

**Centers for Disease Control and Prevention  
EARLY HEARING DETECTION AND INTERVENTION  
Ad Hoc - Teleconference  
September 7, 2004**

**Topic: “How to Establish Chapters for  
Family Voices and Hands & Voices”**

**TO:** Listserve Members  
**FROM:** Dr. Danielle S. Ross  
**SUBJECT:** Conference call information and agenda.  
**DATE:** September 7, 2004, 2:00-3:00pm EST

The next EHDI Ad Hoc teleconference will be on Tuesday, **September 7, 2004 from 2:00 to 3:00 pm Eastern** time. To join in, call: **1-866-842-6975**. You will be greeted by an automated voice and asked to enter a Passcode. **PASSCODE: 218840 (plus the # key)**. If you have any questions please contact Marcus Gaffney ([Mgaffney@cdc.gov](mailto:Mgaffney@cdc.gov) / 404-498-3031).

Downloadable documents for this call will be available at: <http://www.infanthearing.org/checkpoint/cdc/> . The username is “**cdc**” and the password is also “**cdc**” (without the quotation marks). If the presentations are not currently available on this website, please continue to check back.

An internet based captioning service will be available at no charge during this teleconference if requested. If you would like further information or to schedule use of this captioning service, please inform Marcus Gaffney ([MGaffney@cdc.gov](mailto:MGaffney@cdc.gov) / 404-498-3031).

**Agenda**

- I. Welcome
- II. Leeanne Seaver: Executive Director of Hands & Voices  
Janet DesGeorges: Executive Director of Colorado Families for Hands & Voices
- III. Leau Phillips: Training and Technical Assistance Coordinator at Family Voices  
Donene Feist: Chair, Chapter Development Committee, Family Voices Board of Directors
- IV. Questions and Discussion

## Roughly Edited Transcript

>>**DANIELLE ROSS:** GOOD AFTERNOON, EVERYBODY. THIS IS DR. DANIELLE ROSS FROM CDC. I'D LIKE TO WELCOME ALL OF YOU TO THIS MONTH'S EARLY HEARING DETECTION AND INTERVENTION AD HOC TELECONFERENCE TITLED, HOW TO ESTABLISH CHAPTERS OF FAMILY VOICES AND HANDS & VOICES. I'D LIKE TO THANK OUR SPEAKERS FOR AGREEING TO PRESENT ON THIS CALL AND OF COURSE, EVERYBODY FOR CALLING IN. TODAY, OUR FIRST SPEAKERS ARE LEEANNE SEAVER, THE EXECUTIVE DIRECTOR OF HANDS & VOICES AND JANET DesGEORGES, EXECUTIVE DIRECTOR OF COLORADO FAMILIES FOR HANDS & VOICES.

OUR SECOND SPEAKERS ARE LEAU PHILLIPS, TRAINING AND TECHNICAL ASSISTANCE COORDINATOR AT HANDS & VOICES AND DONENE FEIST, CHAIR OF THE FAMILY DEVELOPMENT COMMITTEE, FAMILY VOICES BOARD OF DIRECTORS.

SO OUR FIRST SPEAKERS, LEEANNE SEAVER AND JANET DesGEORGES FROM HANDS & VOICES, AND THEY WILL TALK TO US ABOUT HOW TO ESTABLISH A CHAPTER FOR HANDS & VOICES. WELCOME, LEEANNE AND JANET.

>> **JANET DesGEORGES.** HI, THANK YOU. I'M THE DIRECTOR FOR COLORADO FAMILIES FOR HANDS & VOICES. I'M PLEASED TO BE HERE. WE'RE THE PROUD PARENTS OF THREE DAUGHTERS. WE LIVE HERE IN BOULDER, COLORADO AND OUR 13-YEAR-OLD DAUGHTER SARAH IS HARD OF HEARING.

>> **LEEANNE SEAVER:** HELLO. I AM THE EXECUTIVE DIRECTOR OF HANDS & VOICES NATIONAL. VERY EXCITED TO BE HERE ON THIS CALL WITH YOU TODAY. HOWEVER MUCH I APPRECIATE YOU'VE PRONOUNCED JANET'S LAST NAME CORRECTLY, DR. ROSS, SHE LOOKS FORWARD TO THE MISPRONUNCIATION OF HER NAME WITH EVERY INTRODUCTION. SHE PREFERS JANET DEGORGEOUS. SO MAKE A MENTAL NOTE THERE EVERYONE.

WELL, TELECONFERENCES ARE ALWAYS AN INTERESTING ANIMAL. WE'VE GOT TO GET THROUGH THE TECHNOLOGY, WHICH I'M SO PLEASED THAT WE WERE ABLE TO DO TO INCLUDE ANY DEAF OR HARD OF HEARING PARTICIPANTS TODAY. AND I KNOW DR. ROSS HAS REMINDED ALL OF US ABOUT THE MUTE AND THE HOLD. I PERSONALLY IF BACKGROUND MUSIC COMES ON I ENJOY THAT. I ALWAYS THINK MY WORDS ARE MORE PROFOUND IF MUSIC ACCOMPANIES THEM BUT WE'LL DO OUR BEST HERE TODAY. AND WE'RE GOING TO SHORTEN OUR PART OF THE PRESENTATION JUST A LITTLE BIT, BECAUSE WE WANT TO LEAF PLENTY OF TIME FOR QUESTIONS, AND WE APPRECIATE ALL OF YOU WHO HAVE TAKEN THE TIME OUT OF YOUR BUSY SCHEDULES TODAY TO JOIN US. WE HOPE THAT AT THE END OF THIS PRESENTATION TODAY, YOU WILL ON YOUR ONE TO TWO TO THREE-PAGE TO DO LISTS, I KNOW ALL OF YOU ARE SO BUSY, WILL NOW ADD, START A HANDS & VOICES CHAPTER IN OUR STATE. WE HOPE TO KIND OF CONVINCED YOU OF THE NEED AND THE HOW-TOES AND MAKE IT AS EASY AND FAMILY-FRIENDLY AS POSSIBLE. SO WE ARE REALLY PLEASED TO BE HERE.

HANDS & VOICES IS ALSO, WE'RE PLEASED TO KIND OF ANNOUNCE TODAY A PARTNERSHIP, A COOPERATIVE AGREEMENT, BETWEEN CDC AND THE MARY DOWNS HEARING SENT -- MARION DOWNS HEARING CENTER. THIS YEAR IN SOME PROJECTS HANDS & VOICES WILL BE INVOLVED IN THE PARENT ADVOCACY AND SUPPORT PART OF THAT PROJECT SO WE JUST WANTED TO MENTION AND ACKNOWLEDGE THOSE AGENCIES TODAY. WE'RE PLEASED TO BE WITH THEM.

>> Leeanne: FOR MANY OF YOU THERE'S ALREADY A HANDS & VOICES CHAPTER IN EXISTENCE OR JUST STARTING UP SO YOU KNOW WHO YOU ARE, OR WILL BE EASILY ABLE TO FIND OUT WHO YOU ARE.

AND WE ARE JUST KIND OF REFLECTING BRIEFLY ABOUT THE HISTORY OF OUR ORGANIZATION. HANDS & VOICES STARTED IN COLORADO ALMOST 10 YEARS AGO. AND BECAUSE OF THE MODEL THAT WE ESTABLISHED HERE AND THE SUCCESS THAT WE'VE HAD, AND BECAUSE OF OPPORTUNITIES THAT WE'VE HAD THROUGH VARIOUS CONFERENCES, TRAININGS, PRESENTATIONS, ALL OVER THE COUNTRY AND EVEN SOME OUTSIDE THE COUNTRY, WE HAVE BEEN ASKED REPEATEDLY HOW DID YOU GUYS DO IT? AND CAN WE DO THAT HERE?

FROM THOSE HUMBLE BEGINNINGS CAME THE ACTUAL ORGANIZATION OF OUR GROUP AS A NATIONAL FAMILY SUPPORT ORGANIZATION, A NONPROFIT ORGANIZATION. AND WE HAVE CREATED MECHANISMS TO HELP OTHER PEOPLE DO A HANDS & VOICES TYPE ACTIVITY IN THEIR OWN STATES, AND WE HAVE A NUMBER OF THEM CROPPING UP ALL OVER THE COUNTRY, WHICH YOUR HANDOUT ALLUDES TO LATER. WE ARE UNIQUE IN THE ORGANIZATIONS THAT SUPPORT FAMILIES AND PROFESSIONALS WHO SERVE CHILDREN WHO ARE DEAF OR HARD OF HEARING IN THAT WE DON'T ORGANIZE AROUND THE NOTION OF ONE SUPERIOR COMMUNICATION METHODOLOGY. AND IN FACT, OUR RALLYING POINT IS REALLY MORE CLOSELY DESCRIBED AT THE VERY END OF THE MISSION STATEMENT THAT YOU'LL SEE IN YOUR HANDOUTS.

WE BELIEVE THAT ALL KIDS DESERVE TO HAVE AN EXCELLENT EDUCATION. THEY DESERVE THE OPPORTUNITY TO BE SUPPORTED TO THEIR HIGHEST POTENTIAL, AND THAT FAMILIES NEED INFORMATION THAT WILL SUPPORT THEM AS THEY MAKE THE BEST CHOICES FOR THEIR CHILD IN THE CONTEXT OF THEIR VALUES AND THEIR VISION AND GOALS FOR THEIR CHILD. AND WE ALSO BELIEVE AND A HALLMARK OF OUR ORGANIZATION, IS OUR COLLABORATIVE NATURE WITH THE PEOPLE WHO ARE WORKING WITH OUR FAMILIES, AND NOT ONLY DO WE SUPPORT FAMILIES AT THE INDIVIDUAL LEVEL, BUT WE, IN EACH CHAPTER, WORK VERY DILIGENTLY TO BE PART OF THE SYSTEM THAT SERVES US.

>> **Janet:** I THINK THAT HANDS & VOICES IN ITS UNIQUENESS -- WHEN YOU THINK ABOUT DEAFNESS AND THE HISTORY OF PROFESSIONS OR IN DEAF EDUCATION THROUGHOUT THE YEARS, THE ARGUMENT THAT HAS DRAWN A LINE IN THE SAND BETWEEN MANY PEOPLE AROUND WHAT COMMUNICATION CHOICE IS RIGHT FOR ALL DEAF AND HARD OF HEARING CHILDREN, AND WE OFTEN CITE A RESEARCH STUDY THAT ACTUALLY LOOKED AT THE RESEARCH AROUND I THINK OVER 160 RESEARCH STUDIES ASKING THE QUESTION, "WHICH COMMUNICATION CHOICE REALLY EMBODIES SUCCESS FOR DEAF AND HARD OF HEARING CHILDREN?" AND AT THE END OF THAT, THAT SYNTHESIS OF THOSE RESEARCH STUDIES, THE BASIC BOTTOM LINE WAS THAT THERE REALLY ISN'T ONE RIGHT METHODOLOGY FOR ALL DEAF AND HARD OF HEARING CHILDREN.

WE WERE PLEASED TO SEE THAT, BECAUSE WE HAD COME UP WITH A MOTTO EARLIER THAN THAT CALLED, AND OUR MOTTO REALLY EMBODIES WHAT OUR ORGANIZATION IS, IS WHAT WORKS FOR YOUR CHILD IS WHAT MAKES THE CHOICE RIGHT. WE'VE BEEN ASKING THE QUESTION FOR SO LONG, WHAT COMMUNICATION RIGHT -- WHAT COMMUNICATION MODE OR LANGUAGE IS RIGHT FOR DEAF AND HARD OF HEARING CHILDREN? AND WE HAVE REALLY STOOD UP TO THE PLATE AND SAID, NOT WHAT COMMUNICATION CHOICE, BUT WHAT NOW? ONCE WE'VE FOUND COMMUNICATION THAT WORKS FOR OUR CHILDREN, NOW WHAT? WHAT ABOUT EDUCATION? WHAT ABOUT THE AGENCIES, THE ORGANIZATIONS, PROFESSIONS, THAT SERVE OUR FAMILIES? WHAT ABOUT THE ISSUES THAT ARE GOING TO GET WHAT WE AS PARENTS ALL WANT FOR OUR DEAF AND HARD OF HEARING CHILDREN? WHICH IS A SUCCESSFUL LIFE EMBODIED IN GETTING A GOOD EDUCATION AND BEING READY TO BE OUT THERE IN THE WORLD.

SO DEAFNESS HAS A LOW INCIDENCE. FOR THOSE OF US WHO LIVE IN STATES, PARTICULARLY MORE RURAL STATES, WE HAVE JUST FOUND THE IMPACT AND -- OF BEING ABLE TO COME TOGETHER AS PARENTS, REGARDLESS OF THE INDIVIDUAL CHOICES THAT WE'VE CHOSEN FOR OUR KIDS AND BEEN ABLE TO REALLY MOVE FORWARD AND TO MAKE AN IMPACT AND A

DIFFERENCE IN OUR STATE.

>> **Leeanne:** ONE OF THE THINGS THAT WE THINK ABOUT A LOT AS CHAPTERS FORM IN DIFFERENT PLACES IS FOR SOME PEOPLE, COMING TOGETHER WITH A GROUP OF PARENTS AND PROFESSIONALS, THAT EXPERIENCE IS REALLY GOING TO ACHIEVE THEIR GOALS IF THEY GET SOME INTERPERSONAL HELP WITH THEIR CHILD. AND FOR THEIR OWN FAMILY SITUATION. AND SOMETIMES THOSE PEOPLE [ BEEPS ] ARE ONLY LOOKING FOR ONE OTHER PARENT TO NETWORK WITH, OR ONE SPECIFIC ANSWER TO A QUESTION.

BUT OFTENTIMES WE REALLY SEE PARENTS WHO ARE RISING TO POSITIONS OF LEADERSHIP WHERE THEY'RE INTERESTED IN NOT ONLY CREATING THOSE HIGHEST POTENTIALS FOR THEIR OWN CHILD BUT THEY WANT TO CREATE A SYSTEM THAT WILL DO THAT FOR ALL KIDS. AND REGARDLESS OF HOW THOSE KIDS ARE COMMUNICATING, REGARDLESS OF THE CHOICES THAT THEIR FAMILY HAS MADE, WE HAVE IN OUR RANKS, PARENTS WHO HAVE BEEN TRAINED TO ADVOCATE EFFECTIVELY NOT ONLY FOR THEIR OWN CHILD, BUT FOR OTHER KIDS WHO ARE COMMUNICATING DIFFERENTLY.

I THINK A QUESTION THAT WE OFTEN ASK WHEN CHAPTERS ARE STARTING THEIR PROCESS OF START-UP AND PUTTING TOGETHER BOARDS AND CREATING THEIR OWN CHARACTERISTIC AS A STATE ORGANIZATION IS FOR PARTICULARLY THE LEADERSHIP, CAN YOU SUPPORT A CHOICE THAT SOMEBODY ELSE MAKES THAT'S DIFFERENT THAN THE ONE YOU MADE FOR YOUR CHILD AND YOUR OWN FAMILY SITUATION? AND IT'S BEEN A WONDERFUL EXPERIENCE TO SEE FAMILIES WHO ARE ABLE TO HAVE THAT VALUE, AND TO SUPPORT IT, AND NOT TO BE DIVIDED BY THE WHOLE COMMUNICATION METHODOLOGY WAR, QUOTE, UNQUOTE, THAT HAS TENDED TO SEPARATE US FROM EACH OTHER, AND FROM THE THINGS THAT MAKE US STRONG IN A UNITED WAY AROUND THE GOALS THAT WE ALL SHARE.

>> **Janet:** AND I THINK ONE OF THE WAYS THAT VALUE REALLY COMES FOR PARENTS IS THE OPPORTUNITY TO BE WITH OTHER FAMILIES. I KNOW PERSONALLY FOR ME, COMING INTO THIS EXPERIENCE AND NOT KNOWING ANY OTHER DEAF OR HARD OF HEARING CHILDREN, OR FAMILIES, THE MORE FAMILIES THAT I MET, AS I CAME TOGETHER WITHIN -- AS JUST A MEMBER OF HANDS & VOICES IN OUR STATE, THE MORE I BEGAN TO REALLY UNDERSTAND AND LIVE THAT VALUE, BECAUSE I SAW DIFFERENT FAMILIES MAKING DIFFERENT INDIVIDUAL CHOICES FOR THEIR KIDS, AND SO THAT VALUE REALLY GREW FOR ME. SO REALLY, ONE OF THE FIRST OUTCOMES OF BEGINNING TO BRING FAMILIES TOGETHER IN YOUR STATE IS THAT VALUE GROWS, BECAUSE YOU'RE ABLE TO MEET OTHER PEOPLE WITH OTHER LIFE EXPERIENCES AND OTHER CHOICES. AND THAT'S REALLY -- A REALLY VALUABLE, WONDERFUL THING AND IT ACTUALLY HELPS CREATE THAT VALUE OF NON-BIAS THAT OUR ORGANIZATION REALLY ENDORSES, AND HAS AS A QUALIFIER FOR A STATE THAT WOULD BEGIN A CHAPTER. SO I THINK MOVING FROM THE INDIVIDUAL CHOICE THAT WE AS PARENTS MAKE TO THE MORE SYSTEMATIC, OR ORGANIZATIONAL, OUTLOOK, IT'S AMAZING HOW MUCH WE, AS FAMILIES, HAVE IN COMMON.

WHEN YOU GET PAST THE METHODOLOGY ISSUE, THE ISSUES AROUND -- IN EDUCATION, WE AS AN ORGANIZATION GO IN AND ADVOCATE FOR FAMILIES IN EDUCATIONAL IEPs AND IT'S AMAZING SO MANY OF THE SAME ISSUES THAT COME IN SO IN THE END, I THINK WE HAVE MORE IN COMMON THAT THAT WHICH SEPARATES US. WE WON'T BELABOR THAT POINT TOO MUCH MORE ON THIS, EXCEPT THAT THAT IS WHAT MAKES THIS ORGANIZATION UNIQUE. AND IT IS THE ABILITY FOR ALL OF US PARENTS IN A STATE AND THE PROFESSIONALS THAT WOULD SUPPORT OUR ORGANIZATION THAT IS WHAT MAKES THIS UNIQUE AND DIFFERENT. AND REALLY, I THINK DRIVES THE ENGINE IN A SENSE OF MOTIVATION FOR STATES TO GET GOING. SO IT'S A REALLY EXCITING THING. WE'VE SEEN STATES KIND OF EMBRACE THIS, AND MOVE FORWARD, AND WE'LL TALK A LITTLE BIT MORE ABOUT THE NUTS AND BOLTS. IN FACT, I KNOW WHERE OUR TIME, 20 MINUTES IS A REALLY SHORT TIME FOR US.

SO I DID WANT TO MENTION NOT ONLY IS OR ORGANIZATION FOR FAMILIES ACROSS THE

SPECTRUM OF MODE AND LANGUAGE CONSIDERATIONS, BUT ALSO ACROSS THE SPECTRUM OF DEGREE OF HEARING LOSS. AND THAT IS REALLY IMPORTANT FOR A LOT OF THOSE PARENTS WHOSE KIDS FALL UNDER THE HARD OF HEARING CATEGORY. WE HAVE A STAFF MEMBER WHO HAS A CHILD AND REALLY LOOKS TO SUPPORT IN OUR STATE KIDS WITH UNILATERAL HEARING LOSS. AND SO NOT ONLY THE DIVERSITY OF COMMUNICATION OPTIONS BUT THE DIVERSITY OF THE DEGREE OF HEARING LOSS, THAT WE REALLY REPRESENT AND TRY TO SUPPORT FAMILIES, YOU KNOW, EVEN IF THEIR KIDS HAVE UNILATERAL HEARING LOSS, OR MILD OR MODERATE. A LOT OF TIMES THOSE FAMILIES FEEL DISCONNECTED TO SUPPORT, YOU KNOW, ASKING THE QUESTION, DO WE REALLY FIT IN HERE? AND HANDS & VOICES IS ALL ABOUT THAT, AS WELL. SO IT'S AN EXCITING FOUNDATION FROM WHICH TO BUILD AN ORGANIZATION IN YOUR STATE THAT COULD REALLY LOOK AT MOVING SYSTEMATIC CHANGE. FAMILIES ARE THE THING THAT ALL AREAS HAVE IN COMMON. PART C AND PART B, SCREENING, IDENTIFICATION, AND EARLY INTERVENTION AND AN EHDI SYSTEM, ALL THE DIFFERENT PROFESSIONALS, THE COMMON DENOMINATOR OF ALL THESE THINGS IS THE FAMILY MOVING THROUGH THEM, EITHER BEING IMPACTED OR SERVED BY THEM SO THE OPPORTUNITY TO BRING FAMILIES TOGETHER AS EQUAL PLAYERS IN THE SYSTEMS THAT ARE BEING BUILT ARE REALLY A POWERFUL TOOL IN ORDER TO EFFECT CHANGE, AND BETTERING THE SERVICES FOR FAMILIES.

>> **Leeanne:** ANOTHER COMMON DENOMINATOR THAT WE HAVEN'T BEEN TOO EXCITED ABOUT IS IF YOU'LL LOOK AT THE STATISTICS, THAT COVER DECADES AND DECADES OF INFORMATION ABOUT WHAT WE KNOW ABOUT OUR KIDS WHEN THEY LEAVE HIGH SCHOOL AND EMERGE INTO ADULTHOOD, THEY HAVE NOT REALLY SIGNIFICANTLY CHANGED IN ANY POSITIVE WAY FOR MANY, MANY, MANY YEARS. MANY OF US ARE FAMILIAR WITH THAT HORRIBLE, YOU KNOW, 3RD TO 4TH GRADE READING LEVEL STATISTIC BUT WE ALSO KNOW THAT AS CURRENT AS THIS EARLY IN 2000, WE SEE KIDS WHO ARE SCORING ON THE A.C.T. TESTS AND THE S.A.T. TESTS SIGNIFICANTLY BELOW IN EVERY ACADEMIC AREA THEIR HEARING PEERS AND THAT IS YOUR AVERAGE DEAF OR HARD OF HEARING KIDS.

SO WHEN YOU THINK ABOUT FAMILY INVOLVEMENT, WHAT WE REALLY WANT TO EMPHASIZE IS THAT THE ONE PIECE THAT HAS BEEN MISSING THROUGH THE YEARS IN OUR OPINION, HAS BEEN THE MORE MEANINGFUL INVOLVEMENT OF FAMILIES IN A WAY THAT ACTUALLY CREATES CHANGE TO THOSE KINDS OF DISMAL NUMBERS. WE DON'T WANT TO MOVE INTO A FUTURE, NOW THAT WE HAVE THE BENEFIT OF IDENTIFYING THESE BABIES AT BIRTH AND SERVING THEM WELL WITH EARLY INTERVENTION, WE DON'T WANT TO TAKE THOSE ADVANTAGES AND UNDO THEM WITH A SYSTEM IN THEIR SCHOOL-AGE YEARS, AGE 3 ON UP, THAT WILL UNDO THOSE ADVANTAGES. SO WE ARE WORKING VERY HARD TO -- TOWARDS A GOAL NO LESS THAN CHANGING THE WORLD, CHANGING THE ENTIRE FUTURE, FOR NOT ONLY THE EXCEPTIONAL DEAF OR HARD OF HEARING CHILD, BUT THE AVERAGE KID. THEY ALL DESERVE THAT KIND OF OUTCOME. AND THAT'S WHERE OUR SIGHTS ARE SET.

>> **Janet:** SO NOW THAT YOU'RE ADDED TO YOUR TO-DO LIST, CHANGE THE WORLD, WE'RE GOING TO TELL YOU HOW TO DO THAT. ON YOUR HANDOUT THERE'S SOME NUTS AND BOLTS OF GETTING A CHAPTER STARTED. AND THE BEST WAY TO DO THAT IS TO REALLY GO TO OUR WEBSITE AND YOU CAN DOWNLOAD A FIVE-STEP START-UP PLAN, AND IT SOUNDS EASY. AND I JUST WANT TO LET YOU KNOW THAT SOME STATES HAVE RALLIED AROUND THE CONCEPT OF AN ORGANIZATION, AND WITHIN A VERY SHORT PERIOD OF TIME, TWO TO THREE MONTHS, ARE KIND OF UP AND RUNNING. OTHER STATES HAVE HAD DIFFERENT CONSIDERATIONS AND ISSUES, AND HAVE CHOSEN TO KIND OF TAKE THE SLOW TRACK TO GETTING A STATE CHAPTER GOING.

WE ARE A PRETTY FLEXIBLE NATIONAL ORGANIZATION. IN FACT, WHAT YOU'LL FIND IS THAT WE'RE DEPENDING ON YOU AND YOUR STATES TO REALLY IDENTIFY AND PRIORITIZE THE ISSUES THAT YOU FEEL ARE THE MOST RELEVANT IN YOUR STATE. WE'VE TRIED TO CREATE A PARAMETER, AND REALLY SOME GOOD TECHNICAL ASSISTANCE TO GET YOU GOING. BUT YOU'LL FIND THAT WE LEAVE A LOT OF -- THERE'S A LOT OF GRAY AREAS IN A SENSE THAT

WE'VE PURPOSELY LEFT FOR YOU AND YOUR STATES TO FIGURE OUT SO THAT YOUR ORGANIZATION WILL WORK THE BEST FOR YOUR DIFFERENT ISSUES, CONSIDERATIONS. SOME STATES ALREADY HAVE A BUNCH OF SMALL, YOU KNOW, PARENT GROUPS GOING. OTHER STATES HAVE ABSOLUTELY NOTHING GOING ON.

IT JUST REALLY DEPENDS ON THE NEEDS AND WE CAN HELP YOU KIND OF LOOK THROUGH THE NEEDS IN YOUR STATE, AND BECAUSE OF OUR COLLABORATION THIS YEAR WITH THE MARION DOWNS HEARING CENTER, WE'RE REALLY EXCITED, WE'LL HAVE SOME MORE TOOLS TO BE ABLE TO HELP STATES DO THAT. BUT I THINK TO REALLY GO TO OUR WEBSITE AND DOWNLOAD THE FIVE-STEP START-UP PLAN. THERE'S ALSO AN ORGANIZATIONAL GUIDE I THINK PUT IN THE HANDOUTS IS 48 PAGES. IT'S ONLY COMPARED PAGES SO THAT SHOULDN'T SCARE YOU TOO BAD. TO LOOK THROUGH THERE. BUT THE BEST WAY TO START THE DIALOGUE IS TO E-MAIL LEEANNE AND I, AND WE'RE HAPPY TO KIND OF BEGIN THAT PERSONAL CONTACT OF KIND OF LOOKING AT HOW YOU MIGHT WANT TO APPROACH IT IN YOUR STATE.

>> **Leeanne:** LOTS OF TIMES WHEN STATES ARE STARTING UP, THEY ASK A QUESTION LIKE, WHAT DO WE DO FIRST? AND OUR ANSWER TO THAT IS, YOU DO WHAT YOU FEEL IS THE MOST IMPORTANT THING TO DO. IF YOU HAVE DOWNLOADED THE HANDOUT, YOU'LL SEE A SLIDE THAT TALKS ABOUT STATE CHAPTERS AND JUST EMPHASIZES THE DIFFERENT KINDS OF AGENDAS THAT THEY MIGHT HAVE. EVERY STATE LOOKS A LITTLE BIT DIFFERENT FROM ONE ANOTHER IN TERMS OF THEIR PRIORITIES AND THAT IS FINE. PRIORITIES ARE DEVELOPED BY THE PEOPLE WHO ARE LIVING THERE. AND KNOW WHAT THE ISSUES ARE. AND KNOW WHO THE PLAYERS ARE. AND ALSO, YOU KNOW, ARE BRINGING WHATEVER SKILL SET THEY HAVE TO THE TABLE. SO THAT'S AS IT SHOULD BE.

BUT ALL OF THOSE THINGS, AND ALL THOSE UNIQUE EXPRESSIONS OF THIS ORGANIZATION, ARE UNIFIED BY THE MISSION AND PHILOSOPHY WE ALL SHARE. PART OF THE APPLICATION PROCESS TO CREATE A CHAPTER DOES INVOLVE PULLING PEOPLE TOGETHER THAT BRING DIVERSE PERSPECTIVES, DIFFERENT HATS THAT THEY WEAR WITHIN THE ENTIRE SPECTRUM OF DEAF AND HARD OF HEARING ISSUES OR PROFESSIONS, OR THE ROLE THAT YOU WOULD PLAY IN THAT. AND WHEN A CHAPTER SENDS US AN APPLICATION, IT REFLECTS HOW THEY HAVE CONNECTED ALL OF THOSE DIFFERENT TYPES OF PEOPLE TOGETHER, AND HOW THEY'RE GOING TO BE ABLE TO SUSTAIN THEMSELVES THROUGH THAT DIVERSITY AND THROUGH THAT COMMITMENT THAT EVERYBODY HAS TO CREATE SOMETHING THAT WILL TRULY IMPACT INDIVIDUAL KIDS AND ENTIRE SYSTEMS.

>> **Janet:** WE HAVE FIVE MINUTES LEFT SO WE WANT TO GO AHEAD AND OPEN UP TO QUESTIONS. AND, YES, WE DO HAVE THE ANSWER FOR FUNDING ISSUES. ANYWAY, GO AHEAD AND ASK AWAY ANY QUESTIONS THAT YOU MIGHT HAVE.

>> **BARB PETERSON:** HI, THIS IS BARB PETERSON FROM BOYSTOWN. I HAVE TWO DEAF DAUGHTERS WHO BOTH ARE SCHOOL-AGE. ONE'S A SENIOR AND ONE IS AN 8TH GRADER. CAN YOU GIVE ME SOME EXAMPLES OF WHAT YOUR ORGANIZATION HAS BEEN SUCCESSFUL WITH IN THE STATE OF COLORADO?

>> **Janet:** SURE. I THINK I COULD APPROACH IT IN A LOT OF DIFFERENT WAYS, INDIVIDUALLY AND SYSTEMICALLY. WE'VE BEEN INVOLVED SYSTEMICALLY WITH INFORMATION DISSEMINATION TO FAMILIES. THE LAW REQUIRES FAMILIES TO BE EDUCATED BY THE VERY EDUCATIONAL SYSTEM IN ORDER TO BE EQUAL MEMBERS OF THE IEP TEAM, YET THAT IS VERY SORELY LACKING, USUALLY. SO WE AS AN ORGANIZATION HAVE TAKEN UPON OURSELVES AND IN COLLABORATION, ACTUALLY, WITH THE DEPARTMENT OF EDUCATION, TO TRAIN PARENTS TO BE EQUAL, TO GIVE THEM THE INFORMATION AND KNOWLEDGE THAT THEY NEED, SO THAT THEY CAN WALK THROUGH THE DOOR OF AN IEP AND NEGOTIATE APPROPRIATE SERVICES FOR THEIR KIDS. I CANNOT TELL YOU HOW PASSIONATE I AM ABOUT THIS ISSUE, BECAUSE CURRENTLY, WHEN FAMILIES WHO DON'T UNDERSTAND OR KNOW THEIR RIGHTS UNDER THE LAW HAVE A VERY DIFFICULT TIME AND ARE OFTEN MET WITH A LOT OF BARRIERS, ILLEGAL OR

OTHERWISE, IN GETTING APPROPRIATE EDUCATIONAL SERVICES FOR THEIR KIDS. SO WE HAVE BEEN REALLY SUCCESSFUL IN TRAINING PARENTS, NOT JUST PARENT LEADERS, BUT EVERY PARENT IN THIS STATE, WHO WOULD AVAILABLE THEMSELVES OF OUR WORKSHOPS IN ORDER HOW TO BE EFFECTIVE TO GET THE SERVICES THAT THEY NEED IN EDUCATION FOR THEIR KIDS.

>> **Leeanne:** I'LL ADD TO THAT ONE OF THE WAYS THAT WE HAVE DONE THAT, ONE OF THE MANY WAYS WE HAVE DONE THAT, IS THROUGH LITERALLY PARTICIPATING AS A PARENT ADVOCATE WITH THE SPECIALIZATION IN DEAFNESS AND HEARING LOSS AT IEP MEETINGS SO THAT'S HOW WE WORK AT THE INTERPERSONAL LEVEL. AT THE SYSTEMS LEVEL WE BECAME INVOLVED WITH OUR STATE DEPARTMENT OF EDUCATION ALMOST 10 YEARS AGO, WITH THE COLORADO SYMPOSIUM ON DEAFNESS, LANGUAGE AND LEARNING, WHICH FOR ALL OF ITS YEARS WAS TARGETED TO PROFESSIONALS. AND WAS THE EVENT WHERE EVERYBODY WENT AND GOT TRAINED ON LATEST EVERYTHING RELATED TO DEAF EDUCATION. WHEN WE BECAME INVOLVED IN IT, FIRST WITH JUST MAKING SOME PRESENTATIONS THERE, WE SAW THE NEED TO PROVIDE AN OPPORTUNITY LIKE THAT TO PARENTS STATEWIDE, SO TO FAST FORWARD TO THE END OF THIS STORY, AT THE CURRENT TIME, WE NOW OFFER THE PARENT STRAND AS PART OF THAT THREE-DAY STATE SYMPOSIUM AND IT IS OFTEN THE MOST WIDELY ATTENDED ASPECT OF OUR SYMPOSIUM. PARENTS ARE SOMETIMES OUTNUMBERING PROFESSIONALS AT THIS CONFERENCE. AND EVERY YEAR, WE SEE MORE AND MORE PEOPLE FROM OUT OF STATE ATTENDING.

SOME PEOPLE ON THIS CALL HAVE PROBABLY PARTICIPATED AT THE SYMPOSIUM. WE SEE THAT AS A VERY, VERY IMPORTANT OUTREACH OPPORTUNITY FOR PARENTS AND PROFESSIONALS TO PARTICIPATE IN THE SAME KINDS OF TRAININGS, BECAUSE WE ALL HAVE THE SAME KINDS OF GOALS. SO WHILE YOU MAY PARTICIPATE IN THE PARENT STRAND, YOU MAY ALSO MINGLE THROUGH AND SIT IN A NUMBER OF PROFESSIONAL SESSIONS THAT ARE OFFERED. THE NEWSLETTER THAT WE DISTRIBUTE QUARTERLY IS WITH EVERY ISSUE BECOMING INCREASINGLY NATIONAL IN SCOPE. WE WANT TO HEAR FROM ALL OF OUR STATE CHAPTERS ABOUT WHAT'S GOING ON. BUT IT ALSO FOCUSES AND WOULD GIVE YOU LOTS OF EXAMPLES OF HOW THE COLORADO MODEL HAS EXPANDED TO ACTUALLY BE PART OF THE SYSTEM THAT SERVES ALL DEAF AND HARD OF HEARING KIDS IN THIS STATE.

>> **Janet:** OUR STATE ORGANIZATION HAS ALSO BEEN INSTRUMENTAL IN LOTS OF LEGISLATION, ADVOCACY, HEARING AID INSURANCE, DEAF CHILD BILL OF RIGHTS, ASL AS FOREIGN LANGUAGE REQUIREMENT. WHEN YOU GET PARENTS IN TO TESTIFY, THE INTERPRETER STANDARDS BILL. SO WE'RE VERY INVOLVED LEGISLATIVELY, AND SO IT'S -- YOU'LL NOTICE OUR FIRST REACTION TO THIS WAS NOT EMOTIONAL SUPPORT TO ONE ANOTHER, WHICH IS REALLY ONE OF THE FOUNDATIONS. WE PROVIDE AND GROW WITH ONE ANOTHER EMOTIONALLY, BUT THAT'S KIND OF TYPICALLY WHAT YOU THINK OF AS A PARENT ORGANIZATION, AND THAT'S ON OUR LIST. BUT WE'RE REALLY INTERESTED IN CREATING CHANGE IN OUR STATE. PARENTS OFTEN ARE ASKED TO SIT ON COMMITTEES AND TASK FORCES, AND WE'VE BEEN IN THIS LONG ENOUGH THAT WE UNDERSTAND THAT WE NEED TO BE AT THE TABLES WHERE DECISIONS ABOUT MONEY ARE BEING MADE IN OUR STATE. SO WE ACTUALLY HAVE REPRESENTATION NOW AT TABLES IN OUR STATE WHERE BUDGETS ARE BEING CONSIDERED, AND DECISIONS ARE BEING MADE. AND SO THOSE ARE JUST A COUPLE OF EXAMPLES.

>> **Leeanne:** WE COULD GO ON AND ON. BUT IF THAT'S -- IF THAT TOUCHES ON WHAT YOU'RE LOOKING AT, YOU CAN SURE E-MAIL US FOR MORE INFORMATION. WE CAN GIVE YOU LOTS MORE EXAMPLES. IF YOU HAVE MORE QUESTIONS OR WOULD LIKE MORE INFORMATION OUR WEBSITE IS [www.handsandvoices.org](http://www.handsandvoices.org) AND OUR EMAIL IS: [parentadvocate@handsandvoices.org](mailto:parentadvocate@handsandvoices.org)

>> **Danielle:** OUR NEXT SPEAKERS ARE LEAU PHILLIPS AND DONENE FEIST FROM FAMILY VOICE AND THEY'LL TALK TO US ABOUT HOW TO ESTABLISH A CHAPTER FOR FAMILY VOICES. WELCOME AND THANK YOU FOR AGREEING TO PRESENT TODAY.

>> **Leau:** DONENE AND I ARE PART OF A NATIONAL NONPROFIT GRASSROOTS ORGANIZATION THAT AT THE PRESENT TIME HAS SOME REPRESENTATIVE EITHER A STATE COORDINATOR OR A CHAPTER REPRESENTATIVE IN ALL 50 STATES, TWO TERRITORIES AND THE DISTRICT OF COLUMBIA. FAMILY VOICES' MISSION IS TO ADVOCATE ON BEHALF OF CHILDREN AND YOUTH WITH SPECIAL HEALTHCARE NEEDS. THAT MEANS THAT WHETHER OR NOT THE SPECIAL HEALTHCARE NEEDS RESULTS IN A DISABILITY PER SAY, WE'RE STILL THERE FOR THEM. SO OUR INTENT WHEN WE DECIDED TO DO THE WHOLE IDEA OF STATE CHAPTERS WAS THAT THERE WOULD BE A FUNDED MANDATE FROM THE GOVERNMENT, THE FAMILY OPPORTUNITY ACT AT SOME POINT AND WE WANTED TO HAVE INDIVIDUALS OR ORGANIZATIONS IN EACH STATE THAT WERE CERTIFIED AS 501C3s THAT COULD APPLY FOR THAT MONEY INSTANTLY TO BE FUNDED TO BE A FAMILY TO FAMILY HEALTH INFORMATION CENTER.

IT HASN'T EXACTLY TURNED OUT THAT WAY BUT THERE WAS A LOT OF RESEARCH DONE ON CHAPTER DEVELOPMENT, AND WHAT NEEDED TO GO INTO CHAPTERS AND HOW BOARDS NEEDED TO BE SET UP, AND WE CAME UP WITH THE CHECKLISTS THAT WERE ON THE -- AS PART OF OUR HANDOUTS. AND WE HAVE TWO DIFFERENT OPPORTUNITIES FOR PEOPLE TO BE CHAPTERS. WE CAN EITHER BE STAND-ALONE CHAPTERS, THE MOM AT THE KITCHEN TABLE, WHICH SEEMS TO BE QUITE SUCCESSFUL FOR US, AND WE ALSO HAVE THE OPTION OF BEING A CHAPTER AT AN EXISTING NONPROFIT. AND THOSE PLACES HAVE THE OPPORTUNITY TO USE THE SAME BOARD OF DIRECTORS, THE SAME AUDIT, THE SAME 501C3 STATUS AS THEIR PARENT ORGANIZATION, EXCUSE ME, BUT THEY CAN ALSO -- THEY ALSO HAVE TO HAVE AN ADVISORY COMMITTEE SPECIFIC TO HEALTHCARE ISSUES. SO WE HAVE PEOPLE WHO HAVE CHAPTERS. IT TURNED OUT THAT WE HAVE 16 CHAPTERS AFTER ABOUT I DON'T KNOW HOW MANY YEARS, DONENE, 8 YEARS OF DEVELOPING CHAPTERS?

WE ARE 16 CHAPTERS, AND IT'S ABOUT HALF AND HALF. HALF ARE PEOPLE LIKE DONENE, WHO DEVELOPED THEIR OWN FREESTANDING NONPROFIT ORGANIZATION, AND THE OTHER HALF ARE AT PARENT TRAINING INFORMATION CENTERS, THEY'RE AT PARENT TO PARENTS. THE ONE IN COLORADO IS AT C.P. OF COLORADO SO WE'VE HAD, YOU KNOW, AGAIN, AS LEEANNE AND JANET SAID, THE WHOLE IDEA OF EVERY STATE DETERMINING HOW THEY NEED TO DO IT IS WHAT WE WENT WITH. SOME OF THE LESSONS WE LEARNED IN CHAPTER DEVELOPMENT [ BEEPING ] BECAUSE WE HAD SOME MONEY TO HELP PEOPLE DO SOME CHAPTERS AND TO DEVELOP SOME CHAPTERS BUT IN SOME INSTANCES WE KIND OF FEEL LIKE YOU KNOW THAT LITTLE TOWN THAT GATHERS UP ALL THE MONEY TO SEND THEIR STAR STUDENT OFF TO COLLEGE SO THEY'LL COME BACK AND BE THE TOWN DOCTOR? AND THEN WHEN THEY GET THROUGH SCHOOL, THEY DECIDE THEY'D RATHER PRACTICE IN AN E.R. IN THE INNER CITY? SO WE HAVE SOME CHAPTERS THAT WHILE WE'RE INCREDIBLY PROUD OF THE IMPACT THEY HAVE IN THEIR OWN STATE, BUT THERE'S NOT A LOT OF RECIPROCITY FOR THE NATIONAL ORGANIZATION. AND SO SOME OF THE LESSONS THAT WE LEARNED ARE THAT YOU NEED TO HAVE VERY CLEARLY DEFINED EXPECTATIONS OF BOTH THE PARENT ORGANIZATION AND THE CHAPTERS. SO THAT THERE IS SOME RECIPROCITY SO YOU GET TO BE A CHAPTER AND USE THIS, AND THEN THIS IS WHAT COMES BACK TO US.

BECAUSE WE WERE LOOKING AT FUNDED CHAPTERS. WE WEREN'T JUST LOOKING AT ORGANIZATIONS. NOW, WE DO HAVE AMAZING RELATIONSHIPS WITH ALL OF THESE PEOPLE. IT'S JUST THERE'S NOT A LOT OF BENEFIT TO THE NATIONAL ORGANIZATION, BECAUSE IT WASN'T CLEARLY THOUGHT OUT AT THE TIME. WE WERE JUST TRYING TO GET THOSE PEOPLE WITH A NONPROFIT STATUS SO THAT THEY COULD GET THE MONEY FROM THE FAMILY OPPORTUNITY ACT, WHICH STILL HASN'T PASSED. ANOTHER LESSON WE LEARNED IS THAT PEOPLE HAVE TO BE GIVEN THE OPPORTUNITY TO GO WITH THE EBB AND FLOW OF THEIR LIVES. SO WHILE PEOPLE CAN BE INCREDIBLY ACTIVE AS A CHAPTER OR AS A STATE COORDINATOR FOR FIVE OR SIX YEARS THERE HAS TO BE THAT FLEXIBILITY TO ALLOW THEM TO STEP BACK AND HAVE SOMEBODY ELSE STEP IN IF THEIR LIFE CHANGES. AND THAT SEEMS TO BE ONE OF THE THINGS THAT WE DO BEST. DONENE CAN TALK TO YOU ABOUT THE CHAPTER FROM THE PERSPECTIVE OF BEING A CHAPTER AND HAVING GONE THROUGH THAT

PROCESS.

>> **Donene:** AS THE OTHER TWO GIRLS INDICATED AND LEAU, IT'S NOT AN EASY PROCESS AND IT WAS SOMETHING THAT WE HAD TO -- WE HAD TO -- I HAVE A BOARD AND WE HAD TO REALLY SIT DOWN AND IDENTIFY WHAT OUR GOALS WERE, IF THIS IS SOMETHING THAT WE WERE READY FOR, BECAUSE PART OF THAT WAS INCORPORATING AS A NONPROFIT AND THAT WAS PROBABLY THE BIGGEST PUSH BEHIND US STARTING A STATE CHAPTER, IS YOU CAN'T APPLY FOR ANY FUNDING, WHETHER IT BE STATE, FEDERAL, LOCAL, FOUNDATION MONEY, WHATEVER, TO DO SOME SYSTEMS CHANGE AND EDUCATION AND PUT OUT NEWSLETTERS UNLESS YOU HAVE SOME FUNDING SO THAT WAS KIND OF OUR EMPHASIS FOR GETTING GOING.

ONE THING I WILL HAVE TO SAY IS WE DID LOOK AT INCORPORATING UNDER AN EXISTING NONPROFIT, OR STARTING OUR OWN. AND THAT WAS SOMETHING THAT WE STRUGGLED WITH FOR A VERY LONG TIME. AND WE MET ABOUT THAT MANY, MANY TIMES. WE DECIDED TO INCORPORATE AS OUR OWN CHAPTER OF THE FAMILY VOICES NATIONAL, AND ONE OF THE REASONS THAT WE DECIDED TO DO THAT WAS BECAUSE MY BIGGEST FEAR AS THE DIRECTOR OF OUR STATE CHAPTER WAS THAT WE WOULD INCORPORATE UNDER SOMEBODY ELSE'S NONPROFIT OR THEIR UMBRELLA AND THEN THE DIRECTOR WOULD CHANGE AND THEN WE WOULD HAVE TO GO THROUGH THIS WHOLE PROCESS AGAIN AND I DIDN'T WANT TO HAVE TO PUT EITHER MY BOARD OR THE PARENTS THAT SERVE ON MY BOARD OR THE PROFESSIONALS THROUGH THAT. SO WE DECIDED TO INCORPORATE ON OUR OWN WAS ONE OF THE BIGGEST REASONS WHY WE DECIDED TO DO THAT. NORTH DAKOTA DOESN'T HAVE A LOT OF FUNDING, SO WE'RE -- ALTHOUGH WE ARE A STATE CHAPTER, WE DO HAVE SOME STRUGGLES STILL. EVEN WITH SOME FUNDING. SO IT'S NOT SOMETHING THAT YOU JUST JUMP INTO AND YOU HAVE FUNDING BECAUSE IT'S A LOT OF WORK. I DON'T KNOW, LEAU, DO YOU WANT TO ADD ANYTHING ELSE?

>> **Leau:** I THINK THAT OUR INTENT IS DIFFERENT THAN HANDS & VOICES. BECAUSE WE WERE LOOKING TO ESTABLISH THESE FAMILY TO FAMILY HEALTH INFORMATION CENTERS, AND WE DO HAVE 16 OF THEM. RIGHT NOW. BECAUSE PEOPLE WERE FUNDED IN A VARIETY OF WAYS, NOT THROUGH THE FEDERAL -- OR FAMILY OPPORTUNITY ACT. BUT THE IDEA -- IT IS A LOT OF WORK TO INCORPORATE AS YOUR OWN INDIVIDUAL 501C3. WE'VE PROVIDED A LOT OF TECHNICAL ASSISTANCE AROUND WRITING ARTICLES OF INCORPORATION, AND HOW TO ESTABLISH A BOARD. AND WORKING WITH PEOPLE TO KEEP THEIR BOARD ON TASK, AND, YOU KNOW, THOSE KIND OF THINGS. AND SO IT'S TURNED OUT TO BE A LOT OF WORK TO DO WITHOUT THE BACKING OF THE FAMILY OPPORTUNITY ACT. I DON'T THINK PEOPLE REGRET IT EXACTLY, BUT I KNOW THAT IT'S JUST BEEN A REAL STRUGGLE. AND I DON'T MEAN TO SOUND NEGATIVE BECAUSE THERE'S A LOT OF POSITIVE STUFF THAT HAS COME OUT OF THE CHAPTER DEVELOPMENT. AND A LOT OF OUR CHAPTERS ARE FUNDED THROUGH NCHB OR THROUGH MEDICAID TO BE THESE FAMILY TO FAMILY HEALTH INFORMATION CENTERS BUT THERE'S ALSO BEEN A LOT OF YEARS OF WAITING AND THEY STILL ADVOCATE AND THEY STILL VOLUNTEER IN THEIR STATE AND THEY STILL SERVE ON ALL OF THE COMMITTEES AND DO THE GOOD WORK THEY'VE ALWAYS DONE. THEY'RE STILL JUST DOING IT AS A VOLUNTEER. I WAS GOING TO ASK AT THIS POINT IF ANYBODY HAD ANY QUESTIONS.

>> **DR. PAT EL:** THIS IS DR. PATEL CALLING FROM CHICAGO. I DON'T KNOW IF ILLINOIS HAS A CHAPTER OR NOT. DO YOU KNOW ANYTHING ABOUT ILLINOIS?

>> **Leau:** ILLINOIS DOES NOT HAVE A CHAPTER. WE HAVE SOME FAMILY VOICES REPRESENTATIVES THERE. THEY DID NOT GO ALL THE WAY TO FILLING OUT, TO DOING THE CHAPTER DEVELOPMENT TO THE END. BUT, YES, THERE ARE -- THERE ARE FAMILY VOICES NETWORK MEMBERS IN ILLINOIS. THE WAY THAT WE DESIGNATE PLACE NETWORK MEMBERS AS PEOPLE WHO HAVE AGREED TO DO A SERIES OF THINGS, LIKE COLLECT DATA AND BE ON REGIONAL CONFERENCE CALLS AND REGIONAL LISTSERVS, AND SUBMIT SOME INFORMATION TO THE NATIONAL OFFICE. WE HAVE ABOUT 40,000 GENERAL MEMBERS WHO ARE PEOPLE WHO RECEIVED OUR INFORMATION, WHO CALL US FOR INFORMATION, OR CALL THEIR STATE

REPRESENTATIVES FOR INFORMATION. SO WE HAVE 120 -- OR 114 NETWORK MEMBERS THAT ARE DESIGNATED THAT IF SOMEBODY CALLS INTO OUR NATIONAL OFFICE, WE'LL GIVE THEM THAT PERSON IN THE STATE, AND SO WE DO HAVE TWO PEOPLE IN ILLINOIS.

>> **DR. PATEL:** DO YOU HAVE THEIR NAMES?

>> **Leau:** YES I DO. CALL OUR 800 NUMBER AND WE'LL GIVE THEM TO YOU. IT'S 8 -- OH 1-888, 835-5669. BE SURE YOU DON'T DIAL 1-800 BECAUSE THEN YOU GET A PORN LINE.

>> **Donene:** IN NORTH DAKOTA WE'RE SET UP AS A HEALTH INFORMATION AND EDUCATION CENTER ALTHOUGH WE DON'T RECEIVE THE FEDERAL MONEY FROM CMS OR MCHB BUT WE DO DO A LOT OF INFORMATION FOR FAMILIES, A LOT OF TIMES FAMILIES DON'T KNOW WHERE TO GO REGARDING THEIR HEALTHCARE. THEY DON'T KNOW WHERE TO GO. WE DON'T HAVE A LOT OF FAMILY ORGANIZATIONS IN NORTH DAKOTA. WE HAVE TWO. WE HAVE OUR PARENT TO PARENT, WE HAVE FAMILY VOICES, AND WE HAVE THE FEDERATION OF FAMILIES. SO THERE'S A REAL SEPARATION AS FAR AS WHERE FAMILIES CAN GO TO GET INFORMATION. AND THAT WAS ONE OF THE OTHER REASONS WHY I KIND OF WANTED TO INCORPORATE AS OUR OWN NONPROFIT, SIMPLY BECAUSE -- AND WE ALSO HAVE OUR PARENT TRAINING AND INFORMATION CENTERS AS WELL, BUT WE DIDN'T HAVE WHAT A LOT OF STATES ARE VERY COMFORTABLE WITH SO WE WANTED TO MAKE SURE WE HAD THE SAME OPPORTUNITIES FOR OUR FAMILIES IN NORTH DAKOTA. THERE AGAIN, YOU HAVE TO WEIGH OUT THE NEEDS OF YOUR STATE AND HAVE SOME REAL HONEST DIALOGUE ON HOW THINGS ARE GOING TO BE SUSTAINING.

>> **Leau:** ANY OTHERS?

>> **UNKOWN:** THIS IS OMAHA AGAIN. HOW ARE YOU DIFFERENT FROM THE AMERICAN SOCIETY FOR DEAF CHILDREN?

>> **Donene:** ONE THING FOR FAMILY VOICES IS WE FOLLOW THE MATERNAL AND CHILD HEALTH BUREAU DEFINITION OF A CHILD WITH SPECIAL HEALTHCARE NEEDS. SO THEY MIGHT HAVE -- BE A CHILD WITH A CHRONIC HEALTH ILLNESS OR A DISABILITY OR A MENTAL HEALTH ILLNESS AND THAT'S WHERE WE'RE DIFFERENT. I DON'T KNOW ABOUT THE OTHER ORGANIZATION.

>> **UNKOWN:** THAT QUESTION WAS DIRECTED TOWARDS HANDS & VOICES OR IF WE MAY JUST SUBMIT A RESPONSE TO IT EVEN IF IT DOESN'T. THE SOCIETY FOR DEAF CHILDREN DOES HAVE AT ITS CORE VALUES THE COMMITMENT TO USING AMERICAN SIGN LANGUAGE OR SIGNED COMMUNICATION WITH CHILDREN WHO ARE DEAF OR HARD OF HEARING AND PROVIDING THAT KIND OF SUPPORT. AND HANDS & VOICES, WE HAVE MEMBERS OF OUR ORGANIZATION WHO ARE ALSO MEMBERS OF AMERICAN SOCIETY FOR DEAF CHILDREN BUT THEY MAY -- WE MAY ALSO HAVE MEMBERS, AND DO ALSO HAVE MEMBERS, FROM AUDITORY-VERBAL INTERNATIONAL, OR FROM A.G. BELL, OR FROM ANY STATE ASSOCIATION FOR THE DEAF. BECAUSE WE DON'T RALLY AROUND ONE NOTION OF A SUPERIOR COMMUNICATION MODALITY, BUT RATHER THAT FAMILIES HAVE THE RIGHT TO MAKE GOOD CHOICES FOR THEIR OWN KIDS, AND WILL IF THEY GET GOOD INFORMATION. WE HAVE PEOPLE FROM ALL OF THOSE DIFFERENT PERSPECTIVES WHO ARE PART OF OUR ORGANIZATION. SO THAT WOULD MAKE US UNIQUE FROM AMERICAN SOCIETY FOR DEAF CHILDREN.

>> **JANET:** LET ME JUST ADD TOO IN TERMS OF PROFESSIONALS WHO ACCESS OUR ORGANIZATION AND UTILIZE OUR ORGANIZATION IN DIFFERENT WAYS BY ASKING TO BE A PART OF COMMITTEES. WHAT WE FOUND IS THEY FEEL COMFORTABLE IN ASKING OUR ORGANIZATION TO REPRESENT. THEY KNOW THAT WE WILL REPRESENT FAMILIES ACROSS THE SPECTRUM, SO WE'RE ABLE -- SO INSTEAD OF HAVING TO ASK THREE OR FOUR DIFFERENT PARENTS PER SE TO BE ON A COMMITTEE SOMETIMES THEY'LL ASK OUR

ORGANIZATION BECAUSE WE'LL BE REPRESENTATIVE OF THE ENTIRE SPECTRUM OF FAMILIES.

>> **Danielle:** ARE THERE ANY MORE QUESTIONS FOR ANY OF OUR SPEAKERS?

>> **KYRA MURPHY:** I HAVE A QUESTION. THIS IS KYRA MURPHY. I AM HERE IN NEW ORLEANS, LOUISIANA. I'M THE PARENT COORDINATOR OF THE HEARING, SPEECH AND VISION PROGRAM. AND MY DAUGHTER HAS A PROFOUND BILATERAL HEARING LOSS. SHE'S 5 AND A HALF. HER NAME IS EVE. AND I HAVE BEEN LOOKING TO STARTING A CHAPTER FOR A WHILE NOW. I HAVE TWO QUESTIONS. ONE IS --

>> **Danielle:** WHICH ORGANIZATION WERE YOU THINKING OF STARTING A CHAPTER?

>> **Kyra:** HANDS & VOICES. SORRY. ONE QUESTION IS, WHEN FORMING A GROUP, I GUESS IT WOULD BE FOR NUMBER ONE IN THE FIVE STEPS, WHEN FORMING A GROUP, ARE YOU SPEAKING OF PARENTS, OR ARE YOU SPEAKING OF THE RECOMMENDED REPRESENTATION ON THE ADVISORY BOARD?

>> **Leeanne:** LET ME JUST MAKE SURE WE UNDERSTAND YOUR QUESTION. YOU'RE ASKING FOR -- IN THE START-UP, NUMBER 1, OF THE BOARD OF DIRECTORS FOR YOUR ORGANIZATION. THAT LIST, THE RECOMMENDED REPRESENTATION, IS FOR THE BOARD OF DIRECTORS FOR THE ORGANIZATION, YES. THAT'S THE ANSWER.

>> **Janet:** SOMETIMES A GROUP IS TWO PARENTS, TWO PARENTS WHO COME TOGETHER AND SAY, LET'S START A HANDS & VOICES CHAPTER AND THIS IS SOMETHING THAT I THINK WE CAN GET BEHIND, BECAUSE THIS NEEDS AN UNBIASED APPROACH TO SUPPORTING FAMILIES. AND SO IT CAN BE COMPRISED OF TWO PEOPLE IN THE VERY BEGINNING TO GET THE BALL ROLLING BUT THEN IT GROWS FROM THERE.

>> **Leeanne:** ALSO, I THINK WE WERE JUST TALKING ABOUT THIS THE OTHER DAY, THAT AS YOU BUILD YOUR CONSENSUS OF DIFFERENT PEOPLE, YOU KNOW, YOU'RE NOT GOING TO HAVE EVERY SINGLE POSSIBLY EVERY SINGLE ONE OF THESE ELEMENTS ON YOUR BOARD ALL THE TIME. AT DIFFERENT TIMES, PEOPLE KIND OF COME AND GO, OR MAYBE A PERSON CAN WEAR MORE THAN ONE HAT OR ANYTHING. THIS IS JUST KIND OF WHAT WE'VE FOUND OVER THE YEARS, AND LOOKING AT COLORADO AS A MODEL OF THAT. BUT IT HAS TO REALLY START WITH A FOUNDATION OF PEOPLE WHO CAN REALLY ENDORSE AND EMBRACE THE PRIMARY MISSION AND VISION OF THE ORGANIZATION. THAT'S REALLY THE MOST IMPORTANT THING. AND THEN LIKE LEEANNE SAID, IT KIND OF GROWS FROM THERE. BUT TO TELL YOU THE TRUTH, IN EACH STATE, IT HAS BEEN ONE OR TWO PARENTS KIND OF RUNNING WITH IT, AND THEN RALLYING PEOPLE, SOMETIMES VERY QUICKLY, SOMETIMES A LITTLE SLOWER, AROUND THAT. DOES THAT ANSWER YOUR QUESTION?

>> **Kyra:** YES. BUT ALSO, WHENEVER YOU ARE SENDING IN YOUR APPLICATION FOR APPROVAL, YOU HAVE TO HAVE THAT BOARD TOGETHER. AND HOW MANY -- HOW BIG OF A GROUP, OR HOW DIVERSE, DOES IT HAVE TO BE FOR APPROVAL?

>> **Leeanne:** THE LIST OF PEOPLE THAT WE RECOMMEND FOR REPRESENTATION ON YOUR BOARD? THE ORGANIZATIONAL MANUAL. IT'S NOT A REQUIREMENT, THOUGH, THAT YOU HAVE EVERY SINGLE PERSON THAT WE HAVE RECOMMENDED FOR REPRESENTATION ON THERE. IN OTHER WORDS, IF YOU ARE HAVING DIFFICULTY FINDING SOMEBODY WHO COULD REPRESENT A PERSPECTIVE AROUND CUED SPEECH, YOU KNOW, THAT DOESN'T MEAN THAT YOU CAN'T SEND YOUR APPLICATION IN UNTIL THAT'S FILLED. THE NOTION HERE IS NOT REALLY TO GET T's CROSSED, I's DOTTED, BUT TO SOMEHOW LOOK AT THE PEOPLE AS BEING IN SOME WAY REPRESENTATIVE OF A HETEROGENOUS VISION OF EFFECTIVE SYSTEMS, EDUCATIONAL SYSTEMS, AND SUPPORT FOR FAMILIES. SO IT MIGHT BE A GROUP OF ONLY A HALF A DOZEN PEOPLE, WITH, YOU KNOW, ROOM TO GROW, OR IT MIGHT BE A DOZEN PEOPLE.

BUT IT'S USUALLY SOMEWHERE IN BETWEEN THERE, AND BY THE REQUIREMENT OF THE BYLAWS, THERE WILL ALWAYS BE A MAJORITY OF PARENTS ON THE BOARD.

>> **Janet:** ALSO, IT'S NOT JUST THE TECHNICALITY OF GETTING APPROVED. IT'S REALLY THE FOUNDATION OF WHO THE COMMUNITY WILL REALLY SEE YOU AS IN AN ORGANIZATION. YOU KNOW, THE POINT AROUND HAVING PROFESSIONALS ON YOUR BOARD FOR US ISN'T -- IS BECAUSE WE'RE COLLABORATIVE BY NATURE, BUT THOSE VERY PROFESSIONALS ON YOUR BOARD ARE OFTEN THE ONES THAT CAN HELP FIND FUNDING SOURCES, OR IN-KIND PRINTING OR JUST PRACTICALLY SPEAKING, THAT LIST IS REALLY TO HELP THE ORGANIZATION GET OFF THE GROUND. AND THEN AS YOU GO OUT AND ARE, YOU KNOW, ENDORSING THIS ORGANIZATION WITHIN YOUR STATE, PEOPLE WILL BE LOOKING TO SEE WHO IS A PART OF YOUR BOARD, TO SEE IF YOU TRULY ARE, YOU KNOW, HAVE THAT DIVERSITY OF PERSPECTIVE, AND SO WHILE STILL -- WHILE STILL EACH INDIVIDUAL EMBRACING THE MISSION AND THE THEME OF HANDS & VOICES. SO YOU KNOW, EVEN HERE IN COLORADO, WE DON'T LOOK AROUND AND MAKE SURE NECESSARILY ALL THE TIME THAT EVERY HAT IS FILLED, BUT THERE IS A LEVEL OF CREDIBILITY IN OUR STATE WHEN WE KNOW THAT DIVERSITY AT THE LEADERSHIP EXISTS. IT'S HARD TO SAY. WE SUPPORT ALL THE CHOICES THAT FAMILIES MAKE AND WE JUST HAPPEN TO HAVE SIX PARENTS WHO ALL HAVE KIDS WITH COCHLEAR IMPLANTS OR ALL HAVE KIDS WHO USE ASL. SO PRACTICALLY SPEAKING, DIVERSITY IS HELPFUL IN JUST BUILDING CREDIBILITY IN YOUR STATE.

>> **BARBARA NICODEMIS:** HI, THIS IS BARBARA NICODEMIS FROM TENNESSEE. I'M A PEDIATRIC AUDIOLOGIST, A CONSULTING AUDIOLOGIST FOR NEWBORN HEARING SCREENING. I HAVE A QUESTION. I ALSO WORK WITH THE TIPS PROGRAM, TENNESSEE INFANT PARENT SERVICE PROGRAM. I'M HAVING A KICKOFF MEETING FOR A PARENT GROUP ON MONDAY WHICH IS FOR PARENTS THAT ARE INTERESTED IN STARTING A PARENT GROUP IN EAST TENNESSEE. THEY HAVE VOICED THAT THEY ARE INTERESTED IN SETTING UP A WEBSITE FOR EAST TENNESSEE FAMILIES OF NEWLY IDENTIFIED CHILDREN WITH HEARING LOSS. I WAS WONDERING IF FAMILY VOICES OR HANDS & VOICES IF THEY HAVE AN AVENUE FOR GROUPS TO PUT A WEBSITE OUT.

>> **Leau:** THIS IS LEAU WITH FAMILY VOICES. WE HAVE STATE PAGES UP ON OUR WEBSITE. THEY CAN CERTAINLY ADD THEIR LINK TO THAT. BUT WE DON'T HAVE ANY WAY TO SUPPORT A WEBSITE. WE DON'T HAVE OUR OWN SERVER OR ANYTHING LIKE THAT MAYBE THEY WANT TO CONTACT THE FAMILY VOICES OF TENNESSEE, KENTUCKY, ISN'T IT?

>> **UNKNOWN:** THIS IS TENNESSEE WE HAVE A FUNDED SITE IN TENNESSEE AT THE TENNESSEE COALITION FOR DISABILITY. DARA HOWE IS OUR PERSON THERE THAT COULD PROBABLY GIVE YOU SOME -- THEY HAVE A LOT OF RESOURCES AT THAT -- IT'S FAMILY VOICES AT THE TENNESSEE DISABILITY COALITION.

>> YES, BUT THE INDIVIDUAL'S NAME THAT YOU SAID?

>> **Leeanne:** THIS IS LEEANNE AT HANDS & VOICES. I WANTED TO SAY I LIKE WHAT WE JUST HEARD, AT HANDS & VOICES WE ALSO HAVE A NATIONAL WEBSITE, AND WE ARE IN FACT RIGHT NOW, THANKS TO THE MARION DOWNS HEARING CENTER COOPERATIVE AGREEMENT, RAMPING UP OUR WEBSITE TO MORE INCLUSION AND TECHNICAL SUPPORT FOR OUR STATE CHAPTERS. WE WILL IN SHORT ORDER HAVE THE ABILITY FROM OUR HOME PAGE TO IMMEDIATELY LINK TO THE HANDS & VOICES CHAPTER IN ANY STATE. SO NOT ONLY WILL WE BE DOING THAT AND CROSS-PROMOTING ONE ANOTHER, BUT WE ALSO HAVE TECH SUPPORT ON STAFF TO HELP FAMILIES, AND LOCAL CHAPTERS SET UP THEIR WEBSITE AND UNDERSTAND THE LINKING PIECES TO HAVE THE ABILITY TO ALSO CHAT WITH EACH OTHER AND DO [ INAUDIBLE ] WORKING ON A METHOD FOR OTHER KINDS OF FEATURES.

>> **UNKNOWN:** I'M REAL EXCITED ABOUT STARTING THIS. I HAVE A SON WHO HAS A MILD HEARING LOSS, IT'S A PROGRESSIVE KIND OF THING. BUT BASICALLY I'M CONSIDERED A PROFESSIONAL BECAUSE I'M IF I'VE BEEN WORKING IN THE FIELD BUT THERE'S THESE FOUR

FAMILIES WHO ARE COMING TOGETHER TO REALLY START SOME SORT OF SUPPORT GROUP HERE, AND ON THE AGENDA IS TO CONTACT FAMILY VOICES. AND I'M DEFINITELY GOING TO GIVE THEM THE INFORMATION ON HANDS & VOICES, ALSO.

>> **Donene:** THIS IS DONENE IN NORTH DAKOTA. I WAS GOING TO SAY WHETHER IT BE FAMILY VOICES OR THE OTHER ORGANIZATION I THINK IT WOULD BE BENEFICIAL FOR ALL FAMILIES TO GET IN TOUCH WITH THE FAMILY VOICES STATE COORDINATOR IN EACH STATE. THERE MIGHT BE A POSSIBILITY THAT MAYBE THAT STATE HASN'T DEVELOPED A CHAPTER YET AND THERE MAY BE INTEREST OUT THERE. OR THEY MAY WANT TO GET INVOLVED IN SOME OF THE ACTIVITIES THAT ARE GOING ON IN EACH STATE. IN NORTH DAKOTA, I ALSO HAVE A SON WITH A PRETTY PROFOUND HEARING IMPAIRMENT ACTUALLY, SO I'M IN TOUCH WITH THE OTHER FAMILIES IN NORTH DAKOTA THAT ALSO HAVE A CHILD WITH A HEARING IMPAIRMENT. BUT NOT ONLY ARE WE INVOLVED WITH THOSE FAMILIES, PER SE, BUT WE'RE INVOLVED WITH THE FAMILIES ACROSS THE STATE THAT HAVE CHILDREN WITH DISABILITIES AND CHRONIC HEALTH ILLNESS OF ALL KINDS. SO I THINK THERE'S BENEFIT FROM BOTH ORGANIZATIONS TO GET INVOLVED. SO THAT WAS SOMETHING I WAS GOING TO SAY.

>> **UNKNOWN:** I THINK THAT'S A REALLY GOOD POINT AND I WANT TO ADD THAT THE PRESIDENT OF OUR COLORADO HANDS & VOICES CHAPTER IS ONE OF THE CO-DIRECTORS OF COLORADO FAMILY VOICE, AS WELL. SO LINKING TO EXISTING RESOURCES IS A HUGE, HUGE PRIORITY IN OUR ORGANIZATION.

>> **Danielle:** I THINK WE SHOULD PROBABLY WRAP UP. I HATE TO CUT OFF A REALLY LIVELY DISCUSSION. I THINK WE'RE ENDING ON A REALLY POSITIVE NOTE HERE. SO I'D LIKE TO THANK YOU ONCE AGAIN FOR OUR SPEAKERS, AND THEIR WONDERFUL PRESENTATIONS. AND ALSO THANK EVERYBODY FOR CALLING IN. THE NEXT AD HOC TELECONFERENCE WILL BE ON NOVEMBER 2ND AT 2:00 EASTERN TIME. WE'LL ANNOUNCE THE TOPIC CLOSER TO THAT DATE. THE NEXT SPECIAL TOPICS TELECONFERENCE WILL BE ON OCTOBER 26 AT 3:00 EASTERN TIME. AND WE'LL ANNOUNCE THAT TOPIC, ALSO, CLOSER TO THE DATE. SO THANK YOU VERY MUCH, EVERYBODY. AND HAVE A GOOD WEEK.

[ END OF CALL - 3:05 P.M. EST ]

**Roughly Edited Transcript**