOCUS ON THIS NEXT STAGE OF THE EXPANDING IDL AND ADL WHERE THE LEVEL OF DISTRESSED THAT WAS TALKED ABOUT AND THE STUDIES THAT HAVE DEMONSTRATED THE STRESS CAREGIVERS MAY DIE FASTER. THAT'S WHERE MOST OF THE CAREGIVING

INTERVENTION RESEARCH HAS OCCURRED TODAY. IN THE NEXT SLIDE, WHAT IS SUCCESSFUL TERMS OF IMPLEMENTING CAREGIVING INTERVENTIONS. THIS OVERALL CATEGORIZATION IS ONE I UTILIZE IN THE VARIETY OF MY WORK. OUR FINDINGS ARE IN LINE WITH MED AD ANALYSIS. THAT IS GROUPING LARGE NUMBER OF STUDIES AND SEEING WHAT THEY IMPACT. WE HAVE USED THE AMERICAN PSYCHOLOGICAL ASSOCIATION CRITERIA TO EVALUATE WHAT HAS HAD THE BEST IMPACT OF CAREGIVING DISTRESSED. IF YOU LOOK AT THE TOP, EDUCATION, CARE MANAGEMENT AND SUPPORT GROUPS. THESE ARE WHAT'S AVAILABLE OUT THERE IN THE COMMUNITY. UNFORTUNATELY IT'S WHAT WE HAVE THE LEAST EVIDENCE IN TERMS OF SUPPORTING IMPACT ON HELPING WITH CAREGIVER DISTRESS. THE NEXT TWO ENVIRONMENTAL AND TECHNOLOGICAL, ENVIRONMENT GOING INTO HOMES AND ENVIRONMENTS REDUCING THE ENVIRONMENTAL PRESS. IMAGINE A PERSON HAS A LOT OF MATERIAL STACKED AROUND, THERE'S NOISE IN THE ENVIRONMENT. HOW DO WE REDUCE THAT THAT HAS A NEGATIVE IMPACT ON OUR LOVED ONE AS WELL AS INCREASE THE SUPPORT AND REDUCE THE STRESS FOR THE CAREGIVER. THERE ARE TECHNOLOGICAL INTERVENTIONS. I'M BEGINNING TO MOVE AWAY FROM THAT AS A CATEGORY, THAT TECHNOLOGY, WHETHER IT'S TELEPHONE AND WEB AND APPLICATIONS. THERE STILL GOING TO BE MARRIED IN SOME CAPACITY WITH EDUCATION OR SOME KIND OF SKILL DEVELOPMENT OR SUPPORT. THE THREE CATEGORIES AT THE BOTTOM, PSYCHOTHERAPY, COUNSELING ARE WHAT I'M GOING TO FOCUS ON NEXT. THESE ARE THREE CATEGORIES THERE'S THE MOST EVIDENT TO DEMONSTRATE THEY HAVE IMPACT ON CAREGIVER DISTRESS. BEFORE I LEAVE THIS SLIDE, PLEASE LET ME REINFORCE, I'M NOT SAYING I DON'T BELIEVE IN EDUCATION, I DON'T BELIEVE IN CARE MANAGEMENT, WE JUST NEED TO FIGURE OUT HOW DO WE HELP ENHANCE OR GET BETTER OUTCOMES OUT OF THERE AND PERHAPS THEY NEED TO BE MARRIED IN SOME CAPACITY WITH OTHER TYPES OF STRATEGIES. WE'LL SEE SOME OF THAT IN THE SLIDES TO COME. THE FIRST CATEGORY ON THE NEXT SLIDE IS PSYCHOTHERAPY COUNSELING. BARRY MENTIONED WE KNOW THEY CAN BE EFFECTIVE. THERE'S EVIDENCE FOR COGNITIVE BEHAVIOR APPROACHES WHERE PEOPLE ARE TAUGHT HOW TO MONITOR AND CHANGE THEIR THINKING AND BEHAVIOR. CAREGIVERS IN THIS SITUATION ARE TYPICALLY SCREENED FOR HIGHER ON GREATER LEVELS OF PSYCHIATRIC MORBIDITY. WITHIN THESE, THERE TENDS TO BE MORE EMPHASIS ON THE DEVELOPMENT AND USE ON THE THERAPEUTIC RELATIONSHIP. ON AVERAGE, THESE THERAPISTS OR INTERVENTIONIST TEND TO HAVE ADVANCED DEGREES. WE DEFINITELY NEED ADDITIONAL STUDIES IN THIS ARENA. THERE ARE SOME PRELIMINARY EVIDENCE APPROACHES PARTICULARLY AS CHANGES BEGINS TO OCCUR THAT LEADS TO GRIEF AND LOSS IN REACTION. ON THE NEXT SLIDE, PSYCHO EDUCATIONAL SKILL TRAINING. THERE IS THE LARGEST CATEGORY. THERE'S A VARIETY OF INTERVENTIONS THAT FOCUSES ON DIFFERENT DEPRESSED TARGET. SUCH AS CARE RECIPIENT, BEHAVIOR MANAGEMENT. THESE EMPHASIZE SKILL BUILDING, TEACHING COPING SKILLS HOW TO MANAGE THE EMOTIONAL AND BEHAVORIAL PROBLEMS. THE TARGET CAN BE THE CARE RECIPIENT OR CAREGIVER OR BOTH. THESE ARE COUPLED WITH BASIC SUPPORT OF EDUCATION IN TERMS OF CAREGIVING ISSUES OR THE DISEASE FOR EXAMPLE, ALZHEIMER'S DISEASE. IT IS NOT DONE AT THE LEVEL THAT YOU'LL SEE IN A MULTICOMPONENT INTERVENTION. EXAMPLES OF THESE INCLUDE -- CAREGIVING PROGRAM, CATHLEEN AND JERRY -- JUST TO NAME A FEW. I AM GOING TO MOVE ON TO THE NEXT SLIDE AND ON THIS NEXT SLIDE, THERE IS -- I WANTED TO USE THIS AS AN EXAMPLE OF HOW THE ALZHEIMER'S DISEASE SUPPORTIVE SERVICES PROGRAM SUPPORTED BY THE AOA HAS SUPPORTED EVIDENCE-BASED AND INNOVATION PROJECTS FOR FAMILY CAREGIVERS. YOU CAN SEE WITH THE MOON AND STARS AND SUNS IT'S AN OPPORTUNITY FOR ORGANIZATIONS WITHIN STATES TO TRANSLATE THESE PROGRAMS AND EMBED THEM INTO THE COMMUNITY. I'M GOING TO TALK LITTLE BIT ABOUT OUR TRANSLATION OF COPING WITH CAREGIVING. THIS MAP ALSO RELATES TO TWO OTHER INTERVENTIONS. ON THE NEXT SLIDE, I TOOK THE COPING WITH CAREGIVING. WHEN I MOVED TO ARIZONA, I TOOK STEVE BACK FROM OUR COMMUNITY PARTNERS AS WELL AS PAST PARTICIPANTS AND PILOT PARTICIPANTS TO BEGIN TO TAILOR MORE FOR ORGANIZATIONS THE COPING WITH CAREGIVING PROJECT. INSTEAD OF HAVING ALL GROUP, WE BEGIN ALTERNATE SKILL GROUPS OVER THE TELEPHONE THE KINDS OF SKILLS PEOPLE WERE LEARNING IN THEIR CLASSES. THIS BUILDS ON THE MOOD MANAGEMENT, STRESS MANAGEMENT, COMMUNICATION, PROBLEM SOLVING, BEHAVIOR MANAGEMENT AND KINDS OF ACTIVITY WE'RE COPING WITH CAREGIVING. THESE GRANTS AND PROJECTS REALLY HELP PARTNERSHIPS. WHAT I THINK IS REALLY IMPORTANT TO REINFORCE, THE TWO

ALZHEIMER'S ASSOCIATION CHAPTERS ACROSS THE STATES OF ARIZONA AND NEVADA, TOOK THIS AND WE TRAINED THEM AND EMBEDDED AND MOVED INTO THEIR PROGRAMMING OF THEIR CHAPTER IN RELATIONSHIP WITH THE AREA AGENCIES TO ASSIST WITH RESPITE WHEN NEEDED BY THE FAMILY MEMBERS TO ATTEND THE GROUP SESSION. WE'RE STILL IN THE MIDDLE OF THIS PROJECT. WE HAVE OUTCOMES COMING IN THE SUMMER BUT OVERALL, THE BENEFITS THAT PEOPLE ARE REPORTING ARE QUITE HIGH WITH OVER 95% REPORTING SIGNIFICANT BENEFIT. I WANT TO THEN TALK A LITTLE BIT ABOUT MULTICOMPONENT INTERVENTIONS WHERE WE INCORPORATE TWO OR MORE, THAT'S THE NEXT SLIDE, INCORPORATE TWO OR MORE CONCEPTUALLY DIFFERENT APPROACHES. THERE ARE ONLY THREE PROJECTS AS WE REVIEWED THE LITERATURE THAT REALLY MET THIS CATEGORY. WE NEED -- IT WARRANTS REPLICATION AS WELL AS LOOKING AT OTHER OPTIONS ABOUT HOW TO BUILD THESE. TWO OF THESE THREE ARE BEING TRANSLATED AS PART OF AOAADSSP EVIDENCE-BASED PROJECT. ON THE NEXT SLIDE, IF I CAN SPEAK TO A MOMENT TO THE NYU CAREGIVER INTERVENTION. THIS ENHANCE COUNSELING AND SUPPORT INTERVENTION REALLY HAS THREE OVER ARCHING COMPONENTS. TWO INDIVIDUAL AND FOUR FAMILY COUNSELING SESSIONS THAT TEACH CAREGIVERS WAYS TO MANAGE THE PATIENT'S BEHAVIOR AND PROMOTE FAMILY COMMUNICATION. IT ALSO PROVIDES EDUCATION AND LENGTHS TO COMMUNITY RESOURCES. THE SECOND COMPONENT IS AN ONGOING SUPPORT GROUP FOR EMOTIONAL SUPPORT IN EDUCATION AND THE THIRD IS AN AD HOC COUNSELING COMPONENT TO HELP MANAGE CRISIS AND VARIOUS CHANGES IN TRANSITION THAT OCCUR OVER TIME. THE NYU CAREGIVER INTERVENTION DEMONSTRATED ITS ABILITY TO -- FOUND AN IMPACT NOT ONLY REDUCING DEPRESSION BUT ALSO ON REDUCING NURSING HOME PLACEMENT. ON THE NEXT SLIDE, THE REACH II INTERVENTION WAS BUILT FROM THE INITIAL REACH PROJECT THAT TOOK COMPONENTS FROM SIX DIFFERENT REACH SITES. WE TOOK THESE COMPONENTS LIKE COMPONENTS FROM COPING WITH CAREGIVING AND THEN CREATED OUR MULTICOMPONENT PACKAGE. SO THIS MULTICOMPONENT INHOME INDIVIDUAL INTERVENTION, AS OPPOSED TO A GROUP-BASED INTERVENTION, IT INVOLVES, EDUCATION AND SKILL TRAINING. HOWEVER IT'S CONFINED WITH TELEPHONE SUPPORT GROUP AS WELL AS COMPUTER TELEPHONE INTEGRATED SYSTEM. IT ALLOWED RAPID DIALING OR CONNECTION TO RESOURCES IN THE

COMMUNITY AND THE ABILITY TO CREATE RESPITE FUNCTION FOR THE PERSON THAT WAS LIVING IN THE HOME WITH THE CAREGIVER. IT ADDRESSED FIVE KEY AREAS THAT ARE LINK TO A CAREGIVER RISK PROFILE. WE USE THAT RISK OR FILE TO TARGET PARTICULAR CAREGIVING CONCERNS. YOU SEE THE FIVE DIFFERENT AREAS LISTED THERE RANGING FROM SAFETY AND SOCIAL SUPPORT TO BEHAVIOR PROBLEMS, THE EMOTIONAL WELL BEING OF THE CAREGIVER AND SELF-CARE AND HEALTH BEHAVIORS. IT'S IMPORTANT TO LET YOU KNOW THAT THIS PARTICULAR INTERVENTION IS ONE THAT HAD THREE DIFFERENT ETHIC AND RACIAL GROUPS. WE REALLY NEED TO ENHANCE OUR WORK IN CAREGIVER INTERVENTIONS IN TERMS OF DIVERSITY. THIS TARGETED HISPANIC, NON-HISPANIC WIDE AND AFRICAN-AMERICAN CAREGIVERS. ON A QUALITY OF LIFE OUTCOME INDICATOR THAT INCORPORATED DEPRESSION, BURDEN, SOCIAL SUPPORT AND PROBLEMS, WE SAW REDUCTION FOR HISPANIC AND NON-HISPANIC CAREGIVERS SHOWING GREATER IMPROVEMENT IN THESE AREAS. IT WAS ALSO TRUE FOR AFRICAN-AMERICAN SPOUSAL CAREGIVERS BUT NOT FOR NON-SPOUSE. WHICH RAISES THE ISSUE THAT THERE'S STILL MORE WORK TO DO. IF WE TURN ON THE NEXT SLIDE WITH THE CHRONIC STRESS TRAJECTORY CAREGIVING, JUST TO REINFORCE IN YOUR MIND WHERE WE ARE. KNOWING NOT THAT MUCH ABOUT INITIATING. WHAT I JUST GONE OVER THE VAST MAJORITY OF CAREGIVING RESEARCH HAS HAPPENED AS MORE EXPANDED LEVEL OF CARE RECIPIENT NEED. ON THE NEXT SLIDE, I LIKE TO TALK A LITTLE BIT ABOUT PLACEMENT. I'M GOING TO USE DATA THAT CAME FROM THE INITIAL REACH PROJECT WHERE WE RECRUITED OVER 1200 FAMILY CAREGIVERS ACROSS THE SIX SITES. REACH FOLLOWED CAREGIVERS AND CARE RECIPIENTS ACROSS 18 MONTHS. SOME OF THOSE CARE RECIPIENTS WERE PLACED DURING THAT TIME PERIOD. IT WON'T COME AS A SURPRISE FOR PEOPLE THAT WORK WITH FAMILY CAREGIVERS. IN RECENT QUALITATIVE WORK THAT I DOING, LOOKING AT PEOPLE THAT LACED THEIR LOVED ONE, THAT FOR SPOUSES, THERE'S AN CREDENTIAL AMOUNT OF LONELINESS AS A PERSON IS PLACED BECAUSE THEY'RE OFTEN LIVING ALONE IN A HOUSE. I THINK THAT MIGHT BE A PICTURE THAT HELPS US UNDERSTAND A LITTLE BIT MORE ABOUT WHAT'S GOING ON HERE WITH PLACEMENT. ANXIETY RESULTS WERE SIMILAR. ON THE NEXT SLIDE THAT I WANTED TO JUST TOUCH ON A LITTLE BIT WE KNOW ABOUT CAREGIVER RESPONSES AFTER CARE RECIPIENT DEATH. I THINK IT

MAYBE SURPRISING TO SEE THE IMPACT OF INTERVENTIONS HERE. THIS IS DRAW FROM THE ORIGINAL REACH PROJECT BECAUSE THE REACH II PROJECT ONLY FOLLOWED PEOPLE FOR SIX MONTHS. THE ORIGINAL REACH PROJECT FOLLOWED PEOPLE FOR 18 MONTHS. WE'VE SEEN THAT IN REACH, THERE WERE SIGNIFICANT DECLINES IN DEPRESSIVE SYMPTOMS AFTER THE DEATH OF A CARE RECIPIENTS. THESE ARE FELL SUBSTANTIALLY BELOW CAREGIVING LEVELS. IT'S INTERESTING TO NOTE INVOLVE ONE OF THE PSYCHOSOCIAL INTERVENTIONS THAT HAVE BEEN HAPPENING AT THE REACH SITE LIKE THE COPING WITH CAREGIVING INTERVENTION, HAD IMPACT ON WHETHER OR NOT THE CAREGIVING COMPLICATED GRIEF. SIMILARLY IN THE NYU CAREGIVING INTERVENTION, INTERVENTION PARTICIPANTS REPORTED FEWER DEPRESSIVE SYMPTOMS AFTER BEREAVEMENT. IF WE LOOK AT THE NEXT SLIDE. I FILLED OUT ACROSS THE CARE CHRONIC STRESS TRAJECTORY. AS WE MOVE INTO PLACEMENT, THERE IS STILL DISTRESS FOR THE CAREGIVING, AND THE NEED FOR REENGAGEMENT WITH OTHERS OUTSIDE OF THEIR CAREGIVING RESPONSIBILITY. AT THE DEATH OF LOVED ONE, THERE IS RELIEF AND RECOVERY FOR THE VAST MAJORITY AFTER THAT. IN CLOSING, I WANT TO LOOK AT THE NEXT COUPLE SLIDES HERE. THE FIRST ONE, FOR A PROGRAM THAT'S SPECIFICALLY TARGETING PEOPLE FACING CARING FOR SOMEBODY WITH OTHER TYPES OF BEHAVORIAL HEALTH OR MENTAL HEALTH CONCERNS. THERE IS A FAMILY TO FAMILY PROGRAM. IT'S A HIGHLY STRUCTURED COURSE THAT MANY OF YOU MAY BE FAMILIAR WITH THAT LAST TWO OR THREE HOURS SESSION FOR 12 WEEKS. IT'S OFFERED BY NAMI TRAINED FAMILY MEMBERS. IT HAS A PROBLEM SOLVING V SKILLS COMPONENTS, COACHING AND THERE HAS BEEN EVIDENCE FOR IMPROVED PROBLEM COPING FOCUS FOR PEOPLE WHO PARTICIPATE IN THIS AS WELL AS KNOWLEDGE ABOUT MENTAL ILLNESS. UNFORTUNATELY THEY DID NOT FIND REDUCTION IN CAREGIVER AND STRESS. THIS HIGHLIGHTS THE NEED FOR FUTURE WORK IN THIS AREA. USING SOMETHING LIKE FAMILY TO FAMILY OR DRAWING FROM WHAT CAN WE LEARN FROM THE SKILL TRAINING AND MULTICOMPONENT INTERVENTION THAT HAVE BEEN TRIED TODAY TO APPLY THEM TO OTHER TYPES OF MENTAL HEALTH AND BEHAVORIAL HEALTH CONCERNS FACED BY OLDER ADULTS. WHAT CAN WE DO FOR THOSE CAREGIVERS IN TERMS OF CHANGING OFFERING OR REPACKAGING INTERVENTION. ON THE FINAL SLIDE THAT I HAVE THAT I'M GOING TO TALK ABOUT, I

REALLY ENCOURAGE A CALL FOR MULTIPLE LEVELS OF INTERVENTION. HOW CAN HEALTHCARE ORGANIZATIONS AND COMMUNITY-BASED ORGANIZATIONS CREATE CARE PATHWAY PARTNERSHIPS THAT WILL BE USEFUL. WE KNOW THERE ARE STRUGGLE ABOUT HANDOFF AMONG US. AT THE COMMUNITY LEVEL, WHAT ABOUT MEDIA CAMPAIGNS INTERVENTIONS WITH CONTINUOUS CARE. AT THE POLICY LEVEL, THERE'S THE AMA, TEN OR SO YEARS AGO, ENCOURAGED THE CAREGIVER SELF-ASSESSMENT TOOL. WE IN ARIZONA AND OTHER STATES ARE REALLY LOOKING AT RESPITE TOOLS TO HELP ASSESS THE CAREGIVER. ALL OF THESE REPRESENT IN MY OPINION, DEPENDING UPON WHERE THEY'RE EMBEDDED SHIFTS IN POLICY. FINALLY, I PROVIDED A SERIES OF SLIDES THAT WILL BE AVAILABLE THAT ARE REFERENCES AND INCLUDE SOME BOOKS, THE RESEARCH ARTICLES I CITED. THE FIRST LINK IS ACTUALLY A LINK TO THE ADSSD PROGRAMS I MENTIONED. THOSE ARE THERE FOR YOU TO REVIEW AFTERWARDS. NOW I LIKE TO TURN IT OVER TO DR. SARA HONN OUALLS. >> THANK YOU, I'M DELIGHTED TO JOIN YOU TODAY ALSO. NEXT SLIDE WILL PROVIDE FOR YOU THE KEY ISSUES I'M GOING TO TALK ABOUT TODAY. I'M GOING TO STEP BACK NOW TO SORT OF CLINICAL ADVANTAGE POINT HERE AND TALK ABOUT THREE COMPLICATING ISSUES. HOW DO YOU DECIDE WHERE TO FOCUS WHEN CAREGIVERS GIVE YOU MANY PROBLEMS IN COMPLICATED SITUATIONS. HOW DO YOU HELP FAMILIES NAVIGATE SERVICE SYSTEM AND HOW DO YOU DEAL WITH PERSONAL CONFLICTS WITHIN THE FAMILY. ON THE NEXT SLIDE, WE CAN THINK ABOUT WHERE YOU BEGIN. IT'S REALLY KEY TO RECOGNIZE THAT FAMILIES DON'T USE OUR LANGUAGE AS BARRY MENTIONED EARLIER, THEY MAY NOT THINK OF THEMSELVES AS CAREGIVERS. THEY'RE FAMILIES DOING WHAT FAMILIES DO. THEY'RE NOT USING OUR LANGUAGE. THEY'RE NOT OFTEN USING MEDICAL LANGUAGE OR SOCIAL SERVICE LANGUAGE FAMILIAR TO US FROM THE SETTINGS THAT WE WORK IN. OFTEN OUR OPPORTUNITY FOR ENGAGEMENT IS BRIEF. THEY TELL US A STORY, THEY GIVE US A CONCERN AND WE HAVE A MOMENT IN TO USE THAT AS A LENS TO ENTER A WIDE RANGE OF CONCERN THAT'S THEY HAVE. IT'S INCUMBENT UPON US TO CONSIDER THE CONTACT OF OUR ENCOUNTER. WHAT'S THE REALISTIC OF THAT MOMENT THAT WE HAVE AND THE CONTEXT WE'RE IN. I ENCOURAGE PEOPLE TO REALLY LISTEN TO THE FOCUS THE STORY. IS IT ON THE CAREGIVER HIM OR HERSELF ABOUT THE STRESS THAT PERSON IS EXPERIENCING. OR

IS THE CAREGIVER IS DISCUSSING CARE RECIPIENT IN CONCERNS OF GETTING ACCESS SERVICES AND MOVE THAT PERSON THROUGH THE CARE SYSTEM. ARE CARE DECISIONS PENDING. THE GENERAL IDEA IS TO TRY TO BUILD AN ALLIANCE AT THIS MOMENT IN TIME THAT WE SHARE WITH THEM IN THE BRIEF -- MOMENT THAT WE HAVE. A REALLY LARGE ISSUE FOR CAREGIVERS IT'S CHALLENGING FOR THEM TO INTERFACE WITH SERVICE SYSTEMS. MOST OF US AT ANY POINT IN OUR ATTEMPT DEVELOPMENT, DON'T KNOW ABOUT THE NEXT STAGE OF FAMILY DEVELOPMENT AND ALL THE RESOURCES RELEVANT TO IT. FIGURED OUT ON A NEED TO KNOW BASIS. CAREGIVERS ARE PERSONS -- CAREGIVERS REALLY DISCOVERED THE SERVICE SYSTEM RIGHT WHEN THEY'RE IN THE MOMENT OF GREATEST NEED. THEY COME TOO THAT MOMENT WITH A DIFFERENT LANGUAGE AND OFTEN DIFFERENT FRAME. INEVITABLY THEY GET FRUSTRATED AND OFTEN THE SERVICE SYSTEM CAN GET FRUSTRATED WITH THEM AS WELL. THEY CAN END UP BEING MUTUAL BLAME AND DISCONNECTION AND STRESS FOR EVERYONE INVOLVED JUST IN THE PROCESS OF TRYING TO ENGAGE AND GETTING SERVICES. FAMILY QUESTIONS ARE VERY PRACTICAL. THEY COME INTO THE SYSTEMS WITH VERY PRACTICAL QUESTIONS. WHEN SHOULD I BE WORRIED. DO I KNOW THAT THIS IS THE MOMENT TO STEP IN. HOW DO I KNOW. HOW I KNOW WHAT'S REALLY GOING ON AT HOME WHEN I'M NOT THERE. HOW MUCH RISK IS THERE. YES HE'S EXPLODING MORE OFTEN THAN ANGER. I'M OVERWHELMED OR MY FAMILY MEMBERS AND I WHO ARE SHARING THIS CARE DISAGREE ABOUT WHAT NEEDS TO HAPPEN. WHAT DO WE DO ABOUT THAT. ALTHOUGH THE FAMILY QUESTIONS ARE PRACTICAL, THEIR OFTEN ENDS UP BEING THIS DISCONNECT BETWEEN WHAT THE FAMILY IS SEEKING AND WHAT THE SERVICE SYSTEM IS PROVIDING. IN THIS PARTICULAR SLIDE, WE'RE THINKING ABOUT THE HEALTH SYSTEM. THE FAMILY MAY ASK THE QUESTION, WHY WON'T THEY TALK TO ME. I'M THE ONE WHO HAS TO TAKE CARE OF HER. WHY DON'T THEY TELL ME ABOUT ALL THE OPTIONS. OR, THEY THINK I HAVE A LOT MORE CONTROL OVER THIS PERSON THAN I DO. ON THE OTHER HAND, THE HEALTH SYSTEM MAY BE ARTICULATING STATEMENTS BEHIND THE SCENES LIKE, WE CAN'T TALK TO THE FAMILY. THIS IS THE PATIENT WHO'S IN CHARGE OF HIS OR HER LIFE. IF THE FAMILY WERE INVOLVED IN A BETTER WAY, SHE WOULDN'T BE STRUGGLING SO MUCH. OR WHY WON'T THE FAMILY LET US DO OUR JOB. WE TRYING TO TAKE CARE OF

THIS PERSON AS BEST WE CAN. OR FAMILY NEEDS TO TAKE MORE CHARGE OR ELSE THIS PERSON WILL NEVER GET THEIR FEET ON THE GROUND. A SIMILAR DISCONNECT ON THE NEXT SLIDE CAN BE ILLUSTRATED IN THE HOUSING SYSTEM. I'M USING THIS AS AN ILLUSTRATION. THE FAMILY EXPERIENCES ALL TYPES OF CHALLENGES IN THAT SYSTEM BECAUSE WALK IN WHERE SOMETHING MAYBE LIVING AND SEEING FOR EXAMPLE, SHE'S SITTING FOR HOURS. I THINK IN THIS SETTING, SHE NEEDS A BATH OR A FEEDING. WHY DO THE STAFF RESENT ME FOR BEING THERE. HOW COME PEOPLE DON'T SEEM TO KNOW WHAT'S GOING ON. ON THE OTHER HAND, HOUSING PROVIDERS MAY BE TAKING THE POSITION OF WELL, FAMILIES WANT US TO CARE FOR THEIR LOVED ONES AS IF THEIR THE ONLY PERSON WE HAVE. WE HAVE A LOT OF CLIENTS. WHY CAN'T THEY LET US DO OUR JOB. IT'S A HANDOFF AND IT'S MY TURN TO TAKE CARE IF THEY ASK ME. OR I DREAD SEEING THE FAMILY COME IN BECAUSE I KNOW THEY WILL FIND SOMETHING WRONG TO TALK ABOUT. THESE KIND OF DISCONNECTS, REFLECTS DIFFERENT LANGUAGES AND OUR WORK FROM CAREGIVERS CAN BENEFIT FROM US COACHING THE CAREGIVERS. WE KNOW AS PROFESSIONALS THAT THE SERVICE SYSTEMS ARE COMPLEX AND REQUIRES SUPPORT FOR SUCCESSFUL NAVIGATION. CERTAINLY THE FAMILY ARE GOING TO NEED HELP. MOST SYSTEMS HAVE MULTIPLE POINTS OF ENTRY. ONCE ENTERED AT WHATEVER THAT POINT OF ENTRY IS THAT ONE FINDS, THERE'S OFTEN A LACK OF CLEAR PATHWAY. NO SINGLE PROVIDER OWNS THE PROBLEM. I ALWAYS SAY WHEN THE DAY IS DONE, THE FAMILY OWNS THE PROBLEM. AT 5:00 ON FRIDAY WITH THE DISCHARGE, THE FAMILY IS SUPPOSE TO FIND THE SOLUTION. FAMILIES DON'T ALWAYS UNDERSTAND THAT THE PROVIDERS ARE DEFINING THEIR ROLES FAIRLY SPECIFICALLY WHEREAS THE FAMILIES VIEW THEIR ROLES AS BROADER. THAT CAN LEAVE SOME DISCONNECT IF THE FAMILY ISN'T COACHED HOW TO WORK THEIR WAY THROUGH THE SYSTEM. TO THE BEST OF OUR ABILITY, IT HELPS IF WE CAN MAKE THE SYSTEM USER FRIENDLY. REALLY OFFERING VERY CLEAR PATHWAYS TO HELP. TELL PEOPLE THE EXACT LOCATION AND WHAT TO EXPECT FROM THE SERVICE. GIVING THEM SPECIFIC CONTACT INFORMATION AS WE CAN. MAY BE EVEN ANTICIPATING WHAT WON'T BE THERE AT THAT NEXT SERVICE STEP IN THE WAY THAT THE FAMILY MEMBER MIGHT HOPE IT WILL. OFFERING THE FAMILY THE OPTION TO RETURN IF THEY LOSE THEIR WAY THAT THAT PROCESS. CERTAINLY OFFERING STRATEGIES WITH SUCCESS. CAREGIVERS ARE VERY FOCUSED ON PRACTICAL. WELL, HE'S NEVER GOING TO GO TO THE DOCTOR OR SHE WON'T TAKE HER MEDICINE. I THINK IT'S VERY HELPFUL IF WE CAN FOCUS ON THOSE WHAT THEY NEED TO DO AND COACH THEM ON HOW TO DO IT. THE THIRD POINT I WANT TO TALK ABOUT A LITTLE BIT IS WHEN WE GOT INTERPERSONAL CAREGIVING CONFLICTS. OFTEN WHEN I WORK WITH FAMILIES I HAVE MORE THAN ONE PERSON IN THE ROOM. WHEN THAT HAPPENS, IT'S VERY COMMON THAT PEOPLE HAVE DIFFERENT IDEAS ABOUT WHAT OUGHT TO HAPPEN FOR THE CARE RECIPIENT. I'VE LEARNED TO START WITH SOME VALUES CLARIFICATION. WHAT DO YOU WANT MOST FOR THE CARE RECIPIENT. I LISTEN CAREFULLY FOR THE ALMOST UNIVERSAL DILEMMA THAT FAMILY MEMBERS END UP EXPRESSING ABOUT THEIR DESIRE FOR BOTH INDEPENDENCE AND SAFETY AS GUIDING VALUES. WHEN I HEAR THAT IN INDIVIDUAL AFTER INDIVIDUAL, I CAN THEN SUMMARIZE THAT WHAT WE ALL HEARD. LIKE, NAMING THE -- AMBIVALENCE. WE WANT OUR FAMILY MEMBER TO BE SAFE. I ALSO NOTICE WHEN PARTICULAR FAMILY MEMBERS HAVE BECOME THE VOICES FOR ONE SIDE OR THE OTHER OFTEN ONE FAMILY MEMBER IS QUICK TO NOTICE WHEN INDEPENDENT MIGHT BE CONSTRAINED WHEREAS ANOTHER FAMILY MEMBER IS OUICK TO NOTICE WHEN SAFETY MIGHT BE AT RISK. THAT MAY COME OUT WITHIN THE FAMILY AS YOU JUST DON'T CARE OR YOU'RE ALWAYS TRYING TO TAKE CONTROL. I REFRAME THOSE AS SIMPLY THE VOICES THAT THESE FAMILY MEMBERS HAVE DEVELOPED THAT ARE EXPERTS FOR ONE SIDE OF THAT AMBIVALENCE TO THE OTHER. WE ALL SHARE BOTH SIDES. I WELCOME YOU TO COMMENT WHEN YOUR VOICE OF EXPERTISE IS READY IN THE FAMILY. IT KIND OF DEPATHOLOGYIZE THAT CONFLICT AND MOVE AWAY FROM INFLECTING THAT AMBIVALENCE. KEEPING IN MIND THAT THE FAMILY THAT'S WE WORK WITH OFTEN HAVE A VERY LONG HISTORY. THE RELATIONSHIPS ARE DECADES OLD. OFTEN, WE'RE SEEING THE DYNAMICS THAT WERE IN PLACE STEAL BETWEEN SIBLINGS AT THE TIME THEY LEFT HOME. THAT WAS THE LAST TIME THEY WERE REALLY TOGETHER. THEY HAVE NOT PROBABLY DONE ANY SIGNIFICANT PROBLEM SOLVING TOGETHER THAT WAS MORE COMPREHENSIVE THAN PLANNING A HOLIDAY EVENT. GIVEN THE PERSONALITIES ARE RELATIVELY STABLE, WE REALLY CUE EACH OTHER FOR THOSE OLD DYNAMICS. IT'S VERY EASY FOR THEM TO GO BACK INTO THEM AND MAKE STATEMENTS

LIKE, YOU ALWAYS, OR EVEN WHEN WE WERE KIDS. YET, OUR WORK WANTS TO FOCUS NOT ON THE 20 OR 30-YEAR-OLD CONFLICTS, WE'RE FOCUSED IN THE HERE AND NOW. THE NEXT SLIDE, I WORK ON REALLY HELPING THE FAMILY GET FOCUSED IN ON WHAT IS THE CHALLENGE OF THIS MOMENT RECOGNIZING THAT WHATEVER THE CAREGIVING CHALLENGE OF THE MOMENT IS, IT SITS SMACK AT THE INTERSECTION OF INDIVIDUALS, DEVELOPMENTAL TRAJECTORIES THEY HAVE THEIR OWN THINGS GOING ON. THE STRESSES AND OPPORTUNITIES OF THIS MOMENT THROUGHOUT THEIR LIVES, INCLUDING CAREGIVING, AND THEN THE FAMILY DEVELOPMENT STAGE THAT EACH PERSON IS IN. A DAUGHTER OR SON OF AN AGING CARE RECIPIENT MIGHT ALSO BE LAUNCHING A CARE RECIPIENT. WHEN I WORK WITH CAREGIVERS, I TRY TO END MY INTERVENTION EPISODE AND I THINK OF IT AS EPISODE INTERVENTION BECAUSE THEY OFTEN NEED TO CYCLE BACK THROUGH WHEN THE NEXT STRESSOR OCCURS. BY INVITING THEM TO WIDEN THEIR LENS. TO THINK ABOUT THE CAREGIVING AND THE APPROACH THEY HAVE TAKEN AND THE PROBLEM SOLVING RESULT IN A ROLE STRUCTURE. HOW DOES THAT ROLE STRUCTURE FIT WITHIN THE OTHER ROLES CAREGIVERS LIFE. I TRY TO HELP THEM THINK ABOUT MAPPING OUT THE CAREGIVING STRUCTURE WITH THE FAMILY AS A WHOLE. WHO'S DOING WHAT AND WHO'S ROLE FIT WHERE. THEN LOOK AT THE BROADER IMPACT ON THE STRUCTURE OF ALL THE FAMILY MEMBERS. BEYOND THE CAREGIVER AND CARE RECIPIENT HOW DO CAREGIVING STRUCTURE INFLUENCE OTHER FAMILY MEMBERS. WHAT WE DON'T WANT TO DO IS SET UP A CAREGIVING STRUCTURE THAT THE CAREGIVER CAN IMPLEMENT SUCCESSFULLY BUT GREAT COST TO TEENAGERS AND THE FAMILY OR OTHER CARE RECIPIENTS. JUST PAUSING TO SORT OF THINK FOR A MOMENT THROUGH THIS WIDER LENS WHO'S DEVELOPMENT MIGHT BE AT RISK FROM THIS CAREGIVING STRUCTURE AND THE WAY THEY PUT IT TOGETHER, CAN BE REALLY PRODUCTIVE TO HEAD OFF SOME PROBLEMS THAT COULD ARISE OTHERWISE. IN SOME, I'M ALWAYS LOOKING FOR THE SMALLEST CHANGE IN A FAMILY THAT WILL MAKE A DIFFERENCE. SOMETIMES WE NEED TO TEACH COMPREHENSIVE SKILLS AND SOMETIMES WE NEED TO GIVE EDUCATION. IN CONFLICTED FAMILIES WHAT WE KNOW IS THAT THE WHEEL REALLY DOES END UP TAKING A GOOD BIT OF OUR TIME. 20% OF THE FAMILIES WILL DOMINATE OUR CLINICAL PRACTICE OR OUR SERVICE DELIVERY SYSTEM BECAUSE THEY ARE LONG TERM

MESSY FAMILIES OR THEY ARE FILLED WITH PERSONALITY DISORDERS. IT REALLY HELPS
ME TO GET GROUNDED TO COME BACK TO MOVING IN SMALL STEPS. WHAT CAN I DO, WHAT
CAN'T I DO. SOMETIMES THINKING STRATEGICALLY, AGAIN THE SMALLEST CHANGE THAT
CAN MAKE A DIFFERENCE. THE THAT'S THING I'M EVENING GO COMMENT ABOUT THE
DEVELOPMENT OF CAREGIVING BRIEFCASE. IT IS A VERY RICH RESOURCE THAT RESIDES ON
THE WEBSITE OF AMERICAN PSYCHOLOGICAL ASSOCIATION. YOU CAN SEE THE ADDRESS
THERE. IT PROVIDES ALL KINDS OF BACKGROUND INFORMATION ON FACTS AND STRATEGIES
AND SUMMARIZES THE RESEARCH PROVIDES SOME SUGGESTION ABOUT PRACTICAL ISSUES IF
YOU'RE A MENTAL HEALTH PROVIDER, HOW DO YOU BUILD FOR THAT AND WHAT CAN'T YOU DO
AND WHAT ARE SOME UNIQUE ETHICAL ISSUES ARRIVES. I WILL INVITE YOU TO USE THAT
RESOURCE AS IT IS USEFUL TO YOU. NOW I'M READY TO TURN THIS BACK TO GREG LINK.
THANK YOU.

>> THANK YOU SARA. THANK YOU ALSO TO BARRY AND DAVID FOR ALL THE GREAT INFORMATION THAT EACH OF YOUR PRESENTATIONS CONTAIN. EVERYONE ON THIS WEBINAR CAN AGREE THAT WE DEALING WITH A VERY MULTIFACETED AND COMPLEX ISSUE. I ALSO THINK IT'S SAFE TO SAY THAT BECAUSE OF THAT WE LIKELY NEED MULTIFACETED, VERY PERSON CENTERED APPROACHES AS WE EXPLORE THE BEST POSSIBLE WAYS FOR ADDRESSING FAMILY CAREGIVER NEEDS NO MATTER WHAT THEIR SITUATION. WE LEARNED TODAY ABOUT A NUMBER OF VERY WELL TESTED, WELL DEVELOPED INTERVENTIONS AND HOW THOSE COULD BE ADAPTED AND APPLIED TO CAREGIVERS OF INDIVIDUALS WITH BEHAVORIAL HEALTH ISSUES. I ALSO THINK WE KNOW THERE'S LIKELY -- WE KNOW OF GOOD INTERVENTIONS AND APPROACH THAT'S NEED RESEARCH. BEFORE I OPEN THE LINES FOR QUESTIONS, I WANT TO TALK A COUPLE MINUTES ON THE NEXT SLIDE ABOUT THE CURRENT FAMILY CAREGIVER SUPPORT LANDSCAPE IN THE U.S. I KNOW THAT WE HAVE A LOT OF FOLKS ON THE LINE LISTENING. MANY OF WHOM WORK IN THE BEHAVORIAL HEALTH SYSTEM, MANY WHOM WORK IN THE BEHAVORIAL HEALTH SYSTEMS. I LIKE TO USE THIS TIME TO HELP EVERYONE HOPEFULLY THINK ABOUT SOME OF THE PARTNERSHIP OPPORTUNITIES THAT ARE OUT THERE AND AVAILABLE TO THEM. CURRENTLY WE HAVE A NUMBER OF FEDERAL PROGRAMS THAT SUPPORT FAMILY CAREGIVERS IN SOME WAY. I HEARD A COUPLE FOLKS MENTION THE

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM. I'LL TALK A LITTLE BIT ABOUT THAT IN A JUST A COUPLE MINUTES. WE HAVE DIRECT SERVICE PROGRAMS AND SERVICES AVAILABLE LIKE RESPITE THAT MAY BE SOME DEFINITE BENEFIT AS PART OF THEIR OVER ALL APPROACH TO SUPPORTING THEIR NEED. THEN WE HAVE SPECIFIC PROGRAMS BUILT AROUND CONDITION SUCH AS ALZHEIMER'S AND DEMENTIA. THEN AS WE ALL KNOW, MANY STATES HAVE THEIR DISCREET PROGRAM THAT'S MAYBE LIKELY PARTNERS. I JUST WANT TO TALK FOR A QUICK SECOND ABOUT THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM. IT IS A PROGRAM THAT'S AVAILABLE IN EVERY STATE AND TERRITORY. IT WAS CREATED AS PART OF THE 2000 REAUTHORIZATION OF OLD AMERICAN ACT. IT CONTAINS TWO COMPONENTS. IN 2006, THE OLD AMERICA'S ACT WAS REAUTHORIZED AND THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM WAS MODIFIED A LITTLE BIT TO EXPAND SOME OF THE AGE GROUP AND CATEGORIES TO INDIVIDUALS THAT CAN BE SERVED. A FEW THINGS TO NOTE ABOUT THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM, IT FOCUSES ON THE FAMILY MEMBER AS THE SERVICE RECIPIENT. THE CAREGIVER PROGRAM HAD A GENESIS IN WORK DONE PREVIOUSLY IN A NUMBER OF STATES TO SUPPORT FAMILY CAREGIVERS. IT HAS A PACKAGE OF FIVE SERVICES DEMONSTRATED TO BE OF MOST USE AND VALUE TO FAMILY CAREGIVERS. WHAT'S MOST IMPORTANT, IT'S INTEGRATED WITHIN THE STRUCTURE OF AGING AND SERVICES NETWORK. IT'S WITHIN THAT NETWORK AND WITHIN THAT STRUCTURE THAT I THINK WE HAVE THE OPPORTUNITY FOR PARTNERSHIPS ACROSS BEHAVORIAL HEALTH PROGRAMS AND ACROSS OTHER SERVICE PROGRAMS TO BEST MEET THE NEEDS OF FAMILY CAREGIVERS. I PUT UP HERE JUST THE REQUIRED SERVICES THAT ARE AVAILABLE UNDER THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAMS. I THINK WE HAVE A LOT OF OPPORTUNITIES WITHIN THE COUNSELING SUPPORT GROUP AND TRAINING SERVICE CATEGORY FOR 3E TO LOOK FOR TAPPING INTO SOME OF THE GREAT WORK THAT HAS BEEN DONE WITH ALZHEIMER'S DISEASE SUPPORTIVE SERVICES, PROGRAM AND SOME OTHER BEHAVORIAL HEALTH INTERVENTIONS THAT MAY BE IN EXISTENCE FOR EXPLORING WAYS TO BETTER SERVE FAMILY CAREGIVERS. FINAL SLIDE. I LEAVE THIS SLIDE AS THE LAST ONE. WHAT WE TALK ABOUT SOME OF THE PARTNERSHIP OPPORTUNITY THAT'S COULD EXIST BETWEEN THE AGING NETWORK. WE HAVE OUR STATE UNITS ON AGING. I THINK IT'S ALSO SOME

TREMENDOUS OPPORTUNITIES FOR MENTAL HEALTH SERVICE PROGRAMS AND PROVIDERS

THROUGH PARTNER WITH CAREGIVER SUPPORT PROGRAMS WITH STATE CAREGIVER COALITIONS

WITH LOCAL CAREGIVER COALITIONS AND THE RESPITE COALITION AS WELL AS EXPLORING

WITH THESE PROGRAMS THE BEST WAYS TO DEVELOP SUPPORT GROUP OPTIONS, IMPLEMENT

TRAINING PROGRAMS FOR FAMILY CAREGIVERS AND THE CARE RECIPIENT AS WELL AS

EDUCATION OPPORTUNITIES. I WANT TO THANK EVERYONE FOR YOUR ATTENTION DURING THE

WEBINAR. I WANT TO MOVE NOW TO THE QUESTION AND ANSWER PORTION OF THIS WEBINAR

FOR THE TIME THAT WE HAVE LEFT. YOU CAN TYPE YOUR QUESTIONS INTO THE CHAT BOX

FEATURE. THEN OUR HOST WILL SELECT THE QUESTIONS AND READ THEM AND THE

PRESENTERS WILL HAVE THE OPPORTUNITY TO RESPOND.

>> THANK YOU GREG. FIRST QUESTION IS ABOUT MEDITATION. DO THE PRESENTERS HAVE
ANY COMMENT ON MEDITATION AS AN INTERVENTION? LIKE THE MINDFUL BASE, STRESS
REDUCTION OR MINDFULNESS BASE COGNITIVE THERAPY. DO YOU HAVE ANY ADDITIONAL
COMMENTS ON THESE INTERVENTIONS THAT YOU LIKE TO SHARE? ANY OF THE PRESENTERS
CAN RESPOND.

>> SURE. THIS IS DAVID COUN. I GUESS THE ONE COMMENT I WOULD MAKE, THERE ARE A NUMBER OF PROGRAMS THAT HAVE INCORPORATED MINDFUL BREATH AS PART OF STRESS REDUCTION. NOT NECESSARILY THE EXACT APPROACH YOU'RE TALKING ABOUT. THERE'S BEEN EVIDENCE OF PEOPLE USING MEDITATIVE WORK ALONG WITH YOGA TO HELP REDUCE STRESS. I THINK THAT THERE'S AN OPPORTUNITY FOR HERE AND THERE'S BEEN SOME PRELIMINARY WORK BUT I HAVEN'T SEEN THE KIND OF SAME LEVEL THAT WE WERE USING TO COMPARE THINGS THAT I WAS USING TO COMPARE THINGS. BARRY AND SARA MAY HAVE COMMENTS AS WELL.

>> THIS IS BARRY. I THINK THE MEDITATION IN GEM AS DAVID SAID IS STRESS
REDUCTION. I ALSO THINK THAT CERTAIN MEDITATIONS WHICH AIM AT WHAT'S CALLED
NONREACTIVE AWARENESS, IS A VERY IMPORTANT SKILL FOR CAREGIVERS TO HAVE. TO BE
ABLE TO OBSERVE THE CARE. THAT ALLOWS CAREGIVERS TO REALLY CONSERVE THEIR
ENERGY AND FUNCTION MORE EFFECTIVELY. I THINK MEDITATION HELPS FOSTER THAT.

- >> THANK YOU. OUR NEXT QUESTION IS, WHAT DO YOU THINK ABOUT A CENTRALIZED

 CAREGIVER SUPPORT THROUGH A SPECIALIZATION THROUGH CERTIFICATION THAT WILL TRAIN

 FOLKS TO EITHER WORK DIRECTLY WITH FAMILIES AND INFORMAL CAREGIVERS BECOME

 ACTIVIST IN THEIR COMMUNITY AND CREATE EVIDENCE-BASED PROGRAMS? GENERAL COMMENT

 ABOUT THAT?
- >> THIS IS GREG. I THINK THAT'S AN INTERESTING CONCEPT AND ONE THAT MAYBE WORTH EXPLORING A BIT MORE. I THINK ANY METHOD THAT WE CAN USE TO REACH OUT TO FAMILY CAREGIVERS TO INFORM THEM AND EDUCATE THEM ABOUT THE FACT WHAT THEY ARE DOING IS CAREGIVING. THEIR LIKELY TO BECOME STRESSED AND WOULD LIKELY BENEFIT FROM SOME TYPE OF INTERVENTION, I THINK WOULD BE A GREAT IDEA. I ALSO THINK THAT IT TAKES SOME SPECIAL TRAINING TO EFFECTIVELY WORK WITH FAMILY CAREGIVERS IN ANY NUMBER OF SITUATIONS.
- >> THANK YOU. OUR NEXT QUESTION IS, I WORK IN A RURAL STATE, SOUTH DAKOTA, DO
 YOU HAVE ANY COMMENTS ON PROVIDING CAREGIVER SUPPORT SUCH AS RESPITE, EDUCATION
 ETCETERA IN RURAL AND FRONTIER AREAS OF THE COUNTRY?
- >> WELL, THIS IS GREG. AGAIN, I CAN SPEAK FROM THE EXPERIENCE THAT WE'VE HAD IN IMPLEMENTING THE LIFE SPAN RESPITE CARE PROGRAM. THE WHOLE FUNCTION OF THAT PROGRAM IS TO INCREASE THE AVAILABILITY RESPITE CARE SERVICES. IT CAN BE DONE IN ANY NUMBER OF WAYS. WE HAVE A NUMBER OF RURAL STATES WHO HAVE USED THEIR LIFE SPAN RESPITE CARE GRANTS TO DEVELOP VOUCHER PROGRAMS AND OTHER CONSUMER DIRECTED OPTIONS FOR RESPITE SERVICES WHETHER IT'S PAYING NEIGHBORS OR FRIENDS OR OTHER FAMILY MEMBER WHO MAY LIVE CLOSE BY TO PROVIDE THAT RESPITE CARE. OR EXPLORING THE POSSIBILITY OF DEVELOPING VOLUNTEER SOURCES THROUGH FAITH-BASED COMMUNITY AND OTHER COMMUNITY SERVICE ORGANIZATIONS AS SOURCES OF RESPITE CARE. A COUPLE OF THE STATES THAT I WORKED WITH HAVE ALSO WORKED CLOSELY WITH THEIR UNIVERSITY SYSTEMS AS A VOLUNTEER SOURCE OF RESPITE. STUDENTS WHO ARE COMPLETING HUMAN SERVICES DEGREES, WHO MAY HAVE A VOLUNTEER REQUIREMENT FOR THEIR DEGREE, THEY'VE BEEN TRAINED AS RESPITE CARE PROVIDERS IN CERTAIN SITUATIONS. THEY FULFILL THEIR VOLUNTEER REQUIREMENT AND THEY'RE ABLE TO

PROVIDE RESPITE. THERE ARE A NUMBER OF OPTIONS I'D BE HAPPY TO TALK WITH YOU MORE ABOUT WHERE YOU CAN FIND MORE INFORMATION ABOUT THAT.

>> I WAS GOING TO SAY I THINK THE IDEA OF LOOKING FOR PLACES WHERE PEOPLE ARE RECEIVING SERVICES IS REALLY KEY. BARRY JACOBS EMPHASIZES PRIMARY CARE. THERE ARE A LOT OF PEOPLE PROVIDING SUPPORT TO FAMILY MEMBERS WHO ARE CAREGIVERS. WE CAN FIND THOSE FOLKS AND GET SOME TRAINING TO THEM, THEY CAN NOT ONLY DO RESPITE, THEY CAN PROVIDE SUPPORT EDUCATION AND NAVIGATION SUPPORT AS WELL. >> I GUESS I WOULD SAY THAT WE HAVE SUCCESSFULLY OR THE CHAPTERS HAVE SUCCESSFULLY NAVIGATED. IF YOU'RE NOT AWARE ABOUT ARIZONA, WE HAVE LARGE RURAL AREAS. AS SARA ELUDED, WE HAVE IDENTIFIED PLACES THAT THE CHAPTER CAN HOUSE OR HAVE MEETINGS AND PARTNERSHIP WITH OTHER ORGANIZATIONS IN THE COMMUNITY. IT DOES REOUIRE FOR EXAMPLE, IF YOU'RE GOING TO HAVE FACE TO FACE GROUP, FOR X NUMBER OF THOSE PEOPLE COME IN BUT IT'S WE TOOK FEEDBACK TO HAVE A GROUP TELEPHONE INDIVIDUAL COACHING MIXTURE WAS FOR THIS. IT ALSO -- IT'S INTERESTING WHEN I HEAR THIS ABOUT DOING INTERVENTION, IS RELATES TO PEOPLE WHO ARE HOME BOUND IN URBAN AREAS. THERE ARE GROWING NUMBERS OF WEB BASED PROGRAMS, DVD PROGRAMS THAT ARE BASED OFF OF EVIDENCE-BASED PROGRAMS TO HELP REACH PEOPLE THAT HAVE DIFFICULTY GETTING OUT OF THEIR HOME. THE FLIP SIDE IS, WE ALSO TALKS SOMETIMES IN RURAL AREAS, SOMETIMES THAT CAN BE -- WE WANT PEOPLE TO GET OUT AND ENGAGE. PART OF THEIR CHALLENGE IS STAYING IN THE HOME. IT MEANS HAVING THAT COMBINATION THAT GREG MENTIONED OF CONSUMER DRIVEN, IS THERE ANOTHER FAMILY MEMBER OR ANOTHER FRIEND PERHAPS IN THAT AREA THAT COULD DO THE RESPITE DEPENDING ON HOW IT WORKS WITH THE SYSTEM ETCETERA. OR AS SARA MENTIONED, IS THERE AN AREA THEY CAN COME THROUGH THE CARE RECIPIENT CAN BE CARED FOR WHILE THEY PARTICIPATE. IT'S WORKING ALL OF THOSE OUT THAT WE HAVE SEEN DIFFERENT MODELS WORK I WOULD SAY.

>> THANK YOU. OUR NEXT QUESTION IS CAN THE PRESENTERS COMMENT ON CAREGIVING IN GREECE? SOME OF THE CAREGIVERS I WORK WITH ARE TAILORED TO CARE CLIENTS AND GRIEVED ON TOP OF STRESS IS OFTEN THE CASE.

- >> I CERTAINLY SEE THIS AN AWFUL LOT. I THINK SEEING A LOVED ONE DECLINING IN GENERAL IS GRIEF PROVOKING. VERY FREQUENTLY CAREGIVERS WERE STRUGGLING EMOTIONALLY TO ACCEPT THAT THEIR LOVE ONE IS GOING DOWNHILL AND PERHAPS DYING. I THINK YOUR POINT IS WELL TAKEN. I THINK THAT IS PART OF THE WAY WE SUPPORT CAREGIVERS WE NEED TO HELP IDENTIFY THE GRIEF FOR THEM, NORMALIZE IT AND HELP THEM COME TO TERMS WITH WHAT'S HAPPENING. LOT OF HOSPICE SERVICES DEALING WITH GRIEF AND FREQUENTLY THEY PROVIDING COUNSELING AFTER THE LOVED ONES DEATH. MY CAREGIVERS I WORK WITH UP TO A YEAR AFTER THE -- JUST TO HELP THEM GRIEVE. BUT COME TO AN APPRECIATION OF ALL THE WORK THEY DID AND NOT BLAME THEMSELVES FOR THE CARE RECIPIENT'S DEATH.
- >> I WOULD ALSO COMMENT THAT ANOTHER QUESTION I SEE IN THE CHAT BOX IS ABOUT THE DIFFERENCE BETWEEN SPOUSAL CAREGIVERS AND ADULT CHILD CARE GIVERS. THE GRIEVING PROCESS IS DIFFERENT. LOT OF IT IS YOU LOSING SOMETHING DIFFERENT. IT REMINDS ME TO NOT ONLY FOCUS ON THE LOSS OF THE PERSON BUT ALSO PAY ATTENTION TO THE LOSS OF LIFE STRUCTURE. SPOUSES WHO ARE CAREGIVERS ARE LOSING A LOT OF LIFE STRUCTURE AS THE PARTNERSHIP IS CHANGING IN VERY SIGNIFICANT WAYS DUE TO ILLNESS OF THE CARE RECIPIENT. ADULT CHILDREN ARE LOSING A PARENT OR A PERSON FROM ANOTHER GENERATION. IT MAY OR MAY NOT AFFECT THEIR LIFE STRUCTURE. THEIR DAYTO-DAY LIFE MAY NOT BE AFFECTED AS MUCH AS THE SPOUSAL CAREGIVER. PAY ATTENTION TO THE GRIEF. THE GRIEF IS MORE THAN THE PERSON.
- >> I WOULD ADD ON THAT, I THINK IT'S INTERESTING THAT WE KNOW FROM A DIFFERENT CULTURAL GROUP THAT HOW GRIEF, IT SEEMS TO BE THERE ARE SOME FOLKS THAT GRIEVE ALONG THE WAY IF THERE'S A PROGRESSIVE KIND OF ILLNESS GOING ON. THERE ARE OTHERS THAT TEND TO DO IT ALL AT THE END AND THERE ARE OTHERS THAT DO IT IN A VARIETY OF DIFFERENT WAYS. I THINK JUST TOUCHED ON THIS THAT THERE WAS EVIDENCE IN THE REACH PROJECT AS WELL AS IN THE NYU THAT PARTICIPATION IN SOME KIND OF PSYCHOSOCIAL INTERVENTION HELPED REDUCE DEPRESSIVE SYMPTOMS AFTERWARDS, HELPED TO PREVENT COMPLICATED BEREAVEMENT OR GRIEF. I THINK WE NEED TO BETTER UNDERSTAND WHAT ARE THOSE COMPONENTS SO WE CAN HELP BETTER PREVENT TO FOLKS WHO

ARE DOING THE VERY WORK OF THE INDIVIDUAL ASKING THE QUESTION. HOW DO WE PROVIDE SOMETHING THAT MAKE THIS CLEARER FOR FOLKS THROUGH THIS PROCESS.

- >> THANK YOU. IS THERE ANY TROUBLE ON CAREGIVER DEATH RATE? THAT IS CAREGIVERS
 THAT PASS AWAY BEFORE THE CARE RECIPIENT?
- >> THAT'S A GOOD QUESTION. I KNOW THAT -- I DON'T HAVE THE DATA IN FRONT OF ME.

 I KNOW THAT RICH SCHULTZ AND SCOTT BEACH LOOKED AT THE CAREGIVER DEATH

 TRAJECTORY FOR PEOPLE THAT ARE STRESSED. I'M NOT AWARE OF IT. IT'S A PRETTY

 HARD DATA TO COLLECT WHEN YOU THINK ABOUT IT.
- >> WE HAVE TIME FOR ONE MORE QUESTION. THAT IS, THIS IS FOR DR. COUN. HAVE THE FOUR AREAS WITH LESS EVIDENCE OF EFFECTIVENESS, BEEN EVALUATED AND FOUND TO BE LESS EFFECTIVE OR ISSUE THERE HASN'T BEEN REAL EVALUATION OF THE EFFECTIVENESS OF THESE APPROACHES.
- >> THERE HAVE BEEN SOME STUDIES BUT THEY HAVEN'T REACHED THE CRITERIA WE'VE USED. I THINK THERE ARE DIFFERENT WAYS TO THINK ABOUT IT. WHEN YOU THINK ABOUT EDUCATION ALONE, ALL OF US THINK ABOUT IT, WHEN SOMEBODY TELLS YOU SOMETHING, IF THERE'S NOT KIND OF FOLLOW-UP OR A WAYS TO HELP COACH YOU THROUGH HOW TO INTEGRATE THAT INTO YOUR LIFE, IT MAYBE CHALLENGING FOR YOU. I THINK THAT THE RESPITE, WE ALL KNOW RESPITE IS VALUABLE. THE QUESTION IS CAN WE MYRIAD SOMETHING HOW THAT PERSON UTILIZES THAT RESPITE TIME. I THINK IT'S CRITICAL. CASE MANAGEMENT I THINK ONE OF THE CHALLENGES WITH CASE MANAGEMENT, THOSE OF YOU THAT DO CARRY CASE MANAGEMENTS, THERE'S A WIDE VARIETY OF THAT. LOOKING AT GOOD CONTROLLED STUDIES HELP WITH THAT AND IS THERE AN OPPORTUNITY TO INFUSE OTHER TYPES OF ACTIVITY THAT'S WE'RE SEEING WORKING IN OTHER TYPES OF INTERVENTIONS INTO THAT. IN TERMS OF SUPPORT GROUP, IT IS GETTING A LITTLE BIT BLURRIER AS SOMETIMES PEOPLE CALL SOMETHING A SUPPORT GROUP AND WE DIDN'T DO WHAT PEOPLE CALLED. WE LOOKED AT WHAT THEIR COMPONENTS WERE. I THINK IT'S ALSO LOOKING AT WHAT -- WHERE DOES THE LINE CROSS BETWEEN PROVIDING INFORMATION AND SUPPORT AND PROVIDING SKILL TRAINING OR SOMETHING ELSE THAT MAY HELP PEOPLE MANAGE THEIR SITUATION MORE. WE NEED MORE WORK IN THIS AREA AND I THINK AGAIN, I THINK WE

SEE IT AS SUPPORT GROUPS ARE BECOMING MARRIED WITH MULTIPLE COMPONENT PACKAGE

AND HAVE BEEN USEFUL IF THAT COMPONENT PACKAGE. I THINK WE NEED MORE WORK IN

THESE AREAS.

>> OKAY, THANK YOU. THAT WAS OUR LAST QUESTION. THAT CONCLUDES OUR WEBINAR. I WANT TO THANK EVERYONE WHO LOGGED ON AND PARTICIPATED AND VIEWED THIS WEBINAR. I HOPE YOU FOUND THE INFORMATION USEFUL. I WANT TO THANK OUR SPEAKERS TODAY FOR YOUR TIME AND FOR YOUR EXPERTISE. I WANTED TO LET FOLKS KNOW THAT THIS IS THE LAST WEBINAR IN THE SERIES OLDER AMERICAN BEHAVORIAL HEALTH SERIES. FOR THOSE OF YOU JOINED THE WEBINAR TODAY, YOU WILL RECEIVE A COPY OF IT ALONG WITH A LIST OF RESOURCES ON CAREGIVING. MANY OF THOSE RESOURCES THE FOUR OF US TOUCHED ON TODAY, YOU WILL HAVE INFORMATION ABOUT THOSE AND LINKS DIRECTLY TO THEM. WITH THAT I WILL CONCLUDE AND GIVE A BIG THANK YOU TO EVERYONE FOR TUNING IN. THANK YOU SO MUCH.