March 18, 2019

PLEASE STAND BY YOUR MEETDING WILL BEGIN
PLEASE STAND BY. YOUR MEETING WILL BEGIN SHORTLY.
>> GOOD MORNING. THE MEET WILLING START IN A FEW MINUTES. IF YOU ARE ON THE LINE, PLEASE PUT YOUR PHONE ON MUTE. THANK YOU.

Introductions:

>> GOOD MORNING, EVERYONE. I THINK WE'RE ABOUT READY TO START. MY NAME IS **DAVID ROSENTHAL**, AND I'M THE CO-CHAIR FOR THIS TASK FORCE. SO WELCOME. WELCOME TO ALL OF YOU THIS MORNING TO OUR FIRST TASK FORCE MEETING. I'M VERY EXCITED TO SEE ALL OF YOU HERE. I ALSO WANT TO VERY QUICKLY INTRODUCE, IF YOU DON'T MIND, MY CO-CHAIR, MARK BENTON. THE TWO OF US WILL BE WORKING TOGETHER AND WORKING WITH ALL OF YOU THROUGHOUT THIS PROJECT. WE ARE JUST A LITTLE BIT PAST OUR TIME. SO WE WANT TO HIT THE GROUND RUNNING. SO I'M GOING TO ASK ADAM AND WHERE'S ROB? ADAM, ARE YOU GOING TO COME UP? WE'LL HAVE ADAM COME UP AND GET US STARTED WITH OUR PRESENTATIONS. THANK YOU.

>> GOOD MORNING. GOOD MORNING. MY NAME IS **ADAM ZOLOTOR**, I'M THE PRESIDENT OF THE NORTH CAROLINA INSTITUTE OF MEDICINE. WE WOULD LIKE TO START BY HAVING EVERYBODY IN THE ROOM INTRODUCE THEMSELVES. THERE ARE A LOT OF PEOPLE HERE. WE WILL ASK YOU TO BE BRIEF. TELL US WHO YOU ARE AND AGENCY OR CONSTITUENCY YOU REPRESENT AND WE'LL TRY TO GET THROUGH INTRODUCTIONS QUICKLY. I'M GOING TO START ON THIS TABLE AND WE'RE GOING TO PASS THE MICROPHONE AROUND.

>> **SAM CLARK**. I'M WITH THE NORTH CAROLINA HEALTHCARE FACILITIES ASSOCIATION REPRESENTING NURSING FACILITIES.
>> THIS IS **TOVAH**, I'M WONDERING IF PEOPLE COULD STAND SO EVERYONE CAN SEE EVERYONE.
>> GREAT IDEA. THANK YOU, TOVAH.
>> HELLO. GOOD MORNING, EVERYONE. I'M **BRAD TROTTER**. I'M WITH THE DIVISION OF MENTAL HEALTH DEVELOPMENT OF DISABILITITIES AND SUBSTANCE ABUSE SERVICES.
>> THANK YOU.
>> GOOD MORNING, EVERYONE. MY NAME IS **DONNA NICHOLSON**. I AM A NURSE AND HAVE WORKED WITH PHYSICIAN PRACTICES OVER MANY YEARS. RIGHT NOW, I AM WITH MEDICAL MUTUAL OF NORTH CAROLINA WHICH IS MEDICAL MALPRACTICE COMPANY AND I HAVE THE RISK MANAGEMENT DIVISION. SO WE ARE ALWAYS LOOKING FOR WAYS WE CAN DELIVER BETTER CARE TO OUR PATIENTS.
>> GOOD MORNING. I'M **ALICIA SPENCER** WITH NORTH CAROLINA HANDS AND VOICES AND I'M ALSO THE MOTHER OF TWO BOYS THAT HAVE HEARING LOSS.
>> GOOD MORNING. I'M **SHELLEY CRISTOBAL**, AND I'M HERE FROM THE NORTH CAROLINA ACADEMY OF AUDIOLOGY AND HAVE A PRIVATE AUDIOLOGY PRACTICE IN THE DURHAM AREA.
>> MY NAME IS **ALISON DAHLE** AND I AM THE REPRESENTATIVE FOR THE NORTH CAROLINA HOUSE OF REPRESENTATIVES, DISTRICT 11.
>> HELLO, EVERYONE. MY NAME IS **TOVAH WAX** AND I'M SIGNING NOW BECAUSE I AM HERE REPRESENTING THE DEAF COMMUNITY FROM THE NORTH CAROLINA COUNCIL FOR THE SERVICES FOR THE DEAF AND HARD OF HEARING. I GREW UP USING MY SPEECH AND SO FROM NOW ON NOT TO CONFUSE THE INTERPRETERS I WILL USE MY VOICE FOR THE REST OF THIS MEETING AND MY ROLE AND ANOTHER ROLE THAT I HAVE, AN INTERIM ROLE I HAVE, IS HELPING DOING RESEARCH ABOUT HEALTHCARE ACCESS FOR DEAF AND HARD OF HEARING PEOPLE. SPECIFICALLY THE ELDERLY. SO GOOD

MORNING.
>> HELLO, EVERYONE. MY NAME IS **CRYSTAL BOWE**, AND I'M A FAMILY PHYSICIAN FROM GASTON COUNTY, NORTH CAROLINA.
>> **VICKY SMITH**, EXECUTIVE DIRECTOR OF ALLIANCE OF DISABILITY ADVOCATES.
>> **MAGGIE SAUER**, DEPARTMENT OF HEALTH AND HUMAN SERVICES, DIRECTOR OF RURAL HEALTH AND A FORMER PRACTICING SPEECH AND LANGUAGE PATHOLOGIST.
>> GOOD MORNING. I'M **KATHY SMITH**. I'M WITH THE ASSOCIATION FOR HOME AND HOSPICE CARE OF NORTH CAROLINA.
>> GOOD MORNING. I'M **GLENN SILVER**, PROGRAM PLANNER AND EVALUATOR FOR THE DIVISION OF SERVICES FOR THE DEAF AND HARD OF HEARING.
>> GOOD MORNING. MY NAME IS **DENNA SUKO**, AND I'M DIRECTOR OF SPECIAL MANAGEMENT SERVICES WITH THE NORTH CAROLINA MEDICAL SOCIETY AND ALSO DIRECTOR FOR THE NORTH CAROLINA SOCIETY OF OTOLARYNGOLOGY.
>> GOOD MORNING. **JULIE BISHOP**, AND I'M HERE REPRESENTING THE HEARING LOSS ASSOCIATION OF AMERICA NORTH CAROLINA CHAPTER.
>> GOOD MORNING. **LISA WAINWRIGHT** WITH (INAUDIBLE) AND SUBSTANCE USE DISORDERRER AND I THINK I'M HERE REPRESENTING MY OTHER SIX COLLEAGUES IN THAT ENDEAVOR.
>> GOOD MORNING. MY HAIM IS **SAM HEDRICK**. I'M WITH THE DEPARTMENT. I MONITOR AND COORDINATE THE SETTLEMENT AGREEMENT WITH TRANSITION TO COMMUNITY LIVING.
>> GOOD MORNING. I'M **LAURA THORPE**. I'M AN AUDIOLOGIST WITH HEARING LIFE.
>> GOOD MORNING. I'M **MELISSA SPECK**. I'M WITH THE HEALTH POLICY OFFICE AT BLUE CROSS/BLUE SHIELD NORTH CAROLINA.
>> GOOD MORNING. I'M **HANK BAUERS**. I'M WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES WHERE I'M ASSISTANT DIRECTOR WITH THE DIVISION OF AGING AND ADULT SERVICES.
>> GOOD MORNING. I'M **STEVE BARBER** REPRESENTING HEARING LOSS ASSOCIATES OF AMERICA, WAKE CHAPTER.
>> GOOD MORNING. I'M **JENNIFER MARTIN** WITH THE NORTH CAROLINA PHYSICAL THERAPY ASSOCIATION.
>> GOOD MORNING. I'M **KATHY DOWD**. I AM THE EXECUTIVE DIRECTOR OF THE AUDIOLOGY PROJECT. WE ARE WORKING WITH CDC TO RAISE AWARENESS OF THE LINK BETWEEN DIABETES AND HEARING LOSS, AND WE DO HAVE HANDOUTS FOR A WEBINAR SERIES WE'RE DOING AT THIS POINT.
>> GOOD MORNING, EVERYONE. I'M **ANNA LLOYD** AND I'M CHIEF OF SUPPORT WITH THE DIVISION OF VOCATIONAL REHABILITATION SERVICES.
>> GOOD MORNING. I'M **MARK BENTON**. I'M THE DEPUTY SECRETARY FOR HEALTH SERVICES WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. ALSO CO-CHAIR OF THE TASK FORCE.
>> HI. GOOD MORNING. MY NAME IS **BETH LOVETTE**. ACTING DIRECTOR OF DIVISION OF PUBLIC HEALTH WHICH IS DIVISION OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES.
>> HELLO, GOOD MORNING, EVERYONE. I'M **ASHLEY BENTON**. I'M THE DEAF/DEAF-BLIND SERVICES COORDINATOR WITH THE DIVISION OF SERVICES FOR THE DEAF AND HARD OF HEARING AND I'M HERE REPRESENTING THE DEAF-BLIND COMMUNITY, AND LET ME EXPLAIN TO YOU JUST A LITTLE BIT ABOUT MY COMMUNICATION. IF NOT, YOU MIGHT BE WONDERING WHAT'S GOING ON OVER HERE. I DO HAVE SOMEONE BEHIND ME GIVING ME VISUAL INFORMATION ON MY BACK THROUGH A SYSTEM OF TOUCH SIGNALS SO I CAN'T SEE WHAT'S GOING ON IN THE ROOM. SHE GIVES ME THAT INFORMATION ON MY BACK AND I HAVE TWO INTERPRETERS INTERPRETING FOR ME TACTILELY ON MY HAND
>> **HOLLY RIDDLE**, WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. I'M OFFICED WITH SAM HEDRICK AT TRANSITION OF COMMUNITY LIVING WHERE I AM THE HOLMESTEAD COORDINATOR.
>> GOOD MORNING. I'M **COREY DUNN** WITH DISABILITY RIGHTS NORTH CAROLINA, THE STATE

PROTECTION AND ADVOCACY AGENCY.
>> GOOD MORNING. I'M **RONDA OWEN** AND WITH I'M WITH THE DIVISION OF HEALTH BENEFITS. THAT'S OUR NEW NAME AND WE'RE WITH THE DIVISION OF MEDICAL ASSISTANCE AND EVERYONE KNOWS US AS NORTH CAROLINA MEDICAID.
>> GOOD MORNING. I'M **JENNIFER GILL** WITH LEADING AGE NORTH CAROLINA. WE REPRESENT NONPROFIT RETIREMENT COMMUNITIES IN THE STATE AND MY ROLE IS DIRECTOR OF COMMUNICATIONS.
>> GOOD MORNING. I'M **BETH HORNER**. I'M THE DIRECTOR OF CUSTOMER EXPERIENCE IN COMMUNICATION FOR THE NORTH CAROLINA STATE HEALTH PLAN FOR TEACHERS AND STATE EMPLOYEES.
>> GOOD MORNING. MY NAME IS **BETH HATHAWAY**. I'M PRESIDENT OF THE NORTH CAROLINA OCCUPATIONAL THERAPY ASSOCIATION. I ALSO OWN A PEDIATRIC PRIVATE PRACTICE IN RALEIGH.
>> GOOD MORNING. I'M **JAN WITHERS**. I'M THE DIRECTOR OF THE SERVICES FOR THE DEAF AND HARD OF HEARING AND I AM THRILLED TO SEE ALL OF YOU HERE WITH US THIS MORNING.
>> GOOD MORNING. I'M GONNA SIGN WITH ONE HAND BUT THE INTERPRETERS CONTINUE TO SIGN BECAUSE I DON'T KNOW HOW TO TALK AND SIGN WITH DEAF PEOPLE HERE NOT SIGNING. I'M A SIGN LANGUAGE INTERPRETER. I'M ALSO HERE TO REPRESENT CODA, CHILDREN OF DEAF ADULTS AND I HAVE LOTS OF LIFE EXPERIENCE HAVING PARENTS WHO ARE DEAF WHO WENT THROUGH A LOT OF MEDICAL EXPERIENCES.
>> HELLO. I'M **DAVID HENDERSON**. I'M CEO OF THE NORTH CAROLINA MEDICAL BOARD. THE BOARD'S A STATE AGENCY RESPONSIBLE FOR THE LICENSING AND REGULATION OF PHYSICIANS, PHYSICIAN ASSISTANTS, AND A FEW OTHER HEALTHCARE PROVIDERS AND I AM THE SON OF TWO DEAF EDUCATORS.
>> GOOD MORNING. MY NAME IS **JAMES COLEMAN**. I AM ASSISTANT HERE WITH THE NORTH CAROLINA INSTITUTE OF MEDICINE.
>> GOOD MORNING. MY NAME IS **ROBERT** AND I'M A PROJECT DIRECTOR AT THE NORTH CAROLINA INSTITUTE OF MEDICINE FOR THIS TASK FORCE.
>> HELLO. I'M **LEE WILLIAMSON**. I AM THE COMMUNICATION ACCESS MANAGER WITH THE DIVISION OF SERVICES FOR THE DEAF AND THE HARD OF HEARING.
>> GOOD MORNING. I'M **BERKELEY** AND I'M THE ASSOCIATE DIRECTOR OF THE NORTH CAROLINA INSTITUTE OF MEDICINE.

Adam Zolotor Presentation: Overview of the NCIOM

>> IT'S SO WONDERFUL TO SEE YOU ALL HERE TODAY, AND I'M GOING TO TRY TO FIND MY PRESENTATION. SO FOR THE NEXT 25 MINUTES OR SO,S I'M GOING TO JUST INTRODUCE YOU TO THE NORTH CAROLINA INSTITUTE OF MEDICINE AND THE CHARGE FOR THIS TASK FORCE AND THEN I'M GOING TO HAND IT OVER TO JAN WITHERS, WHO'S GOING TO TALK ABOUT HER VISION FOR THE TASK FORCE AND THE WORK OF THE DIVISION. WE'RE GOING TO FOLLOW THAT BY A DIFFERENCE IN DIFFERENCE ACTIVITY SO WE'RE ALL INTRODUCED TO CHALLENGES THAT PEOPLE MIGHT ENCOUNTER IF THEY ARE LANGUAGE ACCESS IMPAIRED AND EXPERIENCING DIFFERENCES IN CARE. AND THIS MIGHT WORK. YES. OKAY. FOR THOSE OF YOU WHO ARE NOT FAMILIAR WITH THE NORTH CAROLINA INSTITUTE OF MEDICINE, WE WERE CREATED BY AN ACT OF LEGISLATION IN 1983 BY THE NORTH CAROLINA GENERAL ASSEMBLY AND WE HAVE A BROAD MANDATE TO BE CONCERNED WITH THE HEALTH OF THE PEOPLE OF NORTH CAROLINA, MONITOR AND STUDY HEALTH MATTERS, RESPOND AUTHORITATIVELY WHEN FOUND ADVISABLE AND RESPOND TO REQUESTS FROM OUTSIDE SOURCES FOR ANALYSIS AND ADVICE TO AID IN FORMING BASIS FOR HEALTH POLICY DECISIONS. MOVING AROUND, I'M GOING TO TRY NOT TO TRIP WHILE I'M TALKING. THE NORTH CAROLINA INSTITUTE OF MEDICINE STUDIES ISSUES

AT THE REQUEST OF THE GENERAL ASSEMBLY, STATE AGENCIES, AND HEALTH PROFESSIONAL ORGANIZATIONS AND OUR BOARD OF DIRECTORS. WE OFTEN WORK IN PARTNERSHIP WITH OTHER AGENCIES AND ORGANIZATIONS TO STUDY HEALTH ISSUES. AND I JUST WANT TO GIVE YOU A SENSE OF THE BREADTH OF THE KIND OF WORK WE DO, AND THIS IS A LIST OF RECENT TASK FORCES. YOU HAVE THIS HANDOUT IN FRONT OF YOU. I'M NOT GOING TO READ IT TO YOU, BUT YOU CAN SEE RIGHT NOW, WE'RE WORKING ON SETTING INDICATORS OR GOALS FOR HELPING NORTH CAROLINA 2030. WE HAVE A TASK FORCE ON A RISK-APPROPRIATE PERINATAL SYSTEM OF KEER AND TASK FORCE ON SERIOUS ILLNESS CARE THAT ARE ALL ONGOING. WE ALSO PUBLISH THE NORTH CAROLINA INSTITUTE OF MEDICINE-- I'M SORRY, NORTH CAROLINA MEDICAL JOURNAL. THE MEDICAL JOURNAL IS A JOURNAL OF HEALTH POLICY ANALYSIS AND DEBATE. IT COMES OUT EVERY OTHER MONTH AND FOCUSES ON THEMES WITH EACH ISSUE. IT IS CIRCULATED TO MORE THAN 170,000 PEOPLE, MOSTLY HEALTH POLICY AND HEALTHCARE PROFESSIONALS. WHEN THE NORTH CAROLINA INSTITUTE OF MEDICINE CREATES A TASK FORCE, IT'S GENERALLY COMPRISED OF 30 TO 60 PEOPLE. SO YOU LOOK AROUND THE ROOM THIS IS A BIGGER TASK FORCE. THE TASK FORCE IS GUIDED BY CO-CHAIRS WHO WILL HELP US WITH THE MEETINGS, AND YOUR CO-CHAIRS AND DAVID ROSENTHAL AND MARK BENTON, DURING INTRODUCTIONS. THE TASK FORCE INCLUDES MEMBERS THAT THEY REPRESENT, STATE AND LOCAL POLICYMAKERS, AGENCY OFFICIALS, HEALTH PROFESSIONALS, INSURERS, BUSINESS AND COMMUNITY LEADERS, CONSUMERS AND OTHER INTERESTED INDIVIDUALS. AND ALL MEETINGS ARE OPEN TO THE PUBLIC. I MENTION THAT ON THE ONSET BECAUSE IF PEOPLE WANT TO BRING GUESTS OR IF THEY NEED TO SEND SOMEBODY-- TO STAND IN FOR THEM AT A MEETING, GUESTS ARE ALWAYS WELCOME AND MEETINGS ARE OPEN TO THE PUBLIC BUT WE DO ASK YOU TO LET US KNOW, TO RSVP TO ROB AND JAMES, SO THAT WE KNOW WHO'S COMING. THE TASK FORCE WORK IS GUIDED BY A SMALLER STEERING COMMITTEE. THESE ARE PEOPLE WITH EXPERTISE AND KNOWLEDGE IN THE AREA THAT WILL HELP SHAPE THE AGENDA AND IDENTIFY ISSUES FOR POTENTIAL SPEAKERS AND DISCUSSION. IF YOU ARE ON THE STEERING COMMITTEE, CAN YOU JUST RAISE YOUR HANDS SO PEOPLE KNOW WHO IS ON OUR STEERING COMMITTEE? CORYE AND LEE AND JAN AND DAVID. IS THERE ANYBODY ELSE HERE ON THE STEERING COMMITTEE? GREAT. THANK YOU. WE'LL HAVE PRESENTATIONS DURING OUR WORK TOGETHER. THAT INCLUDES SUMMARIES, DATA, DESCRIPTION OF PROGRAMS, CHALLENGES AND BARRIERS, BEST PRACTICES AND NATIONAL DEVELOPMENTS. PRESENTERS MAY INCLUDE TASK FORCE MEMBERS, RESEARCHERS, NATIONAL AND STATE LEADERS, STATE HEALTHCARE PROFESSIONALS, CONSUMERS AND NCIOM STAFF. THE JOB OF THE STAFF IS TO TRY TO PULL THIS ALTOGETHER. WE'LL BE PREPARING AGENDAS, INVITING SPEAKERS, GATHERING INFORMATION AND DATA, AND STUDIES TO INFORM THE WORK OF THE TASK FORCE. WE'LL ALSO WRITE THE FIRST DRAFT OF RECOMMENDATIONS AND A REPORT TO COME OUT OF OUR WORK TOGETHER. THE WAY THAT TYPICALLY PROCEEDS IS THAT WE TRY TO LISTEN TO THE VOICE IN THE ROOM, THE PREFERENCES IN THE ROOM AND TRY AND HAVE A FIRST CRACK AT DRAFTING RECOMMENDATIONS. WE THEN BRING THEM TO THE STEERING COMMITTEE AND ASK THE STEERING COMMITTEE DID WE HEAR THIS RIGHT? IS THIS ABOUT WHAT THE ROOM WAS SAYING? THEN WE'LL BRING THAT BACK TO THE ENTIRE TASK FORCE TO MAKE SURE WE ARE REFLECTING THE WISDOM OF THE GROUP. SOMETIMES VOTING IS NECESSARY TO ASSURE THAT WE HAVE CONSENSUS AND PRIORITIZE RECOMMENDATION. WE'LL DO THE SAME THING WITH THE FULL TEXT OF THE REPORT, HAVING IT REVIEWED BY STAFF, STEERING COMMITTEE AND ULTIMATELY THE TASK FORCE FOR APPROVAL. THE TASK FORCE, AGAIN, WILL BE CIRCULATED MULTIPLE TIMES BEFORE FINALIZED. IT WILL BE REVIEWED BY MEMBERS OF THE NORTH CAROLINA INSTITUTE OF MEDICINE BOARD OF DIRECTORS, AND THEN THE REPORT AND RECOMMENDATIONS WILL BE DISTRIBUTED WIDELY. WE GENERALLY SEND OUT ABOUT A THOUSAND COPIES OF THE TASK FORCE REPORT AND ISSUE BRIEFS. WE ALSO PUBLISH THE ISSUE BRIEF IN THE NORTH CAROLINA MEDICAL JOURNAL WHICH, AGAIN, HAS A CIRCULATION OF ABOUT 170,000. WE'LL ALSO DO NEWSLETTER AND SOCIAL MEDIA

WORK AROUND THE DISSEMINATION OF THE TASK FORCE REPORT AS WELL AS PRESENT THE REPORT AND RECOMMENDATIONS WHEN INVITED. WE ALSO DO UPDATE OF EACH OF OUR REPORTS ABOUT FIVE YEARS AFTER PUBLICATION OF THE REPORT TO SEE HOW FAR WE'VE COME IN ACCOMPLISHING OUR RECOMMENDATIONS, AND OUR TRACK RECORD IS THAT WE HAVE PARTIAL OR FULL IMPLEMENTATION OF BETWEEN 50 AND 90% OF THE RECOMMENDATIONS THAT COME OUT OF ALL OF OUR PREVIOUS TASK FORCES. I DO WANT TO MENTION WE HAVE A WEBSITE SPACE DEDICATED TO THIS TASK FORCE. ALL OF THE MATERIALS WILL BE AVAILABLE ON THIS PAGE INCLUDING CALENDAR INFORMATION, DIRECTIONS, ALL OF THE PRESENTATIONS WILL BE UPLOADED TO THIS PAGE WITHIN ABOUT TWO DAYS AFTER OUR TASK FORCE MEETINGS AS WELL AS MEETING SUMMARIES. WE'LL DO EVERYTHING WE CAN TO HAVE FULL ACCESS TO MEETINGS FOR PEOPLE WHO CAN'T COME AND PARTICIPATE IN PERSON. WE ACKNOWLEDGE THAT FOR PEOPLE THAT ARE HARD OF HEARING THAT MAY NOT BE AS EASY AS IT IS FOR PEOPLE THAT ARE HEARING AND WE'RE DOING THE BEST THAT WE CAN WORKING WITH DIVISION STAFF TO BE ABLE TO ACCOMMODATE NEEDS AS BEST WE CAN. I SHOULD MENTION AT THIS TIME THAT THIS IS A GREAT SPACE FOR MEETINGS, BUT IT'S NOT ALWAYS AVAILABLE. WE WANTED TO HAVE OUR FIRST MEETING HERE BECAUSE THE TECHNOLOGY FOR FACILITATING COMMUNICATION MORE BROADLY WAS BETTER. WE'RE NOT SURE WHERE OUR SECOND MEETING WILL BE YET. OUR SECOND MEETING WILL BE IN OUR OFFICE SO THOSE WHO HAVE BEEN TO OUR OFFICE BEFORE KNOW WE'RE IN MORRISVILLE AND WE'LL MAKE SURE THAT YOU HAVE DIRECTIONS TO THAT. I THINK THAT OUR PLAN AT THIS TIME IS TO SEE HOW THAT GOES AND IF WE CAN ACCOMMODATE ADEQUATELY, THEN WE'LL HAVE FURTHER MEETINGS IN OUR OFFICE IF WE FEEL LIKE THIS SPACE IS WORKING BETTER FOR PEOPLE, THEN WE'LL MEET HERE WHEN IT'S AVAILABLE. THE PURPOSE OF OUR TASK FORCE, OUR WORK TOGETHER IS TO EXAMINE THE LIMITATIONS THAT PEOPLE WHO ARE DEAF AND HARD OF HEARING FACE WHEN ACCESSING HEALTHCARE AND WE THINK OF THAT BROADLY. SO THAT'S NOT JUST DOCTORS' VISITS. IT INCLUDES HOSPITAL SERVICES, EMERGENCY SERVICES, PHARMACY SERVICES, PHYSICAL THERAPY, MENTAL HEALTH THERAPY, SUBSTANCE ABUSE THERAPY, ALL THE THINGS WE NEED TO ACCESS IN HEALTHCARE, WE WANT TO DO A BETTER JOB OF UNDERSTANDING WHAT BARRIERS LOOK LIKE AND WHAT THE CONSEQUENCES OF THOSE BARRIERS ARE. WE ALSO WANT TO UNDERSTAND THIS IN THE CONTEXT OF STATE AND FEDERAL LAWS AND REGULATIONS. AND IDENTIFY SOLUTIONS TO ADDRESS THESE CHALLENGES. LASTLY, WE WANT TO IDENTIFY SYSTEM DESIGN FEATURES THAT CAN BE UNIVERSALLY IMPLEMENTED TO ENHANCE CARE AND DECREASE ISOLATION IN HEALTHCARE SYSTEMS AND LONG-TERM CARE SETTINGS FOR PEOPLE WHO ARE DEAF AND HARD OF HEARING. AND I JUST WANT TO SAY THAT SUPPORT FOR THIS TASK FORCE COMES FROM THE DEPARTMENT OF HEALTH AND HUMAN SERVICES AND LEADING AGE NORTH CAROLINA. YOU HAVE MY CONTACT INFORMATION, MY PHONE NUMBER AND EMAIL AS WELL AS ROB'S PHONE NUMBER AND EMAIL AND OUR WEBSITE. AND AGAIN, WE'RE SO EXCITED ABOUT THIS WORK. HAPPY FOR OUR PARTNERSHIP WITH THE DIVISION AND THE DEPARTMENT AND LOOK FORWARD TO WORKING WITH ALL OF YOU ON IT. AND I'M GOING TO INTRODUCE JAN WITHERS, THE DIVISION DIRECTOR, NEXT. HANG ON ONE SECOND.

Jan Withers Presentation: Introduction to the Task Force & Definitions

>> HELLO. GOOD MORNING, EVERYONE!

I AM JAN WITHERS, THE DIRECTOR OF THE DIVISION OF SERVICES FOR THE DEAF AND HARD OF HEARING. WE ARE A DIVISION UNDER THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. EARLY-- I STARTED MY CAREER AS A MENTAL HEALTH COUNSELOR BACK IN THE '80s. I WAS BORN DEAF. I'VE ALWAYS BEEN DEAF. AND I SHARE THAT BACKGROUND INFORMATION WITH YOU BECAUSE I WANT YOU TO KNOW THAT THIS IS SOMETHING THAT I THOUGHT ABOUT. I'VE TALKED ABOUT, AND I LOOKED FORWARD TO FOR A VERY LONG TIME AND THAT'S WHY I'M FEELING SO THRILLED TODAY TO SEE ALL

OF YOU HERE TOGETHER IN ONE ROOM AND THAT THIS HAS FINALLY COME TO FRUITION. WE HAVE A WONDERFUL OPPORTUNITY HERE, A VERY POSITIVE TO MAKE GREAT CHANGES. I WANT TO START OFF BY QUOTING HELEN KELLER. SHE SAID, "BLINDNESS SEPARATES PEOPLE FROM THINGS. DEAFNESS SEPARATES PEOPLE FROM PEOPLE."
REMEMBER THAT AS WE GO FORWARD WITH THIS WORK. IT'S VERY IMPORTANT. LATER THIS AFTERNOON, I WILL BE ABLE TO GIVE YOU A MORE IN-DEPTH VISION OF THIS TASK FORCE AND WHAT I HOPE TO SEE US ACCOMPLISH EVENTUALLY, BUT FIRST OF ALL, I DO NEED TO START WITH THE BASICS. FROM MY EXPERIENCE AND THE EXPERIENCE OF MY STAFF, PEOPLE OFTEN MISUNDERSTAND OR DON'T UNDERSTAND A LOT ABOUT PEOPLE THAT ARE DEAF, HARD OF HEARING AND DEAF-BLIND. SO I THOUGHT I WOULD START OUT BY SETTING A FOUNDATION SO THAT WE CAN HAVE A MORE SUCCESSFUL DISCUSSION OF OUR ISSUES AND YOU CAN USE MORE ACCURATE INFORMATION. FIRST OF ALL, I HAVE A QUESTION FOR YOU. HOW MANY OF YOU KNOW SOMEONE PERSONALLY, EITHER THROUGH WORK OR IN YOUR PERSONAL LIFE, HOW MANY OF YOU KNOW A PERSON WHO IS HARD OF HEARING? OKAY. HOW MANY OF YOU KNOW A PERSON EITHER AT WORK OR IN YOUR PERSONAL LIFE WHO HAS A HEARING AID? OKAY. I SEE A FEW MORE HANDS TO THAT SECOND QUESTION. THAN THE FIRST QUESTION. PEOPLE THAT WEAR HEARING AIDS ARE HARD OF HEARING BUT I SEE THAT EVERY TIME, MORE PEOPLE RAISE THEIR HAND ON THE SECOND QUESTION NOT REALIZING THOSE FOLKS ARE HARD OF HEARING. THIS IS ONE OF THE REASONS THAT I WANT TO MAKE SURE I EXPLAIN THE BASICS. OH!
AND BY THE WAY, YOU MIGHT BE WONDERING WHY I'M USING THIS MUSIC STAND UP HERE AND WHY I'M NOT STANDING BEHIND THE PODIUM. IF I STOOD BEHIND THE PODIUM AND SIGNED, NO ONE WOULD BE ABLE TO SEE ME. THAT'S WHY I USE THIS STAND WHICH IS A LITTLE BIT SHORTER. THAT'S ONE SIMPLE EXAMPLE OF ALL THE DIFFERENT SOLUTIONS THAT DEAF PEOPLE HAVE TO COME UP WITH WHEN WE'RE FUNCTIONING IN A WIDE VARIETY OF DIFFERENT ASPECTS IN OUR LIFE. DEAF PEOPLE TYPICALLY PRE-LINGUALLY DEAF PEOPLE, THOSE WHO WERE BORN DEAF OR BECAME DEAF BEFORE THEY DEVELOPED SPEECH, AND I'M AN EXAMPLE OF THAT GROUP, PRETTY FREQUENTLY, DEAF PEOPLE RELY ON VISUAL MEANS OF COMMUNICATION. FOR EXAMPLE, SIGN LANGUAGE. THEY CAN ALSO USE AUDITORY MEANS, LIKE HEARING AIDS AND COCHLEAR IMPLANTS, BUT THEY USUALLY PREFER TO USE SOME VISUAL MEANS OF COMMUNICATION THROUGH SIGN LANGUAGE OR ANOTHER METHOD FOR THEIR COMMUNICATION. HARD OF HEARING PEOPLE, AND THEY MIGHT BE BORN HARD OF HEARING, BUT THEY'RE MORE LIKELY TO BECOME HARD OF HEARING LATER IN LIFE AS AN ADULT, HARD OF HEARING PEOPLE USUALLY RELY ON AUDITORY MEANS FOR COMMUNICATION. AND OFTEN, IN SOME SITUATIONS, THEY WILL ALSO RELY ON VISUAL MEANS OF COMMUNICATION LIKE THE CAPTIONING YOU SEE HERE AROUND THE ROOM. THEY DON'T TYPICALLY IDENTIFY THEMSELVES AS PART OF THE DEAF COMMUNITY. THERE ARE SOME WHO DO. AUDIOLOGICALLY, THEY MAY BE HARD OF HEARING BUT CULTURALLY, THEY MAY IDENTIFY AS DEAF. DEAF-BLIND PEOPLE RUN THE GAMUT. A DEAF-BLIND PERSON MIGHT BE SOMEONE WHO IS DEAF WITH A SLIGHT VISION LOSS AND THEN THEY CAN BE A FULL MEMBER OF THE DEAF COMMUNITY. YOU MIGHT HAVE SOMEONE TO THE OTHER END OF THE EXTREME WHO IS COMPLETELY DEAF AND COMPLETELY BLIND. YOU MIGHT HAVE SOMEONE WHO HAS A VERY MILD HEARING LOSS AND A MILD VISION LOSS OR MAYBE A MILD HEARING LOSS AND A FULL VISION LOSS. THEY CAN FUNCTION AS PART OF THE DEAF COMMUNITY OR THEY CAN CONSIDER THEM AS PART OF THE HEARING COMMUNITY AND IDENTIFY AS HEARING PREDOMINANTLY. ONE EXAMPLE YOU'VE ALREADY SEEN HERE IS ASHLEY BENTON. SHE CONSIDERS HERSELF AS PART OF THE DEAF COMMUNITY, AND RELIES ON TACTILE SIGN LANGUAGE FOR COMMUNICATION, WHERE YOU CAN SEE HER HAND ON TOP OF THE HAND OF THE INTERPRETER THAT'S INTERPRETING FOR HER. THERE ARE SOME DEAF-BLIND PEOPLE THAT ARE ACTUALLY CONSIDERED TO BE LOW VISION, WHICH MEANS THEY NEED TO SIT CLOSE TO AN INTERPRETER TO BE ABLE TO SEE THAT INTERPRETER SIGN OR THEY WILL

READ LARGE PRINT MATERIALS. WE ALSO HAVE A CATEGORY OF PEOPLE THAT REFER TO AS LATE DEAFENED. THOSE ARE PEOPLE WHO BECOME DEAF LATER IN LIFE, EITHER AS A TEENAGER OR AS AN ADULT. THEY'VE ALREADY DEVELOPED ENGLISH LANGUAGE, AND THEN THEY BECOME DEAF LATER, AND THEN THEY'LL GET TO THE POINT WHERE THEY'RE NOT ABLE TO BENEFIT FROM AUDITORY MEANS OF COMMUNICATION AND THEY'LL HAVE TO SWITCH TO VISUAL MEANS OF COMMUNICATION. THOSE ARE PEOPLE THAT TYPICALLY DON'T KNOW SIGN LANGUAGE. THERE ARE SOME THAT DO BUT MOST OF THEM USUALLY DON'T. LATE DEAFENED PEOPLE USUALLY DON'T KNOW SIGN LANGUAGE, BUT AGAIN, SOME DO. NOW THE NEXT CATEGORY I HAVE UP HERE IS DEAF PLUS AND THIS IS A TERM THAT WE IN THE DEAF COMMUNITY USE TO DESCRIBE PEOPLE THAT ARE DEAF WITH ADDITIONAL DISABILITIES. FOR EXAMPLE, THEY MAY BE DEAF AND ALSO HAVE CEREBRAL PALSY. THEY MAY HAVE A DEVELOPMENTAL DISABILITY, AND THEIR ADDITIONAL DISABILITY MAY HAVE AN IMPACT ON HOW THEY FUNCTION AND HOW THEY COMMUNICATE AS A DEAF PERSON. IN GENERAL, WE DO NOT USE THE TERM HEARING IMPAIRED. ALTHOUGH, THERE ARE SOME-- YOU NEED TO KNOW THAT THERE ARE MANY PEOPLE IN THE DEAF COMMUNITY THAT DO CONSIDER THE TERM HEARING IMPAIRED TO BE OFFENSIVE. HEARING LOSS IS A TERM THAT IS TOTALLY ACCEPTABLE. THE HEARING LOSS ASSOCIATION OF AMERICA INCLUDES THE TERM HEARING LOSS, HLAA, OKAY. SOMETIMES IT CAN BE A MOUTHFUL TO SAY DEAF, HARD OF HEARING AND DEAF-BLIND SO IF YOU PREFER NOT TO SAY THAT, YOU CAN SAY PEOPLE WITH A HEARING LOSS. ANOTHER IMPORTANT THING FOR YOU TO KEEP IN MIND IS THAT MANY DEAF, HARD OF HEARING AND DEAF-BLIND PEOPLE ARE A PART OF OTHER GROUPS AS WELL. THEY'RE AFRICAN-AMERICANS. THEY'RE HISPANIC. THEY'RE GAY, STRAIGHT. THEY RUN THE WIDE GAMUT OF RELIGIONS LIKE MOST OF US DO. THEY MIGHT BE ATHEISTS. THEY MIGHT BE AMISH, WHAT HAVE YOU. THERE'S AN ARRAY OF DEAF AND HARD OF HEARING AND DEAF-BLIND PEOPLE THAT IDENTIFY THEMSELVES AS ALL OF THESE OTHER DIFFERENT GROUPS. THEY ARE MEMBERS OF ALL THESE DIFFERENT GROUPS, SO PLEASE KEEP THAT IN MIND AS WE GO FORWARD WITH THIS WORK AND THIS TASK FORCE PROCEEDS. BEFORE I MOVE ON, I DO WANT TO SHARE WITH YOU A QUICK STORY. I MET A SIGN LANGUAGE INTERPRETER AND I BELIEVE IT WAS IN BALTIMORE, WHERE THEY HAVE A LARGE HASIDIC JEWISH COMMUNITY AND SHE WAS CALLED TO INTERPRET FOR AN EMERGENCY INVOLVING A HASIDIC DEAF GENTLEMAN AND THAT CREATEDDED A HUGE CONFLICT BECAUSE SHE'S FEMALE AND HE'S MALE AND HE SHOULD NOT BE LOOKING AT HER AS A FEMALE IN HIS CULTURE. THERE ARE CULTURAL RULES THAT CREATED A VERY INTERESTING DYNAMIC THERE IN THAT SETTING. NOW, MANY OF YOU ARE FAMILIAR WITH THE TERM PEOPLE FIRST LANGUAGE. SO YOU MIGHT SAY, SO-AND-SO WHO IS DEAF OR SO-AND-SO WHO IS HARD OF HEARING, YOU TALK ABOUT THE PERSON FIRST AND GENERALLY, DEAF PEOPLE ARE AN EXCEPTION TO THIS RULE. WE IDENTIFY AS DEAF FIRST. AND IT IS CULTURALLY APPROPRIATE TO SAY DEAF PEOPLE, DEAF MAN, DEAF WOMAN, AND TO USE THE TERM DEAF FIRST BECAUSE DEAF PEOPLE IDENTIFY AS A MEMBER OF A CULTURAL MINORITY WITH OUR OWN LANGUAGE AND OUR OWN SOURCE OF PRIDE. WE HAVE PRIDE IN THAT IDENTITY. NOW, THAT'S NOT AS OFTEN THE CASE WITH HARD OF HEARING PEOPLE. YOU ALSO-- YOU ALL SOMETIMES HEAR HARD OF HEARING PERSON AND THAT'S OKAY. IT'S ALSO OKAY TO USE A PERSON WITH A HEARING LOSS. I THINK PROBABLY THE BEST THING TO DO IS TO FIND OUT FROM THAT PERSON THEMSELVES HOW THEY IDENTIFY AND WHAT THEIR PREFERENCE IS. TO THIS DAY, PEOPLE, INCLUDING WELL-EDUCATED PROFESSIONALS, EXPRESS SURPRISE WHEN THEY HEAR THAT AMERICAN SIGN LANGUAGE IS NOT A UNIVERSAL LANGUAGE, AND IT IS, IN FACT, A BONA FIDE LANGUAGE. AMERICAN SIGN LANGUAGE MEETS ALL OF THE LINGUISTIC REQUIREMENTS TO BE CONSIDERED A FULL LANGUAGE. THERE ARE HUNDREDS OF SIGN LANGUAGES ACROSS THE WORLD. THERE ARE REGIONAL DIALECTS AS WELL. I AM USING SOME SIGNS THAT YOU WOULD NOT SEE IN OTHER STATES, FOR EXAMPLE. BUT THEY WOULD USUALLY KNOW WHAT I'M SAYING, OKAY. THEY WOULD RECOGNIZE THAT AS A DIALECT, IN MY SIGN LANGUAGE. THERE ARE A COUPLE OF SIGNS, FOR EXAMPLE, FOR BIRTHDAY, DEPENDING ON WHAT REGION YOU ARE LOCATED IN.

BRITISH SIGN LANGUAGE IS TOTALLY DIFFERENT THAN AMERICAN SIGN LANGUAGE, SURPRISINGLY ENOUGH. AMERICAN SIGN LANGUAGE HAS NOTHING TO DO WITH ENGLISH AT ALL, OKAY. AMERICAN SIGN LANGUAGE, ASL, IS A RICH, SOPHISTICATED, COMPLEX LANGUAGE CAPABLE OF SUPPORTING COMMUNICATION IN A WIDE VARIETY OF ISSUES, PHILOSOPHIES. WE CAN TALK ABOUT PHYSICS, MEDICINE, ANYTHING YOU WANT TO TALK ABOUT CAN BE TALKED ABOUT IN OUR RICH, SOPHISTICATED LANGUAGE. WE ARE ALSO CAPABLE OF HAVING MISUNDERSTANDINGS AND MISCOMMUNICATIONS JUST LIKE PEOPLE WHO HEAR DO. CHILDREN WHO ARE BORN DEAF OR WHO BECOME DEAF BEFORE THEY ACQUIRE LANGUAGE OR LEARN TO SPEAK FACE CHALLENGES IN ACQUIRING LANGUAGE. NOT BECAUSE THEY'RE DEAF OR HARD OF HEARING BUT BECAUSE EDUCATION-- THE EDUCATION SYSTEM AND THE EARLY INTERVENTION SYSTEM IS NOT SET UP TO APPROPRIATELY MEET THE NEEDS OF THESE CHILDREN. WE DO KNOW OF A NUMBER OF PROGRAMS ACROSS THE COUNTRY THAT ARE DOING WELL. THERE ARE DEAF CHILDREN OF DEAF PARENTS WHO DEVELOP LANGUAGE NORMALLY, IMMEDIATELY, AND THEY MEET THE SAME MILESTONES AS CHILDREN WHO CAN HEAR OF PARENTS WHO CAN HEAR. ALL RIGHT. NOW I WANT TO TALK WITH YOU ABOUT COMMUNICATION ROLES HERE FOR OUR MEETING, AND YOU MAY HAVE NOTICED ON YOUR NAME TENTS THAT ON THE BACK OF OUR NAME TENT, WE HAVE OUR COMMUNICATION ROLE. I WANTED TO EXPLAIN WHY WE HAVE COMMUNICATION RULES SET FOR THIS IT MOOING. ANYTIME YOU HAVE DEAF, HARD OF HEARING, DEAF-BLIND AND HEARING PEOPLE GETTING TOGETHER IN ONE ROOM WITH ALL OF US HAVING DIFFERENT WAYS OF COMMUNICATING, ALL TRYING TO COMMUNICATE IN ONE MEETING AND US USING AMERICAN SIGN LANGUAGE INTERPRETERS, SUCH AS WE HAVE TODAY, THERE IS THE POTENTIAL FOR MAYBE ONE GROUP DOMINATING THE CONVERSATION MORE THAN ANOTHER GROUP THAT'S PRESENT IN THE ROOM. SO WE WANT TO MAKE SURE THAT EVERYONE HAS AN EQUAL PLAYING FIELD FOR OUR DISCUSSIONS GOING FORWARD, AND SO THAT EVERYONE HAS AN OPPORTUNITY TO TAKE A TURN IN THE COMMUNICATION SO WE HAVE JUST A FEW BASIC RULES, AND THE CO-CHAIRS WILL REMIND YOU OF THESE RULES AS NEEDED. THE FIRST ONE IS WAIT IF YOU WANT TO SPEAK. WAIT, PLEASE RAISE YOUR HAND AND WAIT ONE OF THE CO-CHAIRS TO RECOGNIZE YOU BEFORE YOU START SPEAKING. AND PLEASE BEGIN BY STATING YOUR NAME BEFORE YOU MAKE YOUR COMMENT. STATING YOUR NAME ALLOWS PARTICIPANTS ACROSS THE ROOM TO KNOW WHO'S SPEAKING AND IT'S ALSO A BIG ROOM SO IT KIND OF HELPS US WHEN WE CAN'T SEE ACROSS THE ROOM, IT HELPS US KNOW WHO IS SPEAKING. I WANT TO SHARE A FEW TIPS WITH YOU SO THAT YOU'LL BE BETTER COMFORTABLE AND KNOW BETTER HOW TO COMMUNICATE THROUGH AMERICAN SIGN LANGUAGE INTERPRETERS AND I HAVE TO TALK ABOUT LAG TIME. AS YOU JUST SAW AND YOU JUST WITNESSED IT RIGHT THERE. I STOP SIGN AND SHE STILL SPEAKS FOR ANOTHER HALF SENTENCE. THIS IS ONE REASON WE NEED TO YOU WAIT, RAISE YOUR HAND AND WAIT TO BE RECOGNIZED SO WE CAN WAIT FOR THE INTERPRETERS TO GET UP AND FINISH SPEAKING AND MOVE ON TO THE NEXT PERSON SPEAKING. ALSO WHEN AN INTERPRETER IS INTERPRETING FOR YOU, DON'T LOOK AT THE INTERPRETER, LOOK AT THE DEAF PERSON PRESENTING. THEY'RE ALSO NOT PARTICIPANTS IN THIS TASK FORCE, SO YOU SHOULD BE ABLE TO PROCEED AS IF THEY'RE NOT REALLY THERE. INTERPRETERS ARE GOVERNED BY THE REGISTRY OF INTERPRETERS FOR THE DEAF , PROFESSIONAL CODE OF CONDUCT. SO IF YOU ARE WONDERING WHY THEY'RE BEHAVING IN A SPECIFIC WAY IT'S BECAUSE THEY MUST ADHERE TO THEIR ROLE AND MAKE SURE THEY DO NOT PARTICIPATE IN THE MEETING WITH US TODAY. ANOTHER THING TO THINK ABOUT AS WE MOVE FORWARD WITH THESE TASK MEETINGS IS OUR TAG LINE, AS YOU SEE UP HERE ON THE SCREEN. COMMUNICATE, COLLABORATE, AND CONNECT. AND YOU WILL SEE WHY WE HAVE PICKED THIS AS OUR TAG LINE. EVERYTHING RELATED TO THESE THREE CONCEPTS, OUR DEMOGRAPHICS, OUR CURRENT SERVICE LANDSCAPE, THESE ARE ALL THINGS THAT YOU'RE GOING TO BE LEARNING ABOUT LATER, THE SERVICES THAT WE PROVIDE AND SUCH, WE WILL BE EXPLAINING TO YOU INFORMATION THAT WILL HELP YOU UNDERSTAND WHY WE ARE WHERE WE ARE TODAY AND HOW EVERYTHING THAT

WE'RE GOING TO TALK ABOUT TIES IN TO THESE THREE CONCEPTS AND OUR TAG LINE. AND WITH OUR VERY NEXT ACTIVITY, WE'RE GOING TO MOVE ON TO THE DIFFERENT DIFFERENT WORLD ACTIVITY. FROM OUR EXPERIENCE, WE HAVE LEARNED THAT FOR YOU TO TRULY UNDERSTAND OUR EXPERIENCE AND TO CONTRIBUTE TO THIS TASK FORCE, IT HELPS IF YOU GET A LITTLE BIT OF A TASTE OF WHAT IT'S LIKE TO BE DEAF, HARD OF HEARING, AND DEAF-BLIND. AND IT'S AN EYE-OPENING EXPERIENCE. I AM LOOKING FORWARD TO YOUR COMMENTS AFTER THE ACTIVITY. LET ME GO AHEAD NOW AND INTRODUCE ONE OF OUR STAFF THAT IS TAKING THE LEAD ON THIS ACTIVITY AND THAT IS DARIAN BURWELL AND SHE'S THE MANAGER OF OUR CENTER HERE IN RALEIGH AND SHE WILL GIVE YOU INSTRUCTIONS ON WHAT YOU NEED TO DO IN THIS ACTIVITY. I HOPE YOU'LL ENJOY THIS. THANK YOU.

Different, Different World Activity:

>> THANK YOU, JAN. THE GOOD MORNING, EVERYBODY. MY NAME IS **DARIAN BURWELL** AND I'M HAPPY TO BE WITH YOU TODAY TO PROVIDE THIS ACTIVITY. OUR STAFF LOVED DOING THIS ACTIVITY. WE ALWAYS LOOK FORWARD TO IT AND IT'S A GREAT OPPORTUNITY FOR EVERYONE TO LEARN FROM EACH OTHER. THIS IS AN ONGOING EXFOR MANY OF YOU. SO I KNOW WE'VE DONE INTRODUCTIONS BUT I WANT TO INTRODUCE MYSELF AND SOME VOLUNTEERS THAT WE HAVE AROUND THE ROOM FOR THIS DIFFERENT, DIFFERENT WORLD. SO WE'LL START WITH OUR FIRST TABLE IN THE BACK.
>> HI. MY NAME IS **JEFF GREER**, I'M THE DEAF SERVICES SPECIALIST.
>> MY NAME IS **JULIET BARBEN**. I'M A VOLUNTEER.
>> **KAREN CAPUTO**. HARD OF HEARING SPECIALIST-- WAS A HARD OF HEARING SPECIALIST. I DON'T KNOW WHAT I AM NOW. I'M A RETIREE AND WORK FOR THE DIVISION OF SERVICES FOR DEAF AND HARD OF HEARING FOR 25 YEARS. SO THANK YOU.
>> MY NAME IS **MARTINA MOORE-REED**. I'M A COMMUNITY ACCESSIBILITY SPECIALIST.
>> I'M BETH COLEMAN. I'M WITH GREENSBORO REGIONAL RESOURCE CENTER AS THE TELECOMMUNICATIONS CONSULTANT IN GREENSBORO.
>> GOOD MORNING, EVERYBODY. I'M **KAY**, AND I'M THE HARD OF HEARING SERVICE SPECIALIST UP THERE IN THE RALEIGH OFFICE.
>> HI, GOOD MORNING, EVERYONE. MY NAME IS **VICKY STROMWELL** AND I'M A VOLUNTEER HERE FOR DSDHH FOR A DIFFERENT, DIFFERENT WORLD. I'M A MEMBER OF THE COMMUNITY.
>> HI, GOOD MORNING, EVERYONE. MY NAME IS **NICOLE ALLMAN**. I'M THE DEAF-BLIND SPECIALIST IN THE RALEIGH REGIONAL CENTER AND I ALSO HAVE A COMMUNICATION SUPPORT TEAM. **DUSTIN**, WHO IS FUNCTIONING AS MY SSP, SUPPORT SERVICE PROVIDER. HIS ROLE IS TO PROVIDE ME WITH ENVIRONMENTAL COMMUNICATION AND HUMAN GUIDING TECHNIQUES AND I ALSO HAVE TWO INTERPRETERS.
>> HI, GOOD MORNING. MY NAME IS **JENNIFER CABE** I'M THE TELECOMMUNICATIONS CONSULTANT IN THE RALEIGH OFFICE.
>> ALL RIGHT. THIS IS **DARIAN**. THANK YOU, EVERYONE. NOW I WANT TO GIVE YOU AN IDEA OF WHAT DIFFERENT, DIFFERENT WORLD IS. IT'S AN OPPORTUNITY FOR YOU TO SHARE THE EXPERIENCE OF DEAF, HARD OF HEARING, AND DEAF-BLIND PEOPLE. SO I WANT YOU GUYS THAT ARE GOING TO BE PARTICIPATING TO GO AHEAD AND-- SORRY. I'M TRIPPING OVER MYSELF. WE HAVE STATIONS AROUND THE ROOM. EACH STATION HAS A DIFFERENT SCENARIO THAT YOU WILL GET TO EXPERIENCE. I'M GOING TO GIVE YOU A VERY BRIEF EXPLANATION OF THIS. SO THE FIRST STATION, YOU'RE JUST GOING TO BE AN OBSERVER. MEANING, YOU'RE GOING TO SIT WITH EARPLUGS AND A BLINDFOLD AND JUST SIT THERE. YOU GET TO WAIT UNTIL YOU ARE CALLED TO MOVE TO THE NEXT STATION. THE SECOND STATION, YOU WILL BE GIVEN A MENU, LIKE YOU'VE GONE TO A HOSPITAL AND YOU HAVE TO CHOOSE WHAT YOU'RE GOING TO EAT IN THE HOSPITAL . THE THIRD TABLE IS A LIPREADING EXERCISE WHERE YOU HAVE A FOLLOW-UP APPOINTMENT WITH YOUR PHYSICIAN. THE NEXT TABLE WE HAVE MEDIOCRE

INTERPRETER, MAYBE A PROFESSIONAL INTERPRETER WASN'T AVAILABLE AND YOU KIND OF GOT WHAT YOU WERE STUCK WITH AND THE NEXT ONE IS A HEARING TEST. THE NEXT ONE IS A PATIENT WHO NEEDS A CCTV. NEXT WE HAVE ONE WHERE YOU'LL BE GIVEN VISION-RESTRICTED GOGGLES AND YOU HAVE TO FILL OUT A FORM, AND THEN THE NEXT ONE IS JUST SOME ASSISTIVE TECHNOLOGY THAT YOU'LL GET TO EXPERIENCE. SO EACH STATION YOU'LL HAVE ABOUT TWO MINUTES FOR THE EXPERIENCE AND FOR THOSE OF YOU WHO HAVE ALREADY EXPERIENCED A DIFFERENT, DIFFERENT WORLD, YOU DO NOT HAVE TO PARTICIPATE BUT THOSE WHO HAVE NOT, WE WANT YOU TO NOW GO AHEAD AND WHO START FINDING ONE OF THE NATIONS. IT WILL BE TWO PEOPLE PER STATION. DOES ANYONE HAVE ANY QUESTIONS BEFORE WE MOVE FORWARD? YES. IS OUR STAFF READY? CHECKING IN WITH ALL THE. SO GO AHEAD AND START MAKING YOUR WAY TO SOME OF THE STATIONS, TWO PEOPLE PER STATION. IT DOESN'T MATTER WHERE YOU START. ALL RIGHT. OH, JUST ONE MORE QUESTION, YES.
>> WE HAVE MORE PEOPLE THAN STATIONS. SO WHAT IS THE SUGGESTION FOR HOW TO HANDLE THAT?
>> OKAY. WE WILL BE ROTATING SO IF WE GO AHEAD AND PUT TWO PEOPLE AT EACH TABLE, WE WILL WORK PEOPLE IN, BUT-- TWO MINUTES, WE WILL MOVE INTO THE NEXT STATION SO WE CAN START ROTATING PEOPLE IN FROM THE FRONT. ALL RIGHT. SO GO AHEAD AND MAKE YOUR WAY TO A STATION. TRY TO GET A SEAT. AND DON'T START THE ACTIVITY UNTIL WE'VE GOT EVERYONE SITUATED AND WE WILL START ALL AT THE SAME TIME. JUST CHECKING AROUND THE ROOM TO MAKE SURE THAT EACH STATION HAS THE PEOPLE. SO THE FIRST STATION THERE, YOU'RE GOING TO BE OBSERVING BY SITTING THERE WITH A BLINDFOLD AND EARPLUGS. I WANT TO MAKE SURE EVERYONE IS SETTLED, THAT WE HAVE TWO PEOPLE AT EACH STATION. REMEMBER, YOU'LL HAVE ABOUT TWO MINUTES PER STATION SO WHEREVER YOU'RE SITTING NOW, YOU'RE GOING TO MOVE TO YOUR LEFT AT THE END OF THAT TWO MINUTES AND WE WILL LET YOU KNOW WHEN. YOU WILL BE MOVING AROUND THE ROOM TO THE LEFT. DO WE HAVE THE ABILITY TO FLASH THE LIGHTS HERE? I'M JUST WANTING TO CHECK. THIS IS DARIAN. DO WE HAVE THE ABILITY TO FLASH THE LIGHTS? IF NOT, WE WILL USE THE INTERPRETER TO YOU'LL CAT SWITCHES. I'LL JUST USE THE INTERPRETER TO CALL EACH OF OUR SWITCHES. NOW, SOME OF YOU AT YOUR STATION ARE GOING TO BE USING EARPLUGS. EVERYONE SHOULD HAVE SOME IN FRONT OF YOU. I WANT TO MAKE SURE THAT EVERYONE HAS ACCESS TO THOSE EARPLUGS. WE'LL GO AHEAD AND START.

[PERFORMING BREAKOUT ACTIVITY]

ALL RIGHT. TIME'S UP. WE'LL GO AHEAD AND MOVE TO THE NEXT STATION. REMEMBER. MOVE TO YOUR LEFT. WE'RE MOVING COUNTERCLOCKWISE THROUGH THE ROOM. KEEP YOUR EARPLUGS IN THROUGHOUT THE WHOLE ACTIVITY, PLEASE. ALL RIGHT. IF YOU HAVE NOT YET STARTED, GO AHEAD AND START AT THE TABLE YOU'RE AT NOW. ALL RIGHT. TIME'S UP. GO AHEAD AND MOVE TO THE NEXT STATION. ALL RIGHT. BEGIN. ALL RIGHT. TIME IS UP AT THE STATION. GO AHEAD AND MOVE AGAIN TO YOUR LEFT COUNTERCLOCKWISE. ALL RIGHT. GO AHEAD AND START AT THIS STATION. OKAY. TIME IS UP. IF YOU HAD PLEASE NOW MOVE TO YOUR LEFT. EVERYONE MOVE TO YOUR LEFT. GO AHEAD AND START AT THIS STATION. ALL RIGHT. TIME'S UP. MOVE TO THE NEXT STATION. ALSO, FOR COMMUNICATION ACCESS PURPOSES, THE NOISE IN THE ROOM IS GETTING A LITTLE BIT TOO HIGH. I'M GOING TO ASK PEOPLE TO KEEP IT QUIET SINCE THERE ARE NO INTERPRETERS THERE, WE DON'T KNOW WHAT'S HAPPENING. SO WE'LL KEEP THAT SIDE CONVERSATION DOWN, PLEASE. GO AHEAD AND START AT YOUR CURRENT STATION. ALL RIGHT. TIME'S UP. PLEASE PROCEED TO THE NEXT STATION. ALL RIGHT. GO AHEAD AND START. ALL RIGHT. TIME'S UP. MOVE TO THE NEXT STATION. ALL RIGHT. GO AHEAD AND START. IT'S TIME TO MOVE TO THE NEXT STATION. ALSO, AGAIN, THE NOISE LEVEL OF THE

CONVERSATIONS ON THE SIDE OF THE ROOM IS GETTING LOUDER AND LOUDER. PLEASE KEEP THOSE CONVERSATIONS QUIET. AGAIN, THE SIDE CONVERSATION S ON THE SIDE OF THE ROOM IS GETTING LOUDER AND LOUDER, PLEASE KEEP THOSE CONVERSATIONS QUIET. GO AHEAD AND START AT YOUR CURRENT STATION. IF YOU HAVEN'T STARTED, GO AHEAD. ALL RIGHT. TIME'S UP. PROCEED TO THE NEXT STATION. GO AHEAD AND START. TIME'S UP. AGAIN, MOVING TO YOUR NEXT STATION. EXCUSE ME. FOR THE SAKE OF TIME, THOSE STANDING ON THE SIDE OF THE ROOM, IF YOU WANT TO GO AHEAD AND HAVE A SEAT AT YOUR TABLES. ALL RIGHT. TIME'S UP. GO AHEAD AND MOVE TO THE NEXT STATION.
THIS IS THE LAST ROUND, THE LAST ROTATION. WHEN WE'RE DONE, WE WILL GO BACK TO YOUR SEATS. GO AHEAD AND MOVE TO THE NEXT STATION. ONCE YOU'RE SEATED, GO AHEAD AND GET STARTED. LAST STATION. ALL RIGHT. TIME IS UP. WE HAVE COMPLETED THE DIFFERENT, DIFFERENT WORLD ACTIVITIES SO IF EVERYONE CAN MAKE THEIR WAY BACK TO YOUR TABLES.

Debrief of Different, Different World Activity:

>> I THINK WE HAVE ONE PERSON STILL FINISHING OFF AT THEIR STATION OVER THERE. OKAY.
THIS IS DARIAN. THERE ARE A COUPLE OF PEOPLE WHO HAVEN'T QUITE FINISHED YET. IF YOU WILL MAKE YOUR WAY TO THE SEATS. I'LL JUST WAIT FOR EVERYBODY TO TAKE A SEAT AGAIN BEFORE WE MOVE FORWARD. OKAY. SO EVERYONE TAKE A DEEP BREATH. RELAX. WE HAVE SOME QUESTIONS FOR YOU. SO THE FIRST QUESTION, HOW DID YOU FEEL ABOUT THAT EXPERIENCE? IF ANYONE WOULD LIKE TO RAISE YOUR HAND AND REMEMBER TO IDENTIFY YOURSELF BEFORE YOU MAKE A COMMENT. WOULD ANYONE LIKE TO SHARE WHAT THAT EXPERIENCE FELT LIKE? NO ONE HAS ANYTHING TO SAY?
[LAUGHTER]
OH, OKAY. THANK YOU.
>> MICROPHONE, PLEASE.

>> IN SOME RESPECTS-- MY NAME IS **ALLISON DAHLE**. AT SOME TABLES I FELT VERY SUPPORTED AND HELPED AND AT OTHER TABLES, I FELT LIKE I WAS TOTALLY MISUNDERSTOOD, DIDN'T UNDERSTAND AT ALL WHAT WAS GOING ON, AND IT TOOK A LONG TIME TO CATCH UP, ESPECIALLY AT THE LIP READING AND WHEN SOMEONE ELSE WAS INTERPRETING THAT WAS POORLY DONE. WE WERE BEARS RUNNING IN THE WOODS AT ONE POINT, AND IT WAS A MEDICAL APPOINTMENT.
[LAUGHTER]
SO IT WAS A MESS. THANK YOU.

>> OKAY. THANK YOU. ANY OTHER COMMENTS? YES. WE HAD ONE HERE IN THE FRONT.

>> OKAY. SO MY NAME IS **BETH HATHAWAY** AND I HAVE A CHILD ON MY CASE LOAD WHO WAS BORN BLIND AND DEAF, AND AS AN OCCUPATIONAL THERAPIST, IT'S MY JOB TO HELP HER FIGURE OUT HOW TO PLAY. THE FIRST STATION WHERE I ACTUALLY SIMULATED WHAT HER WORLD IS LIKE WAS VERY EYE-OPENING FOR ME AND I THINK WILL INFORM MY PRACTICE DOWN THE ROAD. I'M ALSO-- SOME SAY I'M NOSEY BUT I THINK I'M JUST INQUISITIVE, BUT I FELT LIKE I WAS MISSING SOMETHING AND WANTED TO PARTICIPATE MORE.

>> OKAY. THANK YOU. YES, WE HAVE LIZ.

>> AS AN OBSERVER, I'VE DONE THIS ACTIVITY BEFORE. MY NAME IS **LIZ ROBERTSON**. YOU GOT THIS. WHERE DID YOU GO? YOU KNOW WHO YOU ARE. I WAS OBSERVING PEOPLE WHEN THEY FIRST SAT DOWN WITH THE EARPLUGS AND THE VISOR ACROSS THEIR EYES AND IT WAS INTERESTING THAT WHEN

A LOT OF PEOPLE WERE ABLE TO TAKE THE VISOR OFF, THEY DID THE SIGH OF
[SIGHING]
I THOUGHT THAT WAS INTERESTING.

>> OKAY. YES.
>> I LIKE YOUR STRATEGY OF GRABBING THE WHOLE THING.
[LAUGHTER]

I'M **SHELLEY CRISTOBAL**, AND I'M AN AUDIOLOGIST, AND I SPEND MOST OF DAY WITH FOLKS WHO HAVE ACQUIRED HEARING LOSS LATER IN LIFE AND WHAT STRUCK ME IS HOW MANY OF MY PATIENTS COME TO ME WITH A DEGREE OF HEARING LOSS EQUIVALENT TO THE EAR PLUGS OR GREATER, AND WOULD NOT SELF-IDENTIFY AS HAVING TROUBLE HEARING OR STARTING TO THINK THEY'RE HAVING A LITTLE TROUBLE.

>> OKAY. THANK YOU. YES, WE HAVE ANOTHER COMMENT.

>> **TOVAH WAX** HERE. I, MYSELF, AM DEAF, AND I DO FEEL COMPELLED TO COMMENT THAT I HAVE BEEN INVOLVED WITH THIS KIND OF DWW ACTIVITY BEFORE AND HAVE EXPERIENCED BOTH SIDES OF IT. I DO FEEL THAT IT'S IMPORTANT TO UNDERSTAND, FOR SOME OF YOU, WHO MAY HAVE FELT DISTURBED BY THE EXPERIENCE OF BECOMING VISUALLY AND HEARING IMPAIRED THAT YOU MIGHT FEEL SOME NEGATIVE REACTION OR SOME FRIGHTENED REACTION ABOUT THIS, YOU KNOW, BEING AFRAID THAT IT WILL HAPPEN TO YOU LATER IN LIFE OR WHATEVER. BE AWARE THAT FOR MANY OF US WHO WERE BORN WITH OR LIVED FOR A VERY LONG TIME WITH HEARING IMPAIRMENT AND/OR VISUAL IMPAIRMENT THIS IS NORMAL TO US, NORMAL EXPERIENCE. WE DON'T FEEL DISTURBED OR UPSET OR ANXIOUS ABOUT IT ALL THE TIME. THIS IS ALL WE KNOW. SO PLEASE KEEP THAT IN MIND THAT IT IS NOT AS FEARFUL OR AS HORRIBLE AN EXPERIENCE THAT IT MAY APPEAR TO HAVE BEEN TO DO THIS BECAUSE FOR THE REST OF US, WE'VE HAD IT ON OUR LIVES AND THIS IS-- IT'S OUR LIFE, OKAY.
>> THANK YOU, TOVAH. SO NOW, ANOTHER QUESTION. AS YOU GUYS ARE GOING BACK TO YOUR OFFICES OR HOSPITALS, WHEREVER IT IS YOU WORK, WHAT ARE YOU GOING TO TAKE BACK FROM THIS EXPERIENCE BACK TO YOUR JOBS? ANY IDEAS? ANY FEEDBACK YOU'RE GOING TO TAKE WITH YOU? YES. THIS IS CRYSTAL DOWD. ONE OF THE THING I AM GOING TO PUSH FOR IN MY OWN CLINIC, AND I'M A FAMILY PHYSICIAN, IS HAVINGIVE IPADS WHICH IS WHAT WE USE FOR EMERGENCY INTERPRETER SERVICES BUT ENCOURAGING EVERYONE TO HAVE THEM AT EVERY STATION. WHAT WE FOUND AND WHAT I FOUND THROUGH PREVIOUS INTERACTIONS WAS HAVING INTERPRETERS SCHEDULED WASN'T GOOD ENOUGH. IF SOMEBODY JUST WALKED IN AND WANTED TO COMMUNICATE, THEY DIDN'T NEED TO WAIT FOR AN INTERPRETER. WE ENDED UP WITH SOME OF THE SITUATIONS THAT HAPPENED AT THE TABLE. HAVING THE iPADS IS OUR STOP GAP MEASURE FOR NOW TO GET THINGS DONE SO PEOPLE CAN COMMUNICATE IN A WAY THAT THEY'RE COMFORTABLE, BUT IT LOOKS LIKE HAVING MORE WAYS FOR THEM TO COMMUNICATE WITHOUT HAVING TO PLAN THAT COMMUNICATION WOULD REALLY BE BENEFICIAL AND USING TECHNOLOGY WOULD HELP WITH THAT.

>> OKAY. THANK YOU. ANY OTHER COMMENTS? YES, WE HAVE ANOTHER ONE HERE IN THE MIDDLE OF THE ROOM.

>> THIS IS **EILEEN CARTER**. I REPRESENT THE NORTH CAROLINA PT ASSOCIATION, AND I'M ALSO A PHYSICAL THERAPIST IN WILSON, NORTH CAROLINA, AND WE SERVE THE EASTERN NORTH CAROLINA SCHOOL FOR THE DEAF. SO I'M GOING TO GO BACK AND TAKE ASL AGAIN.

[LAUGHTER]
I KNOW A LITTLE BIT, BUT I REALIZE WITH MY FRUSTRATION AND TELLING THE LADY SHE WAS A BAD GIRL BECAUSE SHE KEPT HER--
[LAUGHTER]
AND PUT EVERYTHING IN FRONT OF HER FACE THAT I REALIZED THAT WE COULD DO BETTER AT THIS, AND I HAVE A WONDERFUL PT ASSISTANT THAT WORKS WITH ME AND WE KNOW ENOUGH TO GET WITH THEM. OUR CHILDREN ARE DEAF PLUS AT THE SCHOOL FOR THE DEAF. AND THIS IS GOING TO BE A GREAT COLLABORATION TO GO BACK AND REALLY SERVE AND JUST SHARE AND SEE WHAT WE CAN DO BETTER. THANK YOU.

>> THANK YOU. NOW, I KNOW ALL OF YOU ARE GOING TO GO BACK AND YOU'RE GOING TO HAVE A LOT OF IDEAS AND YOU'RE GOING TO THINK ABOUT THIS. REMEMBER, THE DIVISION OF SERVICES FOR DEAF AND HARD OF HEARING ARE HERE. YOU CAN CONTACT US AT ANYTIME AND WE CAN OFFER ANY TRAINING AND ASSISTANCE THAT WE CAN IN YOUR OFFICE. I KNOW WE DON'T HAVE TIME TO DELVE INTO EVERYTHING HERE. WE WANTED TO GIVE YOU AN IDEA WHAT OUR EXPERIENCE WAS LIKE AND WE'RE HERE FOR FURTHER TRAINING AND OTHER EXPERIENCES DOWN THE ROAD. THANK YOU SO MUCH FOR YOUR TIME.
[APPLAUSE]

>> THIS IS **JAN**, THANK YOU, DARIAN, AND THANK YOU TO THE STAFF AND VOLUNTEERS THAT HELPED AND ALSO FOR YOUR PARTICIPATION IN THE DIFFERENT, DIFFERENT WORLD. WE DID PLAN TO HAVE ANOTHER STATION THAT WOULD SIMULATE THE DIFFERENCE BETWEEN A MILD, MODERATE, AND SEVERE HEARING LOSS. UNFORTUNATELY, THE PERSON THAT WAS BRINGING THE RECORDING THAT WE USE FOR THAT FELL ILL AND HAD TO RETURN HOME. WASN'T ABLE TO MAKE IT HERE TODAY. BUT PART OF THAT WAS TO GIVE YOU AN IDEA, TODAY WITH THE EARPLUGS, YOU KIND OF GOT AN IDEA WHAT A MILD HEARING LOSS WOULD HAVE BEEN LIKE AND WHAT YOU CAN MISS EVEN WITH A MILD HEARING LOSS. ALSO REMEMBER THAT THERE ARE A LOT OF DIFFERENT, LIMITING FACTORS LIKE BACKGROUND NOISE AND HEARING LOSS CAN HAPPEN AT DIFFERENT FREQUENCIES. IF YOU HAVE A LOW FREQUENCY VER VERSUS A HIGH FREQUENCY LOSS, IT CAN HAVE VASTLY DIFFERENT IMPACTS. IF YOU'LL WATCH THIS VIDEO, IT WILL GIVE YOU A BETTER IDEA OF THAT. OKAY. WHILE WE'RE WAITING ON THAT, I KNOW THERE'S TECHNICAL PROBLEM. I WANTED TO TOUCH ON SOMETHING THAT I MENTIONED EARLIER ABOUT CHILDREN WHO ARE BORN DEAF OR BECOME DEAF BEFORE ACQUIRING SPOKEN LANGUAGE. THE REASON THAT I BROUGHT THAT UP IN PARTICULAR IS THAT THERE ARE DEFICIENCIES IN OUR EARLY INTERVENTION AND EDUCATION SYSTEMS AND THAT'S JUST NOT NORTH CAROLINA THAT'S AROUND THE COUNTRY. THAT I ALLOT OF THESE CHILDREN ARE NOT ACQUIRING LANGUAGE AT THE SAME TIME THAT MOST PEOPLE DO. WHAT THAT MEANS IS THAT THE NATIONAL AVERAGE READING LEVEL OF THOSE CHILDREN CAPS OUT AT AROUND FOURTH GRADE. IF YOU THINK ABOUT THAT POPULATION AND THEY'RE TRYING TO NAVIGATE OUR HEALTHCARE SYSTEM. TRYING TO FILL OUT INSURANCE FORMS OR MEDICAL FORM, TRYING TO UNDERSTAND WHAT THE DOCTOR IS EXPLAINING TO THEM, AND WHAT IF THEY HAVE A COMPLICATED MEDICAL PROCEDURE THAT THEY'RE UNDERGOING. I JUST WANT YOU TO KEEP THAT IN MIND. HOW ARE WE GOING TO DEAL WITH THAT POPULATION WHEN YOU ENCOUNTER THEM IN YOUR JOBS?

>> PARTIALLY INAUDIBLE VIDEO

Overview of Hearing Loss Population, Major Issues, Legal Mandates: Jan Withers & Glenn Silver:

>> (**JAN**) SO MAYBE NOW YOU HAVE A LITTLE BIT OF AN IDEA FROM THAT. ABOUT 90% OF PEOPLE WHO NEED OR COULD BENEFIT FROM A HEARING AID, IF YOU TAKE THAT WHOLE GROUP, ABOUT 16% OF THAT POPULATION ACTUALLY HAS ONE. SO IMAGINE TRYING TO ACCESS THE HEALTHCARE SYSTEM NEEDING THE HEARING AID AND NOT HAVING ONE. QUICKLY, WAY TOP WALK YOU THROUGH A FEW IDENTIFICATION MODES. SO AS YOU'RE ALREADY AWARE, THERE IS A LARGE VARIETY WITHIN THE COMMUNITY OF PEOPLE WHO HAVE HEARING LOSS AND A GREAT NUMBER OF DIFFERENT WAYS THAT THEY PREFER TO RECEIVE AND PROVIDE INFORMATION. IT COULD BE SIGN LANGUAGE. IT COULD BE USING SPEECH. IT COULD BE THROUGH TACTILE OR WRITTEN COMMUNICATION, AUDITORY, THERE'S A WIDE VARIETY OF COMMUNICATION METHODS WITHIN THAT SPECTRUM. SOME THINGS THAT MY STAFF AND I HAVE SEEN OVER AND OVER IS THE IDEA THAT ONE SIZE FITS ALL WITH COMMUNICATION. YOU WOULD BE SHOCKED HOW MANY PROVIDERS OUT IN THE COMMUNITY DON'T RECOGNIZE OR UNDERSTAND THAT WHAT THEY'RE CHOOSING IS NOT EFFECTIVE AND IS NOT GOING TO LEAD TO EFFECTIVE COMMUNICATION. BUT POLICIES ARE SET IN SUCH A WAY THAT IT PROMOTES A ONE-SIZE-FITS-ALL APPROACH. I WANT TO PROVIDE AN EXAMPLE OF WHAT THAT LOOKS LIKE. THERE'S ONE AGENCY HERE IN NORTH CAROLINA THAT CAME UP WITH A WAY TO MEET THE COMMUNICATION NEEDS OF ALL PEOPLE WITH HEARING LOSS, KIND OF THE WAY THAT THEY WERE APPROACHING THAT AND THEY CHOSE A DEVICE CALLED AN UBI DUO, WITH I IS A DUAL TYPEWRITER, WHERE YOU HAVE PEOPLE STANDING ON OPPOSITE SIDES OF IT AND THEY EACH HAVE A KEYBOARD AND SMALL SCREEN TO TYPE BACK AND FORTH. THINK ABOUT THE GROUP THAT I JUST MENTIONED. IF THEY HAVE ABOUT A FOURTH GRADE READING LEVEL, THAT'S OBVIOUSLY NOT GOING TO BE VERY EFFECTIVE WHEN YOU START TALKING ABOUT A COMPLICATED MEDICAL PROCEDURE. AND OF COURSE, THERE ARE ALSO A LOT OF HARD OF HEARING WHO DO NOT KNOW SIGN LANGE. SO YOU HAVE TO COME UP WITH POLICIES AND APPROACHES THAT RECOGNIZE THE IDEA OF EFFECTIVE COMMUNICATION DEPENDS ON THE INDIVIDUAL. THE SO BASICALLY, YOU NEED TO LOOK AT WHAT ARE THE NEEDS AND REQUIREMENTS OF THAT INDIVIDUAL AND WHAT SERVICES WILL HELP ACHIEVE EFFECTIVE COMMUNICATION FOR THAT PERSON? THE TERM "EFFECTIVE COMMUNICATION" ACTUALLY APPEARS IN THE AMERICANS WITH DISABILITIES ACT, OR THE ADA. AND ESSENTIALLY, IT MEANS THAT COMMUNICATION AND INFORMATION IS TRANSMITTED BETWEEN PARTIES CLEARLY AND UNDERSTANDABLY JUST AS IT WOULD BE FOR ALL PARTIES THAT ARE NOT DEAF, HARD OF HEARING, AND DEAF-BLIND. SIMPLE, RIGHT? NOW HOW WE ACHIEVE THAT IS WHERE IT GETS A LITTLE MORE COMPLICATED. I LIKE TO JOKE THAT THEY MAY HAVE A WONDERFUL INTERPRETER, BUT IF MY DOCTOR ISN'T A GOOD COMMUNICATOR, THE INTERPRETER SHOULD MAKE THAT CLEAR THROUGH THE INTERPRETTATION. AS I SAID, WE ACHIEVE EFFECTIVE COMMUNICATION THROUGH A VARIETY OF MEANS AND IT'S VERY COMPLICATED SOMETIMES. SO HERE WE HAVE A LIST OF SOME DIFFERENT TYPES OF SERVICES OR TOOLS OR PIECES OF EQUIPMENT THAT COULD POTENTIALLY BE USED. NOW, SOME OF THESE ARE VERY LOW COST AND THEY COULD BE EFFECTIVE FOR QUITE A LARGE NUMBER OF PEOPLE. SO IF YOU START LOOKING DOWN THE LIST, LET'S SEE. A PERSONAL AMPLIFIER, FOR INSTANCE, COMMONLY WE CALL THOSE POCKET TALKERS, COSTS ABOUT $160, I THINK, AND THEY CAN HELP A HIGH NUMBER OF PEOPLE THAT HAVE HEARING LOSS, THOSE DEVICES ARE GOOD MAYBE TO KEEP IN YOUR OFFICE TO HAVE ON HAND IF SOMEONE NEEDS THEM. ONE OF THE THINGS THAT WE DO AS AN AGENCY IS EDUCATE PROVIDERS ON WHAT OPTIONS YOU COULD USE FOR A VARIETY OF DIFFERENT PEOPLE. AND WE WILL BE TALKING MORE ABOUT THAT LATER. AND HERE IN THE ROOM WE VERY SEVERAL EXAMPLES TODAY. YOU SEE WE HAVE CAPTIONS ON A COUPLE DIFFERENT SCREENS. THAT'S SOMETHING YOU COULD PROVIDE WITHIN YOUR OFFICES, EVEN AS A PHYSICIAN. TACTILE AMERICAN SIGN LANGUAGE AMERICAN INTERPRETERS YOU SEE IN THE ROOM, ASSISTIVE DEVICES THAT ARE BUILT

INTO THE MICROPHONES AND THE FM SYSTEM HERE. THAT'S WHY IT'S IMPORTANT FOR EVERYONE TO USE A MICROPHONE WHEN YOU MAKE A COMMENT. IF YOU JUST YELL, THAT'S NOT GOING TO BE EFFECTIVE FOR PEOPLE IN THE ROOM WHO HAVE HEARING LOSS, SO THAT'S WHY WE USE THE MICROPHONE EVERY TIME WE SPEAK. NOW THE NEXT THING WE'RE GOING TO TALK ABOUT IS SOME DEMOGRAPHIC INFORMATION AND FOR THAT, I'M GOING TO TURN IT OVER TO OUR PROGRAM PLANNER EVALUATOR, GLENN SILVER. OH, AND ONE THING I WANT TO ADD BEFORE GLENN COMES UP. WE DID FIND A COUPLE OF ERRORS IN THE SLIDES OVER THE WEEKEND. SO WE WANT TO PASS OUT SOME REPLACEMENT POWERPOINTS THAT HAVE THE CORRECT INFORMATION. SO WE WILL BE DOING THAT. I APOLOGIZE FOR THE INCONVENIENCE OF THAT. GLENN, GO AHEAD.

>> THANK YOU VERY MUCH. I KNOW ROB HAD PASSED SOME OF THEM OUT.

>> HI THIS IS **ROB**. I CAME AROUND AND PASSED SOME OF THE NEW POWERPOINTS OUT. THEY SHOULD BE IN THE MIDDLE OF THE TABLE, BUT IF ANYONE DOES NOT HAVE ONE, I CAN COME AND BRING YOU SOME COPIES. ALSO, SORRY, ONE MORE THING. ALL OF THIS INFORMATION IS GOING TO BE ON OUR WEBSITE, TOO, IF YOU END UP NOT GETTING A HANDOUT FOR SOME REASON TODAY.

>> **(GLEN)** OKAY. SO IF YOU DON'T HAVE ONE THAT WAS NOT IN YOUR BINDER, JUST RAISE YOUR HAND AND ROB WILL GET YOU ONE, GET IT TO YOU. THANK YOU, ROB. ONE OF THE THINGS YOU HAVE BECOME AWARE OF IS THAT THOSE OF US THAT HEAR CAN HAVE PEOPLE WALKING AROUND AND DOING STUFF AND SPEAKING AT THE SAME TIME, BUT PEOPLE WHO USE AMERICAN SIGN LANGUAGE, WE DON'T WANT TO DO THAT. THAT'S WHY I'M WAITING FOR EVERYBODY TO GET SEATED AND SETTLED BECAUSE THEY WON'T BE ABLE TO SEE IF PEOPLE ARE BETWEEN HER AND YOU. OKAY. ALL RIGHT. THANK YOU VERY MUCH. SO AS JAN WAS SAYING, I'M GOING TO TALK ABOUT SOME DEMOGRAPHICS WITH YOU. EVERY YEAR, WE UPDATE OUR DEMOGRAPHICS IN THE DIVISION AND ONE OF THE THINGS IS THOSE ACCOMMODATIONS THAT JAN WAS TALKING ABOUT, THOSE COMMUNICATION ACCESS TOOLS, THE NUMBER OF PEOPLE THAT NEED THEM IS VERY LARGE OR THE POTENTIAL NUMBER OF PEOPLE BECAUSE WHEN WE TALK ABOUT PEOPLE WITH HEARING LOSS THAT'S A VERY DIVERSE AND BROAD GROUP AS WE HAVE IN THIS ROOM. SOME PEOPLE HAVE HEARING LOSS AND DON'T KNOW IT. AND IT'S UNDIAGNOSED AND IT GOES ALL THE WAY FROM THAT TO PEOPLE WHO ARE DEAF OR DEAF-BLIND AND EVERYTHING IN BETWEEN. SO YOU CAN SEE THE CURRENT NUMBERS FOR NORTH CAROLINA THAT THE TOTAL NUMBER OF RESIDENTS WITH HEARING LOSS, AGE 128 AND OVER IS ABOUT 1.2 MILLION.
THAT'S ABOUT 16% OF THE POPULATION. AND WHAT WE'RE GOING TO SEE ON THE NEXT SLIDE IS WHERE THOSE PEOPLE ARE CONCENTRATED AT AND YOU CAN SEE MOST OF THEM ARE AGE 75 AND OVER. AND WHAT THIS SLIDE MEANS IS THAT WHEN YOU LOOK AT THOSE PERCENTAGES, OUT OF EVERYBODY IN THE STATE THAT'S 18 AND OLDER, 16%. FOR EVERYBODY THAT'S 75 AND OVER, 46%, ALMOST HALF THE PEOPLE 75 AND OVER HAVE HEARING LOSS-- 75 AND OVER, ALMOST HALF THE PEOPLE 75 AND OVER HAVE HEARING LOSS. THIS STATE IS AGING, ESPECIALLY IN THE EASTERN PART OF THE STATE. THE POPULATIONS, THE DEMOGRAPHICS, THOSE COUNTIES, THE PROPORTION OF PEOPLE WHO ARE 75 AND OVER OR 65 AND OVER IS INCREASING FOR A NUMBER OF REASONS. YOUNGER PEOPLE ARE MOVING OUT AND A LOT OF PEOPLE THAT ARE COMING TO THOSE AREAS ARE RETIREES. AND THE NEXT GROUP ARE THOSE THAT ARE 65 TO 74 AND THE YOUNGER GROUP MAKES UP THE SMALLEST PROPORTION. AND NOT ONLY DO WE HAVE A HIGH NUMBER OF PEOPLE WITH HEARING LOSS CURRENTLY THAT NUMBER IS GROWING. MUCH MORE SO THAN THE GENERAL POPULATION. SO IN 2017, WHICH IS WHAT THE DATA IS MOST RECENT FROM, THE MOST RECENT DATA THAT WE HAVE, AND ABOUT 1.2 MILLION PEOPLE WITH HEARING LOSS. IN THE NEXT 10 YEARS OR SO, THAT NUMBER IS

GOING TO INCREASE TO ABOUT 1.6 MILLION. SO THAT MEANS THAT'S A 33% INCREASE IN THE POPULATION OF PEOPLE WITH HEARING LOSS. THE GENERAL POPULATION IN THAT TIME IS ONLY GOING TO GROW BY 21%, SO THE NUMBER OF PEOPLE WITH HEARING LOSS IS GROWING AT 1.5 TIMES GREATER THAN THE GENERAL POPULATION. AND THAT GROWTH, THAT INCREASE, JUST LIKE THE DISTRIBUTION IS GREATEST AMONG PEOPLE WHO ARE ELDERLY, AND THAT HAS A LOT OF IMPLICATIONS. SOME OF YOU REPRESENT VARIOUS AGING AGENCIES AND ORGANIZATIONS, AND I CAN REMEMBER WHEN I USED TO OVERSEE A HOUSING PROGRAM FOR THE CITY OF ROCKY MOUNT FOR HOUSING REHABILITATION, THOSE PROGRAMS MAINLY WERE PEOPLE WHO WERE ELDERLY, THEY WERE PEOPLE WHO BOUGHT HOMES WHEN THEY WERE MIDDLE AGED AND PAID FOR THEIR HOMES BUT COULDN'T AFFORD TO KEEP THEM UP. WHEN YOU START THINKING ABOUT SERVICES, THOSE KINDS OF HOUSING PROGRAMS, AND PEOPLE THAT APPLY FOR THEM, PEOPLE WITH HEARING LOSS MAY BE UNDERREPRESENTED BECAUSE WHEN I WAS DOING THAT, THE WAY WE COMMUNICATE IS THE WAY WE COMMUNICATE WITH HEARING PEOPLE. WE INVITE PEOPLE TO FORUMS. YOU MAKE PHONE CALLS. YOU MAKE FOLLOW-UP PHONE CALLS. YOU USE A LOT OF COMMUNICATION THAT PEOPLE WITH HEARING LOSS MIGHT NOT HAVE ACCESS TO. SO THEY COULD BE UNDERSERVED IN A LOT OF DIFFERENT PROGRAMS. SO THAT'S JUST SOME OF THE IMPLICATIONS OF THIS DEMOGRAPHIC. ANOTHER IMPLICATION IS COST AND THE COST CAN FALL INTO THREE CATEGORIES. YOU'VE GOT DIRECT CALLS OF PREVALENCE BASED, WHICH IS HOW MUCH MONEY I SPEND WHEN I GO TO THE DOCTOR AND WE HAVE RESEARCH THAT'S BEING DONE THAT RIGHT NOW AND THE PRELIMINARY RESULTS OF THAT RESEARCH, AND YOU PROBABLY WILL BE HEARING ABOUT THIS LATER FROM OTHER MEMBERS OF THE TASK FORCE, IS THAT PEOPLE WITH HEARING LOSS, AND THEY CATEGORIZE PEOPLE WITH HEARING LOSS WITH OTHER-- THE TERM THEY USE IS IMPAIRMENTS. IT'S NOT A TERM THAT WE USE BUT THAT'S THE TERM THAT THE SURVEY USES, BUT THEY LUMP THEM ALL TOGETHER BUT THE ESTIMATES THAT WE HAVE THAT A PERSON WITH HEARING LOSS ON AVERAGE WILL SPEND 67 TIMES AS MUCH FOR HEALTH COSTS, DIRECT HEALTH COSTS GOING TO THE DOCTOR. AVERAGE PERSON MAY SPEND AROUND $3,000. A PERSON WITH HEARING LOSS WILL SPEND 20. THERE'S-- GOING TO THE LAST ONE, THE INTANGIBLE COSTS. THERE'S QUALITY OF LIFE COSTS, AND WE'RE BEGINNING TO DEVELOP SOME INDICATORS OF THAT AT THE DIVISION. TWO INDICATORS ARE THE QUALITY OF THE COMMUNICATION THAT PEOPLE HAVE. ONCE THEY GET ASSISTED LISTENING DEVICE, WE EXPECT THAT QUALITY OF COMMUNICATION TO IMPROVE, HOW YOU TALK WITH YOUR FAMILY, YOUR FRIENDS, AND YOUR SOCIAL LIFE. ANOTHER QUALITATIVE INDICATOR IS YOUR FEELING OF INDEPENDENCE. NOW THAT YOU CAN HEAR AND INTERACT AND DO THINGS INDEPENDENTLY, YOU SHOULD HAVE A HIGHER LEVEL OF INDEPENDENCE. THOSE ARE TWO INTANGIBLE COSTS. YOU CAN'T REALLY QUANTIFY THEM BUT THEY'RE VERY IMPORTANT. AND THEN THE MIDDLE ONE ARE THE INDIRECT COSTS. AND THOSE INDIRECT COSTS IS WHAT WE DID IS WE USED A MODEL THAT'S CALLED LIKE THEY USE IN ECONOMIC DEVELOPMENT. ECONOMIC IMPACT ANALYSIS. WHEN THEY'RE TRYING TO LURE BUSINESSES TO DIFFERENT AREAS, THERE'S A MODEL THEY USE AND THEY PLUG SOME NUMBERS INTO IT. WELL, WE TOOK THAT MODEL AND APPLIED THE NUMBERS FOR PEOPLE WITH HEARING LOSS INTO IT, AND THIS IS WHAT WE GOT. UNTREATED HEARING LOSS IN THIS STATE, IN 2009, COST-- AND THOSE NUMBERS ARE RIGHT-- 7 AND THAT'S NOT MILLION-- BILLION, ALMOST $8 BILLION. 2014, 10 BILLION. BY 2030, IT WILL BE OVER 13 BILLION. AND THIS IS THE RIPPLE EFFECT AND WHAT IT MEANS IS THAT PEOPLE WITH HEARING LOSS, SAY, FOR EXAMPLE, SOMEBODY THAT'S DEAF AND BECAUSE THEY MAY HAVE TROUBLE INTERVIEWING, GETTING A JOB, THEY MAY BE UNDEREMPLOYED OR UNEMPLOYED. SO THOSE OF US THAT HAVE JOBS, WHEN WE PAY RENT. WE PAY TAXES, WE BUY THINGS. WE GO TO THE STORE, THE LESS INCOME YOU HAVE, THE LESS YOU DO WITH THOSE THINGS. SO IT'S THE RIPPLE EFFECT, AND THAT RIPPLE EFFECT HAS THIS EFFECT ON THE ECONOMY. SO IT'S NOT JUST THE WORK THAT WE'RE DOING, IT DOESN'T JUST IMPACT DIRECTLY PEOPLE WITH HEARING LOSS, IT IMPACTS ALL OF US. BECAUSE WHEN

ANY SEGMENT OF OUR SOCIETY CAN'T GET JOBS AND CAN'T OR UNDEREMPLOYED IN JOBS THAT THEY WOULD LIKE TO HAVE BUT CAN'T GET, THAT AFFECTS US AND THAT'S WHAT IT COSTS THE STATE. AND THIS IS THE MAIN THING, THE JOBS. THIS IS THE NUMBER OF JOBS THAT IT COSTS THE STATE. JOB LOSSES ATTRIBUTABLE TO UNTREATED HEARING LOSS AND THIS IS A CONSERVATIVE MODEL. THERE'S SOME OTHER RESEARCH THAT'S BEEN DONE BY MEDICAL DOCTOR AT HARVARD AND OTHER PLACES WHERE THE NUMBERS ARE MUCH, MUCH GREATER THAN THIS. SO WE SAY OVER 100,000 JOBS IN 2009 TO 2030 COULD BE ALMOST 200,000. IN CONTRAST, THERE'S A BENEFIT. IF WE PROVIDE ACCESSIBLE COMMUNICATION AND IF WE PROVIDE COMMUNICATION ACCESS, THEN THERE'S A BENEFIT TO IT AND THIS IS A VERY CONSERVATIVE MODEL. IF WE WOULD DO THAT, WE WOULD CREATE BY 2030 PROBABLY AROUND 7,000 ADDITIONAL JOBS OR MORE. AND THOSE HAVE AN ECONOMIC BENEFIT THAT WOULD ADD A HALF BILLION DOLLARS TO THE ECONOMY. AND THAT'S JUST IF 3% OF THE PEOPLE WERE REACHED. SO IF WE REACH MORE THAN THAT, THOSE NUMBERS GO UP. SO IT DOESN'T TAKE A LOT FOR IT TO HAPPEN. IT DOESN'T JUST AFFECT PEOPLE DIRECTLY BUT IT AFFECTS US AS RESIDENTS OF THIS STATE, AS NORTH CAROLINIANS AND IN THE BROADER COMMUNITY AND SO THAT'S ONE OF THE REASONS THAT THE WORK WE'RE DOING IS VERY, VERY IMPORTANT. NOT JUST FOR THE HEALTH OF THE PEOPLE BUT FOR THE HEALTH OF THE STATE AND THE QUALITY OF LIFE FOR EVERYBODY. AND SO THERE'S NOT ONLY THE ECONOMIC COSTS. THERE'S ALSO SOME LEGAL IMPLICATIONS AND JAN IS GOING TO COME BACK AND BRING YOU UP TO SPEED ON THOSE.

>> THANK YOU, GLENN. SO THERE ARE TWO THINGS THAT I WANT TO MENTION RELATED TO THE DEMOGRAPHICS THAT WE JUST SHARED AND THE COST, SO WE JUST FOUND FROM A STUDY THAT SHOWS THAT ON AVERAGE, THE PERSON WITH HEARING LOSS OR PERSON WITH NO HEARING LOSS SPENDS ABOUT $3,000 A YEAR ON HEALTHCARE. WHILE A PERSON THAT HAS HEARING LOSS SPENDS CLOSER TO $20,000 PER YEAR. THAT'S QUITE A DESPAIR-- DESPAIRTY AND THAT'S AN INCREDIBLE INDIVIDUAL IMPACT AND WHAT YOU SAW HERE IS BROADER ECONOMIC IMPACT BUT DON'T FORGET ABOUT THE INDIVIDUAL IMPACT AND WE HAVE INFORMATION THAT MAY BE BENEFICIAL FOR THOSE WHO ARE RUNNING CCRCs, SO IT'S CONTINUED CARE AND RETIREMENT COMMUNITIES, WHICH INCLUDES NURSING HOMES, ADULT CARE HOMES, SOME INFORMATION THAT MAY HELP WITH YOUR BOTTOM LINE SO HOW YOU CAN OPERATE YOUR FACILITY. THE OTHER THING THAT I WANTED TO MENTION IS THAT THE CDC HAS A STUDY THAT SHOWS PEOPLE WHO HAVE HEARING LOSS ARE MORE LIKELY TO REPORT THAN THE GENERAL POPULATION HAVING FEARS OR FAIR OR POOR HEALTH. SO WE'RE GOING TO BE LOOKING FOR THE SPECIFIC NUMBERS ON THAT. WE'LL BE EMAILING THOSE TO YOU. THOSE ARE TWO THINGS TO KEEP IN MIND. OKAY. SO NOW TALKING ABOUT SOME OF THE LEGAL IMPLICATIONS. TWO OF THE LAWS WE WANT TO TALK ABOUT THAT RELATE TO WHAT WE'RE DOING. AND THE SECOND LAW HERE PERTAINS MOSTLY TO FACILITIES AND PLACES THAT RECEIVE FEDERAL MONEY. SO THE ADA HAS BROADER IMPACTS BECAUSE IT INCLUDES ALSO PRIVATE ENTITIES AND PRIVATE BUILDINGS, PRIVATE PROVIDERS , SO YOU HAVE SOME GENERAL INFORMATION FROM DISABILITY RIGHTS NORTH CAROLINA, I BELIEVE, IN YOUR BINDERS. AGAIN, WE CAN (INAUDIBLE) BUT THERE ARE SOME IMPORTANT THINGS THAT WE WANT TO MENTION IN PARTICULAR. THE U.S. DEPARTMENT OF JUSTICE HAS A COMMUNICATION ACCESS OFFICE AND THEY HAVE RULES AND GUIDELINES THAT YOU CAN FOLLOW AND I THINK THAT WILL BE BENEFICIAL FOR EVERYONE AS WELL. THE BOTTOM LINE HERE IS THAT WE DO HAVE FEDERAL LAWS THAT REQUIRE PROVIDERS TO PROVIDE ACCOMMODATIONS. AND WHAT WE'RE DOING HERE TO ADDRESS THAT IS TRYING TO THINK ABOUT HOW WE CAN GET THE WORD OUT ABOUT THAT, HOW WE CAN HELP PEOPLE UNDERSTAND PROVIDERS' ACCOMMODATIONS AND WHAT THEY'RE REQUIRED TO OFFER. I THINK NOW IT'S ABOUT TIME FOR LUNCH. WE'RE ABOUT 7 MINUTES EARLY SO I GUESS WE'LL TRY TO WRAP THAT UP, BUT BEFORE WE DO THAT I WANT TO SEE IF ANYONE HAS ANY QUESTIONS THUS FAR. YES, WE HAVE--

>> THIS IS **ALISON DAHLE**. WHY IS HEALTHCARE-- WHAT DRIVES THE HEALTHCARE FOR DEAF AND HARD OF HEARING UP? IS IT THE--

>> THAT'S A GOOD QUESTION. THERE ARE SEVERAL REASONS THAT THAT COST IS HIGHER. REMEMBER, ONE OF THE THINGS WE TALKED ABOUT ARE THOSE THREE BROADER CATEGORIES OF PEOPLE THAT HAVE HEARING LOSS? SO SOMEONE WHO'S DEAF-BLIND MAY BE PART OF THE ISSUE IS TRANSPORTATION OR NOT HAVING GOOD ACCESS TO THAT. NOT HAVING SOMEONE TO GUIDE THEM AROUND A LARGE HOSPITAL, TO FIND A SPECIFIC HEALTHCARE FACILITY OR OFFICE. ALSO, A LOT OF TIMES PEOPLE, THEY CAN'T AFFORD THE TRANSPORTATION OPTIONS THAT ARE AVAILABLE. SO THERE ARE A LOT OF DIFFERENT SERVICES BUT IF THOSE SERVICES, EVEN WHEN THEY ARE AVAILABLE, IF THOSE DRIVERS DON'T HAVE THE COMMUNICATION SKILLS AND THE TRAINING TO GUIDE SOMEONE THAT'S DEAF-BLIND. FOR EXAMPLE, IF I DON'T HAVE THAT COMMUNICATION SKILL AND THE DEAF-BLIND PERSON NEEDS TRANSPORTATION THEN THE TYPE OF TRANSPORTATION THAT THEY CAN GET WITH THE APPROPRIATELY SKILLED PROVIDER IS GOING TO MAKE A BIG DIFFERENCE. THAT'S REALLY TRUE OF BOTH DEAF AND HARD OF HEARING COMMUNITIES. SOMETHING THAT PEOPLE PUT OFF HEALTHCARE BECAUSE THEY'RE TRYING TO NAVIGATE COMMUNICATION BARRIERS, SO WHILE THEY'RE DOING THAT, TRYING TO FIND AN APPOINTMENT SOMEWHERE TO GET WHERE THEY CAN GET ACCOMMODATIONS, THEY HAVE TO PUT OFF HEALTHCARE. SO PEOPLE-- THINK ABOUT THE IDEA, IF YOU BUILD IT, THEY WILL COME. THAT'S WHY OFTEN PEOPLE WE SHARE INFORMATION WITH EACH OTHER ABOUT WHICH DOCTORS ARE WILLING TO PROVIDE INTERPRETERS AND WHEN YOU FIND A PLACE THAT IS WILLING, A LOT MORE PEOPLE THAT HAVE HEARING LOSS WILL SHOW UP. SO THE COST OF AN INTERPRETER CAN BE LARGER FOR ONE SINGLE APPOINTMENT BUT OVER TIME WITH THE INCREASED NUMBER OF PATIENTS, IT'S OFFSET BY THAT BUT IT CAN BE A FINANCIAL OBSTACLE TO THE OFFICES. SO FOR HARD OF HEARING PEOPLE WHO BECOME HARD OF HEARING AS ADULTS, AND I THINK THE SAME IS TRUE OFTEN OF DEAF PEOPLE, MANY LACK THE SELF-ADVOCACY SKILLS THAT THEY NEED TO SPEAK UP AND SAY THIS IS THE ACCOMMODATION I NEED. AND THERE'S A HIGH LEVEL OF PASSIVITY IN THE POPULATION. BECAUSE PEOPLE ARE OVERWHELMED AND OPPRESSED BY THESE LARGER HEALTHCARE SYSTEMS AND DON'T KNOW HOW TO SPEAK UP OR COMBAT THAT. SO THOSE ARE SOME OF THE MORE COMMON OF WHAT I SEE OF WHY HEALTHCARE COSTS MAY BE HIGHER. WE HAVE ANOTHER COMMENT OR QUESTION.

>> **TOVAH WAX** HERE. I THINK ANOTHER ASPECT OF YOUR QUESTION HAS TO DO WITH THE FACT THAT THE ECONOMIC ISSUES FOR HEALTHCARE FOR DEAF AND HARD OF HEARING PEOPLE IS ENORMOUS. WE ARE LEARNING ABOUT DIFFERENT MEDICAL CONDITIONS THAT ARE CORRELATED WITH UNTREATED HEARING LOSS THAT DRIVE THE COST OF CARE UP NOT JUST ACCOMMODATION COSTS BUT ALSO HEALTHCARE COSTS, SO THIS HAS COME ABOUT AS A RESULT OF THAT INCREASING AWARENESS. I THINK FOR MANY PROVIDERS, THE ECONOMICS OF PROVIDING ACCOMMODATION, BOTH FOR TREATED AND UNTREATED HEARING LOSS, IS A DRIVING CONSIDERATION IN ADDITION TO THE ISSUES THAT JAN HAS MENTIONED.

>> YES, WE HAVE ANOTHER COMMENT.

>> THIS IS **CRYSTAL**. SOME OF THE DIRECT COSTS I HAVE FOR PATIENTS WHO HAVE INSURANCE ARE CO-PAYS FOR GOING TO THE DOCTOR, PRIMARY DOCTOR, ME, CO-PAYS FOR THEIR SPECIALIST. EVEN WHEN THEY HAVE INSURANCE, I HAVE HAD PATIENTS DELAY THEIR HEARING AIDS OR COCHLEAR IMPLANTS BECAUSE OF LACK OF COVERAGE AND WHEN THEY HAVE COVERAGE, IT CAN COST-- I WAS QUOTED

LAST WEEK PATIENTS WHO WERE QUOTED $4,000 TO GET THEIR HEARING AID, $4,900 AND THAT'S A LOT TO COME UP WITH. THEY HAVE TO BE FIXED. THEY GET LOST. THEY HAVE TO BE REPAIRED. THEY HAVE TO GET NEW ONES AND THAT'S $5,000 EASILY IF YOU HAVE GOOD COVERAGE JUST TO GET YOUR HEARING AID.

>> SO **VICKY SMITH**. HOLDING IT UP CLOSE. VICKY SMITH. I'LL SAY IT AGAIN. THE OTHER COST OF HEALTHCARE IS THAT IF THERE IS NOT-- IF THE PHYSICIAN DOES NOT GET AN INTERPRETER THEN THEY RELY ON INDIVIDUALS' FAMILY MEMBERS WHO MIGHT BE GIVING EMOTIONAL INFORMATION SO THE EMOTIONAL IMPACT AND THE EMOTIONAL MESSAGE, OR THEY MIGHT BE GIVING MISINFORMATION BECAUSE THEY AREN'T CERTIFIED IN THAT LEVEL, WHICH THEN MEANS THEY DON'T GET APPROPRIATE LET ALONE ADEQUATE HEALTHCARE, WHICH THEN ADDS TO THE COST.

>> THANK YOU, YES. IF I MIGHT ADD TO THAT, THERE'S A COST TO DELAY ORIOLES A COST TO THOSE REPEATED VISITS BECAUSE A PATIENT MAYBE DIDN'T UNDERSTAND THE INSTRUCTIONS THE FIRST TIME AND NOW THEIR HEALTH IS DETERIORATED FURTHER AND THEY'RE HAVING REPEATED VISITS AS A RESULT OF THAT. THAT'S A COMMON EXAMPLE. YES, WE HAVE ANOTHER HAND UP. JULIE.

>> HAVE HELLO. THIS IS **JULIE** WITH THE HEARING LOSS ASSOCIATION OF AMERICA. JAN, THANK YOU FOR DISTINGUISHING ADULTS WHO ACQUIRE A HEARING LOSS AS AN ADULT BECAUSE WE SEE ON THE LOCAL LEVEL AND THE NATIONAL LEVEL A BIG DIFFERENCE IN PEOPLE'S ABILITIES TO RECOGNIZE THEIR HEARING LOSS AS THEY AGE AND I HOPE WE-- I HOPE THERE'S A WAY TO BRING OUT ANY STATISTICS THAT MIGHT BE AVAILABLE ON LIKE WHAT YOU JUST GAVE IN TERMS OF LIKE IF YOU LOOK AT A POPULATION OF 65 AND OLDER, HOW MANY OF THOSE HAVE ADULT ONSET TYPE HEARING LOSS BECAUSE IT REALLY IS DIFFERENT IN TERMS OF HOW THEY REACT TO IT AND THEY ARE REALLY UNPREPARED FOR THIS HORRIBLE THING THAT HAS HAPPENED TO THEM, SO I THINK WE NEED TO REALLY IDENTIFY THEM AS ALMOST A SEPARATE GROUP. PEOPLE WHO ACQUIRE HEARING LOSS AS AN ADULT BECAUSE IT IS A VERY DEVASTATING THING THAT HAPPENS.

>> ABSOLUTELY. YOU'RE ABSOLUTELY RIGHT. AND THERE'S A GRIEVING PROCESS THAT PEOPLE HAVE TO GO THROUGH WHEN THEY FIND OUT THEY HAVE HEARING LOSS FOR THE FIRST TIME, AND THAT ALSO IMPACTS THEIR ABILITY TO SELF-ADVOCATE. WE HAVE A VERY NICE VIDEO ON HEARING LOSS AND I CAN'T REMEMBER-- THERE'S A WELL-KNOWN ACTRESS IN SORT OF THE HARD OF HEARING WORLD AND SHE IS DEMONSTRATING HOW YOU ADVOCATE FOR YOURSELF AND WHEN I SAW THAT, I THOUGHT TO MYSELF, THAT'S NOT NORMAL. THAT'S MAYBE 5% OF PEOPLE THAT COULD REALLY SPEAK UP FOR THEMSELVES THE WAY SHE DOES IN THIS VIDEO. THERE REALLY IS A LOSS OF PASSIVITY AND A FEELING OF INTIMIDATION AND BEING OVERWHELMED AND NOT WANTING TO ADMIT TO THE PERSON THAT YOU'RE INTERACTING WITH THAT YOU DON'T UNDERSTAND THEM OR ASKING SOMEONE TO PLEASE REPEAT THEMSELVES AND IT BECOMES AN ESPECIALLY DIFFICULT ISSUE WHEN YOU'RE TALKING ABOUT COMPLICATED MEDICAL PROCEDURES AND THEN SOMEONE'S LEFT WITH LIMITED INFORMATION OR MAYBE COMPLETELY MISUNDERSTOOD INFORMATION THAT RESULTS IN A GREATER OR SIGNIFICANT MEDICAL ISSUE IN THE FUTURE. ALL RIGHT. SO I BELIEVE NOW IT IS TIME FOR LUNCH.
[LAUGHTER]
SO THANK YOU SO MUCH FOR YOUR QUESTIONS. WHAT TIME ARE WE COMING BACK AFTER LUNCH?
>> CAN YOU HEAR ME NOW?

>> SORRY ABOUT THAT. THIS IS **ADAM**. I JUST WANTED TO ANSWER JAN'S QUESTION. LUNCH IS SET UP BACK HERE AND WE'RE GOING TO BE STARTING BACK PROMPTLY AT 1:00.

[LUNCH HELD]

>> THIS IS **JAN**. I'M SORRY. REALLY QUICKLY. THERE'S A COUPLE OF THINGS I WANT TO MENTION BEFORE WE STOP FOR LUNCH. SO ONE OF THE PAPERS YOU HAVE IS AN EVALUATION FORM FOR THE DIFFERENT, DIFFERENT WORLD EXPERIENCE. IF YOU WOULD NOT MIND, PLEASE TAKE JUST A FEW MINUTES, MAYBE TWO MINUTES, TO FILL THOSE OUT. SECOND, WE HAVE A PHOTO CONSENT FORM THAT WE WOULD LIKE EVERYONE TO SIGN IF YOU DON'T MIND. OH, THE PHOTO CONSENT IS UNNECESSARY. SO GREAT. I WAS JUST TOLD THAT WE DIDN'T NEED THE PHOTO CONSENT BUT THE EVALUATIONS FOR THE DIFFERENT, DIFFERENT WORLD ARE ON THE TABLES. FEEL FREE TO FILL THOSE OUT AND SHARE YOUR FEEDBACK ABOUT THAT EXPERIENCE WITH US. THANK YOU. TEST TEST TEST TEST

[MEETING WILL RESUME SHORTLY]

[YOUR MEETING WILL BEGIN SHORTLY]
[YOUR MEETING WILL BEGIN SHORTLY]

Panel: (Liz Robertson – Child of Deaf Adult**; Stephanie Johnson –** Late Husband was deaf**; Julie Bishop –** developed hearing loss later in life**; Jan Withers –** Born Deaf**; Ann Krohn (Video) –** Deaf woman with hearing child**; Ashley Benton –** Deaf-Blind**; Bill Lamb –** mother developed hearing loss later in life**)**

DON'T IDENTIFY AS HAVING A HEARING LOSS AND IT DID REMIND ME OF A STORY OF THIS MAN WHO WAS VERY CONCERNED ABOUT HIS WIFE. HE THOUGHT HIS WIFE HAD A HEARING LOSS AND SO HE DECIDED TO TEST HIS WIFE'S HEARING. SO HE DECIDED, OKAY, WHAT I'LL DO IS STAND ACROSS FROM HER ON THE OPPOSITE SIDE OF THE ROOM WHILE SHE'S WORKING IN THE KITCHEN.
SHE'S STANDING AT THE SINK WORKING IN THE KITCHEN AND HE WAS STANDING BEHIND HER ACROSS THE ROOM AND HE ASKED AND HE DECIDED AND I'M GOING TO ASK HER WHAT'S FOR DINNER? HE SAID, OKAY, HONEY, WHAT'S FOR DINNER? OBVIOUSLY, SHE DIDN'T HEAR BECAUSE SHE DID NOT RESPOND. HE WALKED A LITTLE BIT CLOSER AND HE SAID, HONEY, WHAT'S FOR DINNER? THERE WAS NO RESPONSE AGAIN. HE STARTED GETTING CONCERNED SO HE WALKED A LITTLE CLOSER. MAYBE ABOUT FIVE FEET AWAY FROM HER AND HE ASKED AGAIN, HONEY, WHAT'S FOR DINNER? AND AGAIN, THERE WAS NO RESPONSE. HE GOT UP RIGHT BEHIND HER AND SAID, HONEY, WHAT'S FOR DINNER? AND SHE TURNED AROUND AND SAID, FOR THE FOURTH TIME, CHICKEN.
[LAUGHTER]
>> SORRY F WE CAN HOLD. WE HAVE A MICROPHONE ISSUE. THAT'S BETTER. THANK YOU. ALL RIGHT. SO THAT WAS A HEARING TEST FOR EVERYONE IN THE ROOM.
[LAUGHTER]

ALL RIGHT. THIS AFTERNOON, WE HAVE A PANEL OF SEVEN PEOPLE. ONE HAS JOINED US ON THE PHONE. SO HOPEFULLY, WE'VE GOT EVERYTHING WORKED OUT HERE UP FRONT. WE'RE GOING TO GO AHEAD AND START OFF BY INTRODUCING PEOPLE. IF YOU WOULD, STAND UP, INTRODUCE YOURSELF AND GO DOWN THE ROAD. STAND UP, PLEASE.

>> HI. I'M **LIZ ROBERTSON**. I'M A CODA, CHILD OF DEAF ADULTS.
>> I'M **STEPHANIE JOHNSON**, AND MY FIRST HUSBAND WAS DEAF.
>> I'M **JULIE BISHOP**, I ACQUIRED A HEARING LOSS IN (INAUDIBLE). HELLO. I'M JAN WITHERS AND I WAS

BORN DEATH DEAF TO A HEARING FAMILY.
>> HELLO. **I'M ASHLEY BENTON**. I'M DEAF-BLIND. I WAS BORN WITH A SIN DROAM KOHLED USHER'S SIN SYNDROME WHICH MEANS YOU HAVE A HEARING LOSS AND VISION LOSS THAT BECOMES PROGRESSIVE. AS I BECOME OLDER, I LOST MORE OF MY HEARING AND VISION. WHEN I FIRST STARTED OUT AS A CHILD, I COMMUNICATED IN THE ORAL METHOD AND I SWITCHED TO VISUAL MEANS AS I LOST MORE OF MY HEARING AND VISION.
>> THIS IS DAVID SPEAKING. BILL, ARE YOU ON THE PHONE?
>> I AM.
>> IF YOU WOULDN'T MIND GO AHEAD AND INTRODUCE YOURSELF, PLEASE
>> **BILL LAMB** AND I'M THE EXECUTIVE DIRECTOR OF RESIDENTS AND LONG-TERM CARE AND I HAD A MOTHER WHO BECAME VERY HARD OF HEARING AS SHE AGED.
>> THANK YOU, BILL. JUST HOLD TIGHT, AND WE'LL COME BACK TO YOU IN A BIT, AND WE ALSO HAVE A PERSON ON VIDEO AND I'M SORRY, I DIDN'T CATCH HER NAME, AND JAN IS SAYING IT'S **ANN CROHN**.

THIS IS **DAVID** SPEAKING. ANN WAS NOT ABLE TO BE HERE WITH US IN PERSON SO SHE HAS PROVIDED A VIDEO OF HER STORY, AND WE'LL WATCH THAT VIDEO LAST. OUR PANELISTS ARE GOING TO TALK ABOUT THEIR EXPERIENCES WITH THE MEDICAL HEALTHCARE SYSTEM AND WE HAVE A WIDE VARIETY OF EXPERIENCES AND MANY OF US HAVE SUFFERED THE SAME EXPERIENCES BUT THIS IS AN OPPORTUNITY FOR YOU TO HEAR WHAT THEY HAVE TO SAY ABOUT THEIR EXPERIENCES IN NAVIGATING THE SYSTEM. HOPEFULLY, THIS WILL BE TO YOUR BENEFIT AND WE'LL GO AHEAD AND START WITH LIZ.

Liz Robertson:
>> YOU MUST UNDERSTAND. I HAVE I ALARD TIME PICKING A LANGUAGE TO SPEAK FROM. MY PARENTS ARE BOTH DEAF AND BOTH DECEASED NOW. DADDY WAS BORN IN 1903 AND MOM WAS BORN IN 1918. I GREW UP AS SIGN LANGUAGE BEING MY NATIVE LANGUAGE. AS I WAS TRYING TO SAY AT THE BEGINNING, IT'S HARD FOR ME WHEN I KNOW THERE'S DEAF PEOPLE IN THE ROOM TO NOT SIGN AND I'M GOING TO CHOOSE TO SIGN AND TALK AT THE SAME TIME WHICH IS A VIOLATION OF OUR CODE ETHICS. TOO BAD. MY NAME IS LIZ.
[LAUGHTER]
MY PARENTS ARE BOTH DEAF. LET ME GO BACK A LITTLE BIT. I WON'T GO THROUGH THE WHOLE A TO Z STORY, FOR THOSE OF YOU WHO KNOW ME. I WAS ADOPTED BY PEOPLE-- BY A WOMAN SHE WAS ACTUALLY DEAF HERSELF AND I WAS ADOPTED TO MY PARENTS WHO ARE BOTH DEAF . PRIOR TO THE ADOPTION, OF COURSE, I WAS BORN IN 1957. YOU DO THE MATH-- 62, IF YOU CAN'T. MY MOM-- WHEN I REFER TO MOM AND DADDY, THAT'S THE PEOPLE WHO RAISED ME. THAT'S MY MOM AND MY DADDY. MAMA WAS PREGNANT AT ONE TIME DURING, I GUESS, THE '40s MAYBE, LATE '40s AND SHE WENT ON A CARNIVAL RIDE AND ENDED UP HAVING A MISCARRIAGE BUT SHE DIDN'T KNOW SHE WAS PREGNANT. SO THE DOCTORS DECIDED BECAUSE SHE WAS DEAF THEY NEEDED TO DO A HYSTERECTOMY TO PREVENT FURTHER BIRTHS OF DEAF PEOPLE. MAMA DIDN'T KNOW THAT. PAPERWORK WAS GIVEN TO HER. SHE SIGNED IT. FROM MY UNDERSTANDING. I WASN'T THERE OBVIOUSLY, BUT SHE SIGNED THE PAPERWORK AND EVENTUALLY MY GRANDMOTHER WAS AN RN NURSE AND I'M SORRY. MY MOM SIGNED THE PAPERWORK BUT DIDN'T REALIZE WHAT SHE HAD SIGNED BECAUSE IT WAS ALL IN ENGLISH, MEDICAL ENGLISH. MY GRANDMOTHER, HER MOTHER, WAS AN RN NURSE AND WHEN THEY READ THE PAPERWORK, THEY FOUND OUT SHE COULD NOT HAVE ANY CHILDREN. SHE WAS DEVASTATED AND EVENTUALLY, MY BIOLOGICAL MOTHER WAS PREGNANT WITH ME AND SHE COULDN'T KEEP ME, FEMALE, AND FLORIDA BLAH, BLAH BLAH. MOM AND DADDY KNEW BEING A SMALL DEAF WORLD IN GOLDSBORO, MY GRANDMOTHER FOUND OUT I WAS UP FOR ADOPTED ME. LONG STORY SHORT, THEY ADOPTED ME AND I WAS WITH THEM FROM FIVE DAYS OLD UNTILMENT

DEAFNESS IS HEREDITARY IN MY BIOLOGICAL FAMILY. FOR MY MOM AND DAD, MY DAD BEING OLDER AND HE HAD A LOT OF HEART PROBLEMS AND HEALTH PROBLEMS AND SOME OF THE THINGS I WAS INTERPRETING AS A FIVE-YEAR-OLD IN THE DOCTOR'S OFFICE IN THE HOSPITAL. LOTS OF STORIES WITH THAT. I GOT SICK. I HAD TO INTERPRET FOR ME WITH MY MOM AND DAD IN THE DOCTOR'S OFFICE. DADDY DIED WHEN I WAS 21. HIS EXPERIENCE WAS PROSTATE CANCER, BUT AT THAT TIME, THERE WASN'T A LOT OF DIALOGUE ABOUT IT AND DURING THE '70s, THERE WASN'T A LOT OF CERTIFIED INTERPRETERS, AS FAR AS R.I.D, RICH INTERPRETING FOR THE DEAF HAD JUST BEGUN, CERTIFICATION IN THE '70s. DADDY WAS GIVEN A PIECE OF PAPER MY NAME IS LIZ, AND I'M GOING TO BE BLUNT WITH YOU. HE WAS GIVEN A PIECE OF PAPER THAT SAID TOMORROW MORNING, WE'RE GOING TO CUT YOUR BALLS OFF. IT WAS A PIECE OF PAPER. MENT I REMEMBER THAT. I WAS IN THE AIR FORCE. I CAME UP FROM CHARLESTON, SOUTH CAROLINA, AND THE NEXT THING MY DADDY SHOWED ME WAS, WHY? WHY THEY DO THIS TO ME? MAMA, BLESS HER HEART, SHE COULD TALK A LITTLE BIT, WHICH WAS BAD FOR HER IN SOME WAYS BECAUSE SHE COULD TALK. THE DOCTORS THOUGHT SHE DIDN'T NEED AN INTERPRETER, BUT SHE DIDN'T UNDERSTAND WHAT YOU WERE SAYING AND IF YOU ARE SICK AND YOU'RE IN THE HOSPITAL, YOU'RE A LITTLE BIT, YOU KNOW, DELUSIONAL ANYWAY, SO SHE HAD A LOT OF WRITING COMMUNICATION THAT HAPPENED WITH THE DOCTORS THAT WERE NOT EFFECTIVE. I FOUGHT FOR MANY, MANY YEARS TO GET HER INTERPRETERS FOR THE HOSPITAL. THIS WAS IN THE-- THIS WAS 1980s, 1990s-- SHE DIED IN 1998. IT'S THE SAME THING NOW. YOU STILL HAVE TO FIGHT FOR INTERPRETERS, THE APPROPRIATE INTERPRETER. WHAT DOES THAT MEAN? THERE'S PLENTY OF STORIES ABOUT THAT. ONE OF THE THINGS THAT I REALIZED ALSO THAT THE MEDICAL PROFESSION DOESN'T SEEM TO REALLY GET, MY MOM'S DEATH CERTIFICATE WHEN SHE PASSED AWAY, WE GOT THE DEATH CERTIFICATE. I THINK THE FIRST REASON FOR CAUSE OF DEATH WAS CONGENITAL HEART FAILURE. I DO REMEMBER THE SECOND REASON, AND THE SECOND CAUSE WAS DEAFNESS.

>> THIS IS DAVID. THANK YOU, LIZ. SO I THINK FROM THERE, I WANT TO GO TO BILL ON THE PHONE AND THEN WE'LL COME BACK TO YOU, STEPHANIE. BILL, ARE YOU THERE?
>> I AM.
>> GREAT. I WANT YOU TO GO AHEAD AND SHARE YOUR COMMENTS, PLEASE.

Bill Lamb:

>> OKAY. SO THE EXPERIENCE I HAD WITH MY MOTHER, AND THE LAST YEAR OF HER LIFE, LAST TEN YEARS PROBABLY, SHE BECAME INCREASINGLY DEAFENED AND INCREASINGLY ISOLATED FROM THE PEOPLE AROUND HER. NOW THE LAST FOUR AND A HALF YEARS OF HER LIFE, SHE SPENT IN THE NURSING FACILITY. NOW, IN ADDITION, PRETTY HARD OF HEARING, SHE HAD A STROKE WHICH MEANT SHE LOST THE VISION IN HER RIGHT EYE AND SHE HAD MACULAR DEGENERATION IN HER LEFT EYE. SO SHE HAD A COMBINATION OF BLINDNESS, THE ISOLATION THAT COMES FROM BLINDNESS AND DEAFNESS. SHE HAD PRETTY EXPENSIVE HEARING AIDS, VISUAL HEARING AIDS THAT REALLY DIDN'T WORK WELL WITH HER, AND THE PROBLEMS SHE RAN INTO, A NURSING HOME IN THE DINING ROOM OR IN THE ACTIVITIES ROOM, ANY OF THOSE KINDS OF THINGS, YOU GET SO MUCH AMBIENT NOISE THAT IT-- IT'S VERY CONFUSING. IT'S VERY-- IT'S JARRING TO THE EXTENT THAT MY MOTHER BASICALLY WITHDREW TO HER OWN ROOM WHERE ESSENTIALLY WHAT SHE WOULD DO WOULDBE TO WATCH TELEVISION AND LISTEN TO THE RADIO ALL DAY. SO THE-- IT CREATED A PROBLEM IN HER-- SOCIAL INTERACTIONS WITH OTHER RESIDENTS IN THE FACILITY, BUT IT ALSO CREATED A PROBLEM WITH THE STAFF WHO WERE PROVIDING CARE AND SUPPORT TO HER. SHE WAS NOT ABLE TO REALLY COMMUNICATE HER NEEDS AND THEY WERE NOT ABLE TO DETERMINE A LOT OF THINGS THAT WERE GOING ON WITH MY MOTHER. SHE WAS ABLE TOP TALK ON THE TELEPHONE WITH A SPEAKER ARRANGEMENT OR SOME KIND OF AMPLIFICATION DEVICE, SO THATS WHAT A GOOD THING BECAUSE

WHAT WE ENDED UP DISCOVERING WAS THAT A DEVICE THAT RADIO SHACK MADE THAT WAS A PLUG-IN EARPHONE AND I CARRY ON A CONVERSATION WITH HER AT HER BEDSIDE SPEAKING THROUGH THIS DEVICE AND THAT ACTUALLY HELPED A LOT, SO FOR THE PEOPLE WHO WANT TO OR WILLING TO SPEND THE TIME TO DO THAT WITH MY MOTHER, THAT ACTUALLY TURNED INTO BEING FAIRLY EFFECTIVE. YOU KNOW, OUTSIDE OF THAT, SHE REALLY WAS NOT ABLE TO CARRY ON CONVERSATIONS AND IT WAS, YOU KNOW, A COMBINATION OF THE AUDITORY AND VISUAL DEFICITS. SHE NEVER REALLY HAD SERIOUS DEMENTIA BUT SHE DID HAVE SOME AND YOU ADD ALL THOSE THINGS TOGETHER AND SHE HAD-- SHE REALLY, REALLY STRUGGLED BUT THE HEARING ISSUE WAS SOMETHING THAT HAD A PROFOUND EFFECT ON HER. WE WERE CONNECTED TO A CHURCH AND SHE WOULD GET VISITS FROM CHURCH MEMBERS ON OCCASION AND THEY DIMINISHED. THEIR INABILITY TO COMMUNICATE WITH HER AFFECTED IT AND ESSENTIALLY HAD A CHILLING EFFECT ON THEIR RETURNING. SO SHE HAD PROBABLY TWO OR THREE FRIENDS FROM CHURCH THAT WENT OVER THE FOUR-YEAR PERIOD SHE WAS IN THE NURSING HOME AND I CAN TELL YOU THERE WERE A NUMBER OF OTHER PEOPLE WHO JUST WOULD NOT-- WOULD NOT DO WHAT THEY NEEDED TO DO TO GET OFFER THAT. IT WAS NOT EXACTLY A POSITIVE EXPERIENCE FOR HER, AND-- I DID TRY TO GET SOME ASSISTANCE FROM SOME OF THE STATE AGENCIES, BUT IT WAS LIMITED AND FRANKLY, AT THAT TIME, IT WAS NOT REALLY VERY SATISFACTORY. WE WERE KIND OF LEFT TO OUR OWN DEVICES IN TERMS OF HOW DO WE ADDRESS THESE ISSUES. THAT'S MY STORY AND IT HAS SENSITZED ME TO THE IMPACT THAT LATE DEAFNESS REALLY HAS ON OLDER ADULTS, THAT-- IT'S NOT SOMETHING YOU PREPARE FOR AND OUTSIDE OF GETTING CAUGHT UP IN THE HEARING AID MARKET, WHEN THINGS GO WRONG, IT'S REALLY NOT A WHOLE LOT OF PLACES YOU CAN TURN, OR AT LEAST THAT WAS MY EXPERIENCE.

>> THIS IS **DAVID**. THANK YOU, BILL.
>> SURE.
>> SO EVEN FROM WHAT WE'VE HEARD ALREADY, YOU HEARD A CASE OF A PERSON WHO WAS BORN DEAF OR BECOME-- OR BECAME DEAF BEFORE ACQUIRING A SPOKEN LANGUAGE. WE ALREADY HAD AN EXPERIENCE WITH A LATE-DEAFENED INDIVIDUAL. YOU SEE THAT THERE IS ALREADY A COMMON THREAD EMERGING, THAT'S THE BREAKDOWN OF COMMUNICATION BECAUSE OF THAT DISABILITY.
>> RIGHT.
>> SO I THINK WE'RE GOING TO CONTINUE TO HEAR THAT AS WE GO THROUGH THE PANEL BUT NOW I'LL TURN IT BACK OVER TO STEPHANIE.

Stephanie Johnson:
>> I'M GOING TO CHOOSE TO SPEAK AND LET THE INTERPRETERS SIGN. I'M REALLY RUSTY. AGAIN, MY NAME IS STEPHANIE JOHNSON. I WAS MARRIED TO THE MOST INTELLIGENT MAN I'VE EVER MET FOR 29 YEARS. HIS NAME WAS DANIEL JOHNSON. SO OFFENSE TO YOU GENTLEMEN IN HERE. I'M SURE YOU'RE SMART, TOO.
[LAUGHTER]
ANYWAY, HE WAS DEAF BUT HE DIDN'T LOSE HIS HEARING UNTIL HE WAS 8 1/2 YEARS OLD SO HE HAD A REALLY STRONG ENGLISH BASE, WHICH AS LIZ HAS ALREADY MENTIONED, HE ALSO SPOKE WHEN HE TALKED BUT IT'S A BLESSING AND A CURSE WHEN YOU GO OUT IN PUBLIC AND YOU COMMUNICATE WITH PEOPLE IF YOU HAVE ANY KIND OF SPEECH BECAUSE THE ASSUMPTION IS YOU CAN HEAR BETTER THAN YOU DO. BECAUSE HE WAS 8 1/2, HE ALSO WAS YOUNG ENOUGH TO ACQUIRE AMERICAN SIGN LANGUAGE EQUALLY TO HIS ENGLISH FOUNDATION. SO HE CODE SWITCHED BACK AND FORTH QUITE READILY. HE WAS A MASTER. HE EVEN HAD SOME RUDIMENTARY SPANISH BECAUSE HE WAS BORN IN SOUTH AMERICA AND LIVED THERE UNTIL HE LOST HIS HEARING. HE HAD LOTS OF EXPERIENCES WITH DOCTORS AND MEDICAL FACILITIES BECAUSE WE HAD-- WE HAVE TWO CHILDREN THAT HAVE MEDICAL

ISSUES, SO FROM THE TIME THEY WERE NEWBORNS -- WELL, DIAGNOSED AT SEVEN MONTHS OLD, HE WOULD ACCOMPANY US TO THE DOCTOR'S OFFICE OR TO THE MEDICAL CLUNNICS. NOW, THE DOCTOR'S OFFICES NEVER HAD INTERPRETERS. SOMETIMES DAD WOULD HAVE TO TAKE THE CHILD TO THE DOCTOR AND THEY WOULD WRITE NOTES BACK AND FORTH. BUT USUALLY WE HAD PRETTY GOOD SUCCESS WITH THE TEACHING HOSPITALS, EVEN BEFORE ADA, TULANE UNIVERSITY MEDICAL CENTER WAS PROVIDING AN INTERPRETER. UNC MEDICAL CENTER PROVIDED HIM INTERPRETERS, BUT IT WAS THE LOCAL DOCTOR'S OFFICE OFFICES THAT WE HAD ISSUES WITH. HE WAS DIAGNOSED WITH SLEEP APNEA AND THERE WAS ONE PULMONOLOGIST IN OUR TOWN AND THAT WAS THE ONLY PERSON THAT TREATED THE SLEEP APNEA AND DANIEL, HE HAD A DOCTORATE DEGREE AND HE WENT AND MADE AN APPOINTMENT TO SIT DOWN WITH THAT DOCTOR, THAT PULMONOLOGIST AFTER HOURS AND ADVOCATED FOR INTERPRETING SERVICES FOR HIMSELF AND HIS OTHER PATIENTS AND DHHS PROVIDED AN INTERPRETER FOR THAT SITDOWN MEETING. IT WAS NOT WHAT DANIEL HOPED IT WOULD TURN OUT TO BE. THE DOCTOR AND HE NEGOTIATED BACK AND FORTH AND DANIEL ACCEPTED THAT IF THE DOCTOR WOULD WRITE EVERYTHING THAT HE WOULD SPEAK TO A HEARING PERSON, THEN DANIEL WOULD ACCEPT IT. NOW UNDERSTANDING YOU HAVE 15 MINUTES TO SEE A PATIENT, THERE'S NO WAY YOU CAN WRITE DOWN EVERYTHING. SO THE NEXT APPOINTMENT, HE COMES HOME AND I SAID, SO WHAT WERE YOUR SLEEP NUMBERS? WHAT DID THEY SHOW YOU? HE SAID NOOT NOTHING. HERE'S THE PAPER. THE DOCTOR HAD WRITTEN SOMETHING LIKE, YOU NEED ANTIBIOTIC AND THEN DIARRHEA, AND I'M LIKE, WHAT? WHAT IS THAT TELLING YOU? IS THAT ANYTHING THAT IS WHAT THE DOCTOR WOULD HAVE TOLD ME IF I HAD BEEN SITTING THERE? NO, IT WASN'T. TO ADD SALT TO THE WOUND, DANIEL IN 2009 STARTED TO HAVE SOME PROBLEMS THAT HE WASN'T SURE WHAT WAS CAUSING, SOME PAIN, SOME RECTAL PAIN, AND SO HE WENT TO SEE ONE OF THE ONLY -- WHAT ARE THOSE DOCTORS CALLED THAT DO THE COLONOSCOPYS? GASTROENT ROLLINGS AND HE WENT TO SEE THE ONE IN TOWN AND I DON'T KNOW WHAT THEY DISCUSSED BUT AS SOON AS HE HOLD YOU HAVE RECTAL PAIN, OKAY, LET'S DO A COLONOSCOPY AND FIND OUT WHAT'S GOING ON. HE TO GO SIT WITH A SCHEDULER AND HE TOLD HER, HER NAME WAS JENNIFER, I NEED A SIGN LANGUAGE INTERPRETER. THE COLONOSCOPY IS DONE IN THE OFFICE. WE GET THERE TWO WEEKS LATER, I'M THERE TO TRANSPORT HIM AND TO BE HIS CAREGIVER. NEXT THING I KNOW THE NURSE IS COMING OUT TO THE WAITING ROOM, WE NEED YOU TO SIGN. I SAID SIGN WHAT? HE CAN SIGN HIS OWN NAME. I'M LIKE A LITTLE BIT BLIND NOW. I WASN'T THEN. ANYWAY, I SAID, HE CAN SIGN HIS OWN NAME. WHY DO YOU NEED ME TO SIGN FOR HIM? NO, NO. WE NEED TO YOU DO SIGN LANGUAGE. I SAID, WAIT A MINUTE. HE ASKED FOR AN INTERPRETER. WHERE'S THE INTERPRETER? SHE SAID, WE DON'T EVER HAVE INTERPRETERS HERE. THAT WAS IN JUNE 2009. THE NURSE KEPT COMING OUT AND TELLING ME I HAD TO COME IN AND INTERPRET FOR HIM. THEN THE DOCTOR CAME OUT TO THE WAITING ROOM AND I JUST KEPT SAYING I'M NOT YOUR PATIENT. YOU NEED TO TALK TO YOUR PATIENT. HE DIDN'T ASK ME TO COME INTERPRET AND I'M NOT GOING BACK THERE UNLESS HE WANTS ME TO COME BACK THERE. YOU NEED TO TALK TO YOUR PATIENT ABOUT THIS. THE DOCTOR CAME OUT, ALL RED IN THE FACE, WE'LL JUST RESCHEDULE FOR TOMORROW AT THE HOSPITAL. I SAID, WHAT DO YOU MEAN? HE'S CLEANED OUT? YOU ARE GOING TO MAKE HIM WAIT UNTIL TOMORROW AT THE HOSPITAL? WHY? WHAT MEDICAL REASON WOULD THERE BE FOR HIM TO HAVE TO GO TO THE HOSPITAL? HE SAID, THEY HAVE RESOURCES . I SAID YOU DO TOO, ON YOUR WALL, ALL OF YOUR ANTIQUE CALLS, THE PICTURES, YOU HAVE RESOURCES, TOO. YOU'RE JUST NOT USING THEM. YOU NEED TO TALK TO MY HUSBAND. HAS HE SAID HE WANTS TO GO TO THE HOSPITAL TOMORROW? HE SAID, I HAVEN'T TALKED TO HIM. HE'S YOUR PATIENT AND YOU NEED TO TALK TO HIM. SEE WHAT HE WANTS TO DO. HE SAID I WANT TO WRITE NOTES. YOU WRITE NOTES. YOU WRITE NOTES EVERYTHING YOU WRITE ME. I DON'T WANT TO WAIT UNTIL TOMORROW. FOUR MONTHS LATER WITH A DIAGNOSIS OF HEMORRHOIDS FROM THE COLONOSCOPY THAT I THINK WAS NOT REALLY EFFECTIVE, FOUR

MONTHS LATER HE WENT TO A SURGEON TO HAVE THE HEMORRHOIDS REMOVED ONLY TO HAVE A MUCOSAL MELANOMA MASS AND AND OBVIOUSLY HE'S NOT HERE ANYMORE. SO FOUR MONTHS OF MISDIAGNOSIS BECAUSE A DOCTOR GOT FLUSTERED AND MAYBE DIDN'T DIAGNOSE IT CORRECTLY. THE PLACES THAT HE WENT, WE CHOSE TO GO TO MD ANDERSON MEDICAL CENTER. THEY WERE WONDERFUL. INTERPRETERS EVERY TIME FOR EVERYTHING. I AM JUST GRATEFUL THAT IN 2011, VRI WAS NOT AS PREVALENT AS IT IS NOW IN THE HOSPITALS BECAUSE, CAN YOU IMAGINE, CHEMO AND HAVING A MONITOR PUT IN YOUR FACE? I'M JUST GRATEFUL THAT HE HAD REAL, LIVE INTERPRETERS WHEN HE WAS GOING THROUGH HIS CANCER TREATMENTS. THANK YOU.

>> THIS IS **DAVID**. THAT WAS VERY TOUCHING STORY. THANK YOU FOR SHARING THAT. JULIE.

Julie Bishop:

>> HELLO, I'M JULIE BISHOP. I ACQUIRED A VERY UNUSUAL HEARING LOSS AFTER THE BIRTH OF MY FIRST CHILD IN MY MID-30s. WHEN I WENT BACK TO WORK, I WAS CONSULTANT, ENVIRONMENTAL CONSULTANT THAT PREPARED LARGE ENVIRONMENTAL IMPACT STATEMENTS SO OUR MEETINGS THAT WE WOULD HAVE WERE VERY BIG, PROBABLY THE SIZE OF ONE OF THOSE TABLES AND WE'D HAVE PEOPLE FROM DIFFERENT AGENCIES ALL CONTRIBUTING TO PREPARING THESE ENVIRONMENTAL IMPACT STATEMENTS AND THESE STATEMENTS GO ON FOR DECADES SOMETIMES, SO I'M AT MY FIRST MEETING AFTER HER BIRTH, EVERYTHING WAS FINE BUT THEN SUDDENLY THE HEATING AND AIR CONDITIONING SYSTEM CAME ON OVERHEAD, AND IT WAS LOUD, BUT EVERYONE WAS SPEAKING GIBBERISH. IT WAS A FRIGHTENING EXPERIENCE. IT REALLY WAS. I DIDN'T KNOW WHAT WAS-- WAS I HAVING A STROKE? I DIDN'T KNOW. THEN THE SYSTEM WENT OFF AND I WAS FINE. BUT THESE THINGS KEPT HAPPENING AND FINALLY I WENT TO-- BECAUSE I KNEW HOW IMPORTANT MY COMMUNICATION SKILLS WERE FOR MY JOB AND LIFE, I IMMEDIATELY WENT TO AN AUDIOLOGIST AND DID A TEST AND MY HEAR MY TONE WAS PERFECTLY NORMAL AND WHEN THEY TESTED ME IN NOISE, IT WENT DOWN TO 10% I WAS HEARING. THEY DIDN'T KNOW WHAT THE CAUSE OF THAT COULD BE AT THAT TIME, SO THEY DID MRIs. THEY THOUGHT MAYBE MS OR SOMETHING LIKE THAT, THEY COULDN'T DETERMINE WHAT IT WAS. I WAS KIND OF STUCK IN A PLACE WHERE HEARING AIDS I DIDN'T NEED BECAUSE I COULD HEAR SOUNDS, BUT IT WAS ONLY A NOISE AS IT PROGRESSED, EVEN A SMALL AMOUNT OF NOISE MADE IT LIKE PEOPLE WERE GIBBERISH. SO EVENTUALLY, I WENT ON LIKE THIS FOR 20 YEARS AND FINALLY, I GOT A DIAGNOSIS OF SOMETHING CALLED AUDITORY NEUROPATHY AND WHAT HAPPENS IS THERE'S TWO TYPES OF HAIR CELLS, THE OUTER HAIR CELLS WHICH ALLOW YOU TO HEAR NOISE AND SEND IT TO THE BRAIN AND THEN THERE'S INNER HAIR CELLS THAT SENDS TIMING INFORMATION TO THE BRAIN, SO MY HEARING WAS LIKE HUMMING. SO IT WAS LIKE
[IMITATING HUMMING NOISE]
I DIDN'T REALIZE THAT UNTIL I WAS FINALLY IMPLANTED AND THEN THE COCHLEAR IMPLANT RESTORED THE SINK-- SYNCHRONY THAT I HAD. THEY DO BELIEVE THIS IS A MAJOR COMPONENT TO AGE-RELATED HEARING LOSS AND THAT MAY EXPLAIN AT LEAST PARTIALLY WHY OLDER PEOPLE DON'T LIKE THEIR HEARING AIDS BECAUSE IT JUST MAKES THINGS LOUDER. IT DOESN'T HELP IMPROVE THE QUALITY OF THE SOUND. SO I'M GOING TO ADDRESS A SITUATION. FORTUNATELY, I HAVEN'T BEEN A PATIENT EXCEPT WHEN I HAD MY COCHLEAR IMPLANT INSTALLED, BUT ABOUT EIGHT YEARS AGO, BEFORE I HAD THE IMPLANT MY HUSBAND HAD-- IT WAS CHRISTMAS EVE AND HE HAD GONE TO-- HE HADN'T FELT WELL AND HE WENT TO HIS DOCTOR AND THEY DIAGNOSED HIM AS PROBABLE FLU. WELL, ABOUT MIDNIGHT HE WAS MOANING AND GROANING AND I GOT ON DR. GOOGLE AND I MADE HIM GO THROUGH THESE TESTS AND I SAID, YOU'RE HAVING APEN APPENDICITIS, CHRISTMAS EVE, EMERGENCY ROOM, NOT A LOT OF STAFF. THEY RUSHED HIM. THEY THOUGHT IT HAD RUPTURED. THEY PUT ME IN A ROOM WITH A COUPLE OTHER FAMILIES THAT WERE THERE AND THE ONLY DEVICE THEY

HAD WAS A PHONE HANGING ON THE WALL AND MESSAGES WOULD COME, YOU KNOW, THE PHONE WOULD RING AND PEOPLE WOULD GO UP TO IT AND THEY WOULD CALL OUT SOMEBODY'S NAME OR TALK ON THE PHONE. I REALLY DIDN'T UNDERSTAND WHAT THE PHONE WAS ALL ABOUT. BY THAT TIME, I COULD NOT USE THE PHONE AT ALL. IT DIDN'T MATTER HOW LOUD IT WALLS. I JUST COULDN'T USE IT. SO I HAD TO CALL MY DAUGHTER. SHE CAME AND HELPED ME FIGURE OUT THAT, BUT IT WAS REALLY A BAD EXPERIENCE BEING IN AN EMERGENCY SITUATION AS A SPOUSE SINCE, HE'S HAD A COUPLE OTHER PLANNED SURGERIES, HIP REPLACEMENT, THAT TYPE OF THING AND I'M HAPPY TO SAY THAT I APPRECIATE ALL THE NEW TECHNOLOGY IN THE WAITING ROOMS. FOR EXAMPLE, MY FAVORITE THING IS WHERE THEY HAVE THE SCREEN. THEY GIVE YOU AN OUTPATIENT NUMBER WHEN YOU COME IN SO ACROSS THE SCREEN, LIKE FIVE TIMES THAT SIZE, YOU COULD FOLLOW WHERE THE PATIENT IS. SO PRE-SURGERY, SURGERY, AFTER-SURGERY, WHAT'S IT CALLED? THEY HAVE YOU ON ANESTHESIA HOLD.
[SCATTERED VOICES]
>> YEAH. YOU KNOW WHERE THEY'RE AT AND I HAD ARRANGED FOR THE SURGEON TO COME AND SPEAK TO ME AFTER THE SURGERY AND NO PROBLEM AT ALL. THEY TOOK ME IN A SEPARATE ROOM. I THINK THAT'S ALL I'M GOING TO TALK ABOUT TODAY. AS A GROUP, THE HEARING LOSS ASSOCIATION OF AMERICA, WE HAVE ONE OF OUR FAVORITE TOPICS IS GOING TO DOCTORS' APPOINTMENTS, YOU WALK IN, YOU SIGN IN, YOU SIT DOWN AND WAIT AND IT WOULD COULD BE A ROOM MAYBE HALF THIS SIZE, BUT THERE MAY BE FOUR, FIVE DOORS WHERE MEDICAL ASSISTANTS ARE COMING OUT AND CALLING PEOPLE. WELL, IF YOU MISS THE CALL, WHICH MOST PEOPLE DO, THEY DON'T COME BACK TO TRY TO FIND YOU AND SO YOU NOTICE THAT OTHER PATIENTS CAME IN AFTER YOU ARE GOING IN AND THEN YOU GO UP AND SAY, YOU KNOW, DID YOU FORGET ME? THEY'LL TELL YOU, WELL, WE THOUGHT YOU LEFT. THAT SEEMS TO BE THE NUMBER ONE PROBLEM WITH GOING TO THE DOCTOR'S OFFICE. BUT THEYWAY, I HOPE TO DISCUSS MORE AS TIME GOES ON. I HAVE A UNIQUE EXPERIENCE ABOUT HOW PEOPLE HEAR AND HOW THE BRAIN ACCOMMODATES. IT'S JUST AN AMAZING THING WHEN THE BRAIN DOES WHEN ADULTS START LOSING THEIR HEARING. I WAS BEING SHOWED. I DON'T WANT TO KEEP GOING. I HAVE A TENDENCY TO DO THIS. I WAS SHOCKED WHEN THE DOCTOR WHO PERFORMED MY COCHLEAR IMPLANT SAID TO ME SO YOU ARE SEEING MOSTLY WITH YOUR VISION, AREN'T YOU? I LOOKED AT HIM AND SAID, NO. HE SAID, JULIE, WE DID ALL THE TESTS. YOU ARE HEARING WITH YOUR VISION. YOU KNOW, IF WE COULD JUST HAVE THESISHUAL CUES IN-- THE VISUAL CUES IN THE WAITING ROOMS AND HOSPITAL ROOMS, IT COULD HELP PEOPLE WITH HEARING LOSS AND PEOPLE WHO DON'T HAVE HEARING LOSS. I'LL END IT THERE. BUT THANK YOU.

>> THIS IS DAVID. THANK YOU, JULIE. YOU THINK ABOUT TECHNOLOGY AND PEOPLE. THAT'S PART OF WHAT MAYBE IS REQUIRED. YOU HAVE TO UNDERSTAND THE ENTIRE PERSON. MAYBE THERE'S AN ENVIRONMENTAL THING THAT NEEDS TO CHANGE FOR ACCESS. THAT'S WHAT WE MEAN WHEN WE TALK ABOUT UNIVERSAL DESIGN. WE NEED TO CONSIDER AN APPROACH THAT CAN SERVE ALL DIFFERENT PEOPLE. THANK YOU FOR THAT. SO NEXT WILL BE JAN WITHERS. I'LL TURN IT OVER TO HER.

Jan Withers:
SO THE WAITING ROOM SCENARIO THAT YOU JUST MENTIONED, I'VE HAD THE SAME EXPERIENCE, AND I MAKE IT A POINT TO TRY TO STOP AT THE RECEPTION DESK AND LET THEM KNOW, HI. I'M SITTING RIGHT OVER HERE. WHICH DOOR IS THE NURSE GOING TO CALL ME FROM? SO I CAN WATCH THAT DOOR BUT IN THE BACK OF MY MIND, I THINK THERE'S AN EXCEPTION SOMEWHERE AND I'M TRYING TO WATCH ALL THE DOORS AND I CAN'T RELAX SITTING IN THE WAITING ROOM, AND BY THE TIME I ACTUALLY GET IN TO SEE THE DOCTOR, MY BLOOD PRESSURE IS UP.
[LAUGHTER]

SO THINKING ABOUT MY EXPERIENCE, FOR SEVERAL YEARS I MENTIONED I WORKED AS A PROFESSIONAL THERAPIST AND I WOULD ADVOCATE FOR A LOT OF MY CLIENTS TO GET THE APPROPRIATE ACCOMMODATIONS WHICH COULD BE A SIGN LANGUAGE INTERPRETER, WHATEVER THEY NEEDED FOR THEIR HEALTHCARE APPOINTMENTS AND WAS SUCCESSFUL EVERY TIME. UNTIL MY FATHER HAD A MASSIVE STROKE. NOW REMEMBER, WHEN I WAS BORN, MY PARENTS WERE A LITTLE BIT OLDER. I THINK AT THAT TIME, MY MOTHER WAS STARTING TO EXPERIENCE SOME SHORT-TERM MEMORY PROBLEMS AND ESPECIALLY UNDER STRESS THAT WOULD GET WORSE. SO SHE WOULD LOOK TO ME FOR HELP. SHE WOULD WANT ME TO HELP UNDERSTAND WHAT WAS GOING ON WITH MY FATHER AND HELP TO FIGURE OUT WHAT DECISIONS NEEDED TO BE MADE. SO WHEN WE WOULD HAVE A FAMILY SESSION WITH THE DOCTOR AND THE SOCIAL WORKER SCHEDULED, I KNEW THAT EVEN THOUGH SHE WAS HIS PRIMARY CAREGIVER, SHE REALLY NEEDED ME TO HELP HER IN THE DECISION-MAKING PROCESS AND ALSO IN THE FOLLOW-UP CARE AFTER WE LEFT THE ICU. SO I CALLED THE PATIENT RELATIONS OFFICE. AGAIN, REMEMBER, I HAD A LOT OF SUCCESS HELPING ADVOCATE WITH OTHER PEOPLE SO I WAS A VERY SAVVY CONSUMER, A PATIENT, AS IT WERE, SO I CALLED TO REQUEST AN INTERPRETER. AND THIS WAS WELL AFTER THE ADA HAD PASSED AND I WAS TOLD NO BECAUSE I WASN'T THE PATIENT OR THE SPOUSE. I SAID. OKAY, SURE.

LET ME EXPLAIN THE SITUATION AND GIVE YOU SOME MORE INFORMATION, AND I WAS FAMILIAR WITH THE ADA. OF I KNEW SORT OF WHICH PORTIONS TO CITE TO GET WHAT WE NEEDED. I KNEW WHAT TECHNOLOGY MAY BE AVAILABLE FROM WORKING WITH MY DIFFERENT CLIENTS. SO I CALLED AGAIN THE NEXT DAY. NOW YOU UNDERSTAND, THIS FAMILY MEETING WE HAD WAS NOT UNTIL THE FOLLOWING WEEK. THERE WAS STILL TIME, AND AGAIN, IT WAS NOT SUCCESSFUL. I TRIED TO SORT OF CHANGE HOW I WAS APPROACHING IT AND WAS STILL NOT SUCCESSFUL. SO I WHAT WAS AT THIS POINT GETTING A LITTLE EMOTIONAL MYSELF, AND THE THIRD DAY, I WAS ALREADY TOO STRESSED. ALL THE STRESS WITH THE FAMILY SITUATION. I DIDN'T NEED THAT MAKING THINGS EVEN WORSE TRYING TO DEAL WITH THE PATIENT RELATIONS OFFICE . THIS IS BEFORE I STARTED WORKING WITH DSDHH. I DECIDED I WOULD CALL A FRIEND OF MINE WHO WORKED AT THE RALEIGH REGIONAL CENTER AND I ASKED THEM TO SEE IF THEY WOULD STEP IN AND MAYBE ADVOCATE FOR ME. TWO HOURS AFTER I CALLED HER, I RECEIVED A CALL FROM THE SAME WOMAN THAT TOLD ME NO EVERY TIME THAT I CALLED AND SHE ASKED ME, WHEN DO YOU NEED AN INTERPRETER? SO I CALLED MY FRIEND BACK AND I SAID, WHAT DID YOU SAY TO HER THAT CAUSED HER TO SO RAPIDLY CHANGE HER MIND AND AGREE TO PROVIDE AN INTERPRETER FOR THE FAMILY MEETING? AND IT WAS THE SAME THING THAT I HAD ALREADY SAID. SHE CITED THE SAME RELEVANT ARTICLES IN THE ADA AND I REALIZED PART OF IT WAS I WAS LOOKED DOWN AS AN INDIVIDUAL BUT TO GET A CALL FROM STATE GOVERNMENT, STATE AGENCY GOT HER ATTENTION. AND SINCE THEN, I HAVE HEARD SIMILAR ACCOUNTS FROM QUITE A FEW OTHER PEOPLE. THERE'S AN ASCUMTION THAT YOU AS THE PATIENT OR THE FAMILY MEMBER DON'T REALLY KNOW WHAT YOU'RE TALKING ABOUT. SO THIS WAS A LESSON LEARNED FOR ME. I REALIZE THAT IN ORDER TO REALLY GET PEOPLE IN THE DEAF COMMUNITY AND THE HARD OF HEARING COMMUNITIES WHAT THEY NEEDED , THEY NEEDED TO BE ENCOURAGED TO CALL DSDHH, OUR OFFICES, TO GET ADVOCACY . THE SECOND THING THAT I WANTED TO SHARE IS, YOU KNOW, I LIVE IN AN AREA WHERE LARGE HOSPITAL SYSTEMS, AND I USE THOSE SYSTEMS FOR HEALTHCARE SERVICES. SO ANYTIME I HAVE AN APPOINTMENT-- I TYPICALLY USE MY UNDERSTANDING, MY KNOWLEDGE OF THE SYSTEM TO DETERMINE WHO IN THE HOSPITAL SYSTEM THEY'RE CONTRACTING WITH FOR SIGN LANGUAGE INTERPRETING SERVICES BEFORE I CALL THE PATIENT RELATIONS OFFICE AND I WILL CALL THEM AND VERIFY THAT THE OFFICE, WHATEVER SMALLER OFFICE I SPOKE WITH, DID, IN FACT, CONTACT THE CENTRAL PATIENT RELATIONS OFFICE TO MAKE THE INTERPRETER REQUEST. THEN I CONTACT THE INTERPRETING AGENCY THAT THEY CONTRACT WITH TO MAKE SURE THAT THE HOSPITAL SYSTEM CALLED TO CONTRACT AN INTERPRETER BECAUSE SOMETIMES IT DIDN'T MAKE IT THROUGH

ALL THOSE STEPS TO GET TO THE AGENCY TO SECURE AN INTERPRETER. BUT REMEMBER, FROM THE START TIME, WHEN I GET THE APPOINTMENT. I KNOW WHEN I'M SHOWING UP TO WHEN THE AGENCY RECEIVES THE INTERPRETING REQUEST, THERE'S A DELAY. SO I HAVE TO CHECK SOMETIMES TWO OR THREE TIMES TO MAKE SURE THAT THERE'S ACTUALLY GOING TO BE AN INTERPRETER PROVIDED, AND THAT'S BEEN A FREQUENT EXPERIENCE OF MINE. SO I THINK THAT'S WHAT I'LL SHARE FOR NOW.

>> THIS IS DAVID. THANK YOU, JAN. WOW. WHAT A SYSTEM. EVERYTHING IS SET UP AND IT'S SET UP IN A WAY THAT CAN HELP ANY ISSUE THAT SOMEONE ENCOUNTERS, IT'S MUCH MORE EFFECTIVE. SO I THINK THE NEXT PERSON WE'RE GOING TO HEAR FROM IS ASHLEY BENTON.
>> OKAY. .

Ashley Benton:

YES, THIS IS ASHLEY SPEAKING AND WHEN I WAS ASKED TO SHARE MY BARRIERS, I STARTED THINKING ABOUT ALL THE THINGS I COULD SHARE, SOME NEGATIVE, SOME POSITIVE, SOME WERE EMOTIONAL ROLLERCOASTERS, BUT I MOSTLY LOOKED BACK TO THE TIME THAT I WAS PREGNANT WITH MY SON. THE FIRST TIME I WENT TO AN OB/GYN, AND I WENT TO MY REGULAR OB/GYN AND I FOUND OUT I WAS PREGNANT. I WANTED TO KEEP THE SAME DOCTOR. I WAS EXCITED AND I HAD MY PLANS ABOUT WHICH HOSPITAL I WANTED TO GO TO HAVE MY SON AND I WAS MAKING MY PLANS AND GETTING EVERYTHING READY AND REQUESTED AN INTERPRETER FOR ALL THESE APPOINTMENTS AND I HAD BEEN USING AN INTERPRETER FOR MY APPOINTMENTS. I HAD AN ASSISTANT INTERPRETER AND SO I THOUGHT EVERYTHING WAS GOING TO BE IN PLACE. NOW, OF COURSE, WITH THE PREGNANCY, MORE APPOINTMENTS ARE GOING TO BE REQUIRED AND THERE WAS GOING TO BE A LOT MORE GOING ON BUT EVERYTHING WAS GOING WELL WITH MY PREGNANCY AND THEN I WAS TOLD THAT I WAS HIGH RISK, SO I NEEDED TO BE TRANSFERRED TO A DIFFERENT DOCTOR IN A DIFFERENT HOSPITAL AND A DIFFERENT EVERYTHING, AND I THOUGHT, WAIT!
WHY? WHY AM I BEING TRANSFERRED? I DIDN'T UNDERSTAND WHY. I PICKED THAT DOCTOR TO BEGIN WITH BECAUSE A FRIEND OF MY WENT TO THAT DOCTOR. SHE IS HEARING AND SHE WAS TOLD SHE WAS HIGH RISK BUT SHE DID NOT HAVE TO TRANSFER TO A DIFFERENT DOCTOR BUT NOW I'M HIGH RISK AND I HAVE TO TRANSFER TO A DIFFERENT DOCTOR. I STARTED GETTING SUSPICIOUS AND I STARTED TALKING WITH MY HUSBAND AND WE STARTED TALKING ABOUT IT. WE REALIZED IT MIGHT BE AN ISSUE WITH MY INTERPRETER NEEDS. IT WAS A HUGE DISAPPOINTMENT THAT I HAD TO CHANGE EVERYTHING, MY DOCTOR, I HAD TO CHANGE MY HOSPITAL. I ORIGINALLY WANTED TO HAVE MY BABY IN ONE SPECIFIC HOSPITAL. WE HAD TAKEN A TOUR. I HAD CHECKED OUT THE HOSPITAL BUT NOW I HAVE TO GO TO A TOTALLY DIFFERENT HOSPITAL. I TRIED TO THINK POSITIVE. I WENT AHEAD WITH THE CHANGE. THE OTHER HOSPITAL HAPPENED TO HAVE A CONTRACT WITH A WELL-KNOWN INTERPRETER AGENCY. THEY KNOW ME. THAT'S ONE OF THE POSITIVE THINGS. THEY KNOW ME. THEY WERE FAMILIAR WITH MY NEEDS. THE FACT THAT I'M DEAF BLIND AND I NEED AN INTERPRETER THAT IS QUALIFIED TO INTERPRET SPECIFICALLY FOR PEOPLE WHO ARE DEAF-BLIND AND THEY HAD INTERPRETERS READY SO WHEN MY BABY WAS BORN, THERE WAS TONS OF COVERAGE AND INTERPRETERS ONLINE AND THAT WAS A POSITIVE EVEN THOUGH IT WAS A NEGATIVE SWITCHING OVER THERE. IN THE LONG RUN, IT ENDED UP WORKING OUT. THE HOSPITAL DID RESPECT MY NEEDS WHEN I SAID THAT I NEEDED SOMEBODY THAT WAS QUALIFIED TO INTERPRET FOR ME AND MEET MY DEAF-BLIND NEEDS AND THAT, AGAIN, WAS A POSITIVE. ANOTHER THING THAT I EXPERIENCE IN TERMS OF BEING DEAF-BLIND AND HAVING TO NAVIGATE TO A DOCTOR, I DON'T DRIVE, ALL RIGHT. I HAVE TO RELY ON MY HUSBAND OR MY FAMILY MEMBERS, MY MOTHER, FOR EXAMPLE, DRIVES ME OFTEN. THAT'S WHAT I'VE ALWAYS DONE. THAT'S BEEN MY LIFE. MY MOTHER HAS CARRIED ME TO A LOT OF PLACES. MOTHERS ALWAYS CARRY THEIR CHILDREN TO DOCTOR'SAAPPOINTMENTS AND MY MOTHER

STILL HAS TO DO THAT. MY MOM LIVES AN AHOUR AWAY AND IF I HAVE AN APPOINTMENT, THAT MEANS MY MOM HAS TO DRIVE HERE AND DRIVE ME TO MY APPOINTMENT. SHE'S WILLING TO DO THAT AS LONG AS IT'S SCHEDULED IN ADVANCE, BUT A COUPLE OF TIMES MY MOTHER HAS COME UP AND CARRIED ME TO A DOCTOR'S APPOINTMENT AND NO INTERPRETER HAS BEEN PROVIDED. CAN YOU IMAGINE MY MOM DRIVING ALL THE WAY UP TO RALEIGH AND DRIVING ME TO A DOCTOR'S APPOINTMENT FOR US TO GET THERE AND NOT HAVING AN INTERPRETER, AFTER WE WENT THROUGH THE TROUBLE OF MY MOTHER REARRANGING HER SCHEDULE AND I'M ARRANGING MY SCHEDULE AND TRYING TO GET THERE. MY HUSBAND WORKS FULL TIME SO WE WORKED THINGS OUT. IF HE DOES HAVE TO BRING ME, HE TAKES TIME OFF WORK AND MY HUSBAND IS AN INTERPRETER AND WE GET THE REQUEST HE, CAN YOUR HUSBAND INTERPRET FOR YOU? NO, IT'S IT'S NOT APPROPRIATE FOR HIM TO INTERPRET FOR ME. HE NEEDS TO BE THERE FOR EMOTIONAL SUPPORT AS MY HUSBAND. HE SHOULD NOT CROSS OVER AND PROVIDE ME INTERPRETING SERVICES. I SAW A DOCTOR THAT GAVE ME A DIAGNOSIS THAT I DIDN'T AGREE WITH. I ASKED FOR A SECOND OPINION, AND MY HUSBAND'S FRIEND ALSO IS VERY FAMILIAR WITH IRISH SHOES AND IS AN EYE DOCTOR. THEY ASKED ME, DO YOU HAVE USHER'S SYNDROME AND THEY ARE FAMILIAR WITH CONDITIONS RELATED TO USHER'S SYNDROME AND THEY ENCOURAGED ME TO GO TO HIS APPOINTMENT. I CALLED TO MAKE AN APPOINTMENT WITH THEIR OFFICE AND THE VERY FIRST THING THEY SAID, CAN YOUR HUSBAND INTERPRET FOR US? THE PERSON IS SUPPOSED TO KNOW ABOUT USHER SYNDROME. NO, YOU NEED TO PROVIDE A LICENSED SIGN LANGUAGE INTERPRETER WHO IS QUALIFIED TO WORK WITH PEOPLE WHO ARE DEAF AND BLIND. WE WENT BACK AND FORTH COMMUNICATING BY EMAIL AND FINALLY, I REFERRED THEM TO THE RALEIGH REGIONAL CENTER AND I SAID I NEED ADVOCACY. THE RALEIGH REGIONAL CENTER STAFF CONTACTED THEM AND SAID, OKAY, WE AN INTERPRETER SCHEDULED FOR YOUR APPOINTMENT. I REQUEST QUESTIONED WHETHER OR NOT THEY REALIZED THE INTERPRETER NEEDED TO BE EXPERIENCED WITH DEAF-BLIND INTERPRETING. THEY SAID, WELL THIS PERSON IS LICENSED. JUST THE FACT THAT THE INTERPRETER IS LICENSED DOESN'T SAY A LOT ABOUT THEIR QUALIFICATIONS. THEY DECIDED I WOULD GO AHEAD TO THE APPOINTMENT. THEY WENT TO THE APPOINTMENT AND IT WAS HORRIBLE. SHE DID NOT KNOW HOW TO DO TACTILE SIGN LANGUAGE IN MY HAND. SHE DIDN'T KNOW HOW TO GIVE ME ENVIRONMENTAL INFORMATION THAT I MISSED BECAUSE I CAN'T SEE. I HAD TO RELY ON MY HUSBAND FOR QUITE A BIT OF INFORMATION COMING FROM MY DOCTOR. IT WAS AN AWKWARD SITUATION. I DID NOT UNDERSTAND. I HAD TO LOOK AT MY HUSBAND AND SAY I DO NOT UNDERSTAND. MY HUSBAND HAD TO HELP WITH THE COMMUNICATION. HE TO HELP INTERPRET FOR ME. I REALLY WANTED TO SHOW THIS DOCTOR THAT THEY NEEDED TO USE AN STRPER BUT IF I CAN'T COMMUNICATE AND I CAN'T UNDERSTAND THE INTERPRETER, THEN MY HUSBAND HAS TO INTERPRET FOR ME. THE DOCTOR WAS WONDERFUL IN TERMS OF GIVING ME INFORMATION AND MAKING A REFERRAL AND DOING ALL THOSE KINDS OF THINGS THAT DOCTOR HAVES TO DO BUT IN TERMS OF MEETING MY COMMUNICATION ACCESS, IT WAS A FAIL. I HAVE TO CONTINUE EDUCATING PEOPLE CONSTANTLY ABOUT THAT. IT'S A CONSTANT STRUGGLE AND THERE ARE A LOT OF DOCTORS OUT THERE WHO DON'T UNDERSTAND, WHO ARE NOT WILLING TO DO WHAT THEY NEED TO DO. THEY SAY THEY CAN'T AFFORD TO YOU ABOUT I SEE ALL THESE SUCCESSFUL DOCTORS' PRACTICES AND ALL THEY HAVE TO DO IS HIRE A QUALIFIED SIGN LANGUAGE INTERPRETER. IF YOU HIRE SOMEONE THAT IS A VOLUNTEER, YOU GOT A VOLUNTEER INTERPRETER OR YOU HAVE SOMEBODY WITH A PROVISIONAL LICENSE AS AN INTERPRETER, THAT MAKES IT A DISAPPOINTING EXPERIENCE FOR ME IF I CANNOT COMMUNICATE WELL. ONE TIME I WENT TO THE EMERGENCY ROOM AND I WAS NOT ABLE TO CONTACT MY MOTHER AND MY HUSBAND WAS AT WORK AND SO I GOT AN INTERPRETER WHO IS DEAF TO MEET WITH ME AND YOU HAVE TO USE PARATRANSIT SERVICE IF I DON'T HAVE ANYONE TO DRIVE ME AND WITH A PARATRANSIT SERVICE, YOU GOAT A REDUCED TAXI TRIP. I ARRIVED TO THE DOCTOR'S OFFICE. I WENT IN. THERE WAS NOBODY TO HELP ME, EVEN GUIDE

ME INTO THE DOCTOR'S OFFICE AND TO FILL OUT THE PAPERWORK AND THAT WAS JUST A TIME WHEN I TRIED TO GO BY MYSELF. I TRIED TO TAKE THE TAXI TO GO TO THE DOCTOR BY MYSELF WHEN I DID NOT HAVE ANY OTHER RESOURCES AND IT DIDN'T WORK BECAUSE I HAD NO WAY OF COMMUNICATING AND IF A TAXI DRIVER CAN'T COMMUNICATE WITH ME, IT'S VERY DIFFICULT FOR ME TO ASK THEM TO GUIDE ME INTO THE BUILDING AND THEN ONCE I GET INTO THE BUILDING, I HAVE TO NAVIGATE THE BUILDING AND I HAVE TO HAVE SOMEONE HELP ME FILL OUT THE PAPERWORK THAT I CAN'T SEE AND SO I CAN ASK FOR WHAT WE CALL A SUPPORT SERVICE PROVIDER, WHICH IS A PERSON WHO WILL HELP DO THAT WORK FOR ME. THE SUPPORT SERVICE PROVIDER, AN SSP. THE STATE DOES NOT OFFER THAT AS A SERVICE SO WE HAVE TO LOOK FOR SOMEONE TO WORK ON A VOLUNTEER BASE ILLS. THAT PERSON CAN THEN TAKE ME TO THE DOCTOR'S OFFICE BUT AGAIN, THEY'RE FUNCTIONING AS A VOLUNTEER AND GOING INTO A MEDICAL OFFICE WHERE THINGS ARE VERY SERIOUS, AND THEY'RE WORKING ON A VOLUNTEER BASIS AND I'M ALWAYS FEELING GUILTY THAT THEY'RE GIVING UP THEIR TIME AND I AM WONDERING IF I SHOULD BE PAYING THEM BECAUSE THEY'RE COMING TO HELP ME. I THINK THIS SHOULD BE A PAID SERVICE PROVIDED BY THE STATE BECAUSE I NEED SOMEONE TO HELP ME NAVIGATE THE DOCTOR'S OFFICE. MY MOTHER CAN'T ALWAYS COME UP AND BRING ME. MY HUSBAND CAN'T ALWAYS GET OFF WORK. I CONSIDER MYSELF VERY FORTUNATE COMPARED TO A LOT OF DEAF-BLIND PEOPLE THAT DON'T HAVE THE SUPPORT SYSTEM THAT I DO, BUT MY SUPPORT SYSTEM IS NOT GOING TO BE AROUND FOREVER. SOMETIMES PEOPLE ARE NOT AVAILABLE. MY MOM AND HUSBAND SOMETIMES ARE NOT AVAILABLE. IT'S SOMETHING ELSE THAT WE NEED. SOMETHING ELSE TO CONSIDER.

>> THIS IS DAVID. THANK YOU, ASHLEY. HEARING FROM HER ABOUT THE SUPPORT SYSTEM, EVERYONE HAS A DIFFERENT SUPPORT SYSTEM. WE CAN'T ASSUME THAT WHAT'S WORKING FOR ONE PERSON IS GOING TO WORK FOR ANOTHER. THAT BECOMES ANOTHER CHALLENGE FOR PRACTITIONERS BECAUSE YOU HAVE TO KNOW WHO THESE PEOPLE ARE AND WHEN YOU DON'T, IT CAN CAUSE BREAKDOWNS IN COMMUNICATION AND CAUSE THE QUALITY OF THE SERVICE TO SUFFER AND THE QUALITY OF THAT PERSON'S CARE TO SUFFER. SO I BELIEVE THE LAST PERSON WE'RE GOING TO HEAR FROM, WE HAVE ON VIDEO. UNFORTUNATELY, THE VIDEO IS NOT CAPTIONED. SO IS THERE ANYONE HERE THAT REQUIRES A TRANSCRIPT? IF THERE ARE, WE DO HAVE A TRANSCRIPT. JULIE IS ASKING WILL THE CAPTIONS SHOW UP ON THE CAPTIONING SERVICE AS WELL? YEAH, THEY THINK THEY MIGHT. RON, THERE YOU ARE. I THINK WE'RE READY TO HIT PLAY.

Ann Krohn (Video):

>> HI. MY NAME IS ANN KRONE AND I'M FROM MORGANTON, NORTH CAROLINA. MY SON'S NAME IS NATHAN AND THIS IS SOMETHING THAT HAPPENED IN THE MONTH OF SEPTEMBER TWO YEARS AGO. SO MY SON WAS PLAYING BASEBALL. HE'S THE PITCHER ON THE TEAM, AND THAT MORNING, HE CAME TO ME AND TOLD ME THAT HIS SHOULDER WAS HURTING. I THOUGHT MAYBE HE HAD PULLED A MUSCLE. SO WE WENT TO URGENT CARE AND THE NEXT DAY REALIZED HE HAD A FEVER, AND THEN I TOOK HIM TO THE FAMILY DOCTOR AND HIS WHITE BLOOD CELL COUNT WAS HIGH, SO HE WAS SCHEDULED FOR AN MRI LATER THAT AFTERNOON. SO THEN THE DOCTOR CALLED ME AT ABOUT 6:00 P.M. AND SAID HE NEEDED TO BE ADMITTED TO BRENNER CHILDREN'S HOSPITAL EMERGENCY ROOM SO I PACKED UP CLOTHES AND EVERYTHING. WE GOT TO THE CHILDREN'S HOSPITAL WHICH IS IN WINSTON-SALEM, NORTH CAROLINA, AND WHEN WHEN WE ENTERED THE EMERGENCY ROOM, WE WERE GOING THROUGH THE INTAKE PROCESS AND I REQUESTED AN INTERPRETER, AMERICAN SIGN LANGUAGE INTERPRETER.

THEY SAID, OF COURSE, THAT'S FINE. WE'LL PROVIDE THAT. SO WE WERE WAITING IN THE ROOM. THE NURSE CAME IN AND THEY TOLD ME THEY HAD AN INTERPRETER READY AND I WALKED IN AND IT WAS

VRI, VIDEO REMOTE INTERPRETER ON A SCREEN AND I SAID, WELL, WE'LL DO WITH THAT WHILE IT'S HERE. IT'S NOT IDEAL, BUT THEN ON THE SCREEN, THE INTERPRETER KEPT SAYING I CAN'T HEAR. CAN YOU REPEAT THAT? I DIDN'T UNDERSTAND THAT. CAN YOU REPEAT THAT? NOW UNDERSTAND AT THIS POINT, MY SON WAS VERY ILL. I DIDN'T KNOW WHAT WAS GOING ON. THE SCREEN KEPT FREEZING AND I WAS BECOMING INCREASINGLY FRUSTRATED AND ASKED, AGAIN, FOR A LIVE INTERPRETER AND HE SAID, OH, OKAY, SO THEY-- WELL, LET'S DO THIS. WE'LL MOVE IT TO A DIFFERENT ROOM. WE'LL TEST THE SYSTEM AND TRY TO CHANGE IT. HE WAS STAYING OVERNIGHT. THEY TRIED OVERNIGHT TO FIX IT. THEY DID A LOT OF TESTING AND THEY STILL HADN'T GOT A LIVE INTERPRETER. THE NEXT MORNING, STILL NO LIVE INTERPRETER AND THEN THE SCREEN KEPT PIXELATING AND NOW THE MEDICAL STAFF ARE HAVING TROUBLE HEARING THE INTERPRETER ON THE SCREEN. THEY TOOK IT OUT AND STARTED DOING MORE TESTING. AND THEY'RE DOING TESTS ON MY SON AND I STILL DON'T KNOW WHAT'S GOING ON. THEY COME IN AND TELL ME ALL OF A SUDDEN HE NEEDS TO BE TAKEN INTO EMERGENCY SURGERY AND, AGAIN, I DON'T KNOW WHAT'S HAPPENING. THEY'RE ASKING ME TO SIGN PAPERWORK AND THEY PULL THE VRI IN WITH THIS VIDEO REMOTE INTERPRETER. IT'S PIXELATING AND THEY'RE SIGNING SOMETHING THAT LOOKS LIKE A BALL. THEY'RE RUSHING MY SON OFF TO SURGERY. AND SO I KEPT ASKING ABOUT AN INTERPRETER. THEY SAID, OKAY, HOLD, HOLD ON, HOLD ON. SO FINALLY, THE SURGEON CAME OUT AND THEY'RE, AGAIN, SAYING SOMETHING ABOUT SOFTBALL-SIZED SOMETHING AND I DIDN'T KNOW WHAT WAS GOING ON. AFTER THE SURGERY, HE WAS TAKEN INTO THE ICU WHERE HE STAYED WITH THREE DAYS, AGAIN WITH NO INTERPRETER. I STILL HAD NO IDEA WHAT WAS GOING ON WITH MY SON AND I KEPT TELLING THEM, I NEED AN INTERPRETER AND THEY KEPT POINTING AT THE VRI AND I KEPT TELLING THEM AND WRITING BACK AND FORTH, IT'S NOT WOULDING. IT'S FREEZING. IT'S PIXELATING. I CAN'T UNDERSTAND IT. AFTER THE SURGERY MY SON WAS IN A COMA FOR THREE DAYS AND I STILL DIDN'T KNOW WHAT WAS GOING ON. AFTER THE THIRD DAY, HE FINALLY WOKE UP AND I WAS TELLING HIM, I ASKED AND ASKED FOR AN INTERPRETER. THEY KEEP GIVING ME THIS VRI AND TELLING ME THAT THIS IS SUFFICIENT. SO THEN HE WAS TRANSFERRED TO A REGULAR ROOM AFTER ABOUT THE FIFTH DAY, AND I FINALLY GOT THE NURSE TO REFER ME TO THE PATIENT CARE COORDINATOR, AND THEY FINALLY ACKNOWLEDGED THAT I NEED AN INTERPRETER AND FINALLY GOT AN INTERPRETER. BECAUSE I KEPT TELLING THEM TO LOOK, THE VRI IS NOT WORKING AND I SHOWED THE PATIENT CARE COORDINATOR THAT IT KEPT FREEZING AND IT WASN'T WORKING. AND THAT'S WHAT I TOOK FOR THEM, FINALLY, AFTER FIVE DAYS WHEN I HAD NO CLUE WHAT WAS GOING ON AND I TOLD THEM, I DON'T KNOW WHAT'S WRONG WITH MY SON. THEY DID SURGERY. I DIDN'T EVEN KNOW WHY. SHE APOLOGIZED AND SAID, OKAY, WE'LL GET AN INTERPRETER. SO AFTER SEVERAL DAYS WE FINALLY GOT AN INTERPRETER. AND THEN WENT HOME AND WHEN WE HAD TO GO BACK, THEY STILL WOULDN'T WANT TO PROVIDE INTERPRETERS, SO THE FACT THAT THEY KEPT INSISTING ON VRI WHEN I TOLD THEM IT WAS NOT EFFECTIVE AND I NEEDED A LIVE INTERPRETER MEANT THAT WE WERE LEFT WITHOUT COMMUNICATION FOR DAYS AND IT WASN'T UNTIL MUCH LATER THAT I EVEN GOT THE INFORMATION FROM THE DOCTOR. I'M FINDING OUT THAT MY SON WAS LUCKY TO BE ALIVE AND HE COULD HAVE DIED, AND I HAD NO IDEA WHAT WAS WRONG WITH HIM. IT MADE ME SO ANGRY. MY SON WAS THE ONE THAT HEARD HE COULD HAVE DIED AND I DIDN'T EVEN KNOW THAT. HE HAD SOME SORT OF RARE INFECTION THAT, TO THIS DAY, I DON'T KNOW WHAT IT WAS. THE POINT OF ALL THAT IS I HAVE A RIGHT TO KNOW, TO HAVE EQUAL ACCESS TO COMMUNICATION AND VIDEO REMOTE INTERPRETING IS NOT RELIABLE. IF IT KEEPS DYING AND THE INTERPRETER CAN'T HEAR, THE STAFF CAN'T HEAR IT, IT KEEPS FREEZING. UNDERSTAND IF THERE'S AN EMERGENCY AND WHILE YOU WAIT ON AN INTERPRET YOU HAVE TO USE THAT BUT IF ALL I GET IS SOFTBALL, SOFTBALL, THAT'S NOT EFFECTIVE. IT WAS INCREDIBLY ENFIRATING AND-- ENFIRE EIGHTING AND FRUSTRATING EXPERIENCE AND THEY SAID THIS IS LOWER COST. THEY SAID, NO, ACTUALLY HAVING A LIVE INTERPRETER IS A LOWER COST. I SAID SO PROVIDE ONE. IT'S EFFECTIVE COMMUNICATION ACCESS. SO ALL TOTAL, THERE

WAS A PERIOD OF 68 DAYS WHERE WE HAD TO GO BACK TO THE HOSPITAL SEVERAL TIMES. MY SON HAD TO SPEND THE NIGHT ONCE FOR TEN DAYS. HE WAS THERE FOR TWO DAYS AND THEN THREE DAYS, AND THEN FOR THREE DAYS AGAIN. SO THERE WAS ALTOGETHER SIX SEPARATE SURGERIES THAT HE HAD TO HAVE, AND EVERY TIME WE HAD THE SAME ISSUE, SAME DPRUS STRAITIONS. IT WAS JUST NOT A VERY PLEASANT EXPERIENCE WORKING WITH THEM. THANK YOU. I KNOW THAT'S A LONG STORY, BUT THAT'S THE SUM OF IT.

>> THIS IS DAVID. WOW. I CAN'T IMAGINE NOT KNOWING WHAT'S HAPPENING WITH YOUR CHILDREN. CAN YOU IMAGINE GOING TO CHINA WITH YOUR CHILD AND SICK AND PUT IN A HOSPITAL AND THEY REFUSE TO PROVIDE YOU WITH SOMEONE WHO SPEAKS ENGLISH SO YOU CAN INTERPRET. YOU WOULD BE EQUALLY FRUSTRATED, I'M SURE. FOR SYSTEMS TO WORK AND THERE ARE PLACE FLS THE U.S., AND THIS IS-- I HATE TO SAY NOT ATYPICAL. THERE ARE PLACES WHERE YOU CAN GO TO A HOSPITAL AND THEY HAVE INTERPRETERS ON SITE AND READY TO GO ANYTIME BUT THOSE ARE VERY FEW AND FAR BETWEEN. ANOTHER POINT SHE WAS MAKING ABOUT VIDEO RELAY INTERPRETING. I USED TO WORK WITH A SISTER AGENCY AND TO DSDHH IN MINNESOTA, AND WE WOULD DO SURVEYS OF HEALTHCARE NEEDS ACROSS THE COMMUNITY AND ONE OF THE THINGS THAT JUST OVERWHELMING WE HEARD BACK FROM PEOPLE WAS THEY DID NOT WANT VIDEO REMOTE INTERPRETERS. DEAF PEOPLE WEREN'T COMFORTABLE WITH THAT. PREFERRED A LIVE INTERPRETER AND THERE WAS A LOT OF DISCUSSION ABOUT THE REASONS BEHIND THAT, BUT SEVERAL OF THE THINGS PERTAINING TO IMAGINE BEING SICK AND BEING TOLD YOU HAVE TO LOOK AT A VIDEO SCREEN THAT'S NOT REALLY ADJUSTABLE AND YOU HAVE TO ADJUST YOURSELF TO BE ABLE TO SEE THE SCREEN. THE SCREENS ARE VERY SMALL. OFTEN THEY'RE NOT CLEAR. ALL VARIETY OF ISSUES THAT SHE MENTIONED, THE MICROPHONES, THE WiFi RECEPTION, THE BATTERIES, ALL OF THESE THINGS MAKE THAT INFERIOR TO A LIVE INTERPRETER WHICH IS WHY ACROSS THE U.S. MOST DEAF PEOPLE ARE EXPRESSIONING A PREFERENCE FOR A LIVE INTERPRETER. JUST MAKING SURE WE HAVE TIME BUT IT SEEMS LIKE THIS IS A GOOD TIME FOR SOME QUESTIONS FROM THE AUDIENCE FOR OUR PANELISTS. OR ANY COMMENTS TO ADD. YES, JULIE.

Questions for the Panel:

>> THIS IS **JULIE BISHOP**, AGAIN. I HAD THE OPPORTUNITY LAST WEEKEND I WAS AT A WEDDING SHOWER AND ONE OF MY DAUGHTERS, ONE OF THE BRIDESMAIDS HAPPENS TO BE AN EMERGENCY PHYSICIAN AT DUKE. SHE'S A RESIDENT AND I ASKED HER ABOUT WHAT THEY USE AND ACTUALLY, SHE ACTUALLY SIGNS BECAUSE SHE HAD A FAMILY MEMBER THAT WAS DEAF, SO SHE COULD SIGN AND SO THAT'S WHAT SHE NORMALLY DID BUT SHE ALSO USED THE VRI AS A BACKUP, BUT THE POINT I GOT FROM HER IS THAT THEY WANT TO KNOW-- THEY NEED TO KNOW. THEY HAVE A CHECKLIST OF WHAT THEY HAVE TO ASK AND WHAT THEY HAVE TO INSPECT OR I DON'T KNOW THE CORRECT TERMINOLOGY, BUT THEY NEED TO CHECK ALL THESE THINGS OFF BY GETTING SYMPTOMS FROM THE PATIENT SO THEY-- YOU KNOW, THEY WANT TO DO THE RIGHT THING IN GENERAL. SO FROM THAT PERSPECTIVE, WE CAN'T FORGET THAT IT'S FOR THE PHYSICIANS ' INTERESTS, TOO, TO MAKE A CORRECT DIAGNOSIS AND MAKE SURE THAT ALL THOSE BOXES ARE CHECKED TO GET TO THAT DIAGNOSIS. BUT I GOT THE IMPRESSION THAT AT LEAST AT DUKE THEY ARE USING VR IN THE EMERGENCY ROOM BECAUSE OF THE NEED FOR IMMEDIATE RESPONSES SOME OF THE TIME. IS THERE ANY CHANCE THAT VR IS IMPROVING ENOUGH TO BE A STAND-ALONE OPTION? GLF THIS IS JAN SPEAKING AND IT'S ACTUALLY VRI, ER VIDEO REMOTE INTERPRETING, VRI, AND IT DEPENDS. THERE ARE SOME PLACES WHERE THE HOSPITAL HAS THE TECHNOLOGY SET UP JUST RIGHT AND THE RECEPTION IS RELIABLE, THE SIGNAL IS RELIABLE AND THE PICTURE IS CLEAR. BUT THERE ARE MANY SITUATIONS WHERE VRI IS NOT AN APPROPRIATE ACCOMMODATION AND OFTENTIMES THE HOSPITAL STAFF ARE

NOT THE APPROPRIATE PEOPLE TO TELL THE PATIENT WHETHER OR NOT VRI IS APPROPRIATE. IT'S ACTUALLY UP TO THE PATIENT TO TELL THE STAFF WHETHER IT'S WORKING OR NOT AND THE STAFF SHOULD BE ABLE TO SEE THE SCREEN TO TELL IF IT IS OR NOT. THE CONCERN IS THAT HOSPITALS HAVE BECOME OVERLY RELIANT ON VRI AND THEY HAVE TAKEN THE ONE SIZE FITS ALL APPROACH TO PROVIDING ACCOMMODATIONS AND THAT'S WHERE THERE ARE A NUMBER OF ISSUES THAT COME UP. AND IT'S INTERESTING. I LEARNED FROM AN ARTICLE ON FOREIGN LANGUAGE-- SPOKEN LANGUAGE INTERPRETERS THAT MANY PEOPLE WHO SPEAK A FOREIGN LANGUAGE AND USE HOSPITALS HERE IN THE UNITED STATES HAVE A PREFERENCE FOR AN IN-PERSON INTERPRETER. THEY CAN HEAR BUT THEY STILL HAVE THAT PREFERENCE FOR AN INTERPRETER THAT'S LIVE ON SITE. AND THAT'S INTERESTING BECAUSE AUDIO MEANS OF COMMUNICATION ARE MUCH EASIER THAN VISUAL MEANS OF COMMUNICATION THROUGH TECHNOLOGY. SO YEAH.

>> THIS IS **CRYSTAL BOWE**.
>> SO I CAN SAY IN MY CLINIC THE REASON WE STARTED IMPLEMENTING VRI WAS BECAUSE WE HAD A PATIENT COME IN SICK, NOT SCHEDULED, THAT WE COULDN'T COMMUNICATE WITH. IT'S NEVER OUR FIRST CHOICE BUT WE FOUND THAT BY JUST SCHEDULING IN-PERSON INTERPRETERS, IF THE PATIENT MISSED THEIR APPOINTMENT AND SHE ACCIDENTALLY JUST CAME ON THE WRONG DAY, WE COULDN'T COMMUNICATE WITH HER AND WITHIN THE CLINIC SETTING, VRI ALLOWS TO US ENSURE INSTANT COMMUNICATION WITH A PATIENT BUT IT DOESN'T WORK FOR ALL PATIENTS AND IN ALL SETTINGS. IN HOSPITAL SYSTEMS, WE'RE GOING MORE TO VIDEO USE NOT JUST FOR INTERPRETING BUT ALSO FOR SPECIALIST SERVICES THAT AREN'T OFFERED SO IT'S SOMETHING THAT'S HAPPENING MORE FREQUENTLY ACROSS HOSPITAL SYSTEMS FOR A VARIETY OF SERVICES EVEN OUTSIDE OF INTERPRETING. WHEN YOU TALK ABOUT THE USE AND ACCESSIBILITY, IT DEPENDS ON WHERE YOU ARE. I HAPPEN TO BE CLOSE TO A METROPOLITAN AREA BUT I HAVE PHYSICIAN FRIENDS WHO ARE IN EASTERN NORTH CAROLINA WHO CAN NEITHER ACCESS IN-PERSON INTERPRETERS BECAUSE THEY'RE IN HARTFORD COUNTY AND IT'S TOO FAR, NOR DO THEY HAVE THE INTERNET ACCESS FOR VRI AND SO THEY STRUGGLE COMMUNICATING WITH THOSE PATIENTS REGARDLESS OF WHAT THEY'RE TRYING TO DO AND SO YOU'RE RIGHT. EVEN WHEN FOLKS ARE WELL MEANING, THE LACK OF RESOURCES IN PERSON OR THE INFRASTRUCTURE DOES MAKE IT HARD FOR US TO COMMUNICATE WITH PATIENTS AND PROVIDE GOOD CARE. I DON'T KNOW AN EASY ANSWER TO THAT EITHER WAY.

>> THIS IS **DAVID**. THAT'S WHY, HOPEFULLY, THIS TASK FORCE WILL BE ABLE TO TACKLE AND ADDRESS SOME OF THOSE ISSUES. I APPRECIATE YOUR COMMENTS. JULIE.

>> **JULIE**, AGAIN. ONE OTHER THING THAT SHE MENTIONED WAS THAT THEY GET A LOT OF REFERRALS LIKE IF A PATIENT SHOWS UP AT A MINOR EMERGENCY CENTER THAT INSTEAD OF DEALING WITH THEIR HEARING LOSS OR DEAFNESS, THEY WILL SEND THEM TO THE EMERGENCY ROOM AT DUKE, SO I'M WONDERING IF THAT'S A COMMON EXPERIENCE FOR THE DEAF COMMUNITY IF THEY GET REFERRED BECAUSE THE EXISTING MINOR EMERGENCY CENTER OR DOCTOR'S OFFICE ISN'T CONFIDENT DEALING WITH THEM.

>> THIS IS **JAN**. I CAN ADDRESS THAT. IT MEAN ONE OF TWO THINGS. FIRST OF ALL, IT COULD MEAN THAT THEY, THEMSELVES, DO NOT WANT TO PAY FOR THE INTERPRETER SERVICES SO THEY REFER OUT. SECONDLY, THEY MIGHT HAVE A LEGITIMATE REASON FOR REFERRING, BUT I CAN TELL YOU THAT THERE ARE MANY SITUATIONS THAT WE HEAR ABOUT AT DSDHH THAT THERE ARE EFFORTS TO REFER PATIENTS OUT WHEN THEY COULD HAVE SERVED THE PATIENTS THERE AT THEIR OFFICE OR THEIR FACILITY. THERE IS A LOT OF SUSPICION IN THE DEAF COMMUNITY THAT THERE IS-- THE REASON

BEHIND REFERRING OUT IS THE INTERPRETER ISSUE AND STEPHANIE JOHNSON ALLUDED TO THAT AND ASHLEY ALLUDED TO THAT AS WELL. SO YES, YOU SEE THAT THERE'S NOT A LOT OF CONFIDENCE IN THE HEALTHCARE SYSTEM.

>> THIS IS **DAVID**. SOMETIMES WE CALL THROUGH RELAY INTERPRETER OR USING-- SOME PEOPLE USE A TTY OR VIDEO RELAY SERVICES TO CALL AN OFFICE TO REQUEST AN APPOINTMENT AND IMAGINE IF YOU'RE A NEW PATIENT BEING TOLD, OH, NO, WE'RE NOT ACCEPTING NEW PATIENTS NOW. OH, OKAY. WHY NOT? ARE YOU ACTUALLY NOT ACCEPTING NEW PATIENTS, OR IS IT BECAUSE I CALLED YOU THROUGH A RELAY SYSTEM AND YOU FIGURED OUT THAT I'M DEAF AND YOU JUST WANT TO SHUFFLE ME ON TO THE NEXT PRACTICE? SO WE HAVE ANOTHER COMMENT FROM TOVAH.

>>> **TOVAH WAX** HERE. I'VE HAD SIMILAR EXPERIENCES. ONE IN PARTICULAR WAS WHEN MY HUSBAND WHO WAS HEARING WAS HAVING BREATHING HEART PROBLEMS AND THEY KEPT TRYING TO TALK TO HIM INSTEAD OF TO ME BECAUSE I WAS HEARING IMPAIRED, AND AT THAT TIME, I WAS HEARING IMPAIRED. I WAS ACTUALLY DEAF BUT BECAUSE THEY SAW ME AS NOT CAPABLE I HAD TO REALLY BE VERY ASSERTIVE, EVEN RESORTING TO CUSS WORDS TO GET THEM TO PAY ATTENTION TO ME AND TREAT MY HUSBAND AND, TREAT HIM AND TALK TO ME!
THAT WAS ONE EXPERIENCE AND ANOTHER THING THAT IS IMPORTANT, FOR EXAMPLE, I WOULD CALL TO ASK ABOUT MY HUSBAND OR MY MOTHER LATER, IN MORE RECENT YEAR, CONDITION, AND THEY WOULD NOT TALK TO ME BECAUSE I WAS CALLING THROUGH A RELAY AND THEY WERE SUSPICIOUS THAT IT WASN'T CONFIDENTIAL OR THEY COULDN'T CONFIRM THAT IT WAS ME AND THAT'S ANOTHER THING. A LOT OF DEAF PEOPLE WILL USE THE RELAY, VIDEO RELAY, YEAH, VIDEO RELAY CALLS TO TALK TO WHOEVER THEY WANT TO TALK TO, EITHER THE PATIENT OR SOMEONE WHO KNOWS THE PATIENT TO BE AWARE THAT THAT'S ONE WAY THAT DEAF PEOPLE DO COMMUNICATE AND TO FIND WAYS TO VERIFY THE IDENTITY OF THE PERSON WHO IS CALLING. FOR EXAMPLE, IN MY CASE, THEY WOULD ASK FOR THE BIRTH DATE AND A COUPLE OF IDENTIFYING THINGS TO GET THROUGH. IT WOULD OFTEN TAKE LABORIOUS EFFORT TO GET TO TALK TO WHOEVER OR GET SOMEBODY TO TALK TO ME.

>> YES, ADAM, AND THEN WE HAVE ONE MORE AT THIS MIDDLE TABLE.

>> **(ADAM ZOLOTOR)** I JUST WANTED TO SAY THANK YOU SO MUCH FOR SHARING YOUR STORIES. THEY WERE REALLY POWERFUL AND IT'S HARD TO IMAGINE SOME OF THE CHALLENGES DEAF AND HARD OF HEARING PEOPLE FACE GETTING HEALTHCARE. I HAD A REALLY SPECIFIC QUESTION ABOUT THE VIDEO PRESENTER, AND I DON'T KNOW-- I'M SURE MANY OF YOU CAN ANSWER THIS QUESTION. DOES THE ADA COVER PARENTS OF DEAF CHILDREN? OR IF THE CHILD IS HEARING AND THE CHILD IS THE PATIENT, IS THE PARENT-- THE DEAF PARENT ENTITLED TO AN INTERPRETER? IT SOUNDS LIKE A YES, UNEQUIVOCALLY.
>> THAT WAS MY SUSPICION. I GUESS I FIND IT SHOCKING THAT THE HOSPITAL BEING REFERRED TO CONSIDERED THE COMMUNICATION EFFECTIVE, IF IT TOOK FIVE DAYS FOR THE WOMAN IN THE VIDEO TO UNDERSTAND WHAT WAS HAPPENING WITH THEIR CHILD. SO I FEEL LIKE THERE ARE SOME ELEMENTS OF THE CONVERSATION THAT WE'VE HAD THAT SHOULD BE SUBJECT TO SOLUTIONS UNDER OUR CURRENT LEGAL FRAMEWORK. THERE ARE OTHERS THAT ARE GOING TO TAKE MUCH MORE CREATIVE APPROACHES TO UNIVERSAL DESIGN, THIS SEEMS LIKE A REAL MISCARRIAGE OF THE ADA. AM I UNDERSTANDING THE ADA REASONABLY WELL? GLM

THIS IS **DAVID**. YES, YOU ARE.
[LAUGHTER]

THAT'S G WE'RE ALSO TALKING ABOUT HIPAA REQUIREMENTS. YOU KNOW, SOME PRACTICES VIEW HIPAA AS A REASON NOT TO USE VIDEO RELAY SERVICES OR OTHER ACCOMMODATIONS, SO THAT'S ANOTHER ISSUE.
>> YEAH.
[LAUGHTER]

THIS IS **CRYSTAL**. SO IT IS DEVASTATING THAT THESE THINGS HAPPEN TO PATIENTS AND THE ISSUE COMES DOWN TO WHEN WE'RE DEALING WITH PATIENTS THAT YOU HAVE TO LISTEN TO THEM AND USE SOME COMMON SENSE. IN MY OFFICE, I HAVE A PATIENT WHO IS DEAF AND SHE ALWAYS COMMUNICATES VIA MYCHART, WHICH I ENCOURAGED HER TO DO BECAUSE SHE WANTS TO WRITE DIRECTLY TO ME AND SHE WANTS ME TO WRITE BACK TO HER AND SO SHE WOULD WRITE THINGS AND LIKE, WELL, WE KEEP CALLING HER AND SHE WON'T ANSWER AND I KEEP TELLING THEM, SHE'S NOT GOING TO ANSWER. STOP CALLING HER. SHE WANTS TO COMMUNICATE VIA MYCHART, THIS IS THE MOST EFFECTIVE, EASY WAY TO COMMUNICATE WITH HER. IT'S ABOUT LISTENING TO THE PATIENT, YOU GUYS, AND THEN IMPLEMENTING THAT IN A COMMON SENSE WAY BUT ONCE SIZE DOES NOT FIT ALL. YOU'VE GOT TO BEING WILL AT EACH PERSON AND HAVE A WAY TO DOCUMENT IT SO WE'VE GOT A PLAN FOR EACH PERSON. WHAT WORKS FOR THIS PATIENT WOULD NOT WORK FOR SOMEONE ELSE. I WOULD NEVER RECOMMEND IT. IT'S ABOUT LISTENING TO WHAT YOU ASK FOR AND MAKING SURE THAT EVERYBODY APPLIES IT AND THERE ARE WAYS TECHNOLOGY CAN BE USED TO DO THAT AND THE FOCUS HAS TO BE ON WHAT DOES THE PATIENT WANT AND HOW CAN WE USE THE TECHNOLOGY TO GET WHAT THEY WANT SO THAT THEY HAVE GOOD CARE.

>> THIS IS DAVID. YES, THANK YOU.

>> (**STEPHANIE JOHNSON**) AMANY TODAY, I WANT TO RESPOND TO YOU BECAUSE I ACTUALLY DID CONSIDER SUING THAT DOCTOR, THE GASTRO INTERINTEROLOGIST AND FOR SEVERAL MONTHS AFTER SEVERAL MONTHS OF PRAYING ABOUT IT, GOD TOLD ME NOT TO SUE HIM, BUT I DID WRITE HIM A STERN LETTER AND IN MY LETTER, I OUTLINED EVERYTHING EVEN THE FACT THAT IN THIS OFFICE-- GET THIS-- HE HAD FRAMED PATIENTS BILL OF RIGHTS, AND ONE OF THEM WAS COMMUNICATION ABOUT YOUR ILLNESS OR WHATEVER. I WENT IN AND I TOOK PICTURES AND I ADDED THAT TO MY LETTER. AND AT THE END OF MY LETTER I SAID, I FORGIVE YOU BUT OBVIOUSLY, I CAN'T FORGET. BUT I ALSO SAID I AM FRIENDS WITH LOTS OF DEAF PEOPLE IN THIS COMMUNITY. I GO TO BABY SHOWERS, WEDDING SHOWERS, AND THE NEXT TIME I HEAR FROM ANYBODY THAT YOU DON'T PROVIDE AN INTERPRETER BECAUSE YOU ARE THE ONLY GASTROINTEROLOGIST IN TOWN I WILL MAKE SURE TO SUPPORT MY FRIENDS IN LEGAL ACTION. I FEEL LIKE THERE WAS A LITTLE VICTORY BECAUSE ABOUT A YEAR LATER, ONE OF MY FRIENDS SAID, TEXT ME AND SAID, I'M HERE AT THIS DOCTOR'S OFFICE WITH MY HUSBAND AND THEY HAVE AN INTERPRETER. AND THERE ARE THREE OTHER DEAF PEOPLE HERE, TOO. I'M LIKE, OKAY. WELL--
[LAUGHTER]
A LITTLE BIT, OH, IF THAT'S THE WAY HE'S GOING TO DO IT, HE'S GOING TO SCHEDULE ALL THOSE DEAF PEOPLE IN ONE MORNING, OKAY, BUT I FELT LIKE IT WAS A LITTLE VICTORY . BUT WE CAN'T HAVE JUST LITTLE ONE VICTORIES AT A TIME. WE NEED BIG BATTLES WON.

>> THIS IS DAVID. LET'S GO TO LIZ REAL QUICK.

(LIZ ROBERTSON) I KIND OF WANT TO GO WITH WHAT STEPHANIE WENT WITH AND GIVE YOU A POSITIVER AND EXPERIENCE THAT I DID HAVE. I'LL PROBABLY CRY. BUT THAT'S OKAY. MY MOM PASSED

AWAY IN 1998, OKAY. I TOOK HER TO THE HOSPITAL BECAUSE SHE HAD PNEUMONIA. SHE WENT TO THE EMERGENCY ROOM. THIS WAS AT WESTERN QEAR AND WE LIVE IN FUQUAY AND AT THE TIME WE LIVED IN APEX. MY HUSBAND AT THE TIME WAS DEAF. MY MOM AND I WENT TO THE EMERGENCY ROOM AND THEY DIDN'T GET AN INTERPRETER. I ASKED HER AN INTERPRETER. IT TOOK ALL NIGHT. WE FINALLY GOT INTO HER ROOM AND DEBRA HERNANDEZ, I BELIEVE THAT'S THE WOMAN'S NAME RESPONSIBLE FOR MANAGING THE NURSING OR WHATEVER IT WAS THERE WAS AWESOME. MAMA HAD BEEN TO THE HOSPITAL SEVERAL TIMES. SHE HAD HER PACEMAKER PUT INTO HER CHEST EXPERIENCING WAKE MED, BUT THIS PARTICULAR TIME DEBRA LISTENED AND LET ME SCHEDULE THE INTERPRETERS THAT I NEEDED TO SCHEDULE FOR THE TIMES THAT WE NEEDED TO HAVE THEM THERE BECAUSE I STILL HAD TO WORK. I WAS A FREELANCE INTERPRETER. I WAS ON MY WAY ALL ACROSS THE STATE WORKING, INTERPRETING. SHE GAVE ME THE PERMISSION TO SCHEDULE THE INTERPRETERS FOR WHEN THE DOCTORS WOULD BE THERE IN THE MORNING AND WHEN THEY WOULD BE THERE IN THE EVENING. I WANTED TO BE THERE BECAUSE I'M HER DAUGHTER AND I NEEDED TO HEAR WHAT WAS BEING SAID BECAUSE I WAS GOING-- I HAVE ALWAYS BEEN HER CARETAKER. TUESDAY-- NO, SUNDAY OR MONDAY, I DON'T REMEMBER. THEY SAID SHE WOULD BE GOING HOME TOMORROW. ON MY WAY TO GREENVILLE TO INTERPRET, I GOT A CALL THAT SAID, YOUR MOM'S GT&O GONE FULL CODE. I RUSHED BACK TO WAKE MED. GOT THERE. THE INTERPRETER THAT WAS THERE HAPPENED TO BE A COLLEAGUE BUT A GOOD FRIEND OF MINE AS WELL, WE WENT THROUGH THE REST OF THE FOUR DAYS I THINK WITH MAMA BEING IN INTENSIVE CARE AND NEVER WAKING UP AGAIN BUT I HAD A HUSBAND THAT WAS DEAF AND I HAD TWO LITTLE GIRLS AND I NEEDED TO BE A MOM AND I NEEDED TO BE A DAUGHTER AND I NEEDED TO BE A WIFE, AND THEY PROVIDE ME THE OPPORTUNITY TO HAVE INTERPRETERS THERE THE WHOLE TIME THAT I NEEDED. I DIDN'T GO 24/7. I JUST USED MY BRAIN TO SAY THIS IS WHEN I NEED IT. WHEN THE DOCTORS ARE IN HERE TALKING, I DON'T WANT TO TELL MY HUSBAND WHAT THEY SAID. I DON'T WANT TO HAVE TO INTERPRET FOR HIM AND TELL MY GIRLS, MAMA IS NOT GOING TO TAKE IT OR WE'RE GOING TO HAVE TO PULL THE PLUG IN A LITTLE WHILE. I WAS GIVEN THE OPPORTUNITY TO DO THAT. FOR THAT, I AM THANKFUL IT'S NOT HORRIBLE. MY EXPERIENCE HAS NOT BEEN THE BEST WITH THE MEDICAL PROFESSION. I WANTED TO PUT THAT IN THERE. SOMEBODY LISTENED AND I APPRECIATED HER FOREVER, UNTIL THIS DAY. YOU GUYS ARE OUT THERE AND YOU ARE MAKING A DIFFERENCE IN OUR LIVES, TOO.

>> **(UNIDENTIFIED SPEAKER)** I WANTED SUGGEST AN ISSUE THAT'S BEEN A PROBLEM FOR ME. I THINK IT'S A PROBLEM FOR MANY DEAF PEOPLE AND CERTAINLY A PROBLEM FOR ALL DEAF PEOPLE. IT'S A PROBLEM FOR MANY, MANY HARD OF HEARING PEOPLE. I CAN HEAR ON THE PHONE SOMEWHAT, BUT I CAN'T CARRY ON A DECENT CONVERSATION WITH PEOPLE I DON'T KNOW, VOICES I DON'T KNOW ABOUT TOPICS THAT ARE COMPLICATED. SO WHEN I HAVE A MEDICAL ISSUE OR A TECHNICAL ISSUE WITH DELL OR COMPUTER COMPANY OR ANYTHING AT ALL, ANY MAJOR BUSINESS I NEED TO CONTACT, I GO TO THE WEB PAGE, AND I LOOK FOR CONTACTS AND YOU KNOW WHAT IT SAYS, IT SAYS HERE'S MY PHONE NUMBER. THAT'S NOT GOING TO WORK. I CAN'T HEAR VERY WELL. HERE'S A TTY NUMBER. THAT'S NOT GOING TO WORK. I DON'T HAVE A TTY. I'M GUESSING MANY DEAF PEOPLE THAT HAVE TTYs THAT WORK ANYMORE EITHER BECAUSE THEY'RE GONE. ALMOST EVERYBODY THAT'S DEAF ORHARD OF HEARING HAS A SMARTPHONE AND MUCH BETTER THAN HAVING A CONTACT INFORMATION THAT SAYS HERE'S YOUR PHONE NUMBER. HERE'S THE TTY NUMBER. IT OUGHT TO ALSO SAY HERE'S A CHAT LINE AND HERE'S AN SMS LINE, CALL THE NUMBER AND WE CAN TALK TO YOU AND WE CAN TYPE BACK AND FORTH TO YOU OVER THE PHONE ON YOUR MESSAGE SYSTEM ON YOUR SMARTPHONE. YOU NEED TO LEAVE THE TTY NUMBER IN CASE SOMEBODY STILL HAS A TTY THAT WORKS, BUT WE NEED TO HAVE A CHAT LINE AND WE NEED TO HAVE A AN SMS MESSAGING PHONE NUMBER FOR CALLING IN TO DO TEXTS BACK AND FORTH. AND THAT SHOULD BE TRUE NOT JUST FOR THE MEDICAL ENVIRONMENT BUT IT SHOULD BE TRUE FOR ANY COMPANY AT ALL THAT DEALS WITH

THE PUBLIC. I JUST WENT THE DUKE HOSPITAL CONTACT WEB PAGE, DOESN'T HAVE ANY OF THAT STUFF. THEY DO HAVE THE MY CHART STUFF. SO IF YOU'RE ALREADY A PATIENT AND YOU HAVE A MY CHART, THAT WORKS FINE. BUT THE CONTACT PAGE SHOULD STILL HAVE A CHAT WEB ADDRESS AND A MESSAGE PHONE NUMBER SO THAT YOU CAN DO TEXT WITHOUT A TTY, AND THAT WOULD BE A MAJOR IMPROVEMENT FOR EVERY DEAF PERSON IN THE WORLD AND MANY, MANY HARD OF HEARING PEOPLE IN THE WORLD. IT SHOULD BE UNIVERSAL. WE COULD ALMOST GO TO EACH WEBSITE AND GET LAW PASSED THAT WE NEED THOSE THINGS ON THE WEBSITE. IF YOU HAVE CONTACT INFORMATION, YOU CAN LITERALLY GO TO THE WEBSITE AND FILE A COMPLAINT IMMEDIATELY AND HAVE IT FIXED. IT'S NOT A HARD PROBLEM. THEY DON'T NEED HARDWARE. ALL THEY NEED IS A COUPLE OF LINES OF CODE IN THEIR WEB PAGE.

>> THIS IS **DAVID**. OKAY. THANK YOU, STEVE. SO THERE ARE CHALLENGES THAT WE FACE EVEN WITH THE CHAT AND THINGS LIKE THAT. AGAIN, IT DEPENDS ON EACH PERSON AND THEIR EXPERIENCE. I KNOW SOME PEOPLE WHO HAD EXPERIENCES WITH THEIR CHAT LINES. I'VE HAD THEM. THEY THOUGHT I WAS TRYING TO SCAM THEM USING A CHAT LINE. THERE CAN BE ISSUES WITH THAT, BUT AS STEVE WAS POINTING OUT, AND THAT WOULD BE AN OPTION FOR ACCESSIBILITY. THAT'S ONE OTHER WAY TO MAKE THE SYSTEM MORE ACCESSIBLE FOR PEOPLE WHO ARE DEAF AND HARD OF HEARING. I WANT TO TAKE THIS OPPORTUNITY TO THANK OUR PANELISTS FOR YOUR STORIES AND YOUR COMMENTS. VERY POWERFUL AND EMOTIONAL. I REALLY APPRECIATE YOU SHARING THAT WITH US. I'M SORRY FOR THE LOSSES THAT YOU'VE EXPERIENCED. BUT THIS JUST GIVES YOU GUYS AN IDEA OF WHAT WE AS A COMMUNITY FACE AND WE CAN THINK ABOUT WHERE WE'RE GOING TO GO IN THE PROCESS FROM HERE. SO WE CAN TAKE A BREAK AND JAN IS SAYING I DON'T BELIEVE WE HAVE TIME FOR A BREAK.
[LAUGHTER]
DAVID IS SAYING, ALL RIGHT, IF I CAN HAVE THE OTHER PANELISTS RETURN TO YOUR SEATS, WE'LL MOVE FORWARD.
[APPLAUSE]

>> THIS IS **JAN** SPEAKING. I'D LIKE TO ECHO DAVID'S COMMENTS. I DO APPRECIATE ALL OF THE PANELISTS FOR COMING UP HERE AND SHARING THEIR EXPERIENCES WITH US. I DO HAVE TO TELL YOU THAT WE IN THE DEAF, HARD OF HEARING AND DEAF-BLIND COMMUNITY TALK WITH EACH OTHER ALL THE TIME ABOUT OUR EXPERIENCES AND FRUSTRATIONS THAT WE HAVE WHICH ARE SIMILAR TO THIS. THESE ARE ONGOING ISSUES THAT HAVE NOT IMPROVED. MAYBE IN SOME INDIVIDUAL SITUATIONS WE'VE SEEN SOME IMPROVEMENT, BUT LIKE STEPHANIE SAID THIS IS A SYSTEMWIDE ISSUE, WHICH IS WHY WE'RE HERE TODAY. I THINK IT'S BEST FOR ME TO LET YOU KNOW WHAT DSDHH HAS ALREADY DONE. NOW, DSDHH IS NOT THE ONLY DIVISION HERE IN NORTH CAROLINA THAT PROVIDES SERVICES TO DEAF AND HARD OF HEARING PEOPLE. THERE ARE OTHER AGENCIES THAT HAVE ALSO PROVIDED ADVOCACY ON INDIVIDUAL CASES. FOR EXAMPLE, VOCATIONAL REHABILITATION INDEPENDENT LIVING, THE CENTERS FOR INDEPENDENT LIVING, VOCATIONAL REHABILITATION COUNSELORS FOR THE DEAF, MENTAL HEALTH THERAPISTS THAT WORK WITH DEAF AND HARD OF HEARING PEOPLE. WE HAVE ALL PROVIDED SERVICES TO PEOPLE THAT ARE DEAF AND HARD OF HEARING BUT TODAY, I WANT YOU TO THINK ABOUT HOW WE CAN MAKE A DIFFERENCE FROM A SYSTEMS POINT OF VIEW.

Jan Withers: Overview of DSDHH's Actions (Implemented and Proposed)

BUT NOW LET ME SHARE WITH YOU WHAT DSDHH HAS BEEN DOING TO TRY TO ADDRESS THESE ISSUES,

BUT FIRST OF ALL, YOU NEED TO UNDERSTAND WHAT WE DO AS A DIVISION. OUR MISSION IS SIMPLE. IT IS TO WORK WITH OUR PARTNERS, TO PROVIDE DEAF, HARD OF HEARING, AND DEAF-BLIND PEOPLE AND THEIR FAMILIES INFORMATION, SKILLS AND TOOLS THAT THEY NEED TO ACHIEVE EFFECTIVE COMMUNICATION AND ACCESS TO RESOURCES IN THEIR COMMUNITY WHICH WILL THEN RESULT IN INDEPENDENCE AND FULL PARTICIPATION IN SOCIETY. NOW THAT'S COMMON SENSE. THIS IS WHAT MOST PEOPLE HAVE EVERY DAY. BUT HOW DO WE ACHIEVE THAT FOR DEAF, HARD OF HEARING, AND DEAF-BLIND PEOPLE IS MUCH MORE COMPLICATED. BASICALLY, ON A DAILY BASIS, WE SEE TWO BARRIERS. THE FIRST ONE IS THAT MANY INDIVIDUALS WITH HEARING LOSS LACK THE KNOWLEDGE AND RESOURCES TO EFFECTIVELY ADVOCATE FOR THEMSELVES, WHICH WOULD ALLOW THEM TO BE ABLE TO LIVE WELL WITH THEIR HEARING LOSS AND TO BENEFIT FROM ASSISTIVE TECHNOLOGY. THE STORIES THAT YOU'VE HEARD FROM OUR PANELISTS TODAY ARE FROM PEOPLE THAT ARE ALREADY SAVVY, ASSERTIVE FOLKS THAT HAVE SELF-ADVOCACY SKILLS. AIM
IMAGINE ALL OF THE PEOPLE WHO DON'T HAVE THOSE SKILLS. THE SECOND BARRIER THAT WE SEE OFF THE ISN'T THAT HEALTHCARE AND OTHER SERVICE PROVIDERS, SUCH AS SOCIAL SERVICE AND PUBLIC HEALTH PERSONNEL, LAW ENFORCEMENT, JUDICIARY, BUSINESSES, AND SO FORTH, THEY LACK THE KNOWLEDGE AND THE RESOURCES TO ENSURE THAT DEAF, HARD OF HEARING, AND DEAF-BLIND PEOPLE HAVE THE SAME ACCESS TO THEIR SERVICES AND THEIR RESOURCES AS THE GENERAL PUBLIC-- POPULATION. DSDHH IS RESPONSIBLE FOR ADMINISTERING THE CONTRACT THAT PROVIDES RELAY NORTH CAROLINA SERVICES THROUGH THE TELEPHONE HERE IN NORTH CAROLINA. WE ALSO PROVIDE DIRECT CLIENT SERVICES INCLUDING ADVOCACY, CONSUMER SKILL DEVELOPMENT, INFORMATION AND REFERRAL, AND WE ALSO HAVE AN EQUIPMENT DISTRIBUTION SERVICE THAT PROVIDES FREE EQUIPMENT WITH THOSE WITH LOW INCOME. WE ALSO PROVIDE SERVICES TO AGENCIES, ORGANIZATIONS AND BUSINESSES . AND WE DO QUITE A LOT OF OUTREACH AND EDUCATION. WE ACCEPT ANYONE WHO IS DEAF, HARD OF HEARING, OR DEAF-BLIND, THEIR FAMILY MEMBERS AND ANY AGENCY THAT REQUESTS ASSISTANCE FROM US. NO APPLICATION APPLICATION IS NEEDED FOR OUR SERVICES EXCEPT WHEN SOMEONE WANTS TO APPLY FOR OUR EQUIPMENT DISTRIBUTION SERVICE THROUGH OUR TELECOMMUNICATIONS EQUIPMENT DISTRIBUTION SERVICE. OTHER THAN THAT, WE-- WELL, THAT'S THE ONLY TIME YOU HAVE TO APPLY. WE NEVER CHARGE A FEE FOR OUR SERVICE. YOU DO HAVE A LARGER HANDOUT IN YOUR PACKET WITH THIS CHART. THAT'S A STAND-ALONE DOCUMENT, WHICH SHOULD BE A LITTLE BIT EASIER FOR YOU TO READ. WE DO WORK WITH OTHER SYSTEMS OTHER THAN JUST HEALTHCARE SYSTEMS. WE ALSO WORK WITH SOCIAL SERVICES, THE COURTHOUSES, LAW ENFORCEMENT OFFICERS, EMERGENCY PERSONNEL, ET CETERA. THIS CHART ONLY SHOWS SOME OF WHAT WE HAVE BEEN DOING TO ADDRESS ISSUES IN THE HEALTHCARE SYSTEM ONLY. ALL RIGHT. WHAT YOU SEE ON THE BOTTOM HALF OF THE CHART ARE THINGS THAT WE HAVE PROPOSED THAT WE PLAN TO DO. SO I'M JUST GOING TO DO A QUICK RUN-THROUGH OF THESE. FIRST OF ALL, WE HAVE PARTNERED WITH THE UNC SHEP CENTER AND GALLAUDET UNIVERSITY TO DO RESEARCH ON COMMUNICATION ACCESS AND HEALTHCARE FOR PERSONS WITH A HEARING LOSS WHO USE AMERICAN SIGN LANGUAGE, AND YOU'LL HEAR ABOUT THAT A LITTLE BIT MORE LATER AT A FUTURE MEETING. ONE THING THAT YOU WILL HEAR OVER AND OVER AND OVER AGAIN IS THAT PEOPLE DO NOT LIKE VIDEO REMOTE INTERPRETING SERVICES. THAT'S THE INTERPRETER ON THE SCREEN. WE HAVE ASSISTED THE DIVISION OF HEALTH BENEFITS WITH THEIR MEDICAID CONTRACT, ADDRESSING ACCESSIBILITY ISSUES FOR PEOPLE WITH A HEARING LOSS THROUGH THEIR CONTRACTS, THROUGH THEIR CONTRACT THROUGH MEDICAID SERVICES, WE WANT TO MAKE SURE THAT ALL OF OUR CONTRACTORS HAVE THE INFORMATION THAT THEY NEED SO THEY KNOW HOW TO ADDRESS THE ISSUES OF PEOPLE WHO ARE DEAF AND HARD OF HEARING WHEN THEY'RE PROVIDING SERVICES TO THEM, AND YOU'LL SEE UP HERE ON THE SCREEN, THERE ARE TWO COLUMNS. THE LEFT COLUMN IS SPECIFICALLY RELATED TO COMMUNICATION ACCESS AND HEALTHCARE SETTINGS. THE RIGHT-HAND

COLUMN IS SPECIFICALLY RELATED TO SERVING OLDER ADULTS IN IN CONTINUING CARE RETIREMENT CENTERS. NOW AND SOME OF THESE APPLY TO BOTH. YOU'LL SEE THOSE TWO AT THE TOP THAT RUN ACROSS BOTH COLUMNS. THEY APPLY TO BOTH EFFORTS. ON THE LEFT-HAND SIDE WE ARE WORKING WITH DHB TO EXPLORE HOW BEST TO PROVIDE ACCESS TO MEDICAID RECIPIENTS WITH HEARING LOSS AND WE ARE ALSO DOING THAT FOR MEDICAID PROVIDERS. WE PROVIDE TRAININGS, INCLUDING THE DIFFERENT, DIFFERENT WORLD ACTIVITY. THEY ARE PROVIDED TO A VARIETY OF HEALTHCARE PROVIDERS AT DIFFERENT VENUES INCLUDING HOSPITALS AND THROUGH THE AHEC CENTERS. NOW, IN TERMS OF SERVING OLDER ADULTS, WE HAVE ALREADY PRODUCED A TWO-HOUR TRAINING CURRICULUM THAT WE HAVE DEVELOPED FOR LONG-TERM CARE FACILITY WORKERS. THAT HAS BEEN ENFORCED BY THE ASSOCIATION FOR HOME AND HOSPICE CARE OF NORTH CAROLINA. AND BY THE DIVISION OF AGING AND ADULT SERVICES. THEIR UMBUDSMAN AND IT ALSO HAS CONTINUING EDUCATION UNITS THAT HAVE BEEN APPROVED. WE HAVE ALSO PARTNERED WITH DAS UMBUDSMAN, DIVISION OF AGING SERVICES TO SHARE WITH THE UMBUDSMAN REGIONAL STAFF TO THE RESOURCES THAT DSDHH HAS AVAILABLE TO ASSIST THEM WITH IMPROVING HEARING HEALTH AMONG LONG-TERM CARE FACILITY RESIDENTS. ONE OF THE THINGS THAT WE PROPOSE THAT WE DO AND I WOULD LIKE FOR TO YOU KEEP THIS DHART IN YOUR BINDER BECAUSE WE MIGHT NEED TO REFER TO IT LATER ON, WE DO HAVE A VARIETY OF TRAINING AND MENTORING PLANS TO INCREASE THE POOL OF INTERPRETERS QUALIFIED TO WORK IN HEALTHCARE SETTINGS. WE WANT TO DEVELOP SEVERAL TRAINING VIDEOS AND WEBINARS THAT WILL TARGET VARIOUS HEALTHCARE PERSONNEL AND EDUCATE CONSUMERS ON SELF-ADVOCACY. ON THE SIDE OF SERVING OLDER ADULTS, WE WANT TO PARTNER WITH THE NORTH CAROLINA ASSOCIATION OF LONG-TERM CARE FACILITIES TO SHARE WITH THEIR MEMBERS THE RESOURCES THAT DSDHH HAS AVAILABLE TO ASSIST WITH IMPROVING HEARING AMONG THOSE LONG-TERM CARE FACILITY RESIDENTS. WE ALSO WANT TO PARTNER WITH CAP TEL NORTH CAROLINA TO OFFER CAPTEL AND OTHER TOOLS AND CAPTEL IS A BRAND NAME. LET ME EXPLAIN THAT. CAPTEL IS A BRAND NAME FOR CAPTION TELEPHONES. WE-- AS I MENTIONED A FEW MINUTES AGO, WE CONTRACT, WE'RE THE CONTRACT ADMINISTRATORS WITH THE COMPANY THAT PROVIDES RELAY NORTH CAROLINA, THAT CONTRACT ALSO INCLUDES THE PROVISION OF CAPTEL SERVICES AND WE DO HAVE STAFF AND SUBCONTRACTORS THAT GO OUT TO RETIREMENT COMMUNITIES TO EXPLAIN THE CAPTION TELEPHONE AND HOW IT WORKS AND THAT'S OUR WAY OF GETTING INTO THOSE COMMUNITIES AND GETTING THE WORD OUT ABOUT OTHER AVAILABLE RESOURCES INCLUDING THE AVAILABILITY OF CAPTION TELEPHONE SERVICES. AND THEY ALWAYS BRING WITH THEM OTHER INFORMATION AND MATERIALS AND BROCHURES ABOUT DSDHH, JUST IN CASE THERE ARE OTHER THINGS THAT WE CAN DO FOR THOSE RESIDENTS AS WELL. WE ALSO WANT TO PARTNER WITH THE NORTH CAROLINA HEALTHCARE ASSOCIATION TO USE THEIR STATEWIDE TRAINING SYSTEM TO TRAIN HOSPITAL ADMINISTRATORS AND OTHER HEALTHCARE PROVIDERS ON EFFECTIVE COMMUNICATION. WE WANT TO INCREASE THE PARTICIPATION AND KNOWLEDGE ABOUT COMMUNICATION BARRIER IN HEALTHCARE SO PEOPLE WILL BE MORE RECEPTIVE TO PARTICIPATING AND TRAINING REGARDING ADDRESSING THOSE BARRIERS AND WE WANT TO BE ABLE TO ENHANCE THEIR KNOWLEDGE OF RESOURCES TO BE ABLE TO COMBAT THOSE BARRIERS, AND ULTIMATELY WE WANT PEOPLE TO BE ENGAGED IN CONVERSATIONS ABOUT HOW TO ADDRESS THESE BARRIERS BY HIRING AN AMERICAN SIGN LANGUAGE INTERPRETER OR PROVIDING WHATEVER COMBINATION IS NECESSARY TO MEET THE COMMUNICATION NEEDS OF THAT PATIENT. AND LASTLY , GIVEN RECENT RESEARCH THAT WE'VE SEEN RECENTLY ON LINKS BETWEEN HEARING LOSS AND A VARIETY OF A VARIETY OF OTHER HEALTH CONCERNS, DIABETES, THE RISK OF FALLS, AND DEMENTIA, DSDHH IS GOING TO WORK TO INCLUDE HEARING LOSS AS AN AREA OF CONCERN IN HEALTHY CAROLINIANS 2030. ALL OF THOSE THINGS ARE GREAT, BUT WE HAVE ONLY SEVEN REGIONAL CENTERS SERVING ALL 100 COUNTIES OF THE STATE WITH A CENTRAL ADMINISTRATIVE OFFICE WITH A TOTAL STAFF OF 77

PEOPLE. 51 OF THOSE STAFF AT OUR 7 REGIONAL CENTERS. EACH REGIONAL CENTER SPECIALIST TRAVELS BETWEEN 400 AND 900 MILES PER MONTH. NOW THE NUMBER OF OUR POSITIONS, 77, HAS BEEN PRETTY STABLE OVER THE LAST COUPLE OF YEARS, EVER SINCE THE ECONOMIC CRISIS OF 2009. I THINK SINCE THAT TIME, WE HAVE ADDED ONLY THREE, POSSIBLY FOUR POSITIONS. BUT LET'S TALK ABOUT THE NUMBER OF CLIENTS THAT WE'VE SERVED. THE NUMBER OF CLIENTS WE'VE SERVED HAS BEEN PRETTY CONSISTENT. WE'VE GONE BETWEEN 5,000 AND 6,000. THE NUMBER OF AGENCIES AND THEIR STAFF THAT WE HAVE SERVED HAS BEEN FAIRLY CONSISTENT AS WELL. ONE THING THAT WE HAVE NOTICED IS THAT WE ARE VERY LABOR INTENSIVE. SO VACANCIES DO AFFECT US GREATLY, AND THE OTHER THING THAT WE HAVE NOTICED IS THAT THE DEMAND FOR OUR DIFFERENT, DIFFERENT WORLD TRAINING HAS GONE UP EXPONENTIALLY AND SO THAT TAKES AWAY FROM OUR ABILITY TO PROVIDE DIRECT SERVICES TO CLIENTS AND TO PROVIDE SUPPORT TO SOME AGENCIES AND ORGANIZATIONS THAT WE USE TO PROVIDE SUPPORT TO, SO IT'S A TRADE-OFF. AND YOU MAY REMEMBER FROM GLENN'S PRESENTATION THAT THE HEARING LOSS POPULATION IN NORTH CAROLINA IS GROWING BY 33% WHILE THE GENERAL POPULATION IS GROWING BY ONLY 21%. OUR SERVICE DATA HAS BEEN PRETTY MUCH CONSISTENT WITH LITTLE BUMPS IN THE ROAD EVERY NOW AND THEN, ABOUT YOU WE HAVE REACHED CAPACITY. WE JUST BEGAN AN 18-MONTH NEEDS SURVEY TO DO A NEEDS ASSESMENT ACROSS THE STATE OF NORTH CAROLINA. NOT JUST RELATED TO HEALTHCARE. I'M LOOKING TO THIS TASK FORCE TO HELP US WITH THAT THAT PART OF THE PROCESS. THE CHALLENGE FOR US IS THAT WE ARE NOT ONLY SMALL BUT WE ALSO DON'T HAVE THE EXPERTISE OF THE KNOWLEDGE OF THE HEALTHCARE INDUSTRY AND THE HEALTHCARE SYSTEM, SO THAT'S WHERE WE'RE REALLY DEPENDING ON YOU TO HELP US FIGURE OUT HOW WE CAN MAKE BEST USE OF THIS SYSTEM TO LEVERAGE THE RESOURCES THAT WE DO HAVE AND SO THAT YOU CAN ADVISE US ON WHAT ADDITIONAL RESOURCES WE MIGHT NEED TO BE ABLE TO MEET THE NEEDS OF DEAF AND HARD OF HEARING PEOPLE IN THE HEALTHCARE SYSTEM. WE DO HAVE MAJOR GOALS THAT ARE BEING REFERRED TO AS TARGET 2025, SO IF YOU LOOK AT GOALS NUMBER ONE AND THREE, SPECIFICALLY RELATED TO WHAT WE'RE TALKING ABOUT HERE AND BASICALLY, IT'S TO ELIMINATE BARRIERS TO COMMUNICATION ACCESS, WHICH IS NUMBER ONE AND THEN NUMBER THREE, TO INCREASE THE INDEPENDENCE AND EFFECTIVENESS IN COMMUNICATION FOR DSDHH CLIENTS. AS I MENTIONED EARLIER, A BIG CHALLENGE FOR US IS THE SYSTEM. WHO ARE THE KEY PLAYERS? WHAT KINDS OF CHANGES ARE POSSIBLE WITHIN THE CURRENT SYSTEM? I HOPE THAT AS WE PROVIDE YOU A LITTLE BIT MORE INFORMATION THAT WILL HELP YOU HAVE A BETTER UNDERSTANDING OF OUR SITUATION SO THAT OUR NEXT MEETING ON APRIL 5th, WE WILL BE HAVING HOWARD ROSINBLUHM COME. HE'S COMING FROM WASHINGTON, D.C

HE'S THE NATIONAL DIRECTOR OF THE NATIONAL ASSOCIATION OF THE DEAF AND HE HAS A WEALTH OF EXPEERNS AS AN ATTORNEY DEALING WITH COMMUNICATION ACCESS ISSUES IN CHICAGO WHERE HE USED TO LIVE AND NOW IN D.C. AND SO HE'S GOING TO JOIN US AND TALK ABOUT THE LEGAL LANDSCAPE AND HE'S ALSO GOING TO EXPLAIN HIS IDEA FOR ONE POSSIBLE SOLUTION THAT WE FEEL HAS GREAT PROMISE. THIS SOLUTION HAS NEVER BEEN ATTEMPTED STATEWIDE BUT WE THINK THAT WITH YOUR HELP WE MIGHT BE ABLE TO BENEFIT-- WE MIGHT BE ABLE TO ELIMINATE SOME OF THE BARRIERS, IF NOT ALL OF THEM. AND THEN LATER ON, WE WILL BE GETTING INTO MORE DETAIL, A MORE DETAILED DISCUSSION OF THE CLIMATE AT CCRCs. IT'S REALLY AMAZING WHEN YOU THINK ABOUT THE FACT THAT NURSING HOMES HAVE ABOUT 80% OF THEIR RESIDENTS WITH HEARING LOSS, AND WE'VE SEEN SO MANY STAFF IN THESE FACILITIES THAT DON'T SEEM TO HAVE EVEN THE BASIC KNOWLEDGE THAT THEY NEED TO HAVE TO APPROPRIATELY SUPPORT PEOPLE THAT ARE DEAF, HARD OF HEARING, OR DEAF-BLIND IN THE FACILITIES WHERE THEY WORK. WE WANT TO LOOK AT POSSIBILITIES FOR UNIVERSAL DESIGNS, CULTURAL CHANGE WITHIN THESE FACILITIES, SO THAT WE CAN MAKE BETTER USE OF YOUR INFRASTRUCTURE TO HELP YOU MAKE A DIFFERENCE IN THESE

FACILITIES. AND I WANT TO CLOSE WITH THIS LAST SLIDE. PANDO IS A LATIN TERM MEANING I SPREAD OUT. THESE TREES THAT YOU SEE HERE IN THE PICTURE LOOK LIKE FAIRLY YOUNG TREES. THEY MIGHT BE 100 TO MAYBE 175 YEARS OLD. BUT THOSE TREES ARE ACTUALLY LOCATED IN UTAH AND THEY ARE CONSIDERED PART OF THE OLDEST LIVING-- ONE OF THE OLDEST LIVING ORGANISMS IN IN THE WORLD. NOW, MANY OF YOU HAVE HEARD OF BRISTOL COMB PINES AND THE OLDEST TREE, THE ONLY OLDEST INDIVIDUAL TREE IS ABOUT 5,000 YEARS OLD AND THIS IS A CONGLOMERATION OF TREES WHICH IS ONE ORGANISM, AND IT'S ESTIMATED TO BE AT LEAST 80,000 YEARS OLD. ALL OF THOSE INDIVIDUAL TREES ARE NOWHERE NEAR THAT AGE. BUT IT'S THE ROOT SYSTEM THAT JOINS THEM ALL TOGETHER THAT HAS BEEN SPREADING OVER THE YEARS AND SPROUTING NEW TREES THAT HAS BEEN IN EXISTENCE FOR ALL THIS MANY YEARS AND IT HAS BEEN FOUND THAT THESE TREES DO SHARE THE SAME DNA SO THEY HAVE BEEN VERIFIED TO BE ONE ORGANISM. I AM HOPING THAT WITH US HERE TOGETHER THE COMMUNICATION THAT WE SHARE WITH EACH OTHER, THE COLLABORATION, THE CONNECTIONS THAT WE BUILD HERE TOGETHER WILL ALLOW US TO COME UP WITH SOMETHING LIKE THIS GROVE OF TREES HERE IN NORTH CAROLINA THAT WILL LEAD TO THIS ONE BODY IMPROVING SERVICES FOR DEAF, HARD OF HEARING, AND DEAF-BLIND PEOPLE. THANK YOU.
[APPLAUSE]

Robert Kurzydlowski: Meeting Wrap-Up

>> HELLO. OKAY. SO I JUST WANTED TO SAY A COUPLE LAST HOUSEKEEPING THINGS BEFORE WE CAN END THE MEETING TODAY. JUST A REMINDER THAT OUR NEXT MEETING IS GOING TO BE AT THE NORTH CAROLINA INSTITUTE OF MEDICINE. JAMES OR I WILL BE SENDING OUT DIRECTIONS TO THAT, AND UPDATES ON WHERE THAT IS AND IT'S ON OUR WEBSITE AS WELL, TOO. THE BINDERS ARE YOURS TO KEEP. EACH MONTH, WE'LL BRING THE NEW UPDATED INFORMATION FOR YOU, BUT YOU HAVE THOSE BINDERS TO TAKE HOME AND GO OVER BEFORE EACH MEETING ALSO JUST A REMINDER, ALL THIS INFORMATION IN THE BINDER IS GOING TO BE ON OUR WEBSITE AS WELL. ABOUT FINALLY, IF YOU COULD ALL JUST PLEASE LEAVE OUR NAME TAGS, WE WILL TRANSPORT THEM BACK AND FORTH FOR YOU. IF YOU COULD CLIP THEM TO YOUR TABLE TENT AS WELL. THANK YOU SO MUCH FOR COMING TODAY. AND IF EVERYONE CAN GIVE YOUR SURVEYS OR IF YOU WANT TO BRING THEM, THERE'S A BOX UP HERE IN THE FRONT, I BELIEVE. QUESTION IN THE BACK?
>> YES. **LISA WAINWRIGHT**. DO WE HAVE THE SCHEDULE FOR THE UPCOMING MEETINGS SO WE CAN GET THOSE ON THE CALENDARS?

>> I DO HAVE THOSE AND I'M NOT SURE IF THE OUTLOOK CALENDAR INVITES WERE SENT FOR THOSE BUT THEY WILL BE SENT THROUGHOUT AUGUST SO YOU CAN KEEP THE HOLD ON YOUR CALENDARS BUT I HAVE A SHEET OF PAPER WITH ALL SIX MEETINGS ON THEM AS WELL. I CAN HAND THAT AROUND. YES.
>> THANK YOU.