Transcript provided by CART (Communication Access Realtime Translation) provider, "Let's Talk about Dementia and Culture" symposium on November 10, 2020

Please forgive any typos.

BETH SOLTZBERG: WELCOME, EVERYBODY, IF YOU ARE JUST JOINING US.

WE'LL GET STARTED IN ABOUT TEN MINUTES.

WE'RE JUST WATCHING SOME PICTURES FROM COMMUNITY SESSIONS THAT HAVE BEEN TAKING PLACE OVER THE LAST YEAR AND A HALF.

BETH SOLTZBERG: TERRY, I WILL ADD YOU AGAIN NOW.

TERRY: SURE, THANK YOU.

BETH SOLTZBERG: IT SHOULD BE CHINESE.

THAT'S WHAT IT SAYS FOR ME.

DOES IT SAY THAT FOR YOU?

BETH SOLTZBERG: WELCOME IF YOU ARE JUST JOINING US.

I WILL TRY SHARING SOME AUDIO NOW.

(INSTRUMENTAL MUSIC PLAYING)

BETH SOLTZBERG: WELCOME, IF YOU ARE JUST JOINING OF WE'LL GET STARTED IN ABOUT

FIVE MINUTES.

BETH SOLTZBERG: GOOD TO SEE EVERYBODY.

BETH SOLTZBERG: WELCOME, EVERYBODY.
WE'RE ASKING EVERYBODY TO KEEP

THEMSELVES ON MUTE.

IF YOU HAVE ANY QUESTIONS, PLEASE FEEL FREE TO SEND A MESSAGE THROUGH THE CHAT BOX.

WE HAVE ONE.

BETH SOLTZBERG: I AM TURNING THE MUSIC DOWN.

I APPRECIATE THAT FEEDBACK.

STILL TOO LOUD?

OKAY.

I WILL TURN OFF THE MUSIC FOR NOW.

WE'LL HAVE MORE MUSIC A LITTLE BIT LATER, I PROMISE, DURING THE BREAK.

SO, I'M JUST GOING TO GIVE IT ANOTHER MINUTE FOR FOLKS TO JOIN.

MEANWHILE, YOU CAN LOOK AT SOME PHOTOS THAT WE HAVE FROM THE COMMUNITY DEMENTIA EDUCATION SESSIONS THAT HAVE BEEN GOING FOR THE PAST YEAR AND A HALF OR SO.

WELCOME, EVERYBODY.

JUST GOING TO GIVE IT ANOTHER HALF A MINUTE FOR FOLKS TO JOIN.

WELCOME, WELCOME.

WE'LL START IN JUST A MINUTE.

WE HAD OVER 900 PEOPLE REGISTER FOR THIS MEETING, SO I KNOW THAT WE'RE GOING TO

HAVE A FLURRY OF PEOPLE JOINING.

I JUST WANT TO GIVE IT ONE MORE MINUTE.

I SEE NUMBERS CLIMBING UP HERE, JUST LET EVERYBODY JOIN AND GET SETTLED, AND THEN WE'LL START.

IF I COULD ASK EVERYONE WHO IS ON THE MEETING TO PLEASE KEEP YOURSELF ON MUTE, THAT WOULD BE GREAT.

IF YOU HAVE ANY QUESTIONS, JUST FEEL FREE TO PUT THEM IN THE CHAT BOX.

THANK YOU SO MUCH.

SO, I WILL TALK ABOUT CONTINUING EDUCATION UNITS IN JUST A MINUTE.

I SAW A QUESTION ABOUT THAT.

WE'RE GOING TO GO OVER THAT.

ALL RIGHT.

SO, WELCOME.

I'M GOING TO GO AHEAD AND PULL UP MY OTHER SLIDES.

I'D LIKE TO CORDIALLY WELCOME YOU ALL TO TODAY'S SYMPOSIUM, LET'S TALK ABOUT DEMENTIA AND CULTURE.

HOW WE TALK AND TEACH ABOUT DEMENTIA IN CULTURAL AND LINGUISTIC COMMUNITIES.

OF COURSE, EVERY SINGLE ONE OF US IS IN

CULTURAL AND LINGUISTIC COMMUNITIES BECAUSE WE ALL COME FROM SOME SPECIFIC PLACE, SOME SPECIFIC CULTURE, OR CULTURES, SOME SPECIFIC LANGUAGE OR LANGUAGES.

IT'S A VALUABLE THING TO SPEND SOME TIME REALLY DIGGING INTO WHAT THAT MEANS FOR DEMENTIA AWARENESS AND EDUCATION.

SO, I WANT TO THANK YOU SO MUCH FOR BEING HERE TODAY.

MY NAME IS BETH SOLTZBERG AND I AM THE DIRECTOR OF THE ALZHEIMER'S AND RELATED DISORDERS FAMILY SUPPORT PROGRAM AT JEWISH FAMILY AND CHILDREN SERVICE IN WALTHAM, MASSACHUSETTS AND ALSO THE LEAD FOR THE DEMENTIA FRIENDS PROGRAM IN MASSACHUSETTS.

I'VE HAD THE PRIVILEGE OF WORKING HERE AT JFCS FOR ALMOST 8 YEARS, AND I FEEL SO GRATEFUL TO JFCS FOR HAVING BEEN WILLING TO TAKE THE LEAD ON THE DEMENTIA FRIENDS PROGRAM FOR MASSACHUSETTS AND FOR SUPPORTING THE PROJECT THAT WE'RE GOING TO BE TALKING ABOUT TODAY.

MANY OF MY WONDERFUL COLLEAGUES ARE HERE IN THE MEETING WITH ME HELPING WITH THIS TECHNOLOGY, HELPING TO MAKE THINGS RUN

SMOOTHLY, AND I AM BEYOND GRATEFUL FOR YOU ALL.

SO, I WANT TO TAKE A MOMENT NOW AND TELL YOU HOW YOU CAN ACCESS CAPTIONS AND ALSO LANGUAGE INTERPRETATION DURING TODAY'S MEETING.

SO, IF YOU WOULD LIKE CAPTIONS IN ENGLISH, THEN WHAT YOU WOULD DO IS MOVE YOUR CURSOR DOWN TOWARD THE BOTTOM PART OF YOUR ZOOM SCREEN AND CLICK ON THE LITTLE ICON WITH TWO C'S NEXT TO EACH OTHER.

CC.

THEN, YOU CAN CHOOSE TO SHOW THE SUBTITLES AT THE BOTTOM OF YOUR SCREEN.

THERE IS ALSO AN OPTION THERE THAT SAYS SUBTITLE SETTINGS, AND SO IF YOU WOULD LIKE TO CHANGE THE SIZE OF THE FOT OR FONT YOU CAN CLICK ON SUBTITLE SETTINGS AND ALTER HOW THAT LOOKS FOR YOU.

I WILL ASK MARJI TO PUT A URL IN THE CHAT SO IF ANYBODY WOULD LIKE TO LOOK AT THE FULL TRANSCRIPT YOU CAN GO TO THE WEB PAGE THAT MARJI PUT IN THE CHAT AND THAT WAY YOU SEE THE INTERPRETATION LARGE, BUT YOU WON'T BE ABLE TO SEE THE SLIDES AT THE SAME TIME.

THANKS, MARJI.

SO, WE ALSO HAVE LANGUAGE INTERPRETATION DURING THIS MEETING IN MANDARIN, PORTUGUESE, AND IF YOU WOULD LIKE TO LISTEN TO THE MEETING IN MANDARIN, PORTUGUESE, OR SPANISH WHAT YOU WOULD DO IS GO TO THE BOTTOM OF YOUR SCREEN CLICK ON THE SCREEN WHERE IT SAYS INTERPRETATION, THEN CHOOSE THE LANGUAGE.

I WILL ASK OUR INTERPRETERS TO—I WILL ASK OUR INTERPRETERS TO GO AHEAD AND EXPLAIN HOW TO ACCESS INTERPRETATION, SO STEPHANIE, CAN I ASK YOU TO GO FIRST?

I CAN'T HEAR STEPHANIE.

CAN PEOPLE HEAR STEPHANIE?

NO?

SO, LET ME EXPLAIN AGAIN, YOU JUST CLICK ON THE ICON THAT LOOKS LIKE A LITTLE GLOBE HERE, AND THEN YOU WOULD CHOOSE YOUR LANGUAGE, MANDARIN, PORTUGUESE, OR SPANISH, AND YOU SHOULD BE ABLE TO HEAR FROM THERE.

SPEAKER: I CAN SAY IT IN SPANISH IF YOU LIKE?

BETH SOLTZBERG: THAT'S OKAY.

I THINK WE'RE ALL READY.

I THINK PEOPLE PROBABLY HAVE FIGURED IT OUT.

THANK YOU VERY MUCH.

OKAY.

SO, THESE ARE THE LANGUAGES, SO SPANISH, PORTUGUESE AND MANDARIN ARE THE LANGUAGES REQUESTED FOR THIS MEETING.

WE ALSO HAVE DEMENTIA FRIENDS MATERIALS IN RUSSIAN, VIETNAMESE AND HAITIAN CREOLE, AND WE HOPE TO ADD MORE LANGUAGES OVER TIME.

I KNOW THERE ARE PEOPLE FROM MANY DEMENTIA FRIENDS PROGRAMS AROUND THE COUNTRY ON THE LINE WITH US WHO HAVE ALSO DEVELOPED OR ARE IN THE PROCESS OF DEVELOPING DEMENTIA FRIENDS IN OTHER LANGUAGES, WHICH IS WONDERFUL THAT THAT IS TAKING PLACE.

SO, I WANTED TO SAY A FEW THANK YOU TO TUFTS HEALTH PLAN FOUNDATION AND OH FOR SUPPORT FOR THIS PROJECT AND OUR WORK.

I WANT TO THANK DEMENTIA FRIENDS U.S.A. AND GLOBAL DEMENTIA FRIENDS, THE ALZHEIMER'S ASSOCIATION, MASSACHUSETTS NEW HAMPSHIRE CHAPTER FOR THEIR PARTNERSHIP.

I WANT TO GIVE A BIG THANK YOU TO OUR SPEAKERS AND ALSO TO AMY WALSH, MARJI SOKOLL AND JONATHAN JACKSON FOR REALLY HELPFUL ASSISTANCE WITH THE DESIGN OF THE PROJECT AND THIS EVENT.

THANK YOU TO OUR INTERPRETERS AND CAPTION PROVIDER, AND FINALLY THANK YOU ALL FOR BEING HERE AND MAKING THE TIME TO BE PART OF THIS CONVERSATION TODAY.

SO, A LITTLE BIT OF HOUSEKEEPING.

THIS MEETING IS BEING RECORDED.

IT IS POSSIBLE THAT AUDIENCE MEMBERS WILL APPEAR IN THE RECORDING.

IT'S A VERY LARGE MEETING, SO CHANCES ARE YOU WILL NOT APPEAR ON THE RECORDING, BUT IF YOU ARE CONCERNED ABOUT THAT YOU CAN FEEL FREE TO TURN OFF YOUR CAMERA OR CHANGE YOUR SCREEN NAME IF YOU WOULD LIKE.

WE LOVE TO SEE YOUR VIDEO, SO IF YOU FEEL COMFORTABLE PLEASE FEEL FREE TO LEAVE YOUR CAMERA ON.

IF I CAN ASK EVERYONE TO PLEASE KEEP YOURSELF ON MUTE BECAUSE OF THE NUMBER OF PEOPLE THAT WE HAVE HERE IT'S VERY IMPORTANT THAT EVERYONE STAY ON MUTE, SO WE DON'T GET A

LOT OF BACKGROUND SOUND.

SO, IF YOU HAVE QUESTIONS OR COMMENTS AT ANY POINT, PLEASE TYPE THOSE INTO THE CHAT BOX AND MY WONDERFUL COLLEAGUES MAURA MOXLEY, MARJI SOKOLL AND ANN MUSKOPF ARE MONITORING THE CHAT AND WILL HELP US DURING THE Q AND A PERIOD SO WE GET TO AS MANY OF YOUR COMMENTS AND QUESTIONS AS POSSIBLE.

IF YOU ARE HAVING TECHNICAL DIFFICULTIES WITH THE MEETING, PLEASE TYPE YOUR, PUT IN YOUR CHAT QUESTIONS TO ASK TECH HELP.

THAT'S RIGHT UP AT THE TOP OF THE LIST IF YOU GO INTO CHAT, AND ANOTHER WONDERFUL COLLEAGUE WILL DO HER BEST TO HELP YOU OUT.

I WANTED TO LET YOU KNOW THAT THE RECORDINGS AND THE SLIDES ARE GOING TO BE AVAILABLE AFTER THIS MEETING.

WE'RE RECORDINGS THE MEETING IN ALL FOUR LANGUAGES, AND I WILL ALSO BE POSTING THE MEETING TRANSCRIPT AND THE RESOURCE LIST.

HOPEFULLY, MOST OF YOU RECEIVED THE RESOURCE LIST FROM ME IN THE LAST DAY.

IF YOU JUST REGISTERED FOR THE MEETING IN THE LAST HOUR AND A HALF YOU WOULDN'T HAVE

GOTTEN IT, BUT I WILL UPDATE IT WITH ANY SUGGESTIONS THAT YOU MIGHT WANT TO ADD, AND THEN I WILL POST THAT AFTER THE MEETING WITH THE LINK.

IT WILL PROBABLY TAKE ABOUT A WEEK TO GET THAT ALL SET.

SO, FEEL FREE TO SEND ME ANY ADDITIONS TO THE RESOURCE LIST BY THE CHAT FUNCTION OR BY E—MAIL.

AND, I ALSO WANTED TO LET YOU KNOW THAT CONTINUING EDUCATION CREDITS ARE AVAILABLE.

THREE CONTACT HOURS FROM BEEN APPROVED FOR SOCIAL WORKERS AND I ALSO HAVE CERTIFICATES AVAILABLE FOR NURSES AND A GENERAL CERTIFICATE FOR OTHER PROFESSIONS.

SO, TO GET CREDITS YOU NEED TO ATTEND FOR THE WHOLE MEETING, AND THEN YOU NEED TO COMPLETE ANY VALUATION FORM THAT I WILL BE E—MAILING OUT TONIGHT AFTER THE MEETING.

AND IN THAT EVALUATION, YOU CAN CHECK OFF WHAT TYPE OF CERTIFICATE YOU WOULD LIKE.

SO, LET'S TAKE A MOMENT NOW AND SEE WHO IS HERE TODAY.

I WILL DO TWO VERY QUICK POLLS JUST SO WE CAN GET AN IDEA OF WHO IS WITH US.

SO, FIRST LET'S SEE WHO IS ATTENDING FROM WHERE IN THE WORLD.

SO, I JUST LAUNCHED A POLL THAT SHOULD APPEAR ON YOUR SCREEN.

I SEE LOTS OF MASSACHUSETTS FOLKS, MIDWEST IS GAINING.

WE HAVE A HANDFUL OF PEOPLE FROM OUTSIDE THE U.S.

I WILL GIVE IT ANOTHER MOMENT HERE.

IT'S WONDERFUL TO HAVE FRIENDS WITH US FROM ALL OVER.

OKAY.

I'M GOING TO END THE POLLING AND LET'S GO AHEAD AND SHARE RESULTS.

SO, MASSACHUSETTS IS DEFINITELY THE PRIMARY SOURCE OF WHO'S ATTENDING TODAY.

A LITTLE LESS THAN HALF, BUT WE ALSO HAVE THE MIDWEST, SOUTHERN U.S., WESTERN U.S. AND A HANDFUL OF PEOPLE FROM OUTSIDE THE U.S. OF IT'S WONDERFUL TO HAVE YOU HERE.

I WOULD LIKE TO DO ANOTHER LITTLE POLL.

SO I WILL LAUNCH ANOTHER POLL, WHICH IS ASKING ABOUT WHAT BROUGHT YOU HERE TODAY.

YOU CAN CHECK OFF ANY OPTIONS THAT APPLY TO YOU.

SO, ARE YOU A PERSON LIVING WITH DEMENTIA?

ARE YOU A FAMILY MEMBER OR FRIEND, WHAT WE WOULD CALL A CARE PARTNER.

ARE YOU A PROFESSIONAL WORKING WITH PEOPLE WITH DEMENTIA.

ARE YOU A PROFESSIONAL WORKING IN A RELATED FIELD?

OR PERHAPS NONE OF THE ABOVE.

MAYBE YOU ARE JUST HERE BECAUSE THIS IS A TOPIC THAT INTERESTS YOU.

GO AHEAD AND RESPOND IF YOU COULD.

THANKS FOR PARTICIPATING.

I WILL JUST GIVE IT ANOTHER FEW SECONDS.

OKAY.

SO, I WILL STOP THAT POLL AND I WILL SHARE THE RESULTS.

SO, IT LOOKS LIKE WE'VE GOT A LOT OF, 3/4 OF THE MEETING ALMOST IS PROFESSIONALS WORKING WITH PEOPLE LIVING WITH DEMENTIA, BUT WE ALSO HAVE QUITE A NUMBER OF PROFESSIONALS IN RELATED FIELDS.

QUITE A NUMBER OF PEOPLE WHO ALSO ARE

FAMILY MEMBERS OR FRIENDS OF SOMEONE LIVING WITH DEMENTIA.

WE DO HAVE SOME INDIVIDUALS LIVING WITH DEMENTIA HERE TODAY.

OF COURSE, PEOPLE CAN BE IN ALL OF THESE CATEGORIES AT ONCE OR SEVERAL OF THE CATEGORIES.

SO, WELCOME.

IT'S JUST GREAT TO HAVE YOU HERE.

I APPRECIATE YOUR GIVING US A LITTLE INSIGHT INTO WHO YOU ARE.

WE'RE GOING TO CONTINUE ON.

SO, THIS IS WHAT WE'RE DOING TODAY.

WE'RE GOING TO START BY KIND OF SETTING THE SCENE.

WE'LL HEAR A WELCOME FROM NORA MORENO CARGIE THEN A STORY FROM BRIAN VAN BUREN WHO WILL HELP US REMEMBER THIS TOPIC HITS HOME FOR PEOPLE, AFFECTS PEOPLE'S LIVES VERY PERSONALLY THEN WE'LL HAVE OUR CONVERSATION WITH DEMENTIA FRIENDS EDUCATORS WORKING IN FIVE CULTURAL AND LINGUISTIC COMMUNITIES AROUND MASSACHUSETTS, THEN WE'RE GOING TO HAVE SOME MUSIC AND A STRETCH BREAK, JONATHAN JACKSON, STEPHANIE MONROE AND JASON RESENDEZ.

BEFORE WE LAUNCH INTO THAT, I WANT TO DEFINE DEMENTIA AND MAKE SURE WE HAVE A COMMON UNDERSTANDING.

DEMENTIA IS NOT A SPECIFIC DISEASE.

IT'S AN UMBRELLA TERM, AND IT COVERS A LARGE GROUP OF DIFFERENT SYMPTOMS, INCLUDING MEMORY LOSS, BUT ALSO DIFFICULTY PLANNING, MAKING DECISIONS, SOMETIMES DIFFICULTY USING LANGUAGE, SOMETIMES CHANGES IN MOOD OR PERSONALITY.

AND THE CHANGES ARE SIGNIFICANT ENOUGH THAT THEY AFFECT A PERSON'S ABILITY TO GET THROUGH THEIR DAY.

GENERALLY, THE SYMPTOMS GET MORE SEVERE OVER TIME.

THERE ARE MANY MEDICAL CONDITIONS THAT CAN CAUSE THIS GROUP OF SYMPTOMS THAT WE CALL DEMENTIA.

ALZHEIMER'S DISEASE IS THE MOST COMMON MEDICAL DIAGNOSIS BUT THERE ARE MANY OTHERS AND YOU SEE SOME OF THEM UNDER THE UMBRELLA HERE.

VASCULAR DEMENTIA, DEMENTIA WITH LEWY BODIES, FRONTOTEMPORAL, PARKINSON'S, HUNTINGTON'S DISEASE, TRAUMATIC BRAIN INJURY,

AND MANY OTHERS.

SO, AS MANY OF YOU KNOW, DEMENTIA IS SOMETHING THAT'S GROWING MORE PREVALENT AS YOUR POPULATION AGES.

IT'S ESTIMATED IN 2020, 5.8 MILLION AMERICANS LIVE WITH ALZHEIMER'S OR RELATED DEMENTIA.

16 MILLION AMERICANS PROVIDE UNPAID CARE FOR PEOPLE WITH ALZHEIMER'S OR A RELATED DEMENTIA.

NOW, WHEN WE BREAK THESE NUMBERS DOWN, WE SEE SOME REAL DIFFERENCES.

SO, BLACK AMERICANS HAVE ABOUT TWICE THE RISK OF DEVELOPING DEMENTIA RELATIVE TO WHITE AMERICANS.

HISPANIC AMERICANS HAVE ABOUT ONE AND A HALF TIMES THE RISK RELATIVE TO WHITE AMERICANS.

THERE WAS A 2016 LARGE 2016 STUDY DONE IN CALIFORNIA WHICH LOOKED AT MANY DIFFERENT POPULATION GROUPS, AND FOUND THAT AMERICAN INDIANS AND ALASKAN NATIVES HAD A LIKELIHOOD OF DEVELOPING DEMENTIA THAT WAS BETWEEN BLACK AMERICANS AND HISPANIC AMERICANS.

ASIAN—AMERICANS AND PACIFIC ISLANDERS

HAD A LITTLE BIT LOWER RISK THAN WHITE AMERICANS.

AND THERE ARE MANY GROUPS OF PEOPLE WHERE WE JUST DON'T KNOW BECAUSE THEIR PARTICIPATION IN RESEARCH IS IN SUCH SMALL NUMBERS THAT WE REALLY AREN'T ABLE TO ESTIMATE HOW PREVALENT DEMENTIA IS IN THAT GROUP.

WHEN WE LOOK AT ALL RACES AND ETHNICITIES TOGETHER, WE ALSO SEE A BIG GENDER DIFFERENCE WITH WOMEN HAVING ABOUT TWICE THE LIKELIHOOD OF DEVELOPING DEMENTIA DURING THEIR LIFETIME COMPARED TO MEN.

SO, THE BOTTOM LINE IS DEMENTIA HAS A MAJOR IMPACT ON ALL OF OUR COMMUNITIES, AND IT AFFECTS SOME COMMUNITIES AND FAMILIES MORE THAN OTHERS.

SO, WITH THAT I WOULD LOVE TO WELCOME NORA MORENO CARGIE WHO IS A GOOD FRIEND OF OURS.

SHE IS THE PRESIDENT OF TUFTS HEALTH PLAN FOUNDATION WHERE SHE LEADS THE FOUNDATION'S WORK IN HEPT IN HEALTHY LIVING WITH AN EMPHASIS ON OLDER ADULTS AND VICE PRESIDENT OF CORPORATE CITIZENSHIP FOR TUFTS

HEALTH PLAN.

TUFTS HEALTH PLAN FOUNDATION HAS GENEROUSLY SUPPORTED DEMENTIA FRIENDS MASSACHUSETTS'S CAPACITY BUILDING INITIATIVE IN SEVERAL CULTURAL AND LINGUISTIC COMMUNITIES.

SO, NORA, COULD I ASK YOU TO UNMUTE AND SAY A FEW WORDS OF WELCOME?

NORA MORENO CARGIE: THANK YOU SO MUCH, BETH.

I AM SO THRILLED AND HONORED TO BE HERE AMONG GREATNESS, PEOPLE WHO GIVE THEIR TIME AND THEIR EFFORTS FOR THIS REALLY IMPORTANT CAUSE.

EVENTS LIKE THESE ARE JUST SO VALUABLE.

THEY ARE OPPORTUNITIES TO LEARN FROM EACH OTHER, TO SHARE BEST PRACTICES, TO LISTEN ABOUT WHAT'S WORKING, BUT ALSO ABOUT WHAT'S NOT WORKING.

THESE EVENTS INSTRUCT US ON HOW WE CAN HELP EACH OTHER, HOW WE CAN BE REMINDED THAT WE ARE IN THIS WORK TO THE.

THAT WE HAVE COLLEAGUES AND COLLABORATORS WHO HELP US MOVE FORWARD.

WE ARE FORTUNATE TO HAVE SUCH A

SUPPORTIVE COMMUNITY, SO MANY OF US KNOW THE CHALLENGES OF ISOLATION FIRSTHAND, HAVE SEEN WHAT, HAVE SEEN AND EXPERIENCED BOTH LIVING WITH ALZHEIMER'S, THEIR FAMILIES AND CARE GIVES.

SO, AGAIN, I WANT TO THANK YOU FOR BEING HERE.

I WANT TO ESPECIALLY THANK BETH BECAUSE SHE HAS BEEN AN INSPIRATION TO ME FROM THE MOMENT I MET HER, SHE WAS WILLING TO SHARE HER PASSION, HER HUMILITY AND ADVANCING WORK ON DIVERSITY AND INCLUSION.

TO BEGIN THE SESSION THAT THERE ARE LIKE FOUR LANGUAGES BEING COMMUNICATED THROUGH IN TERMS OF THIS MATERIAL IS JUST REALLY EXCITING FOR ME.

BETH, YOUR PASSION FOR THIS WORK HAS BEEN CLEAR TO ME SINCE THE DAY WE MET.

I AM PERSONALLY GRATEFUL FOR YOUR LEADERSHIP AND COMMITMENT, A SISTER IN THE CAUSE.

IN CLOSING, I WANT TO REMIND US THAT WE'VE LEARNED A LOT DURING THIS REALLY DIFFICULT TIME OF CORONA VIRUS.

IT HAS UNCOVERED WHAT FOR SOME OF US

HAS BEEN CLEAR FOR A VERY LONG TIME.

THAT IS, SYSTEMIC RACISM.

SYSTEMIC RACISM IS WORKING.

IT HAS RESULTED IN THE HEALTH DISPARITIES IN COMMUNITIES OF COLOR BUT DISPROPORTIONATE NUMBER OF DEATHS IN THOSE SAME COMMUNITIES.

WE ARE ALL HEARING THE CLEAR CALL FOR CHANGE AND ITS ALL OF OUR JOBS TO CHANGE THE SYSTEMS THAT HAVE LEFT TOO MANY BEHIND.

WE HAVE TO BREAK DOWN THOSE BARRIERS, BOTH LANGUAGE, CULTURE, POINT OF VIEWS, EXPERIENCES, AND TALK AND TEACH EACH OTHER ABOUT DEMENTIA IN A CULTURE AND A WAY THAT RESONATES WITH THE DIVERSITY THAT WE SEE IN OUR COMMUNITIES.

SO, I KNOW YOU HAVE AN EXCITING AFTERNOON PLANNED.

THANK YOU SO MUCH FOR BEING HERE, AND ON BEHALF OF OUR FOUNDATIONS TEAM AND OUR COMPANY, TUFTS HEALTH PLAN, CHARGE ON.

BE WILLING TO DISRUPT THE STATUS QUO, AND THANK YOU FOR INVITING ME.

BETH SOLTZBERG: THANK YOU SO MUCH,

NORA.

I AM SO APPRECIATIVE OF YOUR PARTNERSHIP, YOUR SISTERHOOD AS YOU MENTIONED, AND ALL YOUR SUPPORT, NOT ONLY FOR OUR PROJECT, BUT THROUGHOUT NEW ENGLAND, THE CRITICAL SUPPORT THAT YOUR FOUNDATION PROVIDES.

THANK YOU SO MUCH.

I WOULD LOVE TO NOW INVITE BRIAN VAN BUREN TO UNMUTE AND JOIN US.

BRIAN IS AN ALZHEIMER'S ADVOCATE.

HE IS A BOARD MEMBER OF THE WESTERN CAROLINA CHAPTER OF THE ALZHEIMER'S ASSOCIATION.

HE IS AN ADVISORY COUNCIL MEMBER OF THE DEMENTIA ACTION ALLIANCE, AND BRIAN'S ROLE TODAY IS EXTREMELY IMPORTANT BECAUSE HE HELPS US BRING THIS HOME.

WE DON'T WANT THIS CONVERSATION TO BE ACADEMIC.

WE WANT TO ALWAYS KEEP IN MIND HOW REAL PEOPLE, REAL FAMILIES ARE AFFECTED BY OUR ABILITY TO MAKE EDUCATION, RESOURCES, RESEARCH OPPORTUNITIES, AND CONNECTION OPPORTUNITIES AVAILABLE TO PEOPLE LIVING WITH

DEMENTIA.

SO, BRIAN, COULD I ASK YOU TO UNMUTE?

BRIAN VAN BUREN: YEAH.

BETH SOLTZBERG: THANK YOU.

WE HEAR YOU.

BRIAN VAN BUREN: CAN YOU SEE ME?

HELLO, MY NAME IS BRIAN VAN BUREN AND I AM LIVING WITH ALZHEIMER'S DISEASE.

I LIVE IN CHARLOTTE, NORTH CAROLINA.

I REPRESENT THE FACE OF A BLACK GAY MAN LIVING WITH ALZHEIMER'S DISEASE.

IT IS IMPORTANT FOR ME TO BE SPEAKING TO YOU TODAY AS A MEMBER OF TWO DISTINCT, DIVERSE POPULATIONS.

THE AFRICAN—AMERICAN COMMUNITY AND AS A GAY MAN.

PEOPLE OF BOTH THESE COMMUNITIES EXPERIENCE DISPARITY AND DISADVANTAGES WITH DEMENTIA FROM DIAGNOSIS TO CARE AND SUPPORT, TO OPPORTUNITIES TO LIVE WELL WITH A DISEASE.

AFRICAN—AMERICANS MAKE UP 2% OF ALL CASES OF ALZHEIMER'S, TWICE THE NUMBER OF THE WHITE POPULATION.

BUT AS A RESULT, THEY HAVE FEWER OPPORTUNITIES TO BE INVOLVED IN IMPORTANT LEGAL, FINANCIAL, AND CARE PLANNING DECISIONS.

AND LESS TIME TO COMMUNICATE THEIR PREFERENCES TO THOSE WHO CARE FOR THEM.

I REPRESENT THREE GENERATIONS OF FAMILY MEMBERS LIVING WITH ALZHEIMER'S.

HARDLY SURPRISING WHEN ALZHEIMER'S DISEASE IS THE SIXTH LEADING CAUSE OF DEATH IN THE UNITED STATES AND CURRENTLY THERE IS NO WAY TO PREVENT, CURE.

I WAS DIAGNOSED IN 2015 AND AT THE TIME I WAS WORKING AS AN INTERNATIONAL FLIGHT ATTENDANT ANDS A RESULT OF MY DIAGNOSIS I LOST MY JOB.

I RETREATED TO MY BEDROOM FOR ABOUT THREE MONTHS, GRIEVING, AND BASICALLY JUST GIVING UP HOPE THINKING THAT I WAS GOING TO DIE.

I HAD THE OPPORTUNITY OF OBTAINING A BOOK CALLED BEFORE I FORGET WRITTEN BY A LADY BY THE NAME OF BEA SMITH AND DAN GATSBY.

BEA SMITH WAS THE FIRST AFRICAN—AMERICAN WOMAN TO GRACE THE COVER OF A BEAUTY

MAGAZINE.

SHE WAS AN ENTREPRENEUR, RAN THREE RESTAURANTS, AND HAD MANY LINES WITHIN BED, BATH AND BEYOND.

WHAT HAD HAPPENED WAS BEA WAS ALSO A PERSON WHO ON THE "TODAY" SHOW DID COOKING DEMONSTRATIONS QUITE OFTEN.

IN THE MIDDLE OF A DEMONSTRATION SHE PAUSED AND COULD NO LONGER REMEMBER WHAT SHE WANTED TO SAY.

THIS WAS THE BEGINNING OF HER JOURNEY.

AS AN AFRO—AMERICAN COUPLE THEY FELT THEY HAD A RESPONSIBILITY TO WRITE THIS BOOK, TO BRING LIGHT TO THE FACT THAT MANY AFRO AMERICANS ARE BEING DIAGNOSED.

THE BOOK OFFERS HOPE AND IS KIND OF A BIBLE FOR ME.

IT GUIDES ME THROUGH EVERYTHING.

I DID NOT TELL ANYONE ABOUT MY DIAGNOSIS BECAUSE I THINK I WAS ALMOST ASHAMED.

SO, THEY WERE COMING TO CHARLOTTE AND DOING A BOOK TOUR.

I DECIDED I WOULD GO AND SEE THEM.

SO, DAN GOT UP AND BASICALLY DID MOST

OF THE SPEAKING, AND THEN AFTER SHE WAS FINISHED HE ASKED IF ANYONE HAD ANY QUESTIONS OR ANY COMMENTS.

AND SO, I STOOD UP AND ANNOUNCED TO A ROOM OF STRANGERS WHO I NEVER KNEW THE FACT THAT I HAD ALZHEIMER'S.

I BROKE DOWN CRYING AND DAN CAME FROM THE STAGE AND EMBRACED ME IN HIS ARMS AND SAID, "I GOT YOU, MY BROTHER.

YOU ARE NOT ALONE."

AND THEN HE PROVIDED TO TELL ME THAT HOW BRAVE I WAS BECAUSE HE HAD NOT MET ANYONE ELSE WHO WAS GIVING A FACE TO THIS DISEASE, AND HOW IMPORTANT IT WAS FOR ME TO BECOME A SPOKESPERSON.

I TOOK WHAT HE SAID TO HEART, AND AFTER THAT BECAME INVOLVED WITH LIKE I SAID THE ALZHEIMER'S ASSOCIATION, DEMENTIA ACTION ALLIANCE, AND ACTUALLY NOW I BELONG TO TEN DIFFERENT ORGANIZATIONS.

I AM AN INTERNATIONAL SPEAKER.

LAST YEAR I SPOKE IN SOUTH AFRICA FOR THEIR FIRST DEMENTIA CAFE.

I HAVE BEEN IN MANY PUBLICATIONS, MANY MAGAZINES, I HAVE ATTENDED MANY, MANY, MANY

CONFERENCES SPREADING THE WORD AND GIVING A FACE AS AN AFRO—AMERICAN TO THIS DISEASE.

IN THE BIBLE, JESUS SAYS IN MATTHEW "NOR DO THEY LIGHT A LAMP AND THEY PUT IT UNDER A BUSHEL BASKET.

IT IS SET ON A LAND STAND WHERE IT GIVES LIGHT TO ALL IN THE HOUSE.

JUST SO YOUR LIGHT MUST SHINE BEFORE OTHERS THEY MAY SEE YOUR GOOD DEEDS AND GLORIFY YOUR HEAVENLY FATHER IN HEAVEN."

AT THAT POINT I DECIDED TO BECOME THAT LIGHT.

THANK YOU.

BETH SOLTZBERG: THANK YOU SO MUCH, BRIAN.

I AM JUST DEEPLY GRATEFUL FOR YOUR ADVOCACY AND I KNOW THAT I SPEAK FOR EVERYONE HERE IN JUST SAYING THAT IT'S VERY INSPIRING TO HEAR HOW YOU HAVE TAKEN A CHALLENGE THAT YOU HADN'T EXPECTED, YOU HADN'T ASKED FOR, AND YOU ARE USING YOUR TIME AND ENERGY TO HELP OTHER PEOPLE AND PARTICULARLY TO PUT A FACE ON DEMENTIA FOR THE BLACK AND GAY COMMUNITY.

SO, THANK YOU SO MUCH FOR SHARING THAT STORY AND TALKING ABOUT WHAT IT MEANT TO YOU TO MEET BEA SMITH AND HER HUSBAND, AND THE IMPORTANCE OF FINDING PEOPLE WHO ARE WITHIN ONE'S COMMUNITY WHEN YOU ARE DEALING WITH SOMETHING AS DIFFICULT AS DEMENTIA.

SO, I APPRECIATE THAT AND IF YOU HAVE COMMENTS LATER ON IN THE DAY, WE'LL BE VERY GLAD TO HEAR FROM YOU.

SO, NOW I WOULD LIKE TO GO THROUGH SOME SLIDES TO JUST SET A FRAMEWORK A LITTLE BIT FOR HOW WE'LL SPEND THE REST OF THE AFTERNOON.

SO, THE REASON FOR THIS SYMPOSIUM AND THE TWO YEAR PROJECT BEHIND IT IS THAT DEMENTIA AFFECTS EVERY COMMUNITY, BUT AS WE KNOW, AS WE'VE BEEN TALKING ABOUT, ARE NOT IN THE SAME WAY.

AS YOU'LL HEAR LATER, SOME COMMUNITIES FACE A HIGHER RISK OF DEVELOPING DEMENTIA.

I MENTIONED SOME STATISTICS BUT WE'LL GO INTO THAT IN MORE DETAIL.

YET, MEMBERS OF THESE SAME COMMUNITIES ARE LESS LIKELY TO BE REPRESENTED IN RESEARCH ON DEMENTIA.

AND MEMBERS OF THESE SAME COMMUNITIES ARE LESS LIKELY TO RECEIVE A TIMELY AND ACCURATE DIAGNOSIS, AND OFTEN TO HAVE ACCESS TO SERVICES.

IT'S SO IMPORTANT THAT IN OUR DEMENTIA FRIENDLY INITIATIVES AND OUR DEMENTIA AWARENESS WORK IN MEDICAL RESEARCH AND SO ON WE MAKE SURE THAT EVERYONE IS AT THE DECISION MAKING TABLE, AND PARTICULARLY THOSE WHO ARE NOT GETTING ACCESS TO SERVICES TO THE SAME EXTENT RIGHT NOW.

IF THEY'RE NOT AT THE TABLE WE'RE NOT SERVING ANYONE AND IT ALSO MEANS WE'RE MISSING OUT ON WISDOM AND GUIDANCE FROM SOME MEMBERS OF OUR BROADER COMMUNITY.

SO, WE ALL WANT TO BE ON THE ROAD TO IMPROVEMENT.

WE ALL WANT TO MAKE SURE WE'RE SERVING EVERYONE WELL.

WE WANT TO MAKE SURE WE'RE LEARNING FROM EVERYONE.

AND SO, TODAY WE'RE GOING TO TALK NOT ABOUT A RECIPE.

YOU ARE NOT GOING TO WALK OUT WITH A RECIPE ON THESE ARE THE THINGS YOU SAY OR DO

TO SERVE THIS COMMUNITY OR THAT ONE.

BUT INSTEAD, WE'RE GOING TO TALK ABOUT A NEW LENS THAT YOU CAN LOOK THROUGH OR MAYBE POLISH THAT LENS TO SEE MORE CLEARLY.

SO, WHAT I WANT US TO DO IS FOCUS AND REFOCUS OUR LENS SO THAT WE SEE THINGS AT THREE DIFFERENT LEVELS.

HERE IS WHERE WE'RE GOING TO START.

ANYBODY HERE TODAY IN THIS PLACE?

I HOPE ALL THE HANDS ARE GOING UP.

WE'RE ALL HERE ON PLANET EARTH, THANKS, BRIAN, I SEE YOU AND I'M SURE I THINK I CAN ASSUME THAT WE'RE ALL HERE.

DESPITE THE FACT WE'RE IN ZOOM LAND.

NOT ONLY ARE WE ALL HERE ON THIS BLUE MARBLE BUT WE'RE ALL THE SAME SPECIES, HOMO SAPIENS.

WE DO HAVE DIFFERENT PHYSICAL TRAITS BASED ON WHERE OUR ANCESTORS ORIGINATED CLOSE TO OR FAR FROM THE EQUATOR, IN THE MOUNTAINS OR THE LOW LANDS, BY THE OCEAN, ET CETERA.

WE HAVE SOME GENETIC INHERITANCE BASED ON OUR INDIVIDUAL FAMILY TREES.

BUT, UNDER THE SKIN WE ARE ALL MUCH MORE SIMILAR THAN WE ARE DIFFERENT.

ALL HUMANS ARE SUSCEPTIBLE TO THE BRAIN DISEASES AND INJURIES THAT CAUSE THE GROUP OF SYMPTOMS WE CALL DEMENTIA.

SO, THIS IS ONE LEVEL WHERE WE'RE ALL HUMANS ON PLANET EARTH TOGETHER.

NOW YOU SEE THE BOUNDARIES OF CONTINENTS AND COUNTRIES.

THIS IS THE LEVEL WHERE WE'RE GOING TO SPEND MOST OF OUR TIME TODAY BECAUSE THIS IS WHERE WE TALK ABOUT RACE, ETHNICITY, CULTURE, LANGUAGE, EXPERIENCE OF MIGRATING ACROSS NATIONAL BOUNDARIES.

BUT THERE IS ONE MORE LEVEL WHERE I WANT US TO FOCUS OUR LENS TODAY.

THIS IS THE LEVEL OF INDIVIDUALS.

EACH AND EVERY ONE OF US IS UNIQUE, AND BY THE WAY ALL THE PEOPLE IN THESE PHOTOS ARE DEMENTIA FRIENDS HERE IN MASSACHUSETTS.

EACH PERSON'S UNIQUE, EACH FAMILY IS UNIQUE.

YOU MAY HAVE HEARD THE SAYING WHEN YOU MET ONE PERSON WITH DEMENTIA, YOU MET ONE PERSON WITH DEMENTIA BECAUSE EACH PERSON IS AN INDIVIDUAL FIRST.

THEY ARE NOT THEIR DISEASE.

THEY ARE AN INDIVIDUAL WHO IS LIVING WITH A PARTICULAR CONDITION AT A PARTICULAR STAGE OF DISEASE PROGRESSION.

THEIR DAY IS GOING A PARTICULAR WAY, SO EVERYONE IS UNIQUE.

AND IF WE WANT TO MAKE A POSITIVE DIFFERENCE IN SOMEONE'S LIFE, WE CAN'T APPROACH THEM WITH A RECIPE FOR HOW YOU TREAT PEOPLE IN THEIR GROUP.

THE INDIVIDUAL LEVEL, THIS LEVEL, IS THE LEVEL OF FOCUS WHERE WE ACTUALLY HELP EACH OTHER, WHETHER THAT IS AS A FAMILY MEMBER, A FRIEND, A NEIGHBOR, A COUNCIL ON AGING OUTREACH WORKER, A RESIDENT SERVICES COORDINATOR, A BUS DRIVER, A RESTAURANT WORKER, GROCERY STORE STAFF PERSON, A MEMBER OF THE CLERGY, AND SO ON.

SO, ULTIMATELY WE NEED TO SET ASIDE ASSUMPTIONS AND SEE EACH PERSON AS A UNIQUE INDIVIDUAL.

SO, ALL THREE LEVELS ARE CORRECT, RIGHT?

ALL THREE LEVELS ARE REAL.

YET IT'S HARD FOR OUR MINDS TO MOVE

BETWEEN THESE DIFFERENT LEVELS.

I THINK THAT LEARNING TO FOCUS AND REFOCUS OUR LENS BETWEEN THESE THREE LEVELS IS IMPORTANT FOR ADVANCING EQUITY AND REPRESENTATION.

WE NEED TO PAY ATTENTION TO DIFFERENCES IN CULTURE, LANGUAGE, PLACE OF ORIGIN, IMMIGRATION EXPERIENCE, THE KINDS OF THINGS PEOPLE HAVE EXPERIENCED IN THEIR LIVES.

DISCRIMINATION AS NORA MENTIONED, RACISM.

THESE THINGS ARE EXTREMELY VITAL TO PAY ATTENTION TO, AND WE ARE ALL HUMANS SHARING THE EARTH.

WE HAVE MORE IN COMMON THAN WE HAVE DIFFERENT.

AND WE'RE ALL INDIVIDUALS AND THAT'S THE LEVEL AT WHICH WE HELP EACH OTHER.

SO, NOW WITH THAT IN MIND, I WOULD LIKE TO TELL YOU A LITTLE BIT ABOUT THE DEMENTIA FRIENDS PUBLIC AWARENESS PROGRAM, WHICH I RUN FOR MASSACHUSETTS.

DEMENTIA FRIENDS IS A GLOBAL PUBLIC AWARENESS PROGRAM OPERATING IN 66 COUNTRIES AND IT INVOLVES TRAINING VOLUNTEERS TO LEAVE

INFORMATION SESSIONS IN THEIR COMMUNITY.

THESE SESSIONS FOCUS ON PRACTICAL INFORMATION ABOUT DEMENTIA THAT EVERY MEMBER OF A COMMUNITY NEEDS SO THAT THEY CAN REALLY STAY CONNECTED WITH PEOPLE IN THEIR LIVES WHO LIVE WITH DEMENTIA.

I AM GOING TO SHOW YOU A ONE AND A HALF MINUTE VIDEO THAT GIVES YOU A FLAVOR FOR WHAT DEMENTIA FRIENDS LOOKS LIKE AROUND THE WORLD.

SO, HOPEFULLY THIS WILL RUN.

BETH SOLTZBERG: SEEMS LIKE WE'RE NOT GETTING AUDIO.

I HOPE YOU ARE GETTING AUDIO.

MARJI: NO AUDIO, BETH.

BETH SOLTZBERG: NO AUDIO, OKAY.

HMM.

WELL, I APOLOGIZE FOR THAT.

NOT SURE WHY THERE IS NO AUDIO.

SPEAKER: SORRY, ON THE ZOOM LINK YOU CAN SHARE AUDIO DOWN BELOW.

SHARE COMPUTER AUDIO.

ON BELOW ON THE BAR DOWN BELOW.

I DON'T KNOW IF YOU KNOW HOW THAT GOES.

BETH SOLTZBERG: I THOUGHT I WAS.

SPEAKER: OH, OKAY.

BETH SOLTZBERG: I'M NOT SURE WHY IT'S NOT.

SPEAKER: THE OTHER OPTION IS TO STOP SHARING THE SCREEN.

(MUSIC PLAYING).

BETH SOLTZBERG: LOOK AT THE PICTURES IT'S LITERALLY FIVE MORE SECONDS.

I WILL THE LINK WILL BE AVAILABLE TO YOU AFTER IF YOU WANT TO LOOK AT IT AGAIN.

SORRY ABOUT THAT.

I DON'T KNOW WHAT THE AUDIO ISSUE IS TODAY, BUT ——

SPEAKER: IT STARTED WORKING.

BETH SOLTZBERG: DID IT?

SPEAKER: DO YOU WANT TO GO BACK?

BETH SOLTZBERG: SURE, WE'LL PLAY IT AGAIN.

SPEAKER: IT'S WORKING.

(MUSIC PLAYING).

(MUSIC PLAYING).

(MUSIC PLAYING).

BETH SOLTZBERG: THANKS FOR BEARING WITH ME, EVERYBODY, WITH THE LITTLE AUDIO GLITCH THERE.

I APPRECIATE THAT.

SO, AS YOU SEE, DEMENTIA FRIENDS IS DESIGNED TO WORK IN MANY CULTURES AND LANGUAGES.

BUT WHAT I HAVE LEARNED RUNNING DEMENTIA FRIENDS FOR MASSACHUSETTS IS THAT IT'S NOT ENOUGH TO SET UP A PROGRAM KIND OF THROW OPEN THE DOORS, AND JUST HOPE THAT

EVERYONE WILL PARTICIPATE.

I HAVE BEEN RUNNING DEMENTIA FRIENDS MASSACHUSETTS FOR ABOUT A YEAR, AND IT DID NOT LOOK LIKE THE POPULATION OF MASSACHUSETTS.

I AM WHITE, I AM ONLY FLUENT IN ENGLISH, AND I HAVE A LIMITED NETWORK.

THE WAY THIS PROGRAM WORKS IS I TRAIN VOLUNTEERS TO LEAD INFORMATION SESSIONS ABOUT DEMENTIA IN THEIR COMMUNITIES.

AND WHAT I NOTICED WAS MOSTLY PARTICIPANTS LOOKED LIKE ME.

WE DID NOT HAVE A VERY REPRESENTATIVE GROUP OF PARTICIPANTS.

THE PROBLEM WITH THE VOLUNTEER—BASED INITIATIVE IS THAT INDIVIDUALS AND ORGANIZATIONS AND COMMUNITIES WITH MORE RESOURCES ARE MORE ABLE TO ALLOCATE TIME TO VOLUNTEER IN THIS WAY.

SO, THAT WAS PART OF THE ISSUE IS THAT IT WAS DEPENDENT ON PEOPLE HAVING THE RESOURCES TO BE ABLE TO VOLUNTEER, AND IT WAS ALSO ME AND THE LIMITATIONS OF MY NETWORK.

OOPS.

SO, LET ME TELL YOU NOW A LITTLE BIT

ABOUT MASSACHUSETTS.

SO, WE HERE IN MASSACHUSETTS ARE ON LANDS THAT NATIVE PEOPLE HAVE LIVED ON FOR 12,000 YEARS AND STILL LIVE ON.

WALTHAM, WHERE I AM SITTING TODAY, IS ON THE ANCESTORAL LAND OF THE MASSACHUSETTS AND PAWTUCKET PEOPLE.

TODAY MASSACHUSETTS IS VERY DIVERSE.

THIS MAP USES THE BROAD CATEGORY PEOPLE OF COLOR WHICH WE KNOW IS VERY NON–SPECIFIC.

IT GROUPS A LOT OF VERY DIFFERENT PEOPLE TOGETHER, BUT IT JUST GIVES YOU KIND OF AN IDEA THAT WE ARE A DIVERSE STATE ALMOST 12% OF THE MASSACHUSETTS POPULATION IS SPANISH–SPEAKING.

8.8% IS BLACK OR AFRICAN–AMERICAN.

6.9% IS ASIAN AND 2.4% ARE PEOPLE OF TWO OR MORE RACES.

IN 2018, NINE HALF PERCENT OF THE POPULATION OF MASSACHUSETTS HAD LIMITED ENGLISH PROFICIENCY, SO THAT'S ALMOST ONE OUT OF EVERY TEN PEOPLE.

OVER 70% OF THE MASSACHUSETTS POPULATION WITH LIMITED ENGLISH PROFICIENCY SPEAKS ONE OF THESE AS THEIR PRIMARY

LANGUAGE.

SPANISH, PORTUGUESE, CHINESE, HAITIAN CREOLE, VIETNAMESE, OR RUSSIAN.

THEN THERE ARE MANY, MANY ADDITIONAL LANGUAGES THAT MAKE UP THE REMAINING 30%.

GIVEN THAT THIS IS WHAT MASSACHUSETTS LOOKS LIKE, ARE THE FIRST STEP FOR ME WAS TO REALIZE THAT DEMENTIA FRIENDS MASSACHUSETTS REQUIRED ME TO WORK IN AN INTENTIONAL WAY TO GET US TO WHERE OUR PARTICIPATION COULD BETTER REFLECT OUR STATE'S POPULATION.

THE SECOND STEP WAS TO OBTAIN RESOURCES AND I WAS VERY GRATEFUL TO HAVE SUPPORT AT JFCS AND SUPPORTERS FOR A TWO YEAR PROJECT.

THEN THE THIRD STEP WAS ABOUT RELATIONSHIPS.

SEVERAL MONTHS OF TALKING WITH POTENTIAL PARTNERS TO FIND WHO WAS TRULY INTERESTED AND COULD MAKE THIS A PRIORITY RIGHT NOW, AND HOW I NEEDED IT ADJUST THE PROJECT TO MAKE IT WORK FOR THE PARTNERS.

SO, IN THE END WE FOUND FIVE PARTNERS AND WE BEGAN A TWO—WAY LEARNING PROCESS.

OUR PARTNERS ARE COMMUNITY EDUCATORS IN BLACK OR AFRICAN—AMERICAN, SPANISH—SPEAKING,

PORTUGUESE—SPEAKING, CHINESE—SPEAKING, AND RUSSIAN—SPEAKING COMMUNITIES IN GREATER BOSTON.

FROM THE START WAS THE GOAL THAT WE LEARN FROM EACH OTHER.

SO, TO PROVIDE DEMENTIA FRIENDS SESSIONS TO COMMUNITY MEMBERS, BUT ALSO TO HELP DEMENTIA FRIENDS MASSACHUSETTS LEARN HOW WE EDUCATE ABOUT DEMENTIA IN THESE COMMUNITIES.

I LEARNED IN GENERAL NEW IDEAS ABOUT HOW WE ENRICH OUR INITIATIVE.

SO, I'M GOING TO GIVE YOU JUST A SNAPSHOT OF OUR PROGRESS SO FAR.

THE FIVE COMMUNITY PARTNER TEAMS HAVE LED 61 DEMENTIA FRIENDS INFORMATION SESSIONS RESULTING IN 655 NEW DEMENTIA FRIENDS SO FAR.

SO, OVER 650 PEOPLE HAVE PARTICIPATED IN THESE INFORMATION SESSIONS.

NOW, WHAT WE NEVER EXPECTED WAS THAT THIS PROJECT WOULD ALSO BE ABOUT NEW TECHNOLOGY, BUT BECAUSE OF THE PANDEMIC WE HAD TO CONVERT ALL OF THE MATERIALS AND OUR PARTNERS HAD TO REALLY EXPERIMENT WITH PLATFORMS, INCLUDING THE TELEPHONE, WHATSAPP,

SKYPE, FACETIME, MESSENGER AND ZOOM AS WELL AS ORGANIZING PHYSICALLY DISTANT OUTDOOR GATHERINGS.

IT'S DEFINITELY BEEN A CHALLENGE AND WE NEEDED TO ADJUST OUR GOALS, BUT OUR PARTNERS HAVE FORGED AHEAD, THEY HAVE BEEN EXTREMELY CREATIVE AND PERSISTENT, AND THEY TRIED LOTS OF DIFFERENT THINGS.

YOU JUST SEE A FEW PICTURES HERE.

THEY HAVE DONE AN AMAZING JOB.

SO, I WANTED TO JUST TELL YOU A LITTLE BIT ABOUT WHAT WE'VE HEARD FROM THE EVALUATIONS THAT ALL OF THE PARTICIPANTS FILL OUT.

SO, AT THIS POINT WE HAVE A LITTLE BIT MORE THAN 400 EVALUATIONS BACK.

99% OF RESPONDENTS STRONGLY AGREED OR AGREED THAT THEIR AWARENESS HAS INCREASED ABOUT DEMENTIA, AND SAME PERCENTAGE THAT THEY FEEL MORE CONFIDENT AND EQUIPPED AS A COMMUNITY MEMBER TO RECOGNIZE THE SIGNS AND OFFER SUPPORT TO A PERSON IN THEIR COMMUNITY TRYING TO NAVIGATE.

IT WAS ACTUALLY UNANIMOUS AMONG PARTICIPANTS THAT THEY STRONGLY AGREED OR

AGREED THAT THEY'RE INSPIRED TO DO THIS TO OFFER SUPPORT AND BE A FRIEND TO PEOPLE LIVING WITH DEMENTIA IN THEIR COMMUNITY AND A SLIGHTLY SMALLER PERCENTAGE STRONGLY AGREED OR AGREED THAT THEY ARE LIKELY TO ADOPT DEMENTIA FRIENDLY PRACTICES IN THEIR PERSONAL OR PROFESSIONAL LIFE.

I THINK SOME OF THE COMMENTS WERE LETTING US KNOW THAT PEOPLE NEEDED MORE INFORMATION, THEY NEEDED MORE THAN A ONE—TIME SESSION TO REALLY GET TO THE POINT WHERE THEY UNDERSTOOD HOW TO IMPLEMENT THIS IN A MORE STRUCTURAL WAY, BUT THE SESSIONS REALLY, REALLY HELPED IN TERMS OF OPENING UP THE CONVERSATION, LETTING THEM KNOW THAT THIS IS AN ISSUE WE SHOULD BE TALKING ABOUT, AND BUILDING SOME BASIC AWARENESS.

AND JUST TO GIVE YOU A FEW QUOTES FROM THE PARTICIPANTS THAT I THOUGHT WERE, YOU KNOW, HELPFUL AND UNDERSTANDING WHAT PEOPLE GOT OUT OF THESE SESSIONS.

WE SHOULD HAVE MORE GET TOGETHER AND TALK ABOUT IT WITH OTHERS.

THE WORKSHOP HAS TRULY BEEN AN EYE OPENER AND HELPED ME BETTER UNDERSTAND HOW TO

HELP MY DAD WITH DEMENTIA.

WHAT WE KNOW IS THAT SO MANY PEOPLE, FOR SO MANY PEOPLE THIS ISSUE IS PERSONAL.

EITHER THEY'RE EXPERIENCING SOME CHANGES IN THEIR OWN COGNITION, OR SOMEONE THEY CARE ABOUT IS EXPERIENCING CHANGES.

SECOND QUOTE SAYS I'VE LEARNED TO USE SIMPLE PHRASES TO SPEAK SLOWLY AND LISTEN WITH PATIENCE, SO SOME VERY CONCRETE SKILLS.

I FEEL INSPIRED TO CONTINUE SHARING THIS INFORMATION WITH OTHERS TO REDUCE THE STIGMA.

SO, AS PEOPLE IN VARIOUS COMMUNITIES BECOME MORE AWARE AND EDUCATED, IT'S LIKE PLANTING SEEDS AND THEY CAN REALLY SHARE WHAT THEY LEARNED WITH OTHERS.

LIKE ONE PARTICIPANT SAYS I KNOW MORE NOW AND I CAN PROVIDE SUPPORT IN THE COMMUNITY.

FINALLY, THE SESSION WAS USEFUL TO PUT OURSELVES IN SOMEONE'S SHOES WHO IS LIVING WITH DEMENTIA AND TIPS ABOUT COMMUNICATION AND HOW TO ACT REALLY HELPED.

WHAT WE KNOW IS THAT SOMETIMES WHEN A PERSON DEVELOPS DEMENTIA, THE PEOPLE WHO CARE

ABOUT THEM MAY START TO SORT OF DRIFT AWAY AND NOT STAY IN TOUCH, NOT BECAUSE THEY DON'T CARE BUT BECAUSE THEY DON'T KNOW WHAT TO SAY OR HOW TO ACT.

SO, JUST THIS BASIC INFORMATION IS HELPFUL TO KEEP OUR FAMILIES AND OUR COMMUNITIES STRONG.

SO, I WANT TO CLOSE BY GIVING YOU A FEW POINTERS BASED ON WHAT I HAVE LEARNED ABOUT HOW TO MAKE MY DEMENTIA FRIENDLY INITIATIVE MORE REPRESENTATIVE OF MY COMMUNITY, WHICH IS MASSACHUSETTS.

I AM GOING TO BOIL IT DOWN TO THREE R'S.

REALIZATION, RESOURCES, AND RELATIONSHIPS.

SO, THE REALIZATION WAS I HAD TO TAKE ON THAT THIS WAS AN ESSENTIAL GOAL, THAT IF I AM RUNNING DEMENTIA FRIENDS MASSACHUSETTS I NEED TO BE ON A PATHWAY TO MAKE IT REPRESENTATIVE OF OUR WHOLE STATE.

RESOURCES, IT'S IMPORTANT TO PUT RESOURCES TOWARD IT, AND THAT'S NOT JUST DOLLARS.

IT'S TIME AS WELL.

IT WAS NECESSARY TO TAKE THE TIME TO REALLY TALK WITH VARIOUS GROUPS IN THE COMMUNITY AND FIND WHO WANTED TO FOCUS ON THIS ISSUE FOR A WHILE, AND HAD AN APPETITE TO TAKE ON THIS KIND OF TWO—WAY LEARNING PROCESS.

RESOURCES ARE ALSO DOLLARS.

IT'S VITALLY IMPORTANT THAT COMMUNITY PARTNERS BE FAIRLY COMPENSATED FOR THEIR WORK.

I THINK THERE SOMETIMES IS A PATTERN THAT LARGE ORGANIZATIONS GET GRANTS, AND THEN THEY ASK OTHERS TO BE ON COMMITTEES AND TO REALLY GIVE THEIR TIME FOR FREE.

ESPECIALLY FOR SMALL ORGANIZATIONS, THAT'S JUST NOT FEASIBLE.

SO, WE REALLY NEED TO MAKE SURE THAT WE'RE COMPENSATING PEOPLE REALISTICALLY FOR THE TIME AND EXPERTISE THAT THEY ARE SHARING.

I THINK IN THIS PROCESS THE PRACTICE OF CULTURAL HUMILITY IS A VERY USEFUL STANCE, BE AND IN THE RESOURCE LIST THAT I HAVE SENT OUT AND THAT WE'LL BE POSTING WITH MATERIALS IN A WEEK OR SO AFTER THE EVENT, THERE IS A LINK WHERE YOU CAN LEARN MORE, BUT IN SHORT IT'S

THE AWARENESS, SELF—REFLECTION THAT WE ALL COME FROM A PARTICULAR VIEWPOINT AND THAT WE NEED TO STRIVE TO REALLY LISTEN WITH AN OPEN MIND TO OTHERS.

THERE IS A TREASURE TROVE OF BOOKS, VIDEOS, PODCASTS, ET CETERA OUT THERE WHERE YOU CAN LEARN ABOUT DIFFERENT COMMUNITIES AND YOU CAN LEARN ABOUT SOME OF THE FACTORS THAT MAY BE STUMBLING BLOCKS, THAT MAY MAKE IT HARD FOR PEOPLE TO PARTICIPATE AND TO TRUST AND TO BUILD RELATIONSHIPS, AND WHEN YOU ARE MORE AWARE YOU CAN START TO ADDRESS THOSE AND WORK THROUGH THEM.

THEN BUILD RELATIONSHIPS.

THAT MEANS GO TO WHERE THE PEOPLE YOU WANT TO CONNECT WITH ARE, WHERE THEY ARE DOING THEIR OWN WORK AND SUPPORT THEIR WORK.

SO, TO SHOW UP FOR WHAT THEY ARE DOING AND THEN GET TO KNOW PEOPLE OVER TIME.

YOU KNOW, IT'S IMPORTANT THAT WE NOT KIND OF SHOW UP AND SAY I'VE GOT A GRANT APPLICATION DUE IN ONE WEEK.

ARE YOU IN OR NOT?

BUT TO ACTUALLY BUILD THOSE

RELATIONSHIPS OVER TIME.

THERE IS A WONDERFUL SAYING GO SLOW TO GO FAST.

I HEARD THAT FIRST FROM OLIVIA MASTERY, ONE OF THE FOUNDERS OF DEMENTIA FRIENDLY MASSACHUSETTS, BUT I THINK A LOT OF PEOPLE HAVE SAID IT.

IT BASICALLY MEANS WHEN YOU BUILD THE RELATIONSHIPS AND YOU BUILD A TRUST, THEN THINGS CAN MOVE QUICKLY.

BUT YOU HAVE TO GO SLOW AT THE BEGINNING TO SET THAT FOUNDATION.

DON'T GIVE UP.

KEEP GOING.

I COULD HAVE HAD A FOURTH R WHICH IS ROAD BECAUSE I EXPECT THIS TO BE A LIFELONG ROAD.

I WILL CONTINUE WORKING TO MAKE DEMENTIA FRIENDS MASSACHUSETTS MORE REPRESENTATIVE AS LONG AS I AM WORKING WITH DEMENTIA FRIENDS MASSACHUSETTS.

IT'S A PROCESS THAT NEVER ENDS.

IT'S A JOYFUL PROCESS BECAUSE IT IS SO WONDERFUL TO LEARN FROM PEOPLE WHO SEE THROUGH A DIFFERENT LENS THAN I DO.

I THINK WE NEED TO SEE IT THAT WAY AS A PLEASURE AND AS AN OPPORTUNITY.

SO, WITH THAT I AM GOING TO STOP SHARING MY SLIDES.

I WANT TO INVITE OUR COMMUNITY DEMENTIA FRIENDS, EDUCATORS, TO UNMUTE THEMSELVES AND TO JOIN IN THE CONVERSATION WITH ME.

WHILE THEY UNMUTE I WILL INTRODUCE EACH OF THEM.

SO, WE ARE PRIVILEGED TO HAVE ARNETTA E. BATY AND CARL BYRON BATTY.

A NON—PROFIT BASED IN DORCHESTER, MASSACHUSETTS THAT SUPPORTS COMMUNITIES MEMBERS AROUND TRAINING, EDUCATION, EMPLOYMENT AND HOUSING.

CARL BYRON BATY: IN ADDITION TO THEIR WORK WITH DEMENTIA FRIENDS MASSACHUSETTS, ARNETTA AND CARL HOST SOCIAL CONNECTION PROGRAMS FOR OLDER ADULTS, THEY PROVIDE COMPANION SERVICES AND TEACH OLDER ADULTS HOW TO USE COMPUTERS.

THEY WORK WITH LOCAL FARMING EFFORTS AND DISTRIBUTE HEALTHY FOODS TO HUNDREDS OF HOUSEHOLDS.

I DON'T KNOW HOW THEY HAVE TIME TO SLEEP.

BUT THEY ARE TRULY WONDERFUL MEMBERS OF THEIR COMMUNITY AND ALL OF OUR COMMUNITY.

I WOULD ALSO LIKE TO INTRODUCE IRENE BELOZERSKY, WHO HAS BEEN LIVING IN BOSTON SINCE 1980.

IN MOSCOW SHE WAS AN EDUCATOR, BUT IN THE U.S. SHE OBTAINED A MASTER'S DEGREE IN CLINICAL SOCIAL WORK AND BECAME THE FIRST RUSSIAN SPEAKING SOCIAL WORKER IN BOSTON.

IRENE WORKED EXTENSIVE WITH IMMIGRANTS FROM THE FORMER SOVIET UNION AS A CLINICIAN, DIRECTOR OF RESETTLEMENT SERVICES AND MOST RECENTLY AS A COORDINATOR OF SERVICES TO THE RUSSIAN COMMUNITY IN BOSTON THROUGH THE COMBINED JEWISH PHILANTHROPIES.

SIMULTANEOUSLY, SHE HAS BEEN MAINTAINING AN ACTIVE PRIVATE PRACTICE AS A PSYCHOTHERAPIST.

ALSO, A VERY BUSY PERSON WHO WE'RE LUCKY TO HAVE WITH US.

AND NEXT I WOULD LIKE TO INTRODUCE KUN CHANG 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.

IN ADDITION TO HIS WORK WITH DEMENTIA FRIENDS, KUN HAS BEEN A PRESIDENT OF THE CHINESE FOLK ART WORKSHOP AND PROJECT DIRECTOR OF THE NATIONAL ASIAN PACIFIC CENTER ON AGING FOR OVER 20 YEARS.

WELCOME, KUN.

ALANA DUNDON WORKED A PSYCHOLOGIST, ORGANIZATIONAL CONSULTANT AND HUMAN RESOURCES MANAGER IN BRAZIL AND I DO BELIEVE WE HAVE OTHER FRIENDS JOINING US FROM BRAZIL TODAY, SO SHOUT OUT IF YOU ARE HERE.

SO ALANA DID THIS WORK BEFORE EMIGRATING TO THE U.S.

IN ADDITION TO HER WORK WITH DEMENTIA FRIENDS, SHE HAS WORKED AS A MEDICAL INTERPRETER AND TAUGHT CHRONIC DISEASE SELF—MANAGEMENT COURSES WITH THE LATINO HEALTH INSURANCE PROGRAM, WHICH MANY OF YOU KNOW WONDERFUL ORGANIZATION BASED IN FRAMINGHAM, MASSACHUSETTS.

ALANA IS ALSO A LONG TIME CAREGIVER FOR A FAMILY MEMBER WHO LIVES WITH DEMENTIA.

JACYRA CARVAHLO IS PART OF THE RESIDENT SERVICES TEAM OF INQUILINOS BORICUAS EN ACCION OR IBA, A HOUSING EDUCATION AND ARTS ORGANIZATION SERVING A PUERTO RICAN COMMUNITY IN THE SOUTH END OF BOSTON.

PRIOR TO WORKING AT IBA, JACYRA WORKED FOR SOCIAL SERVICE ORGANIZATIONS SUCH AS EMPATH, COMMUNITY BUILDERS AND CENTRAL BOSTON ELDER SERVICES, WITH A FOCUS ON UNDERSERVED POPULATIONS.

HER PASSION IS TO CONTINUE FIGHTING AGAINST DISPARITIES OF ANY SHAPE OR FORM.

THAT'S GREAT.

AND THEN LAST BUT NOT LEAST FRANCES SAMIDY ORTIZ WAS BORN AND RAISED IN BAYAMON, PUERTO RICO.

SHE HAS A BACHELOR'S IN SOCIAL WORK AND HAS PRACTICED WITH ADULTS, ELDERS AND FAMILIES IN PUERTO RICO.

SHE IS NOW A COORDINATOR IN THE RESIDENCE SERVICES PROGRAM OF IBA WITH JACYRA.

ONE OF HER FAVORITE THOUGHTS IS THIS:

REMEMBER THAT WE ARE ALL AFRAID.

WE HAVE ALL STUMBLED.

EVEN THE MOST SUCCESSFUL PERSON IN THE WORLD.

BUT THIS IS ONLY MADE US STAND UP WITH MORE DETERMINATION AND KEEP TRYING.

FRANCES, THANK YOU SO MUCH FOR THAT THOUGHT.

I THINK THAT'S A GREAT BEGINNING FOR OUR DISCUSSION.

SO, IF ALL OF YOU WHO I JUST INTRODUCED IF YOU WANT TO UNMUTE YOURSELF AND THOSE WATCHING IF YOU WANT TO PUT YOUR VIEW INTO SPEAKER VIEW, YOU WILL BE ABLE TO SEE WHO EVER IS SPEAKING LARGE ON YOUR SCREEN WHEN THEY SPEAK.

FEEL FREE TO DO THAT.

SO, WE HAVE A LITTLE BIT UNDER AN HOUR HERE TO DISCUSS THREE KEY QUESTIONS THAT I WILL BE DISCUSSING WITH OUR PANEL AND FOR THE AUDIENCE, PLEASE FEEL FREE TO PUT YOUR COMMENTS OR QUESTIONS INTO THE CHAT AND WE WILL ADDRESS AS MANY OF THOSE AS WE CAN DURING Q AND A PERIOD.

SO, HERE ARE THE THREE QUESTIONS.

THE FIRST IS, WHAT DOES THE TERM DEMENTIA MEAN TO PEOPLE IN YOUR COMMUNITY?

THEN WE'LL TALK ABOUT WHAT ARE COMMON BELIEFS AND VALUES IN YOUR COMMUNITY ABOUT CARE GIVING OR SUPPORTING THE PERSON LIVING WITH DEMENTIA?

AND THEN FINALLY, WHAT ARE SOME BARRIERS THAT MAKE IT HARDER FOR PEOPLE IN YOUR COMMUNITY TO USE SERVICES OR GET INVOLVED WITH ACTIVITIES RELATED TO DEMENTIA?

SO, I WILL START WITH ARNETTA AND CARL IN THE FIRST QUESTION.

ARNETTA AND CARL, DO YOU WANT TO GIVE US YOUR THOUGHTS ABOUT WHAT DOES THE TERM DEMENTIA MEAN TO PEOPLE IN YOUR COMMUNITY?

PARTICULARLY BEFORE THEY ATTENDED YOUR INFORMATION SESSION.

CARL BYRON BATY: WE HAD A TERM, YOU ALWAYS HAVE PEOPLE GETTING OLD OR SENILE, THEN THERE WAS JUST, IT WAS BELIEF THAT SOMETHING THAT JUST HAPPENS WITH AGE.

ARNETTA BATY: ME AND MY FRIENDS DIDN'T UNDERSTAND WHAT THE WORD DEMENTIA MEANT.

SO, THEY WOULD SAY, OH, THEY ARE JUST, THEY CRAZY.

AS THEY GET OLDER, CRAZIER THINGS HAPPEN.

IT WAS KIND OF INTERESTING BEING THAT I'M FROM THE SOUTH.

MOST OF THE TIMES WHEN OUR PARENTS STARTED DOING THINGS THAT THEY HADN'T BEEN DOING, WE WOULD PUT THEM OR SOME FAMILIES WOULD PUT THEM IN OLD AGE HOMES.

SO OTHER PEOPLE CAN LOOK AFTER THEM.

NOT KNOWING WHAT THE WORD DEMENTIA OR ALZHEIMER'S WAS.

BETH SOLTZBERG: THANKS ARNETTA AND CARL.

IT SOUNDS LIKE ON THE ONE HAND A LOT OF PEOPLE SAW IT AS JUST THIS IS JUST WHAT HAPPENS WHEN YOU GET OLDER.

NOT REALLY SEEING IT AS A MEDICAL PROBLEM THAT NEEDED ATTENTION.

AND THEN ALSO SEEING IT AS A VERY NEGATIVE THING, YOU KNOW, THE PERSON'S CRAZY.

THERE IS SOME STIGMA WITH THAT PROBABLY THAT MAKES IT HARD FOR PEOPLE TO WANT TO

SPEAK UP IF THEY ARE EXPERIENCING SOME CHANGES.

DID I GET THAT RIGHT?

ARNETTA BATY: YES.

CARL BYRON BATY: YES.

BETH SOLTZBERG: THANK YOU.

ARNETTA BATY: DIDN'T WANT THEM TO BE AROUND THE REST OF THE HOUSE.

DIDN'T WANT THEM TO BE AROUND FOR NEIGHBORS TO WATCH THEM.

SO WE PUT THEM AWAY IN A PLACE WHERE OTHER PEOPLE WOULD EXPERIENCING THE SAME THINGS.

SO THEY WOULDN'T BECOME AN EMBARRASSMENT.

BETH SOLTZBERG: I SEE.

THANK YOU.

IRENE, HOW ABOUT YOU?

ANY THOUGHTS ABOUT THE FIRST QUESTION?

IRENE BELOZERSKY: ACTUALLY I REMEMBER GROWING UP I REMEMBER VERY COMMON THINGS PEOPLE SAYING PEOPLE REPEAT WITHOUT THINKING.

ONE WAS THE OLD PERSON IS THE SAME AS A CHILD.

ARNETTA BATY: YES.

IRENE BELOZERSKY: THEN THERE WAS AN EXPRESSION WHEN SOMEBODY, AN OLDER PERSON, BEGAN EXHIBITING DECLINE OR CHANGES, THEY WOULD SAY, OH, THE PERSON IS REVERTING BACK INTO CHILDHOOD.

YOU KNOW?

SO, THERE WAS KIND OF LIKE LOOKING AT PEOPLE WHO HAVE COGNITIVE DECLINE AS LOSING THEIR ADULT QUALITIES, AND WITH THAT LOSING THEIR DIGNITY AND LOSING THEIR RESPECT.

THEY ARE KIND OF NOT BEING TREATED AS EQUALS BUT RATHER WITH SOME KIND OF CONDESCENSIONS BECAUSE THEY ARE LIKE CHILDREN NOW.

THE WORD DEMENTIA WAS NOT LIKE YOU SAID, YEAH, IT WAS NOT WELL—KNOWN.

NEITHER ALZHEIMER'S NOR DEMENTIA.

I LEARNED ABOUT THEM ONLY AFTER I WENT TO SCHOOL SOCIAL WORK HERE.

I DIDN'T KNOW THIS.

IT'S A TERM WHICH IS USED IN THE RUSSIAN LANGUAGE TO DESCRIBE THIS KIND OF COGNITIVE DECLINE OR CONDITION HAS VERY

DEROGATORY CONNOTATION.

I THINK THE CLOSEST TRANSLATION WOULD BE FEEBLE—MINDEDNESS.

ARNETTA BATY: YES, YES, YES.

IRENE BELOZERSKY: SO PEOPLE WITH THAT WERE CALLED FEEBLE—MINDED.

THERE WAS A LOT OF STIGMA, OF COURSE.

WHEN SOMEBODY BEGAN TO SHOW THE SIGNS OF DEMENTIA, SO IT SOUNDED LIKE A SENTENCE THAT THE PERSON WAS SENTENCED TO RAPID DECLINE AND TO BE MOVED SOMEWHERE IN THE BACK ROOM OF THE HOUSE, AND KIND OF DISCOUNTED.

IN RUSSIA THEY DIDN'T HAVE OLD PEOPLE'S HOMES, THEY DIDN'T EXIST.

SO, THE BURDEN WAS ON THE FAMILY.

AND IT WAS A BURDEN BECAUSE THERE ARE NO SERVICES OF ANY KIND AVAILABLE, SO IT WAS USUALLY IT FELL ON THE SHOULDERS OF THE DAUGHTERS TO TAKE CARE OF THE PARENTS.

BUT ON THE OTHER HAND, THE CULTURAL NORMS EXPECTED THAT OLD PARENTS WILL BE TAKEN CARE OF.

THEY WILL NOT BE ABANDONED.

AT VERY PROBABLY HIGH COST TO THE

FAMILY, THEY WERE LOOKED AFTER IN THE HOUSE.

IT WAS VERY DIFFICULT.

I HAVE, YOU KNOW, I REMEMBER I WAS ALREADY LIVING HERE AND I HAD A CLOSE FRIEND WHO STILL, WHO LIVED IN MOSCOW.

SHE WAS IN AN ACCOMPLISHED CAREER PERSON, SHE WORKED.

SHE, HER MOTHER, STARTED HAVING VERY PRONOUNCED SIGNS OF DEMENTIA VERY QUICKLY PROGRESSING.

SO, MY FRIEND HAD TO GO TO WORK EVERY DAY.

THERE WAS NO CHOICE FOR HER.

SO, SHE WOULD LOCK HER MOTHER UP FOR THE WHOLE DAY ALONE AND WHEN SHE WOULD COME HOME SHE WAS EXPECTING TO FIND HORRIBLE, HORRIBLE CONDITIONS, WITH FECES SMEARED ON THE WALLS AND WATER ROTTING, WHATEVER.

IT WAS A DESPERATE SITUATION AND THERE WAS NOTHING TO DO ABOUT IT.

SO A LOT OF PEOPLE HAVE THIS COLLECTIVE EXPERIENCE AND, THEREFORE, THE ATTITUDES TOWARD DEMENTIA GENERALLY HAVE VERY NEGATIVE CONNOTATIONS.

THANK YOU, IRENE.

THAT IS SUCH AN IMPORTANT FRAMEWORK FOR ALL OF US TO THINK ABOUT AND UNDERSTAND ATTITUDES ABOUT DEMENTIA CAN'T BE SEPARATED FROM THE REALITY, THE RESOURCES THAT ARE AVAILABLE TO PEOPLE THAT IF PEOPLE ARE NOT ABLE TO GET THE HELP THAT THEY NEED, THAT'S GOING TO AFFECT HOW THEY VIEW DEMENTIA, AND THEIR WILLINGNESS TO TALK ABOUT IT.

SO, I REALLY APPRECIATE YOUR MENTIONING THAT, AND HERE IN THE UNITED STATES THERE IS TREMENDOUS VARIETY FROM COMMUNITY TO COMMUNITY, FROM REGION TO REGION, IN TERMS OF WHAT PEOPLE CAN AFFORD, WHAT SERVICES ARE AVAILABLE, AND NOT ONLY SERVICES BUT SERVICES IN THEIR LANGUAGE AND THAT FIT FOR THEM CULTURALLY, SO I THINK THAT'S A VERY IMPORTANT POINT THAT YOU ARE MAKING THAT WE NEED TO ALWAYS ASK, WELL, WHAT IS IT THAT PEOPLE ARE FACING IF THEY TALK ABOUT AND ACKNOWLEDGE THAT THIS IS SOMETHING GOING ON FOR THEMSELVES OR SOMEBODY THEY CARE ABOUT.

I ALSO WANTED TO MENTION WHAT YOU SAID ABOUT THE WORD FOR DEMENTIA IN RUSSIAN AND IT'S INTERESTING BECAUSE THE DEMENTIA FRIENDS PROGRAM HAS ITS ROOTS IN JAPAN, AND WHEN THE

PUBLIC HEALTH DEPARTMENT IN JAPAN BEGAN TO ADDRESS DEMENTIA, ONE OF THE FIRST THINGS THEY HAD TO DO WAS TO CREATE A NEW WORD BECAUSE THERE WASN'T A RESPECTFUL WORD IN THE JAPANESE LANGUAGE FOR DEMENTIA.

SO, THEY KIND A NEW WORD AND THEN THEY STARTED THIS MASS PUBLIC AWARENESS PROGRAM THROUGHOUT THE COUNTRY, AND IT WAS ACTUALLY THE WORD THAT WAS KIND OF THE SPARK TO FOCUS ON, I SO APPRECIATE YOU BRINGING THAT UP, TOO.

KUN I WOULD LOVE TO PASS IT ALONG TO YOU.

WHAT ARE YOUR THOUGHTS ABOUT THE FIRST QUESTION?

KUN CHANG: OKAY, SO WE HAVE A VERY SIMILAR TERM IN CHINESE, WE SAY -- WHAT THAT MEANS IS OLD, CRAZY, MAD, DUMB, OLD PERSON BASICALLY.

SO, THAT'S HOW EXACTLY THE SHARING WITH THE SAME AS MY COLLEAGUE MENTIONED.

SO TWO OF US RIGHT NOW WE ALSO TRY TO CHANGE THE LANGUAGE.

INSTEAD OF USING SO-CALLED THE WAY WE SAYING, WE ACTUALLY CHANGED THE WORD AND MORE

LIKE MEMORY LOSS, MORE GENERAL TERM, SO PEOPLE MORE ACCEPT IT ABOUT THIS.

THIS IS WHAT WE ARE TRYING TO DO RIGHT NOW.

TO OUR COMMUNITY THE CHALLENGE TO US IS WHEN WE HAVE SOMEONE, SOME LOVED ONE HAVE THIS, WHAT THAT MEANS TO US.

BASICALLY, WE TALK ABOUT THIS IS OUR FAMILY.

FAMILY HAS TO TAKE CARE ALL.

THAT MEANS THAT HUGE BURDEN TO FAMILY, ESPECIALLY ALL FAMILY BECOME VERY SMALL AND SMALLER, SO AS YOU KNOW WE ONLY HAVE ONE CHILD POLICY IN CHINA.

NO MORE THAN TWO, IT'S VERY COMMON.

SO THE BURDEN TO THE FAMILY BECOMES VERY HEAVY IN GENERAL.

SECOND ALSO TALKING ABOUT LONG—TERM BATTLE.

THIS IS SOMETHING THAT'S NOT GOING AWAY, SO WE HAVE TO FACE HOW TO DEAL WITH THIS.

AGAIN, BECAUSE WE BELIEVE THIS IS THE FAMILY SHOULD TAKE CARE OF THEIR OWN.

WE ARE SELDOM SEEKING SO—CALLED OUTSIDE

RESOURCES IN THE U.S. ALSO THE CHINESE VERY LIMITED RESOURCES AVAILABLE IN OUR COMMUNITY, SO THIS IS ONE THING WE HAVE MUCH DIFFICULTY IN ALL COMMUNITIES TO DEAL WITH THIS KIND OF SITUATION.

SO, THE BURDEN TO THE FAMILY, THE BURDEN TO INDIVIDUALS, ALSO HOW TO, WE WANT TO CONTAIN THIS SO—CALLED DISEASE INSTEAD OF TALKING ABOUT HOW TO HELP THEM.

SO WHEN WE CONTAIN, COULD BE WE NEVER ALLOW THIS INDIVIDUAL LEAVE HOME.

STAY HOME.

SOMEONE JUST KEEP THIS PERSON AT HOME.

SO, WE SEE THAT LACK OF QUALITY TOTAL CHANGE.

SO THIS IS SOMETHING WE HAVE TO LEARN HOW TO ADAPT, HOW TO CHANGE THIS MIND SET TO OPEN UP ALL RESOURCES.

OKAY, THANK YOU.

BETH SOLTZBERG: THANK YOU, KUN.

ALANA?

HOW ABOUT YOU?

WHAT ARE YOUR THOUGHTS ABOUT WHAT THE TERM DEMENTIA MEANS IN YOUR COMMUNITY?

ALANA DUNDON: WELL, FOR BRAZILIAN COMMUNITY THERE IS LIKE WHAT ARNETTA SAID IS PART OF AGING, TOO.

AND THE NAME IS ALZHEIMER'S.

THEY DON'T KNOW EXACTLY WHAT OTHER DEMENTIAS, THEY JUST KNOW SOMETHING WHEN THEY DO A TRAIN BEING LIKE DEMENTIA FRIENDS, SO THE FIRST THING WHEN YOU SAY DEMENTIA IS PEOPLE HAS ALZHEIMER'S.

YEAH, I AGREE WITH IRENE BECAUSE THEY ARE TREATED AS A CHILD.

IN BRAZIL WE HAVE A PROGRAM ON TV THAT IS CALLED NOVELLA, SO EVERY DAY HAS ONE DIFFERENT EPISODE, AND THEY SHOW A LOT ABOUT ALZHEIMER'S.

THEY PUT OUT WHEN PEOPLE WITH ALZHEIMER'S ON THIS SHOW AND TRIED TO TALK ABOUT THIS, BUT I THINK IT'S A LITTLE BIT, IT'S NOT REAL.

YOU KNOW?

THEY PUT IN SOME POINT THAT IS MORE, IS NOT REALITY.

WHEN YOU LIVE WITH SOMEBODY THAT HAS ALZHEIMER'S YOU KNOW EXACTLY WHAT IT IS.

SO THE PEOPLE HAS A WRONG IDEA OF WHAT

IT REALLY MEANS, YOU KNOW?

AND IN BRAZIL IF YOU WANT TO OFFEND SOMEBODY YOU USE THIS TERM.

YOU HAVE DEMENTIA.

SO, IT'S NOT OKAY.

YOU KNOW?

THAT PEOPLE DOESN'T SEE THESE AS A HEALTH PROBLEM.

ONE ISSUE THAT THE FAMILY HAS A LOT OF WORK TO DO WITH THESE PEOPLE WHEN YOU LIVE WITH THESE PEOPLE.

I AM LIVING WITH MY MOM FOR FIVE YEARS, FIVE YEARS THAT'S HOW LONG AGO SHE WAS DIAGNOSED WITH ALZHEIMER'S AND SHE IS IN VERY, VERY BAD CONDITION NOW.

AND LIKE KUN SAID, I DON'T HAVE SIBLINGS, SO IT'S NOT EASY.

WHAT I HEARD, I HEAR, ABOUT MY FAMILY IS YOU HAVE TO TAKE CARE OF HER.

THEY DON'T KNOW EXACTLY WHAT THIS MEANS.

THEY SAY THAT.

OKAY?

THANK YOU.

OF.

BETH SOLTZBERG: THANK YOU, ALANA.

I THINK AGAIN THERE IS SUCH AN IMPACT OF WHETHER MEMBERS OF THE PUBLIC, MEMBERS OF THE COMMUNITY, ARE AWARE AND HAVE SOME KNOWLEDGE AND UNDERSTANDING BECAUSE WHEN YOU'RE A FAMILY MEMBER, AND YOU'RE TRYING TO BALANCE YOUR EMPLOYMENT AND TAKING CARE OF SOMEONE, IF OTHER PEOPLE DON'T UNDERSTAND, IF THEY THINK IT'S JUST A LITTLE FORGETTING, YOU KNOW, IT'S NOTHING, OR MAYBE THEY HAVE A LOT OF JUDGMENTS ABOUT HOW THEY THINK THINGS SHOULD BE HANDLED, IT INCREASES THE BURDEN SO MUCH, SO I APPRECIATE YOUR SHARING YOUR PERSONAL EXPERIENCE AND THAT'S JUST ANOTHER LEVEL OF WHERE COMMUNITY EDUCATION AND COMMUNITY AWARENESS HAS AN IMPACT.

SO I WOULD LOVE TO BRING IN JACYRA AND FRANCES.

FRANCES SAMIDY ORTIZ: THANK YOU EVERYONE FOR BEING HERE AND TO JOIN US.

THE TERM DEMENTIA IN OUR COMMUNITY IN THE LATINO COMMUNITY MEANS LIKE WHEN SOMEONE IS MENTALLY ILL OR CRAZY THEY LIKE TEND TO REJECT THEM OR ISOLATE THEM BECAUSE THEY DO

NOT UNDERSTAND WHAT THE TERM ALZHEIMER'S OR DEMENTIA MEAN, SO WHEN JACYRA AND I STARTED DOING THIS DEMENTIA FRIENDS TRAININGS, WE WERE FASCINATED BY THE IDEA THAT THE TENANTS AND PEOPLE WE WERE TRAINING COULD UNDERSTAND THE DIFFERENCE BETWEEN THIS AND SOME OF THEM COULD GET A REALLY BIT EMOTIONAL FOR IT BECAUSE THINKING ABOUT THE BAD THINGS BECAUSE THEY DID NOT KNOW WHAT THEY WERE DOING, AND WHAT THEY CAN DO NOW SO THEY CAN IMPROVE TO TAKE CARE OF THE FAMILY OR A FRIEND OR SOMEONE ELSE.

BETH SOLTZBERG: THANK YOU.

JACYRA, DID YOU WANT TO ADD ANYTHING?

JACYRA: I WOULD RESPOND TO THE QUESTION TOO, BUT PRETTY MUCH DEMENTIA IN OUR COMMUNITY MEANS, IT'S LIKE WHEN YOU ARE SITTING AT THE TABLE YOU HAVE YOUR PLATE, YOU HAVE YOUR FORK, YOU HAVE YOUR SPOON, YOU HAVE LIKE A REGULAR MEAL AND A DESSERT.

HAVING SOMEONE WHO HAS DEMENTIA IS LIKE HAVING A BROKEN FORK THAT YOU CANNOT USE.

IT'S THROWN ASIDE ON THE TABLE.

THAT'S PRETTY MUCH, LIKE IT'S NOT SOMEONE, IT'S NOT SOMEONE THAT CAN PARTICIPATE IN ANY HUMAN ACTIVITY ANY MORE, SOMEONE YOU CAN HOLD A CONVERSATION WITH.

IT'S JUST SOMEONE THAT JUST SITS THERE LIKE A STATUE AND YOU ARE NOT EVEN THERE.

BETH SOLTZBERG: THANK YOU FOR SHARING THOSE THOUGHTS.

YOU KNOW, I THINK THAT IT'S UPSETTING TO HEAR SOME OF THE MISINFORMATION AND SOME OF THE STIGMA AND KNOWLEDGE, SO WE KNOW HOW THAT AFFECTS PEOPLE IN THEIR REAL LIVES.

IT'S HARD ENOUGH WHEN SOMEONE HAS OR WHEN SOMEONE IS NOTICING CHANGES IN THEIR THINKING THAT CAN BE VERY SCARY AND PEOPLE AROUND YOU MAY NOT BE COMPASSIONATE AND SUPPORTIVE OR MAY NOT KNOW HOW TO FIND HELP.

IT'S JUST MUCH MORE DIFFICULT TO PROVIDE.

ONE COMMENT THAT CAME UP A FEW TIMES WAS THE IDEA OF TREATING SOMEONE AS IF THEY WERE A CHILD I'M JUST CURIOUS WHETHER ANY OF YOU FOUND THROUGH YOUR INFORMS SESSIONS THAT WAS A TOPIC YOU WERE ABLE TO CHANGE PEOPLE'S

THINKING ABOUT, SO IF ANYONE WANTS TO RESPOND TO THAT PLEASE GO AHEAD.

SPEAKER: I WOULD LIKE TO COMMENT ON THAT.

NOT SURE IF YOU GUYS ARE ABLE TO HEAR ME BECAUSE THERE IS A POWER OUTAGE HERE.

BETH SOLTZBERG: WE CAN HEAR YOU.

SPEAKER: SO, AGAIN I AM, I WANT TO BRING SOME CULTURAL PERSPECTIVE FROM TWO THINGS.

I'M INDIAN FROM INDIA AND ALSO I AM MUSLIM BY FAITH.

I AM A HEALTH CARE PRACTITIONER WHERE I PRACTICE PHYSICAL THERAPY.

SO I WANT TO BRING CULTURAL PERSPECTIVE BECAUSE IT'S PRETTY SIMILAR TO COUPLE LIKE THE CHINESE AND THE JAPANESE FOR US CULTURE IS HIGHLY DRIVEN BY FAITH RESOLVING AROUND IT.

WE FEEL LIKE THE BURDEN COMES BACK TO FAMILY MAYBE.

SO, THAT'S —— BUT I THINK IN MY

PERSONAL OPINION, A LOT OF TIMES ALSO IT DEPENDS ON KIND OF THE EDUCATION BREAK DOWN AND WHERE THEY ARE COMING FROM I FIND LIKE THE COMMUNITY'S MORE OPEN TO ADAPT AND OPEN TO LEARN ABOUT IT AND ADAPT ACCORDINGLY.

THAT'S WHAT MY EXPERIENCE HAS BEEN WITH WORKING WITH MY OWN COMMUNITIES AS I'M PROVIDING CARE FOR THEM AND HELP THEM UNDERSTAND DEMENTIA BETTER.

ON THE NOTE OF TWO THINGS THAT WAS MENTIONED, ONE ABOUT THE THEORY OF RETROGENESIS, THAT SEEMS TO BE COMING I DON'T KNOW MAYBE THERE IS SOME KNOWLEDGE THAT PEOPLE LEARN THAT WHEN THEY ARE TELLING THAT THEY ARE REVERTING BACK TO CHILDHOOD, SO I THINK THAT'S INTERPRETED INCORRECTLY.

IN A WAY WE CAN USE THAT KNOWLEDGE TO MEET THE PERSON WHERE THEY ARE, BUT NOT AGAINST IT.

SO IF YOU CAN INTERACT WITH THE PERSON WITH THE DEMENTIA BY UNDERSTANDING WHERE THEIR COGNITION IS, THAT WOULD BE IN YOUR BENEFIT RATHER THAN LOOKING DOWN AT THEM WOULD BE MORE DEMEANING, YOU KNOW?

THAT'S MY PERSPECTIVE.

MAYBE THERE IS SOME KNOWLEDGE THAT CAME OUT AND PEOPLE WERE EXPOSED TO THIS KNOWLEDGE, BUT IT WAS NOT COMPLETE.

ONE THEORY CAN'T JUST BE LOOKED AT BY ITSELF.

THAT'S MY OPINION.

MAYBE THAT IS IN THE KNOWLEDGE THAT CAME OUT AND IT'S NOT COMPLETE, AND PEOPLE ARE LOOKING AT ONLY SEGMENTATION OF IT.

THE OTHER THING WAS, WHAT WAS THE OTHER THING?

I DID HAVE A COMMENT BUT I LOST MY TRAIL OF THOUGHT.

BETH SOLTZBERG: THAT'S OKAY.

THANK YOU, I THINK THAT'S A REALLY INTERESTING POINT.

I JUST WANT TO LET PEOPLE KNOW IF THEY HAVEN'T HEARD OF THAT THEORY THAT YOU MENTIONED, THERE IS A THEORY CALLED RETROGENESIS, WHICH MEANS THAT THE COGNITIVE FUNCTIONS THAT WE LEARN EARLIER IN LIFE ARE THE MOST ENDURING, SO IF A PERSON DEVELOPS DEMENTIA THEY ARE GOING TO HOLD ON TO THOSE COGNITIVE FUNCTIONS THAT THEY LEARNED FROM INFANCY OR FROM WHEN THEY WERE CHILDREN TO

THE POINT THAT SOMEONE MAINTAINS THE ABILITY TO HOLD ON TO A FINGER, TO RESPOND TO RHYTHM, WHICH CAN BE IN MUSIC OR POETRY, BECAUSE THOSE ARE SOME OF THE VERY FIRST COGNITIVE FUNCTIONS THAT DEVELOP IN HUMAN BEINGS.

SO, THE POINT IS BEING MADE THERE IS A THEORY ABOUT HUMAN DEVELOPMENT AND HOW THAT AFFECTS DEMENTIA AND THAT'S ONE THING.

BUT ANOTHER THING IS THIS IDEA THAT PEOPLE BECOME CHILDREN AGAIN.

WE KNOW THAT THEY DON'T.

THEY CONTINUE TO BE THEMSELVES, SO THEY CONTINUE TO BE THE ADULT WHO THEY ARE.

WHEN PEOPLE DEVELOP DEMENTIA, THEY HAVE HAD A LIFETIME OF EXPERIENCES, THEY HAVE A UNIQUE PERSONALITY, THEY COME FROM A PARTICULAR CONTEXT OR SITUATION.

NONE OF THAT DISAPPEARS.

THEY DEVELOP A BRAIN DISEASE, BUT IT IS SOMETHING THAT THEY CONTINUE TO BE THEMSELVES LIVING WITH A DISEASE.

SO WHEN YOU TREAT SOMEONE AS A CHILD, WE'RE REALLY NOT TREATING THEM AS WHO THEY ARE.

IT CAN REALLY BE VERY HARMFUL TO PEOPLE

EVEN THOUGH IT'S UNDERSTANDABLE WHY THERE IS THAT CONFUSION.

JACYRA: I WANT TO ADD WHAT HAPPENS IS THAT BECAUSE YOU KNOW IF YOU ARE DIAGNOSED WITH DEMENTIA AND YOU ARE GOING THROUGH DEMENTIA YOU KIND OF LOSE ABILITY TO DO A LOT OF STUFF FOR YOURSELF, AND THAT KIND OF MAKES PEOPLE LIKE THE PERSON WHO WITH DEMENTIA FEELS LIKE, MAKE THEM FEEL WEAKER LIKE THEY LOSE THEIR POWER PRETTY MUCH AS A HUMAN BEING AND THE OTHER PERSON WHO IS TAKING CARE OF THEM GETS MORE POWER OVER THEM, AND THAT'S, THEY ARE TAKING CARE OF THEM.

YOU KNOW, BRUSHING THEIR TEETH, SHOWERING THEM, AND I THINK THAT'S WHERE THE FEELING OF CHILDHOOD MAY COME OUT OF.

LIKE, HEY, I AM TAKING CARE OF YOU.

I AM YOUR BOSS NOW PRETTY MUCH.

TREAT THEM WHATEVER THEY WANT AND IT CAN BE FRUSTRATING FOR THE PERSON WITH DEMENTIA.

SO THAT'S WHY IT'S REALLY GOOD TO GET THESE TRAININGS SO WE KNOW HOW TO DEAL WITH THIS.

BETH SOLTZBERG: THANK YOU, JACYRA, THAT'S A REALLY IMPORTANT POINT.

GO AHEAD, KUN.

KUN CHANG: I THINK WHEN PEOPLE SAYING THAT, ACTUALLY THE WAY WE FEEL BETTER TO TREAT MY LOVED ONE BECAUSE THE WAY YOU HAVE YOUNG KIDS LIKE THREE AND FIVE, THEY ARE SO CUTE, THEY START DOING CERTAIN THINGS IT'S KIND OF NONSENSE BUT WE ACCEPT IT.

THAT'S THE WAY I FEEL AS A CAREGIVER THEY FEEL MY LOVED ONE, THEY CONDITION DETERIORATES THERE IS A WAY YOU JUSTIFY I FEEL MUCH BETTER, I AM TAKING MY OLDER ONES JUST LIKE YOUNGER ONE, SO WE HAVE MUCH HIGHER TOLERANCE ABOUT BEHAVIOR, ABOUT THIS.

SO I THINK THIS IS THE WAY WE HELP OURSELVES AS A CAREGIVER TO READJUST MY POSITION, TREAT MY LOVED ONE AS A KID.

UNFORTUNATELY, THEY ARE NOT KIDS.

SO THIS IS THE WAY, THIS IS A LITTLE BIT DIFFERENT I THINK THAT'S THE WAY I FEEL PEOPLE HOW JUSTIFIED ABOUT IT.

BETH SOLTZBERG: THANK YOU, KUN.

THAT'S A GOOD POINT AND IT'S AN EXAMPLE OF HOW DELICATE AND COMPLICATED IT CAN BE FOR FAMILIES WHO FIND THEIR WAY WHEN SOMEONE DEVELOPS DEMENTIA, AND THAT FAMILY MEMBERS ARE GRIEVING THE LOSS OF THE RELATIONSHIP THE WAY IT WAS AND THEY ARE OFTEN STRUGGLING TO FIND A WAY TO SUPPORT THIS PERSON JUST AS THE PERSON LIVING WITH DEMENTIA IS STRUGGLING TO FIND THEIR WAY AND TO FIND WAYS TO ADAPT TO HOW THEIR COGNITION IS CHANGING.

AND THAT IS SUCH A VIVID EXAMPLE OF HOW FAMILY MEMBERS ARE NOT MEANING ANY HARM.

IN FACT, IT'S AN EXPRESSION OF CARING AND IT'S A WAY OF THINKING ABOUT THIS PERSON AND BEING FORGIVING THE WAY THEY WOULD WITH A CHILD WHO THEY ADORE AND LOVE.

BUT YET, IT ISN'T, IT DOESN'T FIT WITH WHO THE PERSON IS, SO IT CAN MAKE THAT PERSON FEEL DISRESPECTED OR NOT SEEN AS AN INDIVIDUAL.

BRIAN, I DON'T KNOW IF YOU HAVE ANY THOUGHTS ABOUT THIS.

I GUESS A LOT OF WHAT WE'RE TALKING ABOUT IS SOMETHING YOU'VE ENCOUNTERED?

IF YOU FEEL LIKE MAKING ANY COMMENTS, PLEASE FEEL FREE TO UNMUTE YOURSELF.

SO I WILL GO ON FOR NOW TO THE SECOND QUESTION, BUT, YOU KNOW, THESE QUESTIONS ALL FLOW TOGETHER.

WE WANTED TO TALK A LITTLE BIT ABOUT CARE GIVING OR BEING OF SUPPORT TO SOMEONE WHO IS LIVING WITH DEMENTIA.

AND TO TALK ABOUT SOME OF THE VALUES.

MAY HAVE AROUND THAT BECAUSE WE KNOW CULTURAL COMMUNITIES REALLY VARY IN TERMS OF THEIR EXPECTATIONS ABOUT WHAT'S THE RIGHT WAY FOR A FAMILY TO BEHAVE?

IS THERE A PARTICULAR PERSON IN THE FAMILY WHO IS SUPPOSED TO TAKE THE LEAD AND GIVE CARE AND THINGS LIKE THAT.

I WILL JUST GO THROUGH OUR SPEAKERS AGAIN AND START WITH ARNETTA AND CARL, AND I WONDER IF YOU HAVE ANY COMMENTS ABOUT THAT.

WHAT ARE SOME BELIEFS AND VALUES ABOUT CARE GIVING IN YOUR COMMUNITY?

CARL BYRON BATY: YOU HAD TO TAKE CARE OF WHATEVER HAPPENED.

YOU DIDN'T SEND YOUR FAMILY SOMEWHERE ELSE TO BE CARED FOR.

YOU KEPT THEM HOME.

A LOT OF WHAT I THINK YOU GOT SOMEBODY THAT WILL WANDER OUT OF THE HOUSE AND JUST WANDER OUT, SO A LOT OF PLACES PEOPLE HAVE SOMEBODY IN THE ROOM THAT WAS LOCKED IN THE ROOM.

BUT THAT'S THEIR WAY OF TRYING TO KEEP THEM SAFE.

AND THERE WAS NO EDUCATION ABOUT IT.

SO, YOU JUST, YOU DID THE BEST YOU COULD WITH WHAT YOU HAD.

ARNETTA BATY: YOU KNOW, BETH AND EVERYONE ON THE CALL, AS A YOUNG GIRL GROWING UP IN WEST VIRGINIA WE USED TO ALWAYS SAY GRANDMA WAS NOT FEELING WELL TODAY.

GO SIT WITH GRANDMA SO SHE CAN TELL YOU A STORY.

AS I GREW OLDER, I BEGAN TO THINK THAT GRANDMA WASN'T, WAS NOT FEELING WELL.

GRANDMA WAS FEELING GOODS FOR HER AGE.

SHE LIVED TO BE 103.

SHE COULD TELL YOU STORIES FROM WAY BACK WHEN, BUT AT THE PRESENT SHE WOULD FORGET CERTAIN THINGS.

SO, AS I GREW UP MY MOM STARTED EXPERIENCING SOME OF THE SAME THINGS.

AS A CHILD CARE PROVIDER FOR 20 PLUS YEARS, I ALLOWED MY MOM TO TELL THE CHILD CARE CHILDREN STORIES ABOUT WHAT HAPPENED TO HER IN WEST VIRGINIA.

SO, WE NEVER REALLY PUT GRANDMA, OUR MOM, IN A HOUSE.

THEY STAYED WHERE THEY WERE UNTIL THEY PASSED AWAY.

TO ME, THAT WAS A GREAT EXPERIENCE.

BECAUSE GRANDMA AND MAMA WAS ABLE TO TELL US STORIES THAT WE STILL LIVE BY TODAY.

MY BROTHERS AND SISTERS AND I AND HER GRANDCHILDREN STILL REMEMBER SOME OF THOSE STORIES THAT SHE USED TO TELL.

SO, DEMENTIA REALLY NEVER BECAME A WORD FOR US.

IT WAS JUST GRANDMA WAS GETTING OLD AND SHE LIKED TELLING STORIES.

TAKING CARE OF MY MOM, SHE STARTED TO GET TO BE ABOUT 65, 70, IT WAS A STRUGGLE.

IT TRULY WAS, BECAUSE I WAS WORKING AT HOME, WHICH WAS NOT SO MUCH OF A STRUGGLE, BUT TRYING TO KEEP UP WITH HER WHERE SHE WAS

SO VIBRANT ABOUT WALKING AND GOING PLACES BY HERSELF BUT I HAVE TO THINK THAT'S WHAT SHE WAS USED TO DOING ALL HER LIFE WAS GETTING OUT, GOING AND TALKING TO THE NEIGHBORS, DOING THINGS SHE LIKED TO DO, SO IT TOOK SOME ADJUSTMENT WITH ME TO ADJUST MY SCHEDULE BECAUSE I WAS HOME.

I WASN'T OUT AT A BUSINESS.

I WAS HOME TAKING CARE OF MY CHILDREN AND OTHER PEOPLE'S CHILDREN.

AND GRANDMA WAS NOT ONLY GRANDMA TO MY GIRLS, BUT SHE WAS ALSO GRANDMA TO THE DAYCARE GIRLS.

SO, HER TELLING STORIES TO THEM WAS GREAT.

SHE WAS ABLE TO GO BACK INTO WHAT WE NOW SEE IS THE BOOK SHELF STORIES WHERE SHE COULD REMEMBER SOME OF THE PRESENT BUT COULD REMEMBER A LOT OF THE PAST, AND THEY WERE GREAT STORIES.

SO, TO ME IT WAS A GOOD EXPERIENCE BECAUSE AS I GO ON IN MY STAGES OF LIFE, I CAN UNDERSTAND WHAT'S GOING ON WITH ME AND MY HUSBAND, CARL.

BETH SOLTZBERG: THANKS SO MUCH, ARNETTA.

THANK YOU, CARL.

THAT'S A BEAUTIFUL STORY ABOUT HOW HAVING EVERYONE UNITED AND TOGETHER, STAYING TOGETHER, YOU CAN GAIN SO MUCH FROM THE RELATIONSHIPS AND THAT PEOPLE WHO ARE LIVING WITH DEMENTIA, THEY MIGHT HAVE CERTAIN THINGS THAT BECOME DIFFICULT FOR THEM, BUT THEY HAVE OTHER THINGS THAT THEY CAN DO AND THEY CONTINUE TO BE SUCH AN IMPORTANT MEMBER OF THEIR FAMILY AND THEIR COMMUNITY, AND THE BOOKCASE THAT ARNETTA WAS TALKING ABOUT, THAT'S AN EXERCISE IN THE DEMENTIA FRIENDS PROGRAM IN THE INFORMATION SESSION WHERE WE TALK ABOUT THE BOOKCASE AS A METAPHOR AND THAT SOME OF THE SKILLS FOR THINKING THAT ARE REALLY COGNITIVELY COMPLICATED AND LEARNED LATER IN LIFE OFTENTIMES ARE THE ONES THAT START TO GO, BUT PEOPLE MAINTAIN THEIR EMOTIONAL LIFE, THEIR NEED TO BE CONNECTED WITH OTHERS, AND IN THE CASE OF YOUR FAMILY A LOT OF LONG—TERM MEMORIES.

IT SOUNDS LIKE THAT WAS AMAZING FOR YOU AND ALSO THE CHILDREN IN YOUR HOUSEHOLD TO

REALLY BENEFIT FROM ALL THOSE STORIES.

BUT THANK YOU FOR SHARING THAT.

ARNETTA BATY: YOU ARE WELCOME.

BETH SOLTZBERG: IRENE, HOW ABOUT YOU?

IRENE BELOZERSKY: WELL, I THINK THERE ARE TWO INTERESTING DIFFERENT KIND OF PROCESSES I SEE.

GENERALLY SPEAKING AS I MENTIONED SINCE THERE WAS NO EXPERIENCE WITH ANY KIND OF SERVICES, THE FAMILIES AND THE SOCIAL EXPECTATIONS WAS THAT THE FAMILY IS TAKING CARE OF THE ELDERLY AND WITH PEOPLE WITH DEMENTIA.

IT WAS ALSO KIND OF A MATTER ON HONOR NOT TO GIVE UP ON THE ELDERLY.

TO THE BEST OF THEIR ABILITY FAMILIES WERE TAKING CARE OF THEM.

BUT WHEN THE RUSSIAN COMMUNITY STARTED GROWING AND EXPANDING IN THE UNITED STATES, THE OLD NORMS BEGAN TO CHANGE BECAUSE THEY STARTED ABSORBING THE CURRENT DIFFERENT NEW CULTURE.

SO, I REMEMBER THAT PROBABLY 20, 25 YEARS AGO A HEBREW SENIOR LIFE, IT'S THE BIGGEST FACILITY FOR THE ELDERS IN BOSTON STARTED REACHING OUT TO THE RUSSIAN COMMUNITY, RAISING AWARENESS OF THE AVAILABILITY OF THE NURSING HOME SERVICES.

AND FIRST I THINK IT WAS MET WITH A LOT OF RESISTANCE IN THE COMMUNITY.

IT WAS SHAMEFUL TO PLACE YOUR PARENT IN A NURSING HOME.

IT WAS SHAMEFUL, IT WAS FROWNED UPON.

NOW, 25 YEARS LATER, THIS HAS CHANGED DRAMATICALLY.

I THINK THAT HEBREW SENIOR LIFE HAS ADDED A WHOLE FLOOR DEDICATED TO THE RUSSIAN LANGUAGE SERVICES NOW AND THERE IS ALWAYS A WAITING LIST.

THERE ARE A FEW OTHER NURSING HOME FACILITIES IN BOSTON AND AROUND BOSTON, MASSACHUSETTS CATERING SPECIFICALLY TO THE RUSSIAN LANGUAGE PATIENTS.

SO, THE CULTURAL NORMS DO CHANGE, AND RIGHT NOW I THINK THAT THE EXPECTATIONS ARE THE FAMILY STAYS VERY MUCH INVOLVED, BUT THE DAY—TO—DAY CARE IS RELEGATED TO AN

INSTITUTION.

BETH SOLTZBERG: THANK YOU, IRENE.

I THINK IT'S REALLY IMPORTANT AS WE'RE TALKING ABOUT THIS TO ACKNOWLEDGE THAT EVERY SITUATION IS DIFFERENT, EVERY INDIVIDUAL HAS DIFFERENT NEEDS AND EVERY FAMILY'S DIFFERENT, ARE AND AS YOU ARE POINTING OUT ON THE ONE HAND THERE WAS ALWAYS A VERY POSITIVE VALUE THAT IT'S IMPORTANT FOR RUSSIAN FAMILIES TO CARE FOR THEIR PARENTS AND GRANDPARENTS.

ON THE OTHER SIDE OF THAT, THERE WAS SHAME IF YOU COULDN'T DO IT YOURSELF.

AS WE TALKED ABOUT AT THE BEGINNING THIS UMBRELLA OF DEMENTIA INCLUDES SO MANY DIFFERENT SITUATIONS, DIFFERENT KINDS OF SYMPTOMS, AND THERE ARE MANY –– IN MY WORK AS A SOCIAL WORKER FOR MANY YEARS I'VE KNOWN MANY FAMILIES THAT HAVE REALLY STRUGGLED TO KEEP THEIR LOVED ONE AT HOME AND IT WAS ACTUALLY MUCH BETTER FOR EVERYONE INCLUDING THE PERSON LIVING WITH DEMENTIA WHEN THEY FOUND AN ALTERNATIVE EITHER CARE TO COME INTO THE HOME OR A RESIDENTIAL SETTING, AND I'VE HEARD MANY SONS AND DAUGHTERS SAY THINGS LIKE

NOW I GET TO JUST BE A SON OR I GET TO BE A DAUGHTER.

I CAN ACTUALLY ENJOY MY TIME WITH MY PARENT OR MY WIFE, MY HUSBAND, WHATEVER THE CASE MAY BECAUSE I'M NOT STRUGGLING SO MUCH WITH PHYSICAL NEEDS AND THINGS I'M REALLY NOT TRAINED OR ABLE TO DO.

SO, EVERY SITUATION IS DIFFERENT.

I THINK THE POINT HERE IS THAT VALUES MATTER AND THAT AS WE'RE HELPING EACH OTHER, WE NEED TO RESPECT THOSE VALUES.

WE NEED TO LISTEN FOR THEM BECAUSE IF WE MISS THAT, IF WE DON'T UNDERSTAND THE VALUES IN A PARTICULAR COMMUNITY WE'RE NOT REALLY GOING TO BE ABLE TO HELP AND SUPPORT THAT PERSON.

AND WE NEED TO WORK AGAINST THIS STIGMA SO THAT PEOPLE CAN TALK OPENLY ABOUT WHAT'S GOING ON AND WHAT THEY NEED BECAUSE THEN HOPEFULLY PEOPLE CAN GET THEIR NEEDS MET AND IT WON'T BE THE SAME FOR EVERYBODY.

IT WILL BE DIFFERENT.

IRENE BELOZERSKY: YEAH, I WANT TO ADD THOUGH THAT BECAUSE I THINK THERE IS STILL A

CERTAIN DEGREE OF STIGMA OR GUILT INVOLVED IN PLACING AN ELDER, GRAND PARENT, PARENT, WITH DEMENTIA PLACING IN A NURSING HOME MANY RUSSIAN FAMILIES ARE TRYING TO FIND A MORE ACCEPTABLE COMPROMISE.

THERE IS A LITTLE KIND OF COTTAGE INDUSTRY I THINK WHICH EXISTS NOT ONLY IN BOSTON BUT ACROSS THE UNITED STATES IN MAJOR CITIES WHERE IT'S POSSIBLE TO FIND HIRE ICARETAKER IN THE RUSSIAN COMMUNITY BECAUSE THERE ARE A LOT OF PEOPLE WHO COME HERE TEMPORARILY VISAS OR WHATEVER WAYS FROM RUSSIA TO JUST MAKE SOME MONEY, TO HELP THE FAMILIES BACK IN RUSSIA.

SO, THESE WOMEN ARE WILLING TO TAKE CARE OF THE ELDERS IN THEIR HOMES AND THE COST IS MUCH LOWER THAN IF IT WERE LIKE HIRED THROUGH THE AGENCIES OR PRIVATE CARE ON THE OPEN MARKET.

SO, IT'S ONE OF THE VERY, VERY COMMON AND VERY POPULAR WAYS OF FINDING ADDITIONAL HELP FOR THE ELDERS.

I SEE ADDS ON THE RUSSIAN LANGUAGE SOCIAL PLATFORMS ADS ALL THE TIME EITHER ASKING FOR THIS POSITIONS OR OFFERING HELP.

THE IT'S VERY POPULAR.

BETH SOLTZBERG: THANK YOU, IRENE, VERY INTERESTING.

KUN, HOW ABOUT YOU?

DO YOU HAVE THOUGHTS ON THIS QUESTION?

KUN CHANG: WHEN I WAS YOUNG, MY PARENTS TOLD ME YOU HAVE TO MARRY A RIGHT WOMAN.

NOT JUST LOOKING ON THE OUTSIDE, ALSO LOOKING INSIDE BECAUSE THE WOMAN WILL CHANGE YOUR LIFE TAKING CARE OF YOUR CHILDREN, YOUR PARENTS, YOUR IN—LAWS, EVERYBODY.

SO, WHAT THAT MEAN?

FEMALE IS THE MAJOR CAREGIVER IN ALL COMMUNITIES.

I SEE THIS ACROSS THE BOARD.

EVERYBODY AGREES ABOUT IT.

FEMALE IS SO IMPORTANT TO TAKING CARE OF LOVED ONE.

FOR ALL THREE GENERATIONS IN GENERAL.

BUT WHO MAKES THE DECISION?

UNFORTUNATELY IT'S MEN IN OUR COMMUNITY.

I JUST WENT BACK TO MY MOTHER—IN—LAW'S FUNERAL.

SO, ON THE WHOLE PROCESS THIS IS VERY OLD TRADITIONAL WAY WE HAVE 150 FAMILY MEMBERS ATTEND, AND WHO MAKES THE DECISION?

THE OLDEST SON MAKES THE DECISION.

WHO TAKING CARE OF MY MOTHER—IN—LAW?

IT'S THEIR DAUGHTER TAKING CARE IN THE PAST THREE OR FOUR YEARS.

SO, THAT'S HOW THE FEMALE IS PREDOMINANTLY TAKING CARE OF EVERYTHING, BUT WE SHOULD SEE A CRITICAL POINT IN ALL CULTURE OLDERSON IS IN CHARGE.

IT'S THE PERSON WHO MADE THE DECISION AND EVENTUALLY GO OVER THE FINANCIAL ARRANGEMENT.

SO, I HAVE TO SAY VERY IMPORTANT TO US, TO EVERYBODY, ALL THE MEN, MEN RELY ON WOMEN.

OKAY?

IS SECOND IN THIS PART OF THE U.S. BECAUSE OF THE LANGUAGE BARRIER SOMETIMES SOME FAMILY COULD NOT REALLY SPEAK WELL TO COMMUNICATE WITH THE OTHER CAREGIVER, OTHER HEALTH CARE PROVIDER, OR DOCTOR SOMETIMES THEY RELY ON THEIR GRANDCHILDREN WHO BECOME THE PRIMARY INTERPRETER.

UNFORTUNATELY, NOT ALL THE HEALTH CARE

PROVIDERS HAVE THE INTERPRETER AVAILABLE TO THEM, SO ALSO EVEN IF THEY ARE AVAILABLE IT'S NOT AVAILABLE ALL THE TIME.

YOU ALWAYS NEED TO HAVE SOMEONE IN YOUR FAMILY ABLE TO HELP YOU TO UNDERSTAND THE ASSISTANT UNDERSTAND ABOUT THEM.

SO SOMETIMES THE GRANDCHILDREN BECOME AN IMPORTANT PART OF HELPING THEIR GRANDPARENTS ABOUT THAT.

THIS IS FAMILY—CENTERED CARE IN GENERAL.

SO, HOW DO WE WORK WITH THIS?

HOW TO HELP THE FAMILY?

HOW TO UNDERSTAND ABOUT WE CAN'T SEEK OUTSIDE HELP.

IT'S OKAY ABOUT THAT.

BUT IT IS GOING TO TAKE TIME TO LEARN ABOUT THE PROCESS.

THANK YOU.

BETH SOLTZBERG: THANK YOU VERY MUCH, KUN.

THOSE ARE SUCH IMPORTANT POINTS THAT ARE NECESSARY TO UNDERSTAND IF A PERSON IS WORKING WITH A CHINESE IMMIGRANT COMMUNITY

AND I WOULD THINK THERE ARE OTHER COMMUNITIES THAT WOULD FIND SOME SIMILARITIES IN SOME OF THE THINGS THAT YOU ARE SAYING.

IT'S VERY IMPORTANT TO UNDERSTAND IN CERTAIN COMMUNITIES WHO IS EXPECTED TO TAKE CARE AND ALSO THE ROLE OF YOUNGER FAMILY MEMBERS AS THE GO BETWEEN FOR IMMIGRANT FAMILIES.

I WOULD LOVE TO ASK ALANA IF YOU HAVE COMMENTS YOU WOULD LIKE TO MAKE ABOUT COMMUNITY VALUES AROUND CARE GIVING?

ALANA DUNDON: THE SAME OF IRENE, LIKE PEOPLE, THE FAMILY HAS SHOULD HAVE TO TAKE CARE OF YOUR LOVED ONE, AND THEY FEEL VERY GUILTY IF IT THEY CANNOT, YOU KNOW?

AND ARE THEY DOING IT JUST BECAUSE THEY DON'T WANT TO BE, TO FEEL GUILTY.

YES, THE COST IS ONE BARRIER TOO BECAUSE IT'S A LOT OF EXPENSES TO PLACE THEM IN A NURSING HOME, AND IT'S NOT EVERYBODY WHO HAS A GOOD HEALTH PLAN, HEALTH INSURANCE.

SO, WE HAVE TO WORK AND TAKE CARE OF PEOPLE, SO THAT'S NOT EASY.

THE NEW GENERATION I THINK IS THINKING

A LITTLE BIT DIFFERENT.

I DON'T KNOW BECAUSE WE ARE HERE IN THE UNITED STATES BECAUSE WHEN WE ARRIVE WE LISTEN ABOUT THIS, ABOUT THE NURSING HOME, MORE USUAL IN BRAZIL AND WE LEARNED THAT IT'S NOT BAD THINGS, YOU KNOW?

WE HAVE BAD PLACES IN BRAZIL SO I THINK THIS MAKE THE FAMILY THINK I DON'T WANT TO PUT MY FATHER OR MY MOTHER OVER THERE BECAUSE THE PLACE IS NOT OKAY.

THEY DON'T TREAT VERY WELL THE PERSON WHO IS THERE.

BUT WHEN WE COME HERE AND LISTEN HOW IS THE FUTURE, HOW THE AMERICANS THINK ABOUT, WE START TO THINK DIFFERENTLY, TOO.

BUT IN GENERAL, BRAZILIAN COMMUNITY THINK THAT YOU HAVE TO STAY WITH LOVED ONE UNTIL THE END.

DOESN'T MATTER HOW THESE PEOPLE IS.

YOU HAVE TO BE WITH THEM.

BETH SOLTZBERG: THANK YOU, ALANA.

IT'S BEAUTIFUL TO HAVE THAT VALUE OF A FAMILY STAYING UNITED NO MATTER WHAT HAPPENS WITH HEALTH, ALWAYS STAYING TOGETHER.

AND IT ALSO COULD BE VERY HARD FOR SOME FAMILIES DEPENDING ON THE SITUATION.

IT MIGHT BE NOT A REALISTIC GOAL FOR SOME FAMILIES AND I JUST NOTICE THERE WAS A QUESTION IN THE CHAT ABOUT HOW PEOPLE ARE PAYING FOR CARE AND THAT IS A HUGE CHALLENGE AROUND THE WORLD.

IT'S A HUGE CHALLENGE AROUND THE UNITED STATES.

WE'RE HERE IN MASSACHUSETTS WHERE WE DO HAVE THE HIGHEST RATE OF INSURANCE, SO LARGER PERCENTAGE OF OUR POPULATION HAS HEALTH INSURANCE IN MASSACHUSETTS THAN ANY OTHER STATE IN THE COUNTRY.

WE'RE LUCKY IT'S ABOVE 97% BUT EVEN SO HEALTH INSURANCE DOESN'T PAY FOR MANY YOU CAN SAY MOST OF THE CARE THAT PEOPLE ARE GOING TO NEED WHEN THEY ARE HELPING DEMENTIA.

ALANA DUNDON: WHO COMES FROM OTHER COUNTRIES, IT DOESN'T HAVE YOUR WHOLE FAMILY HERE, SO SOMETIMES YOU ARE VERY ALONE, YOUR FAMILY IS REALLY, REALLY IS SMALL, SO YOU DON'T HAVE TOO MANY PEOPLE TO HELP YOU.

SO IT'S WORSE.

BETH SOLTZBERG: THAT'S A GREAT POINT AND ALSO WHEN PEOPLE EMIGRATE HERE, THEY HAVE A FRAME OF REFERENCE.

THEIR IDEAS ABOUT SOMETHING LIKE NURSING HOMES COMES FROM THEIR HOME COUNTRY.

IT'S IMPORTANT TO BE AWARE OF THAT.

THANK YOU, ALANA.

ALANA DUNDON: YOU ARE WELCOME.

BETH SOLTZBERG: JACYRA WOULD YOU LIKE TO MAKE COMMENTS?

JACYRA: THE SAME AS MY COLLEAGUES ALREADY COMMENTED.

THE SAME BELIEVE THAT FAMILY IS THE PRIMARY CARETAKER.

USUALLY THEY PASS THE RESPONSIBILITY TO THE OLDEST WOMEN IN THE FAMILY TO BE LET'S SAY IF MY GRANDMOTHER HAS IT, MY MOM WOULD BE OR MY AUNT WOULD BE THE ONE, THE PRIMARY TAKER OR WHOEVER LIKE IS OLDER AND DOESN'T HAVE TOO MUCH FAMILY RESPONSIBILITY LIKE DON'T HAVE LIKE YOUNG KIDS OR THEY DON'T HAVE

ANY JOB.

SOMEBODY THAT'S ALREADY ALSO RETIRED FROM WORK.

OR ALSO LIKE I FORGOT HIS NAME.

HE SAID GRANDCHILDREN ALSO HELP.

SO, PRETTY MUCH FAMILIES JUST SWAP, TAKE TURNS, HEY, CAN YOU SAY WITH HER TODAY OR CAN YOU STAY WITH HER TODAY BECAUSE WE HAVE TO DO SOMETHING, THEY JUST TAKE TURNS, PRETTY MUCH BABY—SITTING THE DEMENTIA PERSON.

AND ANOTHER THING TOO IS THAT AT TIMES WHEN THINGS GET REALLY BAD, THEY WOULD RATHER CHOOSE NURSING HOMES IF IT'S GETTING TOO TO PROGRESSIVE AND THEY DON'T HAVE THE RESOURCERS BECAUSE IT'S PHYSICALLY DRAINING AND MENTALLY DRAINING THEY WOULD PUT THEM IN A NURSING HOME.

YEAH.

BETH SOLTZBERG: THANK YOU, JACYRA.

SO, I WANT TO GO ON TO THE LAST QUESTION.

WE HAVE ABOUT TEN MINUTES TO TALK ABOUT THAT.

THEN WE HAVE A LITTLE BIT OF TIME TO

TAKE SOME COMMENTS AND QUESTIONS FROM THE CHAT, AND THERE IS WONDERFUL COMMENTS AND RESOURCES BEING SHARED.

PLEASE KEEP THAT UP.

THAT'S GREAT.

SO THE LAST QUESTION WE WANT TO DISCUSS IS, WHAT ARE SOME BARRIERS THAT MAKE IT HARDER FOR PEOPLE IN YOUR COMMUNITY TO USE SERVICES OR GET INVOLVED WITH ACTIVITIES RELATED TO DEMENTIA?

I WILL START WITH ARNETTA AND CARL AGAIN.

ARNETTA BATY: SOME OF THE BARRIERS THAT WE FIND IN BLACK COMMUNITIES IS THAT A LOT OF PEOPLE ARE NOT AWARE.

THEY DON'T —— I AM NOT SEEING THIS IN THE NEGATIVE WAY BUT IT FEELS LIKE SOME PEOPLE DON'T WANT TO KNOW.

THEY FEEL LIKE THEY'VE HEARD IT BEFORE, THREE, FOUR YEARS AGO, AND ARE NOT WILLING TO COME INTO THE PRESENT WHERE WE'RE FINDING THAT DEMENTIA, ALZHEIMER'S, AND OTHER DISEASES OF THE BRAIN START EARLY THAN WHAT WE FIRST THOUGHT.

THEY DON'T WANT TO PUT THEMSELVES INTO EVEN THINKING THAT IT COULD POSSIBLY START AS EARLY AS 15, 20, 25 YEARS OF AGE.

THEY WANT TO LABEL IT AS SOMETHING, SOME OTHER TYPE OF DISEASE AND NOT THINK ABOUT ALZHEIMER'S AND DEMENTIA.

WE'VE HAD A LITTLE BIT OF A STRUGGLE TRYING TO GET PEOPLE TO LISTEN TO OUR INFORMATION SESSIONS.

BUT ONCE THEY LIKE SAY CARL IS LISTENING AND I AM THE PRESENTER, ONCE HE HAS LISTENED HE SPREADS THE WORD THROUGH WORD OF MOUTH.

NOW EVERYBODY WANTS TO HEAR MORE.

EVERYBODY IS UNDERSTANDING WHAT IS GOING ON WITH THEIR FAMILY PERSON THAT'S EXPERIENCING SOME DIFFICULTIES.

AND THE PERSON THAT'S EXPERIENCING THE DIFFICULTIES ARE LEARNING MORE ABOUT WHAT'S GOING ON WITH THEM.

BETH SOLTZBERG: THANK YOU.

IT SOUNDS LIKE THERE IS A LOT OF FEAR AND IT'S NATURAL A LOT OF TIMES PEOPLE DON'T WANT TO TALK OR THINK ABOUT DEMENTIA BECAUSE

THEY'RE AFRAID OF IT.

AND THAT MAKES IT SO MUCH MORE IMPORTANT THAT THE EDUCATE IS SOMEBODY THAT TRUST.

I APPRECIATE WHAT YOU SAID ABOUT WORD OF MOUTH, THAT SOMETIMES THAT'S MORE IMPORTANT THAN IT BEING SOME AUTHORITY FIGURE, BUT FROM OUTSIDE OF THE COMMUNITY.

IT'S MORE IMPORTANT THAT IT COMES FROM SOMEONE WHO THEY TRUST AND FEEL A CONNECTION WITH.

THAT MAYBE CAN OVERCOME THAT FEAR ENOUGH FOR PEOPLE TO BE WILLING TO LISTEN AND ONCE THEY LISTEN, EVERYTHING CHANGES BECAUSE THEY ARE ABLE TO REPLACE THAT FEAR WITH REAL KNOWLEDGE.

ARNETTA BATY: YOU KNOW IT'S A GOOD THING THAT MY OTHER COLLEAGUES SPEAK TO DIFFERENT LANGUAGES, SO THAT IF WE HAVE A SESSION THAT SOMEBODY DOES NOT SPEAK OR DOES NOT UNDERSTAND FLUENT ENGLISH, THAT WE'RE ABLE TO REFER TO THAT PERSON.

AND HAVE THEM HEAR IT IN THEIR LANGUAGE.

BETH SOLTZBERG: THAT'S GREAT, THANK YOU.

ONE OF THE THINGS WE FOUND THROUGH THERE GROUP, THE PROBABLY PROJECT, OUR COMMUNITIES ARE SO DIVERSE SO WHEN WE SAY LET'S SAY RUSSIAN COMMUNITY, THERE ARE PEOPLE IN THAT COMMUNITY WHO ARE MORE COMFORTABLE IN ENGLISH.

THERE ARE PEOPLE WHO ARE MORE COMFORTABLE IN RUSSIAN.

WE NEED TO RESPOND AND BE MORE CREATIVE ABOUT HOW WE REACH PEOPLE NO MATTER WHAT THEIR PREFERED LANGUAGE OR THEIR CULTURE IS.

THANK YOU, ARNETTA.

IRENE, CAN I HAND IT TO YOU?

IRENE BELOZERSKY: I THINK THAT OF COURSE OBVIOUSLY THE LANGUAGE IS ONE OF THE FIRST THING WHICH COME TO MIND BECAUSE IF THERE ARE FOR EXAMPLE SOMEWHERE IN THE SENIOR CENTER THERE IS A GROUP FOR ALZHEIMER'S PATIENTS WHERE THEY USE MUSIC OR WHATEVER TO ENGAGE THEM, IT WILL NOT BE ACCESSIBLE TO THEM, ARE TO THE MAJORITY OF THE RUSSIAN PATIENTS BECAUSE OF THE EVERYTHING BEING IN

ENGLISH AND THE MUSIC WILL BE THE ONE THEY ARE NOT FAMILIAR WITH BECAUSE IT WILL BE COMING FROM A DIFFERENT, YOU KNOW, COUNTRY.

SO, THE KIND OF LIKE GROUPS SERVICES, SUPPORTIVE SERVICES FOR RUSSIAN SPEAKING PATIENTS WITH DEMENTIA HEAVILY DEPEND ON THE LANGUAGE AND CULTURE.

THEY ARE JUST NOT THERE.

HOWEVER, OTHER RESOURCES I THINK ARE EASILY ACCESSIBLE BECAUSE IT'S MOSTLY FOR THEIR CARE TAKERS, FOR THEIR FAMILY MEMBERS WHO ARE FLUENT IN ENGLISH BY NOW AND IT'S NOT A PROBLEM.

WHAT I THINK IS A PROBLEM AND I HAVE ENCOUNTERED IT FOR MANY YEARS IN MY PROFESSIONAL CAPACITY IS WORKING WITH A COMMUNITY WORKING THE SOCIAL SERVICES IS GENERALLY GETTING PEOPLE TO LEARN ABOUT SOMETHING IMPORTANT, TRYING TO MAKING PEOPLE PAY ATTENTION TO HELPFUL INFORMATION AVAILABLE TO THEM IS AN UPHILL BATTLE.

WHEN I WORKED AT THE JEWISH PHILANTHROPISTS WE DEVELOPED A WONDERFUL PROGRAM WHICH PROVIDES INFORMATION SERVICES TO THE ELDERS AND THEIR FAMILIES CALLED

SENIOR DIRECT.

IT TOOK A LOT OF EFFORT AND A LOT OF TIME TO JUST GET THE WORD OUT INTO THE COMMUNITY BECAUSE I THINK THAT GENERALLY PEOPLE ARE RESISTANT TO LEARN ABOUT THINGS LIKE DEMENTIA, IF IT DOESN'T CONCERN THEM DIRECTLY.

SO, NOBODY WANTS TO KIND OF KNOW THINGS IN ADVANCE AND WHEN SOMETHING HAPPENS, THEN THEY BEGIN TO SCRAMBLE TO TRY AND FIND INFORMATION.

I'VE SEEN IT REPEATING OVER AND OVER AGAIN.

SO, COMMUNITY OUTREACH IS VERY CHALLENGING.

BETH SOLTZBERG: THANK YOU, IRENE.

YOUR POINT IS EXCELLENT.

IT'S ONE OF THOSE POINTS THAT BRINGS ME BACK TO OUR PICTURE OF PLANET EARTH BECAUSE THAT REALLY IS HUMAN NATURE I THINK IS TO AVOID DIFFICULT SUBJECTS, BUT THEN WE AREN'T PREPARED.

SO THANK YOU FOR THAT.

KUN WANT TO GIVE YOUR THOUGHTS?

IS.

KUN CHANG: NO DOUBT ABOUT THAT.

THE REASON WE ARE HERE IS BECAUSE OF LANGUAGE AND CULTURE.

THIS IS THE MOST DIFFICULT FOR US TO EVERYBODY WHO SERVING THE DIVERSE COMMUNITY.

SO, MY GENERAL SUGGESTION IS WHAT DO WE NEED?

FIRST, BUILDING CAPACITY.

WHAT KIND OF CAPACITY DO WE NEED?

ONE, WE NEED TO HAVE MORE BILINGUAL, BICULTURAL WORK FORCE TO SERVE THE COMMUNITY.

WE ALSO NEED TO CHANGE OUR VALUE ABOUT THAT.

WHAT DOES THAT MEAN?

IT MEANS PAYING MORE TO THOSE FRONT LINE WORKERS.

INCREASE THE VALUE IN THE IMMIGRANT COMMUNITY WE VALUE OUR KIDS IF THEY ARE LAWYERS, THEY'RE ENGINEERS, COMPUTER SCIENCE, THEY MAKE MORE MONEY.

DO WE MAKE MORE MONEY AS HELPING AS A PERSONAL CAREGIVER?

NO.

THAT'S SOMETHING WE HAVE TO LOOK INTO

IT THIS.

INCREASE THE VALUE.

VALUE IS BASED ON THE REWARD.

ALSO, BASED ON THE SOCIAL LEVEL, SOCIAL CLASS.

WHAT KIND OF THING DO WE HAVE TO CHANGE OUR BELIEF ABOUT THE FRONT LINE WORKERS.

THEY ARE THE MOST VALUABLE PIECE OF THE SERVICE SECTOR.

WE NEED TO VALUE THEM.

GIVE THEM REWARD ABOUT THAT.

WE ALSO VERY IMPORTANT HOW TO WORK TOGETHER, PARTNERSHIP.

JUST LIKE BETH MENTIONED ABOUT THAT.

YOU CANNOT RELY ON MAINSTREAM ORGANIZATIONS WHO DON'T SPEAK THE LANGUAGE, WHO DON'T HAVE A FACE LIKE ME BECAUSE THEY WILL HAVE TO MAKE HUMAN CONNECTION SOMEONE WE KNOW, SOMEONE WITH A FACE FAMILIAR LIKE US SO WE CAN MAKE A CONNECTION.

SO, THE PARTNERSHIP IS IMPORTANT.

WORK WITH A GRASSROOTS ORGANIZATION WHO WORKS DAILY IN THE COMMUNITY.

THAT IS SOMETHING WE HAVE TO LOOK INTO THAT.

THE LAST THING ABOUT THAT IS SHARING RESOURCES.

DON'T KEEP ALL OF THE FUNDING IN YOUR POCKET.

SHARE THE RESOURCE JUST LIKE THIS PROJECT.

LET THE grassroots ORGANIZATIONS BE REUNITED, BRING VALUE, ALSO BE PAID.

THANK YOU.

BETH SOLTZBERG: THANK YOU SO MUCH, KUN.

THIS IS SUCH AN IMPORTANT, THERE ARE SO MANY IMPORTANT THINGS YOU SAID, BUT I WANT TO UNDERSCORE WHAT YOU SAID ABOUT FRONT LINE WORKERS AND AS WE'RE THINKING ABOUT TALKING AND TEACHING ABOUT DEMENTIA IN DIFFERENT CULTURAL AND LINGUISTIC COMMUNITIES WE HAVE TO KEEP IN MIND FRONT LINE WORKERS.

HERE IN MASSACHUSETTS 40% OF OUR DIRECT CARE WORK FORCE ARE IMMIGRANTS, AND A HUGE PERCENTAGE ARE NOT ABLE TO MAKE ENOUGH OF A LIVING FROM THEIR WORK, THEY'RE VERY HARD, VERY VALUABLE WORK, AND THEY REQUIRE FOOD STAMPS OR OTHER PUBLIC BENEFIT PROGRAMS TO SUPPLEMENT THEIR INCOME.

THESE ARE THE PEOPLE WHO ARE TAKING CARE OF OUR MOST VULNERABLE FAMILY MEMBERS.

AND OFTEN THEY ARE TAKING CARE OF FAMILY IN THEIR HOME COUNTRY AS WELL.

SO, THESE ARE PEOPLE WHO ARE THE HARDEST WORKING PEOPLE I HAVE EVER MET AND WE NEED TO THINK ABOUT THE VALUE AND IMPORTANCE OF WHAT THEY ARE DOING AND CHANGE OUR IDEAS ABOUT WHERE RESOURCES NEED TO FLOW.

SO I APPRECIATE THAT COMMENT.

ALANA, DO YOU HAVE THOUGHTS ABOUT BARRIERS IN YOUR COMMUNITY?

ALANA DUNDON: OF COURSE, ALWAYS THE LANGUAGE IS A BARRIER, BUT I WILL TALK ABOUT MASSACHUSETTS.

I DON'T KNOW ABOUT ANOTHER STATE.

HERE WE HAVE A LOT OF PLACE THAT HAVE, THAT THERE HAS INTERPRETERS AND BUT THE BRAZILIAN COMMUNITY IS A VERY I DON'T KNOW IF I CAN SAY LAZY FOR KNOWLEDGE, YOU KNOW?

BECAUSE FOR WORK THEY WORK SO HARD.

THEY WORK 11, 12 HOURS EVERY DAY, 7 DAYS A WEEK.

SO THEY DON'T FIND TIME TO GO IN ONE COURSE, ESPECIALLY WHEN THEY DON'T KNOW ANYBODY OR THE PEOPLE DOESN'T HAVE ANY ISSUES, ANYTHING ABOUT THEM THEY WANT TO TALK ABOUT.

SO, THE PEOPLE JUST LOOKING FOR HELP WHEN THEY REALLY NEED IT, NOT JUST FOR TO KNOW A LITTLE BIT MORE AND WHO KNOWS CAN HELP OTHER PEOPLE AND DO SOME VOLUNTEERS JOBS OR THEY COME TO WORK VERY HARD.

SO THEY WORK TOO MUCH SOMETIMES.

EVEN FORGET THE FAMILY, ARE THE KIDS AND THIS IS WE ARE SEEING THAT'S NOT OKAY FOR THE RELATIONSHIP.

YOU KNOW?

IT'S CHANGING A LOT.

SO THE HEALTH INSURANCE OF COURSE.

THEY THINK EVERYTHING IS RELATED OF HEALTH INSURANCE.

MOST, YES, IT IS BUT SOMETIMES THERE ARE PLACES THAT HELP YOU AND YOU DON'T KNOW BECAUSE YOU JUST LEAVE.

YOU GO TO WORK AND BACK HOME.

SO, THEY HAVE A MYTH, YOU KNOW, THEY BELIEVE IN ONE THING AND CANNOT OPEN THEIR

MIND FOR OTHER WAYS.

BETH SOLTZBERG: THANK YOU, ALANA.

FRANCES, I THINK YOU WERE GOING TO TALK ABOUT QUESTION THREE?

CAN I TURN IT OVER TO YOU?

FRANCES SAMIDY ORTIZ: YES.

SO, SOME OF THE BARRIERS THAT MAKE IT HARDER FOR PEOPLE IN A COMMUNITY TO USE OUR SERVICE IS THAT THEY THINK THEY'RE GOING TO BE MISUNDERSTOOD OR JUDGED BECAUSE THEY HAVE THE CONDITION.

THERE IS A STIGMA EVEN WITH THE CAREGIVER.

WHEN THEY KNOW THAT THEY ARE TAKING CARE OF THEIR MOM, GRANDFATHER, OR FAMILY THEY DO NOT ASK FOR HELP UNTIL SOMEBODY ELSE SEE THEM THAT THEY ARE BEING TOO MUCH, THEY HAVE TOO MUCH CHARGING THEM AND NOT THINKING ABOUT THEMSELVES.

THEY ARE THINKING ABOUT THE SELF—CARE THEY NEED TOO WHEN YOU ARE TAKING CARE OF A PERSON WITH DEMENTIA.

SO, WE TRY TO GET THEM TO UNDERSTAND THIS BECAUSE LIKE IRENE SAYS NOBODY GOT

INFORMATION UNTIL YOU ARE PASSING, SO WE CAN PUT THE BOOTH, THE TABLE, PUT MUSIC WE CAN PUT ANYTHING ABOUT DEMENTIA BUT NOBODY IS GOING TO PAY ATTENTION UNTIL YOU ARE PASSING THIS.

AND IN LIKE I SAID BEFORE IN OUR, IN THE LATINO COMMUNITY IT'S A BIG STIGMA BECAUSE THEY THINK THAT THEY'RE GOING TO JUDGE YOU OR THAT THEY WILL MAKE FUN OF YOU OR THAT, LOOK, YOU ARE TAKING CARE OF YOUR MOM THAT IS LOSING THINGS OR IS THAT GETTING LOST OR THAT IS OUTSIDE DIRTY AND PEOPLE JUST DOES NOT UNDERSTAND.

BETH SOLTZBERG: THANK YOU VERY MUCH, FRANCES.

CARL, I UNDERSTAND YOU HAD A COMMENT YOU WANTED TO MAKE?

THEN WE'LL TAKE ONE OR TWO FROM CHAT BEFORE OUR BREAK.

KED, CARL.

CARL BYRON BATY: YOU THINK ABOUT THE FEAR, BUT YOU DON'T THINK ABOUT THE GUILT AND SHAME.

WHAT DO YOU WANT TO THINK OF ME IF I, IF YOU FIND OUT THAT I WAS SUFFERING WITH SOMETHING.

HOW IS YOUR OPINION OF ME GOING TO CHANGE?

THAT WILL STOP SOMEBODY FROM EVEN WANTING TO KNOW.

BETH SOLTZBERG: YEAH.

ABSOLUTELY.

I APPRECIATE THAT COMMENT VERY MUCH.

I REMEMBER IN ONE OF THE DISCUSSIONS THAT OUR GROUP HAD, ONE PERSON BROUGHT UP THE COMPARISON TO HEART DISEASE.

THAT IF SOMEONE HAS HEART DISEASE THEY DON'T USUALLY FEEL EMBARRASSED TO ADMIT IT, YOU KNOW?

THEY SAY, OH I HAVE TO WATCH MY HEART, MY BLOOD PRESSURE, MAYBE I HAVE TO CUT DOWN ON SALT OR I HAVE TO TAKE SOME MEDICATION OR GO TO THE DOCTOR, BUT THERE IS A DIFFERENT STIGMA AROUND CHANGES IN OUR BRAIN AND CHANGES IN THINKING.

AS YOU ARE SAYING, CARL, IT MAKES IT SO MUCH HARDER TO TALK OPENLY ABOUT IT.

THEN IT'S ALMOST LIKE A VICIOUS CIRCLE BECAUSE IF PEOPLE DON'T TALK OPENLY, THAT'S WHY I THINK SO BRIAN VAN BUREN WHO SPOKE AT THE BEGINNING I THINK IT'S, IT MAKES SUCH A DIFFERENCE TO HEAR FROM SOMEONE LIKE BRIAN WHO IS LIVING WITH DEMENTIA, WHO IS MAKING SUCH A DIFFERENCE, SUCH A POSITIVE DIFFERENCE IN OUR COUNTRY.

I THINK HE SAID HE IS PART OF TEN ORGANIZATIONS RIGHT NOW.

YOU KNOW, SO A PERSON CONTINUES TO BE PART OF THEIR FAMILY, THEY CONTINUE TO CONTRIBUTE AND MAKE A DIFFERENCE, THEY ARE STILL THEMSELVES.

UNLESS WE CAN TALK OPENLY THEN THIS FEAR JUST GROWS AND GROWS.

BUT THANK YOU FOR THAT.

SO, I AM GOING TO ASK MAURA IF SHE WOULD CHECK IN WITH US.

MAURA MOXLEY IS AN EXPERT IN THIS TOPIC, HAVING WORKED FOR THE ALZHEIMER'S ASSOCIATION FOR MANY, MANY YEARS AND IN OTHER ROLES AS A SOCIAL WORKER, AND MAURA HAS A VERY DIFFICULT JOB, WHICH IS SHE HAS BEEN WATCHING THE CHAT AND I AM GOING TO ASK IF

YOU HAVE ONE OR TWO COMMENTS OR QUESTIONS THAT HAVE POPPED UP THAT YOU WOULD WANT TO BRING UP TO THE ——

MAURA MOXLEY: HAPPY TO BE HERE.

PEOPLE LIKE THE (ER'S GLASSES.

LOTS OF SCHOOL GLASSES OF OUR PRESENTERS SO THANKS FOR THAT.

I HAVE A FEW QUESTIONS.

WE'LL SEE WHAT WE CAN GET TO.

MAYBE I WILL THROW TWO OUT AND I WILL LET YOU MANAGE THEM, BETH.

ONE, THERE WAS A LOT OF TALK ABOUT DEMENTIA FRIENDLY TRAINING FOR CARE GIVES AND PEOPLE WHO WORK IN THE FIELD.

IF THERE WERE ANY ESPECIALLY CULTURALLY SENSITIVE TRAININGS THAT PEOPLE MIGHT HAVE COME ACROSS THAT INCLUDE KIND OF DEMENTIA FRIENDLY COMPONENTS?

AND A SECOND QUESTION THAT WAS JUST ASKED IS RELATED TO PEOPLE ASKING REPETITIVE QUESTIONS WITH DEMENTIA AND HOW DO WE KIND OF THINKING ABOUT THE CULTURAL LENS, THE QUESTION OF WHAT IS WRONG WITH ME AND THAT NEEDING TO KIND OF MANAGE THAT QUESTION OFTEN WITHOUT REALLY, YOU KNOW, SCARING THEM AND

HOW DO I EXPLAIN DEMENTIA TO FOLKS THAT ARE GETTING DIAGNOSED WITH DEMENTIA.

BETH SOLTZBERG: THANKS.

WE'LL TALK ABOUT THESE TWO QUESTIONS AND THEN I WANT TO GIVE EVERYONE A CHANCE TO HAVE A LITTLE BREAK AND STRETCH BEFORE WE HAVE OUR SECOND PANEL.

GREAT QUESTIONS.

SO REGARDING CULTURALLY SPECIFIC OR CULTURALLY ATTUNED TRAINING, I MEAN, THIS IS ONE OF THE BIG QUESTIONS THAT WE'RE WRESTLING WITH.

SO, THE DEMENTIA FRIENDS PROGRAM IS ONE OF MANY KINDS OF CURRICULA THAT'S OUT THERE THAT'S BEING TRANSLATED INTO DIFFERENT LANGUAGES AND ADAPTED INTO DIFFERENT, FOR DIFFERENT CULTURAL GROUPS.

IF THERE ARE ANY PEOPLE ON THE CALL WHO ARE FROM A DEMENTIA FRIENDS PROGRAM IN A DIFFERENT PART OF THE COUNTRY WHO HAVE, YOU HAVE DEVELOPED AND ADAPTED VERSION IF YOU WANT TO PUT THAT IN THE CHAT THAT WOULD BE GREAT.

HERE IN MASSACHUSETTS WE HAVE OUR

MATERIALS IN 7 LANGUAGES.

I KNOW THAT MANY OF MY COLLEAGUES AROUND THE COUNTRY HAVE WORKED WITH DIFFERENT LANGUAGES AND IT'S NOT JUST LANGUAGES, YOU KNOW, THERE'S VERSIONS FOR PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES.

THERE ARE VERSIONS FOR PEOPLE OF DIFFERENT AGES, YOU KNOW, THE MAIN POINT IS WE NEED TO REACH PEOPLE IN A WAY THAT'S GOING TO BE MEANINGFUL FOR THEM.

AND DEMENTIA FRIENDS CERTAINLY ISN'T THE ONLY KIND OF TRAINING OR AWARENESS PROGRAM.

THERE ARE A LOT OF OTHER ONES.

IN THE RESOURCE LIST THERE WERE SOME LINKS TO ORGANIZATIONS THAT HAVE DEVELOPED REALLY GOOD RESOURCES IN DIFFERENT LANGUAGES OR FOR DIFFERENT CULTURES.

YOU KNOW, STEPHANIE WHO IS GOING TO BE SPEAKING THIS AFTERNOON, STEPHANIE MONROE, FOR EXAMPLE WORKS WITH A WONDERFUL PLAY, WHICH IS STEPHANIE I DON'T KNOW IF YOU, IF YOU ARE ON, IF YOU WANT TO SAY ANYTHING ABOUT IT?

BUT THERE IS A LINK WHERE YOU CAN WATCH

THAT IN THE CHAT.

I AM JUST GOING TO LOOK AND BE ABLE TO TELL YOU THE RIGHT THING.

IT'S CALLED FORGET ME NOT.

IT'S WRITTEN AND DIRECTED BY GARRET DAVIS AND IT'S, IT SHOWS AN AFRICAN—AMERICAN FAMILY WHO ARE DEALING WITH THE FATHER OR GRANDFATHER'S ALZHEIMER'S DISEASE AND TRYING TO FIND THEIR WAY THROUGH IT AND HOW IT AFFECTS ALL OF THE DIFFERENT RELATIONSHIPS.

SO, I THINK IT'S WONDERFUL TO SEE MATERIALS IN THE ARTS, NOT ONLY KIND OF TRADITIONAL TRAINING PROGRAMS, BECAUSE SOMETIMES THAT IS HOW YOU OVERCOME THE FEAR AND GET PEOPLE INTERESTED TO ACTUALLY LEARN.

ANY OF THE OTHER PANELISTS HAVE A COMMENT ABOUT RESOURCES OR TRAININGS?

OKAY.

WELL YOU CAN REST ASSURED THAT IN THE RESOURCE LIST YOU ARE GOING TO FIND LINKS TO MANY, MANY GOOD RESOURCES.

THEN TO ADDRESS THE SECOND QUESTION ABOUT REPETITIVE QUESTIONS, THIS IS DEFINITELY SOMETHING THAT WE TALK ABOUT TO SOME EXTENT IN THE DEMENTIA FRIENDS

INFORMATION SESSION, AND THAT IT'S VERY IMPORTANT TO PUT YOUR SELF—IN THE SHOES OF THE PERSON LIVING WITH DEMENTIA THAT PERSON IS EXPRESSING FEELING OR A CONCERN AND THERE IS A PHRASE I ACTUALLY HEARD THIS PHRASE FROM THE ALZHEIMER'S ASSOCIATION THE FIRST TIME FOCUS ON THE FEELINGS NOT THE FACTS.

THIS PERSON ASKED ME THE SAME QUESTION FIVE TIME IN THE LASTIER.

THEY DON'T KNOW THEY ASKED THE QUESTION FOR THE LAST FIVE TIMES AND THEY ARE EXPRESSING THE NEED.

WHAT'S THE EMOTION BEE LINED THAT QUESTION AND CAN I ADDRESS THAT?

AND WHAT IT MIGHT BE IS JUST TO KEEP ANSWERING THE QUESTION IN A PLEASANT WAY.

FOR THE PERSON HAVING TO DO THAT IT CAN BE HARD, IT CAN BE TAXING.

IT CAN BRING UP A LOT OF EMOTIONS IF YOU ARE A FAMILY MEMBER TO HEAR THE SAME QUESTION AGAIN AND AGAIN.

YOU NEED TO GET SUPPORT.

YOU NEED TO HAVE BREAKS AND PEOPLE YOU CAN TALK TO WHERE YOU GET SUPPORT BECAUSE THAT'S A HARD THING.

DOES ANYONE ELSE WANT TO COMMENT ON THAT QUESTION?

SPEAKER: IF YOU HAVE SOMEBODY DOING SOMETHING REPETITIVE MAYBE YOU WANT TO CONSIDER REDIRECTING THEM WITH SOME SORT OF ACTIVITY?

BETH SOLTZBERG: THAT'S A GREAT POINT, KATHY.

THANK YOU YEAH, SO SOMETIMES THE PERSON MIGHT BE BORED AND THEY NEED SOMETHING TO ENGAGE THEIR MIND AND HAVE FUN, YOU KNOW?

JUST LIKE WE ALL DO.

WE ALL NEED A CHALLENGE.

SPEAKER: I WASN'T ASKING ABOUT, EXCUSE ME, ABOUT REPETITIVE QUESTIONS.

I HAVE CLIENTS WHO ALWAYS CALL ME EVERY DAY OR TWO AND SAY, WHAT IS WRONG WITH ME?

WHY CAN'T I REMEMBER ANYTHING?

AND I HAVE TO KEEP EXPLAINING TO THEM WITHOUT SCARING THEM WHY THEY ARE SUDDENLY LIVING IN AN INDEPENDENT OR ASSISTED LIVING, WHY THEY CAN'T DRIVE.

IT'S NOT REPETITIVE QUESTIONS LIKE WHAT ARE WE DOING TODAY?

IT'S EXPLAINING OVER AND OVER AGAIN THAT THEY HAVE DEMENTIA AND POSSIBLY ALZHEIMER'S.

THE HOW DO YOU DO THAT?

BETH SOLTZBERG: THANK YOU, DAVIDA FOR CLARIFYING THAT.

DOES ANYONE HAVE A COMMENT?

I THINK THAT'S VERY CHALLENGING WHENEVER IT'S SOMETHING THAT MIGHT FEEL LIKE BAD NEWS OR SOMETHING SCARY AND THE QUESTION COMES UP AGAIN AND AGAIN.

AND THERE REALLY ISN'T ONE SIZE FITS ALL.

IT DEPENDS ON THE PERSON.

YOU KNOW, SOME PEOPLE ARE ABLE TO TAKE IN MORE MEDICAL INFORMATION THAN OTHER PEOPLE, BUT AGAIN I THINK THE IDEA OF FOCUSING ON THE FEELINGS RATHER THAN THE FACTS IS A GOOD GUIDE BECAUSE IF YOU BEGIN TO EXPLAIN THE DIAGNOSIS AND YOU SEE THAT THE PERSON IS GETTING MORE UPSET, THEN MAYBE THAT ISN'T THE MOST PRODUCTIVE WAY TO DO IT.

AND MAYBE THE MOST PRODUCTIVE IS TO SAY IT IN A SOFTER WAY OR TO REDIRECT.

MAURA I SEE YOU UNMUTED.

DO YOU HAVE A COMMENT?

GO AHEAD, PLEASE.

MAURA MOXLEY: I WAS GOING TO SAY I AM GLAD DAVIDA CLARIFIED.

SOMETIMES IT REMINDS US OF OUR OLD DAYS OF ORIENTATION OF LONG AGO WE USED TO PRACTICE THAT AND PRACTICE SOMETIMES IT'S NOT ALWAYS BRINGING SOMEONE INTO THE REALITY.

WE HAVE TO MEET THEM WHERE THEY ARE AT.

I THINK BETH YOU DID A GREAT JOB DESCRIBING IT.

I DIDN'T KNOW I WAS UNMUTED, I AM SORRY.

BETH SOLTZBERG: I APPRECIATE THAT, MAURA.

SO, THANK YOU FOR THOSE QUESTIONS AND FOR THE RESOURCES THAT ARE BEING SHARED IN THE CHAT.

I WANT TO GIVE A BREAK NOW BECAUSE WE'VE BEEN ON ZOOM FOR A LONG TIME.

AND FOLKS NEED TO STAND UP AND MOVE AROUND.

GET A DRINK OF WATER, WHATEVER THEY

NEED TO DO.

SO, I AM GOING TO GO AHEAD AND PUT ON OUR ROLLING SLIDE SHOW OF WONDERFUL PHOTOS FROM DEMENTIA FRIENDS SESSIONS AND I AM GOING TO TRY TO PUT ON MUSIC AGAIN.

WE PUT A PLAY LIST TOGETHER WITH CONTRIBUTIONS FROM ALL OF OUR COMMUNITY PARTNERS.

I WILL TRY TO MAKE THAT PLAY.

THEN WE'LL COME BACK AT 3:15 AND WE WILL, AND I WILL INTRODUCE OUR NATIONAL LEADERS WHO ARE GOING TO LEAD A DISCUSSION FOR THE LAST PART OF THE DAY.

PLEASE PLAN TO COME BACK AT 3:15.

UNTIL THEN ENJOY THE SOUNDS AND THE SIGHTS.

BETH SOLTZBERG: I'M GOING TO STOP SHARING HERE AND WE'RE GOING TO START TO COME BACK TO THE.

HOPEFULLY, THE MUSIC IS OFF.

DOES ANYBODY STILL HEAR MUSIC IN THE BACKGROUND?

NO?

OKAY, THANK YOU.

TODAY I'VE BEEN FINDING SOME STRANGE CHALLENGE WITH AUDIO THAT I NEVER HAD BEFORE, SO WELCOME BACK, EVERYBODY.

I HOPE YOU HAD A LITTLE STRETCH BREAK AND GOT SOMETHING, A DRINK OF WATER OR SOMETHING.

I WANT TO THANK ARNETTA AND CARL AND KUN AND IRENE AND ALANA AND FRANCES AND JACYRA FOR THAT WONDERFUL DISCUSSION.

BEFORE I INTRODUCE YOUR NEXT SPEAKERS FRANCES LET ME KNOW SHE AND JACYRA WANT TO INVITE PEOPLE TO TAKE PART IN A DEMENTIA FRIENDS SESSION THEY WILL HOLD IN SPANISH LATER MONTH.

FRANCES, DO YOU WANT TO UNMUTE YOURSELF AND LET PEOPLE KNOW ABOUT THAT?

FRANCES SAMIDY ORTIZ: YES, JACYRA AND I ARE DOING THE DEMENTIA FRIENDS WORKSHOP ON NOVEMBER 12 AND NOVEMBER 17 VIA ZOOM.

I WROTE IT IN THE CHAT.

IF YOU ARE INTERESTED IN PARTICIPATING, PLEASE SEND US AN E—MAIL TO EITHER OF US TO JACYRA OR ME SO WE CAN SEND YOU THE LINK, SO YOU CAN PARTICIPATE.

REMEMBER, IT'S IN SPANISH AND THANK

YOU.

BETH SOLTZBERG: GREAT.

THANK YOU SO MUCH.

THERE RIGHT THERE IS AN EXAMPLE OF AN OPPORTUNITY TO GET SOME TRAINING IN SPANISH.

SO, WHAT I WANTED TO DO NOW IS INTRODUCE JONATHAN JACKSON AND STEPHANIE MONROE AND JASON RESENDEZ WHO ARE HERE WITH US FROM BOSTON AND WASHINGTON, D.C., AND THEY WILL TAKE US THROUGH THE FINAL PART OF TODAY'S SYMPOSIUM.

THEY ARE GOING TO BE TALKING WITH US FOR ABOUT AN HOUR, A LITTLE LESS THAN AN HOUR ABOUT REALLY THE BIGGER PICTURE, WHAT WE CAN LEARN FROM RESEARCH AND FROM NATIONAL ADVOCACY EFFORTS ABOUT HOW TO ADDRESS DISPARITIES.

THEN WE'RE GOING TO HAVE ABOUT TEN OR 15 MINUTES TO HEAR MORE QUESTIONS AND COMMENTS, AND THEN HAVE A LITTLE TIME TO WRAP UP.

SO, PLEASE CONTINUE TO PUT YOUR QUESTIONS AND COMMENTS INTO THE CHAT BOX AS WE GO.

I WILL INTRODUCE YOUR THREE SPEAKERS.

JONATHAN JACKSON PHD WILL MODERATE THE PANEL, DR. JACKSON IS THE DIRECTOR OF THE COMMUNITY ACCESSORY CRUTEMENT AND ENGAGEMENT OR CARE RESEARCH CENTER AT MASSACHUSETTS GENERAL HOSPITAL AND HARVARD MEDICAL SCHOOL.

CARE INVESTIGATES THE IMPACT OF DIVERSITY AND INCLUSION ON THE QUALITY OF HUMAN SUBJECTS RESEARCH AND LEVERAGES DEEP COMMUNITY ENGAGEMENT TO BUILD TRUST AND OVERCOME BARRIERS TO CLINICAL TRIAL PARTICIPATION.

DR. JACKSON ALSO WORKS AS COGNITIVE NEUROSCIENTIST, INVESTIGATING THE EARLY DETECTION OF ALZHEIMER'S DISEASE.

DR. JACKSON SERVES ON THE LEADERSHIP TEAM OF SEVERAL ORGANIZATIONS FOCUSED ON COMMUNITY HEALTH AND HAS WRITTEN GUIDANCE FOR LOCAL, STATEWIDE AND NATIONAL GROUPS ON RESEARCH ACCESS, ENGAGEMENT, AND RECRUITMENT.

STEPHANIE J MONROE SAT DIRECTOR OF EQUITY AND ACCESS AND THE EXECUTIVE DIRECTOR OF AFRICANAMERICANSAGAINSTALZHEIMER'S WHICH IS A NETWORK AGAINST USAGAINSTALZHEIMER'S WHICH IS A NATIONAL ADVOCACY ORGANIZATION

BASED IN WASHINGTON, D.C.

AFRICANAMERICANSAGAINSTALZHEIMER'S WAS FOUNDED IN 2013 AND IS THE FIRST NATIONAL NETWORK CREATED SPECIFICALLY TO RESPOND TO THE DISPARATE IMPACT THAT ALZHEIMER'S DISEASE HAS IN THE AFRICAN—AMERICAN COMMUNITY.

BY WORKING NATIONALLY, LOCALLY, AND THROUGH STRATEGIC PARTNERSHIPS, AFRICANAMERICANSAGAINSTALZHEIMER'S IS RAISING AWARENESS OF THE IMPACT OF ALZHEIMER'S HEALTH DISPARITIES ON COMMUNITIES OF COLOR AND WOMEN, AND THE NEED FOR GREATER MINORITY PARTICIPATION AND CLINICAL TRIALS.

PARTICULARLY, LOOKING AT RISK REDUCTION AS WELL AS FINDING A CURE.

AN ATTORNEY WITH THREE DECADES OF FEDERAL, PUBLIC POLICY EXPERIENCE, STEPHANIE IS FORMER ASSISTANT SECRETARY OF EDUCATION FOR CIVIL RIGHTS.

PRIOR TO SERVING IN THAT POSITION SHE ENDED A 25 YEAR CAREER ON CAPITOL HILL AFTER HOLDING A NUMBER OF KEY STAFF POSITIONS IN THE UNITED STATES CONGRESS.

I WONDER IF THIS WEEK YOU HAVE BEEN GLAD NOT TO BE IN THOSE ROLES?

VERY CONTENTIOUS UP THERE ON THE HILL, BUT WE'RE HONORED TO HAVE YOU THERE WITH US, STEPHANIE.

JASON RESENDEZ.

JASON IS THE EXECUTIVE DIRECTOR OF THE USAGAINSTALZHEIMER'S CENTER FOR BRAIN HEALTH EQUITY, WHICH IS A NEW CENTER THAT WE ARE VERY EXCITED TO HEAR ABOUT AND JASON IS ALSO HEAD OF THE LATINOS AGAINST ALZHEIMER'S COALITION, WHICH IS A NETWORK OF USAGAINSTALZHEIMER'S.

FROM CLINICAL TRIAL INCLUSION TO PAID FAMILY LEAVE FOR DEMENTIA CARE GIVES, JASON CHAMPIONS BRAIN HEALTH EQUITY AT EVERY LEVEL OF THE HEALTH CARE SYSTEM.

THE CENTER FOR BRAIN HEALTH EQUITY IS AN EXCITING NEW INITIATIVE AND I'M SURE JASON WILL TELL US MORE ABOUT IT DURING OUR TIME TOGETHER.

AND I AM ALSO SO PLEASED THAT BRIAN VAN BUREN IS WITH US, WHO IS AN ALZHEIMER'S ADVOCATE.

WE HEARD FROM BRIAN EARLIER AND I UNDERSTAND THAT HE MAY HAVE SOME COMMENTS AS WELL.

SO, JONATHAN, CAN I TURN IT OVER TO YOU?

JONATHAN JACKSON: YOU CAN INDEED.

THANK YOU SO MUCH, BETH.

IT'S A REAL PLEASURE TO BE HERE.

I HOPE EVERYONE IS DOING WELL.

I KNOW IT HAS BEEN A STRESSFUL FEW WEEKS FOR SOME, AND A STRESSFUL FEW YEARS FOR MOST.

WE ARE COMING TO THE END OF A LONG DAY.

SO, INSTEAD OF HAVING A HIGHLY SCRIPTED PANEL, I DECIDED TO BRING IN TWO PEOPLE THAT I INTERACT WITH ON A PRETTY REGULAR BASIS TO TALK ABOUT THE THINGS THAT WE TALK ABOUT ON A PRETTY REGULAR BASIS.

SO, HOPEFULLY WE CAN MAKE THIS A BIT MORE ENGAGING AND CONVERSATIONAL, AND THERE IS ONE SORT OF SMALL DEVIATION I WOULD LIKE TO POTENTIALLY INTRODUCE, AND THAT'S IF FOLKS HAVE COMMENTS OR QUESTIONS OR THOUGHTS, PLEASE PUT THEM IN THE CHAT.

YOU KNOW, I THINK WE CAN TRY TO ADDRESS SOME OF THESE THINGS IN REAL—TIME AS WE'RE TALKING JUST BECAUSE I THINK AT THE END OF A

LONG DAY, WHERE WE HAVE BEEN KIND OF INTERACTING AND COMING WITH EACH OTHER FOR HOURS, MAYBE A LITTLE BIT MORE CONVERSATION AND CHAT IS WHAT WE NEED.

SO, THE FIRST THING THAT I WANTED TO DO THOUGH IS KIND OF INTRODUCE AND ORIENT YOU TO THE NEXT DISCUSSION TOPIC FOR THE NEXT HOUR.

WE'RE GOING TO BE TALKING ABOUT AS BETH SAID THE BIGGER PICTURE.

WE'RE GOING TO BE TALKING A LITTLE BIT ABOUT THE NATURE OF HEALTH DISPARITIES.

WE'RE GOING TO BE TALKING ABOUT SOME OF HOW THAT INTERACTS WITH THE SPACE THAT WE SEE FOR CARING FOR SOMEBODY WHO IS LIVING WITH DEMENTIA, FOR THE AUTONOMY OF INDIVIDUALS LIVING WITH DEMENTIA, WE'LL TALK A LITTLE BIT ABOUT RESEARCH AND SOME OF THE LATEST INFORMATION THAT WE HAVE AND WHETHER THAT IS APPROPRIATELY INTERSECTS WITH OUR IDEAS OF WHAT WE ACTUALLY SERVE AS BEING DEMENTIA FRIENDLY.

BUT BEFORE WE GET INTO ALL OF THOSE CONVERSATIONAL POINTS, ABOUT OF WE GET INTO ALL OF THAT CHAT, I DID WANT TO TURN THINGS OVER TO JASON RESENDEZ.

MR. RESENDEZ ACTUALLY HAS A VIDEO HE WOULD LIKE TO SHARE THAT KIND OF TALKS, THAT WILL I THINK SET THE TONE FOR A LOT OF TALKING POINTS WE HAVE TODAY.

SO, JASON, IF YOU ARE READY I WOULD LIKE TO TURN IT OVER TO YOU.

JASON RESENDEZ: SURE, THANKS ALL FOR HAVING US.

WE JUST HELD A SUMMIT, VIRTUAL SUMMIT, MAYBE MANY OF YOU PARTICIPATED AND WE'RE GRATEFUL IF YOU DID.

BUT AS PART OF THAT, WE HAD WHAT WE CALLED MOMENTS OF INSPIRATION AROUND THE IMPORTANCE OF ADDRESSING THE ISSUES WE'LL TALK ABOUT TODAY AND FOLKS LIKE BRIAN VAN BUREN PROVIDED SOME OF THOSE MEMBERS AND DR. JONATHAN JACKSON, BUT ALSO ONE OF OUR GOALS WAS TO REORIENT THE CONVERSATION AROUND ALZHEIMER'S AND BRAIN HEALTH FROM ONE PRIMARILY FOCUSED ON DISPARITIES IN HEALTH, TO TALK ABOUT IT FROM AN EQUITY PERSPECTIVE AND A CIVIL RIGHTS PERSPECTIVE, AND ONE OF THE WAYS THAT WE DID THAT WAS BY FEATURING REVEREND AL SHARPTON.

SO WE WANT TO SHARE A MESSAGE FROM REVEREND SHARPTON WITH ALL OF YOU.

SO PLEASE BEAR WITH ME WHILE I TRY TO SHARE MY SCREEN.

HERE WE GO.

I HOPE WE CAN ALL HEAR THIS.

SPEAKER: MY MOTHER RAISED MY SISTER AND I IN BROOKLYN, NEW YORK BY HERSELF.

I WAS A CHILD OF A SINGLE PARENT.

ONCE I WAS FULLY GROWN AND ON MY JOURNEY, SHE MOVED BACK SOUTH.

SHE WAS FROM ALABAMA.

AND SLOWLY SHE BEGAN TO DEVELOP ALZHEIMER'S AS WELL AS DEMENTIA.

AND SHE HAD TWO CHILDREN OLDER THAN US DOWN IN ALABAMA AND THEY WOULD CALLED ME SAY, SHE IS STARTING TO FORGET THINGS.

SHE WOULD LEAVE THE HOUSE AND DIDN'T KNOW HOW TO GET BACK.

FINALLY, WE DECIDED TO PUT HER IN THE NURSING HOME AND SHE DIDN'T EVEN KNOW WHO I WAS AT ONE POINT WHEN I WENT TO VISIT HER, AND I THINK THAT ONE OF THE REASONS I AM SO COMMITTED TO THIS GROUP IS THAT THERE IS

NOTHING THAT CAN PREPARE YOU FOR GOING TO SEE YOUR MOTHER, WHO IN MY CASE WAS MY MOTHER AND FATHER, AND THEN DON'T KNOW WHO YOU ARE.

WE NEED TO TAKE THE HEALTH CONDITIONS IN BLACK AMERICA MORE SERIOUSLY.

WE NEED TO BE MORE ENGAGED WHEN WE SEE THE BLACKS TWICE MORE LIKELY TO FACE ALZHEIMER'S AND DEMENTIA.

ONE IN THREE SENIORS IN THIS COUNTRY DIE FROM —— THIS IS SOMETHING THAT IS AS IN MY OPINION NEEDING A SENSE OF URGENCY AS ANYTHING WE FIGHT IN CIVIL RIGHTS AND THE RACE GAP IN TERMS OF HEALTH CARE IS SOMETHING THAT WE SHOULD NOT TOLERATE OR ACT LIKE IT'S SOME BACK PAGE PROBLEM.

THERE MUST BE AN AGGRESSIVE MANNER STRATEGY THAT INCLUDES EVERYTHING, INCLUDING POOREST IN THE BLACK COMMUNITY.

SOME PEOPLE DON'T HAVE HEALTHCARE FACILITIES IN THE COMMUNITY SO YOU'VE GOT TO BE ABLE TO DEVELOP THEM.

HEALTHCARE IS A CIVIL RIGHT AND WE NEED TO TALK ABOUT THE DISPARITIES LIKE WE TALK ABOUT IN THE CRIMINAL JUSTICE AND BUSINESS AND WE NEED TO USE YOUR PLATFORMS TO GET THE

MESSAGE OUT.

SECONDLY, WE NEED TO CONSTANTLY BE ON THE LEGISLATORS BACKS BECAUSE THEY ARE THE ONES THAT REGULATE AND DEAL WITH ALL OF THIS.

TO SAY THAT PART OF WHAT THEY NEED TO KNOW HAS BEEN DEALING WITH HEALTH CARE COMPANIES AND ALL IS WHAT IS THEIR PLAN FOR DIVERSITY?

WHAT IS THEIR PLAN TO WORK WITH THOSE THAT ARE IN THE INDUSTRY THAT THEY ARE IN THE SERVICE OF COMMUNITIES THAT HAVE BEEN INSTITUTIONALLY BLACK?

JONATHAN JACKSON: BACK TO YOU, JONATHAN, WHILE I FIGURE OUT HOW TO TURN THAT OFF.

WE WERE GETTING I THINK AN EARLY WARNING ABOUT AUDIO ISSUES AND SO BETH, THANKS FOR THAT ADVANCE NOTICE.

I THINK THERE IS A GHOST IN THE MACHINE THAT'S AFFECTING US ALL TODAY.

BUT I WANTED TO JUST KIND OF HIGHLIGHT SO MANY REALLY IMPORTANT PARTS OF THAT VIDEO FROM REVEREND SHARPTON.

SO, WHEN WE WERE TALKING ABOUT THE

IMPORTANCE OF RECOGNIZING THE HIGH RISK OF DEMENTIA IN CERTAIN COMMUNITIES OF COLOR, WE KNOW THAT IN BLACK AND AFRICAN—AMERICAN COMMUNITIES IT'S BETWEEN TWO AND FOUR TIMES MORE LIKELY TO AFFECT OUR OLD AREA ADULTS.

WE KNOW IN OUR HISPANIC AND LATINO COMMUNITIES IT MAY BE ONE AND A HALF TIMES MORE LIKELY TO STRIKE, AND SO WE HAVE I THINK A REALLY SOLEMN DUTY TO BE THOUGHTFUL ABOUT THE BURDEN OF DEMENTIA AND THE OPPORTUNITIES OF DEMENTIA WITHIN COMMUNITIES OF COLOR IN PARTICULAR.

WE KNOW THAT THERE ARE MANY THINGS THAT WE SIMPLY DON'T KNOW ABOUT OTHER UNDERSERVED FOLKS WHEN IT COMES TO DEMENTIA RISK.

WE KNOW THAT FOLKS WHO IDENTIFY AS ONE OF THE QUEER COMMUNITIES, SO LGBT QIA AND PLUS, WE KNOW THAT THESE INDIVIDUALS MAY BE LESS LIKELY TO HAVE A CARE PARTNER OR SOMEONE THAT THEY CAN POTENTIALLY INTERACT WITH AND GET SUPPORT FROM.

SO, WHEN WE TALK ABOUT WHAT IT MEANS TO HAVE CULTURALLY ATTUNED SERVICES AND CARE, WHEN WE TALK ABOUT A LOT OF THESE MATTERS WE HAVE TO RECOGNIZE WHAT THE ACTUAL REAL HARMS

ARE IN THE SPACE.

SO, I WANTED TO ACTUALLY TURN THINGS OVER TO STEPHANIE MONROE FOR JUST A FEW MINUTES.

SO, STEPHANIE I WANTED TO KNOW IF YOU COULD TELL US A LITTLE BIT ABOUT WHAT YOU DO AND WHY IT'S IMPORTANT TO FOCUS ON THE AFRICAN—AMERICAN PRESENCE IN THE DEMENTIA SPACE?

WHY IS THIS SO IMPORTANT AND WHAT ARE SOME OF THE UNIQUE CHALLENGES THAT YOU SEE WITH THIS GROUP?

STEPHANIE J. MONROE: ABSOLUTELY.

WELL, BY WAY OF A LITTLE BIT OF BACKGROUND I WANTED TO JUST SHARE THAT WHEN I BEGAN SORT OF WORKING IN THIS ALZHEIMER'S SPACE BACK IN 2010 LITTLE DID I KNOW THAT A FEW YEARS LATER MY FATHER WOULD ACTUALLY RECEIVE A DIAGNOSIS OF ALZHEIMER'S DISEASE.

THAT MY MOM'S SISTER WOULD A FEW YEARS AFTER THAT RECEIVE A DIAGNOSIS OF LEWY BODIES DEMENTIA.

SO, GOD HAD ME IN THAT SPACE FOR A REASON TO LEARN AND UNDERSTAND, ALTHOUGH I CAN TELL YOU THAT EVEN THOUGH I AM

PROFESSIONALLY INVOLVED IN THAT SPACE, WHEN IT COMES TO YOUR FAMILY IT'S FAMILY AND THE DENIAL AND CHALLENGES THAT EVERYONE SPOKE ABOUT IN THE FIRST HALF OF THIS CALL WERE ABSOLUTELY APPLICABLE TO ME.

SO, I REALLY APPRECIATE EVERYONE'S COMMENTS, WHICH I CAN CERTAINLY SAY WERE ABSOLUTELY APPLICABLE, REGARDLESS OF THE FACT THAT MY FAMILY GREW UP IN BALTIMORE, NOT IN THE CAROLINAS, THAT WE HAVE A LOT OF PROFESSIONALS IN OUR FAMILY.

WE ARE SUFFERING.

WE ARE FACING THE SAME CARE GIVING CHALLENGES, THE LACK OF PAID LEAVE, FRANKLY THE LACK OF GOOD DIAGNOSIS, BIAS IN TERMS OF THE FIRST DOCTOR WE WENT TO WITH MY DAD ASKED HIM WHY HE WOULD WANT TO KNOW.

AND HAVING TO BE THAT VOICE AND POWER THAT PUSHES THROUGH ALL OF THESE BIASES AND BARRIERS THAT JUST COME AT YOU, SO I REALLY APPRECIATED LISTENING TO THE FIRST CONVERSATION.

IT'S ABSOLUTELY ESSENTIAL.

WE LOOK AT AFRICAN—AMERICANS IN ALL OF THE HEADWAY THAT THANKFULLY WE HAVE BEEN ABLE

TO MAKE THROUGH CIVIL RIGHTS MOVEMENT, THROUGH SLAVERY, INTO TODAY THAT WE DON'T WIPE OUT ALL OF THOSE GAINS BY VIRTUE OF A DISEASE THAT ROBS PEOPLE AND FORCES THEM INTO A LEVEL OF DEPENDENCE THAT WAS NEVER REALLY PLANNED FOR OR EXPECTED OR SERVICES THAT ARE READILY AVAILABLE TO HELP FAMILIES NAVIGATE THIS.

IT'S ABSOLUTELY ESSENTIAL.

AFRICAN—AMERICANS ARE ABOUT 13.4 OR 5% OF THE POPULATION, YET 20% OF ALZHEIMER'S CASES ARE AFRICAN—AMERICANS.

EVEN WITH THOSE NUMBERS, 33% OF THE OVERALL COST OF ALZHEIMER'S DISEASE ARE BEING BORN BY AFRICAN—AMERICANS, SO VERY QUICKLY YOU BEGIN TO SEE THIS DISPARITY AND WHY DOES THIS EXIST?

AND HOW DOES A COMMUNITY THAT ALREADY IS FACING SO MANY OTHER CHALLENGES NOW HAVE THIS LUMPED ON TOP OF THEM.

SO, OUR ORGANIZATION WHEN IT WAS FOUNDED WE WEREN'T INTERESTED IN REPLICATING WORK THAT WAS ALREADY BEING DONE.

WE WANTED TO SPEAK WHERE THERE WAS NO VOICES.

WE WANTED TO BE THE VOICE OF PEOPLE WHO WERE -- I CAN'T JUST SAY ECONOMICALLY UNDER PRIVILEGED BUT WHO WERE JUST OVERBURDENED WITH THIS DISEASE WITHOUT EFFECTIVE UNDERSTANDING AND AWARENESS AND ACCESSIBILITY AND ACCESS TO BOTH KNOWLEDGE AND SERVICES THAT THEY NEEDED TO ADDRESS THE ISSUE HEAD ON.

SO, THAT'S WHAT WE HAVE BEEN ABOUT.

WE HAVE BEEN ABOUT COLLECTING DATA BECAUSE WE KNOW THE DATA DRIVES A LOT OF DECISION MAKING IN WASHINGTON, D.C.

WE SPENT MANY YEARS OUT IN THE FIELD SPEAKING DIRECTLY TO COMMUNITIES, BRINGING TOOLS INTO COMMUNITIES FOR THEM TO BE ABLE TO LEVERAGE TO RAISE AWARENESS IN BLACK AMERICAN COMMUNITIES.

WE SPENT A LOT OF TIME FIGURING OUT WHAT WAS THE BEST WAY OF DELIVERING THOSE MESSAGES AND WAYS THAT COULD BE TRULY UNDERSTOOD REGARDLESS OF A PERSON'S EDUCATION.

WE SORT OF KIND THE PHRASE ED-U-TAINMENT BUT MAKING SURE PEOPLE UNDERSTOOD THIS WAS NOT A PROBLEM THEY WERE

EXPERIENCING ALONE, THAT THERE WERE, IN FACT, LOCAL ENTITIES THAT COULD ADDRESS THAT.

IN MANY CASES WE WERE THE FIRST AFRICAN–AMERICAN PRESENCE GOING INTO THE COMMUNITIES TO SORT OF GIVE PERMISSION FOR A LOT OF NON–WHITE OR NON–BLACK ORGANIZATIONS TO ACTUALLY HAVE ACCESS TO PEOPLE.

SO, WE SERVED AS CONNECTIVE TISSUE TO SHOW FOLKS HOW TO DO IT AND WHAT YOU NEED TO DO TO FOLLOW THROUGH.

IT'S STILL A LEARNING PROCESS.

I CAN SAY WHENEVER I GO OUT IN COMMUNITIES IT'S REALLY WONDERFUL.

PEOPLE ARE WHEN YOU GIVE THEM PERMISSION TO TALK, THEY ARE REALLY INTERESTED IN TALKING.

I THINK THAT THE AWARENESS OF THE BLACK COMMUNITY ABOUT THE ALZHEIMER'S IS NOT SOMETIMESERS DISEASE WHERE SOMETIMES YOU REMEMBER AND SOMETIMES YOU DON'T.

WE CAN CALL IT WHAT IT IS AND SEEK THE HELP, AND NOT FEEL SHAME, NOT PUT THAT PERSON IN THE CORNER AS MUCH BUT RECOGNIZE THAT THIS IS A DISEASE THAT WE CAN ADDRESS.

OUR NEXT STEP IS TO REALLY MAKE SURE

THAT CARE GIVES WHO OFTEN BECOME THE VOICE OF THE PATIENT, THE PERSON WITH ALZHEIMER'S DISEASE, THEY NEED A LOT OF SUPPORT AS WELL AND WE HAVEN'T DONE A GOOD JOB AT REALLY VALUING CARE GIVES WHO CARE FOR ADULTS AS MUCH AS WE HAVE CARE GIVES WHO CARE FOR CHILDREN.

SO, WE'RE TRYING TO EVEN THAT PLAYING FIELD AND BRING THOSE NEEDS OUT OF THE SHADOWS.

JONATHAN JACKSON: THANK YOU SO MUCH, STEPHANIE.

JASON, I WANT TO TURN IT BACK OVER TO YOU FOR A COUPLE MINUTES.

I KNOW YOU AND STEPHANIE OFTEN TOUT AN EXPRESSION WHICH IS THIS EXPRESSION CALLED BRAIN HEALTH EQUITY.

THE CAN YOU TALK TO US A LITTLE BIT ABOUT WHAT BRAIN HEALTH EQUITY MEANS?

IN PARTICULAR, I WOULD LIKE IF YOU COULD REALLY TO HIGHLIGHT WHAT EQUITY MEANS AS OPPOSED TO JUST EQUALITY.

SO, THERE MAY BE SOME PEOPLE HERE IN THE ZOOM ROOM THAT MIGHT FEEL THAT SURE

AFRICAN—AMERICANS, LATIN X IDENTIFYING INDIVIDUALS MIGHT HAVE SOME TROUBLE, BUT, GOSH, EVERYBODY IS HAVING TROUBLE.

EVERYBODY IS STRUGGLING WITH DEMENTIA.

WE NEED TO GIVE THEM THE SAME RESOURCES WE'RE GIVING EVERYONE ELSE.

IS THAT WHAT IS MEANT BY BRAIN HEALTH EQUITY OR IS THERE SOMETHING ELSE THAT WE HAVE IN MIND JAYS THIS.

JASON RESENDEZ: THIS REFERENCES ONE OF THE QUESTIONS IN THE CHAT.

RESEARCH IS POINTING MORE AND MORE TO THE ANSWER BEING YES.

AND THAT'S REALLY WHAT IS THE UNDERPINNING OF THE CONCEPT OF EQUITY AND FOR US BRAIN HEALTH EQUITY.

SO BRAIN HEALTH EQUITY RECOGNIZES THAT WE DON'T ALL HAVE THE SAME OPPORTUNITY FOR BRAIN HEALTH AND FOR GOOD BRAIN HEALTH ACROSS THE LIFESPAN.

WE'RE ALL BORN AT DIFFERENT ADVANTAGE POINTS WHEN IT COMES TO THE ABILITY TO HAVE A HIGH QUALITY EDUCATION.

THE ABILITY TO NOT STRUGGLE WITH HOMELESSNESS.

THE ABILITY TO HAVE INCOME AND FOOD SECURITY.

SO, THESE DIFFERENCES THAT ADD UP ACROSS A LIFESPAN TO ERODE YOUR OPPORTUNITY FOR BRAIN HEALTH IN LATER LIFE AND REALLY AGAIN ACROSS THE LIFESPAN, SO THAT'S WHAT WE MEAN WHEN WE TALK ABOUT BRAIN HEALTH EQUITY.

WE HAVE TO RECOGNIZE THAT WE'RE NOT ALL STARTING FROM THE SAME STARTING POINT WHEN IT COMES TO BRAIN HEALTH AND THAT WE NEED TAILORED SUPPORTS AND SOLUTIONS TO ADDRESS SOME OF THOSE GAPS THAT ARE BEYOND OUR CONTROL, THAT ARE SOCIETAL AND NOT WITHIN MY INDIVIDUAL ABILITY TO MODIFY.

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SO, WHEN WE THINK ABOUT THE DIFFERENCE BETWEEN EQUALITY AND EQUITY, EQUALITY SAYS WE ALL NEED THE SAME RESOURCES, GETTING THE SAME OR EQUAL RESOURCES WILL GIVE US THE SAME EQUAL OUTCOME, AND WE KNOW THAT'S NOT THE CASE BECAUSE WE'RE NOT STARTING FROM THE SAME ADVANTAGE POINT.

THERE IS A GREAT GRAPHIC FROM THE ROBERT WOOD JOHNSON FOUNDATION THAT HAS, THAT SHOWS THE DIFFERENCE BETWEEN EQUALLY AND

EQUITY AS THREE DIFFERENT BICYCLES FOR THREE DIFFERENT PEOPLE.

IT'S SHOWING THAT IF YOU HAVE THREE DIFFERENT PEOPLE THAT ARE DIFFERENT HEIGHTS OR DIFFERENT LEVELS OF ABILITY, AND YOU GIVE THEM ALL THE SAME BIKE, THEY ARE NOT ALL GOING TO BE ABLE TO USE THAT BIKE IN THE SAME WAY.

BUT IF YOU GIVE THEM A BIKE THAT IS FITTED TO THEIR NEEDS, RIGHT?

THEY ARE ABLE TO GET DOWN THE SAME PATH AND DOWN THE SAME ROAD I THINK MORE EASILY.

I AM DOING A HORRIBLE JOB OF EXPLAINING A GRAPHIC I THINK IS REALLY COOL, SO I WILL TRY TO SHARE THAT IN THE CHAT.

I THINK THAT'S BASICALLY THE UNDERPINNING IS THIS IDEA THAT WE NEED TAILORED SUPPORTS AND SOLUTIONS, SO ALZHEIMER'S AND CENTER FOR BRAIN HEALTH EQUITY WE'RE FOCUSED ON THE IDEA.

EXCELLENT, BEAUTIFUL.

THERE IT IS.

WE'RE FOCUSED ON THIS GRAPHIC BRINGING THIS GRAPHIC TO LIFE WHEN IT COMES TO BRAIN HEALTH MESSAGING.

YOU KNOW, THIS IS A REALLY GREAT TIME IN TERMS OF WHERE RESEARCH IS CATCHING UP AND AMAZON.COM FACE KIND OF THE LIVED REALITY AROUND THINGS LIKE SOCIOECONOMIC IMPACT ON OUR OPPORTUNITY FOR BRAIN HEALTH.

AND ALSO AROUND THINGS LIKE RISK MODIFICATION AND RISK REDUCTION.

BUT WE KNOW THAT MESSAGING AND THAT OPPORTUNITY ISN'T BEING EQUALLY DISTRIBUTED TO THOSE COMMUNITIES THAT NEED IT MOST.

WE'RE TALKING ABOUT THIS IDEA OF SOUL CYCLES IS GREAT FOR YOUR BRAIN OR PILATES GREAT FOR BRAIN HEALTH PARTICULARLY FOR COMMUNITIES THAT ARE LOWER RESOURCED.

SO, WE'RE FOCUSED ON CULTURALLY TAILORING MESSAGING AND SOLUTIONS AND STRATEGIES TO THOSE COMMUNITIES THAT NEED THEM MOST.

WE'LL BE WORKING WITH FOLKS LIKE DR. JACKSON, THE CDC, AND THE NATIONAL ASSOCIATION OF BLACK NURSES, NATIONAL ASSOCIATION OF HISPANIC NURSES TO DEVELOP THOSE STRATEGIES AND MAKE SURE THAT THEY ARE EQUITABLE AND NOT JUST EQUAL.

JONATHAN JACKSON: ALL RIGHT.

SO, I AM GOING TO STOP SHARING NOW.

HOPEFULLY EVERYBODY WAS ABLE TO SEE THAT.

THIS WAS A SCREEN SHARE FROM THE ROBERT WOOD JOHNSON FOUNDATION.

SO, I WANTED TO KIND OF ADDRESS SOME OF THE QUESTIONS THAT HAVE BEEN COMING INTO THE CHAT.

SO, FIRST OF ALL, I AM GOING TO TURN IT BACK OVER TO STEPHANIE TO TALK ABOUT COMMUNITY OUTREACH IN PARTICULAR OR THE FORGET ME NOT PROGRAM, BUT I WANT TO QUICKLY JUMP IN AND TALK ABOUT WHY RISK LEVEL IS HIGHER IN CERTAIN COMMUNITIES RELATIVE TO OTHERS WHEN IT COMES TO DEMENTIA RISK.

NOW, ONE OF THE REASONS WHY PEOPLE OFTEN SAY THAT DEMENTIA IS HIGHER IN CERTAIN COMMUNITIES IS BECAUSE OF CO—MORBID FACTORS.

THEY MAY SAY THAT THERE IS A HIGHER RISK OF STROKE AND DIABETES, HEART DISEASE IN CERTAIN COMMUNITIES, AND THESE COMMUNITIES ARE ALSO AT HIGHER RISK FOR DEMENTIA.

WE KNOW THAT IS PART OF THE ANSWER.

BUT WHAT I THINK IS ALSO IMPORTANT TO

RECOGNIZE IS THAT WE KNOW THAT THERE IS MORE TO IT THAN THAT.

WE DON'T KNOW WHAT THE REST OF IT IS.

THIS IS WORK I HAVE DONE PERSONALLY AS A RESEARCHER IN THE SPACE TRYING TO UNDERSTAND AND EXPLAIN THESE DISPARITIES WHERE IF YOU TAKE A CLOSER LOOK AT THE WAY THAT WE DEFINE ALZHEIMER'S DISEASE, YOU KNOW, IN PARTICULAR THE BUILD UP OF PLAQUES AND TANGLES IN THE BRAIN, YOU CAN SEE THAT THE CO—MORBID FACTORS WE OFTEN TALK ABOUT DON'T FULLY EXPLAIN IS THE BUILDUP OF THESE BETWEEN SAY WHITE INDIVIDUALS AND BLACK IDENTIFYING INDIVIDUALS.

SO, CO—MORBIDITIES IS PART OF THE ANSWER.

THE OTHER PART OF THE ANSWER IS WE SIMPLY DON'T KNOW.

THE REASON WHY WE DON'T KNOW IS BECAUSE WE DON'T HAVE EQUITABLE PARTICIPATION OF ALL GROUPS IN RESEARCH OPPORTUNITIES.

THERE ARE LOTS AND LOTS OF REASONS FOR THAT AND WE'LL GET INTO THAT I PROMISE.

BUT WE HAVE TO RECOGNIZE THAT THE CO—MORBID ANSWER IS AN INCOMPLETE ONE, AND I

THINK IT ALSO TENDS TO REINFORCE INDIVIDUAL FACTORS THAT CONTROL AND CONTRIBUTE TO ALZHEIMER'S DISEASE RATHER THAN THE SYSTEMIC FACTORS THAT REALLY GOVERN IT.

SO, ONE MORE POINT THAT I WANTED TO BRING UP WITH REGARDS TO A QUESTION WE KNOW POVERTY AND SOCIOECONOMIC STRESS HAVE DIRECT IMPACTS ON YOUR LIKELIHOOD TO DEVELOP SOMETHING LIKE ALZHEIMER'S DISEASE OR ANY KIND OF DEMENTIA FRANKLY, BUT PART OF THE ANSWER IS THAT INDIVIDUALS WHO ARE POOR OR SOCIOECONOMICALLY DISADVANTAGED, THEY ARE MUCH MORE LIKELY TO LIVE IN HIGH POLLUTION AREAS, AND THERE IS NEW AND REALLY, REALLY CONVINCING RESEARCH ABOUT THE ENVIRONMENTAL IMPACT ON YOUR DEMENTIA RISK.

SO, FOLKS WHO LIVE REALLY CLOSE TO HIGH POLLUTION PLACES LIKE SUPERFUND SITES, MAJOR ROADWAYS, THEY LIVE LIKE IN THE WRONG DIRECTION BUT NEAR AN AIRPORT, THE PARTICULATE MATTER IN THE AIR, ESPECIALLY THAT SMALL PARTICULATE MATTER, PMP 2.5 DOES SEEM TO BE ASSOCIATED WITH DEMENTIA RISK.

IT'S NOT JUST A MATTER OF NOT HAVING RESOURCES.

IT'S THAT THESE ARE INDIVIDUALS THAT ARE LIKELY TO LIVE IN PLACES THAT HAVE HIGH POLLUTION IN THE AIR, WHICH DOES SEEM TO FURTHER DRIVE THAT IMPACT.

SO, THERE ARE DIRECT AND INDIRECT FACTORS THAT CONTRIBUTE TO DEMENTIA RISK.

SO, NOW I WANT TO TURN THINGS BACK OVER TO STEPHANIE MONROE TO TALK TO US A LITTLE BIT ABOUT COMMUNITY OUTREACH, BEFORE COVID AND MAYBE JUST JASON AND STEPHANIE TOGETHER CAN TALK A LITTLE BIT ABOUT COMMUNITY OUTREACH DURING THE PANDEMIC.

BUT, STEPHANIE, I WOULD LOVE FOR YOU TO TALK TO US A LITTLE BIT ABOUT FORGET ME NOT.

WE HEARD ABOUT IT BEFORE, BUT TELL US WHAT THIS PLAY IS ABOUT, WHY IT'S SO POWERFUL, WHY PEOPLE SEEM TO LIKE IT AND WHAT DOES IT HAVE TO DO WITH MAYBE THIS IDEA OF BEING DEMENTIA FRIENDLY.

STEPHANIE J. MONROE: YEAH, ABSOLUTELY.

THANK YOU.

I WOULD SAY THERE IS SOMETHING MAGICAL ABOUT THE FORGET ME NOT PLAY, EXCEPT IT WAS CREATED WITH THE PARTICULAR AUDIENCE IN MIND.

WE WERE INTENTIONAL ABOUT HAVING FRANKLY AN ALL BLACK CAST TO GO INTO A BLACK COMMUNITY, TO DELIVER MESSAGES IN THE WAY THAT MANY OF THESE COMMUNITIES WANTED TO RECEIVE INFORMATION, TO PUT MAKE SURE THAT IT WAS FULL OF INFORMATION BUT DELIVERED IN SUCH A WAY PEOPLE DIDN'T EVEN REALIZE THEY WERE BEING EDUCATED.

WE WOULD SHOW THE TRUTH OF WHAT HAPPENS IN ALZHEIMER'S AND IN A FAMILY.

WE ALLOW THE AUDIENCE TO COME INSIDE AND TO ASK AND HAVE ANSWERED QUESTIONS THAT THEY HAVE.

WE PROVIDE THEM OPPORTUNITIES TO CONNECT AGAIN TO LOCAL RESOURCES.

WE HUMANIZE CLINICAL TRIALS AND BRING PEOPLE UP WHO ALREADY PARTICIPATED IN RESEARCH.

WE ASK QUESTIONS ABOUT TUSKEGEE BEFORE THEY HAVE A CHANCE TO BE ASKED BY THE AUDIENCE.

WE TRY TO DISPEL MYTHS.

WE CREATE TRANSPARENCY AND WE ALSO BRING LOTS OF INFORMATION, SO IT'S JUST A TOOL.

BUT WE HAVE FOUND IT TO BE VERY EFFECTIVE AND WE WERE SORT OF SURPRISED AT THE END OF THE PLAY PEOPLE WERE SO SELL PASSIONED, THEY SO JUST WANTED TO DO SOMETHING, AND SO FOR US TO TALK ABOUT WHY AND WHAT WE NEEDED TO BE ABLE TO FIND BETTER TREATMENTS AND POSSIBLY A CURE OR TO EVEN UNDERSTAND WHY THIS DISEASE WAS SO PREVALENT IN THE BLACK COMMUNITY, PEOPLE VOLUNTEER.

THEY WERE LIKE, I WANT TO PARTICIPATE.

I AM WILLING TO DO THIS, AT LEAST CALL ME AND TELL ME WHAT I CAN DO.

THEY WANTED TO DO SOMETHING DESPITE I GUESS RUMORS OR MISINFORMATION THAT BLACKS WON'T PARTICIPATE IN RESEARCH BECAUSE OF TUSKEGEE.

HALF THE PEOPLE WE BROUGHT IN DIDN'T KNOW ABOUT TUSKEGEE.

THERE WERE OTHER REASONS.

THERE WAS A LACK OF TRUST.

THERE WAS FEAR.

THERE WAS LACK OF ACCESSIBILITY.

THE PLACES CONDUCTING THE CLINICAL TRIALS WERE, YOU KNOW, 20 MILES AWAY.

THEY HAVE TO MANEUVER THROUGH A

TRANSPORTATION SYSTEM.

THEY WEREN'T GETTING FULLY REIMBURSED.

THERE WERE LOTS OF FACTORS ABOUT IT.

SO, WE HAD TO WORK WITH THE COMMUNITIES AND COME IN AS A LISTENER AND PARTNER WITH PEOPLE WHO WERE ON THE GROUND.

BUT I THINK IT'S A VERY, IT'S VERY MUCH A LEARNING EXPERIENCE FOR US, FROM THE PEOPLE ON THE GROUND WHO HAD AN OPPORTUNITY TO CONNECT WITH REAL PEOPLE AND FOR REAL PEOPLE TO CONNECT WITH US, SO IT REALLY WAS A TRI LEGGED STOOL.

IT'S CHANGED A BIT.

WE HAVEN'T BEEN DOING IT LIVE BECAUSE OF COVID.

THERE ARE SOME COMMUNITIES I THINK THERE IS A YOU TUBE CHANNEL WITH THE PLAY, ONE OF THE VIDEO RECORDINGS IS AVAILABLE FOR PEOPLE.

SOME CENTERS ARE ACTUALLY RUNNING SMALL EXCERPTS OF THE PLAY IN ORDER TO FACILITATE CONVERSATIONS THROUGH A ZOOM TYPE PLATFORM.

SO WE'RE WORKING TO FIGURE OUT HOW TO EXPAND THAT.

I THINK THE LESSON LEARNED IS THAT WE

NEED TO BE CULTURALLY SENSITIVE NOT JUST WHAT WE SAY TO COMMUNITIES BUT HOW WE SAY AND THAT WE'RE DELIVERING MESSAGES TO THEM THE WAY THEY WANT TO RECEIVE IT.

SOME PARTICULAR CULTURES MIGHT BE VERY HAPPY TO COME OUT OR DO A ZOOM CALL WITH A VERY LEARNED PHD THAT'S GOING TO SPEAK AT A 12TH GRADE LEVEL.

OTHERS WANT SOMETHING THAT'S MUCH MORE DOWN—TO—EARTH AND THAT THEY CAN RELATE TO.

WE NEED BOTH OF THOSE THINGS, BUT WE NEED TO UNDERSTAND AND TAKE OUR CUE FROM WHAT THE COMMUNITY IS INTERESTED IN.

JONATHAN JACKSON: SO, JASON, IS THERE ANYTHING THAT YOU WOULD LIKE TO ADD ABOUT HOW WE CAN ENGAGE COMMUNITIES AND HOW WE CAN DO THAT WITH EQUITY AND SORT OF CULTURAL HUMILITY?

JASON RESENDEZ: YEAH, I THINK A COUPLE OF THINGS.

ONE IS REALLY UNDERSTANDING COMMUNITY, RIGHT?

SO, WHEN WE DO OUR LATINO OUTREACH WORK WE GO INTO THIS KNOWING THAT LATINO DOESN'T

MEAN THE SAME THING, IT'S NOT A MONOLITHIC COMMUNITY.

I THINK THAT'S ONE OF THE THINGS THAT YOU PROBABLY HAVE BEEN HEARING A LOT ABOUT WITH THE ELECTION RESULTS AND SEEING SOME OF THE DATA COMING OUT.

THIS IS SOMETHING WE HAVE KNOWN FOR SINCE THE EXISTENCE OF BEING LATINO THAT WE'RE NOT ALL BOUND BY THE SAME CULTURAL VALUES, THE SAME CULTURE AND HERITAGE.

REALLY UNDERSTANDING WHAT THAT MEANS, RIGHT?

NOT JUST IN THE LATINO COMMUNITY THAT'S APPLICABLE TO SEVERAL COMMUNITIES, SO WHEN YOU ARE THINKING ABOUT YOUR OUTREACH AND ENGAGEMENT EFFORTS REALLY UNDERSTANDING WHAT THAT COMMUNITY MAKE UP IS, AND THIS IS WHERE DATA BECOMES REALLY IMPORTANT AND POWERFUL TO HELP YOU UNDERSTAND WHAT YOUR COMMUNITY LOOKS LIKE IN TERMS OF THE MAKE—UP OF LATINO VERSUS OUR PUERTO RICANS VERSUS DOMINICANS VERSUS MEXICAN AMERICANS, AND WHAT IS IT IN YOUR COMMUNITY WHEN IT COMES TO LATINOS THAT ARE PREDOMINANT?

AND THEN TAIL ORGANIZORING YOUR

OUTREACH AND ENGAGEMENT BASED ON CULTURAL NORMS IN THOSE COMMUNITIES.

ONE IS WE HAVE AN ENGAGEMENT PLATFORM NOT TO THE LEVEL OF FORGET ME NOT OF THE FORGET ME NOT FOR US IS THE GOLD STANDARD AND I AM ALWAYS IN A OF THE AMAZING STEPHANIE HAS DONE.

WE HAVE ONE CALLED WHO IS YOUR COCO?

IS IT'S BUILT OFF THE DISNEY COCO FILM WHICH HAS A VERY POWERFUL THEME AROUND MEMORY LOSS AND ALSO CARE GIVING.

TO HAVE THAT THEME IS COUCHED WITHIN THE MEXICAN AMERICAN HOLIDAY OF DAY OF THE DEAD OR MEXICAN HOLIDAY DAY OF THE DEAD.

NOT ALL MEXICAN AMERICANS CELEBRATE THIS.

THIS IS A TRADITION THAT'S PRIMARILY MEXICAN, THAT IF YOU ARE CUBAN OR DOMINICAN IT DOESN'T HAVE THE SAME CULTURAL RESONANCE.

I WOULDN'T GO TO MIAMI AND EXPECT A GREAT TURN OUT FOR THE DAY OF THE DEAD EVENT.

SO IT'S KIND OF LOOKING AT THAT ENGAGEMENT TACTIC AND STRATEGY AND UNDERSTANDING THAT IS GOING TO WORK IN CERTAIN COMMUNITIES BUT MAYBE NOT AS WELL IN

OTHERS AND ADAPTING BASED OFF OF THAT UNDERSTANDING.

SO, I THINK IT IS UNDERSTANDING WHO YOUR TARGET COMMUNITIES ARE, LEVERAGING DATA TO UNDERSTAND THAT, TALKING TO INDIVIDUALS TO UNDERSTAND THE CULTURAL NORMS, AND THEN DEVELOP YOUR ENGAGEMENT STRATEGY BASED OFF OF THAT INFORMATION.

SO, I WOULD SAY IT COMES DOWN TO NOTHING ABOUT US WITHOUT US.

SO HAVING THOSE COMMUNITIES AS PART OF THE CONVERSATION LIKE STEPHANIE DID WITH FORGET ME NOT, SO THAT THEY ARE DESIGNING THE PROGRAM DEVELOPMENT IN OUTREACH ALONG WITH YOU AND THAT'S GOING TO HELP TO GUARANTEE THAT SUCCESS AND CULTURAL RESONANCE.

SOMEBODY ASKED, HOW DO WE DO THIS DURING COVID?

THOSE SAME LESSON APPLY AND ARE EVEN MORE URGENT DURING COVID.

TO HAVE THESE INDIVIDUALS AS A PART OF THIS PROCESS THEN IT GOES TO SOMETHING WE SAY ALL THE TIME BUT IT NEVER GETS ANY LESS RELEVANT, WHO ARE THE TRUSTED MESSENGERS WITHIN THOSE COMMUNITIES THAT ARE ALREADY

DOING THIS KIND OF WORK, EVEN IF IT'S NOT AROUND DEMENTIA.

THIS IS HOW WE STARTED WITH THE LATINOS AGAINST ALZHEIMER'S COALITION.

WE WENT TO ORGANIZATIONS DOING GREAT WORK AND DIABETES AND HEART DISEASE AND PAINTED THE CONNECTION BETWEEN DEMENTIA AND DIABETES AND HEART DISEASE AND SAID THIS IS AN EXTENSION OF THAT WORK.

THAT REALLY ENABLED US TO HAVE A DIFFERENT KIND OF CONVERSATION BECAUSE THEY WERE ALREADY TRUSTED, THEY ALREADY KNEW THE CONTENT FROM A DIFFERENT ANGLE SO WE'RE ABLE TO PIGGYBACK AND CREATE A NEW SKILL SET FOR THEM AROUND BRAIN HEALTH AND DEMENTIA, SO I THINK THAT IDENTIFYING THOSE FOLKS THAT ARE ALREADY DOING THE WORK AND FIGURING OUT HOW YOU CAN ADD VALUE TO THE FOLKS THAT THEY ARE SERVING WITH YOUR PROGRAMMING, MESSAGING, RESOURCES, ET CETERA.

STEPHANIE J. MONROE: THERE IS ONE EXAMPLE THAT I LOVE TO SHARE.

SO, OFTEN WE WOULD GO TO THESE COMMUNITY EVENTS AND WE WOULD HAVE SOMEONE

TALK ABOUT NUTRITION BECAUSE THAT'S REALLY ESSENTIAL FOR JUST IN GENERAL HEALTHY AGING.

WE HAVE DOCTORS TALK ABOUT THE MEDITERRANEAN DIETS IN FRONT OF AN AUDIENCE OF AFRICAN—AMERICANS WHO ARE NOT MEDITERRANEAN, THEY ARE LIKE WHAT DOES THAT MEAN?

I HAVE TO EAT OLIVES ALL THE TIME?

WHAT ARE YOU SAYING TO ME THAT I NEED TO DO?

WE HAD ONE DOCTOR THAT CAME UP AND SAY JUST VERY SIMPLY, JUST PUT COLOR ON YOUR PLATE.

YOU HAVE GREEN, ORANGE, MAYBE SOME BROWN.

SHOULDN'T BE BROWN WITH WHITE COVERED IN GRAVY.

THAT'S NOT THE HEALTHIEST THING TO DO.

BUT SOMEONE THAT CAN REALLY CONNECT AND BREAK THINGS DOWN IN A WAY THAT IS EASILY ACCESSIBLE FOR PEOPLE, THEN PEOPLE CAN IMPLEMENT THAT.

SO THAT'S WHAT WE NEED TO BE I THINK VERY INTENTIONAL ABOUT IS BREAKING DOWN THE WAY WE SHARE WITH DIFFERENT CULTURES AND

RECOGNIZING YOU ARE NOT GOING TO TELL CERTAIN COMMUNITIES TO NEVER EAT THIS LOVELY THING THEY HAVE BEEN EATING FOREVER.

YOU ARE GOING TO TELL THEM ABOUT HOW TO MODIFY THAT.

HOW TO DO MODIFY RISK.

HOW TO ADD THINGS TO THEIR DIET.

HOW TO ADD IN EXERCISE SO IT DOESN'T REQUIRE GYM MEMBER MEMBERSHIP.

SOME OF THE DATA IS OUT IN TERMS OF HOW EFFECTIVE THESE CAN BE.

WE KNOW CERTAINLY IT MAKES THINGS EASIER FOR PEOPLE TO AGE AND TO BE ABLE TO STAND AND NOT TO HAVE MOBILITY CHALLENGES AND THINGS OF THAT NATURE, WHICH IS ALL GOOD.

JONATHAN JACKSON: LOOKS LIKE WE HAVE MR. VAN BUREN IS BACK.

MR. VAN BUREN, BEFORE YOU GET STARTED I JUST WANTED TO KIND OF RESPOND TO ONE OF THE QUESTIONS IN THE CHAT TO CINDY RYAN WHO IS ASKING ABOUT THE PROGRAM THAT WAS COORDINATED WITH DAY OF THE DEAD.

I THINK JASON THE PROGRAM WAS CALLED WHO IS YOUR COCO, AND THIS IS COCO AS IN THE

DISNEY PIXAR MOVIE, IS THAT CORRECT?

JASON RESENDEZ: THAT'S RIGHT.

I WILL PUT IN THE CHAT A LINK TO AN OVERVIEW OF THAT.

JONATHAN JACKSON: OKAY.

ALL RIGHT.

MR. VAN BUREN, SO WE'RE TALKING ABOUT THE NATURE OF LIVING WITH DEMENTIA, WE'RE TALKING ABOUT WHAT THAT MUST BE LIKE AND WE'RE KIND OF TALKING ABOUT THAT IN TERMS OF DEALING WITH HISTORIC AND CURRENT RACISM.

DO YOU HAVE ANY THOUGHTS AROUND THESE THAT YOU WOULD LIKE TO SHARE ABOUT YOUR OWN EXPERIENCE OR WHAT YOU HAVE SEEN WITH OTHERS?

IS.

BRIAN VAN BUREN: YES.

ONE POINT I WANT TO MAKE IS TO ENGAGE AFRICAN-AMERICAN COMMUNITIES IN ALZHEIMER'S CALLS, THE ALZHEIMER'S ASSOCIATION IS PARTNERING WITH THE AFRICAN METHODIST EPISCOPAL CHURCH A PREDOMINANTLY AFRICAN-AMERICAN DENOMINATION OF APPROXIMATELY 4 MILLION MEMBERS IN THE UNITED STATES.

WHEN IT COMES TO MY OWN DIAGNOSIS AND

PROCESS, IT WAS VERY DIFFICULT BECAUSE NUMBER ONE ONCE THE DOCTOR GAVE ME MY DIAGNOSIS, THAT WAS IT.

HE DID NOT TELL ME WHAT TO DO.

HE DID NOT GIVE ME ANY RESOURCES, SO I WAS KIND OF LOST UNTIL I WAS SMART ENOUGH TO GET ON THE COMPUTER AND START DOING RESEARCH AND I FOUND ALZHEIMER'S ASSOCIATION, WHICH REALLY, REALLY HELPED ME GET THROUGH THIS PROCESS.

JONATHAN JACKSON: YES, SIR.

SO WHEN WE ARE TALKING ABOUT DEMENTIA FRIENDLY COMMUNITIES AND BEING DEMENTIA FRIENDS, YOU KNOW, WOULD YOU SAY THAT HAVING A TIMELY DIAGNOSIS IS PART OF THE PROBLEM THAT WE NEED TO SOLVE HERE?

YOU KNOW, IS IT A MATTER OF BEING TAKEN SERIOUSLY BY YOUR DOCTOR OR HAVING DIFFERENT DOCTORS OR WHAT IS THE DEMENTIA FRIENDLY WAY TO GET A FAIR AND TIMELY DIAGNOSIS.

BRIAN VAN BUREN: GOOD QUESTION.

WELL, ACTUALLY I AM PART OF AN ORGANIZATION NOW THAT IS LOOKING AT DEMENTIA

FRIENDLY AIRPORTS BASED OUT OF LONDON.

FOR THOSE OF YOU WHO NOT HAVE DEMENTIA YOU WOULD BE SURPRISED HOW DIFFICULT IT IS TO MANEUVER IN AN AIRPORT.

I HAVE PROBLEMS JUST GETTING MY TICKET FROM THE KIOSK.

SO, WHAT I HAVE DONE IS I HAVE A CARD THAT EXPLAINS THAT I HAVE DEMENTIA AND WHAT MY LIMITATIONS ARE.

I GIVE IT TO THE CUSTOMER SERVICE REP BEFORE THE FLIGHT.

THEY ALLOW ME TO BOARD THE FLIGHT BEFORE EVERYONE ELSE AND IF I AM MAKING A CONNECTION THEY HAVE SOMEONE TO ASSIST ME TO MY NEXT FLIGHT.

JONATHAN JACKSON: THAT BRINGS UP ANOTHER QUESTION.

SO WE'VE TALKED EFFECTIVELY ALL DAY ABOUT THESE DEMENTIA FRIENDLY SPACES AND HOW WE CAN BE DEMENTIA FRIENDS.

BUT AT THE END OF THE DAY IN ORDER TO DO THIS WELL IT REQUIRES RESOURCES.

SO, HOW CAN WE, HOW CAN WE POSSIBLY BUILD A DEMENTIA FRIENDS PROGRAM AND DEMENTIA

FRIENDLY SPACES IN COMMUNITIES THAT ARE HISTORICALLY UNDER RESOURCED?

THIS IS FOR ALL THREE OF OUR PANELISTS HERE.

HOW DO WE DO THAT?

HOW DO WE BASICALLY CREATE A SPACE THAT REQUIRES MORE RESOURCES GIVEN THAT THEY DON'T HAVE ENOUGH RESOURCES IN THE FIRST PLACE?

STEPHANIE J. MONROE: I WAS GOING TO SAY I COMPLETELY AGREE ABOUT THE RESOURCE PROBLEM BUT I CAN SPEAK ABOUT MY EXPERIENCE WAS MY FATHER THAT ARE VERY FRUSTRATING.

YOU WANT INDIVIDUALS TO BE ABLE TO GO TO A DOCTOR WHETHER IT'S FOR TREATMENT OF DEMENTIA OR FOR OTHER KINDS OF ISSUES.

ONE OF THE FIRST FRUSTRATING EXPERIENCES IS ASKING MR. JOHNSON, HAVE ANY YOUR MEDICATIONS CHANGES, CAN YOU GIVE ME A LIST, THINGS I HAVE TO REMIND THEM HE HAS DEMENTIA.

HE IS NOT GOING TO BE ABLE TO ANSWER THOSE QUESTIONS.

SO NOT REALLY RELEVANT.

FIND A DIFFERENT WAY TO GET THAT

INFORMATION.

SO, I FEEL LIKE SOMETIMES BEING DEMENTIA FRIENDLY IS NOT TRYING TO OR NOT INTENTIONALLY HUMILIATING PEOPLE.

PUTTING THEM IN A POSITION WHERE THEY FEEL VERY ASHAMED AND THEY FEEL LIKE THEY ARE BEING PUT IN A POSITION OF BEING JUDGED FOR NOT BEING SMART OR BEING SILLY.

JUST ASKING THE QUESTIONS THAT NEED TO BE ASKED AND PROVIDING OTHER OPPORTUNITIES FOR PEOPLE TO ENGAGE.

I THINK THAT'S HOWEVER YOU MANEUVER THROUGH THE COMMUNITY.

THAT YOU SHOULDN'T ALWAYS HAVE TO HAVE A CARD OR HAVE AN EXPLANATION THAT ONCE AND DONE SHOULD BE THE RULE.

YOU SHOULD BE ABLE TO PUT SOMETHING IN YOUR AIRLINE RECORD THAT IS SHARED.

EXMEDIA GETS ALL KINDS OF INFORMATION ABOUT YOUR CHOICES AND FOOD AND EVERYTHING ELSE, YOUR STATUS, YOU SHOULD BE ABLE TO GO IN THERE.

I THINK WE NEED TO BE FORWARD—THINKING AND PUT OURSELVES OR GET INFORMATION ABOUT DEMENTIA COMMUNITIES ABOUT WHAT THEY NEED AND

WHAT WOULD HELP THEM, AND OTHER CAN BE PROACTIVE TO HELP TO BE ACCOMMODATING AS WE DO WITH PEOPLE WITH DISABILITIES.

JONATHAN JACKSON: I WOULD JUMP IN ON THE RESOURCE QUESTION AND OFFER TWO THOUGHTS ON THAT.

ONE, I THINK IT GOES BACK TO WHAT I SAID EARLIER ABOUT UNDERSTANDING WHAT'S HAPPENING AT THE COMMUNITY LEVEL AROUND MAYBE RELATED ISSUES.

DIABETES, HEART DISEASE AND ARE THERE WAYS TO TAP INTO THAT INFRASTRUCTURE.

THAT'S NOT THE BEST SOLUTION OBVIOUSLY.

WE WANT MORE RESOURCES.

AND I THINK SECOND IS WE NEED TO RECOGNIZE AND DEMAND A BETTER PUBLIC HEALTH RESPONSE OF DEMENTIA.

AT THE STATE LEVEL AND AT THE NATIONAL LEVEL.

THE RESOURCE THAT WE INVEST AT THE FEDERAL LEVEL IN DEMENTIA RESPONSE IS LAUGHABLE COMPARED TO THE AMOUNT THAT WE INVEST IN RESEARCH.

CERTAINLY COMPARED TO THE AMOUNT THAT

WE INVEST IN PUBLIC HEALTH RESPONSE TO OTHER HEALTH ISSUES COMPARABLE TO THE IMPACT OF DEMENTIA ON SOCIETY, SO I THINK WE HAVE TO THINK ABOUT WE'RE, YOUR SERVICE PROVIDERS BUT THOSE SERVICES CAN BE BETTER DELIVERED AND YOU WILL BE BETTER RESOURCED TO DELIVER THOSE SERVICES IF YOU ALSO THINK OF YOURSELVES AS ADVOCATES AND AS FOLKS THAT HAVE A VOICE TO POLICY MAKERS LOCALLY AT THE CITY LEVEL, AT THE STATE LEVEL AND AT THE FEDERAL LEVEL TODAY FOR EXAMPLE THE U.S. SENATE APPROPRIATIONS COMMITTEE ANNOUNCED THEY WERE RECOMMENDING A $350 MILLION DOLLAR INCREASE FOR ALZHEIMER'S RESEARCH, WHICH INCLUDES A COMPONENT FOR THE PUBLIC HEALTH INFRASTRUCTURE PROJECT THROUGH THE CDC WHICH IS GREAT, BUT THE HOUSE WHATS A MUCH SMALLER NUMBER THAT WOULDN'T INCLUDE ANY OF THAT FUNDING FOR A PUBLIC HEALTH RESPONSE.

SO, I THINK THERE IS REALLY AN IMPORTANT OPPORTUNITY HERE THAT RECOGNIZES THE FACT THAT RESOURCE AND INFRASTRUCTURE IS LIMITED AND WE NEED TO DEMAND BETTER FOR OUR WORK AND THE ABILITY TO DO THE WORK THAT NEEDS TO BE DONE.

STEPHANIE J. MONROE: MANY RESOURCE COMMUNITIES WE NEED TO LOOK AT WHAT THE DATA TELLS US ABOUT WHERE PEOPLE WHO AREN'T MOST IMPACTED BY THIS DISEASE RECEIVE THEIR HEALTH CARE.

AND MAKING SURE IT'S NOT JUST GOING TO VERY LARGE CENTERS BUT ALSO PART OF THAT AND THE RESOURCES ACCOMPANYING THAT GOES TO PLACES LIKE COMMUNITY HEALTH CENTERS THAT ARE EMBEDDED IN COMMUNITIES THAT SPECIFICALLY ARE CREATED TO SERVE VULNERABLE COMMUNITIES.

MAKE SURE THEY HAVE AND THEY HAVE SKILLED, TRAINED PEOPLE WHO ARE ABLE TO GET SOME OF THIS AND ACTUALLY SERVE PEOPLE WHERE THEY ARE, NOT FORCE PEOPLE TO GO OUT OF A SYSTEM THEY ARE ALREADY COMFORTABLE WITH.

BRIAN VAN BUREN: ONE OF THE POINTS I WANT TO MAKE IS THAT LIVING WITH DEMENTIA DOES NOT MEAN I AM SUFFERING I LIVE WELL.

I JUST HAVE TO DO THINGS MUCH DIFFERENT THAN BEFORE.

MANY OF MY COHORTS WHO ALSO ARE LIVING WITH DEMENTIA DO MANY, MANY, MANY THINGS.

WE JUST HAVE TO ADJUST IT AND MAKE IT SO IT FITS US, BUT THE IDEA OF US SUFFERING IS JUST NOT REAL.

JONATHAN JACKSON: I WANT TO PULL IN A FEW COMMENTS AND THOUGHTS FROM THE CHAT.

KRISTEN WROTE A FEW MINUTES AGO I FEEL LIKE DOCTORS ARE RELUCTANT TO USE THE TERM DEMENTIA.

I HAVE SEEN MORE DOCS USE COGNITIVE IMPAIRMENT.

DOES THAT LINEUP WITH YOUR EXPERIENCE, MR. VAN BUREN?

JASON AND STEPHANIE, WHAT MIGHT BE GOING ON HERE?

MR. VAN BUREN DO YOU SEE DEMENTIA MORE OR COGNITIVE IMPAIRMENT MORE?

WHICH TERM DO YOU HEAR MORE?

BRIAN VAN BUREN: I HEAR COGNITIVE IMPAIRMENT.

THE REALITY IS DOCTORS ARE REALLY AFRAID TO GIVE THE DIAGNOSIS.

I'M NOT SURE PART OF IT IS I JUST DON'T THINK THEY ARE AS EDUCATED AS THEY SHOULD BE AROUND THE SUBJECT.

JONATHAN JACKSON: I WOULD AGREE WITH THAT HAVING SEEN MANY DOCTORS IN ACTION AROUND THIS.

JASON AND STEPHANIE?

JASON RESENDEZ: I WOULD SAY IT'S ALL OVER THE PLACE BECAUSE OF THE LEVEL OF EDUCATION AROUND COGNITIVE IMPAIRMENT, COGNITIVE DECLINE, BRAIN HEALTH GENERALLY.

IT'S A BIG FOCUS OF OUR WORK AND A LOVE THE FOLKS IN THE SPACE TO INCREASE OUR HEALTH SYSTEM READINESS AND THAT MEANS PROVIDERS UNDERSTANDING THE NUANCES AND DIFFERENCES BETWEEN THE DIFFERENT TERMS, WHICH IS CRITICAL AND TODAY WE HAD ONE OF OUR AMAZING ADVOCATES WHO IS AN AFRO LATINA FROM NEW YORK WHO HELPED HER MOM, A DOMINICAN IMMIGRANT NAVIGATE THE DIAGNOSIS PROCESS.

AT ONE POINT HER NEUROLOGIST GAVE HER A PRINT OUT OF E—MAILS AND SAID GOOGLE ALZHEIMER'S.

YOUR MOM HAS ALZHEIMER'S, GOOGLE IT.

WAS LITERALLY THE QUOTE HE GAVE TO HER, SO IT'S NOT JUST ABOUT WHAT TERMS TO USE, BUT HOW TO USE THEM.

HOW TO HAVE A CONVERSATION.

I THINK THAT'S AN IMPORTANT PART OF BEING DEMENTIA FRIENDLY AND WHY A LOT OF THE DEMENTIA FRIENDS PROGRAM WAS BECAUSE IT CREATES A CULTURE OF INCLUSIVITY AROUND THESE ISSUES, SO THAT WE ARE ABLE TO HAVE THESE KINDS OF, THESE DIFFICULT CONVERSATIONS OR OFTEN STIGMATIZED CONVERSATIONS.

I WOULD LOVE TO SEE THE AMA ADOPT A DEMENTIA FRIENDS PROGRAM SO THAT THEIR DOCTORS AND PROVIDERS ARE CONSIDERED DEMENTIA FRIENDS BECAUSE I THINK THAT'S REALLY LACKING RIGHT NOW IN THE HEALTH SYSTEM.

STEPHANIE J. MONROE: I WOULD ADD TO THAT HAVING SPENT SOME TIME WITH GERIATRICS AND INDIVIDUALS IN THIS SPACE.

MANY OF THEM ALSO DON'T LIKE DELIVERING A DIAGNOSIS FOR WHICH THERE IS NO TREATMENT.

THEY DON'T LIKE DELIVERING CANCER DIAGNOSIS IF THEY FEEL LIKE THERE IS NO EFFECTIVE TREATMENT BECAUSE AS JASON SAID THEY ARE NOT USED TO VIEWING CARE SUPPORT AND CARE PLANNING OR CONNECTING TO COMMUNITY RESOURCES AS PART OF THEIR PRESCRIPTION,

RIGHT?

THAT NEEDS TO BECOME PART OF THEIR NORMAL PRESCRIPTION IS THIS IS WHERE YOU GO NEXT.

THIS IS RESEARCH.

CANCER, VERY MUCH MAKES PARTICIPATING RESEARCH PART OF THEIR CARE CONTINUUM, AND WE HAVEN'T REALLY DONE THAT IN ALZHEIMER'S OR DEMENTIA.

PEOPLE THAT ARE OLDER AND OLD ENOUGH LIKE I AM TO REMEMBER WHEN YOU DIDN'T EVER TALK ABOUT CANCER, YOU CALLED IT WHATEVER ELSE THAT THING WAS, BUT YOU DIDN'T WANT TO SAY THE C WORD.

YOU KNOW?

BECAUSE OF STIGMA.

WE HAVE TO JUST WE HAVE TO CALL IT WHAT IT IS IN ORDER TO DEFEAT IT AND NOT LET IT TO BEAT US.

JONATHAN JACKSON: I WANTED TO JUMP IN AND SAY THAT FROM THE CLINICIAN'S PERSPECTIVE COGNITIVE IMPAIRMENT AND DEMENTIA MAY BE USED DIFFERENTLY THAN THE WAY WE USE IT WITHIN OUR COMMUNITIES.

SO, FOR SOME, THEY MAY THINK OF MILD COGNITIVE IMPERATIVES WHICH IS A SPECIALIZED TERM THAT PEOPLE USE, WHICH IS NOT QUITE DEMENTIA, IT IS FOR SOME PEOPLE THEY FEEL THAT IT'S SORT OF A PREDEMENTIA BUT SOME PEOPLE NEVER SORT OF PROGRESS FROM THIS STAGE OF MILD COGNITIVE IMPAIRMENT TO DEMENTIA AT ALL.

THERE ARE SPECIAL TERMS OF ART THAT WE HAVE HISTORICALLY USED AND THOSE OF US WHO ARE ON THE SIDE OF WORKING WITH DOCTORS AND CLINICIANS, CERTAINLY NEED TO RECOGNIZE THAT WORDS HAVE MEANING AND THEY HAVE DIFFERENT MEANINGS FOR DIFFERENT COMMUNITIES.

SO, I WANTED TO ACTUALLY JUMP BACK INTO THE CHAT.

SO THERE ARE TWO GREAT QUESTIONS FROM LEAH AND LEAH I HOPE I AM NOT PUTTING YOU ON THE SPOT.

IF YOU WOULD BE WILLING TO UNMUTE YOURSELF AND KIND OF ASK YOUR QUESTIONS TO THE PANEL, I WOULD LOVE TO KIND OF GET A CHAT GOING ABOUT THINKING ABOUT COMMUNITY OUTREACH AND ENGAGEMENT.

LEAH ARE YOU STILL IN THE ZOOM?

SPEAKER: YEAH, HI, STILL HERE.

JONATHAN JACKSON: GO AHEAD.

SPEAKER: MY FIRST QUESTION WAS, JASON, THANK YOU, FIRST OF ALL FOR EVEN MENTIONING THE DIFFERENCES WITHIN LATINO COMMUNITY AND ALSO LOOKING WITHIN THE AFRICAN—AMERICAN COMMUNITY AND HOW DIVERSE IT IS WITHIN WHAT WE CONSIDER TO BE SUCH A HOMO GENOUS TERM.

HOW DO YOU PRIORITIZE THE TERM COMMUNITY BECAUSE THAT TERM IS WIDELY DEFINED VERY DIFFERENTLY IN EVERY SINGLE DISCIPLINE, ANTHROPOLOGY HAS MULTIPLE TERMS THAT WE USE INSTEAD OF COMMUNITY NOW BECAUSE IT'S JUST SO TRICKY.

WHENEVER YOU DO USE THE TERM YOU HAVE TO SAY EXACTLY WHAT YOU MEAN BY IT AND HOW TO QUALIFY IT.

SO, I WAS JUST WONDERING WHAT YOUR THOUGHTS WERE ON THAT IN TERMS OF YOUR COMMUNITY OUTREACH?

MY SECOND QUESTION WAS WITHIN COMMUNITY OUTREACH HOW DOES WESTERN MEDICINE INTERACT WITH TRADITIONAL MEDICINE?

AND TRADITIONAL PRACTICES?

DO YOU BRING THAT IN?

DO YOU BRING IN TRADITIONAL HEALERS, WHATEVER THE CULTURALLY SPECIFIC OR RELEVANT TERM WOULD BE FOR THAT GROUP OF PEOPLE, BUT ARE THOSE PEOPLE BROUGHT IN TO HELP WITH DESCRIBING WHAT'S HAPPENING?

TO HELP FIND A PATH TO TREATMENT?

BECAUSE IN MY OWN RESEARCH AND WITH THE PEOPLE THAT I WORK WITH AT MY MUSEUM, THERE ARE PEOPLE WHO DON'T TRUST WESTERN MEDICINE.

THEY TRUST THEIR TRADITIONAL HEALERS.

SO, HOW DO YOU WORK ON THAT ASPECT OF IT AS WELL?

JASON RESENDEZ: THOSE ARE GREAT QUESTIONS.

YOU HAVE ME IN THE HOT SEAT.

FOR BOTH WE DON'T DO ENOUGH OF CRITICALLY THINKING ABOUT EITHER ISSUE.

I THINK FOR THE TERM COMMUNITY I THINK WHEN WE DO, WHEN WE ARE WORKING AT THE NATIONAL LEVEL BUT WE DO HAVE CALIBRATIONS IN SPECIFIC COMMUNITIES AND WITHIN THOSE CITIES COMMUNITIES LATINO, AFRICAN—AMERICAN, WHEN WE DEVELOP OUR COMMUNITY STRATEGIES THERE WE ARE

TALKING TO COMMUNITY BASED ORGANIZATIONS AND UNDERSTANDING WHAT THE ECOSYSTEM LOOKS LIKE AND HOW WE CAN ADD VALUE TO THAT ECOSYSTEM.

SO I THINK BETTER CONCEPTUALIZING COMMUNITY IS SOMETHING WE DON'T DO ENOUGH OF AND THEN SHOULD BE DOING BECAUSE I THINK AN INTERDISCIPLINARY APPROACH IS CRITICAL.

IT'S CHALLENGING TO THINK WHAT IS A COMMON VOCABULARY ACROSS DISCIPLINES AROUND THESE TERMS AND WE NEED TO DO BETTER AT FIGURE THAT OUT.

SECOND, IN TERMS OF NON—WESTERN MEDICINE, SO WE HAVEN'T EMBRACED THAT FULLY.

THAT IS ACTUALLY BROUGHT UP IN SEVERAL TIMES PARTICULARLY WORKING IN THE SOUTHWEST WHERE FOLKS COME UP AND ASK ABOUT THIS ISSUE.

WHAT I SAY WE TO DO IS CERTAINLY NOT THINK ALL OF OUR SOLUTIONS WILL BE DELIVERED BY A PERSON IN A WHITE COAT.

THAT CERTAINLY IS NOT THE CASE HERE.

PARTICULARLY BECAUSE OF MANY OF THE ISSUES WE OUTLINED EARLIER ABOUT THE INTIMATE LINKS BETWEEN SOCIOECONOMIC ISSUES AND DEMENTIA RISK AND ACCESS TO SERVICES AND SERVICE UTILIZATION, SO WE ARE BIG PROMOTERS

ARE LEVERAGING COMMUNITY HEALTH NAVIGATORS AND COMMUNITY HEALTH WORKERS.

SO, THAT'S NOT NECESSARILY I DON'T THINK THAT FITS INTO THE TRADITIONAL TERM OF NON—WESTERN MEDICINE, BUT CERTAINLY FITS INTO THE IDEA OF LOOKING BEYOND THE TRADITIONAL HEALTH SYSTEM TO HELP INDIVIDUALS NAVIGATE RESOURCES, ACCESS SERVICES, AND LEARN ABOUT STIGMATIZED ISSUES LIKE ALZHEIMER'S AND DEMENTIA.

I THINK THAT'S REALLY CRITICAL IS THE IMPORTANCE OF BUILDING AND INVESTING IN COMMUNITY HEALTH WORKERS, LAY COMMUNITY LEADERS, BUILDING UP THEIR HEALTH LITERACY AROUND DEMENTIA AND ALZHEIMER'S AND EMPOWERING THEM TO HELP THE COMMUNITY NAVIGATE THESE ISSUES AND WE SEE A LOT, SOME STATES DO THAT WAY BETTER THAN OTHERS.

SOME HEALTH SYSTEMS DO THAT WAY BETTER THAN OTHERS, SO WE HAVE BEEN ADVOCATING FOR A LONG TIME FOR BETTER SUPPORTS AND REIMBURSEMENT FOR COMMUNITY HEALTH SERVICES.

OUR COMMUNITY HEALTH NAVIGATOR SERVICES, SO I THINK THERE IS A LONG ROAD THERE BUT AN IMPORTANT ONE TO INVEST IN.

JONATHAN JACKSON: THEN I AM JUST GOING TO JUMP IN.

USUALLY AS MODERATE I TRY TO TAKE A BACK SEAT, BUT I THINK I HAVE PARTICULAR INSIGHT INTO THIS QUESTION.

I THINK THIS SPEAKS TO A LOT OF OTHER QUESTIONS AROUND COMMUNITY ENGAGEMENT.

SO NUMBER ONE, WHEN IT COMES -- BE SPECIFIC ABOUT THE COMMUNITY YOU ARE TRYING TO REACH OUT TO.

IF YOUR COMMUNITY IS AFRICAN-AMERICANS OR IF IT'S LATINOS, THAT'S NOT SPECIFIC ENOUGH.

JUST IN THE SAME WAY THAT IF YOU WERE SAYING THAT WE'RE TRYING TO REACH OUT TO WHITE PEOPLE, PEOPLE WOULD BE LIKE WELL, WHICH ONES?

SIMILARLY WE HAVE TO RECOGNIZE THAT LEVEL OF DIVERSITY AND THAT NEED FOR SPECIFICITY.

THE SECOND THING THAT I WOULD SAY IS THAT IT'S NOT SIMPLY ENOUGH TO BE SPECIFIC ABOUT WHO WITHIN A COMMUNITY YOU ARE TRYING TO REACH OUT TO, BUT YOU ALSO NEED TO BE

SPECIFIC ABOUT WHAT IT IS THAT YOU ARE TRYING TO ACHIEVE.

YOU KNOW, COMING AS SOMEBODY FROM THE RESEARCH WORLD WHERE IT FEELS LIKE THE ONLY THING THAT WE WANT IS FOR PEOPLE TO COME AND PARTICIPATE IN OUR RESEARCH STUDIES, WE ARE STARTING TO RECOGNIZE THAT THERE ARE OTHER THINGS PEOPLE CAN DO AROUND HEALTH AND AROUND RESEARCH THAT ARE REALLY BENEFICIAL.

SO, YOU CAN SERVE AS A STUDY AMBASSADOR.

YOU CAN BE ON AN INSTITUTIONAL REVIEW BOARD REVIEWING ETHICS OF A STUDY.

YOU CAN BE CONNECTED TO SOCIAL SUPPORTS AND SERVICES RATHER THAN PARTICIPATE IN A RESEARCH STUDY, AND WE HAVE SEEN GREAT EXAMPLES OF PEOPLE WHO HAVE BEEN ABLE TO DO THIS AND DO THIS WELL, EITHER PREPANDEMIC AND DURING THE ONGOING COVID 19 PANDEMIC AS WELL.

SO BEING SPECIFIC ABOUT YOUR AUDIENCE AND BEING SPECIFIC ABOUT THE DELIVERIBLES AND BEING SPECIFIC ABOUT, SORRY, BEING FLEXIBLE ABOUT WHAT PEOPLE MIGHT BE ABLE TO GET OUT OF IT AND OR CONTRIBUTE USUALLY MAKES THIS MUCH EASIER FOR FOLKS AND IT DOES GIVE YOU THAT

ABILITY, SO I HAVE A VERY COMPLICATED, VERY ACADEMIC LOOKING MULTI DIMENSIONAL FRAMEWORK WE CAN GET INTO IT IF PEOPLE ARE INTERESTED, BUT WHAT I WANT TO DO IS MAYBE JUMP INTO SOME OF THE OTHER QUESTIONS THAT ARE COMING IN.

SO, ONE OF THE QUESTIONS THAT I SAW SCROLLING BACK UP THROUGH THE CHAT COMES FROM AMY WALSH, WHO ASKS HOW DO YOU BALANCE AGENCY WITHOUT EMBARRASSMENT FOR A PERSON LIVING WITH DEMENTIA?

SO, HOW IS IT THAT YOU CAN, YOU PROVIDE SOME SUPPORT WITHOUT INFANT ILIZING OR EMBARASSING SOMEONE.

MR. VAN BUREN I WANT TO START OFF BY ASKING YOU THIS QUESTION.

HOW DO YOU BALANCE INDEPENDENCE AND SUPPORT WITH SOMEONE LIVING WITH DEMENTIA?

WHAT IS IT WE ARE SUPPOSED TO BE DOING?

BRIAN VAN BUREN: COME BACK TO ME.

I NEED TO THINK ABOUT IT.

JONATHAN JACKSON: STEPHANIE, LET'S TALK TO YOU.

HOW DID YOU MANAGE THAT WHEN YOU WERE

TRYING TO BE A CARE PARTNER FOR YOUR FATHER?

STEPHANIE J. MONROE: SO, WE STILL ARE.

I THINK LETTING MY DAD SPEAK SO LONG AS HE HAD A VOICE, RIGHT?

GIVING HIM AN OPPORTUNITY NOT JUMPING IN AHEAD BECAUSE THE DELAY IN HIM RESPONDING FOR EXAMPLE HE WAS BEING ASKED QUESTIONS IT WAS SECONDS BEFORE HE HAD TO BE ABLE TO RESPOND AND JUST GIVING HIM THAT ABILITY TO DO THAT OR GIVE HIM PROMPTS.

NOT TO BE HIS VOICE UNTIL HE WOULD GET TO THE POINT AS HE IS NOW WHERE HE WILL ASK ME TO TELL PEOPLE WHAT IT IS.

SO SORT OF RESPECTING WHERE THEY ARE AND NOT BEING ASHAMED OF WHERE THEY ARE AND LETTING THEM KEEP THEIR INDEPENDENCE AND SELF—NESS BECAUSE THEY ARE STILL THERE.

LET THEM EXPRESS THAT.

I THINK THAT'S REALLY HELPFUL.

I FEEL WITH MY DAD IN PARTICULAR THAT COVID HAS BEEN HARD BECAUSE OF THE ISOLATION.

I THINK THAT MAKES DEMENTIA LOOK WORSE.

BUT IT'S AMAZING HOW QUICKLY WHEN I WILL REMOVE HIM HE IS IN AN INDEPENDENT

LIVING FACILITY.

WHEN I REMOVE HIM FROM THE FACILITIESY AND WE ENGAGE IN.

CANS OR WE'RE DRIVING AND HE GETS TO IDENTIFY TREES AND ANIMALS AND CARS AND LAUGH IT'S LIKE HE SNAPS BACK.

THE RESILIENCE IS THERE.

JUST EXPERIENCING THAT AND BEING AWARE AND WITH HIM AS HE IS GOING THROUGH THOSE MOMENTS, AND NOT ASK A LOT EVER QUESTIONS THAT HE CAN'T ANSWER.

THAT'S HOW WE MANAGED IT.

JONATHAN JACKSON: ALL RIGHT.

MR. VAN BUREN, I WANT TO KNOW IF YOU HAVE ANY THOUGHTS.

I AM HAPPY TO BACK TO YOU IN A FEW MINUTES.

THERE IS ALWAYS PLENTY TO TALK ABOUT.

THE I GUESS MY QUESTION IS HOW DO YOU STAY INDEPENDENT?

HOW DO YOU DEFINE ASKING FOR HELP?

BRIAN VAN BUREN: GOOD QUESTION.

MANY PEOPLE ARE SURPRISED THAT I STILL

LIVE ALONE BY MYSELF AND DON'T BELIEVE I SHOULD.

THAT INCLUDES MY DOCTOR.

I SOLVED THAT PROBLEM BY GETTING TWO ROOMMATES.

ALEXA AND SIRI.

SHE IS TALKING.

WHAT ALEXA DOES FOR ME IS SHE TELLS ME WHEN TO TAKE MY MEDICATION, WHAT APPOINTMENTS I HAVE, WHEN I COME INTO THE HOUSE AND I TELL HER WHERE MY KEYS ARE, WHICH IS SO DIFFERENT THAN HAVING TO SPEND AN HOUR LOOKING FOR MY KEYS, SO I WOULD SAY ALEXA, WHERE ARE MY KEYS?

AND SHE WILL TELL ME.

I DON'T THINK I CAN LIVE ALONE WITHOUT THESE TWO ASSISTANTS, S THESE THINGS.

IT WORKS.

STEPHANIE J. MONROE: GREAT.

JONATHAN JACKSON: THAT'S FANTASTIC.

WE I THINK WE HAVE NOT TALKED ENOUGH AS A GROUP ABOUT BUILDING IN DIFFERENT KINDS OF PHYSICAL, DIGITAL, SOCIAL SUPPORTS TO FOLKS

WHO ARE TRYING TO BALANCE THAT NEED FOR SOME SUPPORT WITH THE NEED TO REMAIN INDEPENDENT.

I THINK THAT'S WONDERFUL, SO THANK YOU SO MUCH FOR THAT, MR. VAN BUREN.

I WANTED TO JUST KIND OF GIVE EVERYBODY A CHANCE TO WRAP UP HERE.

THERE ARE SO MANY REALLY GOOD QUESTIONS THAT I WISH WE COULD HAVE JUMPED IN.

BUT LET'S JUST GO TO OUR PANELISTS AND DO KIND OF FINAL THOUGHTS ABOUT THE NEED FOR DEMENTIA FRIENDLY COMMUNITIES ABOUT THE RESOURCES THAT ARE COMING OUR WAY AND ABOUT HOW TO ACHIEVE BRAIN HEALTH EQUITY WITH SOME OF THESE INFRASTRUCTURES THAT WE'RE PLANNING.

WHERE DO WE GO FROM HERE AND WHAT DO WE DO NEXT?

STEPHANIE J. MONROE: YEAH, I WILL START BY SAYING, YOU KNOW, DEMENTIA FRIENDLY COMMUNITIES REALLY HELP PEOPLE UNDERSTAND THAT THEY CAN MEET PEOPLE WHERE THEY ARE WITH WHAT THEY NEED.

THEY ARE NOT RECEIVING THE KIND OF SUPPORT THEY SHOULD.

THEY SHOULD BE GETTING LOTS OF PUBLIC

AND STATE AND PUBLIC HEALTH AND OTHER SUPPORT TO REALLY MAKE THIS A CAMPAIGN, AND EQUIP COMMUNITIES TO DEVELOP NOT JUST PROGRAMS BUT TO EMPOWER INDIVIDUALS TO BE THEIR TRUE SELVES THROUGHOUT THIS WHO PROCESS AND WHOLE JOURNEY.

I HAVE BEEN VERY APPRECIATIVE.

I CAN TELL YOU HONESTLY I IMMEDIATELY WHEN I HEARD THE TERM INITIALLY MANY, MANY YEARS AGO I WAS CONCERNED THAT THIS WOULD BE LIKE SETTLING FOR DEMENTIA.

RIGHT?

NOT BEING, ARE NOT CONTINUING TO POWER THAT URGENCY THAT IF WE WERE JUST GOING TO ACCEPT IT AND I WANTED US TO FEED IT BUT NOW I REALIZE THAT'S HOW YOU DEFEAT IT.

THE DISEASE IS THE ENEMY, THE PEOPLE ARE NOT.

WE HAVE TO MAKE SURE THAT PEOPLE HAVE THE ABILITY TO REALLY BE THEIR TRUE SELVES FOR AS LONG AS THEY CAN.

AND VENTURE FROM THE COMMUNITIES CAN HELP THAT OUT.

JONATHAN JACKSON: THANK YOU.

WE'LL GO TO JASON NEXT AND WE'LL GIVE OUR LAST WORDS TO MR. VAN BUREN.

JASON, WHAT HAVE YOU GOT?

JASON RESENDEZ: THE BEST FOR LAST.

BUILDING OFF WHAT STEPHANIE SAID THE DEMENTIA FRIENDLY COMMUNITIES ARE IMPORTANT BECAUSE THE DEMENTIA FRIENDLY PROCESS GIVES US A COMMON VOCABULARY AROUND WHAT PEOPLE SEE AS A REALLY DIFFICULT ISSUE TO TALK ABOUT.

YOU KNOW, HIGHLY STIGMATIZED ISSUES SO JUST THAT ABILITY TO BRING THAT OUT OF THE SHADOWS AND UNABLE FOLKS TO UNDERSTAND THAT THIS IS SOMETHING YOU CAN TALK ABOUT AND SHOULD TALK ABOUT AND IS SOMETHING THAT ENABLES US TO CREATE CONNECTIONS AMONG US.

I THINK THAT'S SUPER POWERFUL AND I HAVE BEEN AN LGBT ACTIVISTS AND THAT'S WHY I LOVE BRIAN TALKING ABOUT HIS IDENTITY AS A GAY BLACK MAN IN THE LGBT MOVEMENT ONE OF THE WAYS WE GOT GAY MARRIAGE FOR EXAMPLE WAS BY TALKING ABOUT KNOWING INDIVIDUALS WHO ARE LGBT Q.

I THINK IT'S THE SAME THING WITH DEMENTIA AND SORT OF BEING ABLE TO TALK ABOUT OUR EXPERIENCES AND OUR CONNECTIONS AND

HAVING THIS COMMON VOCABULARY IN A SENSE OF UNITY WITH A DISEASE THAT'S BEEN TRADITIONALLY AND FAMILY OF DISEASES THAT HAVE BEEN TRADITIONALLY EXTREMELY ISOLATING.

SO, IF ANYTHING I THINK THE POWER OF THIS MOVEMENT IS TO ADDRESS THAT SENSE OF ISOLATION.

I THINK THAT UNDERSCORES THE IMPORTANCE OF EQUITY, THAT THIS IS SOMETHING THAT MUST BE SHARED EQUITABLY AND IT'S HARD BECAUSE AS WE TALKED ABOUT THE RESOURCE ISSUES THAT JONATHAN BROUGHT UP, YOU KNOW, YOU ARE NOT GETTING A LOT.

I THINK THAT'S ONE OF THE THINGS THAT I WILL TAKE AWAY FROM THIS IS HOW MUCH RESOURCES HAVE BEEN TALKED ABOUT ALL THROUGHOUT THIS SYMPOSIUM.

YOU KNOW, WE'RE NOT BEING RESOURCED TO DO THIS WORK TO THE LEVEL THAT WE SHOULD BE.

I KNOW IT'S HARD TO PRIORITIZE EQUITY WHEN THAT'S THE CASE, BUT I THINK IT'S SUPER CRITICAL, SUPER IMPORTANT AND I WILL DO WHATEVER I CAN TO MAKE SURE THAT YOU HAVE THE RESOURCES THAT YOU NEED TO DO IT SO THANKS FOR HAVING ME AND BEING LET ME BE PART OF THE

CONVERSATION.

JONATHAN JACKSON: MR. VAN BUREN, WHAT WOULD YOU LIKE US TO REMEMBER AS WE THINK ABOUT BEING DEMENTIA FRIENDLY?

BRIAN VAN BUREN: WHAT I WAS GOING TO SAY IS DEMENTIA FRIENDLY IS REALLY ASSISTING US IN MANEUVERING THROUGH LIFE.

MY PHARMACY HAD TRAINING ABOUT THREE MONTHS AGO BEING DEMENTIA FRIENDLY AND ONE OF MY ISSUES QUITE OFTEN IS I WILL GO INTO A FACILITY AND FORGET WHY I'M THERE AND WHAT I WANT.

SO WHEN THEY SEE ME KIND OF DAZING THEY ARE ABLE TO RECOGNIZE HE IS HAVING ONE OF THOSE DEMENTIA MOMENTS, SO THEY ARE ABLE TO ASSIST ME.

PEOPLE WHO DON'T HAVE DEMENTIA DON'T REALLY UNDERSTAND ALL OF THE OBSTACLES.

SOMETHING AS SIMPLE AS WALKING ON A CARPET WITH MANY PATTERNS IS VERY CONFUSING FOR ME.

I HAVE FALLEN MANY TIMES, SO I HAVE TO NOW USE A CANE BECAUSE I CAN'T DIFFERENTIATE

STEPS, SO WHEN I STEP DOWN I DON'T REALIZE THAT THERE IS NOT A STEP OR THERE IS A STEP AND I HAVE FALLEN AND BROKEN MY NOSE, MY RIBS, MY ARM COUPLE OF TIMES.

IT'S VERY IMPORTANT TO FOR THE COMMUNITY TO EDUCATE THEMSELVES IN TERMS OF WHAT WE NEED AND HOW TO ASSIST US TO MANEUVER THROUGH THIS PROCESS.

JONATHAN JACKSON: THANK YOU SO MUCH, MR. VAN BUREN.

THANK TO YOU JASON AND STEPHANIE FOR JUMPING IN AND TALKING WITH ME ABOUT DEMENTIA FRIENDLY.

I WILL SAY IN RESPONSE TO SOME OF THE QUESTIONS PLEASE CENTER HEALTH, PLEASE CENTER WELLNESS ANDED THAT APPLIES FOR SELF—CARE AS WELL AS FOR THOSE OF YOU SERVING AS CARE PARTNERS, PLEASE BE WELL IN ALL THINGS AND I WILL TURN IT BACK OVER TO BETH.

THANK YOU.

BETH SOLTZBERG: THANK YOU SO MUCH JONATHAN, THANK YOU STEPHANIE, THANK YOU JASON, THANK YOU BRIAN.

IT'S BEEN A PLEASURE FOR ME TO LISTEN TO YOU AND TO SEE THE COMMENTS AND THE ENTHUSIASM IN THE CHAT.

BRIAN, I THERE WAS JUST A MESSAGES ONE OF THE PARTICIPANTS SAID SHE CAN LISTEN TO YOU ALL DAY.

I WISH WE HAD MORE HOURS ALTHOUGH I AM AWARE IT'S LATE IN THE DAY ON THE EAST COAST.

IT'S A BIT EARLIER IN HAWAII WHERE SOME OF OUR PARTNERS ARE JOINING, BUT IT'S BEEN A VERY RICH, AMAZING AFTERNOON, AND I JUST APPRECIATE IT.

I WANT TO MENTION A COUPLE OF QUESTIONS THAT CAME IN.

MY HELPERS WHO HAVE BEEN MONITORING CHAT HAVE FLAGGED THESE.

THEN I WANT TO SAY SOME THANK YOU AND WE'LL WRAP UP.

SO, ONE POINT WAS REGARDING THE CHALLENGES IN DIFFERENTIATING DEMENTIA AND VARIOUS FORMS OF MENTAL ILLNESS.

ONE COULD EVEN EXPAND THAT, YOU KNOW, SOMETIMES IT'S VERY HARD TO DIFFERENTIATE THE IMPACT OF DEMENTIA FROM HEARING LOSS FOR EXAMPLE.

THERE IS A LOT OF INTERCONNECTION.

FROM A DEMENTIA FRIENDLY STANDPOINT, I WOULD SAY THE DIRECTION THAT THE DEMENTIA FRIENDLY MOVEMENT IS GOING WORLDWIDE IS TO REALLY THINK OF LIVING WITH DEMENTIA AS LIVING WITH A DISABILITY.

AND THAT COULD BE A PHYSICAL OR COGNITIVE DISABILITY.

SO, IN A WAY PART OF MY RESPONSE TO THAT COMMENT IS THAT WE NEED TO JUST THINK BROADLY ABOUT HOW WE MAKE OUR COMMUNITIES ACCESSIBLE FOR EVERYBODY.

THEN THERE WAS ANOTHER QUESTION ABOUT COMMUNITY OUTREACH DURING THE PANDEMIC.

CERTAINLY IT'S BECOME SO CHALLENGING AND A LOT OF TIMES SMALL ORGANIZATIONS ARE STRUGGLING TO DO REALLY IMPORTANT WORK IN THEIR COMMUNITIES AND THE RESOURCES NEEDED TO KIND OF PIVOT TO NEW WAYS OF REACHING PEOPLE THAT'S A BIG CHALLENGE.

BUT I HAVE TO SAY I HAVE BEEN SO INSPIRED BY WORKING WITH THE COMMUNITY PARTNERS WHO YOU MET EARLIER AND SEEING HOW THEY HAVE GONE THROUGH A PROCESS OF OFTEN POLLING THEIR COMMUNITIES MEMBERS TO FIND OUT

WHAT TECHNOLOGY PEOPLE HAVE, AND THEN REALLY KIND OF TRYING DIFFERENT THINGS AND PIECING SOMETHING TOGETHER.

IN A WAY, IT'S SIMILAR TO WHAT JASON AROUND STEPHANIE YOU WERE SHARING EARLIER AND THIS WAS A BIG THEME IN YOUR AMAZING SUMMIT THAT WAS JUST THE OTHER WEEK, THAT WE NEED TO THINK ABOUT BRINGING RESOURCES TO THE COMMUNITIES, NOT MAKING COMMUNITY MEMBERS TRAVEL TO THE RESOURCES, AND I THINK WITH REGARD TO TECHNOLOGY, WE HAVE TO THINK ABOUT WHAT ARE PEOPLE ALREADY USING?

SO A LOT OF PEOPLE USE THE TELEPHONE.

A LOT OF PEOPLE USE THE TELEVISION THAT COULD BE CABLE NEWS.

SOME CULTURAL GROUPS USE SKYPE TO BE IN TOUCH WITH FAMILY MEMBERS IN THEIR HOME COUNTRY, SO WE NEED TO ASK THE QUESTION AND FIND OUT, WHAT ARE PEOPLE ALREADY USING AND FEEL COMFORTABLE WITH?

IT MAY NOT NECESSARILY BE MAKING EVERYBODY USE ZOOM.

BUT I WILL SAY WHAT I HAVE SEEN IS OUR COMMUNITY PARTNERS FOUND THEIR WAY THROUGH.

THEY FIGURED IT OUT AND HAVE CONTINUED

DOING THE OUTREACH AND CONNECTING WITH PEOPLE.

IT'S ALL THE MORE IMPORTANT.

I WANT TO SAY A HUGE THANK YOU TO EVERYONE.

I WANT TO FIRST THANK THE INTERPRETERS WHO MUST BE EXHAUSTED BY NOW, THANK YOU TO TINA AND TERRY AND AFRENIO AND STEPHANIE FOR PROVIDING STULT INTERPRETATION IN MANDARIN, PORTUGUESE AND SPANISH.

AND THANK YOU TO DONNA FOR PROVIDING CAPTIONING IN ENGLISH.

THANK YOU TO ALL OF OUR SPEAKERS.

IT HAS BEEN A REALLY, REALLY INSPIRING AFTERNOON FOR ME HEARING YOU AND I JUST APPRECIATE YOUR ALL SHARING FROM YOUR OWN EXPERIENCES AND EXPERTISE.

WHILE THERE IS SO MUCH MORE TO SAY I HOPE THIS CONVERSATION HAS GIVEN YOU ALL SOMETHING YOU CAN TAKE BACK AND LOOK FOR WAYS TO IMPLEMENT.

I WILL E—MAIL EVERYONE AN EVALUATION SURVEY, AND WOULD REALLY APPRECIATE YOUR FEEDBACK, SO PLEASE TAKE A FEW MINUTES TO COMPLETE IT.

THOSE WHO ARE REQUESTING CONTINUING EDUCATION IT IS REQUIRED THAT YOU COMPLETE IT.

I AM GOING TO BE ADDING IN THE RESOURCES THAT PEOPLE WERE SHARINGS THROUGH THE CHAT TO OUR RESOURCE LIST.

HOPEFULLY, IN ABOUT A WEEK, WE'LL BE ABLE TO POST THE RECORDINGS AND THE RESOURCE LIST AND SLIDES FROM TODAY.

I WILL NOTIFY YOU ALL BY E—MAIL WHEN THOSE ARE AVAILABLE.

SO, WITH THAT, I AM HAPPY TO STAY ON IF ANYONE HAS LAST QUESTIONS THAT THEY DIDN'T GET ANSWERED.

I WILL PUT UP OUR ROLLING SLIDE SHOW AGAIN IF ANYBODY DIDN'T GET A CHANCE TO SEE IT EARLIER.

IF ANY OF THE PANELISTS WANT TO STAY ON FOR A COUPLE OF MINUTES THAT'S FINE.

PLEASE FEEL FREE.

I WANT TO AGAIN FROM MY HEART THANK YOU ALL FOR WHAT YOU HAVE SHARED TODAY.

THANK YOU ALL FOR BEING HERE.

SPEAKER: THANK YOU, BETH.

A BIG ROUND OF APPLAUSE, EVERYBODY TO YOU.

THIS WAS REALLY AWESOME.

GREAT WAY TO SPEND THE AFTERNOON.

I LEARNED SO MUCH.

THANK YOU.

SPEAKER: THANK YOU.

BETH SOLTZBERG: THANK YOU SO MUCH.

SPEAKER: THANK YOU, BETH.

SPEAKER: BYE ARNETTA AND CARL.

THIS IS GAIL.

IT WAS VERY INSIGHTFUL.

ARNETTA BATY: GLAD YOU JOINED US.

SPEAKER: THANK YOU.

SEE YOU LATER.

SPEAKER: THANK YOU, BOSTON!

SPEAKER: THANK YOU.

SPEAKER: THANK YOU, WE STAYED THE COURSE.

SPEAKER: LONG JOURNEY.
IT WAS WORTHWHILE.