

NOVEMBER 15, 2022

>> WELCOME TO THOSE WHO ARE ARRIVING. WE'LL START THE PROGRAM IN ABOUT FIVE MINUTES. FEEL FREE TO SAY HELLO IN THE CHAT IF YOU WOULD LIKE TO SEE. WE SEE YOU, NORA. DO YOU WANT TO COME OFF MUTE AND JUST TEST YOUR AUDIO.

>> WELCOME EVERYBODY. FOR THOSE WHO ARE ARRIVING, WE'LL START THE MEETING IN A FEW MINUTES. AND WE'LL START THE INTERPRETATION CHANNELS IN A FEW MINUTES. WE'RE JUST DOING A TEST RIGHT NOW.

>> THANK YOU VERY MUCH. WELCOME EVERYBODY. WELCOME. WE WILL START IN A FEW MINUTES. IT IS WONDERFUL TO SEE IN THE CHAT PEOPLE FROM SO MANY LOCATIONS. THANK YOU FOR BEING HERE.

>> I WANT TO ASK IF THEY HAVE TO SIGN IN TO GET THE CERTIFICATE, BETH?

>> IN ORDER TO GET THE CERTIFICATE, YOU JUST HAVE TO BE HERE FOR THE WHOLE TIME. ZOOM WILL AUTOMATICALLY... ZOOM WILL AUTOMATICALLY TAKE CARE OF MONITORING YOUR TIME HERE. YOU DON'T NEED TO DO ANYTHING ELSE, JUST BE HERE. THAT'S A GOOD QUESTION.

(FOREIGN LANGUAGE INTERPRETATION)

WELCOME EVERYONE. WE WILL START IN JUST A MOMENT. WELCOME EVERYONE. WE WILL START IN JUST A MINUTE.

>> SOMEONE ASKED IS THERE ANY VOLUME. I'M ASSUMING --

>> I THINK WE WERE NOT SAYING ANYTHING. WELCOME. WHILE PEOPLE ARE GATHERING, I WILL PUT ON SOME MUSIC.

>> THE INTERPRETER OPTIONS HAVEN'T SHOWN UP YET.

>> YES, THEY WILL START IN A FEW MINUTES.

>> ANN, CAN YOU LET ME KNOW IF YOU SEE MY SLIDE?

>> YES.

>> OKAY, VERY GOOD, THANK YOU. I'M GOING TO STOP THE MUSIC AND WE'LL WELCOME EVERYONE. WELCOME EVERYONE TO LET'S TALK ABOUT DEMENTIA AND CULTURE. WE'RE SO GLAD TO HAVE YOU HERE.

I WANT TO FIRST GET OUR LANGUAGE CHANNELS STARTED. I'M GOING TO ASK EACH INTERPRETER TO EXPLAIN HOW TO JOIN THE LANGUAGE CHANNEL AND THEN WE'LL OPEN THE LANGUAGE CHANNELS. THOSE WHO WOULD LIKE TO HEAR THE PROGRAM IN ENGLISH, WILL ALSO NEED TO CLICK ON THE LITTLE GLOBE AND CHOOSE ENGLISH AT THAT POINT. SO, COULD YOU START AND EXPLAIN HOW

PEOPLE WHO NEED MANDARIN CAN JOIN THE INTERPRETATION CHANNEL.

>> YES, THANK YOU, BETH. (FOREIGN LANGUAGE INTERPRETATION).

>> OKAY, GO AHEAD.

**>> THANK YOU. ROSEANNE CAN YOU EXPLAIN IN PORTUGUESE NOW?
(FOREIGN LANGUAGE INTERPRETATION).**

>> THANK YOU. STEFANY, CAN YOU EXPLAIN FOR SPANISH?

**>> THANK YOU. AND CAN YOU PROVIDE THE INSTRUCTIONS IN
VIETNAMESE AND AFTER THAT, I WILL START THE INTERPRETATION AND YOU WILL
SEE THE GLOBE AT THAT MOMENT. GO AHEAD.**

**THANK YOU. OKAY, I'M STARTING THE INTERPRETATION CHANNELS.
EVERYONE SHOULD SEE A GLOBE DOWN IN THEIR ZOOM CONTROLS. AND JUST
CLICK ON THAT AND CHOOSE THE LANGUAGE THAT YOU WANT. SO, IF YOU ARE
USING ENGLISH, JUST CHOOSE ENGLISH AND FOR ONE OF THE OTHER LANGUAGES,
GO AHEAD AND CHOOSE THAT. THANK YOU TO THE INTERPRETERS.**

**SO, NOW I'D LIKE TO JUST LET YOU KNOW THAT WE ALSO HAVE CAPTIONS
AVAILABLE IN ENGLISH. AND IF YOU WOULD LIKE TO ENABLE CAPTIONS, CLICK ON
THE CC AT THE BOTTOM OF YOUR SCREEN. IF YOU DON'T SEE IT, YOU CAN CLICK
WHERE IT SAYS "MORE" AND THERE ARE THREE DOTS AND THEN YOU SHOULD BE
ABLE TO SEE IT. YOU CHOOSE SHOW SUBTITLES. THANK YOU TO DENISE FOR
PROVIDING CAPTIONS IN ENGLISH. WE REALLY APPRECIATE ALL THE
INTERPRETERS AND THE CAPTION PROVIDER.**

**AND SO NOW I WANT TO SAY SOME OTHER THANK YOU BEFORE WE GET
STARTED. THANK YOU TO OUR MAJOR SUPPORTERS, JEWISH FAMILY AND
CHILDREN'S SERVICE, RUNS THE DEMENTIA FRIENDS PROGRAM FOR ALL OF
MASSACHUSETTS. AND I JUST HAVE TO BOAST BECAUSE I'M PROUD WE HAVE BEEN
CHOSEN BY THE "BOSTON GLOBE" AGAIN AS ONE OF THE HUNDRED BEST
WOMEN-LED ORGANIZATIONS IN MASSACHUSETTS. AND I WANT TO GIVE A
SHOUT-OUT TO THE CEO, GAIL SHULMAN FOR LEADING US. I THANK
POINT32HEALTH PLAN FOUNDATION. YOU WILL HEAR MORE ABOUT THE ROLE
SUPPORTING OUR WORK AND YOU WILL HEAR FROM NORA IN A FEW MOMENTS. I
THANK THE CHARITABLE TRUSTS, WHICH IS A KEY FUNDER FROM THE START OF THE
WORK AND HAS BEEN FUNDING OUR DEMENTIA FRIENDS INITIATIVE IN
SYNAGOGUES AS WELL. THANK YOU TO THE SILVER SPONSORS, EMBRACE
HOMECARE AND MASSACHUSETTS COUNCILS ON AGING. IT IS REALLY IMPORTANT
TO BE ABLE TO PROVIDE AN EVENT LIKE THIS FREE OF CHARGE FOR PEOPLE TO
ATTEND. AND OUR SILVER SPONSORS ARE REALLY IMPORTANT IN MAKING THAT**

POSSIBLE. THANK YOU.

AND I WANT TO THANK YOU OUR PROPOSAL PARTNERS, ALZHEIMER'S ASSOCIATION MASSACHUSETTS/NEW HAMPSHIRE CHAPTER, DEMENTIA ACTION ALLIANCE AND NATIONAL COUNCIL OF DEMENTIA MINDS. YOU WILL HEAR MORE ABOUT THE ORGANIZES -- THE ORGANIZATIONS DURING THE PRESENTATION TODAY. THANK YOU TO SPEAKERS, INTERPRETERS AND MANY HELPERS, WE ARE GRATEFUL FOR EACH AND EVERY ONE OF YOU.

AND MANY COLLABORATING ORGANIZATIONS AS WELL THAT ARE PART OF THIS WORK. THOSE WHO HAVE PURCHASED CONTINUING EDUCATION UNITS, I WANT TO LET YOU KNOW, YOU DO NEED TO ATTEND THE WHOLE EVENT AND TO COMPLETE THE EVALUATION SURVEY, WHICH WE'LL EMAIL TO YOU AFTER THE EVENT. AND THIS PROGRAM HAS BEEN APPROVED FOR THREE SOCIAL WORK CONTINUING EDUCATION UNITS AND WE CAN PROVIDE A CERTIFICATE. OOPS... PROVIDE A CERTIFICATE FOR NURSING AND OTHER PROFESSIONS. THIS MEETING IS BEING RECORDED AND WE'LL EMAIL EVERYONE WHO REGISTERED FOR THIS EVENT A LINK TO A WEBPAGE WHERE WE'LL HAVE RECORDING SLIDES AND RESOURCES. IT'LL TAKE PROBABLY A WEEK OR TWO BEFORE YOU RECEIVE THAT. YOU WILL GET THAT. AND PLEASE KEEP YOURSELF ON MUTE TODAY. WE HAVE A VERY LARGE GROUP, AT THIS POINT WE HAVE MORE THAN 450 PEOPLE WITH US. AND WE HAD 700 PEOPLE REGISTERED. SO, WE DO NEED TO ASK YOU TO STAY ON MUTE. WE DO WANT TO HEAR FROM YOU. SO IF YOU HAVE QUESTIONS OR COMMENTS AT ANY POINT, PLEASE TYPE THOSE INTO THE CHAT BOX. MY COLLEAGUE, MARGIE, WILL WATCH THE CHAT BOX AND WE'RE GOING TO MAKE SURE TO RESPOND TO AS MANY QUESTIONS AND COMMENTS AT THE -- IN THE LAST PART OF TODAY'S PROGRAM AND ALSO AS WE GO ALONG. IF YOU ARE HAVING ANY TECHNICAL DIFFICULTIES, PLEASE CHAT ASK TECH HELP, WHICH IS RIGHT AT THE TOP OF YOUR LIST OF PARTICIPANTS. AND ANN WILL BE ABLE TO HELP YOU.

SO LET'S TAKE A MOMENT AND SEE WHO IS HERE TODAY. I WANT TO LAUNCH A QUICK POLL. HAVE YOU TAKE A MOMENT AND LET US KNOW SOMETHING ABOUT WHO YOU ARE, IF YOU HERE AS A PERSON LIVING WITH DEMENTIA. IF YOU ARE HERE AS A PERSON WITH A FRIEND OR RELATIVE LIVING WITH DEMENTIA. IF YOU ARE HERE BECAUSE THIS IS RELATED TO YOUR PROFESSION. OR IF YOU ARE JUST HERE BECAUSE YOU ARE INTERESTED. I'LL WAIT A FEW MORE MINUTES AND THEN WE'LL SEE WHO IS HERE. OKAY. IT LOOKS LIKE THE RESPONSES HAVE STOPPED COMING IN. I'M GOING TO SHARE THE RESULTS. IT LOOKS LIKE MOST PEOPLE ARE HERE AS PROFESSIONALS. WE ALSO HAVE A MIX OF PEOPLE WHO ARE HERE WHO ARE LIVING WITH DEMENTIA AND WELCOME. WE ARE GRATEFUL YOU

ARE HERE AND WE WANT TO HEAR YOUR PERSPECTIVE. WE WELCOME YOUR COMMENTS AT ANY POINT. THERE ARE A NUMBER OF PEOPLE WHO ARE HERE BECAUSE THEY HAVE SOMEONE IN THEIR LIFE WHO IS LIVING WITH DEMENTIA. WE ARE GLAD YOU ARE HERE AND WE WANT TO RESPOND TO YOUR QUESTIONS AND COMMENTS AS WELL. IT IS WONDERFUL SEVERAL OF YOU ARE HERE JUST BECAUSE YOU'RE INTERESTED. THIS TOPIC AFFECTS ALL OF US.

GLAD EVERYBODY IS HERE. IF YOU HAVE NOT DONE SO ALREADY, PLEASE FEEL FREE TO SAY HELLO IN THE CHAT. AND SHARE WHERE YOU ARE GEOGRAPHICALLY AND A LITTLE BIT ABOUT YOURSELF, IF YOU WOULD LIKE. GOING ON NOW. OF AND TALK ABOUT THE PLAN FOR TODAY. THE TIMES ARE APPROXIMATE, IN A MOMENT, NORA OF POINT32HEALTH FOUNDATION WILL GIVE A SHORT WELCOME. AND THEN I'M GOING TO SET UP OUR TOPIC FOR TODAY BY TALKING ABOUT DISPARITIES DIFFERENCES AND WHY COMMUNITY PARTNERS ARE SO IMPORTANT. AFTER THAT, I WILL INTRODUCE OUR COMMUNITY PARTNERS, AND WE'LL HAVE A PERSONAL STORY AND WE'LL HAVE A ROUNDTABLE DISCUSSION WITH COMMUNITY PARTNERS WHICH IS THE HEART AND SOUL OF WHAT WE'RE HERE TO DO TODAY. TO HEAR ABOUT TALKING ABOUT DEMENTIA IN DIFFERENT CULTURAL AND LINGUISTIC COMMUNITIES. THERE WILL BE A SHORT BREAK DURING WHICH WE HAVE A VIDEO WITH PHOTO MONTAGES AND MESSAGES FROM COMMUNITY PARTNERS YOU CAN WATCH, IF YOU WISH. YOU ARE WELCOME TO TAKE A BREAK, DO WHAT YOU NEED TO DO AND COME BACK. AND THEN THE LAST PRESENTATION WILL BE WHAT WE CALL THE ROAD TO REPRESENTATION, I'LL BE TALKING ABOUT HOW DEMENTIA FRIENDS MASSACHUSETTS HAS STRUCTURED ITSELF TO BECOME MORE INCLUSIVE AND REPRESENTATIVE OF THE MANY COMMUNITIES THAT WE SERVE HERE IN MASSACHUSETTS. WE HAVE RESERVED THE LAST 25 MINUTES TO DISCUSS YOUR QUESTIONS AND COMMENTS. AGAIN, PLEASE PUT THEM IN THE CHAT AT ANY POINT.

>> BETH, I'M SORRY TO INTERRUPT. VIETNAMESE IS NOT ON THE GLOBE TO BE INTERPRETED.

>> IT IS NOT?

>> NO.

>> THANK YOU FOR LETTING ME KNOW.

>> FOLKS ARE LETTING ME KNOW IN THE CHAT.

>> IT WAS THERE.

>> EARLIER IT WAS. NOW I DON'T SEE IT EITHER. THAT'S WHY I TYPED IT. I DON'T WANT TO INTERRUPT YOU.

>> I'M TRYING TO ADD AN INTERPRETER. I THINK WHAT HAPPENED, I HAD

TO SPECIALLY ADD THAT TO THE MEETING BECAUSE IT IS NOT ONE OF THE OPTIONS THAT ZOOM PROVIDES. THEN WHEN I TESTED INTERPRETATION AND ENDED IT, IT TURNED IT OFF. I'M TRYING NOW TO ADD AN INTERPRETER. LET ME SEE HOW I DO THIS. I'M SORRY, BEAR WITH ME FOR A MOMENT PLEASE.

>> IN THE MEANTIME, I WILL PUT THE PROGRAM BOOKS IN THE CHAT.

>> THANK YOU. IF YOU CAN PUT THE PROGRAM BOOKS AND THE... LET'S SEE. AND THE RESOURCE LIST IN THE CHAT. LET ME SEE IF THAT WORKED. I ADDED LINA AND VIETNAMESE. UPDATE. I'M TRYING TO MAKE IT UPDATE. IT SAYS IT IS ADDED. I'M GOING TO TRY DOING IT AGAIN. DID IT WORK THAT TIME?

>> YES.

>> THANK YOU EVERYONE. I APOLOGIZE FOR THAT. VERY GOOD. OKAY. AS YOU SEE, ANN ADDED THE PROGRAM BOOK WHERE YOU CAN SEE THE AGENDA AND ALSO THE RESOURCE LIST. WE ARE HOPING TO ADD TO THAT RESOURCE LIST IF YOU HAVE ANY GREAT DEMENTIA INFORMATION AND SUPPORT RESOURCES THAT ARE AVAILABLE NATIONWIDE AND FOCUS ON ONE OR SEVERAL UNDERSERVED COMMUNITIES, PLEASE PUT THEM IN THE CHAT AT ANYTIME TODAY OR EMAIL ME. WE'LL ADD THEM. AND PLEASE NOTE THAT THE ALZHEIMER'S ASSOCIATION HELPLINE AND THE NATIONAL ASIAN PACIFIC CENTER ON AGING HELPLINE ARE AVAILABLE IN MANY LANGUAGES. AND THOSE ARE AT THE TOP OF THE RESOURCE LIST. SO, IF YOU HAVE A CONCERN ABOUT SOMEONE, YOU HAVE QUESTIONS THAT DON'T GET ANSWERED TODAY, PLEASE CALL ONE OF THE HELPLINES. AND WITH THAT, I'M HONORED TO INTRODUCE NORA CARGIE, PRESIDENT OF POINT32HEALTH FOUNDATION AND THE VICE-PRESIDENT FOR CORPORATE CITIZENSHIP OF POINT32HEALTH. AND IN THIS DUAL ROLE, SHE HELPS TO SHAPE STRATEGIES TO SUPPORT NONPROFIT ORGANIZATIONS WORKING TO ADDRESS SYSTEMIC DISPARITIES AND ELIMINATE BARRIERS TO ACCESS. SHE SERVES ON THE GOVERNOR'S COUNCIL TO ADDRESS AGING IN MASSACHUSETTS, THE BOARD OF THE CONNECTICUT COUNCIL FOR PHILANTHROPY, THE EXECUTIVE FORUM FOR BOSTON COLLEGE CENTER FOR CITIZENSHIP AND THE ELDER STAKEHOLDER GROUP OF THE MASSACHUSETTS EXECUTIVE OFFICE OF THE ELDER AFFAIRS AND AS A MENTOR FOR A LATINO MID-CAREER PROFESSIONAL DEVELOPMENTAL PROGRAM. SHE IS AN ALUM OF LEAD BOSTON. AND JUST DOES SUCH IMPORTANT WORK. POINT32HEALTH FOUNDATION HAS BEEN FUNDING DEMENTIA FRIENDS MASSACHUSETTS AND REALLY MAKING IT POSSIBLE. IT WILL GIVE ME GREAT PLEASURE TO WELCOME NORA TO SAY A FEW WORDS OF WELCOME. NORA, IF YOU COULD GO AHEAD AND UNMUTE YOURSELF, YOU GOT THE FLOOR.

>> THANK YOU SO MUCH, BETH. WHAT AN AMAZING GATHERING. I WANT

TO EXPRESS MY APPRECIATION FOR YOU AND YOUR LEADERSHIP IN CHAMPIONING WORK THAT STRIVES TO ELIMINATE INEQUITIES. IT IS CULTURALLY SENSITIVE AND LINGUISTICALLY APPROPRIATE, EVEN WHEN TECHNOLOGY FAILS US. YOUR WORK IS MEANINGFUL AND RELEVANT BECAUSE IT IS CENTERED IN COMMUNITY. POINT32HEALTH FOUNDATION IS NEW, BUT WE ARE -- WE BUILD ON THE LEGACY OF HARVARD PILGRIM HEALTHCARE AND TUFTS HEALTHCARE FOUNDATION. WE FOLLOW YOUR EXAMPLE. YOU WORK SO HARD TO ENSURE INCLUSION IS AT THE HEART OF EVERYTHING YOU DO. WE TOO WORK TO LEAD WITH COMMUNITY, EQUITY, AND INCLUSION. WE LIKE YOU, BELIEVE WE NEED TO BE CLOSE TO THOSE WITH LIVED EXPERIENCES IN ORDER TO GET THE BEST ANSWERS TO ISSUES FACING YOU. WE VALUE EVERYONE INVOLVED IN THE EFFORT, EVERYONE AT THE TABLE HERE, AND WE WANT TO SAY THAT YOU AND THE TEAM AT JEWISH FAMILY AND CHILDREN'S SERVICES ARE ACTIVE IN REMARKABLE WAYS TO EXPAND THE EFFORT IN MASSACHUSETTS. MANY DISPARITIES ARE REAL. SYSTEMIC RACISM IS REAL. AND LED TO DISINVESTMENT IN COMMUNITIES OF COLOR. CO-CREATING THE PROGRAMS WITH ADVOCATES WHO ARE DIVERSE AND COMMUNITIES THAT SERVE, YOU ARE REINVESTING, RECOMMITTING. BETH, AND YOUR TEAM, YOU ARE LIVING YOUR VALUES. LEADING WITH COMMUNITY, LISTENING AND LEARNING TO UNDERSTAND. LEADING PEOPLE -- MEETING PEOPLE WHERE THEY ARE. THAT'S WHAT WE DO. THIS APPROACH ACKNOWLEDGES COMMUNITIES AT STRENGTH, THEIR WISDOM, AND THAT OFTEN THE SMARTEST IDEAS ARE FOUND IN SMALL COMMUNITY-BASED ORGANIZATIONS. WE ARE PRIVILEGED AND HONORED TO HAVE YOU AS A PARTNER, THANK YOU FOR THE OPPORTUNITY TO SUPPORT THIS IMPORTANT WORK. THIS DAY AND TO LEARN FROM THE SPEAKERS TODAY. AND THEN I WANT TO CLOSE BY ACKNOWLEDGING AND APPLAUDING YOUR INNOVATIVE WORK. THE NATIONAL RECOGNITION FOR LIVING WELL WITH DEMENTIA AT THE CAFE IS FURTHER PROOF THAT YOU LEAD BY EXAMPLE. YOUR WORK IS CREATING COMMUNITIES OF SUPPORT AND COMPANIONSHIP. THANK YOU FOR ALL YOU DO. HAVE AN AMAZING SESSION TODAY.

>> THANK YOU SO MUCH, NORA. IT IS ALWAYS VERY INSPIRING TO HEAR FROM YOU AND WE ARE GRATEFUL FOR YOUR WORK AND FOR YOUR SUPPORT. NOW, WE'LL JUMP INTO THE FIRST PRESENTATION.

>> BETH, DO YOU MIND, I HAVE A NOTE THAT WE'RE NOT SURE IF THE VIETNAMESE INTERPRETATION IS GOING THROUGH. JUST WANT TO CHECK IT IS. ANDREW SAID HE COULDN'T HEAR IT.

>> IT DOES SHOW IT IS AN AVAILABLE CHANNEL. ANDREW, YOU MAY HAVE TO STOP AND RECONNECT TO IT BECAUSE IT DID STOP FOR A WHILE. THANK YOU.

I APPRECIATE EVERYONE'S PATIENCE WITH THE TECHNICAL DIFFICULTIES. I WANT TO JUST INTRODUCE MYSELF A LITTLE BIT BETTER. MY NAME IS BETH SOLTZBERG, I'M A SOCIAL WORKER AT JEWISH FAMILY & CHILDREN'S SERVICE IN WALTHAM, MASSACHUSETTS. AND NORA MENTIONED OUR WORK WITH MEMORY CAFES, WE HAVE A PROGRAM CALLED, THE MEMORY CAFE PERCOLATOR THAT HELPS ORGANIZATIONS WITH THEIR EFFORTS TO RUN THESE SOCIAL PROGRAMS FOR PEOPLE LIVING WITH DEMENTIA AND THOSE WHO CARE ABOUT THEM. I ALSO HAVE THE PRIVILEGE OF LEADING THE DEMENTIA FRIENDS PROGRAM FOR MASSACHUSETTS AND WORKING WITH OUR COMMUNITY PARTNERS AS WELL AS OTHER SPECIFIC GROUPS, LIKE SYNAGOGUES THROUGH OUR SYNAGOGUE INITIATIVE. LET'S START AT THE BEGINNING. WHAT IS DEMENTIA? THIS IS A GRAPHIC FROM THE ALZHEIMER'S ASSOCIATION THAT I'M SURE IS FAMILIAR TO MANY OF YOU. DEMENTIA IS AN UMBRELLA, IT INCLUDES CHANGES IN MEMORY AND OTHER KINDS OF THINKING. THERE ARE MANY CONDITIONS THAT CAN CAUSE IT. IT'S NORMAL TO HAVE A HARDER TIME REMEMBERING THINGS AS WE GET OLDER AND SOMETIMES PEOPLE WONDER AM I DEVELOPING DEMENTIA. I JUST WANT TO SAY A FEW WORDS ABOUT THAT. THERE ARE TREATABLE CAUSES OF MEMORY LOSS AND CONFUSION THAT CAN LOOK LIKE MAYBE THEY ARE DEMENTIA, BUT THEY'RE NOT. HERE ARE SOME. DEPRESSION, GRIEVE, SOME NUTRITIONAL IMBALANCE, AN INFECTION, DEHYDRATION, SIDE-EFFECTS OF MEDICATION. FOR THOSE WHO ARE HERE BECAUSE OF A CONCERN ABOUT YOURSELF OR SOMEONE YOU CARE ABOUT, PLEASE TALK WITH A HEALTHCARE PROVIDER IF YOU ARE CONCERNED AND THAT WAY THE PERSON CAN HELP YOU TO BEGIN TO UNDERSTAND WHAT MIGHT BE GOING ON. IT MAY BE SOMETHING THAT CAN BE TREATED. I ALSO WANT TO MENTION THAT DEMENTIA AFFECTS THE WHOLE CIRCLE OF PEOPLE THAT CARE. IT AFFECTS THE PERSON LIVING WITH DEMENTIA, BUT IT ALSO AFFECTS THE PEOPLE WHO ARE CLOSE TO THEM. FAMILY AND FRIENDS ALSO NEED SUPPORT AND INFORMATION. AND MANY RESOURCES ARE AVAILABLE ON THE RESOURCE LIST, YOU WILL FIND A LINK TO A GUIDE PUT TOGETHER BY THE DIVERSE ELDER'S COALITION. IT WAS BASED ON A LOT OF RESEARCH IN MANY CULTURAL AND LINGUISTIC COMMUNITIES. ONE OF THE INTERESTING THINGS THEY FOUND IS THAT THE TERM CAREGIVER IS NOT USED IN EVERY COMMUNITY. SOME COMMUNITIES PEOPLE WOULD SAY, I HELP MY MOTHER OR I HELP MY FATHER OR MY SISTER OR MY HUSBAND, THEY DON'T USE THE TERM "CAREGIVER" BECAUSE IT IS JUST PART OF LIFE THAT YOU HELP FAMILY WHEN THEY NEED IT.

>> I'M SORRY -- BETH. SORRY TO INTERRUPT. WE STILL CAN'T HEAR THE TRANSLATION IN VIETNAMESE.

>> HMM... THE SLIDES AND RECORDING WILL BE SHARED. I DO NOT KNOW WHY -- IT SAYS THAT THE VIETNAMESE INTERPRETATION IS WORKING. MAYBE THAT PERSON NEEDS TO JOIN THE VIETNAMESE CHANNEL. IF YOU NEED INTERPRETATION, YOU HAVE TO CLICK ON THE--I WILL QUICKLY GO BACK.

>> I DON'T WANT YOU TO WORRY. IF YOU CAN GIVE US THE NAME OF THE VIETNAMESE AND PORTUGUESE INTERPRETERS, I CAN REACH OUT TO THEM DIRECTLY.

>> LINA IS THE VIETNAMESE INTERPRETER AND ROSEANNE IS THE PORTUGUESE INTERPRETER.

>> THANK YOU SO MUCH. JUST CONTINUE ON AND I'LL SPEAK WITH THEM.

>> THANK YOU VERY MUCH, JESSICA, I APPRECIATE THAT. VERY GOOD. SO, I THINK MOST OF YOU ON THE LINE HERE ARE PROFESSIONALS, SO YOU'RE REALLY AWARE OF THE LARGE IMPACT OF DEMENTIA. THIS IS FROM THE ALZHEIMER'S ASSOCIATION'S FACTS AND FIGURES. THIS HAS A HUGE EMOTIONAL, FINANCIAL IMPACT AT THE INDIVIDUAL FAMILY LEVEL AND THE LEVEL OF THE NATION. I HAVE BEEN TALKING ABOUT WHY DEMENTIA IS HARD. I ALSO WANT TO SAY PEOPLE CAN LIVE WELL WITH DEMENTIA AND THIS IS A VERY IMPORTANT MESSAGE HERE TODAY. I'M GOING TO SHOW YOU A FEW IMAGES. THIS IS KATE, WHO LIVES WITH DEMENTIA IN AUSTRALIA. SHE FOUNDED DEMENTIA ALLIANCE INTERNATIONAL. SHE EARNED GRADUATE DEGREES AFTER HAVING BEEN DIAGNOSED WITH DEMENTIA. AND EMILY IS AN ADVOCATE LIVING WITH DEMENTIA IN SINGAPORE. AND I THINK SHE MIGHT BE HERE WITH US TODAY. IF YOU ARE, EMILY, WE'RE HONORED TO HAVE YOU. WELCOME. AND LET'S SEE -- SORRY. I'M RUNNING INTO SOME TECHNICAL ISSUES AS WELL. EMILY IS ALWAYS AN EXTRAORDINARY PERSON WHO IS AN ADVOCATE IN SINGAPORE WHO IS HELPING TO GUIDE SINGAPORE'S WORK AND REALLY THE INTERNATIONAL CONVERSATION ABOUT LIVING WELL WITH DEMENTIA. AND THE LAST PHOTOS ARE PERFECTLY ORDINARY PEOPLE ENJOYING THEMSELVES AT MEMORY CAFES. I ALSO WANT TO MAKE THE POINT THAT PEOPLE CAN LIVE WELL WITH DEMENTIA IN ALL KINDS OF WAYS. SOMETIMES BY BECOMING AN ADVOCATE, SOMETIMES BY JUST FINDING WAYS TO ADAPT AND GET SUPPORT AND PARTICIPATE IN A GROWING NUMBER OF GOOD RESOURCES THAT CAN ENHANCE THE QUALITY OF LIFE.

LATER YOU WILL HERE FROM ANITRA ABOUT HER JOURNEY, LIVING A FULL LIFE WITH DEMENTIA. THIS IS JUST IMPORTANT TO KEEP IN MIND, WHILE WE ARE TALKING ABOUT THE CHALLENGES OF DEMENTIA, OUR GOAL IS FOR PEOPLE TO LIVE WELL WITH DEMENTIA AND WE NEED TO STAY FOCUSED ON THAT. AND SO NOW WE'RE GOING TO FOCUS A LENS AT A FEW DIFFERENT LEVELS. I WANT YOU TO

PRETEND THAT YOU ARE IN A FIELD AND YOU HAVE A CAMERA AND YOU ARE FOCUSING IT. MAYBE FIRST YOU FOCUS IT AT THE DISTANT MOUNTAINS AND SO YOU CAN SEE THOSE SHARPLY. THEN YOU FOCUS IT AGAIN. YOU CAN SEE SOME HILLS THAT ARE CLOSER TO YOU. AND THEN YOU FOCUS IT ONE MORE TIME, YOU CAN SEE A FLOWER THAT IS VERY CLOSE TO YOU. ALL OF THOSE THINGS ARE THERE, THEY ARE ALL REAL, BUT WE CAN'T NECESSARILY SEE THEM ALL AT THE SAME TIME. WE'RE GOING TO DO THAT NOW. WE'LL DO IT TALKING ABOUT DEMENTIA. WE'LL FOCUS IT AT THREE DIFFERENT LEVELS. A GLOBAL LEVEL, WHICH IS LIKE THE FAR AWAY MOUNTAINS, WE'RE LOOK AT A COMMUNITY LEVEL, WHICH IS LIKE THE HILLS THAT ARE A BIT FARTHER, AND THE INDIVIDUAL PERSPECTIVE, WHICH IS LIKE THAT FLOWER. LET'S START FOCUSING ON THE GLOBAL LEVEL. THE GLOBAL POPULATION IS RAPIDLY AGING, MORE AND MORE PEOPLE IN THE UNITED STATES AND WORLDWIDE ARE LIVING WITH DEMENTIA. FOR THOSE OF YOU WHO SAW THE MOST RECENT WORLD ALZHEIMER'S REPORT BY THE ALZHEIMER'S DISEASE INTERNATIONAL, YOU WOULD HAVE LEARNED THAT MORE AND MORE LOW AND MIDDLE-INCOME COUNTRIES ARE REALLY SEEING THE IMPACT OF DEMENTIA. IN ADDITION, I'M IN THE UNITED STATES, THAT'S MY FOCUS HERE, OUR COMMUNITIES ARE MULTICULTURAL; SO, FOR OUR MANY COMMUNITY MEMBERS WHO EMIGRATED FROM ANOTHER COUNTRY, THEY TOOK THEIR HERITAGE WITH THEM, THAT IS IMPORTANT FOR THEM AND FOR THEIR CHILDREN AND THEIR GRANDCHILDREN AND SO ON. SO, IF YOU ARE WORKING WITH IMMIGRANT COMMUNITIES, IT'S IMPORTANT TO LEARN SOMETHING ABOUT HOW DEMENTIA IS VIEWED IN THEIR HOME COUNTRY. THAT CONTINUES TO INFLUENCE THEIR EXPERIENCE OF DEMENTIA HERE IN THE UNITED STATES. AND FINALLY, WHEN WE THINK ABOUT WHO ARE THE PEOPLE PROVIDING DIRECT HANDS-ON CARE, MORE THAN A THIRD IN THE UNITED STATES ARE IMMIGRANTS. I KNOW HERE IN MASSACHUSETTS, THAT STATISTIC IS AT LEAST 40%. SO IT IS VERY IMPORTANT THAT WE THINK OF A GLOBAL PERSPECTIVE. NOW, WE'RE GOING TO FOCUS THE LENS AGAIN AND WE'RE GOING TO THINK ABOUT IT AT THAT MIDDLE LEVEL. A LINGUISTIC CULTURAL GEOGRAPHIC COMMUNITY PERSPECTIVE. WHEN WE LOOK AT THAT PERSPECTIVE, WE SEE THERE ARE DISPARITIES. DISPARITIES ARE DIFFERENCES IN HEALTH AND HEALTHCARE BETWEEN GROUPS THAT STEM FROM BROADER INEQUITIES. IN OTHER WORDS, THE DIFFERENCES AREN'T BECAUSE OF SOMETHING INHERENT ABOUT THE GROUPS OF PEOPLE, THEY ARE BECAUSE OF THE CONDITIONS IN WHICH THEY LIVE. AND WE SEE DISPARITIES IN THE RISK OF DEVELOPING DEMENTIA, ACCESS TO GETTING A DIAGNOSIS, AND ACCESS TO RESEARCH PARTICIPATION AND ACCESS TO INFORMATION AND SERVICES. WE'RE GOING TO TALK ABOUT EACH OF THESE

AREAS. LET'S START WITH DISPARITIES IN THE RISK OF DEVELOPING DEMENTIA. I WANT TO MENTION A STUDY THAT WAS PUBLISHED IN 2016, IT WAS A VERY LARGE STUDY. AND LOOKED AT A 14-YEAR PERIOD. IT LOOKED AT SIX DIFFERENT ETHNIC OR RACIAL GROUPS. IT WAS A VERY IMPORTANT STUDY BECAUSE IT COMPARED A LARGE GROUP OF PEOPLE OVER A LONG PERIOD OF TIME BROKEN INTO THE GROUPS. IT FOUND THAT IN THIS GROUP OF PEOPLE THAT WAS RESEARCHED, AFRICAN AMERICANS HAD THE HIGHEST RISK OF DEVELOPING DEMENTIA. THE NEXT HIGHEST GROUP WAS AMERICAN INDIAN AND ALASKA NATIVE. AND LATINO, THEN PACIFIC ISLANDER, AND THEN WHITE, AND ASIAN-AMERICAN. AND THOSE ARE THE CATEGORIES THAT THIS RESEARCH TEAM USED. SO, IT IS VERY IMPORTANT TO SEE THAT THERE ARE DIFFERENCES IN HOW LIKELY DIFFERENT POPULATION GROUPS ARE TO DEVELOP DEMENTIA. WE HAVE TO ASK WHY IS THAT? TO STAY ON THIS THEME OF THE RISK OF DEVELOPING DEMENTIA, THERE'S SOME OTHER RESEARCH I WANT TO POINT OUT. THERE WAS A STUDY PUBLISHED IN 2019 BY COLLEAGUES THAT FOUND THAT LGBTQ+ PEOPLE WERE ALMOST A THIRD MORE LIKELY TO REPORT CHANGES IN THEIR MEMORY AND THINKING. THIS IS ALSO CALLED SUBJECTIVE COGNITIVE DECLINE, WHICH MAY BE AN EARLY SIGN OF DEMENTIA. WOMEN ARE ALSO MORE LIKELY THAN MEN TO DEVELOP DEMENTIA. 2/3 OF PEOPLE LIVING WITH DEMENTIA ARE WOMEN AND 2/3 OF PEOPLE WHO CARE FOR SOMEONE LIVING WITH DEMENTIA ARE WOMEN. THAT IS PROFESSIONAL AND FAMILY MEMBERS. IT IS MAJORITY WOMEN. WE DON'T KNOW ALL THE REASONS FOR THE DIFFERENCES, BUT THESE DIFFERENCES ARE THERE. THAT IS SOMETHING THAT WE NEED TO LOOK AT. NOW WE'LL TALK ABOUT DISPARITIES IN ACCESS TO GETTING A DIAGNOSIS. GETTING A DIAGNOSIS CAN TAKE MANY VISITS TO A HEALTHCARE PROVIDER, IT MAY REQUIRE HAVING A HEALTHCARE PROVIDER IN YOUR GEOGRAPHIC AREA WHO HAS EXPERTISE. IT CAN TAKE A LOT OF PERSISTENCE. LATER YOU WILL HEAR ANITRA TALK ABOUT HER EXPERIENCE AND HOW IT TOOK TIME TO GET AN ACCURATE DIAGNOSIS. THERE ARE MANY BARRIERS POSSIBLE. SOME COULD BE OUTRIGHT DISCRIMINATION AND ALSO JUST LACK OF ACCESS TO THE RESOURCES THAT IT TAKES TO GO THROUGH THIS PROCESS. PARDON ME. ONE RECENT FINDING IS THAT BLACK PARTICIPANTS IN ALZHEIMER'S DISEASE RESEARCH STUDIES WERE 35% LESS LIKELY TO BE DIAGNOSED THAN WHITE PARTICIPANT, EVEN THOUGH WE KNOW BLACK INDIVIDUALS ARE MORE LIKELY THAN WHITE INDIVIDUALS TO HAVE DEMENTIA. SO IT SHOWS THAT THERE'S A REAL PROBLEM WITH BEING ABLE TO GET THAT DIAGNOSIS. AND THAT IS FROM A 2021 STUDY. AND BY THE WAY, LINKS TO ALL THE STUDIES ARE IN YOUR RESOURCE LIST. LET'S TALK ABOUT ANOTHER CATEGORY, DISPARITIES IN

RESEARCH PARTICIPATION. NOW, YOU MIGHT BE INVOLVED IN RESEARCH OR YOU MIGHT SEE IT AS SOMETHING THAT IS NOT RELATED TO YOUR DAY-TO-DAY LIFE. RESEARCH IS VERY IMPORTANT BECAUSE IT IS HOW TOOLS FOR DIAGNOSIS AND TREATMENT ARE DEVELOPED. IT IS REALLY HOW WE KNOW WHAT WE KNOW. EVERY STATISTIC, I'M TELLING YOU, WE HAVE THAT STATISTIC BECAUSE SOME RESEARCHERS GOT FUNDS AND THEY SPENT YEARS STUDYING TO COME UP WITH THIS INFORMATION.

SO RESEARCH IS REALLY CRITICAL. AND FROM THE NATIONAL INSTITUTE ON AGING, FROM LAST YEAR, WE HAVE THIS STATISTIC. LATINO AND BLACK AMERICANS MAKE UP LESS THAN 10% OF ALL CLINICAL TRIAL PARTICIPANTS IN ACTIVE ALZHEIMER'S AND RELATED DEMENTIA RESEARCH. SO, WE KNOW THAT LATINO AND BLACK AMERICANS HAVE A HIGHER RISK OF DEMENTIA THAN WHITE AMERICANS. THEY ARE LESS LIKELY TO BE REPRESENTED IN RESEARCH ON ALZHEIMER'S AND RELATED DEMENTIA. SO THIS IS A PROBLEM. IT IS ALSO A PROBLEM WE DO NOT HAVE ANY RESEARCH INFORMATION ABOUT MANY DEMOGRAPHIC GROUPS. SO, THERE ARE MANY CULTURAL GROUPS, MANY LANGUAGE GROUPS, WHERE THERE JUST IS NOT ANYTHING KNOWN ABOUT THEIR RISK OF DEMENTIA HERE IN THE UNITED STATES. OOPS. I'M SORRY. SOMEHOW I JUST JUMPED AHEAD. LET ME JUMP BACK REALLY QUICK.

SO, WE'LL TALK ABOUT ONE FACTOR INFLUENCING THE PROBLEM WITH RESEARCH PARTICIPATION, WHICH IS LACK OF TRUST. THIS IS FROM AN ALZHEIMER'S ASSOCIATION STUDY DONE IN 2021. IT SHOWS THE PERCENTAGE OF ADULTS IN THE UNITED STATES WHO BELIEVE MEDICAL RESEARCH IS UNFAIR, IT IS BIASED AGAINST PEOPLE OF COLOR. YOU SEE WITH EVERY CATEGORY HERE, WHITE, HISPANIC, BLACK AMERICANS, ASIAN AMERICANS, NATIVE AMERICANS, MORE THAN A THIRD OF PEOPLE WHO RESPONDED BELIEVE IT IS BIASED. FOR AFRICAN AMERICAN, BLACK AMERICANS, IT IS 62%, MORE THAN HALF OF THE PEOPLE THAT RESPONDED BELIEVE THAT MEDICAL RESEARCH IS BIASED. THERE ARE MANY RESEARCHERS AND ADVOCATES AND COMMUNITY ORGANIZATIONS THAT ARE HARD AT WORK TO SOLVE THIS PROBLEM. YOU'LL HEAR LATER FROM SOME OF THE COMMUNITY PARTNERS WHO HAVE ALSO BEEN WORKING TO BUILD A BRIDGE TO THE RESEARCH COMMUNITY. SO, THERE IS A LOT OF REALLY IMPORTANT WORK BEING DONE RIGHT NOW. IT BECOMES SORT OF A VICIOUS CYCLE BECAUSE THERE ARE -- THERE IS A LONG LEGACY THAT HELPS US UNDERSTAND WHY THERE IS LACK OF TRUST. ONE OF THE RESOURCES IN YOUR RESOURCE -- YOUR LIST, IS THIS BOOK, MEDICAL APARTHEID, IT IS A VERY IMPORTANT ACCOUNT OF HOW AFRICAN AMERICANS HAVE BEEN MISTREATED, DISCRIMINATED AGAINST, AND EVEN ABUSED

IN THE MEDICAL SYSTEM IN THE UNITED STATES SINCE COLONIAL TIMES UNTIL NOW. SO THERE ARE REASONS FOR THE LACK OF TRUST. WE HAVE TO WORK TOGETHER TO MOVE BEYOND IT BECAUSE WE NEED TO CHANGE THIS PROBLEM OF REPRESENTATION IN RESEARCH SO THAT WHAT WE LEARN CAN INCLUDE AND BENEFIT EVERYONE. THIS IS SOMETHING THAT IS RECOGNIZED AS AN IMPORTANT ISSUE FOR A LONG TIME. THIS IS JUST A LIST OF BIPARTISAN ACTIONS FROM THE UNITED STATES CONGRESS OVER TIME. TRY TO MAKE PROGRESS IN MAKING MEDICAL RESEARCH MORE INCLUSIVE AND REPRESENTATIVE -- INCLUSIVE AND REPRESENTATIVE OF THE DIVERSE POPULATION IN THE UNITED STATES. AND MOST RECENTLY, LAST YEAR, THE JOHN LEWIS NATIONAL INSTITUTE ON MINORITY HEALTH PUT FUNDS AND ENERGY TOWARDS THIS. SO EVEN THOUGH THERE ARE A LOT OF PEOPLE VERY DEDICATED TO MAKING CHANGE, IT TAKES TIME. RESEARCH TAKES YEARS AND SO, IT IS SOMETHING WE JUST NEED TO KEEP PUSHING FORWARD ON.

THOSE OF YOU WHO ARE HERE AND PART OF THE RESEARCH COMMUNITY, WHO ARE WORKING ON INCLUSION IN RESEARCH, PLEASE FEEL FREE TO MAKE ANY COMMENTS IN THE CHAT ABOUT THIS TOPIC AS WE GO. WE HAVE TALKED ABOUT THE FACT THERE ARE DISPARITIES. WE TALK ABOUT THE FACT WE DON'T EVEN KNOW VERY MUCH ABOUT SOME GROUPS OF PEOPLE OR ANYTHING BECAUSE THE RESEARCH HAS NOT BEEN DONE. SO, NOW I WANT TO INTRODUCE A DIFFERENT WAY TO LOOK AT RISK FACTORS AND HOW TO REDUCE THE RISK OF DEMENTIA. AND SO, WE ARE GOING TO -- OOPS. SORRY, MY ZOOM CONTROLS JUST JUMPED. I APOLOGIZE FOR THAT. HERE WE GO. WE'LL TALK ABOUT SOMETHING CALLED NON-MODIFIABLE AND MODIFIABLE RISK FACTORS. SEE IF I CAN MOVE THESE CONTROLS OUT OF MY WAY. HERE WE GO. THERE ARE SOME RISK FACTORS FOR DEMENTIA THAT WE CAN'T CHANGE AND WE CALL THEM NON-MODIFIABLE. AND THESE ARE AGING AND GENETICS. WE'RE GETTING OLDER, THAT'S A FACT. I THINK IT IS A WONDERFUL THING, BUT IN ANY CASE, WE DON'T HAVE CONTROL OVER THAT. AND GENETICS IS SOMETHING WE DON'T HAVE CONTROL OVER. IF YOU LOOK AT ALL THE PEOPLE IN THE WORLD LIVING WITH DEMENTIA, THERE'S A FAIRLY SMALL NUMBER OF THOSE PEOPLE WHO HAVE A VERY STRONG GENETIC LINK TO DEMENTIA. ONE EXAMPLE WOULD BE PEOPLE WITH DOWN SYNDROME. THEY HAVE AN EXTRA CHROMOSOME, WHICH CAUSES DOWN SYNDROME AND THAT ALSO CAN CAUSE ALZHEIMER'S DISEASE. THERE ARE A SMALL -- RELATIVELY SMALL NUMBER OF FAMILIES WHO HAVE GENES THAT MAKE THEM VERY LIKELY TO DEVELOP ALZHEIMER'S OR SOME OTHER CONDITION THAT CAUSES DEMENTIA. FOR MOST PEOPLE, THE ROLE OF GENETICS ISN'T AS BIG. LET'S TALK ABOUT MODIFIABLE

RISK FACTORS. WHAT WE CAN CHANGE. SOME OF THESE WE CAN CHANGE AS A SOCIETY, AS AN INDIVIDUAL, SOME WE REALLY HAVE TO WORK TOGETHER AS A SOCIETY. WE CALL THEM REDUCING RISK OR MODIFYING RISK FACTORS, WE DON'T SAY WE COULD PREVENT IT. AND THAT'S AN IMPORTANT DISTINCTION. I WANT TO EXPLAIN BEFORE I SHOW YOU WHAT FACTORS HAVE BEEN IDENTIFIED THROUGH RESEARCH. THINK ABOUT GARDENING. I'M SURE SOME OF YOU LIKE TO PLANT SEEDS, MAYBE LIKE TO GROW VEGETABLES OR FLOWERS. AND I WANT YOU TO JUST THINK ABOUT THAT FOR A MOMENT. WHEN YOU PLANT A GARDEN, YOU DO LOTS OF THINGS TO TRY TO HAVE THOSE PLANTS GROW AND THRIVE. YOU WILL WATER THEM, YOU WILL WEED THEM, YOU WILL TAKE STEPS TO TRY TO KEEP THEM STRONG AND HEALTHY, BUT YOU CAN'T GUARANTEE THAT YOU WILL GET THE FLOWERS AND FRUIT OR VEGETABLES THAT YOU ARE HOPING FOR. THERE ARE SO MANY FACTORS. THE WEATHER IS A FACTOR. MAYBE IT'S GOING TO RAIN TOO MUCH OR NOT ENOUGH. MAYBE THE SOIL OR THE SEEDS HAVE A PROBLEM WITH THEM THAT YOU DON'T KNOW ABOUT. MAYBE YOU'RE SEEDLINGS ARE COMING UP GOOD AND STRONG THAT WILL ATTRACT WOODCHUCKS AND OTHER CREATURES THAT WANT TO EAT THE PLANTS. MY POINT IS WE CAN ONLY CONTROL SO MUCH. WE CANNOT PREVENT DEMENTIA BY DOING HEALTHY BEHAVIORS. WE CAN JUST REDUCE OUR RISK. IT IS GOOD TO DO ALL THE THINGS, THEY ARE HEALTHY FOR US IN MANY WAYS. THERE'S NO HARM TO IT, BUT WE CAN'T PREVENT DEMENTIA. IF SOMEONE DEVELOPS DEMENTIA, IT IS NOT THEIR FAULT. IT DOESN'T MEAN THAT THEY DIDN'T DO THE HEALTHY THINGS, SOMEBODY MIGHT DO ALL THE HEALTHY THINGS AND STILL DEVELOP DEMENTIA.

THIS IS A WONDERFUL GRAPHIC FROM THE ALZHEIMER'S ASSOCIATION AND I KNOW IT IS HARD TO SEE IT ON THE SCREEN. THERE'S A LINK TO THIS IN ENGLISH AND SPANISH IN YOUR RESOURCE LIST. AND I'LL JUST GO OVER THESE QUICKLY. THESE ARE IDEAS THAT HAVE BEEN PROVEN NOW BY RESEARCH TO HELP REDUCE RISK. PROBABLY ONE OF THE MOST IMPORTANT ONES IS TO EXERCISE. SO, IT SAYS HERE BREAK A SWEAT. EXERCISE IS VERY GOOD FOR OUR HEARTS AND FOR OUR BRAINS. STUDYING, WORKING HARD, DOING HARD BRAIN WORK, HELPS OUR BRAINS. AVOIDING SMOKING. TAKING CARE OF EVERYTHING THAT KEEPS OUR HEART HEALTHY IS VERY IMPORTANT. AVOIDING HEAD INJURY. EATING A HEALTHY DIET. GETTING ENOUGH SLEEP. TAKING CARE OF MENTAL HEALTH. SO, GETTING SOME HELP AND SUPPORT WHEN YOU ARE STRUGGLING WITH MENTAL HEALTH. STAYING SOCIALLY CONNECTED. AND AGAIN, CHALLENGING YOURSELF BY DOING THAT KIND OF BRAIN WORK THAT IS CHALLENGING. ALSO, RESEARCH HAS SHOWN THAT IT IS VERY IMPORTANT TO TREAT SENSORY IMPAIRMENTS. IF

SOMEONE HAS A HEARING LOSS OR VISION LOSS, IT IS IMPORTANT TO SEE IF THERE'S A WAY TO GET SOME HELP WITH THAT THROUGH ASSISTIVE TECHNOLOGY SO THE PERSON CAN CONTINUE TO GET ALL THAT VISUAL AND AUDITORY INPUT AND STAY SOCIALLY CONNECTED AND ACTIVE. AND THERE'S MORE RESEARCH UNDERWAY, LOOKING AT THINGS LIKE AIR POLLUTION AND MANY OTHER FACTORS THAT MAY AFFECT RISK.

NOW LOOKING AT IT THIS WAY, WE CAN ASK A DIFFERENT QUESTION ABOUT DISPARITIES. WE CAN ASK: WHERE ARE THERE BARRIERS TO ACCESS? WHEN YOU LOOK AT THE HEALTHY BEHAVIORS, THINK ABOUT YOUR COMMUNITY AND DOES EVERYONE HAVE A PLACE TO EXERCISE SAFELY. DOES EVERYONE HAVE THE ABILITY TO GET A GOOD NIGHT SLEEP. OR IF SOMEONE IS WORKING TWO OR THREE JOBS TO AFFORD FOOD, ARE THEY GOING TO BE ABLE TO HAVE A HEALTHY SLEEP SCHEDULE. YOU GET THE IDEA. THIS WILL GIVE US A DIFFERENT WAY TO THINK ABOUT DISPARITIES AND HOW WE AS A SOCIETY NEED TO WORK TO SUPPORT ONE ANOTHER TO REDUCE THE RISK OF DEMENTIA.

SO IN SOME OF THE AREAS, WE CAN MAKE A CHANGE JUST AS INDIVIDUALS. YOU SEE THE PEOPLE HERE IN THE PICTURE, TAKE A DANCE CLASS. THAT IS A GREAT THING TO DO AT ANY AGE. IT WILL GIVE THE COGNITIVE CHALLENGE, KEEPS US SOCIALLY CONNECTED, GIVES US EXERCISE; HOWEVER, THAT KIND OF CHALLENGE THAT WE TAKE ON MAYBE AS ADULTS OR OLDER ADULTS, IT DOESN'T MAKE UP FOR ALL THOSE YEARS OF SCHOOL. HAVING GOOD SCHOOLS OPEN TO ALL CHILDREN IS ALSO INCREDIBLY IMPORTANT AND THAT'S SOMETHING WE NEED TO DO AS A SOCIETY. NOW, I'D LIKE TO FOCUS THE LENS ONE MORE TIME, SO REMEMBER THE CAMERA, WE'LL FOCUS ONE MORE TIME ON THE INDIVIDUAL PERSON PERSPECTIVE. AND I WANT TO MAKE A FEW COMMENTS ABOUT THAT. YOUR INDIVIDUAL RISK IS NOT NECESSARILY THE SAME AS YOUR GROUP'S RISK. I HAVE GIVEN YOU LOTS OF STATISTICS AND MAYBE FOR SOME OF YOU, YOU ARE THINKING -- I'M IN A HIGH-RISK GROUP AND FEELING WORRIED. I WANT TO LET YOU KNOW, THOSE STATISTICS ONLY ARE TRUE FOR LARGE GROUPS OF PEOPLE. FOR YOU, AS AN INDIVIDUAL, YOUR RISK IS BASED ON YOUR OWN HEALTH, YOUR FAMILY'S HEALTH, YOUR LIFE SITUATION, YOUR HEALTH BEHAVIORS, AND SO MUCH MORE. IT MAY BE YOU ARE PART OF A GROUP WITH A HIGHER RISK, BUT YOU YOURSELF MAY NOT HAVE A HIGHER RISK. EACH PERSON IS UNIQUE. AS WE GO THROUGH OUR AFTERNOON AND WE'RE TALKING ABOUT CULTURAL PATTERNS, WE NEED TO KEEP IN MIND THAT NOT EVERYONE FOLLOWS THE PATTERNS. I WANT YOU TO THINK FOR A MOMENT ABOUT SOMEONE YOU KNOW WHO MIGHT NOT FOLLOW SOME OF THE CULTURAL PATTERNS OF THEIR GROUP. MAYBE IT IS YOU,

MAYBE IT IS SOMEONE YOU KNOW. WE ARE ALL DIFFERENT, WE ARE ALL COMPLICATED PEOPLE. AND WE HAVE MANY FACETS. SO, I HAVE BEEN TALKING ABOUT GROUPS AS IF THEY ARE SEPARATE, BUT SOMEONE MAY HAVE A PARENT, WHO IS PART OF ONE ETHNICITY OR RACE AND ANOTHER PARENT PART OF ANOTHER. A PERSON MAY BE PART OF THE LGBTQI+ COMMUNITY AND THAT CAN AFFECT THEIR EXPERIENCE OF LIVING WITH DEMENTIA OR GETTING ACCESS TO HEALTHCARE AND SERVICES. PEOPLE HAVE MANY FACETS. AND FINALLY, EFFECTIVE SUPPORT IS ALWAYS GOING TO FOCUS ON THE INDIVIDUAL. SO, IT IS VERY GOOD TO LEARN ABOUT CULTURAL PATTERNS AND DISPARITIES, BUT THEN WHEN WE'RE WORKING TO SUPPORT A SPECIFIC PERSON, WE REALLY NEED TO FOCUS THE LENS ON THAT INDIVIDUAL SITTING WITH US AND LISTEN TO THEM. AND I JUST WANT TO GO BACK TO A POINT I MADE BEFORE, WHICH IS TO KEEP IN MIND THAT PEOPLE CAN LIVE WELL WITH DEMENTIA AND THESE ARE PICTURES FROM DEMENTIA ACTION ALLIANCE. THEIR INFORMATION IS IN THE RESOURCE LIST. THAT ALWAYS HAS TO BE OUR GOAL -- SUPPORT PEOPLE IN LIVING WELL WITH DEMENTIA. OKAY, NOW I WANT TO COME BACK TO THE ISSUE OF TALKING ABOUT DEMENTIA. WE HAVE TALKED ABOUT A LOT OF DIFFERENT KINDS OF BARRIERS AND DISPARITIES. AND AS YOU KNOW, PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILIES AND FRIENDS, NEED A LOT OF DIFFERENT SUPPORT AND WE'LL FOCUS IN ON TALKING ABOUT DEMENTIA BECAUSE IT REALLY IS THE GATEWAY TO KNOWLEDGE AND SUPPORT. IN FACT, THE WORLD ALZHEIMER'S REPORT THAT JUST CAME OUT FOUND THAT INFORMATION ABOUT DEMENTIA IS THE CRITICAL FACTOR THAT IS MOST NEEDED WORLDWIDE. I THINK ONCE WE HAVE MORE CONVERSATION AND LESS STIGMA, THEN WE WILL LEARN WHAT ELSE IS NEEDED AND BE ABLE TO MOVE FORWARD. LET'S TALK ABOUT WHAT THE BARRIERS ARE TO TALKING. AND YOU KNOW, THE FIRSTS ONE IS FEAR. PEOPLE ARE MORE AFRAID OF DEMENTIA THAN THEY ARE AFRAID OF CANCER AND HEART DISEASE. SEVERAL SURVEYS HAVE SHOWN THAT. FEAR LEADS TO SILENCE AND STIGMA. THIS HAS AN IMPACT NOT JUST AT THE INDIVIDUAL LEVEL, THE LAUNCH OF THE ALZHEIMER'S WORLD REPORT, ONE SPEAKER WAS MIKE, WHO STARTED THE CONVERSATION ABOUT DEMENTIA AND HER COUNTRY. SHE STARTED THE FIRST NONPROFIT DEDICATED TO ALZHEIMER'S AND DEMENTIA IN BOTSWANA. AND TALKED ABOUT MEETING WITH THE HEALTH MINISTRY AND THERE WAS DISCOMFORT OR RESISTANCE TO TAKING STEPS. HER COMMENT IS, PEOPLE RESIST OF WHAT THEY DO NOT KNOW. WE HAVE A PROBLEM OF FEAR, SILENCE AND STIGMA, AND BECAUSE THERE IS THAT SILENCE, PEOPLE DON'T KNOW ABOUT IT, THEY DON'T FEEL COMFORTABLE TALKING ABOUT IT AND THEY BACK AWAY.

THE NEXT BARRIER HERE IS LATE OR NO DIAGNOSIS. SO BECAUSE THERE IS SILENCE AND STIGMA, VERY OFTEN PEOPLE DO NOT SEEK MEDICAL HELP, THEY DON'T GET A DIAGNOSIS AT ALL OR THEY GET IT VERY LATE AND THEN IT IS HARD TO GET HELP AND SUPPORT. THERE ARE LANGUAGE BARRIERS. YOU WILL HEAR ABOUT THAT FROM OUR COMMUNITY PARTNERS. NOT JUST WHAT LANGUAGE PEOPLE SPEAK, BUT ALSO HEALTH LITERACY. IS SOMEONE ABLE TO UNDERSTAND THE INFORMATION THAT IS PROVIDED, EVEN IF IT IS IN THEIR LANGUAGE. IT MAY BE WRITTEN IN A WAY THAT IS EASIER FOR MEDICAL STAFF TO UNDERSTAND AND HARD FOR JUST EVERYDAY PEOPLE TO UNDERSTAND. GEOGRAPHIC BARRIER, NOT EVERYONE LIVES IN AN AREA WHERE THEY HAVE ACCESS TO NEUROLOGISTS OR OTHER SPECIALISTS WHO MIGHT BE ABLE TO HELP WITH A MORE COMPLICATED DIAGNOSIS OR WHERE THEY CAN GET SERVICES. LACK OF CULTURAL SERVICES. BECAUSE OF ALL THE SILENCE AND FEAR, IT IS EXTREMELY IMPORTANT FOR PEOPLE TO HAVE A TRUSTED PLACE TO GO FOR HELP. AND IN MANY AREAS, THERE IS NOT SOMETHING IN THAT CULTURE -- OOPS. I'M SO SORRY. I DON'T KNOW WHY IT KEEPS JUMPING FORWARD LIKE THIS. LET ME GET THERE. RELATED TO THAT, MAYBE FEW PROVIDERS FROM THE LINGUISTICAL COMMUNITY. SOMEONE DOESN'T SEE SOMEONE THAT LOOKS LIKE THEM WHO THEY FEEL COMFORTABLE WITH. THERE ARE COMMUNITY PROVIDERS WHO DO HAVE THE LANGUAGE AND CULTURAL CONNECTION, BUT MAY NOT HAVE THE TRAINING IN DEMENTIA. THIS IS SOMETHING WE TALKED ABOUT A LOT IN OUR COMMUNITY PROVIDERS GROUP, FOR EXAMPLE, THERE ARE MANY SMALL DAY PROGRAMS THAT ARE RUN BY IMMIGRANT COMMUNITIES. SO THEY HAVE THAT LANGUAGE AND CULTURAL CONNECTION FOR THE OLDER ADULTS WHO MAY SERVE. THEY MAY NOT HAVE ANY TRAINING ON DEMENTIA. THEY MAY NOT KNOW HOW TO HANDLE SITUATIONS THAT COME UP FROM A PARTICIPANT WHO IS LIVING WITH DEMENTIA. AND BELIEF SYSTEMS, MANY COMMUNITIES HAVE A BELIEF THAT DEMENTIA IS NOT A DISEASE, IT IS JUST A NORMAL PART OF AGING. PEOPLE MAY NOT GET SUPPORT AND THERE ARE ALSO COMMUNITIES THAT HAVE BELIEF THAT IT'S DUE TO SOMETHING BAD THE PERSON HAS DONE, IT'S SOMETHING TO BE ASHAMED OF. OF COURSE, THAT ALSO PREVENTS GETTING -- REACHING OUT AND GETTING HELP. THERE ARE COMMUNITIES THAT HAVE BELIEFS THAT DEMENTIA IS NOT -- SHOULDN'T BE STIGMATIZED AND OLDER PEOPLE ARE TREASURED AND SHOULD BE SUPPORTED. THERE ARE POSITIVE BELIEFS AS WELL. TRAUMA. WHEN YOU THINK ABOUT IMMIGRANTS OR OTHER GROUPS OF PEOPLE WHO HAVE EXPERIENCED TRAUMA, MAYBE THEY EXPERIENCED DISCRIMINATION OR RACISM. DISCRIMINATION BECAUSE OF BEING PART OF A GENDER OR SEXUAL ORIENTATION MINORITY AND SO FORT, MAYBE HAVE TRAUMA

THAT WILL MAKE IT HARDER FOR THEM TO FEEL CONFIDENT REACHING OUT FOR SUPPORT. LEGACY OF DISCRIMINATION, WE TALKED ABOUT. AND FINANCIAL BARRIERS AS WELL. IT CAN BE REALLY HARD TO FIND THE TIME AND RESOURCES TO REACH OUT AND GET SUPPORT AROUND DEMENTIA. WHAT ELSE, I INVITE YOU TO PUT IN THE CHAT ANY OTHER COMMENTS YOU HAVE ABOUT BARRIERS TO OPEN COMMUNICATION ABOUT DEMENTIA. DENIAL, I SEE, THANK YOU. JUDGMENT. FAMILY DENIAL. ABSOLUTELY. LACK OF FAMILY SUPPORT. TABOO. AND THESE THINGS -- FEAR. THESE CAN CREATE A CYCLE BECAUSE THEY MAKE IT HARD TO TALK ABOUT IT AND THEN BECAUSE WE DON'T TALK ABOUT IT, IT FEELS VERY SCARY. TODAY REALLY IS ALL ABOUT HELPING US FIND WAYS TO BREAK THAT SILENCE. THIS IS THE GOAL. THIS IS A QUOTE FROM SANDY WHO IS LIVING WITH DEMENTIA. HE SAYS: I'M EAGER TO SEE ALL THOSE LIVING WITH DEMENTIA AND THEIR CARE PARTNERS BREAK THROUGH THE BARRIER WALL OF STIGMA AND LIVE FULFILLING AND PRODUCTIVE LIVES. BREAKING THROUGH THE WALL IS NOT THE SAME FOR EVERYBODY. FOR SOME PEOPLE IT MEANS BECOMING AN ADVOCATE OR WE CAN USE THE TERM SELF-ADVOCATE. SOMEONE WITH DEMENTIA WHO BECOMES AN ADVOCATE FOR THEMSELVES. THIS CAN BE A VERY EMPOWERING EXPERIENCE FOR SOMEONE LIVING WITH DEMENTIA. IT CAN PROVIDE A LOT OF MEANING AND PURPOSE IN LIFE. FOR THE PUBLIC, IT CAN BE THE SINGLE MOST POWERFUL WAY TO REDUCE STIGMA. WHEN PEOPLE HEAR FROM SOMEONE DIRECTLY WHO IS LIVING WITH DEMENTIA, THEY CAN CHANGE THEIR MINDS ABOUT WHAT DEMENTIA MEANS. AND I WANTED TO SHARE THE LOGOS OF SOME ORGANIZATIONS THAT HAVE REALLY GOOD RESOURCES TO HELP PEOPLE MEET OTHER PIERCE -- MEET OTHER PEERS WHO LIVE WITH DEMENTIA AND FIND THEIR VOICE AS ADVOCATES. THESE ARE IN THE RESOURCE LIST. IN THE RESOURCE LIST YOU WILL ALSO FIND A TOOLKIT DEVELOPED BY THE STRIDE PROGRAM, WHICH IS WORKING WITH PEOPLE IN THE UK, BRAZIL, INDIA, INDONESIA, KENYA, JAMAICA, MEXICO, AND SOUTH AFRICA, WHICH HAS A NUMBER OF VIDEOS OF PEOPLE LIVING WITH DEMENTIA. THERE ARE RESOURCES OUT THERE FOR THOSE WHO WANT TO CONNECT WITH OTHERS, WHO WANT TO BECOME SELF-ADVOCATE AND FOR THOSE WHO WANT TO SHARE THE VOICES OF PEOPLE LIVING WITH DEMENTIA. HOWEVER, NOT EVERYONE IS GOING TO WISH TO BECOME AN ADVOCATE IN THIS PUBLIC WAY. THIS IS SOMETHING THAT WE TALKED ABOUT IN OUR COMMUNITY PARTNERS GROUP, THIS IS NOT A CULTURAL FIT FOR EVERYONE. IT IS NOT A FIT FOR EVERYONE INDIVIDUALLY. WHAT EVERYONE NEEDS IS TO BE ABLE TO COMMUNICATE IN ORDER TO SEEK INFORMATION AND SUPPORT. SO, WE NEED TO BREAK THE SILENCE FOR EVERYONE TO BE ABLE TO DO THOSE THINGS. AND THIS IS WHY IT IS SO

IMPORTANT TO HAVE A TRUSTED COMMUNITY MEMBER BE THE ONE TO PROVIDE EDUCATION AND AWARENESS ABOUT DEMENTIA. IN THE PHOTOS YOU SEE, YOU SEE PEOPLE WHO LED THE FIRST DEMENTIA FRIENDS MASSACHUSETTS SESSIONS IN ARABIC AND THIS IS JUST AN EXAMPLE OF HOW COMMUNITY PARTNERS, PEOPLE WHO ARE TRUSTED IN THE COMMUNITY, THEY ARE REALLY SO IMPORTANT TO MAKE THIS CHANGE, TO BREAK THE SILENCE. I'M JUST ABOUT TO WRAP UP HERE. I JUST WANT TO ORIENT YOU A LITTLE BIT TO DEMENTIA FRIENDS. THAT'S THE WAY THAT OUR PROJECT IS BREAKING THE SILENCE AROUND DEMENTIA. IT IS A GLOBAL PUBLIC AWARENESS INITIATIVE. THERE ARE TWO STEPS. IT IS VERY SIMPLE. FIRST, WE TRAIN COMMUNITY MEMBERS TO BE WHAT WE CALL CHAMPIONS. THEN CHAMPIONS LEAD A ONE-HOUR INTERACTIVE WORKSHOP ABOUT DEMENTIA IN THEIR COMMUNITY. AND JEWISH FAMILY AND CHILDREN'S SERVICE, WHICH RUNS DEMENTIA FRIENDS MASSACHUSETTS, HAS CONTRACTED WITH COMMUNITY PARTNERS SINCE 2019. WE HAVE REALLY FOUND THAT COMMUNITY PARTNERS ARE THE KEY TO GETTING THIS INFORMATION OUT TO MANY GEOGRAPHIC AND CULTURAL AND LINGUISTIC COMMUNITIES. HOW DID WE CHOOSE WHICH COMMUNITIES TO FOCUS ON? WE LOOKED AT COMMUNITIES WITH A DEMONSTRATED HIGHER RISK OF DEMENTIA. FOR EXAMPLE, BLACK, AFRICAN AMERICAN, LATINO/HISPANIC, PEOPLE WITH DOWN SYNDROME. WE LOOKED AT THE POPULATION OF MASSACHUSETTS TO SEE WHICH POPULATIONS HAD LIMITED ENGLISH PROFICIENCY. WE TALKED TO A LOT OF PEOPLE, A LOT OF INDIVIDUALS AND ORGANIZATIONS TO FIND WHO IS INTERESTED. IT WAS REALLY A COMBINATION OF OUTREACH AND BUILDING ON EXISTING RELATIONSHIPS. CERTAINLY, THIS A WORK IN PROGRESS, WE HAVE NOT REACHED NEARLY ALL THE COMMUNITIES IN MASSACHUSETTS. AND THIS IS AN ONGOING PROCESS. I ALSO WANT TO MENTION THAT THE INTERNATIONAL ASSOCIATION FOR INDIGENOUS AGING RUNS DEMENTIA FRIENDS FOR AMERICAN INDIAN AND ALASKAN NATIVE COMMUNITIES NATIONWIDE. AND THEIR CONTACT INFORMATION IS IN THE RESOURCE LIST. SO, WITH THAT, I'M SO DELIGHTED TO INTRODUCE OURSELVES COMMUNITY PARTNERS. I'M GOING TO TELL YOU A LITTLE ABOUT EACH OF THE COMMUNITY PARTNERS AND THEN YOU CAN SEE THEIR FULL BIOGRAPHIES IN THE PROGRAM BOOK. SO, I WILL JUST GO THROUGH THIS LIST OF WONDERFUL FOLKS AND THEN I'M GOING TO INTRODUCE NIA MOSTACERO AFTER THAT, SHE'LL SHARE THE STORY AND WE'LL HAVE THE COMMUNITY PARTNERS ROUNDTABLE.

I WILL PAUSE HERE. I THINK OUR INTERPRETERS... I KNOW I'M TALKING FAST TO CATCH UP. WE HAD SOME TECHNICAL ISSUES. LET YOU TAKE A BREATHER. SO, I'M SO PLEASED TO INTRODUCE ARNETTA AND CARL -- A

NONPROFIT BASED IN DORCHESTER, MASSACHUSETTS SUPPORTING COMMUNITY MEMBERS AROUND TRAINING, EDUCATION, AND HOUSING. THEY WORKED WITH DEMENTIA FRIENDS MASSACHUSETTS SINCE 2019. BONNIE, IS THE PRESIDENT OF THE OHIO COUNCIL FOR COGNITIVE HEALTH, HOME OF DEMENTIA FRIENDS. BONNIE, MARTY, AND THEIR TEAM DEVELOPED THE VERSION OF DEMENTIA FRIENDS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES THAT KATHY SERVICE HAS MODIFIED AND IS USING HERE IN MASSACHUSETTS. BONNIE WAS GRACIOUS TO JOIN US TODAY TO ADD HER VOICE TO THIS CONVERSATION.

KUN, IS THE ASSOCIATE DIRECTOR OF THE GREATER BOSTON CHINESE GOLDEN AGE CENTER. AN ORGANIZATION THAT PROVIDES COMPREHENSIVE WELLNESS SERVICES TO ASIAN OLDER ADULTS AND FAMILY MEMBERS. INCLUDING HOUSING, NUTRITION, DAY PROGRAMS, TRANSPORTATION, AND CAREGIVER SUPPORT. AS YOU WILL HEAR LATER, KUN IS INSTRUMENTAL IN THE COMMUNITY PARTNER WORK OF DEMENTIA FRIENDS MASSACHUSETTS FROM THE START. HE AND HIS TEAM PROVIDE EDUCATION IN MANDARIN AND CANTONESE. ALANA, WORKED AS A PSYCHOLOGIST, ORGANIZATIONAL CONSULTANT AND HUMAN RESOURCE MANAGER IN BRAZIL BEFORE COMING TO THE UNITED STATES. SHE NOW WORKS AS A BILINGUAL OUTREACH COORDINATOR AT A CENTER FOR OLDER ADULTS AND WAS A LONG-TIME CAREGIVER FOR A FAMILY MEMBER WHO LIVED WITH DEMENTIA. SHE HAS WORKED WITH DEMENTIA FRIENDS MASSACHUSETTS SINCE 2019, PROVIDING EDUCATION IN PORTUGUESE. TIRSA, A PATIENT NAVIGATOR AND HEALTH EDUCATOR AT THE LATINO HEALTH INSURANCE PROGRAM. A COMMUNITY-BASED PROVIDER OF MEDICAL AND DENTAL CARE. EDUCATION AND ADVOCACY. AND TIRSA IS THE PASTOR AND LEADER OF WOMEN'S MINISTRY FOR A CHURCH SERVING THE SPANISH-SPEAKING COMMUNITY. AND SHE IS WORKED WITH DEMENTIA FRIENDS FOR THE LAST YEAR AND HALF. PROVIDING EDUCATION IN SPANISH. SAW, MOVED TO THE UNITED STATES FROM A REFUGEE CAMP IN THAILAND TEN YEARS AGO. HE IS A BUSINESS ADMINISTRATION STUDENT AND CONDUCTS COMMUNITY OUTREACH AT THE SOUTHEAST ASIAN COALITION OF CENTRAL MASSACHUSETTS. SAW IS THE PRESIDENT OF THE WORCESTER -- COMMUNITY. HE WORKED WITH DEMENTIA FRIENDS SINCE 2021. ALONG WITH THE COLLEAGUES, HE PROVIDES EDUCATION. KATHY SERVICE, HAS WORKED IN THE FIELD OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SINCE 1976. SHE IS A NURSE PRACTITIONER AND WAS ONE OF THE FIRST NURSES NATIONALLY TO BE CERTIFIED IN THE SPECIALTY OF DEVELOPMENTAL DISABILITIES NURSING. KATHY HAS SERVED ON LOCAL, NATIONAL, AND INTERNATIONAL ADVISORY BOARDS, INCLUDING THE NATIONAL TASK GROUP ON DEMENTIA

INTELLECTUAL DISABILITIES. AND WORKED WITH DEMENTIA FRIENDS FOR A FEW YEARS AND SINCE 2021, HAS BEEN FOCUSING ON PROVIDING DEMENTIA EDUCATION FOR PARTICIPANTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES. JUDITH IS RESIDENT WELLNESS DIRECTOR AT CSI SUPPORT AND DEVELOPMENT SERVICES. JUDITH TRAINED AS A PHYSICIAN IN MEXICO, FRANCE, AND THE UNITED STATES. AND COMPLETING A MASTER'S IN AGING SERVICES MANAGEMENT. SHE WORKED WITH DEMENTIA FRIENDS SINCE 2021 AND SHE LEADS DEMENTIA EDUCATION IN HAITIAN-CREOLE AND SPANISH. AND PARTNERSHIPS WITH MEDICAL INSTITUTIONS TO ENABLE RESIDENTS TO ACCESS SERVICES AND TO PARTICIPATE IN CLINICAL TRIALS. AND NOW, I'M DELIGHTED TO INTRODUCE ANITRA/NIA. SHE IS LIVING WITH DEMENTIA AFTER BEING DIAGNOSED. I MET HER -- PART OF THE NATIONAL COUNCIL OF DEMENTIA MINDS AND I'M GRATEFUL TO NIA FOR JOINING OUR COMMUNITY PARTNERS MEETING TO DEVELOP TODAY'S PROGRAM. AND GRATEFUL THAT SHE WILL SHARE HER STORY WITH US TODAY. BECAUSE AT THE CENTER OF THE CONVERSATION, WE NEED THE VOICES OF PEOPLE WHO ARE LIVING WITH DEMENTIA. ALONG WITH THOSE WHO CARE ABOUT THEM AND OTHER EXPERTS. SO, WITH THAT, NIA, I WILL GIVE YOU THE FLOOR.

>> GREAT. GOOD MORNING, CAN YOU HEAR ME?

>> YES, WE CAN HEAR YOU.

>> THANK YOU. I WANT TO TAKE YOU A JOURNEY OF MY DEMENTIA DIAGNOSIS. I STARTED DURING MY LAST TWO YEARS OF ACTIVE DUTY, WHEN I BEGAN TO NOTICE PROBLEMS WITH MY MEMORY AND COORDINATION. AND VARIOUS JOB-RELATED ROLES, I FOUND MYSELF MAKING ERRORS IN MY PAPER WORK, MISSING MEETINGS AND FORGETTING THINGS. I FELT AS THOUGH MY TROOPS AND MY COMMANDER WERE TAKING CARE OF ME MORE THAN I WAS TAKING CARE OF THEM. A TURNING POINT FOR ME CAME ONE DAY WHEN I FORGOT HOW TO START MY CAR. ALARMED, I RAISED MY CONCERN TO MY PRIMARY CARE MANAGER AND THEY REFERRED ME TO A MENTAL HEALTH CARE PROFESSIONAL. INITIALLY, THE DOCTORS ATTRIBUTED MY SYMPTOMS TO JOB-RELATED STRESS AND DEPRESSION, BUT I WAS EXPERIENCING HALLUCINATIONS AND SLEEPWALKING. AFTER SEEING A SERIES OF SPECIALISTS, NEUROPSYCHOLOGIST, RHEUMATOLOGIST, AND SLEEP SPECIALISTS, MY NEUROLOGIST ORDERED A PET SCAN AND IT REVEALED BRAIN ATROPHY RELATED TO ALZHEIMER'S DISEASE. WHEN I RECEIVED THE DIAGNOSIS, MY NEUROLOGIST LOOKED SADDER THAN I DID. HE SAID HE ONLY HAD A HANDFUL OF PATIENTS MY AGE WITH ALZHEIMER'S DISEASE. AND I WAS SHOCKED AS WELL BECAUSE I THOUGHT THE DISEASE ONLY AFFECTED OLDER PEOPLE. FROM THAT EXPERIENCE, I LEARNED THAT YOU NEED TO LISTEN TO YOUR

BODY. BE A STRONG ADVOCATE FOR YOURSELF. I KNEW I WAS EXPERIENCING SOMETHING MORE THAN STRESS, I THOUGHT THAT MAYBE I HAD A BRAIN TUMOR BECAUSE I WAS THAT MUCH OFF. ALZHEIMER'S NEVER CROSSED MY MIND. MY DOCTOR RECOMMENDED I CONTACT THE ALZHEIMER'S ASSOCIATION FOR INFORMATION AND RESOURCES. AND HE ENCOURAGED ME TO GET MY AFFAIRS IN ORDER. I ALSO WATCHED THE 2014 FILM, STILL ALICE, IT WAS LOOKING IN A MIRROR. IN 2022, I WAS DIAGNOSED WITH CHRONIC TRAUMATIC ENCEPHALOPATHY AND TRAUMATIC BRAIN INJURY, THE DAMAGE WAS DONE. THROUGH MY LOCAL ALZHEIMER'S ASSOCIATION CHAPTER, I JOINED THE SUPPORT GROUP, WHICH WAS VERY HELPFUL. I HELPED TO ORGANIZE THE YOUNGER ONSET SUPPORT GROUP FOR PEOPLE IN EARLY STAGES OF THE DISEASE UNDER 65 YEARS OF AGE. I HAVE TAKEN STEPS TO ADDRESS MY FUTURE, CREATING A WILL, ESTABLISHING A POWER OF ATTORNEY, AND ADVANCED CARE DIRECTIVE, ALL AT THE -- AT THE REQUEST OF MY NEUROLOGIST. I LIVE INDEPENDENTLY, BUT I HAVE HIRED A HOUSEKEEPER TO HELP WITH CHORES. TAKING STEPS TO ADDRESS MY FUTURE HAS GIVEN ME A PEACE OF MIND AND PUTTING PLANS IN PLACE IS REALLY IMPORTANT TO HELP REDUCE STRESS. I TELL PEOPLE THAT YOUR LIFE IS NOT OVER JUST BECAUSE YOU HAVE A DEMENTIA DIAGNOSIS. YOUR FUTURE MAY LOOK DIFFERENT FROM WHAT YOU PLAN, YOU CAN STILL HAVE A FULFILLING LIFE, JUST AS I DO. MY ADVICE TO OTHERS FACING THIS DISEASE IS TO TELL THOSE THAT YOU LOVE... THAT YOU CHERISH THEM. KEEP MAKING MEMORIES, PUT TOGETHER A BUCKET LIST, GET CRACKING. THANK YOU, BETH.

>> THANK YOU SO MUCH, NIA. THAT'S SUCH IMPORTANT AND INSPIRING WORDS. WE ARE REALLY GRATEFUL THAT YOU HERE WITH US AND I SEE MANY PEOPLE COMMENTING IN THE CHAT WITH APPRECIATION FOR YOU. GET CRACKING! SAYS CINDY. THANK YOU. I KNOW WE WERE HAVING A PROBLEM WITH THE VIETNAMESE CHANNEL AND I HOPE THAT IT IS WORKING NOW. I APOLOGIZE FOR ANYONE THAT IS HAVING DIFFICULTY. NIA, I HOPE YOU CAN LOOK AT THE CHAT AND SEE ALL THE WONDERFUL APPRECIATION FOR YOU THERE.

>> I WANT TO ADD -- DEB WROTE THANK YOU FOR THE SERVICE, NIA.

>> YES, THANK YOU. WHAT I WOULD LIKE TO DO IS BRING ON THE COMMUNITY PARTNERS. JESSICA WILL SPOTLIGHT FOLKS. AND WE WILL BEGIN OUR CONVERSATION. I'LL TAKE A MOMENT. WE'RE GOING TO DISCUSS FOUR QUESTIONS. FOUR QUESTIONS THAT WILL HELP TO GIVE EVERYONE A SENSE OF THE NEEDS AND THE RESOURCES, THE STRENGTHS, THE CHALLENGES, ALL SPECIFIC TO MANY DIFFERENT CULTURAL COMMUNITIES REPRESENTED HERE. WE'RE GOING TO HAVE ABOUT AN HOUR, A LITTLE MORE THAN AN HOUR OF DISCUSSION. THEN

WE'LL TAKE A BREAK AT THAT POINT. LET YOU STRETCH. I'M DELIGHTED TO SEE OUR COMMUNITY PARTNERS HERE ON THE SCREEN. I'M GOING TO ASK THE FIRST QUESTION AND WE'LL START WITH JUDITH WHO BRAVELY WILLING TO START AND WE'LL GO AROUND AND HEAR FROM OUR COMMUNITY PARTNERS. AS I SAID TO THEM, I WANT THIS TO BE MORE OF A CONVERSATION, IT IS ALWAYS A LITTLE HARD TO DO THAT ON ZOOM. AT ANY POINT, IF ANY OF THE COMMUNITY PARTNERS WANT TO ADD SOMETHING, I CAN SEE YOU -- YOU CAN ALWAYS RAISE YOUR HAND AND THAT WILL HELP ME KNOW TO COME BACK TO YOU. SO, WHEN PEOPLE IN YOUR COMMUNITY HEAR THE WORD "DEMENTIA" WHAT DOES IT MEAN TO THEM? WHEN YOU ANSWER, LET US KNOW THE COMMUNITY OR COMMUNITIES THAT YOU ARE SERVING. CAN I GO TO YOU FIRST, JUDITH?

>> GOOD AFTERNOON EVERYONE. ONCE AGAIN, I'M JUDITH. I'M EDUCATING HAITIAN COMMUNITIES, LATINO AND BLACK AFRICAN COMMUNITIES. DEMENTIA MEANS FEAR, MEMORY LOSS. BUT THE MOST IMPORTANT, I REALIZE THAT PEOPLE -- THEY FOUND HOPE. WHAT NIA MENTIONED -- WHAT WAS MENTIONED DURING THE PRESENTATION, THE TOOLS TO ADDRESS DEMENTIA. NOW THE ASIAN COMMUNITY RIGHT NOW ARE ENGAGED AND PARTICIPATING IN RESEARCH. WE ARE INVOLVED IN RESEARCH, MEDICAL INSTITUTIONS IN BOSTON. AND PEOPLE WANT TO KNOW MORE ABOUT THAT. I THINK BRINGS HOPE TO THE COMMUNITY. IT IS NOT ABOUT ONLY FEAR, BUT THEY FEEL THEY HAVE POWER TO ADDRESS DEMENTIA. THEY CAN BRING MORE IN CLINICAL TRIALS, THEY CAN GET MORE INFORMATION AND THEY CAN SHARE STORIES AND INFORMATION TO PEOPLE, THE CHURCH, OR THEIR CHILDREN. AND THEY THINK ABOUT DECISIONS ON LIFE. AS YOU MENTIONED, NIA. MAKE A LIST WHAT YOU WANT AT THE END OF THE LIFE. WHAT YOU HAVE TO FOCUS ABOUT YOUR FINANCES, TO BE RESPONSIBLE. THAT IS VERY GRATEFUL, PEOPLE ARE TAKING CARE AND TAKING STEPS TO MOVE FORWARD WITH DEMENTIA AND THEY CAN LIVE WELL.

>> THANK YOU, JUDITH. I'M GOING TO COME TO YOU NEXT, KUN. I THINK YOU ARE MAKING AN IMPORTANT POINT, WHICH IS WHAT PEOPLE IN YOUR COMMUNITY THINK ABOUT DEMENTIA CHANGES WHEN YOU HELP THEM HAVE INFORMATION AND SOME STEPS THEY CAN TAKE. IT CHANGES AND PEOPLE CAN FEEL MORE HOPE AND LESS FEAR. SO THANK YOU, JUDITH. GO AHEAD, KUN.

>> OKAY. I REPRESENT ASIAN AND CHINESE COMMUNITY. I WILL SHARE A FEW STORIES. FIRST, I HEARD SOMEONE IN CHINATOWN TOLD ME THAT MY MOM WAS GETTING OLD AND BECOME -- WHAT DOES THAT MEAN STUPID? FORGETFUL. OLD AGE. ANOTHER PERSON SAID IT NEVER OCCURRED TO ME THAT MY MOM HAVE ALZHEIMER'S. EVEN I THOUGHT THEY HAVE SOMETHING WRONG. IT IS THE LAST

THING. ANOTHER SAID SOMETHING, FRIENDS ASKS US TO RELOCATE OUR HOME BECAUSE MY MOM'S -- THERE ARE A LOT OF MISUNDERSTANDING THAT SHOW YOU WHAT THE PEOPLE LIVING IN OUR COMMUNITY, THEY ARE USING OTHER WAYS TO EXPRESS THE FRUSTRATION, BUT NEVER REALLY WANT TO ADMIT THIS IS SOMETHING WRONG. THANK YOU.

>> THANK YOU, KUN. THOSE ARE VERY HELPFUL EXAMPLES OF HOW MANY DIFFERENT IDEAS PEOPLE CAN HAVE ABOUT DEMENTIA WHEN THEY HAVE NOT HAD THE OPPORTUNITY TO HAVE SOME KIND OF TRAINING OR EDUCATION. THANK YOU. ALANA, WOULD YOU LIKE TO GO NEXT?

>> YES, BRAZILIAN COMMUNITY, WE CAN LISTEN MORE IS... THEY DON'T ACCEPT THIS DISEASE BECAUSE THEY THINK HOW SOMEONE THEY LOVE IS VERY WELL LOVED SO MUCH, WE FORGET THEM. THIS IS THE MOST THING THEY USE USUALLY TO SAY. AFTER THE SESSION, I THINK THEY CAN UNDERSTAND THEY CAN HELP THEM, ESPECIALLY MAKE THESE PEOPLE AS VERY IMPORTANT PERSON IN THEIR COMMUNITY, IN THEIR FAMILY. THEY CAN UNDERSTAND A LITTLE MORE AND MAKE IT A LITTLE EASIER FOR THEM.

>> THANK YOU. AND TO EXPLAIN A LITTLE BIT ABOUT THE SESSIONS THAT ALANA MENTIONED. THE PEOPLE YOU SEE ALL LEAD DEMENTIA FRIENDS SESSIONS, WHICH ARE LIKE WORKSHOPS. THEY LAST ABOUT AN HOUR. THEY FOCUS ON FIVE KEY MESSAGES ABOUT DEMENTIA AND SOME COMMUNICATION SKILLS. SO, THEY ARE DESIGNED TO BE A WAY THAT PEOPLE CAN LEARN SOME VERY IMPORTANT FUNDAMENTAL INFORMATION ABOUT DEMENTIA. AND ALANA, IT IS REALLY HELPFUL TO HEAR LEARNING THAT INFORMATION CHANGES THE WAY THAT PEOPLE THINK ABOUT DEMENTIA. THAT'S VERY SIMILAR TO WHAT JUDITH SAID, ONCE YOU DO BREAK THE SILENCE, HELP PEOPLE UNDERSTAND AND GIVE THEM SOME WAYS THAT THEY CAN TAKE ACTION, THEY CAN FEEL MORE HOPEFUL. AND KUN, I JUST NOTICED IN THE CHAT, SOMEONE SAID THAT THEY HAD WORKED IN ASSISTED LIVING FOR TEN YEARS AND SOMEONE SAID THAT IT WAS THE 5G NETWORK THAT CAUSE THEIR MOTHER'S DEMENTIA. GOING BACK TO WHAT YOU SAID ABOUT IT, WHEN WE DON'T HAVE THE INFORMATION, WHEN WE DON'T HAVE THE OPPORTUNITY TO RECEIVE THE INFORMATION, WE MAY BELIEVE A LOT OF DIFFERENT THINGS. AND AS IMPORTANT FOR PEOPLE TO HAVE THAT CHANCE TO LEARN THE CORRECT INFORMATION. LET'S SEE. CAN I GO TO KATHY AND THEN BONNIE, IF BONNIE WANTS TO ADD TO WHAT KATHY SAYS.

>> THANK YOU. IN MY COMMUNITY, INCLUDES PEOPLE WITH IDD, INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, AND IT INCLUDES PEOPLE WHO SUPPORT AND CARE FOR THEM IN A VARIETY OF SETTINGS. I THINK IT IS A LITTLE

DIFFERENT WORLD FOR ME -- FOR MANY PEOPLE DON'T KNOW. PEOPLE LIVE IN GROUP HOMES, RESIDENTIAL SETTINGS, CAN LIVE ON THEIR OWN. AND IN DAY PROGRAMS, THERE ARE MANY DIFFERENT SETTINGS THAT PEOPLE WHO HAVE AN INTELLECTUAL OR DEVELOPMENTAL DISABILITIES ARE LIVING. AND SO WITH THIS GROUP OF PEOPLE, WITH PEOPLE WITH IDD, DEMENTIA IS A REAL ABSTRACT TERM. PEOPLE DON'T REALLY FULLY UNDERSTAND IT AND WHAT WE HAVE FOUND THAT WE REALLY NEED TO USE MUCH MORE TANGIBLE CONCRETE EXAMPLES OF -- USING PEOPLE WHO ARE LIVING WITH DEMENTIA THEY MAY KNOW. FOR INSTANCE, A FAMILY MEMBER OR HOUSEMATE OR ON TV. LOTS OF TIME, I WILL SAY DID YOU SEE THAT PERSON ON TV. WHAT DID YOU THINK ABOUT THAT. AND SO THAT IS MUCH MORE EASIER FOR PEOPLE TO UNDERSTAND. I HAVE A FRIEND, WHO IS IN THE 70S WITH AN INTELLECTUAL DISABILITY, I CAN USE MY MOTHER WHO HAD DEMENTIA AS AN EXAMPLE OF WHAT IT MEANS TO LIVE WITH DEMENTIA. THE OTHER THING THAT AROUND CAREGIVERS, THIS IS THE DIFFICULT THING IN THE WORLD OF IDEAS, WE ARE USED TO HELPING PEOPLE TO GROW, DEVELOP AND BE THE BEST THEY CAN BE. THE IDEA OF DEMENTIA IS REALLY ONE OF DISBELIEF AND PEOPLE ARE NOT -- ARE NOT SET FOR THAT. THEY WERE NOT PLANNING FOR THIS. AND THAT CAN BE SOMETHING THAT IS REALLY DIFFICULT, ESPECIALLY FOR OLDER FAMILY MEMBERS, MANY PEOPLE WHO HAVE CHILDREN WITH DOWN SYNDROME, WHO MAY GET ALZHEIMER'S DISEASE AT YOUNGER AGES. THIS IS A DIFFICULT THING AND A LIFELONG COMMITMENT TO THEIR CHILDREN. THAT ALSO IS A HARD THING TO WRAP YOUR NEURONS AROUND. I DO THINK THAT THIS UNDERSTANDING ABOUT PROVIDING SUPPORTS AND -- THE SUPPORTS WE PROVIDE FOR PEOPLE ARE IN THE FIELD OF INTELLECTUAL DISABILITIES IS A LOT OF CHOICES, GETTING OUT IN THE COMMUNITY AND DOING THINGS LIKE THIS. IT DOESN'T ALWAYS WORK FOR PEOPLE WHO ARE LIVING WITH DEMENTIA. I THINK THAT IS THE MOST DIFFICULT THING FOR A LOT OF PEOPLE, JUST TRYING TO UNDERSTAND THIS BASIC CHANGE IN PHILOSOPHY. BONNIE, WHAT DO YOU THINK?

>> I AGREE WITH EVERYTHING YOU SAID, KATHY. I WILL PIGGYBACK ON TWO POINTS. THE FIRST THE COMMENT ABOUT USING CONCRETE EXAMPLES. MANY TIMES WE FEEL THAT WE DON'T USE THE WORD DEMENTIA. AND SOMEONE, I THINK IT WAS MICHAEL KINKAID PUT INTO THE CHAT, THERE'S CULTURES THAT DON'T HAVE A WORD FOR DEMENTIA. I WANT TO HAVE A SHUT-OUT SOMETIMES WE DON'T NEED THE WORD OR THE WORD IS NOT THE MOST IMPORTANT THING. THE MOST IMPORTANT THING IS TO GET PEOPLE TO UNDERSTAND WHAT IS GOING ON AND THAT IS OFTEN THROUGH EXAMPLES. WHEN WE WORK WITH FOLKS IN THE

INTELLECTUAL DISABILITY WORLD, WE TRY TO TALK MUCH MORE ABOUT THE SYMPTOMS AND THE BEHAVIORS AND LESS ABOUT THE WORD ITSELF. AND THE LAST THING I WANTED TO ADD IS THAT THINKING ABOUT THE WORD DEMENTIA IN THE IDD COMMUNITY. WE HAVE TO REVISIT IT VERY OFTEN BECAUSE WE ARE LEARNING SO MUCH MORE EVERY DAY. AND IF WE DON'T DO THAT, PEOPLE'S INFORMATION IS GOING TO BE OUTDATED AND I KNOW IT IS MOVING FAST IN EVERY FIELD, BUT AS KATHY WILL TELL YOU, IN THIS FIELD, EVERY DAY WE LEARN SOMETHING NEW. THANK YOU.

>> THANK YOU SO MUCH. I APPRECIATE WHAT BOTH OF YOU SAID AND I THINK IT IS REALLY IMPORTANT WHAT YOU SAID THAT SOMETIMES THE TERMS ARE NOT AS IMPORTANT AS THE STORIES. BEING ABLE TO GIVE EXAMPLES AND DESCRIBE WHAT IS AFFECTING PEOPLE'S LIVES AND GIVE THEM SOME TOOLS FOR HOW TO COPE WITH THAT, EVEN IF WE DON'T HAVE A WORD EXACTLY TO CALL IT. I DO ALSO WANT TO MENTION THAT THE DEMENTIA FRIENDS PROGRAM, WHICH IS A GLOBAL PROGRAM ADMINISTERED BY THE ALZHEIMER'S SOCIETY IN THE UK, 67 COUNTRIES PARTICIPATING, HAS ITS ROOTS IN JAPAN'S DEMENTIA SUPPORTER PROGRAM. IN FACT, ONE OF THE FIRST STEPS THAT WAS TAKEN IN JAPAN WAS TO COME UP WITH A NEW WORD THAT WAS A MORE RESPECTFUL AND MORE ACCURATE WAY TO DESCRIBE DEMENTIA. AND THEN TO USE THAT NEW TERM AS PART OF THE PUBLIC EDUCATION THEY BEGAN TO DO. IT IS A REALLY GOOD POINT THAT MIKE MAKES ABOUT THE LANGUAGE. ONE OTHER THOUGHT IS JUST THAT DEMENTIA IS BECOMING A BIGGER AND BIGGER ISSUE FOR US GLOBALLY BECAUSE PEOPLE ARE LIVING LONGER. CERTAINLY, THAT IS TRUE FOR THE INTELLECTUAL AND DEVELOPMENTALLY DISABLED COMMUNITY, WHERE MAYBE A GENERATION AGO, PEOPLE WERE NOT NECESSARILY LIVING LONG ENOUGH TO DEVELOP DEMENTIA SO FREQUENTLY. THAT'S TRUE FOR ALL COMMUNITIES AND THAT'S PART OF WHY SOMETIMES WE'RE NOT READY BECAUSE IN THE PREVIOUS GENERATIONS, IT JUST WASN'T AS COMMON. WE ARE NEEDING TO ADAPT. RATES OF YOUNGER ONSET ARE GROWING. THANK YOU. FORTUNATELY, BECOMING MORE AWARE, MORE PEOPLE ARE GETTING DIAGNOSED A BIT EARLIER. CERTAINLY, THERE ARE A LOT OF PEOPLE WHO ARE YOUNGER WHO ARE DEVELOPING DEMENTIA. ARNETTA, CAN WE GO TO YOU NEXT? YOU ARE ON MUTE.

>> OKAY. THERE I GO.

>> WE HEAR YOU NOW.

>> HI, I'M ARNETTA, I LIVE IN THE--DORCHESTER NEIGHBORHOOD. I'M A DEMENTIA FRIENDS CHAMPION. I HAVE BEEN ONE SINCE 2019 AND I'M VERY PROUD THAT DEMENTIA CAME TO THE BLACK AND BROWN COMMUNITIES WITHIN

THE CITY OF BOSTON. A LOT OF THE BLACK AND BROWN FAMILIES AND FRIENDS WERE AFRAID OF THE WORD DEMENTIA, THE WORD ALZHEIMER'S. IN THE OLD DAYS, WHEN MY MOM WAS AROUND, SHE PASSED AWAY FROM DEMENTIA... WE NEVER CALLED IT DEMENTIA, WE ALWAYS CALLED IT OLD-AGE DISEASE. YOU'D TAKE A FAMILY MEMBER, NOT PUT THEM IN A HOME, BUT PUT THEM IN A SEPARATE ROOM IN THEIR HOUSE. AND THAT'S WHERE THEY WOULD STAY THE MAJORITY OF THE TIME. IT WAS KIND OF DOWN HEARTENING. BY BEING A DEMENTIA FRIENDS CHAMPION, LISTENING TO BETH WHEN SHE FIRST INTRODUCED IT TO ME, BEING ABLE TO DO THE INFORMATION SESSION SO I CAN INFORM OTHER BLACK AND BROWN PEOPLE IN THE AFRICAN AMERICAN COMMUNITIES ABOUT WHAT DEMENTIA WAS, WHAT ALZHEIMER'S WAS, SHOWING THEM THAT THIS WAS SOMETHING THAT WE NO LONGER NEEDED TO BE AFRAID OF. WE NEED TO EMBRACE IT AND UNDERSTAND WHAT IS GOING ON IN THE WORD AROUND US WHERE WE CAN SHARE WITH OTHERS SO OTHER FAMILIES GET TO KNOW WHAT DEMENTIA WAS, WHAT ALZHEIMER'S WAS. HOW TO LOOK AT IT THROUGH A DIFFERENT LIGHT WITH THE FAMILY MEMBERS GETTING OLDER AND WANDERING AWAY FROM HOME. I WILL GIVE ONE EXAMPLE OF A SENIOR, HE IS IN HIS 90S, HIS WIFE KNOWS HE HAS DEMENTIA. HIS DAUGHTER KNOWS HE HAS DEMENTIA, BUT HE WAS NOT -- HE DIDN'T WANT TO BE LABELLED AS SUCH A PERSON. HE WENT FOR A DRIVE ONE DAY. THEY FIGURED HE'D GO TO THE STORE AND COME BACK. THE POLICE FOUND HIM ABOUT 20 MILES FROM THE CANADIAN BORDER BECAUSE HE RAN OUT OF GAS. HE WAS IN THE CAR BY HIMSELF. EVEN THOUGH WE LOOK AT PEOPLE DIFFERENT IN THE BLACK AND BROWN COMMUNITIES, WE ARE ALL VERY MUCH THE SAME. WE JUST NEED TO KEEP AN EYE OUT FOR THE SENIORS, AS I CALL THEM, OUR SEASONED SENIORS. THOSE WHO ARE 70 PLUS. SOMETIMES WALK AWAY FROM THE HOUSE AND DON'T COME BACK WHEN WE EXPECT THEM TO. THOSE THAT GO FOR A DRIVE AND TAKE TOO LONG COMING BACK. FOR THOSE WHO LIVE ACROSS THE STREET FROM YOU, YOU NEED TO TAKE UP A CONVERSATION WITH THEM. HELP THEM TO UNDERSTAND WHAT IS GOING ON. THANK YOU.

>> THANK YOU. AND THANK YOU FOR BRINGING IT HOME TO THE PERSONAL LEVEL WITH FAMILY STORIES. THAT IS WHERE THE -- THAT IS WHAT WE NEED TO TALK ABOUT. HOW THIS AFFECTS INDIVIDUALS AND FAMILIES. I SEE GOOD RESOURCES GOING INTO THE CHAT. AGAIN, THE FIRST STEP TO GETTING MORE RESOURCES AVAILABLE AND HELPING PEOPLE FIND THEM IS BEING ABLE TO TALK ABOUT IT. THANK YOU FOR THOSE POINTS YOU MADE. LET'S GO TO TIRSA AND THEN TO SAW.

>> HI, GOOD AFTERNOON -- I TAKE CARE OF MY MOTHER. IT IS A TABOO

BETWEEN US LATINS. AND ALSO THE WHEN PEOPLE ARE NOT EDUCATED IN THIS, THERE IS LOTS OF FRUSTRATION. SINCE I LIVED IT, MY BROTHERS AND SISTERS, THAT ARE LATIN, DON'T ACCEPT THIS. THEY DON'T ACCEPT THAT THIS CAN HAPPEN TO ONE OF THE FAMILY MEMBERS.

>> TIRSA, ONE MINUTE. (SPEAKING SPANISH). TIRSA WILL SPEAK ON THE SPANISH CHANNEL, THEN IT WILL BE INTERPRETED IN ENGLISH.

>> OKAY. CAN ONE OF THE SPANISH INTERPRETERS COME ON THE ENGLISH CHANNEL?

>> I'M HERE. CAN YOU HEAR ME?

>> GO AHEAD AND SPEAK ON THE SPANISH CHANNEL. OTHERS CAN JUST WAIT FOR A MOMENT.

>> THANK YOU VERY MUCH. IN MY CASE, I'M AN EDUCATOR OF DEMENTIA... (MULTIPLE LANGUAGES VOICING AT THE SAME TIME).

>> WE ARE EDUCATED, WE CAN HELP OUR FAMILIES. ONE THING THAT HELPED ME... MY FAMILY DIDN'T ACCEPT IT. SOME FAMILIES DON'T ACCEPT IT. BUT EDUCATION WILL HELP US -- HELP OUR FAMILY MEMBERS. I WAS ABLE TO TAKE CARE OF MY MOTHER UNTIL SHE WENT UP TO HEAVEN. IT IS VERY HARD AND PAINFUL, BUT I CAN SEE THERE IS A SILENCE AMONG PEOPLE, ESPECIALLY AMONG FAMILY MEMBERS. I WORK WITH A LOT OF LATINS. LATINS SUFFER VERY MUCH OVER THIS. THIS SILENCE AFFECTS YOUR HEART. I THINK I'M WORKING A LOT WITH A LOT OF PEOPLE. ONE WAS VERY FRUSTRATED BECAUSE THERE'S NO FAMILY HELP. THE OTHER ONE IS A MEMBER OF THE CHURCH, SHE CRIES AND CRIES. SHE DOESN'T KNOW WHAT TO DO BECAUSE HER MOTHER IS OVER AT HER COUNTRY. AS WE ARE TEACHING THIS EDUCATION ABOUT THIS AND THIS PROCESS, IT IS SOMETHING THAT NEEDS TO REACH OUR FAMILY MEMBERS.

>> THANK YOU, TIRSA. THANK YOU TO -- THANK YOU TO INTERPRETERS. SAW, HOW ABOUT YOU?

>> THANK YOU. I'M SAW, FROM SOUTHEAST ASIA COALITION. AND MY ROLE IS GLOBAL COMMUNITY ORGANIZER AND FOR DEMENTIA, I DO WORK WITH THE BURMESE IN WORCESTER. AND MY CO-WORKER WITH THE VIETNAMESE COMMUNITY. TO US THAT QUESTION, IN MY COMMUNITY, THEY HEAR THE WORD DEMENTIA, MOST SAY DEMENTIA IS FOR REALLY, REALLY OLD PEOPLE. AND DEMENTIA IS FOR PEOPLE WHO ARE VERY FORGETFUL AND DO NOT KNOW OR REMEMBER WHAT THEY JUST SAID. SOME PEOPLE SAY -- THE PERSON IS CRAZY. SOMETHING LIKE THAT. A SMALL COMMUNITY GROUP. THEY CAME HERE AS REFUGEE FAMILIES. THANK YOU.

>> THANK YOU, SAW. YOUR COMMENT BRINGS ME BACK TO NIA BECAUSE

THAT WAS ONE OF THE THERE'S OFTEN A PERCEPTION THAT PEOPLE ARE VERY OLD WHEN THEY DEVELOP DEMENTIA. DO YOU WANT TO MAKE A COMMENT ABOUT BEING A YOUNGER PERSON WHO HOW YOU HAD TO DEAL WITH PEOPLE'S LACK OF UNDERSTANDING OR LACK OF AWARENESS THAT SOMEONE CAN DEVELOP DEMENTIA WHEN THEY ARE YOUNGER.

>> SURE. I AGREE WITH SAW 100%. AND COMING FROM A YOUNGER PERSPECTIVE, I THINK IT IS MORE DIFFICULT BECAUSE I THINK IT IS MORE DIFFICULT BECAUSE PEOPLE DO BELIEVE IT IS AN OLD-PERSON'S DISEASE. WE KNOW STATISTICALLY, IT SHOWS SIGNS, DECADES BEFORE YOU ARE POSSIBLY DIAGNOSED.

>> THANK YOU. LET'S GO TO THE NEXT QUESTION NOW. WHICH IS TO THINK ABOUT THE EXPERIENCES YOU HAD WHEN YOU ARE TEACHING ABOUT DEMENTIA. SO, FOR MOST OF YOU, THIS IS WHEN YOU WERE DOING YOUR INFORMATION SESSION, YOUR DEMENTIA FRIENDS WORKSHOPS, FOR NIA, IT IS IN YOUR ROLE AS AN ADVOCATE, CAN YOU THINK OF ONE THING OR COUPLE OF THINGS THAT HAVE BEEN MOST SURPRISING TO THE PEOPLE THAT YOU EDUCATED? WHAT WERE THE PIECES OF INFORMATION ABOUT DEMENTIA THAT REALLY SURPRISED THEM AND MADE A DIFFERENCE? AND I'LL START WITH JUDITH -- I'M SORRY. NIA, YOU WANT TO GO FIRST NIA AND THEN JUDITH.

>> SURE. ONE THING THAT SURPRISED PEOPLE, BESIDES MY AGE, THE FACT IT IS NOT JUST YOUR MEMORY. IT IS OFTEN COORDINATION PROBLEMS, BEHAVIORAL PROBLEMS, HALLUCINATIONS, THINGS LIKE THAT. SLEEP PROBLEMS. IT IS NOT JUST YOUR MEMORY.

>> THANK YOU. THAT'S A VERY IMPORTANT POINT. GO AHEAD, JUDITH?

>> YES, THE MOST SURPRISING INFORMATION IS THE TREATMENT FOR DEMENTIA IS STILL IN RESEARCH. IN THE MARKETPLACE, ESPECIALLY IN UNDERSERVED COMMUNITY, THERE'S A LOT OF MISINFORMATION. IF YOU TAKE THAT, YOU DID THAT, MISINFORMATION. THAT WAS VERY SURPRISING. THEY REALIZED THE TREATMENT IS STILL IN RESEARCH AND THEY CAN AVOID FRAUD AND SCAM IN THE COMMUNITY. MAKE PEOPLE THINK IF THEY ARE DOING CERTAIN THINGS, THAT'S NOT BAD. HOWEVER, IT IS NOT A TREATMENT FOR DEMENTIA.

>> THANK YOU, JUDITH. I THINK YOU EACH JUST MADE SUCH IMPORTANT POINTS ABOUT THE ROLE OF INFORMATION AND KNOWLEDGE. JUDITH, YOU'RE POINTING OUT THAT EVEN THOUGH WE DON'T HAVE THE TREATMENTS YET THAT WE WISH WE WOULD HAVE AND WE KNOW THE RESEARCH COMMUNITY IS WORKING HARD TOWARD THAT GOAL, KNOWLEDGE CAN HELP PEOPLE TO AVOID... SOME FALSE TREATMENTS THAT MIGHT BE PRESENTED TO THEM. THAT MIGHT BE

HARMFUL OR MAYBE NOT HARMFUL, BUT NOT HELPFUL. THERE IS A LOT OF FALSE INFORMATION OUT THERE. WHEN PEOPLE ARE GIVING ACCURATE INFORMATION, THEY CAN PROTECT THEMSELVES AND I JUST WANTED TO COMMENT, NIA, ON WHAT YOU SAID ABOUT PEOPLE NOT REALIZING THAT THERE ARE MANY SYMPTOMS. NOT JUST MEMORY LOSS, IF SOMEONE DOESN'T KNOW THAT, THEY MAY JUDGE SOMEONE, THEY MAY THINK THAT THE PERSON IS EXHIBITING A SYMPTOM FOR A DIFFERENT REASON. AND THEY MAY NOT RESPOND IN A HELPFUL WAY. THEY RESPOND IN A HARMFUL WAY. AGAIN, THAT KNOWLEDGE AND INFORMATION IS REALLY IMPORTANT. OR AS DARIOUS SAID, A PERSON IS DOING IT ON PURPOSE, THEY DON'T UNDERSTAND IT IS CAUSED BY THE DISEASE. I'M GOING TO TRY TO GO IN THE SAME ORDER THAT WE WENT BEFORE. LET'S GO TO KUN NEXT. IS THERE SOMETHING THAT IS MOST SURPRISING TO THE PEOPLE THAT YOU EDUCATED?

>> YOU CAN SEE MANY PEOPLE IN OUR COMMUNITY HAS MISUNDERSTANDING ABOUT THIS. THINKING IT IS NORMAL AGING, PART OF THE AGING PROCESS. NEVER SEE THIS AS A DISEASE. SO, THEY ALSO THINK THAT PEOPLE FEEL I WANT TO DISTANCE MYSELF FROM THIS PARTICULAR PERSON MAYBE BECAUSE I WOULD -- TOGETHER WITH THE PERSON, I MAY BE AFFECTED. SOMETIMES A LOT OF MISUNDERSTANDING ABOUT THIS. IT IS VERY CLEAR, WE TRY TO DO THE MESSAGE AND SAY THIS IS A BRAIN DISEASE. IT IS NOT WRONG ABOUT THEIR LIFE OR SOMETHING ELSE, SOMETIMES WE HAVE A DISEASE -- THAT'S THE KEY MESSAGE. WE SAY WE TRY TO CONTINUE TO PROMOTE AND TELL PEOPLE ABOUT THAT. IN OUR COMMUNITY, SOMETIMES PEOPLE WANT TO LABEL PEOPLE. WHEN THEY LABEL PEOPLE, THE FAMILY ALSO FEEL THEY WANT TO BE PROTECTED. THEY NEVER WANT TO HAVE THEIR LOVED ONE HAVE THE SITUATION -- HAVE ANY OUTSIDE CONTACT. THEY FEEL THAT SHAME. THERE IS SOMETHING WRONG WITH MY FAMILY. IF THEY SEE IT AS A DISEASE, MAYBE THEY CHANGE THEIR MINDSET. A LONG WAY TO GO IN THE COMMUNITY. CONTINUE EDUCATION IS THE KEY. CONTINUING TO PROMOTE THE KEY MESSAGE. HOPEFULLY, IT CAN GRADUALLY CHANGE THEIR BELIEF. THANK YOU.

>> THANK YOU, KUN. WE'LL GO TO ALANA NEXT. YOU ARE ON MUTE.

>> IN MY COMMUNITY, THEY UNDERSTAND ALMOST -- AS FORGETFULNESS. ONE THING THEY USED TO SAY IS THIS PERSON WITH DEMENTIA HAS BECOME A CHILD AGAIN. AND I TRY TO EXPLAIN TO THEM -- NO, THEY ARE NOT A CHILD AGAIN. THEY ARE ADULTS, THEY HAVE THIS DISEASE. EXPLAIN WHY, WHAT HAPPENED, WHAT THE SIGNS AND HOW WE HAVE TO TREAT. NOT TREAT THEM AS A CHILD. BECAUSE MOST PEOPLE USED TO SAY THAT. SO THEY START TO TREAT THEM AS A CHILD. IT IS NOT THE WAY WE HAVE TO DO WITH THEM.

>> THANK YOU, ALANA, THAT'S AN IMPORTANT POINT TO MAKE. AND I THINK FOR MOST ADULTS, IF THEY ARE TREATED AS A CHILD, IT FEELS DISRESPECTFUL. AND NOT EVERYONE CAN COMMUNICATE HOW THEY FEEL ABOUT THAT BECAUSE OF THE SYMPTOMS OF DEMENTIA. IF SOMEONE HAS MORE ADVANCED DEMENTIA, THEY MAY HAVE TROUBLE EXPRESSING THEMSELVES. BUT THEY STILL FEEL IT, FEEL THE DISRESPECT AND IT WILL CAUSE PROBLEMS IN THE RELATIONSHIP. AND CAUSES PROBLEMS FOR THEIR QUALITY OF LIFE. AND SO THAT TEACHING IS SO VALUABLE THAT YOU ARE DOING. LET'S SEE, ARNETTA? WOULD YOU LIKE TO COMMENT ON THE QUESTION OF WHAT HAS BEEN SURPRISING TO PEOPLE THAT YOU HAVE TAUGHT?

>> I WOULD HAVE TO SAY THAT... MOST OF THE FAMILIES AND INDIVIDUALS THAT WE HAD THE LISTENING SESSIONS WITH, THE INFORMATIONAL SESSIONS, IN PERSON AS WELL AS ON ZOOM, THEY FIND IT SURPRISING THAT DEMENTIA CAN RUN IN THE FAMILY. WHEN IT STARTED OR HOW IT STARTED, WHAT'S GRANDMA, MOM, OR DAD, AUNTY OR GRANDPA IS GOING THROUGH. ONE QUESTION IS CAN I DEVELOP DEMENTIA. CAN I DEVELOP ALZHEIMER'S? HOW DO I TELL? BECAUSE OF ALL -- I DON'T WANT TO SAY BAD PUBLICITY -- BECAUSE OF FORMER RESEARCH METHODS ON THE BLACK COMMUNITIES, A LOT OF BLACK INDIVIDUALS ARE AFRAID TO GO AND FIND OUT ABOUT THEMSELVES. THEY ARE AFRAID TO GO TO THE HOSPITALS OR EVEN TELL THE DOCTORS WHAT THEY ARE EXPERIENCING. AFRAID OF BEING ABLE -- AFRAID OF BEING LABELLED. PRETTY MUCH OUR CHILDREN ARE LABEL WHEN THEY FIRST GO TO SCHOOL. I THINK THAT'S ONE OF THE MOST CHALLENGING FOR THE BLACK AND BROWN COMMUNITIES I WITNESSED AND TALKED ABOUT IN OUR INFORMATION SESSIONS.

>> GREAT, THANK YOU. I NOTICED COMMENTS IN THE CHAT ABOUT USING APPROACHES TO COMMUNICATE WITH PEOPLE AND TO CREATE A SENSE OF COMMUNITY THAT DON'T REQUIRE LANGUAGE. SO ART AND MUSIC AND ARNETTA, WE COLLABORATED ON MEMORY CAFES, WHICH ARE PLACES WHERE PEOPLE DO CREATIVE ACTIVITIES. IT IS A GOOD POINT THAT SOMETIMES IT CAN BE A NICE WAY TO FORM CONNECTIONS WHEN LANGUAGE GETS DIFFICULT. AND WE CAN TALK MORE ABOUT THAT AS TIME ALLOWS. I'M GLAD TO SEE SOME RESOURCES BEING SHARED IN THE CHAT. SO, WE'LL GO NEXT TO KATHY AND THEN BONNIE. WHAT HAS BEEN SURPRISING TO THE PEOPLE THAT YOU LED THE TRAINING FOR?

>> WELL, I THINK WHEN I LED THE TRAINING FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, THAT'S THE GROUP I LED THIS TRAINING FOR, THE THING I HAD TO REINFORCE -- HELP PEOPLE TO UNDERSTAND IS THAT BEHAVIORS THAT THEY SEE IN PEOPLE, WHICH ARE DISTRESSING BEHAVIORS,

THEY TAKE IT PERSONALLY. THEY THINK THE INDIVIDUALS ARE DOING THINGS ON PURPOSE, ET CETERA. I NEED TO REMIND PEOPLE AND THIS IS REINFORCED, IT IS A DISEASE. THE OTHER THING THAT -- SOME PEOPLE ASKED, WILL I CATCH IT. THEY ARE WORRIED ABOUT CATCHING IT FROM SOMEONE ELSE. I THINK THAT'S THE OTHER THING THAT WE HAVE TO EXPLAIN. IT IS NOT THAT KIND OF DISEASE, NOT LIKE AN INFECTION. SO, BEING SIMPLISTIC AND BRINGING IT DOWN SO PEOPLE CAN UNDERSTAND THAT PEOPLE AREN'T IN -- THINGS THAT ARE HAPPENING THAT THE PERSON DOESN'T HAVE CONTROL OVER AND IT IS NOT JUST DOING THIS TO GET BACK AT YOU OR SOMETHING LIKE THAT. I THINK THAT'S ONE THING -- THOSE PARTICULAR PARTICIPANTS. TO GO BACK TO WHAT MANY OF THE OTHER PEOPLE ARE SPEAKING ABOUT IS THE WHOLE CHANGE. FOR MANY PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, IT IS NOT OFTEN WE SEE MEMORY INITIAL. WE SAY CHANGE, CHANGES IN BEHAVIOR USUALLY. THAT HAS TO BE FULLY INVESTIGATED AND KIND OF UNDERSTOOD. THE PROBLEM WITH THAT IN OUR FIELD, ESPECIALLY WE HAVE A NUMBER OF PEOPLE WITH DOWN SYNDROME, YOUNGER ONSET DEMENTIA. BECAUSE THE WORD IS OUT THAT PEOPLE WITH DOWN SYNDROME GET ALZHEIMER'S DISEASE, ANYBODY THAT SHOWS A CHANGE IN BEHAVIOR, EVEN AT AGE 19 AND 20, THEY HAVE DEMENTIA. WHERE THEY DON'T GET THE FULL ASSESSMENT THAT PEOPLE DESERVE TO GET. AND SO THAT -- I HAD PEOPLE RECENTLY SOMEONE ASKED ABOUT A 30-YEAR-OLD PERSON WITH AUTISM. THERE ARE THINGS HAPPENING WHERE WE THINK THE PERSON HAS DEMENTIA. PART OF IT, EVEN THOUGH WE ARE GLAD TO HAVE THE INFORMATION OUT THERE, BUT IT HAS TO BE APPROACHED THOUGHTFULLY AND CAREFULLY FOR PEOPLE. I HAD PEOPLE IN THEIR 19 AND 20S AUTOMATICALLY GET A DIAGNOSIS OF ALZHEIMER'S WHEN IN FACT -- LATER MORE ASSESSMENT IS DONE, IT TURNS OUT IT MAY BE SOMETHING LIKE DEPRESSION OR HYPOTHYROIDISM OR SOMETHING LIKE THAT. BONNIE?

>> TO PIGGYBACK ON WHAT KATHY SAID, WHAT IS MOST USEFUL TO THE PARTICIPANTS AND IN THIS CASE, I MEAN THE FAMILY MEMBERS OR THOSE INDIVIDUALS WHO ARE WORKING WITH THOSE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, IT IS THE SIMPLE INFORMATION ABOUT HOW TO COMMUNICATE. AND PEOPLE ARE JUST SO SURPRISED THAT THE LITTLE SIMPLE THINGS YOU CAN DO IN THE WAY YOU COMMUNICATE CAN MAKE AN INCREDIBLE DIFFERENCE FOR SOMEBODY LIVING WITH DEMENTIA. AND THAT'S -- ALSO SOMETHING THAT IS SO EASY TO TRY AND IMMEDIATELY YOU WILL HAVE SUCCESS. IT IS VERY EXCITING. THE MOST SURPRISING THING THAT WE HAVE FOUND IS THAT PEOPLE ARE JUST SHOCKED THAT THERE IS SO MUCH THEY CAN DO TO HELP

SOMEONE WHO IS LIVING WITH DEMENTIA. THE MESSAGE, AS EVERYONE SAID, THE MESSAGE OUT THERE THIS IS A DEATH SENTENCE AND THERE'S NOTHING YOU CAN DO. THE MESSAGE WE SEND IS -- NO, THERE IS SO MUCH YOU CAN DO TO HELP SOMEONE TO LIVE WITH PURPOSE, MEANING, AND JOY. IT IS REALLY CHANGING THAT FRAME THAT IS -- I THINK -- THE MOST SURPRISING TO THEM, THEY HAVE NO IDEA.

>> THANK YOU, KATHY AND BONNIE. INCREDIBLY HELPFUL. WE'LL GO TO TIRSA AND THEN SAW. YOU WANT TO SHARE WHAT HAS SURPRISED PEOPLE WHO YOU EDUCATED ABOUT DEMENTIA OR WHAT IS IMPORTANT FOR THEM TO LEARN?

>> YES, CAN YOU HEAR ME WELL? SOMETHING THAT WE HAVE BEEN ABLE TO TEACH THE PARTICIPANTS AND THEY HAVE BEEN SATISFIED ABOUT THIS, THEY HAVE BEEN ABLE TO UNDERSTAND THEIR FAMILY MEMBERS. THE FACT THIS IS A PROCESS THAT WE HAVE TO ACCEPT THE CONDITION OF THE PATIENT. FOR EXAMPLE, IF THEY SAY SOMETHING IS BLACK, YOU NEED TO UNDERSTAND WHAT THEY ARE TRYING TO SAY AND GO ALONG WITH THAT. THOSE CLASSES, I HAVE BEEN TEACHING THE PATIENTS HOW TO HAVE A BETTER QUALITY OF LIFE. THE PARTICIPANTS HAVE BEEN ABLE TO UNDERSTAND IT IS A MEMORY LOSS. THEY CAN UNDERSTAND BETTER THEIR FAMILY MEMBERS. I THINK IT IS A SUCCESS TO HAVE THE SESSIONS WITH THE FAMILY MEMBERS. THEY FEEL MORE COMFORTABLE AND PREPARED BECAUSE THERE'S A GUIDE THAT HELPS THEM TO BE BETTER CAREGIVERS IN THEIR COMMUNITIES.

>> THANK YOU, TIRSA. THAT'S REALLY VERY HELPFUL AND IMPORTANT TO FOCUS IN ON THE COMMUNICATION SKILLS AND AGAIN THE POINT THAT EVEN THOUGH THERE IS NOT A MEDICATION RIGHT NOW THAT WOULD CURE THE CAUSES OF DEMENTIA, THERE'S SO MUCH WE CAN DO TO HELP PEOPLE LIVE WELL WITH DEMENTIA, TO HELP FAMILY MEMBERS AND FRIENDS TO UNDERSTAND SO THE RELATIONSHIPS CAN STAY STRONG. THANK YOU FOR THAT. AND SAW... WHAT WOULD YOU SAY HAS BEEN SURPRISING OR IMPORTANT FOR THE PEOPLE YOU HAVE EDUCATED?

>> IN MY DEMENTIA SESSION, MOST PEOPLE ARE HAPPY AND GRATEFUL TO KNOW THE BASICS ABOUT DEMENTIA. SOME PEOPLE WERE SURPRISED THAT EVERYONE CAN GET DEMENTIA, NOT ONLY FOR THE OLD PEOPLE. AND ALSO, WATCHING THE VIDEOS ABOUT DEMENTIA, THE VIDEO SHOW THE EXPERIENCE IS USEFUL. INSPIRE TO LIVE STRONGER BECAUSE OF THE VIDEOS -- THE COMMUNITY WILLING TO HELP DEMENTIA FRIENDS AND WILLING TO BE MORE PATIENT WITH THEIR FAMILY. THANK YOU.

>> THANK YOU, SAW. AND ACTUALLY, I HAVE ONE MORE QUESTION FOR

YOU, SAW. I KNOW THAT YOU AND YOUR COLLEAGUES HAVE DONE SOME TRAINING WITH CHILDREN. WITH YOUNG PEOPLE. I WONDER WHAT HAS THAT BEEN LIKE. HAVE THEY BEEN SURPRISED OR INTERESTED, WHAT IS THEIR REACTION TO THE TRAINING?

>> FOR THE CHILDREN, READ A BOOK TO THE CHILDREN -- NOT USUALLY ASK QUESTIONS. READ TO THEM. WHEN I SEE THE CHILDREN, SOME CHILDREN ARE REALLY LISTENING WHAT TO LEARN. SOME ARE MOVING AROUND. THEY FOLLOW YOU -- THEY ARE EXCITED TO KNOW. WHAT THEY HEAR, THEY DON'T HEAR FROM OTHERS. THIS IS THE FIRST TIME THEY GET EDUCATION. SOMETHING LIKE THAT.

>> THANK YOU FOR YOU AND YOUR COLLEAGUES DOING THAT WORK WITH CHILDREN. IT IS VERY IMPORTANT TO BEGIN THIS EDUCATION YOUNG AND TO MAKE IT MORE COMFORTABLE FOR EVERYONE IN A FAMILY TO UNDERSTAND AND TALK ABOUT WHAT MAY AFFECT THEIR WHOLE FAMILY. AND PLEASE DO KEEP PUTTING YOUR COMMENTS AND QUESTIONS IN THE CHAT. AT 4:00, WE'RE GOING TO FOCUS ON YOUR COMMENTS AND QUESTIONS. IN SOME CASES, WE'RE ABLE TO SPEAK ABOUT THEM AS WE GO, BUT IN SOME CASES, THEY GO BY VERY QUICKLY. MY COLLEAGUE IS MONITORING THE CHAT AND WE'RE GOING TO HAVE 25 MINUTES TO RESPOND TO AS MANY AS YOUR QUESTIONS AND COMMENTS AS POSSIBLE STARTING AT 4:00.

SO, I WANTED TO NOW GO TO OUR NEXT QUESTION, WHICH IS TO ASK... WHAT DOES YOUR COMMUNITY NEED THE MOST WHEN IT COMES TO DEMENTIA? WHAT ARE THE BARRIERS THAT YOU SEE ARE THE MOST IMPORTANT OR WHAT ARE THE NEEDS, THE GAPS, THAT ARE MOST IMPORTANT RIGHT NOW? IF YOU CAN PICK ONE OR TWO THINGS THAT YOU WOULD LIKE TO SEE CHANGED, WHAT WOULD THOSE BE FOR YOUR COMMUNITY? JUDITH, WOULD YOU START?

>> YES, BETH. THE FIRST CHALLENGE IS LACK OF ASSESSMENT. ASSESSMENT FOR DEMENTIA AND THE PRIMARY CARE LEVEL IN THE COMMUNITY. I SERVE THE OLDER ADULTS POPULATION, I SEE AGING IN PLACE IS A PRIORITY FOR PUBLIC HEALTH. HOWEVER, WHEN A MEMBER OR OLDER ADULT HAS DEMENTIA, UNFORTUNATELY, THE ONLY OTHER DESTINATION IS NURSING HOME. ACCELERATE THE TRANSITION FROM HOME TO NURSING HOME. I WOULD LIKE TO SEE MORE TOOLS AND RESOURCES WHERE PEOPLE CAN AGE IN THEIR OWN APARTMENT AND DELAY THE NURSING HOME CHOICE BECAUSE SOMEONE HAS DEMENTIA.

>> THANK YOU, JUDITH. LET'S GO TO KUN NEXT.

>> OKAY. MOST IMPORTANT, CONTINUING EDUCATION. KNOWLEDGE IS POWER. WITHOUT KNOWING THAT... HELPING PEOPLE TO UNDERSTAND THE

DISEASE. LEARN HOW TO WORK WITH THE DEMENTIA. FURTHERMORE, I THINK VERY IMPORTANT TO BUILDING THE CAPACITY. WE NEED MORE CULTURAL SERVICE PROVIDERS. ESPECIALLY, WE NEED TO CONTINUE TO SUPPORT FRONTLINE WORKERS, SUCH AS A HOME HEALTH AIDE, COMMUNITY SERVICE WORKER, THEY ARE ON THE FRONTLINE. THEY DON'T GET PAID THAT MUCH. THEY ARE NOT ABLE TO ATTRACT CERTAIN PEOPLE TO JOIN AS A QUALITY SERVICE. WE SEE THAT OVERWHELMING THE WORKLOAD SITUATION. PEOPLE FRUSTRATED. HOW TO SERVE, HOW TO BUILD SO-CALLED CAPACITY. BUILD THE CAPACITY IN THE COMMUNITY LEVEL, NOT JUST ASIAN COMMUNITY. I BELIEVE THIS IS AMONG ALL COMMUNITIES. FACE THE SAME ISSUE TO CREATE A SENSE OF INCENTIVE. IT CAN'T BE YOU HAVE A GOOD HEART, YOU HAVE TO HAVE FINANCIAL SUPPORT AND ABLE TO PROVIDE CONTINUING -- INCREASE THE CAPACITY TO SERVE ALL COMMUNITIES. THANK YOU.

>> THANK YOU, KUN. AND I THINK DURING THE PANDEMIC, CONDITIONS HAVE BECOME EVEN HARDER FOR DIRECT CARE PROVIDERS. WE SEE A HUGE SHORTAGE OF PEOPLE WHO ARE ABLE TO DO THAT WORK. IN MANY CASES, THERE ARE PEOPLE WHO WANT TO DO THE WORK, BUT THEY CAN'T AFFORD TO BECAUSE THE PAY IS SO LOW. THE WORKING CONDITIONS ARE SO HARD, IT BECOMES VERY DIFFICULT TO KEEP THOSE JOBS. AS YOU SAID, IT IS VERY IMPORTANT TO SUPPORT THOSE PEOPLE AND BUILD THE CAPACITY, BILINGUAL AND BICULTURAL CAPACITY. THIS RELATES TO WHAT JUDITH SAID, WE NEED THAT CAPACITY TO GIVE PEOPLE MORE OPTIONS WHERE THEY CAN CONTINUE TO LIVE IN PLACE AND GET HELP ALONG THE WAY SO THEY DON'T HAVE TO MOVE TO A RESIDENCE RIGHT AWAY. IF THEY CAN JUST GET SOME HELP AT HOME. LET'S GO TO ALANA NEXT?

>> I TOTALLY AGREE WITH KUN. YES. AND WE NEED THE EDUCATION BECAUSE THE BRAZILIAN COMMUNITY NEED TO KNOW ABOUT THE SERVICES WE HAVE THERE. THEY DON'T KNOW ABOUT IT. YES, THE FINANCIAL IS A BIG PROBLEM. IN MY COMMUNITY, THEY HAVE TO TAKE CARE OF THEIR LOVED ONES. THEY DON'T KNOW WHAT SOMETIMES WHAT ENTAILS THIS PROCESS. WHAT WILL BECOME -- THEY SHOULD HAVE TO TAKE CARE OF THEIR FAMILIES. THE BIGGEST BARRIER THEY ENCOUNTER IS LEAVING THEIR LOVED ONE IN A NURSING HOME. THEY DON'T WANT TO DO THAT AT ALL. SOMETIMES WE DON'T HAVE OTHER OPTIONS.

>> THANK YOU, ALANA. AND WE'LL GO TO ARNETTA NEXT.

>> EXCUSE ME. I WOULD HAVE TO SAY... TRAINING ON BOTH HANDS. WE NEED MORE TRAINING, NOT ONLY FOR THE COMMUNITIES IN WHICH WE SERVE, WE NEED MORE CHAMPIONS TO HELP GET THE WORD OUT TO THE FAMILIES. WE NEED

MORE PEOPLE THAT ARE INTERESTED IN SHARING THE INFORMATION ABOUT DEMENTIA. ABOUT ALZHEIMER'S. FAMILIES NEED TO KNOW WHAT IS GOING ON WITH OTHER FAMILY MEMBERS. THERE ARE A FEW CHAMPIONS, DEMENTIA FRIENDS CHAMPION WITHIN THE NEIGHBORHOOD WHERE I LIVE. THEY'RE IN ENGLISH, HAITIAN CREOLE AND OTHER CARIBBEAN LANGUAGES, BUT THEY ARE ALL SO VERY BUSY, A LOT OF THE TRAINING FALLS ON MY LAP. I WOULD LIKE TO SEE MORE PEOPLE, EVEN IF IT IS A FAMILY MEMBER THAT WANTS TO BE TRAINED -- COME TO AN INFORMATION SESSION AND BE TRAINED AS A DEMENTIA FRIEND, SO THEY ARE ABLE TO SHARE. ESPECIALLY IN THE HOUSING DEVELOPMENTS. THERE ARE A LOT OF PEOPLE LIVING IN DEVELOPMENTS, MUCH LIKE WHAT JUDITH TALKED ABOUT. AND WHAT KUN TALKED ABOUT. THOSE DEVELOPMENTS, VHA DEVELOPMENTS, THEY DON'T HAVE ANYONE, OTHER THAN A FEW PEOPLE THAT CAN COME AROUND AND TELL THEM -- GET THEM TO COME TO A ZOOM MEETING AND TELL THEM ABOUT DEMENTIA. I'D LIKE TO SEE MORE TRAINING ON BOTH LEVELS.

>> THANK YOU. I THINK THAT IS A REALLY IMPORTANT POINT ON SO MANY LEVELS. AND I JUST NOTICED IN THE CHAT, SOMEONE ASKING ABOUT RESOURCES, CULTURALLY COMPETENT RESOURCES. I WANTED TO JUST MENTION, I THINK WHAT I HAVE FOUND WITH DEMENTIA FRIENDS, IT DOES COME DOWN TO THE PEOPLE. WE DO NEED THE RESOURCES, WE NEED THE TRANSLATED MATERIALS AND SO FORTH. WE NEED TEACHING TOOLS. IN THE END, WE NEED PEOPLE WHO ARE PART OF THOSE COMMUNITIES WHO CAN ACTUALLY DO WHAT ARNETTA IS TALKING ABOUT AND LEAD THE TRAININGS. THAT'S WHERE THE TRUST IS, PEOPLE WHO ARE PART OF THAT COMMUNITY. THE LAST PRESENTATION TODAY IS GOING TO FOCUS ON THAT AND THAT WE NEED TO HAVE STRUCTURES TO COMPENSATE PEOPLE SO THEY CAN DO THAT WORK. AND I SEE YOUR QUESTION, ELBA, AND WE'LL TALK ABOUT THAT LATER. ABOUT HOW PEOPLE CAN STEP INTO A CHAMPION ROLE OR A LEADERSHIP ROLE. LET'S NOW GO TO KATHY AND BONNIE?

>> I CAN'T HELP ABOUT ECHO WHAT EVERYBODY IS SAYING ABOUT EDUCATION. AND HAVING EVIDENCE-BASED EDUCATION FOR PEOPLE TO UNDERSTAND AND ESPECIALLY IN THE FIELD OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES. AS BONNIE SAID, THE INFORMATION IS CONSTANTLY BEING UPDATED AS MORE RESEARCH IS BEING DONE. THE OTHER THING THAT PEOPLE NEED TO HAVE, BESIDES THE EDUCATION, IT IS COMMUNITY AWARENESS AND HEALTHCARE PROVIDERS TO BE EDUCATED. THERE WAS SOMETHING IN THE CHAT ABOUT EDUCATING HEALTHCARE PROVIDERS. AS FAR AS I KNOW, THERE'S NOT AS MUCH DONE IN THE FIELD OF HEALTHCARE BECAUSE THERE

IS SO MUCH INFORMATION THAT STUDENTS NEED TO HAVE. CHAMPIONING THAT AND MAKING OPPORTUNITIES AVAILABLE FOR ANY NURSES, DOCTORS, ANYBODY -- ALLIED HEALTHCARE PRACTITIONERS AROUND DEMENTIA. THAT'S ALSO IMPORTANT. THE OTHER THING I WANTED TO ADD, FAMILIES, ESPECIALLY NEED SUPPORT. AND INFORMATION. BUT THE THING THAT I HAVE FOUND WITH A LOT OF FAMILY MEMBERS IS NAVIGATION. NAVIGATION, TRYING TO FIGURE OUT HOW TO FIND SOMEBODY, WHERE TO GO, WHAT THE INITIAL STANDS FOR. IF YOU GO INTO AN ORGANIZATION, EVEN BRIDGING THE GAPS BETWEEN THE AGING AND THE INTELLECTUAL DISABILITIES COMMUNITIES AND ALSO THE ALZHEIMER'S COMMUNITY. TRYING TO HAVE PEOPLE WITH SPECIALTIES BEING ABLE TO TALK TO PEOPLE. THOSE ARE THINGS THAT I THINK ARE REALLY IMPORTANT. AND THE BARRIERS I HAVE, IN THE FIELD OF IDD, THERE ARE SO MANY COMPETING DEMANDS. WHO GETS FUNDED. IT IS LIKE QUEEN FOR A DAY, I HATE TO SAY IT. HOW DO WE ADVOCATE FOR PEOPLE TO GET THE FUNDING THAT THEY NEED TO HAVE. ALSO, FOR DIRECT CARE, PEOPLE WHO PROVIDE HANDS-ON SUPPORT. THERE ARE SO MANY PEOPLE WE REALLY NEED TO HAVE PEOPLE SO THEY NEED TO GET PAID ADEQUATELY AND THEY ALSO NEED THE EDUCATION AND UNDERSTANDING. BONNIE?

>> SO, I'M GOING TO DRILL DOWN AS USUAL ON WHAT KATHY SAID AND FOCUS SPECIFICALLY ON PHYSICIANS AND ADVANCED PRACTICE NURSES. AND IN THE DEMENTIA AND IDD FIELD, WE HAVE A UNIQUE PROBLEM I THINK IS NOT SO UNIQUE YOU NOW THAT I THINK ABOUT IT. WE HAVE CLINICIANS WHO HAVE BEEN CARING FOR SOMEBODY FOR THEIR DOWN SYNDROME OR WHATEVER THE ISSUES ARE, THEN THEY GET DEMENTIA SYMPTOMS. AND OFTENTIMES, THAT ONE CLINICIAN IS GOING TO PASS THE PERSON OFF TO THE NEXT. IT WILL GO FROM SOMEONE WHO AN IDD SPECIALIST AND NOW SEEING A DEMENTIA SPECIALIST. AND THE TWO OF THEM ARE NOT SPEAKING TO EACH OTHER. AND SO THEY EACH LOOK AT ONE PART OF THEM AND NO ONE IS LOOKING AND CARING ABOUT THE PERSON. AND SO, IT IS -- I DON'T THINK IT IS ACTUALLY THAT UNIQUE IN THAT MOST PEOPLE WHO HAVE DEMENTIA, ALSO HAVE OTHER COMORBID CONDITIONS. AND SO WHAT HAPPENS WHEN THE ONCOLOGIST IS NOT TALKING TO THE NEUROLOGIST OR WE DON'T REALLY RECOGNIZE THE SYMPTOMS BECAUSE IT IS AN oncologist ONCOLOGIST. WE WORRY ABOUT THAT IN THE FIELD. WHAT WE NEED MOST IS THE COMMUNICATION BETWEEN THE DIFFERENT PROVIDERS SO THEY CAN CARE FOR THE WHOLE PERSON. THANK YOU.

>> THANK YOU, KATHY AND BONNIE. VERY IMPORTANT POINTS. I'LL JUST MENTION, I SAW A QUESTION ABOUT THIS IN THE CHAT. MASSACHUSETTS, WHERE

MOST OF US HERE ARE BASED, BONNIE IS JOINING US FROM OHIO AND NIA FROM IDAHO, REST OF US ARE IN MASSACHUSETTS. WE ARE AN UNUSUAL STATE IN THAT IN 2018, OUR STATE GOVERNMENT PASSED A LAW REQUIRING CONTINUING MEDICAL EDUCATION ABOUT DEMENTIA FOR DOCTORS AND NURSES AND SOME OTHER ALLIED HEALTH PROFESSIONALS. IT IS HARD TO IMPLEMENT BECAUSE AS YOU SAID, THERE ARE COMPETING DEMANDS. THERE ARE SO MANY PRESSURES ON PEOPLE DOING THIS WORK. THEY OFTEN HAVE VERY BRIEF AMOUNTS OF TIME WITH THEIR PATIENTS. SO, IT IS HARD TO ACHIEVE, BUT AT LEAST WE'RE MOVING IN THAT DIRECTION HERE IN MASSACHUSETTS. I HOPE OTHER STATES WILL DO THE SAME. I THINK WHEN THAT LEGISLATION WAS BEING DEBATED, PEOPLE WERE SHOCKED TO HEAR THAT IT WASN'T ALREADY THE CASE THAT MEDICAL PROFESSIONALS HAD TO LEARN SOMETHING ABOUT DEMENTIA, BUT THEY DIDN'T NECESSARILY HAVE TO. SO WE ARE MOVING IN THAT DIRECTION. AND THANK YOU FOR -- KEEP CHATTING. I SEE GREAT THINGS IN THE CHAT. LET'S GO TO TIRSA, SAW, AND NIA, I'D LOVE TO COME BACK TO YOU AFTER THAT AND JUST ASK WHAT NEEDS YOU SEE. WHAT WOULD BE SOMETHING YOU MOST WANT TO SEE CHANGED? SO WE'LL GO TO TIRSA? WHAT DO YOU SEE AS PERSON NEEDS IN YOUR COMMUNITY AROUND DEMENTIA?

>> I SEE THE NECESSITY IN THE LATIN COMMUNITY THAT WE NEED -- THE SAME THING EVERYBODY HAS SAID. SUPPORT, EDUCATION. ONE OF THE MEMBERS OF MY CHURCH HAS HER MOTHER... SHE IS VERY FRUSTRATED AND CALLS ME ALL THE TIME. WHAT CAN WE DO. AND WHAT WE CAN WE DO TO MOTIVATE FAMILIES SO THEY CAN UNITE IN THIS. IN THIS AREA OF TAKING CARE OF THEIR FAMILY MEMBERS. SOMETIMES YOU CAN SEE THAT THE PERSON WHO IS TAKING CARE OF THE PATIENT -- SO IT IS LEFT OVER TO THAT ONE PERSON. I THINK IN MY CASE, WHEN I TOOK CARE OF MY PARENTS, THANK GOD THE DOCTOR WAS A GREAT PERSON. WHEN HE RELEASED MY BROTHER WOULD GO TO THE DOCTOR, HE'D ENFORCE MY FAMILY MEMBERS HELP ME WITH THE CARE OF MY FAMILY. THERE ARE MANY OTHER PEOPLE THAT DON'T HAVE THIS BACKUP BY THEIR FAMILY. IT IS VERY IMPORTANT THAT -- VERY IMPORTANT THAT GET INVOLVED IN THIS AND GIVE SOME KIND OF REFERENCE TO THIS BECAUSE THE DOCTORS -- THIS PATIENT TELLS ME THE DOCTOR HAS NOT SAID ANYTHING TO THE OTHER FAMILY MEMBERS. THIS IS GOING TO GET WORSE. I THINK EDUCATION LIKE JUDITH AND KATHY MENTIONED, WE DO NEED EDUCATION. DOCTORS CAN HELP AND REFER INFORMATION TO FAMILY MEMBERS TO HELP THE CAREGIVER ITSELF. I THINK WE NEED TO HAVE THE FAMILY HELP US.

>> THANK YOU, TIRSA. I'M HEARING SO MUCH ABOUT NAVIGATION AND

COORDINATION. COORDINATION AMONG FAMILY MEMBERS, SO IT IS NOT JUST ONE PERSON WHO IS INVOLVED IN OTHER FAMILY MEMBERS MAY BE STEPPING BACK. NAVIGATION OF RESOURCES SO WHEN A PERSON IS DIAGNOSED WITH DEMENTIA, THEY KNOW WHERE TO GO TO GET HELP AND SUPPORT AND LIVE LIFE WELL. COORDINATION AMONG DOCTORS AND OTHER HEALTHCARE PROVIDERS, ESPECIALLY WHEN THE PURPOSE MAY HAVE MORE THAN ONE MEDICAL CONDITION, WHICH IS VERY COMMON. SO THIS IS A THEME THAT IS COMING UP.

COORDINATION. AND THERE ARE SOME REALLY GREAT TYPES OF SERVICES OUT THERE THAT WILL HELP PEOPLE NAVIGATE AND COORDINATE. THEY ARE JUST NOT EVERYWHERE. THEY ARE NOT ACCESSIBLE IN ALL LANGUAGES AND IN ALL COMMUNITIES. WE NEED MORE OF THAT. SO LET'S GO TO SAW AND THEN NIA.

>> THANK YOU. FOR MY COMMUNITY, MOST PARENTS -- COMMUNITY CAN'T READ OR WRITE ENGLISH OR EVEN THEIR OWN LANGUAGE BECAUSE THEY HAVE NEVER BEEN TO SCHOOL. THE LANGUAGE BARRIER IS ONE THING. I THINK OUR COMMUNITY NEEDS MORE PEOPLE OR SOMEONE WHO CAN COMMUNICATE WITH THEM IN THEIR LANGUAGE TO TEACH THEM ABOUT DEMENTIA AND TO GUIDE THEM. THANK YOU.

>> THANK YOU VERY MUCH, SAW. AND YOU KNOW, I THINK IT IS SUCH AN IMPORTANT REMINDER THAT EVEN IF THERE ARE GOOD RESOURCES AVAILABLE, NOT EVERYONE CAN ACCESS THEM. CAN'T ACCESS THEM BECAUSE OF LANGUAGE BARRIERS, LITERACY BARRIERS, OTHER BARRIERS, FINANCIALS, SOME OTHER BARRIERS WE DISCUSSED. WE HAVE TO KEEP ASKING WHO IS MISSING, WHO IS NOT USING THESE SERVICES AND THEN HOW DO WE IDENTIFY THE BARRIERS AND REMOVE THE BARRIERS.

NIA, HOW ABOUT YOU? WHAT THOUGHTS DO YOU HAVE ABOUT WHAT ARE THE MOST IMPORTANT NEEDS -- SOMETHING YOU WOULD REALLY LIKE TO SEE CHANGED?

>> I'D REALLY LIKE TO SEE THE PROVIDERS BE EDUCATED AS MANY OF THE PANEL MEMBERS HAVE SAID BEFORE. ONE OF MY TERRIBLE MEMORIES, I HAD -- I WENT TO THE VA TO TAKE ADVANTAGE OF THE MEMORY CARE PROGRAM THEY HAD. I WAS TURNED AWAY BECAUSE I WAS TOLD THEY DIDN'T SEE ANYONE MY AGE THERE. AND THEY REFERRED ME TO THE VA NEUROLOGIST, IN TURN TOLD ME I WAS NOT -- I DIDN'T HAVE DEMENTIA, MY SCAN WAS A FLUKE BECAUSE I WASN'T DEMENTED. NOW, IF A NEUROLOGIST WILL SAY THAT, THEN WE HAVE A LONG WAY TO GO AS FAR AS EDUCATION AND EMPATHY GOES.

>> THANK YOU, NIA. I THINK YOU RAISE A REALLY IMPORTANT POINT WHEN YOU SAY EDUCATION AND EMPATHY. SO, THOSE ARE BOTH IMPORTANT.

WHAT WE KNOW ABOUT DEMENTIA CONTINUES TO EVOLVE. IT IS A VERY COMPLICATED AREA. OUR BRAINS ARE ALL VERY UNIQUE. IN ADDITION TO THE FACT THAT SOMETIMES IT CAN BE HARD TO MAKE AN ACCURATE DIAGNOSIS BECAUSE IT IS COMPLEX, THAT EMPATHY IS SO IMPORTANT. HOW DOES THE PERSON COMMUNICATE A DIAGNOSIS OR HOW DO THEY TALK WITH THEIR PATIENT ABOUT WHAT THE NEXT STEPS WOULD BE. I'VE HEARD SO MANY PEOPLE TELL STORIES LIKE YOU ARE SHARING WHERE THEY WERE SPOKEN TO IN A WAY THAT MADE THEM FEEL REALLY HOPELESS, MADE THEM FEEL... DEHUMANIZED. THAT'S A TERRIBLE THING THAT WE SHOULD BE ABLE TO WORK ON FIXING. WHAT I WANT TO DO NOW IS JUST BRING THE ROUNDTABLE TO A CLOSING WITH A POSITIVE QUESTION ABOUT WHAT CAN WE DO TO HELP PEOPLE TALK ABOUT DEMENTIA. WE'LL GO BACK TO THE ISSUE OF OPEN COMMUNICATION. AND I'D LOVE TO HEAR ANY THOUGHTS THAT YOU HAVE ABOUT THE INGREDIENTS YOU THINK HELP PEOPLE START TO FEEL MORE COMFORTABLE IN SAYING THE WORDS, ASKING THE QUESTIONS, REALLY COMMUNICATING OPENLY ABOUT DEMENTIA. SO, I WILL START WITH JUDITH?

>> THANK YOU, BETH. I THINK THAT'S MY FAVORITE QUESTION. I THINK THE EDUCATION SHOULD START AT THE HIGHER LEVEL WITH STAKEHOLDERS. FOR EXAMPLE, I'M WORKING WITH OLDER ADULTS POPULATION, SO I APPLY FOOD STAMPS. I HAVE TO RECERTIFY THEIR LEASE. EARLY STAGE OF DEMENTIA, WHEN WE RECEIVE LETTERS FOR FOOD STAMPS, THEY FORGET -- RENEW THE FOOD STAMP EVERY YEAR. WHAT HAPPENS? IT IS A PUNISHMENT IF YOU START TO BECOME FORGETFULNESS. UNFORTUNATELY, THEY WILL CUT YOUR FOOD STAMPS. I THINK WE NEED TO ADDRESS AT THE HIGHER LEVEL, AS WE GET OLDER, DEMENTIA, IT SHOULD BE A RED FLAG SO EVERYBODY SHOULD PAY ATTENTION THE WAY WE LIVE. WE FORGET A LOT OF TIME. AND THAT'S THE FIRST SIGN IN THE COMMUNITY. FORGET TO PAY THE RENT, FORGET TO RENEW FOOD STAMPS, FORGET TO RENEW THE HEALTHCARE INSURANCE. STAKEHOLDERS, HIGHER LEVEL, GET ALL SERVICES. SOMEONE WHO LIVES WITH DEMENTIA, ESPECIALLY INDEPENDENT LIVING, THEY DON'T HAVE CHILDREN AROUND. THEY DON'T HAVE SOME HOUSING, THEY DON'T HAVE NO SERVICES. AS A PUNISHMENT, THOSE PEOPLE WITH DEMENTIA, THEY NOW HAVE NO FOOD, THEY DON'T HAVE NO SERVICES, NO SERVICES. I THINK DEMENTIA FRIENDS, IN THE FUTURE, SHOULD INCREASE THIS PROGRAM IN THE HIGHER LEVEL, IN THE INSTITUTION LEVEL, AND MAKE DEMENTIA EDUCATION AS A PRIORITY, EVEN IN HUMAN RESOURCES, TO UNDERSTAND PEOPLE. THAT'S MY WISH AND EVERYBODY CAN LIVE WELL WITH DEMENTIA IF THE HIGHER LEVEL KNOWS ABOUT IT.

>> THANK YOU, JUDITH. THE IMPORTANCE OF EDUCATION AND COMMUNICATION AT THE HIGHER LEVEL. THANK YOU. KUN? WHAT ABOUT YOU?

>> I HAVE A DREAM... WE HAVE A PLACE, AN OPEN MIND, OPEN ARM, PEOPLE WE CAN TRUST. SPEAK YOUR LANGUAGE, UNDERSTAND YOUR CULTURE. I THINK THAT'S THE KEY. IF PEOPLE FEEL COMFORTABLE TO TALK ABOUT IT, I THINK CHANGE HOLDS IT. I THINK COMING TO THE STRUCTURE SIDE, SHOULD SOMEBODY COMMUNITY-BASED ORGANIZATION, LOCAL COUNCIL ON AGING, COMMUNITY CENTER, SENIOR CENTER, USUALLY VISIT. FEEL COMFORTABLE TO INTERACT WITH THE PEOPLE. START FROM THERE. THAT WOULD BE A GREAT PLACE TO START. THANK YOU.

>> THANK YOU, KUN. I THINK NIA MAY HAVE GOTTEN DISCONNECTED. JESSICA, IF YOU SEE HER COME BACK IN, CAN YOU SPOTLIGHT HERE AGAIN. WE'LL GO TO ALANA?

>> IN MY COMMUNITY I SEE THEY DON'T HAVE ANY PROBLEM TO TALK ABOUT DEMENTIA. BUT THEY DON'T KNOW WHERE TO LOOK FOR A SERVICE AND HELP TO THEM. SO, I TOTALLY AGREE WITH KUN. WE HAVE TO HAVE SOMETHING -- OTHER LANGUAGES. AND UNDERSTAND ABOUT THE CULTURE BECAUSE IT IS VERY DIFFERENT. WHEN YOU GO SOMEWHERE, THE TREATMENT SOMETIMES IS NOT WHAT THEY EXPECT. IT IS MY DREAM, TOO, KUN. TO HAVE ALL OF THIS.

>> THANK YOU. I LOVE THE WAY YOU ARE BOTH PAINTING THIS PICTURE. IT IS VERY ENCOURAGING. ARNETTA, HOW ABOUT YOU? WHAT DO YOU THINK HELPS OPEN THE COMMUNICATION?

>> I'D HAVE TO AGREE WITH ALANA, WITH JUDITH, AND KUN. WE DO NEED OUR OFFICIALS TO BE MORE EDUCATED ON WHAT IS GOING ON IN THE WORLD WITH DEMENTIA AND ALZHEIMER'S. SO THE PROBLEMS DON'T KEEP HAPPENING OVER AND OVER, WE'RE ALL GETTING OLDER AND WE'LL ALL START TO EXPERIENCE WHAT IS GOING ON WITH OUR SEASONED ELDERLY AND THE SENIOR POPULATIONS. YES, IT DOES NEED TO START AT THE TOP LEVEL. WE NEED TO SHARE MORE WITH EACH OTHER ABOUT WHAT IS GOING ON IN ALL THE DIFFERENT COMMUNITIES.

>> THANK YOU, ARNETTA. KATHY AND BONNIE?

>> OF COURSE, WE TALK ABOUT -- DEMENTIA IS SUCH A POWERFUL AND NEGATIVE WORD, BUT IT IS ALSO AS WE -- EVERYBODY KEEPS TALKING ABOUT, PEOPLE ARE LIVING WITH DEMENTIA. WHAT DO WE DO WHERE PEOPLE HAVE A SENSE OF WELLBEING, WHEN THEY LIVE WITH DEMENTIA. GIVING PEOPLE THINGS TO DO AND WHAT YOU CAN DO. THE ARTS ARE WONDERFUL. THEY ARE FAIRLY FREE ACTIVITIES AND ALSO KEEPING PEOPLE WELL, PHYSICALLY WELL AND

HEALTHY, WHEN LIVING WITH DEMENTIA. IF YOU ARE NOT FEELING GOOD, IF YOUR ARTHRITIS PAIN BOTHERS YOU, IT WILL COME OUT IN OTHER WAYS. IF SOMEONE LIVES WITH DEMENTIA, WE DON'T FORGET ABOUT THE OTHER ASPECTS THAT KEEP OUR LIVES FULL. SOCIALLY ENGAGED AND ALL THINGS THAT ARE GOOD FOR BRAIN HEALTH OVERALL. AND THE OTHER THING THAT I WANTED TO STRESS IS THE VALUE OF SUPPORT GROUPS FOR PEOPLE. THEY ARE LIVING WITH DEMENTIA OR WHO ALSO -- FOR FAMILY MEMBERS -- I FACILITATE AN ONLINE SUPPORT GROUP FOR VIRTUAL GROUP FOR FAMILIES WHO HAVE SOMEONE WITH AN INTELLECTUAL DISABILITY AND DEMENTIA. HAVING THAT CONVERSATION, THE SUPPORT AND YOU WERE TALKING ABOUT, PEOPLE FROM WITHIN THE COMMUNITY, TO BE ABLE TO DISCUSS THE THINGS. AND PEOPLE -- IT IS AMAZING, THE SUPPORT, THE PEOPLE WHO ARE IN SUPPORT GROUPS, JUST HOW HELPFUL THEY ARE TO EACH OTHER. I DON'T UNDERESTIMATE THE VALUE OF THIS FOR A LOT OF PEOPLE. 34 YOUR CULTURE, ET CETERA, HOW HAVING EACH OTHER TO SUPPORT EACH OTHER IS AMAZING. IT IS SO POWERFUL IN ITSELF. BONNIE?

>> WELL, I WANT TO -- YOU TALKED ABOUT WHAT INGREDIENTS THERE ARE. WHAT IS THE RECIPE WE ARE CREATING. KUN AND JUDITH TALKED ABOUT THEIR DREAMS AND I SAW THAT IN THE CHAT, PEOPLE TALKED ABOUT DREAMS. AND JUST SO YOU KNOW, I DON'T DO DREAMS, I DO WISHES, I HAVE MY MAGIC WAND. HOPEFULLY, MY WISHES WILL ALSO COME TRUE. AND I HAVE TWO WISHES OR INGREDIENTS I'D LIKE TO BE PART OF THE FUTURE. FIRST, TO MOVE TOWARDS WHAT WE CALL -- I'M SURE THERE'S A BROADER TERM, STRENGTHS-BASED APPROACH TO DEMENTIA. MEANING, NOT WHAT SOMEBODY CAN'T DO, BUT LET'S FOCUS ON WHAT THEY STILL CAN DO AND BUILD UPON THAT AND SEE THAT SENSE OF VALUE. AND THE SECOND IS... I THINK IT IS VERY, VERY IMPORTANT THAT WE SEND THE MESSAGE THAT EVERYONE IN THE COMMUNITY HAS A ROLE TO PLAY. AND I UNDERSTAND THE IMPORTANCE OF SUPPORT GROUPS AND MANY OTHER THINGS WE HAVE TALKED ABOUT. I CAN'T THINK OF ANYONE WHO DOESN'T HAVE A ROLE. UNLESS, WE INVOLVE EVERYONE AND HELP THEM SEE THAT AND SEE THE STRENGTH, I'M NOT SURE WHAT WE'RE GOING TO COOK WITH THE RECIPE. THANK YOU.

>> THANK YOU, KATHY AND BONNIE. WELL SAID. LET'S GO TO TIRSA AND THEN SAW.

>> SOMETHING VERY IMPORTANT THAT WE NEED TO DO WITH OUR COMMUNITY, THE LATINO COMMUNITY, IN THE CASE OF MY COMMUNITY, WE NEED TO GAIN THEIR TRUST. WHEN WE GAIN THEIR TRUST, WE CAN ALSO GIVE THEM REFERRALS TO THE DIFFERENT RESOURCES AVAILABLE. MANY OF THEM ARE

IMMIGRANTS. THEY DON'T HAVE THE KNOWLEDGE OF THE RESOURCES. I THINK IT IS VERY IMPORTANT TO GAIN THEIR TRUST BECAUSE WE ALWAYS HAVE THE BARRIER THAT DON'T ALLOW PEOPLE TO OPEN UP THEIR HEARTS. I THINK IT IS VERY IMPORTANT TO GET CLOSE TO THEM, TO OPEN THE DOORS SO THEY CAN HAVE THE RESOURCES THAT ARE AVAILABLE IN THE COUNTRY. THANK YOU.

>> THANK YOU SO MUCH. SO IMPORTANT TO EMPHASIZE THE ROLE OF TRUST. AND SAW, WE'LL GIVE YOU THE LAST WORD ON THE ROUNDTABLE.

>> IN OUR COMMUNITY -- TRUST IS IMPORTANT FOR OUR COMMUNITY. IF WE CAN FIND SOMEONE TRUSTWORTHY, SOMEONE IN THE COMMUNITY TO SHARE MORE INFORMATION OR BRING MORE AWARENESS ABOUT DEMENTIA. AND GUIDE THE FAMILY MEMBERS OR HOW TO HAVE A SUPPORT AS WELL AS SHARE THE RESOURCES WITH THE FAMILIES WHO ARE LIVING WITH DEMENTIA AND THEIR FAMILY MEMBER. I THINK IT WOULD BE VERY HELPFUL. MOST PEOPLE IN OUR COMMUNITY FEEL MORE COMFORTABLE SHARING AND BEING MORE OPEN ABOUT THEIR SITUATION WITH THE COMMUNITY LEADER THEY TRUST. IT IS ALSO EASIER FOR THEM TO ASK FOR HELP FOR THEIR COMMUNITY AND LEADER. THANK YOU.

>> THANK YOU, SAW. I THINK IT IS A GREAT NOTE TO CLOSE THIS PART OF THE PROGRAM WITH THE EMPHASIS ON TRUST. AND THAT COMMUNITY CONNECTION. SO, I WANT TO THANK YOU ALL FOR ALL OF YOUR THOUGHTS AND WISDOM. AND IF YOU WANT TO TAKE PEOPLE OFF SPOTLIGHT. WHAT WE'LL DO NOW IS HAVE A BREAK OF ABOUT EIGHT MINUTES. WE'LL COME BACK AT 3:35. I'M GOING TO SHOW A VIDEO THAT OUR COMMUNITY PARTNERS HAVE PREPARED TO SHARE SOME IMAGES FROM THEIR COMMUNITY AND MORE THOUGHTS. YOU CAN TAKE YOUR BREAK, IF YOU NEED TO STAND UP, DO WHATEVER YOU NEED TO DO. THE LINK TO THIS VIDEO WILL ALSO BE AVAILABLE TO YOU IN THE RESOURCES THAT YOU WILL RECEIVE IN A COUPLE OF WEEKS ALONG WITH THE RECORDING AND OTHER RESOURCES. ALSO, IF YOU SPEAK A LANGUAGE OTHER THAN ENGLISH, YOU WILL BE ABLE TO WATCH THIS VIDEO WITH TRANSLATED CAPTIONS ON YOUR OWN. I'M GOING AHEAD TO PLAY IT, FEEL FREE TO STEP AWAY IF YOU NEED TO AND WE'LL START AGAIN AT 3:35.

>> SO, WELCOME BACK EVERYONE. AND I JUST WANT TO SAY THAT AS MUCH AS I USE ZOOM EVERY DAY, I'M STILL LEARNING NEW THINGS. THAT VIDEO DID HAVE -- WE HAD PUT CAPTIONS ON IT, BUT I DIDN'T SEE THEM. SO, I THINK IT IS SOMETHING I DON'T UNDERSTAND ABOUT ZOOM. THERE'S MORE TO LEARN EVERY TIME, BUT YOU WILL RECEIVE THE LINK TO THAT VIDEO AND YOU CAN WATCH IT WITH CAPTIONS IN ENGLISH OR YOU CAN CHOOSE THE AUTO-TRANSLATE

OPTION, IT WILL SHOW YOU CAPTIONS IN ANY LANGUAGE THAT YOU CHOOSE. WELCOME BACK. AND THERE'S TWO MORE THINGS THAT WE'RE GOING TO DO THIS AFTERNOON. I'M GOING TO TALK WITH YOU FOR ABOUT 25 MINUTES ABOUT HOW DEMENTIA FRIENDS MASSACHUSETTS HAS BEEN ABLE TO WORK WITH ALL THE WONDERFUL PEOPLE YOU HAVE BEEN HEARING FROM WHAT WE LEARNED AS A PROGRAM ABOUT HOW TO BECOME MORE INCLUSIVE AND MORE REPRESENTATIVE OF THIS VERY DIVERSE STATE THAT WE SERVE. AND THEN, WE ARE GOING TO SPEND THE LAST 20-25 MINUTES GOING BACK TO YOUR WONDERFUL QUESTIONS AND COMMENTS. THEY ARE SUCH GOOD ONES AND SOME OF YOU ALSO SENT IN WHEN YOU REGISTERED. WE CAPTURED THOSE. WE'RE GOING TO DO OUR BEST TO RESPOND TO THEM AND WE'LL BRING OUR COMMUNITY PARTNERS BACK INTO THAT CONVERSATION. I HOPE YOU CAN STAY WITH US AND THEN WE'LL WRAP UP AT 4:30. WE HAVE JUST UNDER AN HOUR LEFT TOGETHER.

I'M GOING TO WALK THROUGH WHAT I CALL THE FOUR RS. A FRAMEWORK I CAME UP WITH A COUPLE OF YEARS AGO. KUN AND I HAVE DONE PRESENTATIONS ON THE ROAD TO REPRESENTATIONS FOR MASSACHUSETTS COUNCILS ON AGEING AND AMERICAN SOCIETY ON AGING. THANK YOU FOR YOUR PARTNERSHIP IN THAT, KUN. THE FOUR RS ARE REALIZATION, RESOURCES, RELATIONSHIPS, AND ROAD. GOING THROUGH EACH OF THOSE AND I'M SHARING THIS MODEL AS AN EXAMPLE, NOT AS AN IDEAL. I'M SURE MANY OF YOU WHO ARE HERE TODAY ARE PART OF INITIATIVES THAT HAVE REALLY WORKED TO MAKE SOME STRUCTURAL CHANGES SO THAT YOU CAN REACH MORE DIFFERENT COMMUNITIES. I HOPE YOU WILL SHARE WITH US IN THE CHAT, BUT AGAIN, IT IS NOT ABOUT SAYING THIS WAS THE PERFECT WAY, BUT JUST SHARING SOME LEARNINGS THAT WE HAD THAT I HOPE WILL BE HELPFUL AND USEFUL TO OTHERS. I WANT TO START WITH THIS, ONE OF MY FAVORITE QUOTES: WE MAKE THE ROAD BY WALKING FROM SPANISH POET. IT WILL REMIND US THAT WE JUST HAVE TO START AND THE ROAD WILL DEVELOP AND APPEAR IN FRONT OF US AS WE TAKE THE STEPS. SOMETIMES I THINK IT CAN FEEL OVERWHELMING. AND AS YOU SEE THIS PRESENTATION, YOU MIGHT FEEL OVERWHELMED BECAUSE WE HAVE BEEN AT THIS FOR A FEW YEARS. AND WE HAVE WORKED WITH MANY DIFFERENT COMMUNITIES, BUT THE IMPORTANT THING IS TO BEGIN. IT IS TO BEGIN ANYWHERE YOU CAN, ANYWHERE THAT IS SUSTAINABLE FOR YOU. JUST MAKE A START AND WE'LL NEVER STOP WORKING TO IDENTIFY WHO IT IS THAT WE'RE MISSING AND TRYING TO BUILD THE BRIDGES. THE FIRST R IS REALIZATION. AND SO, THE FIRST STEP WAS TO ASK AS DEMENTIA FRIENDS MASSACHUSETTS, HOW DOES OUR PERFORMANCE COMPARE WITH OUR MANDATE? OUR MANDATE IS TO SERVE THE WHOLE STATE OF MASSACHUSETTS. WE HAD TO

START WITH WHAT I CALL THE MR. ROGERS QUESTION. MR. ROGERS IS NO LONGER WITH US, BUT HIS SPIRIT LIVES ON. HE WOULD SAY: WHO ARE THE PEOPLE IN YOUR NEIGHBORHOOD. IN MASSACHUSETTS ALMOST A THIRD OF RESIDENTS ARE NON-WHITE OR HISPANIC AND ALMOST 24% OF MASSACHUSETTS RESIDENTS SPEAK A LANGUAGE OTHER THAN ENGLISH AT HOME. THE MOST COMMON LANGUAGES OTHER THAN ENGLISH SPOKEN IN MASSACHUSETTS, SPANISH, PORTUGUESE, CHINESE, INCLUDING BOTH MANDARIN AND CANTONESE, AND HAITIAN. NATIONALLY, OR ACTUALLY WORLDWIDE, ABOUT 1-3% OF THE POPULATION HAS AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY. SO, WE CAN ASSUME THAT IS TRUE HERE IN MASSACHUSETTS AS WELL. ABOUT ONE PERSON IN 700 HAS DOWN SYNDROME, AS YOU HAVE HEARD, BRINGS WITH IT A HIGHER RISK OF ALZHEIMER'S DISEASE. AND PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES ARE LIVING LONGER AND MORE LIKELY TO DEVELOP DEMENTIA. SO THAT WILL GIVE YOU SOME IDEA OF THE DEMOGRAPHICS THAT WE LOOKED AT. WE LOOK AT OTHER FACTORS, TOO. THAT GIVES AN IDEA AND WE LOOKED AT THE PERFORMANCE. DEMENTIA FRIENDS MASSACHUSETTS STARTED IN VERY LATE 2017. AND SO WE REALLY GOT GOING IN EARLY 2018. A YEAR LATER, IN LATE 2018, WE LOOKED AT THE PERFORMANCE AND WE SAW LESS THAN 5% OF NEW DEMENTIA FRIENDS PARTICIPANTS WERE IN A PRIMARILY NON-ENGLISH SPEAKING COMMUNITY OR A COMMUNITY OF COLOR AND NONE WERE PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES. THAT WAS A DISPARITY, A GAP BETWEEN OUR OPERATION AND WHO WAS PARTICIPATING IN DEMENTIA FRIENDS MASSACHUSETTS. WE HAD TO ASK WHAT WERE THE REASONS FOR THE DISPARITY. IT IS IMPORTANT TO START BY ASKING IS DEMENTIA FRIENDS SOMETHING THAT EVERYBODY NEEDS. IS IT THE APPROPRIATE PROGRAM FOR MANY COMMUNITIES. SO, I THINK THAT THE ANSWER IS YES AFTER LOOKING INTO THAT AND REFLECTING ON THAT. AND I HOPE I CONVINCED YOU BY NOW THAT EDUCATION AND PUBLIC AWARENESS ABOUT DEMENTIA IS VERY MUCH NEEDED IN ALL COMMUNITIES. HERE'S A COUPLE OF QUOTES FROM THE WORLD ALZHEIMER'S REPORT. WONDERFUL RESOURCE FROM ALZHEIMER'S DISEASE INTERNATIONAL. THE LINK IS IN THE RESOURCE GUIDE. AND ONE QUOTE IS, NATIONAL AWARENESS CAMPAIGNS MUST TACKLE STIGMA AND LACK OF EDUCATION ON DEMENTIA, THIS CONTINUES TO BE A BARRIER TO ACCESSING DIAGNOSIS AND POST-DIAGNOSTIC SUPPORT. STIGMA REMAINS PERVASIVE AS A CONSISTENT BARRIER TO ACCESSING DIAGNOSIS, CARE, CONTRIBUTING TO MISINFORMATION, ISOLATION, SHAME, AND EVEN ABUSE AND NEGLECT. AND YOU HAVE JUST HEARD FROM OUR COMMUNITY PARTNERS, AWARENESS, EDUCATION, INFORMATION, ARE CRITICAL. SO I THINK IT

WAS CLEAR THAT IS A RESOURCE THAT PEOPLE NEED THROUGHOUT MASSACHUSETTS. THEN THE QUESTION IS, IS DEMENTIA FRIENDS A GOOD FIT TO PROVIDE THAT. DEMENTIA FRIENDS IS KIND OF SPECIAL IN THAT IT IS A GLOBAL PROGRAM. YOU CAN SEE FROM THIS MAP, IT IS NOT PRESENT EVERYWHERE. IT IS LESS AVAILABLE IN THE GLOBAL SOUTH RIGHT NOW. THERE ARE 167 COUNTRIES USING IT AND THAT CONTINUES TO GROW. SO AT THE HEART OF DEMENTIA FRIENDS, A MODEL THAT WAS DESIGNED TO BE FLEXIBLE AND ADAPTED TO MANY DIFFERENT LANGUAGES AND CULTURAL CONTEXTS. THAT WAS A GOOD STARTING POINT. AND THEN WE DID SOME TESTING. IN JUNE 2018, THE MULTICULTURAL COALITION ON AGING, A WONDERFUL GROUP, ACTIVE IN MASSACHUSETTS FOR A COUPLE OF DECADES, LOOKED AT DEMENTIA FRIENDS, GAVE FEEDBACK AND WE MADE CHANGES TO OUR MATERIALS BASED ON THAT. AND THEN THE GREATER BOSTON CHINESE GOLDEN AGE CENTER TOOK IT ON AS A PILOT. SO, LATER THAT SUMMER, KUN, WHO YOU HEARD FROM AND HIS COLLEAGUE, TRAINED AS CHAMPIONS, THEY TRANSLATED THE WORKBOOK AND TESTED THE CURRICULUM WITH COMMUNITY MEMBERS. AND THEY FELT IT WAS HELPFUL AND APPROPRIATE IN THEIR COMMUNITY. AND THE IDEA OF BECOMING A DEMENTIA FRIEND WAS ACCESSIBLE AND NOT THREATENING BECAUSE SOMETIMES PEOPLE WOULD FEEL THAT THEY SHOULD NOT LET IT BE KNOWN PUBLICLY IF THEY HAD A RELATIVE LIVING WITH DEMENTIA. BUT THEY COULD ATTEND THIS WORKSHOP AS A WAY TO HELP THEIR COMMUNITY TO BECOME A FRIEND, TO BE A GOOD PART OF THEIR COMMUNITY. THAT WAY IT DIDN'T FEEL THREATENING. KUN, FEEL FREE TO ADD ANYTHING TO THAT IF I MISS SOMETHING. SO, IT SEEMED LIKE DEMENTIA FRIENDS WAS A GOOD FIT. THE ROOT OF THE DISPARITY, IT WAS REALLY IN CHAMPION PARTICIPATION. I'M GOING TO SHOW YOU HOW DEMENTIA FRIENDS IS STRUCTURED. I'M THE MASTER TRAINER FOR MASSACHUSETTS. THE PERSON AUTHORIZED TO DO THAT. A LOT OF ADMINISTRATIVE WORK SO IT IS HARD TO BRING ON OTHER PEOPLE DOING THAT. YOU HAVE TO BE EMPLOYED AS THE MASTER TRAINER. THEN, IT WAS A VOLUNTEER MODEL. MY JOB WAS TO TRAIN COMMUNITY MEMBERS TO BECOME DEMENTIA FRIENDS CHAMPIONS AND THEN THEY WOULD LEAD THE INFORMATION SESSION FOR PEOPLE IN THEIR COMMUNITY. THEY WOULD DO THIS AS VOLUNTEERS. THE PROBLEM IS, VOLUNTEER S NEED TIME, THEY NEED AWARENESS OF THE ISSUE, THEY NEED TO SORT OF ALREADY CARE ABOUT THIS. AND BE COMMITTED TO IT AND WE HAVE TALKED SOME ABOUT COMPETING PRIORITIES. THEY HAD TO BE PEOPLE WHO REALLY FELT THEY COULD MAKE TIME FOR THE SPECIFIC ISSUE, EVEN THOUGH THERE MAY BE OTHER CHALLENGES IN THEIR COMMUNITY THAT WOULD BE COMPETING FOR THEIR TIME.

AND THEY NEED TO BE COMFORTABLE WITH THE TYPE OF ACTIVITY. IN THIS CASE, THE ACTIVITY IS TEACHING, FACILITATING WORKSHOPS. NOT EVERYONE HAS THAT EXPERIENCE OR FEELS COMFORTABLE IN THAT ROLE. WE NEEDED ACCESSIBLE MATERIALS AND ACCESSIBLE TRAININGS. AND WHEN WE STARTED, WE ONLY HAD MATERIALS IN ENGLISH. THE TRAINING WAS ONLY IN ENGLISH AND THAT IS STILL THE CASE, UNFORTUNATELY. I'LL TALK MORE ABOUT WORKING WITH INTERPRETERS AND RELATIONSHIPS HELP. WHEN YOU THINK ABOUT VOLUNTEER ACTIVITIES YOU HAVE DONE IN YOUR LIFE, HOW OFTEN HAS IT BEEN BECAUSE YOU HAVE A FRIEND WHO SAID DO THIS WITH ME, I'M PART OF THIS GROUP, WE'LL DO IT THE TOGETHER. THAT'S OFTEN THE CASE, THE PROBLEM IS, IT WILL KEEP THE NETWORK LIMITED TO THE PEOPLE WHO ALREADY FEEL COMFORTABLE PARTICIPATING. THIS BRINGS US TO THE SECOND R. RESOURCES. GIVEN THAT WE SAW THE ROOT OF THE DISPARITY WAS THE PARTICIPATION OF CHAMPIONS, HOW COULD WE ADDRESS THE BARRIERS THAT MAKE IT HARD FOR PEOPLE FROM ALL COMMUNITIES TO BECOME CHAMPIONS. I'M GOING TO TAKE A SIP. RESOURCES, WE REALIZED, WERE NEEDED FOR THREE SPECIFIC THINGS. FOR MATERIALS, TRANSLATING THEM, BUT ALSO MODIFYING THEM IN SOME CASES. TO COMPENSATE COMMUNITY PARTNERS AND FOR INTERPRETATION. SO, IT IS IMPORTANT TO BUILD INTO THE GRANT PROPOSAL RESOURCES TO COMPENSATE PARTNERS. I WANTED TO JUST AHEAD AND SAY WHERE DO THE RESOURCES COME FROM. BECAUSE YOU I IMAGE THAT'S A QUESTION -- I IMAGINE THAT'S A QUESTION ON MANY MINDS. MOSTLY WE WORK FOR NONPROFITS, WE DON'T HAVE ANY EXTRA MONEY FOR EXTRA STAFF. HOW DO WE GET THE RESOURCES TO TRANSLATE, TO GET INTERPRETERS TO CONTRACT WITH COMMUNITY PARTNERS. SO GRANTS USUALLY ARE PHILANTHROPY. AND THE IMPORTANT THING IS TO BUILD INTO YOUR REQUESTS THOSE RESOURCES TO COMPENSATE COMMUNITY PARTNERS FAIRLY. YOU ALSO NEED ENOUGH TIME TO BUILD RELATIONSHIPS TO RECRUIT PEOPLE TO HAVE A LOT OF CONVERSATIONS IN ORDER TO FIND THE PEOPLE WHO ARE INTERESTED. AND BUILD THOSE RELATIONSHIPS. TO TAILOR AND CHANGE THE APPROACH BASED ON FEEDBACK AND THE NEEDS OF DIFFERENT COMMUNITIES BECAUSE THEY WON'T ALL BE THE SAME. I WANT TO REALLY ACKNOWLEDGE THE CRITICAL ROLE OF THE FUNDER HERE. IT WAS TUFTS HEALTH PLAN FOUNDATION AND THEY MERGED WITH ANOTHER FOUNDATION AND NOW THEY ARE RENAMED THE POINT32HEALTH FOUNDATION. YOU HEARD FROM NORA AT THE BEGINNING OF TODAY. AND I WANT US TO ACKNOWLEDGE PHILIP, WHO YOU SEE IN THE SLIDE HERE, WHO HAS BEEN A REALLY CLOSE PARTNER AS OUR PROGRAM HAS EVOLVED. AND I ALSO WANT TO ACKNOWLEDGE WHERE I WORK FOR

PROVIDING ENORMOUS RESOURCES TO PROVIDE THIS WORK. YOU HAVE TO FIND WHERE THE RESOURCES COME FROM, THAT'S THE REALITY. BUT YOU ALSO HAVE TO BUILD INTO THE REQUEST ALL PIECES THAT ARE SO CRITICAL AND SOMETIMES WE DON'T PLAN FOR THEM. LET'S DIG IN TO EACH OF THE TYPES OF RESOURCES.

REGARDING MATERIALS. IT IS EXPENSIVE TO TRANSLATE THINGS. AND SO, WHAT WE REALIZED OVER TIME IS WE NEEDED TO DEFINE A CORE SET OF MATERIALS. THEN GET THOSE TRANSLATED PROFESSIONALLY. IT CAN BE HARD TO TRANSLATE THINGS THAT HAVE TO DO WITH DEMENTIA, AS WE DISCUSSED? LANGUAGES REALLY DON'T HAVE TERMS TO EXPLAIN DEMENTIA. WE WORKED WITH ONE PROFESSIONAL TRANSLATION SERVICES, THEY HAVE MEDICAL INTERPRETERS, AND BY WORKING WITH THEM AGAIN AND AGAIN, I THINK IT HELPED US TO GET THE KIND OF TRANSLATIONS THAT WE NEED. WE ALSO HAD TO REALLY PICK AND CHOOSE WHAT WE WOULD BE ABLE TO AFFORD TO TRANSLATE. WE IDENTIFIED A SET OF SIX MATERIALS, WHICH YOU SEE ON SCREEN HERE. THE PARTICIPANT WORKBOOK, THE VERSION OF THAT IN A POWERPOINT FOR VIRTUAL PRESENTATIONS. THE CHAMPION GUIDE, WHICH HAS A SCRIPT. CHAMPIONS CAN USE WHEN PRESENTING. THE FEEDBACK FORM THAT PARTICIPANTS AT THE WORKSHOPS WILL USING. THE FLYER THAT CHAMPIONS CAN USE TO PROMOTE THEIR SESSION. AND THEN THE SIGN, WE ARE DEMENTIA FRIENDS. THOSE WERE THE MATERIALS WE TRANSLATED. THERE WERE OTHER THINGS WE DIDN'T TRANSLATE BECAUSE THEY WERE NOT CRITICAL AND WE COULDN'T AFFORD IT. YOU HAVE TO REALLY IDENTIFY WHAT IS MOST IMPORTANT. AND THEN ROAD TEST THE MATERIALS. YOU WANT TO TRANSLATE THEM AND THEN HAVE YOUR PARTNERS TRY THEM AND THEN MAKE CHANGES, IF NEEDED. SOME CASES, WE DID NEED TO CORRECT LANGUAGE. WEBSITES ARE LESS CRITICAL BECAUSE PEOPLE CAN AUTO-TRANSLATE THOSE WHEREAS WRITTEN MATERIALS, THEY CANNOT. AND MATERIALS ARE NECESSARY, BUT NOT SUFFICIENT. SO, THIS IS GOING TO BE THE THEME THAT I KEEP COMING BACK TO. TRUSTED COMMUNITY MEMBERS ARE THE MOST ESSENTIAL. AND FAIR COMPENSATION IS NECESSARY. EVEN THOUGH FOR THE MOST PART, IT IS A VOLUNTEER-BASED MODEL, WE WANT TO COMPENSATE PEOPLE WHO WE WERE ASKING TO DO MORE. WE WERE ASKING THEM TO WORK WITH DEMENTIA FRIENDS IN A DIFFERENT LANGUAGE, WE WERE ASKING THEM TO TEST THE MATERIALS GO GIVE US FEEDBACK, WE WERE ASKING THEM TO BASICALLY BUILD A NETWORK IN THEIR COMMUNITY WHERE THERE WAS NO EXISTING NETWORK. AND THEN TO SHARE WHAT THEY LEARNED ON PROGRAMS LIKE THIS TODAY.

WE HAD TO REALLY FIGURE OUT WHAT WAS FAIR COMPENSATION FOR ALL

OF THE WORK. TO THINK ABOUT WHAT ARE THE KEY QUALIFICATIONS FOR PEOPLE THAT SERVE IN THE ROLE. IT IS IMPORTANT TO THINK HARD ABOUT THAT. WHAT WAS MOST IMPORTANT IS A TRUSTED ROLE IN THE COMMUNITY. THE ABILITY TO ENGAGE COMMUNITY MEMBERS AND FACILITATE SESSIONS. IN AN INTEREST IN SPREADING AWARENESS ABOUT DEMENTIA. WHAT WAS NOT NECESSARY WAS PRIOR EXTENSIVE KNOWLEDGE ABOUT DEMENTIA BECAUSE THAT COULD BE TAUGHT. SPECIFIC DEGREES OR CERTIFICATIONS. NOW INTERPRETATION IS THE THIRD RESOURCE I MENTIONED. SO, THINK THROUGH A SUSTAINABLE PATHWAY FOR PEOPLE TO PARTICIPATE. WHOSE FIRST LANGUAGE IS NOT ENGLISH. I AM THE ONLY MASTER TRAINER IN MASSACHUSETTS SO FAR. I ONLY AM FLUENT IN ENGLISH. THAT MEANS CHAMPIONS EITHER HAVE TO SPEAK ENGLISH OR HAVE THE SUPPORT OF A BILINGUAL COMMUNITY PARTNER CHAMPION. AND WE HAVE DONE SOME INTERPRETIVE TRAININGS. REMEMBER THOSE TAKE LONGER, THEY DON'T JUST HAVE THE COST OF THE INTERPRETER, BUT YOU NEED TO ALLOCATE EXTRA TIME. AND ONE POINT I WANT TO MAKE, DO NOT ASK YOUR PARTNERS TO PROVIDE INTERPRETATION OR TRANSLATION FREE OF CHARGE. OUR INTERPRETERS HAVE DONE SOME OF THAT WORK. FOR EXAMPLE, KUN AND HIS TEAM AT GREATER BOSTON CHINESE GOLDEN AGE CENTER, THEY DID THE WRITTEN TRANSLATION OF THE MATERIALS, THAT WAS WONDERFUL BECAUSE THEY KNEW THE PROGRAM. IT WAS PERFECT. BUT THEY WERE PAID FOR THAT. IT IS TEMPTING TO ASK PARTNERS, IT IS FINE IF IT IS SOMETHING SHORT HERE AND THERE, BUT REMEMBER THIS IS TIME-CONSUMING SKILLED WORK AND NEEDS TO BE COMPENSATED FAIRLY. AND THEN THE THIRD R IS RELATIONSHIPS. SO, HOPEFULLY WHEN THE OTHER TWO RS IN PLACE, THIS IS SOMETHING THAT WILL GROW ORGANICALLY. IT DOES REQUIRE SOME INTENTION. DO YOUR HOMEWORK TO LEARN ABOUT THE COMMUNITY PRIORITIES AND WHAT THE BARRIERS ARE TO TRUST THAT MAY BE LONGSTANDING, IN SOME CASES. AVOID THE LAST-MINUTE ASK. OFTENTIMES IN THE NONPROFIT WORLD, WE DO THIS. WE ARE UNDER A LOT OF TIME PRESSURE AND WE MAY APPROACH SOMEONE AND SAY... I HAVE A GRANT PROPOSAL DUE ON MONDAY, I WOULD LIKE YOU TO BE PART OF IT, YOU HAVE TO TELL ME BY TOMORROW. THAT DOESN'T HELP TO BUILD RELATIONSHIPS. IT IS MUCH BETTER TO BUILD RELATIONSHIPS OVER TIME, EVEN WHEN YOU DON'T KNOW YET WHEN YOU ARE GOING TO HAVE A GRANT PROPOSAL OR BE LOOKING FOR FUNDING. YOU NEED TO DO THAT GROUNDWORK IN ADVANCE SO YOU DON'T COME TO PEOPLE AT THE LAST MINUTE. AND SUPPORT COMMUNITY PARTNERS OWN INITIATIVES. THAT'S A GREAT WAY TO GET TO KNOW PEOPLE AND LEARN ABOUT THEIR COMMUNITY. PROVIDE STRUCTURES FOR OPEN COMMUNICATION. FOR US, WE

HAVE A ZOOM MEETING EVERY OTHER MONTH. AND IT IS IMPORTANT THAT WHEN YOU GET ADVICE AND REQUESTS, YOU RESPOND. SO PEOPLE WILL KEEP THOSE COMING. EXPECT EACH COMMUNITY TO HAVE UNIQUE NEEDS, BE FLEXIBLE. THIS IS A TOUGH ONE BECAUSE IT DOES TAKE A LOT OF TIME ON THE ADMINISTRATIVE END. WE HAVE NINE COMMUNITY PARTNERS WHO ARE WORK -- WE ARE WORKING WITH AND NINE DISTINCT CONTRACTS. THEY ARE ALL DIFFERENT BECAUSE NEEDS AND RESOURCES OF EACH PARTNER ARE DIFFERENT, BUT IT IS WORTH SPENDING THAT TIME. IF WE DIDN'T DO THAT, WE WOULDN'T BE ABLE TO WORK WITH SO MANY PARTNERS. YOU SEE A PICTURE FROM OUR ZOOM. RELATIONSHIPS REALLY ALLOW LEARNING. DIFFERENT PERSPECTIVES ON SELF-ADVOCACY, FOR EXAMPLE. WE HAD A REALLY PRODUCTIVE CONVERSATION ABOUT THE ROLE OF ADVOCACY AND THAT FOR SOME COMMUNITIES, THAT FEELS LIKE A REALLY NATURAL FIT TO ENCOURAGE PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY MEMBERS TO TELL THEIR STORY PUBLICLY. IN OTHER COMMUNITIES, THAT REALLY DOESN'T FIT COMMUNITY PATTERNS OR VALUES, BUT WHAT EVERY COMMUNITY NEEDS, IT BEING ABLE TO TALK OPENLY ENOUGH TO BE ABLE TO SEEK INFORMATION AND GET SUPPORT. THE PERSPECTIVE AND NEEDS OF SERVICE PROVIDERS NEED TO BE CONSIDERED. SO OUR PARTNER, KATHY SERVICE AND BONNIE, WHO WORK WITH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES HAVE REALLY MADE US AWARE THAT IT IS SO IMPORTANT TO UNDERSTAND THE CONDITIONS THAT THE WORK IS BEING DONE IN IF WE'RE GOING TO BE ABLE TO DO THE EDUCATION. AND TRUST AND TRAUMA. SO IN 2019-2021, ONE OF OUR PARTNERS WORKED WITH RUSSIAN-SPEAKING COMMUNITIES THAT WERE MOSTLY JEWISH IMMIGRANTS FROM THE FORMER SOVIET UNION. THEY MADE US AWARE THAT TALKING ABOUT DISABILITY WAS VERY DIFFICULT BECAUSE OF TRAUMA EXPERIENCED BY THAT COMMUNITY. AND THE STIGMA OF DISABILITY FROM THE CONTEXT THEY HAD EMIGRATED FROM. AND THAT WAS VERY IMPORTANT BECAUSE IT TOOK A LOT LONGER TO BUILD THE TRUST IN ORDER TO HAVE PEOPLE PARTICIPATE. AND FINALLY, THE VERY LAST R IS ROAD. SO HOW ARE WE DOING AND WHERE DO WE GO FROM HERE? IN THE PAST 14 MONTHS, COMMUNITY PARTNERS HAVE LED 65 OF THE INFORMATION SESSIONS IN THEIR COMMUNITIES. YIELDING OVER 1,200 DEMENTIA FRIENDS. IF YOU PUT THAT IN CONTEXT NOW BETWEEN 23 AND 24% OF OUR NEW DEMENTIA FRIEND PARTICIPANTS ARE IN ONE OF THE FOCAL COMMUNITIES. THIS REALLY MATCHES MASSACHUSETTS DEMOGRAPHICS MUCH BETTER THAN WHEN WE STARTED. HERE'S THE QUESTION, ARE WE THERE YET? AND THE ANSWER IS -- NOPE. THIS PROCESS IS ONGOING. THAT'S WHY I LIKE TO THINK OF IT AS A ROAD. WE ARE ALWAYS LEARNING AND

TRYING TO BECOME MORE INCLUSIVE. WE ARE ADAPTING BASED ON WHAT COMMUNITY PARTNERS AND JF&CS HAVE TO OFFER. I HAD SPOKEN LAST WEEK WITH THE DIRECTOR OF THE LGBTQ+ AGING PROJECT HERE IN BOSTON AND AN AMAZING RESOURCE ON YOUR RESOURCE LIST, WE HAVE BEEN TRYING TO DO DEMENTIA FRIENDS WORK TOGETHER FOR A WHILE. THERE HAS NOT BEEN THE RIGHT MOMENT WHERE EITHER THEIR RESOURCES OR OUR RESOURCES LINED UP. WE'LL GET THERE, IT IS JUST A QUESTION OF CONTINUING ON THAT ROAD. THAT'S JUST ONE EXAMPLE. AND THIS IS A LOT OF WORK. I THINK YOU CAN HEAR THAT FROM WHAT I'M SAYING AND THERE ARE SO SHORTCUTS. THERE IS NOTHING BETTER THAN MUTUAL LEARNING AND KNOWING THAT THE RIGHT PEOPLE ARE AT THE TABLE TO MAKE REAL PROGRESS. SO, I FEEL THAT WE AS DEMENTIA FRIENDS MASSACHUSETTS ARE MAKING REAL PROGRESS AND THAT IS WHAT IT IS ALL ABOUT. I WANT TO GIVE THE LAST WORD TO SOME COMMENTS FROM OUR PARTNERS AND PARTICIPANTS TO SOME QUOTES. I REALLY LIKE SHARING MY NEW KNOWLEDGE WITH MY COMMUNITY. I KNOW A LOT OF PEOPLE WERE SCARED AND IT MAKES ME FEEL GOOD I CAN HOSPITAL GIVE MORE INFORMATION DID GUIDE THEM. THAT'S A COMMENT FROM COMMUNITY PARTNERS. AND FROM ONE OF THE PARTICIPANTS IN THE CHINESE COMMUNITY. I WILL SPEND MORE TIME TO COMMUNICATE PATIENTLY WITH SOMEONE WHO HAS DEMENTIA AND UNDERSTAND THEIR FEELINGS. AND FROM A PARTICIPANT WHO SPEAKS PORTUGUESE, I FEEL INSPIRED TO CONTINUE SHARING THESE EXPERIENCES WITH OTHER PEOPLE TO REDUCE THE STIGMA. AND SO THAT'S WHAT IT IS ALL ABOUT. THAT'S WHAT WE'RE HERE TO DO AND I'M GRATEFUL TO OUR PARTNERS FOR MAKING THIS POSSIBLE. SO, WITH THAT, IT IS TIME TO BRING YOU INTO THIS CONVERSATION. I'M GOING TO STOP SHARING MY SCREEN. AND WE'RE JUST GOING TO HAVE AN OPEN FORUM FOR 20 MINUTES. PLEASE CONTINUE TO SUBMIT YOUR QUESTIONS AND COMMENTS. WE'LL GET TO AS MANY AS POSSIBLE. WE HAVE STILL 375 PEOPLE ON ZOOM. SO, IT IS EASIEST IF YOU COMMUNICATE WITH US THROUGH THE CHAT. IF YOU DO WANT TO SAY YOUR QUESTION OR COMMENT OUT LOUD, YOU CAN USE THE RAISE HAND FUNCTION IN ZOOM. IF POSSIBLE, WE'LL CALL ON YOU. I WANT TO ASK MY WONDERFUL COLLEAGUE, MARGIE, WHO IS MONITORING THE CHAT, IF SHE HAS A QUESTION OR COMMENT PREPARED FOR US TO START?

>> I THINK YOU NEED TO MAKE HER A COHOST AGAIN.

>> IT WORKS. START WITH SIMPLE QUESTIONS. SOMEONE ASKED HOW TO BECOME A DEMENTIA FRIEND?

>> DEMENTIA FRIENDS IS A GLOBAL PROGRAM. WE HERE IN MASSACHUSETTS ARE PART OF DEMENTIA FRIENDS USA. THE LINKS ARE IN THE

RESOURCE LIST. MANY STATES AND TERRITORIES IN THE UNITED STATES HAVE A DEMENTIA FRIEND PROGRAM. IF POSSIBLE, THE BEST THING IS TO REACH OUT TO THAT ORGANIZATION AND THEY WILL GUIDE YOU. ALSO, I'M HAPPY TO FOLLOW UP WITH YOU AFTERWARDS. IF YOU WANT TO PUT IN THE CHAT WHERE YOU ARE LOCATED, I WILL FOLLOW UP WITH YOU LATER THIS WEEK AND FIND THE RIGHT LINK FOR YOU. IF YOU WANT, BY THE WAY, THOSE WHO ARE WATCHING, IF YOU WANT TO PUT YOUR VIEW AS SPEAKER VIEW, FEEL FREE. AS DIFFERENT PEOPLE SPEAK, THEY WILL APPEAR LARGER ON YOUR SCREEN. WE WON'T DO THE SPOTLIGHTS RIGHT NOW. WE'LL LET PEOPLE APPEAR ON THE SCREEN AS THEY SPEAK. THANK YOU, MARGIE. WHAT IS THE NEXT QUESTION.

>> I THINK THIS IS A REALLY IMPORTANT QUESTION. DEMENTIA FRIENDS AND CHAMPION WORK MAY ENCOUNTER SITUATIONS WHEN THERE ARE THINGS THEY SAY OR TEACH CAN BE CONSTRUED AS HEALTHCARE ADVICE AND GUIDANCE. HOW DO WE KEEP FROM RUNNING INTO TROUBLE WITH THIS? HOW DOES DEMENTIA FRIENDS MANAGE RELATED LIABILITY RISKS?

>> THANK YOU. I'M NOT AWARE THAT ANY DEMENTIA FRIEND PROGRAM HAS HAD AN ISSUE, A LEGAL ISSUE, IN TERMS OF LIABILITY. I THINK WE HAVE A GREAT RESPONSIBILITY TO MAKE SURE WE ARE PROVIDING ACCURATE INFORMATION AND GOOD GUIDANCE. SO, IT IS HARD TO DO THIS BECAUSE WE ARE TRAINING COMMUNITY MEMBERS TO LEAD THE SESSIONS. SOME OF THEM HAVE A LOT OF EXPERIENCE, PROFESSIONALLY AND/OR PERSONALLY, BUT SOME OF THEM DON'T. WE DO HAVE A SCRIPT THEY CAN USE. WE ALSO ASK TO REFER THEIR PARTICIPANTS TO THE ALZHEIMER'S ASSOCIATION HELPLINE OR THE NATIONAL ASIAN PACIFIC CENTER ON AGING HELPLINE IF THEY HAVE ANY QUESTIONS THAT GO BEYOND THE INFORMATION THAT IS IN THE WRITTEN MATERIALS. ANY OF THE COMMUNITY PARTNERS THAT WOULD LIKE TO COMMENT ON A SITUATION YOU'VE HAD WHEN YOU HAVE BEEN LEADING A WORKSHOP AND A QUESTION CAME UP THAT SEEMED A LITTLE BIT TOO MUCH LIKE HEALTHCARE ADVICE AND HOW DID YOU HANDLE THAT? ANYBODY WANT TO COMMENT ON THAT?

>> THIS IS BONNIE, I SAY IT IS -- THAT IS WHAT WE FEAR THE MOST. WE KNOW THE INFORMATION IS SO IMPORTANT, BUT WE HAVE TO KEEP IT AT JUST AN INFORMATION SESSION, THIS IS NOT TRAINING. WHEN A PERSON -- WE HAD SITUATIONS WHERE SOMEONE DOES WANT TO TALK ABOUT SPECIFIC INFORMATION, SPECIFIC THINGS, AND WHAT WE'LL DO IS EXPLAIN TO THEM, LET'S TALK AFTERWARDS. ONCE YOU TALK AFTERWARDS, IT IS MORE OF A PRIVATE SITUATION, WHAT YOU ARE ABLE TO DO IS GET THE PERSON TO THE RIGHT RESOURCE. WHAT WE HAVE FOUND, HOWEVER, IS WITH THE IDD POPULATION, IT

IS LESS -- IT IS MORE COMPLICATED TO MANAGE THE DISCUSSION. I THINK KATHY PROBABLY CAN COMMENT ON THAT. WHEN YOU DO THINGS IN THE IDD WORLD, YOU WILL HAVE FAR MORE COMMENTS THAN ANYWHERE ELSE. KATHY?

>> BONNIE, I AGREE WITH YOU BECAUSE IT IS COMPLICATED AND THE RESOURCES WITHIN THE IDD WORLD ARE SO SCANT FOR MANY PEOPLE. THIS IS ACROSS THE COUNTRY AND WORLDWIDE. PEOPLE ARE HUNGRY AND DESPERATE FOR INFORMATION. THAT'S SOMETHING I THINK WE ALL KIND OF WORK WITHIN. WE TRY -- I'M A NURSE PRACTITIONER, I REALIZE THAT. I JUST NEED TO GIVE PEOPLE SOME -- ASK PEOPLE QUESTIONS AND HELP THEM TO GUIDE THEM, WHERE TO SEEK HELP AND WHAT KINDS OF QUESTIONS. HELPING THEM GET INFORMED ABOUT THE QUESTION THAT ARE BENEFICIAL FOR THEM TO ASK HEALTHCARE PROVIDER. TO ME, PART OF THAT IS -- ENABLING PEOPLE, TELLING THEM, THERE ARE RESOURCES, WHERE ARE YOU, WHERE ARE PEOPLE, AND THIS IS WHAT I WOULD SUGGEST TO YOU ABOUT HOW TO PURSUE THIS. IT IS HARD WHEN YOU -- MANY OF THE PARTICIPANTS IN THE AUDIENCE ARE HEALTHCARE PROFESSIONALS. YOU NEED TO FIGURE OUT IN YOUR WORLD AND WHERE YOU LIVE HOW TO MANAGE THIS. I AGREE WITH YOU.

>> THANK YOU, BONNIE AND KATHY. I THINK, WE HAVE TALKED A LOT ABOUT THE CRITICAL ROLE OF NAVIGATION AND THOSE COORDINATION AND LINKING FUNCTIONS. I THINK DEMENTIA FRIENDS CAN BE SOMETHING LIKE THAT. THE CHAMPIONS ARE THE CRITICAL LINK BECAUSE THEY KNOW THE COMMUNITY. THEY ARE TRUSTED IN THEIR COMMUNITY, SO THEY CAN OPEN UP THE DOOR TO COMMUNICATION. THEY AREN'T GOING TO PROVIDE ALL THE INFORMATION THAT IS POSSIBLE ABOUT DEMENTIA. DEMENTIA IS SO COMPLEX AND AS SOMEONE PUT IN THE CHAT, SOMETIMES PEOPLE NEED REFERRALS AND NEED HELP FOR THEIR SPECIFIC SITUATION. THE CHAMPIONS WON'T DO THAT, BUT THEY WILL BE THE ONES TO OPEN THE DOOR, GET THE CONVERSATION STARTED AND THEN PROVIDE THE INFORMATION ABOUT THE SERVICES THAT CAN DO THE REFERRALS. THEY ARE THAT CRITICAL LINK IN THE CHAIN.

>> I HAVE ANOTHER QUESTION. I THINK IT IS A REALLY GREAT QUESTION. WE HAVE TALKED ABOUT DIFFERENT CULTURAL AND LINGUISTIC COMMUNITIES. THIS QUESTION IS, HOW DO THE VARIOUS RELIGIOUS -- I DON'T FEEL THIS HAS BEEN RAISED -- HOW DO THE VARIETY OF RELIGIOUS VIEWS IMPACT HOW DEMENTIA IS SEEN AND UNDERSTOOD IN DIFFERENT COMMUNITIES?

>> THANK YOU, MARJIE. AND THAT DOVETAILS WITH A QUESTION THAT CAME IN WITH THE REGISTRATION ABOUT BELIEF SYSTEMS, INCLUDING RELIGION. AND HOW THAT AFFECTS THE WAY PEOPLE SEE DEMENTIA. THE QUESTION IN THE

ZOOM REGISTRATION WAS, SOME RELIGIONS TEACH ACCEPTANCE OF WHAT LIFE BRINGS. AND HOW DO YOU ENCOURAGE PEOPLE TO SEEK INFORMATION AND HELP IF THAT IS NOT REALLY PART OF THEIR RELIGION AND CULTURE? I'LL SAY A COUPLE OF THINGS ABOUT THAT AND THEN LOVE TO HEAR ANY OF THE COMMUNITY PARTNERS THAT WANT TO COMMENT. I GUESS WHAT I WILL SAY, WHAT WE HAVE HEARD TODAY FROM OUR COMMUNITY PARTNERS, WE HAVE TO WORK WITH CULTURAL VALUES, NOT AGAINST THEM. SO, WHATEVER A PERSON'S BELIEF SYSTEM IS, WE HAVE TO FIND A WAY TO WORK WITH THAT. IF WE CONTRADICT IT, WE WON'T GET ANYWHERE AND WE'LL LOSE THEIR TRUST. SO IT IS POSSIBLE TO WORK WITH SOMEBODY AND TALK WITH THEM ABOUT HOW THIS IS PART OF ACCEPTING WHAT LIFE BRINGS AND A WAY OF GETTING SUPPORT, NOT FEELING ALONE, STAYING CONNECTED. THERE ARE MANY WAYS OF THINKING ABOUT SUPPORT THAT WOULDN'T CONTRADICT THE VALUES. ALSO, TO NORMALIZE GETTING SUPPORT. I WORK WITH MEMORY CAFES AND WE'RE ALWAYS TRYING TO NORMALIZE GOING TO A PROGRAM LIKE A MEMORY CAFE. THERE'S NOTHING STRANGE ABOUT IT. IT IS WONDERFUL. WE HAVE A GOOD TIME. WE HAVE PEOPLE THERE WHO ARE LIVING WITH DEMENTIA, WE HAVE PEOPLE THERE WHO AREN'T LIVING WITH DEMENTIA, WE HAVE PEOPLE OF ALL AGES. WE DON'T WANT PEOPLE TO SEE IT AS STRANGE OR EXTRAORDINARY TO SEEK INFORMATION AND SUPPORT. AS I BELIEVE BONNIE SAID BEFORE, WE DON'T HAVE TO FOCUS ON DIAGNOSTIC LABELS. WE CAN FOCUS ON THE PERSON'S LIVED EXPERIENCE AND WHAT THEY NEED. WHAT ABOUT OTHERS? DO ANY OF THE COMMUNITY PARTNERS WANT TO COMMENT ON HOW RELIGION OR BELIEF SYSTEMS MIGHT AFFECT HOW PEOPLE ARE COPING WITH DEMENTIA IN YOUR COMMUNITY AND HOW YOU WORK WITH THAT?

>> I WANT TO SAY SOMETHING, BETH. CAN YOU HEAR ME?

>> YES, GO AHEAD, JUDITH.

>> I'M CONNECTED WITH MEDICAL INSTITUTIONS IN MANY KIND OF RESEARCH IN BOSTON. HOWEVER, SPIRITUALITY IS NOT YET ON THE TABLE. MANY MEMBERS THEY DON'T WANT TO DO THE PHYSICAL ACTIVITY, THEY DON'T WANT TO CHANGE THE WAY THEY EAT. THEY DON'T HAVE THE CAPACITY TO LEARN ABOUT COMPUTER. HOWEVER, I HAVE SEEN IN THE COMMUNITY HOW CHURCH -- FOR MOST OF THEM -- IS THE UNIQUE STRENGTH OR SUPPORT FOR THEM. THAT'S THE QUESTION WE ARE TRYING TO BRING ON THE TABLE. HOW CAN WE MAKE RESEARCH, WHAT IS THE IMPACT OF SPIRITUALITY IN THE COMMUNITY FOR PEOPLE WHO LIVE WITH DEMENTIA.

>> THANK YOU, JUDITH. THAT'S SUCH A GREAT POINT. AND SOME OF YOU

ARE FAMILIAR WITH MEMORY SUNDAY, AN INITIATIVE IN THE BLACK COMMUNITY IN CHURCHES TO TALK ABOUT DEMENTIA ON THE SECOND SUNDAY IN JUNE -- EVERY YEAR. THERE'S A LINK IN YOUR RESOURCE GUIDE ABOUT THAT. I MENTIONED DEMENTIA FRIENDS MASSACHUSETTS IS WORKING IN SYNAGOGUES. I KNOW MANY COMMUNITY PARTNERS HAVE WORKED WITH CHURCHES, WITH OTHER FAITH COMMUNITIES, BECAUSE JUST AS YOU SAID, THAT'S SUCH AN IMPORTANT CENTER FOR MANY COMMUNITY MEMBERS TO FEEL TRUST. A PLACE WHERE THEY FEEL COMFORTABLE AND THEY ARE WILLING TO SEEK OUT SUPPORT AND INFORMATION. ANYONE ELSE WANT TO COMMENT ON THIS ISSUE OF RELIGION AND BELIEF SYSTEMS.

>> THIS IS BONNIE. I GUESS I WANT TO ADD THAT THIS IS AN EXTRAORDINARILY IMPORTANT TOPIC. IT IS ALSO A VERY BROAD TOPIC IN THAT IT IS NOT JUST RELIGION, THIS KIND OF THING CAN GOING TO COME UP WITH LOTS OF DIFFERENT TOPICS IN THE DEMENTIA FRIENDS PROGRAM. I THINK ONE THING THAT -- TO NOT SCARE PEOPLE AWAY -- WE REALLY LEARN WHEN WE TEACH THE CHAMPIONS TO STAY IN THEIR LANE. WE HAVE A GREAT PROGRAM, WE ONLY GOT AN HOUR. WE FIGURE OUT A WAY TO STAY WITH IT. RELIGION IS ONE THING WHERE WE'LL HAVE DIFFERENCES, BUT THERE ARE GOING TO BE MANY OTHERS AS WELL. AND IN THE CHAMPIONS GUIDE, WE REALLY DO GIVE FOLKS THE OPPORTUNITY TO SAY, IF THIS HAPPENS, YOU CAN SAY THAT. PEOPLE FEEL VERY COMFORTABLE AND CONFIDENT ONCE THEY ARE CHAMPIONS IN DEALING WITH ALL SORTS OF QUESTIONS.

>> THANK YOU, BONNIE. I APPRECIATE YOU PUTTING IT IN A BROADER FRAME. IT COMES BACK TO THE WHOLE IDEA OF FOCUSING THE LENS AT THE INDIVIDUAL LEVEL BECAUSE RELIGION, BELIEF SYSTEMS, SPIRITUALITY, IT IS VERY PERSONAL. IT IS CULTURAL, BUT ALSO PERSONAL. IN THE END, IT IS ABOUT LISTENING TO ABOUT WHAT THAT PERSON HAS TO SAY AND SHOWING RESPECT BECAUSE RESPECT IS ESSENTIAL IF THERE'S GOING TO BE ANY TEACHING IN COMMUNICATION. WE WANT TO SHARE INFORMATION, WE DON'T WANT TO TELL ANYONE WHAT TO BELIEVE. WE WANT TO PROVIDE FACTS AND RESOURCES. MARJIE, YOU WANT TO GO TO ANOTHER QUESTION?

>> I KEEP DEALING WITH THE MUTING. I THINK DARIA PUT IN THE CHAT, I THINK FAITH COMMUNITIES ARE VERY IMPORTANT VENUES TO SPREAD THE AWARENESS BECAUSE IT IS A SAFE PLACE. I'D BE CURIOUS TO HEAR IF PEOPLE WANT TO SHARE ABOUT WHAT IS GOING ON IN THEIR OWN FAITH COMMUNITIES AROUND THAT TOPIC. OR IF IT IS NOT BEING BROUGHT UP.

>> ANYBODY WANT TO RESPOND TO THAT?

>> FAITH-BASE ROOM COULD BE A GOOD WAY TO CONNECT WITH THE PEOPLE BECAUSE THEY HAVE AUDIENCE. IN THE DEMENTIA FRIENDS WORKSHOP, WE WORK TO DELIVER THE FINE MESSAGE. WE WERE NOT ABLE TO ADDRESS ALL KIND OF ISSUE WITHIN THE HOUR. AGAIN, WE WANT TO TRY TO FOCUS ON THE AGENDA. ANYTHING WE WANT TO TALK ABOUT BEYOND THAT IS SOMETIMES NOT -- JUST NOT ABLE TO DO IT. WE HAVE TO OMIT THAT. WE HAVE TO TELL THEM WE DON'T HAVE THE TIME TO DISCUSS. IF YOU WANT TO DISCUSS, WE CAN AFTER. THAT'S HOW WE HANDLE. FOR THE RELIGIONS -- WE NEVER WANTED TO CHANGE PEOPLE'S MINDSET. WE ONLY WANT TO SHARE INFORMATION. OUR GOAL IS TRY TO SHARE AND LET THEM THINK ABOUT IT FROM A DIFFERENT ANGLE. MAYBE WHAT THEY THINK, AT LEAST WE WANT TO SHARE AND IT IS OPEN MIND. NOT TALKING ABOUT RIGHT OR WRONG, TRYING TO CREATE THAT KIND OF ATMOSPHERE SO IT IS EASIER TO RUN THIS GROUP.

>> THANK YOU, KUN. I THINK THAT'S REALLY HELPFUL. YOU HAVE YOUR HAND RAISED, SHIRA. LET'S SEE -- CAN YOU HELP HER TO UNMUTE?

>> THANK YOU SO MUCH. CAN YOU HEAR ME OKAY? WE'RE GOOD.

>> YES.

>> I RECENTLY JOINED CARING AND KIND, I THINK THEY ARE DOING A REALLY GREAT JOB OF LOOKING TO FIGURE OUT HOW THEY CAN PROVIDE SUPPORT FOR DIFFERENT CULTURAL COMMUNITIES. AND I KNOW THERE ARE A FEW OF US NOW SUPPORTING THOSE IN THE JEWISH COMMUNITY AND I THINK WHAT IS NICE ABOUT WHAT WAS DESCRIBED, IT REMINDS ME OF THE STRENGTH-BASED APPROACH RECOMMENDED EARLIER. I THINK WE CAN LOOK AT THE RELIGION OR THE SENSE OF COMMUNITY AS A PLACE TO GO WHERE PEOPLE ARE COMFORTABLE OR AT EASE AND NATURALLY GOING TO REACH OUT AND SEEK SUPPORT. SO THE POSSIBILITY OF JUST FEELING MORE AT EASE AND MORE COMFORTABLE AND BEING ABLE TO FEEL LIKE THINGS ARE TAILORED. YOU TALK ABOUT TRAUMA AND SOMEONE FROM A HAUL COST EXPERIENCE WILL HAVE A DIFFERENT EXPERIENCE AND THE SENSITIVITY TO CULTURAL NUANCE IS IMPORTANT. CERTAINLY BEING DONE THROUGHOUT -- MAYBE NOT TO THE EXTENT WE'D LIKE TO SEE, BUT IT CERTAINLY IS POWER:

>> THANK YOU, I APPRECIATE YOUR COMMENT VERY MUCH AND I APPRECIATE YOU BRINGING UP THE ROLE OF TRAUMA. WHICH THERE WERE A FEW QUESTIONS ABOUT THIS AS WELL. AND THERE ARE MANY INTERCONNECTIONS BETWEEN DEMENTIA AND TRAUMA. HAVING PTSD, FOR EXAMPLE, CAN INCREASE THE PERSON'S RISK OF DEVELOPING DEMENTIA. IF A PERSON HAS EXPERIENCED TRAUMA EARLIER IN THEIR LIFE WHEN -- ESPECIALLY IF SOMEONE IS LIVING WITH

ALZHEIMER'S DISEASE. THEY MAY REVISIT THAT STAGE OF THEIR LIFE IN A VERY VIVID WAY. IT MAY BE HARDER FOR THEM TO PULL THEMSELVES OUT OF THE TRAUMA RESPONSE IF IT GETS TRIGGERED. THERE ARE MANY, MANY FACTORS. THAT'S A REALLY IMPORTANT ONE TO LOOK AT. AND I WANT TO UNDERSCORE THIS ISSUE OF TUNING INTO THE CULTURAL VALUES OR THE RELIGIOUS VALUES. THAT IS REALLY A PLACE TO START. WITHOUT DOING THAT, WE LOSE TRUST, WE'RE NOT ABLE TO FORM THE LINKAGES. WHEN WE DO HAVE THE BEST OF INTENTIONS AND YOU DO YOUR HOMEWORK AND IF YOU ARE CONNECTED TO THE COMMUNITY YOURSELF, IT TAKES TIME. AND THAT'S WHY IT IS THE RESOURCES ARE SO IMPORTANT. THE SECOND R. I THINK ALL THE COMMUNITY PARTNERS HERE WOULD AGREE. THIS IS A VERY TIME-CONSUMING PROCESS FOR THEM TO FIND ORGANIZATIONS, WHETHER THEY ARE CHURCHES OR SYNAGOGUES OR TOWN HALLS OR COMMUNITY GROUPS OR GROUPS OF FRIENDS, GROUPS OF NEIGHBORS, WHATEVER IT MAY BE, WHO ARE WILLING TO COME AND TAKE PART. IT JUST TAKES TIME TO DO THE GROUNDWORK. I KNOW IN OUR WORK WITH SYNAGOGUES, IT HAS BEEN A SLOW PROCESS BECAUSE THE CLERGY ARE DEALING WITH SO MANY ISSUES. AND THEY FEEL PRESSURE FROM ALL SIDES. IT HAS BEEN A PROCESS OF SLOWLY BUILDING THOSE RELATIONSHIPS, EMPOWERING CHAMPIONS WITHIN THAT CONGREGATION AND REALLY SUPPORTING THEM IN BEING ABLE TO BRING THE WORKSHOPS THERE.

SO DON'T BE FRUSTRATED IF AT FIRST IT DOESN'T WORK. IT IS REALLY -- IT IS THAT ROAD. THAT ONGOING ROAD. I THINK WE HAVE TIME FOR JUST ONE MORE QUESTION OR COMMENT. AND THEN WE'LL PULL THINGS TO A CLOSE. IS THERE ONE YOU WANT TO BRING TO THE FLOOR, MARJIE?

>> ONE RAISED IN A COUPLE OF WAYS IS ABOUT THE CAREGIVER, THE CARE PARTNERS, FAMILY MEMBERS, THE TOLL IT TAKES ON THEM FINANCIALLY TO REDUCE THEIR WORK OR STOP WORKING. AND ALSO JUST THE STRESS OF IT ALL. AND TEACHING THEM ABOUT HOW TO RESPOND TO HOW TO TAKE CARE OF THEMSELVES. THAT WAS A COUPLE OF QUESTIONS THAT CAME IN.

>> GREAT, THANK YOU. WOULD ANY OF THE COMMUNITY PARTNERS LIKE TO MAKE A COMMENT ABOUT HOW YOU HAVE SUPPORTED FAMILY MEMBERS IN LEARNING AND WHAT HAS BEEN HELPFUL TO THEM. ALANA, MAYBE I CAN PICK ON YOU HERE.

>> I HAVE EXPERIENCE WITH MY MOM SO IT WAS VERY HARD BECAUSE IT WAS JUST ME. I HAD TO STOP WORKING ALL THE TIME -- THE FULL-TIME JOB TO HELP HER. IN THE END, UNFORTUNATELY, I COULDN'T TAKE CARE OF HER BECAUSE IT WAS 24/7. SHE WENT INTO THE NURSING HOME. WHAT IN MY COMMUNITY

HELPS A LITTLE BIT IS WHEN WE TEACH THEM WHAT IS THE NURSING HOME, HOW THEY WILL TREAT YOUR MEMBER -- YOU KNOW. OR IF THEY REALLY DON'T WANT TO PUT THEM IN THE NURSING HOME, THEY NEED HELP. HELP OF THE FAMILY OR FRIENDS. AND I THINK OUR COMMUNITY IS HELPING EACH OTHER. WHEN THEY DON'T HAVE A BIG FAMILY HERE AND THEY NEED THE FRIENDS. IS THE ONLY WAY -- I LEARNED THAT CAN HELP THEM.

>> THANK YOU, ALANA. I APPRECIATE THAT VERY MUCH. THAT INFORMATION SO THEY CAN NAVIGATE THE MANY CHOICES THAT THEY HAVE TO MAKE AND I WILL SAY, I HAVE BEEN LEADING A SUPPORT GROUP FOR ADULTS WHO HAVE A PARENT OR PARENTS LIVING WITH DEMENTIA FOR SEVERAL YEARS. AND WHAT WE HEAR EVERY YEAR AS FEEDBACK FROM OUR PARTICIPANTS THAT THEY VALUE MOST IS JUST KNOWING THAT THEY ARE NOT ALONE. SO, I THINK BREAKING THE SILENCE SO THAT PEOPLE CAN SPEAK TO ONE ANOTHER SO THEY CAN TALK OPENLY ABOUT DEMENTIA, IT HELPS PEOPLE FEEL LESS ALONE, EVEN WHEN THERE ISN'T A LOT OF -- THERE ISN'T A GREAT ANSWER TO WHAT THEY NEED. IT STILL HELPS TO HAVE THAT SUPPORT. I SAW NIA'S HAND GO UP AND I'D LOVE TO GIVE YOU THE LAST WORD AND THEN WE'LL HAVE TO WRAP UP FOR TODAY. YOU WANT TO UNMUTE YOURSELF, NIA?

>> WELL, I DON'T KNOW IF I DESERVE THE LAST WORD... MY CHALLENGE IS A LITTLE BIT UNIQUE BECAUSE I DON'T HAVE A CAREGIVER. BUT MY SON STILL FEELS THE STRESS OF HAVING TO CHECK ON ME, TAKE ME TO APPOINTMENTS, IF NEED BE. MAKE SURE THAT I'M EATING CORRECTLY. MAKE SURE I'M WORKING OUT. WE HAD TO HIRE A HOUSEKEEPER AND WE DO PREPARED MEALS. SO, WE HAD TO LEAN ON AT MY NEIGHBORS FOR HELP AND OTHER PEOPLE AS WELL. SO, IT IS A UNIQUE STRESS NOT HAVING THE CAREGIVER AS WELL.

>> YES, THANK YOU SO MUCH FOR RAISING THAT ISSUE. AND THAT IS TRUE FOR MORE AND MORE PEOPLE AS WE GET OLDER. AND IT IS TRUE MORE IN SOME COMMUNITIES THAN OTHERS. FOR EXAMPLE, A LOT OF RESEARCH HAS SHOWN THAT LGBTQ+ COMMUNITY, PEOPLE ARE MORE LIKELY TO BE ON THEIR OWN AS THEY GET OLDER. AND SO, THESE ARE ALL IMPORTANT THEMES. HOW DO WE SUPPORT FAMILY MEMBERS AND HOW DO WE SUPPORT INDIVIDUALS WHO DON'T HAVE A FAMILY MEMBER WHO IS REALLY ACTING AS A CAREGIVER FOR THEM. AND I THINK, AGAIN, A GOOD STARTING PLACE IS ALWAYS INFORMATION, CONVERSATION, COMMUNICATION, SO PEOPLE DON'T FEEL ALONE. AND NIA, I JUST LOVE THAT YOU ARE SHARING YOUR STORY WITH US AND THAT YOU ARE JUST TALKING ABOUT THE CONVERSATIONS YOU AND YOUR SON HAVE TO PROBLEM SOLVE. AND I THINK THAT'S WHAT WE WANT TO VIEW AS OUR GOAL, GET TO THE

POINT WHERE WE CAN TALK OPENLY ABOUT DEMENTIA SO WE CAN REALLY PROBLEM SOLVE WITH ONE ANOTHER. SOME OF THE PROBLEMS WE CAN SOLVE AS INDIVIDUALS OR AS A FAMILY, SOME OF THEM, WE NEED TO JOIN HANDS AS NEIGHBORS, AS FAITH COMMUNITIES, AS ORGANIZATIONS, AS GOVERNMENTS, AS A WHOLE NATION, AS A WORLD. BUT TO DO ANY OF THAT, WE HAVE TO START WITH COMMUNICATION. SO, ON THAT NOTE, I WANT TO THANK ALL OF OUR SPEAKERS TODAY, EVERYONE WHO HELPED, I WANT TO THANK OUR INTERPRETERS AND CAPTIONER. I HAVE GOT TO SAY, THIS WAS A HARD MEETING TO INTERPRET AND TO CAPTION AND WE ARE GRATEFUL TO YOU. I WANT TO THANK EACH AND EVERY ONE OF YOU FOR BEING HERE AND BEING PART OF THE CONVERSATION. YOU WILL RECEIVE AN EVALUATION BY EMAIL. PLEASE FILL THAT OUT, GIVE US YOUR FEEDBACK, IF YOU DID PURCHASE CEUs, YOU ARE REQUIRED TO FILL IT OUT, BUT WE'D LOVE FEEDBACK FROM ALL OF YOU. IN A COUPLE OF WEEKS YOU WILL GET LINKS WITH RECORDINGS AND OTHER RESOURCES FROM TODAY. AND CONTINUING EDUCATION CERTIFICATES SHOULD BE OUT TO YOU WITHIN 2-3 WEEKS. THANK YOU ALL VERY MUCH. BE WELL, TAKE CARE, AND KEEP THE CONVERSATION GOING. THANKS EVERYBODY.