

FUNDING CUTS AND REDUCTIONS IN SERVICES BY THE DIVISION OF
MENTAL RETARDATION SERVICES

PUBLIC FORUM

NASHVILLE, TENNESSEE, MARCH 10, 2008

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>> WE'RE GOING TO WAIT ANOTHER -- WE'RE GOING TO WAIT ANOTHER FIVE MINUTES FOR PEOPLE TO COME AND THEN WE'LL START IN JUST A FEW MINUTES.

THANK YOU.

>> WE'RE GOING TO BEGIN.

I WANT TO WELCOME EVERYBODY TO THE PUBLIC FORUM FOR NASHVILLE.

THERE ARE SOME PEOPLE COMING IN.

SO WELCOME.

I WANT TO DO A FEW HOUSEKEEPING CHORES.

GO OVER THE AGENDA AND THE PURPOSE OF TONIGHT IS TO TALK ABOUT THE DMRS FUNDING CUTS AND SERVICE REDUCTIONS AND TO

DO A BRIEF OVERVIEW AND EXPLAIN THEM AND PRIMARILY TO HEAR FROM YOU ABOUT ISSUES THAT YOU'RE HAVING, ISSUES THAT YOU'VE HAD AND CONCERNS THAT YOU HAVE.

AND SO THAT WILL BE PEOPLE COMING UP AND SPEAKING ABOUT THAT.

THE FIRST THING THAT I WANT TO DO IS SOME HOUSEKEEPING DETAIL.

THE BATHROOMS ARE IN THE BACK.

WE HAVE WHAT'S CALLED CART WHICH IS FOR PEOPLE HARD OF HEARING TO BE ABOUT TO VISUALIZE.

THIS WILL ALSO CREATE A TRANSCRIPT SO THERE WILL BE A TRANSCRIPT OF TONIGHT AND ANYBODY WHO SIGNED UP AND IS REGISTERED SO IF ANYBODY HASN'T, LET ME ENCOURAGE YOU, I WILL SENDS A COPY OF THE MANUSCRIPT TO YOU AND DISTRIBUTE THAT SO YOU'LL BE AWARE OF THE ISSUES THAT PEOPLE HAVE.

OVER HERE WE HAVE TWO INTERPRETERS.

IF ANYBODY NEEDS INTERPRETATION OR HELP WITH THAT, PLEASE COME UP FRONT AND SIT UP HERE IN FRONT.

SO THOSE ARE SORT OF THE BACKGROUND PIECES.

THERE IS A HANDOUT.

HANDOUTS IN YELLOW.

THEY ARE ON THE BACK TABLE.

PLEASE GET A COPY.

THERE ARE A NUMBER OF DESCRIPTIONS OF THINGS THAT CAN BE HELPFUL.

PEOPLE CALL AND GO OVER THOSE THINGS THIS EVENING BUT THAT'S MORE DETAILED AND BE ABLE TO HELP YOU.

FIRST I WANTED TO REVIEW THE AGENDA.

PLEASE, COME IN, COME IN.

COME IN.

WELCOME.

COME JOIN US.

PLEASE GO BACK AND REGISTER.

WE HAVE MARTHA BEST WHO WANTED TO GIVE A WELCOME TO PEOPLE.

>> I WOULD BE HAPPY TO.

MY NAME IS MARTHA BEST DEWITT.

I'M ON STAFF HERE AT WESTMINSTER PRESBYTERIAN CHURCH AND IT IS MY PRIVILEGE TO WELCOME YOU ON BEHALF OF THE CHURCH TO THIS HEARING.

YOU ARE WELCOME IN THIS SPACE, ANYWHERE IN THIS SPACE, AND WE HOPE THAT WE ARE ABLE TO PROVIDE FOR YOU A COMFORTABLE SETTING SO THAT THESE CRITICAL ISSUES CAN BE DISCUSSED AND WE CAN SHARE TOGETHER THE WORK THAT WE ALL DO FOR JUSTICE.

THANK YOU TO THOSE OF YOU WHO HAVE ORGANIZED THIS, TO ALL

OF THE AGENCIES THAT HAVE BEEN PART OF PUTTING TOGETHER
THIS HEARING, AND LET US KNOW IF YOU NEED ANYTHING.

YOU'RE WELCOME HERE.

WE'RE GLAD THAT YOU ARE.

THERE ARE HOUSEKEEPING THINGS.

THERE ARE RESTROOMS JUST THROUGH THE DOORS, ACROSS THE ROOM
FROM ME IMMEDIATELY TO THE RIGHT.

AND SOME PEOPLE HAVE PARKED IN FRONT AND WALKED ALL THE WAY
THROUGH THE BUILDING.

AND I'M SORRY THAT YOU DIDN'T KNOW TO COME AROUND AND PARK
RIGHT HERE AND COME UP THE ELEVATOR BUT THE BUILDING WILL
BE OPEN.

YOU SHOULD HAVE NO TROUBLE GETTING BACK OUT THE WAY YOU
CAME AFTER THE MEETING.

>> THANK YOU VERY MUCH.

AND I ALSO WANT TO THANK THE CHURCH FOR HOSTING US AND
HAVING US HERE.

WE REALLY APPRECIATE THAT.

WE'LL JUST GO THROUGH THE AGENDA OF WHAT WE'LL HAVE
TONIGHT.

FIRST, I'M MARK FRIEDMAN.

I'M DIRECTOR OF MIDDLE TENNESSEE ADVOCACY CENTER.

WE PROVIDE ADVOCACY TO PEOPLE WHO ARE CLASS MEMBERS OF PART OF THE SETTLEMENT AGREEMENT, PRIMARILY PEOPLE FROM CLOVER BOTTOM.

I'LL GO THROUGH OUR LIST OF SPONSORS IN A MOMENT.

WE'LL HAVE AN OVERVIEW THAT I'M GOING TO DO WHICH WE'LL USE A HANDOUT THAT I WANT TO MAKE SURE EVERYBODY GETS A COPY OF.

IF YOU CAME IN ON THE FRONT AND SIDES, DESCRIBING THE MONEY REDUCTIONS AND SERVICE CUTS AND DO AN OVERVIEW OF.

THAT SECONDLY THERE WILL BE QUESTIONS AND ANSWERS FROM THE AUDIENCE, SPECIFIC TO THE FUNDING CUTS AND UNDERSTANDING THEM.

WE'LL GET THROUGH THAT, YOU KNOW, 20 MINUTES.

AND THEN WHAT WE REALLY WANTED TO COME TO, THE HEART OF IT IS TIME FOR YOU TO TALK ABOUT YOUR OWN EXPERIENCES, SERVICE REDUCTIONS, PROBLEMS THAT YOU'RE HAVING, ISSUES YOU FACE, THINGS THAT YOU'RE CONCERNED ABOUT.

SO THAT'S THE TIME AND THAT'S THE PURPOSE OF TONIGHT, IS REALLY AN OPPORTUNITY TO HEAR FROM YOU ABOUT THE EXPERIENCES THAT YOU'RE HAVING.

SO THAT WILL BE THE EVENING.

I WANT TO INTRODUCE THE SPONSORS.

THESE ARE A SERIES OF ADVOCACY GROUPS FROM ACROSS TENNESSEE WHO HAVE ALL COME TOGETHER TO SPONSOR PUBLIC FORUMS.

WE HAD THE FIRST ONE LAST WEEK, LAST -- IN KNOXVILLE.

AND TONIGHT'S THE SECOND ONE.

WE HAVE A THIRD ONE TOMORROW NIGHT IN MEMPHIS.

TRYING TO GIVE PEOPLE AN OPPORTUNITY.

THE PEOPLE FIRST OF TENNESSEE RIGHT HERE AT THE LAPTOP IS HERE IS LEANNE BOYCE.

SHE'S THE EXECUTIVE DIRECTOR OF PEOPLE FIRST OF TENNESSEE.

PEOPLE FIRST IS ONE OF THE PARTIES WHO BROUGHT THE LAWSUIT SOME 15 YEARS AGO.

SECOND, THE DISABILITY LAW AND ADVOCACY CENTER AND WE HAVE SHIRLEY SHEA AND ANYBODY ELSE WITH YOU?

NATALIE?

>> MARGARET.

>> AND SHEILA.

>> AND SHEILA.

THANK YOU.

AND THE ARC OF TENNESSEE, I DON'T BELIEVE WE HAVE ANYBODY OF ARC OF TENNESSEE.

WE HAVE ARC OF NASHVILLE.

WE WANT TO ESPECIALLY THANK NORM BECAUSE HE'S THE ONE

RESPONSIBLE FOR GETTING THE PRESBYTERIAN CHURCH.

THANK YOU, NORM, PERSONALLY FOR THAT.

THE TENNESSEE DISABILITY COALITION AND DONNA IN THE BACK.

AND FINALLY MIDDLE TENNESSEE ADVOCACY CENTER MYSELF AND

LETICIA AND TRACY IF YOU'LL STAND UP AND SAYER ARE IN THE

BACK AND LAMONT SITTING HERE.

SO WITH THAT OUR SPONSORS.

NOW I WANT TO TALK ABOUT THE DMRS FUNDING CUTS AND SERVICE

REDUCTIONS, WHAT'S HAPPENING, WHAT'S PLANNED TO HAPPEN.

THIS IS A POWERPOINT OVERVIEW OF THE SERVICE REDUCTIONS AND

FUNDING CUTS THAT ARE PRESENTLY UNDERWAY.

IT TENDS TO GET VERY COMPLICATED.

THE PURPOSE OF DESCRIBING IT IS TRYING TO HELP YOU

UNDERSTAND SO THAT YOU CAN BE APPRISED, YOU CAN BE AWARE,

YOU CAN ACT ACCORDINGLY.

I FOUND IT HELPFUL OVER TIME TO THINK ABOUT THE SERVICE

REDUCTIONS IN TWO PHASES.

AND THE FIRST PHASE IS WHAT MOST PEOPLE ARE AWARE OF THIS

6.1%.

BUT THERE REALLY ARE A WHOLE OTHER SERIES OF SERVICE

REDUCTIONS AND CUTS THAT ARE IN PROCESS SO I THINK OF THAT

AS PHASE TWO.

AND MOST -- SOME OF THOSE BEGINNING TO HAPPEN BUT THE PLAN FOR JULY 1.

SO AS I GO THROUGH THIS CONCEPTUALIZING OR THINKING ABOUT IT AS TWO PHASES.

THE FIRST PHASE OF CUTS THAT ARE HAPPENING NOW, 6.1% AND RIGHT NOW THE LEGISLATORS ARE IN THE PROCESS OF LOOKING AT BUDGETS AND BUDGET CUTS, WHAT FUNDING IS NECESSARY FOR THE DEPARTMENT OF MENTAL RETARDATION SERVICES AND I PUT UP HERE A QUOTE FROM THE LEGISLATIVE HEARINGS, AND MR. NORRIS IN RESPONSE TO QUESTIONS FROM THE STATE LEGISLATORS, DO YOU NEED MORE MONEY?

I DON'T BELIEVE MORE MONEY IS THE WAY TO GO.

WE HAVE TO GET OUR COSTS UNDER CONTROL.

SO THIS PERMEATES THE WHOLE DISCUSSION OF WHAT'S OCCURRING IS THE DEPARTMENT OF MENTAL RETARDATION SERVICES INTENT TO SIGNIFICANTLY REDUCE THE COSTS THAT THEY'RE CURRENTLY SPENDING TO PROVIDE FOR SERVICES.

AND SO THIS RESULTS IN A NUMBER OF SERVICE CUTS.

THE MOST IMPORTANT I WANT TO TALK ABOUT TWO PHASES IS THAT THE 6.1% IS JUST THE BEGINNING OF THESE CUTS.

AND THERE ARE A LOT MORE COMING.

I WANT TO BE SURE YOU UNDERSTAND.

WE'RE GOING TO START WITH PHASE ONE.

THESE ARE THINGS THAT ARE CURRENTLY IN PROCESS.

THERE'S MORE DESCRIPTION IN YOUR HANDOUT.

I'LL GO THROUGH THESE.

JUST TRYING TO DO AN OVERVIEW.

FIRST ONE IS CUTTING THE PAYMENTS OF 6.1%.

I'M SURE EVERYBODY HAS HEARD ABOUT THAT BY NOW, YOU SHOULD HAVE RECEIVED THE LETTER FROM DEPUTY COMMISSIONER STEVE NORRIS DESCRIBING THEM.

AS A FLAT REDUCTION, THE AGENCY SENDING THEIR BILL IN THE MONTH OF DECEMBER AND IF IT WAS \$100 THEY GOT \$94.

SO IT'S JUST A FLAT REDUCTION OF 6/1% OF THE COST OF SERVICE.

THEY WERE EXPECTING TO GET THESE DOLLARS.

AND THAT WAS RESCINDED AND REINSTATED.

SO AS JANUARY 1, EVERYBODY'S PAYMENT THAT WAS APPROVED, THAT WAS EXPECTED AND PEOPLE WERE GETTING, IT'S ALMOST AS IF YOU WENT TO GET YOUR PAYCHECK ON JANUARY 1 ASK THE BOSS SAID OH, IT'S 6% LESS.

WE HAD PROBLEMS AND WE'RE NOT ABLE TO PAY YOU.

WE'RE VERY SORRY.

SO THAT HAS RESULTED, AND I'LL TALK ABOUT THIS MORE, BUT IN

A LOT OF THE THINGS THAT FLOW FROM THAT.

AND HOW DOES AN AGENCY COVER 6.1%?

IT RESULTS IN STAFF BEING LAID OFF, IT RESULTS IN PEOPLE NOT HAVING MUCH TRAVEL.

IT RESULTS IN RESIDENTIAL SERVICES HAVING A LIMIT PUT ON HOW MANY MILES THEY CAN GO PER DAY TO TAKE SOMEBODY.

IT HAS AN ACROSS THE BOARD OUTCOME DIRECTLY AFFECTING THE LIVES OF PEOPLE THAT WE ALL CARE ABOUT.

I'LL TALK ABOUT THAT A LITTLE BIT MORE.

SECONDLY, AND THIS IS WHAT DMRS IS IN THE PROCESS OF DOING.

IN ADDITION TO 6.1% IN SERVICE CUTS, THEY'RE IN THE PROCESS OF REVIEWING ALL CURRENT ISP'S.

THAT'S INDIVIDUAL SERVICE PLANS, EACH INDIVIDUAL IN SERVICE HAS ONE.

USUALLY THEY'RE IN PLACE A YEAR, A YEAR CYCLE.

NOT A CALENDAR YEAR.

WHEN WE'RE DONE TODAY, GOOD FOR A YEAR.

THEY'RE REVIEWING THOSE NOW.

SO THEY'RE RELOOKING AT THOSE.

SO EVEN IF YOU HAD A SERVICE PLAN THAT WAS DONE IN DECEMBER

AND IT WOULDN'T COME UP FOR DECEMBER OF 2008, THEY'RE

CURRENTLY REVIEWING THE PLAN FOR SERVICE REDUCTIONS AND

COST CUTS.

AND SO EVERYBODY'S CURRENTLY IN THAT PROCESS SEEING WHERE THEY CAN REDUCE FUNDS.

THE THIRD THING IS ASKING AGENCIES FOR ADDITIONAL CUTS.

THIS IS WHERE MANAGEMENT STAFF IN EACH REGIONAL OFFICE GOES OUT AND MAKES AN APPOINTMENT WITH EACH AGENCY.

MOST OF YOU HAVE AGENCIES, SOME SERVICE PROVIDER, THEY SIT DOWN WITH THEM AND SAY, WHERE ELSE CAN YOU CUT COSTS?

FREQUENTLY THOSE COSTS ARE RESIDENTIAL PROGRAMS OF PUTTING MORE PEOPLE TOGETHER.

AND DAY SERVICES, THEY'RE REDUCING THE NUMBER OF STAFF.

IF THE PEOPLE ARE IN A GROUP OF TWO OR THREE PEOPLE, OR HAD COMMUNITY OUTINGS, IT'S REDUCING THOSE.

SO THAT'S A NEGOTIATED SETTLEMENT, IF YOU WILL, THAT THEY'RE MAKING WITH EACH OF THE AGENCIES.

EXCUSE ME FOR A SECOND.

ANOTHER MAJOR COST CUTTING INCENTIVE IS ADDITIONAL ROOMMATES OR MOVES TO NEW HOMES.

MR. NORRIS HAS REPEATEDLY TESTIFIED HE THINKS THERE ARE TOO MANY SINGLE PLACEMENTS, SINGLE PLACEMENTS ARE PRIMARILY FOR PEOPLE WHO HAVE BEHAVIORAL PROBLEMS AND HAVE TROUBLE LIVING BY THEMSELVES OR INJURE THEMSELVES OR STAFF OR SOMEBODY

ELSE.

THERE'S A HUGE EFFORT TO REDUCE THAT.

ALSO PEOPLE WHO ARE LIVING TWO TOGETHER, THERE'S A BIG EFFORT TO HAVE PEOPLE LIVE WITH THREE.

THERE'S AN EFFORT TO HAVE PEOPLE MOVE FROM ONE HOME TO ANOTHER SO MORE PEOPLE CAN BE TOGETHER.

THE FIFTH AREA OF REDUCTIONS IS STAFF CUTS IN RESIDENTIAL AND DAY SERVICES.

THIS IS JUST AS A MATTER OF FACT THAT AND THE AGENCY GETS 6% CUT AS YOU WHEN YOUR PAYCHECK WAS CUT, WHERE DO YOU GO TO GET THOSE FUNDS?

THE INCOME FOR THE AGENCY IS JUST DRASTICALLY REDUCED AND THIS IS ONE OF THE WAYS THAT HAPPENS.

WE'RE AT OPEN FORUM THAT WAS HELD BY PDI IN CLARKSVILLE TWO WEEKS AGO AND THEY HAD ALL THE FAMILIES LIKE TONIGHT COME TOGETHER FROM THAT AGENCY AND THE EXECUTIVE DIRECTOR WAS THERE AND SAID THAT THEY WERE GOING TO TRY AND COVER THESE 6% CUTS FROM MANAGEMENT EFFICIENCIES AND HE WAS HOPING IT WOULDN'T AFFECT THEM TOO MUCH.

AND THIS WEEK THEY ANNOUNCED VERY SIGNIFICANT STAFF CUTS.

SO IT'S VERY HARD TO GET AROUND THIS 6% CUT.

AND THE 6.1 IS CUTTING THERAPIES SO THIS IS A VERY, VERY

SIGNIFICANT COST CUTTING MEASURE, AND I'LL TALK ABOUT IT MORE.

IT'S FOR BEHAVIORAL ANALYSTS, THE PHYSICAL THERAPY, OCCUPATIONAL THERAPY, SPEECH, DIETARY, NURSING.

I'LL TALK ABOUT THAT MORE.

ANOTHER AREA THAT MANY PEOPLE AREN'T REALLY AWARE OF IS WHAT'S CALLED AN ICAP.

LET ME ASK YOU TO RAISE YOUR HAND, HOW MANY HAVE HAD AN ICAP DONE FOR THE PERSON -- ABOUT HALF IN THE ROOM.

ICAP IS AN ASSESSMENT THAT THERE'S A WHOLE HANDOUT, A WHOLE PAGE HANDOUT IN YOUR HANDOUTS, IT'S AN ASSESSMENT THAT'S DONE ON THE PERSON, IT'S PROFESSIONAL ASSESSMENT AND IT'S TO LOOK AT WHAT CAN A PERSON DO?

CAN A PERSON BUTTON THEIR TIE, CAN THEY PUT ON THEIR SHOES. CAN THEY EAT BY THEMSELVES?

IT'S MEANS TO MAKE A PLANNING TOOL.

IT'S MEANT TO SET GOALS.

AND IN TENNESSEE IT'S USED AS A FUNDING MECHANISM TO DETERMINE NOT SOLELY BUT PRIMARILY SIGNIFICANTLY DETERMINE WHAT LEVEL OF FUNDING THAT YOU HAVE.

THE STORY AND SET OF QUESTIONS HAVE BEEN CHANGED, SO WHAT WE'RE SEEING NOW IS AS ACCORDING TO THE COURT MONITOR,

WHO'S THE COURT CASE IN WESTERN TENNESSEE IN MEMPHIS, DOWN TO 25% OF THESE ICAP SCORES HAVE BEEN REDUCED.

WHAT THAT MEANS IS THAT EVENTUALLY AS IT GETS DOWN IN MONTHS, YOUR SERVICE LEVELS REDUCE.

VERY SIGNIFICANT ISSUE, THE WAY THE CUT SERVICES.

AND IT'S TAKING AN ASSESSMENT THAT IS MEANT TO SORT OF PLAN THE FUTURE, IT'S BECOMING A WAY TO REDUCE NEW SERVICE LEVELS.

EIGHT IS CHANGING ELIGIBILITY.

THIS IS A TECHNICAL TERM "MEDICALLY NECESSARY" OR "MEDICAL NECESSITY."

I BRING IT TO YOU BECAUSE IT'S A MAJOR CHANGE THAT THE DMRS IS IN THE PROCESS OF MAKING.

WHAT IT'S GOING TO DO IS MAKE THE DEFINITION OF SERVICE DIFFERENT, SAYING THAT YOU, THE PERSON HAS TO HAVE -- HAS TO MEDICALLY NECESSARY FOR THEM TO HAVE THE SERVICE.

AND ONE OF THE KEY PIECES THAT MAKES THAT REALLY DIFFICULT IS THAT THERE'S A COMPONENT IN IT THAT SAYS THAT THE PERSON MUST SHOW PROGRESS THROUGH THERAPIES.

YOU KNOW WHAT WE'RE ABOUT IS HABILITATION AND THERE'S A REASON WHY IT'S CALLED HABILITATION, NOT REHABILITATION.

IT'S NOT LIKE YOU ARE GOING TO THE HOSPITAL AND YOU BREAK

YOUR ARM AND COME HOME FOR THREE WEEKS AND GET REHAB AND YOU'RE BACK TO WORK.

PEOPLE THAT WE'RE HELPING THAT WE LOVE AND CARE ABOUT AND HAVE LONG-TERM NEEDS AND ARE GOING TO BE NEEDING SERVICES AND ASSISTANCE.

IT'S MEDICALLY NECESSARY IS A VERY SIGNIFICANT ISSUE, PARTICULARLY NEED TO GO SHOW PROGRESS.

AND HERE IS A QUOTE FROM THE LETTER, CALLED A DENIAL LETTER.

HOW MANY PEOPLE IN THIS ROOM HAVE GOTTEN DENIAL LETTERS?

ALMOST HALF THE PEOPLE IN THE ROOM.

DENIAL LETTERS, WHEN YOU SEND IN, YOUR INDEPENDENTS COORDINATOR SENDS IN FOR SERVICE.

IT'S ON YOUR ONCE A YEAR WHEN YOU DO AN I.S.P. OR NEW SERVICE OR CHANGE, THEY SEND IN AND THE TEAM COMES TOGETHER, CIRCLE SUPPORT AND DECIDE JOHN NEEDS PHYSICAL THERAPY TWO HOURS A MONTH.

THAT GETS SENT IN TO THE DMRS REGIONAL OFFICE AND WHAT WE HAVE IS A DENIAL OF SERVICE AND REDUCTIONS OF SERVICE.

THE DMRS SENDS BACK A LETTER, CALLED A DENIAL LETTER, THIS IS AN EXAMPLE.

YOUR I.S.P. DID NOT SHOW US THAT YOU HAVE MADE ANY PROGRESS

ON YOUR TREATMENT GOALS.

THE PROBLEM HERE IS THE ISSUE OF MEDICAL NECESSITY, AND THE THERAPY'S EXPECTED TO RESULT IN A MEASURABLE SUSTAINED FUNCTIONAL GAIN.

MANY OF THE PEOPLE YOU AND I CARE AND PEOPLE HERE TODAY HAVE HAD PHYSICAL THERAPY, FOR EXAMPLE, HAVE CONTRACTURES AND NEED HELP ALTHOUGH THEY'RE NOT GOING TO HAVE GAINS, TRYING TO MAINTAIN A PERSON WHERE THEY ARE.

BEHAVIORISM IS ANOTHER EXAMPLE.

SOMEBODY HAS REALLY SERIOUS SELF INJURY USE BEHAVIOR OR HARMFUL TO THEMSELVES OR OTHERS OR THEY SIMPLY NEED TO BE MAINTAINED.

WE'RE NOT REALLY -- WE'RE HOPEFUL, BUT OUR PLAN ISN'T THAT WE'RE GOING TO IMPROVE ALL THOSE THINGS.

WE'RE TRYING TO MAINTAIN PEOPLE.

THIS IS A VERY SERIOUS AND DIFFICULTY.

AND IF NO TO ANY OF THE ABOVE QUESTIONS, THEY ARE TO STOP AND DENY AS NOT MEDICALLY NECESSARY.

THIS IS THE INSTRUCTION MANUAL OF WHAT THEY'RE SUPPOSED TO DO.

NEXT.

SO HERE'S SOME OF THESE ISSUES THAT ARE OF GREAT CONCERN

BECAUSE OF THAT.

AGAIN, THE PROGRESS AND FUNCTIONAL GAINS, BEHAVIORAL THERAPY, PHYSICAL THERAPY, OCCUPATIONAL THERAPY, NURSING. THERE HAVE BEEN A NUMBER OF ISSUES AND NURSING IS SORT OF UP IN THE AIR AND UNCERTAIN AT THIS POINT.

WHERE PEOPLE NEED EXTENSIVE MEDICAL NEED NURSING OR MEDICAL FRAGILE, NEED NURSES TO BE COMING IN.

SOMETIMES THREE TIMES A DAY.

EXCUSE ME.

THE OTHER PIECE THAT'S DIFFICULT IN THIS ARENA IS THAT THE APPROVALS ARE DONE FOR 90 DAYS.

THAT MEANS AT THE ENDS OF 90 DAYS YOU HAVE TO GO THROUGH THE REVIEW PROCESS AGAIN.

AND IF YOU'RE NOT APPROVED AGAIN, THE SERVICE CUTS OFF.

THE PROVIDER DOESN'T PAY.

SO THERE'S A LOT OF AREAS THAT THIS CAN PRESENT DIFFICULTY IN MAINTAINING SERVICES.

NOW I WANT TO SWITCH TO PHASE TWO.

AND AGAIN, REMEMBER, AT THE BEGINNING OF THIS I TALKED ABOUT IT'S MOST USEFUL, I'VE COME TO THINK ABOUT THIS AS TWO PHASES.

SO THAT'S PHASE ONE.

THAT'S ALL THE THINGS THAT ARE STARTING TO HAPPEN NOW.

AND YOU CAN UNDERSTAND A LOT MORE ABOUT THIS IF YOU LISTEN TO SENATOR NORRIS' TESTIMONY.

HE TESTIFIED WEDNESDAY TO THE SENATE HEARING AND THE HOUSE HEARING AND ONLINE AND WEBSITE PAGES ARE IN THE HANDOUT YOU HAVE THAT YOU CAN HEAR DIRECTLY.

I STRONGLY RECOMMEND THAT EACH OF YOU GO AND HEAR FOR YOURSELF EXACTLY WHAT COMMISSIONER NORRIS HAS TO SAY.

SO I'M GOING TO GIVE YOU AN OVERVIEW OF THINGS.

HERE'S PHASE TWO.

THIS IS THE PLAN.

SO WE HAVE ALL OF THE ABOVE CUTS.

TWO, WE HAVE MEDICALLY NECESSARY

THE ISSUE I DESCRIBED AS AFFECTING SERVICES.

THREE, THERE'S ANOTHER PIECE AND THESE ARE CALLED, AS THE TITLE SAYS, PROPOSED WAIVER AMENDMENTS.

JUST IN BRIEF, THESE ARE WAIVER OF PROGRAMS, THE WAIVER IS FUNDED ALMOST TWO THIRDS BY THE FEDERAL GOVERNMENT SO THEY ARE ALL UNDER FEDERAL REGULATIONS.

AS YOU KNOW, ANYTHING WITH THE FEDERAL GOVERNMENT HAS VERY STRINGENT REQUIREMENTS OF WHAT MUST BE DONE.

THE WAIVER, JUST BRIEFLY AGAIN, IS REALLY WHAT THE WORD

MEANS, THE WAIVER.

THE WAIVER ACTUALLY WAIVES WHAT WE CALL ICMR, FEDERAL REGULATIONS THAT ARE VERY, VERY, VERY STRINGENT.

SO THE STATE IS ALLOWED TO WRITE SOME OF THE THINGS IT WANTS TO DO.

SO IT ALLOWS DIFFERENT STATES TO DO DIFFERENT THINGS.

AND ONCE THEY WRITE THOSE WAIVER REQUIREMENTS THEN THEY BECOME THE REGULATIONS.

AND SO THE STATE IS PRESENTLY IN THE PROCESS OF WRITING NEW SET OF WAIVERS.

SO THAT'S WHAT THESE ARE CALLED, THOSE WAIVER AMENDMENTS.

I'M JUST GIVING YOU THE HIGHLIGHTS.

THEY'RE VERY EXTENSIVE AND PAGES AND PAGES.

BUT THE MEDICAL NECESSARY IS THE MOST SIGNIFICANT.

THERE'S AN ELEMENT THAT TALKS ABOUT THE FAMILY MORE DIFFICULT TO BE PAID TO PROVIDE PERSONAL ASSISTANCE, OR PEOPLE GETTING PERSONAL ASSISTANCE.

FIRST OF ALL, YOU HAVE THE 6% CUT THAT HAPPENED BEFORE AND SECONDLY THERE ARE RESTRICTIONS ON FOR EXAMPLE THE NUMBER OF PERSONAL ASSISTANCE HOURS IS CAPPED.

AND DMRS IS IN THE PROCESS NOW OF REDUCING THAT, CHANGING IT, CHANGING IT AGAIN.

AND SO IT'S UNKNOWN.

BUT CAPPING IT FOR THE FIRST TIME OF HOW MANY HOURS THAT YOU CAN GET.

THE OTHER PIECES OF THAT PERSONAL ASSISTANCE ARE GETTING AT LEAST 6% AS PART OF THIS 6% CUT.

THE -- NUMBER FIVE IS THERAPIES REQUESTED TO TENNCARE PROVIDERS AND LIMITING PEOPLE'S HOURS.

THIS IS A MAJOR SHIFT WHICH WOULD HAVE ALL OF THE THERAPIES PROVIDED THROUGH TENNCARE WHICH IS THE MEDICAL ASSISTANCE AGENCY RATHER THAN DMRS.

THE EFFECT OF THIS IS THE THERAPIST WOULD THEN BE OUTSIDE OF WHAT ARE SOME OF THE PROTECTIONS THAT DMRS OFFERS SUCH AS SOME OF THE INVESTIGATION, SOMETHING IS WRONG, OVERSIGHT AND SOME OTHER THINGS.

THE OTHER REALLY SIGNIFICANT ISSUE IS THAT TENNCARES WERE SET UP TO DO REHABILITATION.

AND MEDICAL CARE, NOT HABILITATION.

AND PEOPLE ARE -- THEIR NURSES, FOR EXAMPLE, ARE NOT TRAINED IN MENTAL RETARDATION SO THERE ARE A NUMBER OF AREAS, AND THE NURSING HAS BEEN MOST SPECIFIC AND DIFFICULT.

DMRS HAS STATED THEY RESCINDED THAT AND IT'S NO LONGER THE

CASE, BUT WE AS ADVOCACY GROUPS ARE HAVING THAT CONTINUING, CONTINUE THAT DIFFICULTY AND I HEAR OTHER PEOPLE TALK ABOUT THE DIFFICULTY WE'VE BEEN TOLD.

COMMISSIONER NORRIS TESTIFIED ON WEDNESDAY HE TALKED ABOUT HAVING 21 PROTOCOLS FOR COST SAVINGS.

AND THAT WHAT I DESCRIBED UP TO NOW WERE SEVEN PROTOCOLS HAVE BEEN IMPLEMENTED.

THERE'S ANOTHER 14 PROTOCOLS THAT REMAIN FOR COST CUTTING. AND THAT REMAINS TO BE SEEN WHAT THEY'RE GOING TO BE AND WHAT AFFECT THEY'LL HAVE.

SO NOW WE JUMP TO HOW THIS WILL AFFECT ME, HOW THIS AFFECTS YOU.

THERE'S A HANDOUT ON THIS IN THE HANDOUT THAT YOU HAVE.

BUT I'LL JUST BRIEFLY GO THROUGH THIS.

SOME OF THE THINGS THAT ARE OCCURRING, STAFF CUTS AND RESIDENTIAL DAY SERVICES, LIMITED LIVING PEOPLE WHO LIVE BY THEMSELVES OR TWO PEOPLE LIVING TOGETHER.

REALLY STRONG PUSH FORWARD TO HAVE ADDITIONAL ROOMMATES IN HOMES.

REALLY STRONG PUSH TO COMBINE HOMES AND TWO PEOPLE LIVING TOGETHER, CAN THREE PEOPLE LIVE TOGETHER.

CAN WE GET A LARGER HOUSE THAT MORE PEOPLE CAN LIVE

TOGETHER?

THERAPIST CUTS SIGNIFICANTLY.

TALKED ABOUT THE DENIAL OF SERVICE.

AND PERSONAL ASSISTANCE SALARIES HAVE BEEN REDUCED AND
HOURS CAPPED.

IN YOUR HANDOUT IS A SELF-SURVEY THAT I'D LIKE IF YOU WOULD
GO THROUGH FOR YOURSELVES AS I FINISH UP HERE.

AND IT'S JUST TO THINK ABOUT FOR YOURSELF, WHAT AFFECT
THESE REDUCTIONS ARE HAVING ON A PERSON THAT YOU CARE
ABOUT.

NOBODY IS GOING TO HAVE ALL OF THESE THINGS.

BUT SOME OF THESE THINGS.

AND IN FACT, THERE'S ACTUALLY MORE AS THESE CUTS REDUCTIONS
ARE IMPLEMENTED, HOW IT'S IMPACTING YOU.

SO THIS IS JUST A SUGGESTION TO GO THROUGH AND THINK ABOUT
SOME OF THE IMPACTS.

THE HANDOUTS THAT YOU HAVE, THERE'S A HANDOUT SPECIFIC TO
THE ICAPS THAT TALKS ABOUT THE SCORING SYSTEM, HOW IT
WORKS.

THINGS YOU CAN DO, HOW YOU CAN PARTICIPATE IN IT.

BECAUSE EVERYBODY'S ALLOWED TO BE A PARTICIPANT.

HOW TO FILE AN APPEAL.

THE STATE HAS REPEATEDLY THAT NO ONE WILL BE HURT FROM ANY OF THESE REDUCTIONS OR COST CUTS, AND EVERYBODY HAS A RIGHT TO FILE AN APPEAL.

THERE'S ALSO A HANDOUT FROM THE DISABILITY CENTER AND ADVOCACY CENTER ON THE BACK THAT'S A YELLOW HANDOUT THAT TALKS ABOUT HOW TO FILE AN APPEAL SPECIFICALLY.

AND THE HANDOUT WHO TO CONTACT FOR HELP AND HOW TO ADVOCATE.

SO I'M GOING TO WIND UP AND WE'LL NOW GO TO QUESTIONS IN A MOMENT.

WHAT ARE SOME OF THE THINGS THAT YOU CAN DO?

CALL YOUR STATE LEGISLATORS.

THE LEGISLATURE IS IN SESSION NOW.

THEY ARE DETERMINING THE BUDGET.

THESE DECISIONS WILL BE MADE AND FINALIZED VERY SOON, WITHIN THE NEXT FEW WEEKS.

AND ONCE THE BUDGETS ARE FINISHED, THAT'S -- A LEAF IS TURNED, A CHAPTER OF THE BOOK.

SO THIS IS A VERY, VERY IMPORTANT MOMENT.

SECONDLY IS FILE AN APPEAL IF YOUR SERVICES ARE REDUCED OR DENIED.

THAT'S YOUR RIGHT.

YOU ARE ENTITLED TO DO THAT.

THIRDLY IS FILE A COMPLAINT WITH THE FEDERAL GOVERNMENT.

IN THE HANDOUT IS A DESCRIPTION HOW TO DO THAT.

THERE'S A WEBSITE PREVENT DMRS CUTS WHICH HAS LINKS AND TIES TO THE LEGISLATIVE HEARINGS, THE NEWSPAPER ARTICLES THAT HAVE BEEN DONE, LETTERS FROM OTHER FAMILIES THAT ARE CONCERNED ABOUT THINGS AND RECOMMEND THAT TO USE A WAY TO KEEP UP WITH WHAT'S OCCURRING.

THERE'S A PETITION ON THAT WEBSITE THAT I HIGHLY RECOMMEND THAT YOU SIGN.

AND THERE'S THE ADVOCATE.

SO WITH THAT IT'S REALLY MY SUGGESTION TO YOU TO TAKE ACTION AND TRY TO TAKE STEPS TO ADDRESS ALL OF THESE ISSUES.

SO WITH THAT I'M GOING TO STOP.

QUESTIONS from Audience

WHAT WE'RE GOING TO DO NOW IS HAVE QUESTIONS.

WE'LL ASK YOU TO STAND UP AND JUST HOLD THEM TO THE QUESTIONS ABOUT THE CUTS AND THEN AFTER THAT WE'LL HAVE PEOPLE COMING UP IN FRONT HERE TO THE MICROPHONE AND TELLING US YOUR SITUATION, YOUR STORY OR ISSUE.

SO ARE THERE CUT SPECIFIC WHO HAS A QUESTION SPECIFIC TO THE IMPACT OF THE REDUCTIONS OF CUTS AND I'LL TRY OR OUR SPONSORS, WE'LL CALL ON THEM TO ANSWER THE QUESTIONS PEOPLE HAVE.

I KNOW THERE'S BEEN A WHIRLWIND OF WHAT'S OCCURRING.

YES.

THIS IS SHIRLEY SHEA FROM THE DISABILITY LAWSUIT.

>> MARK, YOU MENTIONED THAT --

>> CAN YOU STAND UP, PLEASE?

>> I'M SORRY.

YOU SAID THAT PERSONAL ASSISTANCE IS GOING TO BE CAPPED.

DO YOU HAVE ANY IDEA TO HOW MANY HOURS?

>> YES, MA'AM?

>> THAT QUESTION WAS BROUGHT UP IN OUR AGENCY NOT LONG AGO.

IF YOU HAVE TWO PARENTS LIVING TOGETHER YOU'LL NOT GET THAT MANY HOURS.

IF THEY HAVE SLEEP HOURS, YOU NEED TO SLEEP THAT LONG, YOU WILL NOT BE OUT.

IT'S ONLY FOR THE TIME THAT THE INDIVIDUAL IS HOME.

>> THERE HAVE BEEN -- MA'AM --

>> WHAT IF THEY DON'T GO TO DAY CARE?

>> THEY GO CB. DAY.

>> LET ME ASK THE GENTLEMEN IN THE BACK.

>> MY NAME IS MAX TICE AND MY DAUGHTER IS I.B.A. AND SHE TAKES CARE OF MY DAUGHTER, AND I'M VERY INTERESTED IN PLANS, CUTS, SERVICES AND PA CAPS.

I COULDN'T HEAR ALL THAT THEY WERE SAYING.

I'M VERY INTERESTED IN THAT.

>> LET ME COME BACK TO THE -- LET ME HOLD THAT FOR A MOMENT.

THE PERSONAL ASSISTANCE HOURS

THERE ARE PROPOSED AMENDMENTS IN GRANT FORM THAT THE DMRS IS CIRCULATING.

AND IF THERE IS A NUMBER OF HOURS AND I DON'T REMEMBER THIS SECOND WHAT DESCRIPTION.

DOES SOMEBODY KNOW WHAT --

>> I BELIEVE IT'S BY AGE GROUP IS WHAT THEY TALKED ABOUT.

>> BY AGE GROUP.

>> I THINK IT WAS ANYWHERE CAPPED AT 84 HOURS MAX PER WEEK.

>> 84.

>> 84 IS THE MAXIMUM BUT I WANT TO SAY 60-SOMETHING.

>>

>> IT TAKES A LOT OF JUSTIFICATION TO VERIFY THE 84 HOURS.

OUR AGENCY WENT THROUGH I.S.P. THAT AND WHEN YOU ASK

WHAT -- WE WERE ASKED WERE -- WE WERE TOLD THAT, YOU KNOW,
THESE ARE JUSTIFIED BECAUSE IT'S CARE IF YOU HAVE A CHILD.
>> I'VE HEARD OFFICIALS IN DMRS SAY THOSE ARE UNDER REVIEW
AND CHANGING.

SO I DON'T THINK WE KNOW WHAT -- I THINK WE CAN EXPECT THE
CAP.

I DON'T THINK WE KNOW WHAT THE NUMBER OF HOURS ARE.

BUT THE OTHER PIECE, JUST REPEATING WHAT THIS WOMAN SAID,
IS THAT IT'S THE REVIEW PROCESS YOU KNOW, OF HOW MANY HOURS
AN INDIVIDUAL WILL GET.

THAT'S PART AND PARCEL OF IT, TOO.

LET ME COME TO THE QUESTION THAT MAX ASKED.

JUST HOLD A SECOND.

ON BEHAVIORAL SERVICES.

AND YOU ASKED, I'M NOT SURE WHAT YOU'RE ASKING.

>> OH, I WAS ASKING FOR CLARIFICATION CONCERNING P.A.

SERVICE BECAUSE I'M -- I'M A PARENT OF A DISABLED CHILD WHO
IS 21.

I ALSO HAVE ANY --

>>YOUR ASKING FOR P.A. PERSONAL ASSISTANCE.

>> I JUST WANTED CLARIFICATION WITH THEIR CONVERSATION
CONCERNING P.A. BECAUSE WE NEED THOSE PERSONAL ASSISTANCE

HOURS DESPERATELY AND WE DON'T WANT THEM TAMPERED WITH.

>> AND I THINK THE ANSWER AT THIS MOMENT IS IT'S UNCLEAR
THE NUMBER OF HOURS THAT WOULD BE.

PART OF THE 6% DOES AFFECT THE AGENCIES THAT PROVIDE
PERSONAL ASSISTANCE.

YES.

WOULD YOU STAND UP PLEASE?

>> THE PERSONAL ASSISTANCE SHALL BE LIMITED TO A MINIMUM OF
386 UNITS, 84 HOURS PER WEEK FOR ADULTS AGE 18 YEARS OR
OLDER AND THE MAX YUM OF 224 UNITS, 56 HOURS PER WEEK FOR
CHILDREN UNDER THE AGE OF 18 YEARS.

THIS IS A PROPOSED WAIVER.

>> ALSO SAYS PARENTS AS WELL, CUT THE UNITS --

>> SIR, WOULD YOU STAND UP.

>> IT TALKED ABOUT PARENTS THAT ARE P.A.'S, ALSO GOING BACK
TO CAP 240 HOURS A WEEK I BELIEVE AND ALSO CUTTING OUT
TRANSPORTATION FOR FAMILY MEMBERS.

>> SO THERE'S THE EFFECT ON P.A. SERVICES ALREADY AT 6%.
REDUCTION THAT THE AGENCY IS GETTING.

AND SOME AGENCIES, THEY'VE REDUCED THE SALARY THAT THE --
OR THE HOURLY WAGE THAT THE PERSONAL ASSISTANTS ARE
GETTING.

AND SO YOU RECALL UNDER PHASE TWO IT WILL BE A FURTHER
REDUCTION ON TOP OF THAT IN THE HOURS ISSUE.

YES, MA'AM.

CAN YOU STANDS UP PLEASE?

>> I DON'T KNOW IF YOU'RE AWARE OF THIS, BUT DMRS ALREADY
HAD A LITTLE CUT GOING ON BACK LAST SUMMER THAT THEY
ALREADY WERE DOING.

EVERY CHILD THAT'S IN SCHOOL, IF THEY'RE NOT IN SCHOOL,
AGENCY GETS PAID AT CB DAY RATE WHICH IS A FLAT RATE THAT'S
USUALLY BASED ON A P.A. FOUR WHEREAS IF YOU'RE DOING A
CHILD IT'S ONE TO ONE.

SO BY THE TIME YOU PAY THE STAFF, THERE IS NO -- NO MONEY.

>> SO WE AS AN AGENCY DO NOT TAKE C.B. DAY AT ALL.

>> WE CAN'T AFFORD IT.

>> THANK YOU.

ANYBODY ELSE?

YES, MA'AM.

>> WHY AND AT WHAT POINT DID THERE BECOME SUCH A BIAS
AGAINST SUPPORTS BEING PROVIDED BY FAMILY MEMBERS?

AND IS THAT SEEN AS A -- IS THAT -- IS THAT SEEN AS A BIAS
AND IS THAT BEING ADDRESSED IN SOME WAY?

>> I TALKED TO A NATIONAL EXPERT ON DISABILITY SERVICES

WHO'S A RESEARCHER, AND HE DESCRIBED TO ME THIS WAY.

THIS IS ONE ANSWER.

WHICH IS THAT UNDER THE WAIVER THAT THE STATES HAVE A CHOICE THEY CAN MAKE TO PROVIDE SERVICES.

HE SAID TENNESSEE MADE A CHOICE TO CHARGE -- TO PROVIDE PRIMARILY LARGER RESIDENTIAL SETTINGS RATHER THAN FAMILY SETTINGS.

NOT EXCLUSIVE BUT PRIMARILY AND THOUGHT THAT WAS ONE -- ONE RESULT OF THAT IS MUCH MORE EXPENSIVE TO PROVIDE.

TENNESSEE HAS A SELF-DETERMINATION WAIVER FOR FAMILIES BUT THAT'S PRETTY SMALL.

BUT TO GO TO YOUR QUESTION ITSELF, WHICH IS THE BIAS AGAINST FAMILIES, IT'S HARD TO UNDERSTAND THE ANSWER TO THAT.

BY AND LARGE FAMILY SERVICES ARE MUCH, MUCH LESS EXPENSIVE.

AND IT'S REALLY VERY SIGNIFICANT QUESTION.

THERE IS A WAITING LIST, HUGE, 6,000 PEOPLE.

THERE'S A WAITING LIST LAWSUIT.

I THINK THAT'S A VERY MAJOR QUESTION THAT THEY SHOULD ANSWER.

SPECIFICALLY IN THE PROPOSED WAIVER AMENDMENTS, THERE IS A PIECE IN THERE FOR PERSONAL ASSISTANCE THAT NOT ONLY IS A

CAP BUT FAMILIES PROVIDE PERSONAL ASSISTANCE GET 75% OF THE WAGE OF OTHER STAFF.

I'M TOLD THAT'S GOING TO BE CHANGED BECAUSE THAT'S ILLEGAL BUT THIS IS AN EXAMPLE OF YOUR QUESTION OF WHY IS THERE A BIAS AGAINST FAMILIES.

ANOTHER -- YES, MA'AM.

>> WOULDN'T THAT BE CONSIDERED LIKE A DISCRIMINATION THOUGH TO DO THAT?

AN OUT AND OUT DISCRIMINATION?

>> I BELIEVE -- I'M TOLD THAT THE 75% DIFFERENCE, THEY HAD TO TAKE IT OUT BECAUSE IT WAS ILLEGAL OR IMPROPER.

ONE THINKS AND ONE ASKS FOR FAIRNESS AND NOT SO MUCH MORE THAN SOMEBODY ELSE BUT THAT THERE IS A SENSE OF FAIRNESS THAT PEOPLE IN ONE AREA OR ONE CATEGORY GET SOME SIMILARITY.

MAYBE IT'S NOT TO BE I GUESS \$1, YOU GET \$1, BUT THERE'S SOME FAIRNESS.

THE FAMILY ISSUE RAISES VERY SIGNIFICANT QUESTIONS.

YES, MA'AM.

>> FROM AN AGENCY STANDPOINT, I'VE WORKED ON BOTH SIDES OF THE PROGRAM, I'VE BEEN WORKING SEVEN YEARS, THERE IS SOME ABUSE TO THE SYSTEM WHEN FAMILIES ARE INVOLVED.

I'M NOT SAYING EVERY FAMILY IS THAT WAY, BUT THERE IS SOME AS FAR AS TIME, AS FAR AS TIME ACTUALLY SPENT WITH THE INDIVIDUAL.

I MEAN, BUT A LOT OF FAMILIES ARE GREAT BUT THEN YOU HAVE A FEW FAMILIES OUT THERE THAT DO NOT DO WHAT YOU ASK THEM TO DO.

THEY CANNOT SEPARATE FROM BEING AN EMPLOYEE TO A PARENT.

>> OTHER QUESTIONS.

WE'RE GOING TO GO TO TESTIMONY NOW -- OH.

YES, MA'AM.

>> PATTY ASPENALL AND I'M A FAMILY MEMBER AND A STAFF THAT WORKS AT AN AGENCY AND I'M GOING TO SAY THAT I DO FIND JUST AS MUCH DISCREPANCY WITH PEOPLE YOU DON'T KNOW AS YOU DO FAMILY MEMBERS.

>> THANK YOU.

YES, MA'AM.

>> I HAVE TO SAY MOST OF THE TIME THOUGH THAT FAMILY MEMBERS WILL GIVE A BETTER CARE BECAUSE THEY KNOW THE PERSON.

ALSO, WHEN YOU HAVE SOMEBODY WITH ALZHEIMERS AND DEMENTIA, YOU DON'T PULL THEM AWAY FROM THEIR FAMILY.

>> YES, MA'AM.

>> I'M A FAMILY MEMBER, MY DAUGHTER, I'M HER PERSONAL ASSISTANT AND I DO IT BECAUSE I'VE HAD PEOPLE NOT SHOW UP, YOU CAN'T TRUST PEOPLE.

I HAVE MADE THE CHOICE, I MAKE THREE TIMES LESS, I'M A RESPIRATORY THERAPIST AND I PUT ON THE STATE WHERE TWO PEOPLE HAVE TO TAKE CARE OF HER DURING THE DAY WHILE I'VE WORKED BUT MY CHILD IS MORE IMPORTANT AND I'M STAYING HOME WITH HER, AND I FEEL LIKE I'M BEING PUNISHED FOR IT.

AND IT'S NOT FAIR TO HER OR TO ME.

AND IT'S -- I'VE CALLED LEGISLATORS.

THEY DON'T KNOW WHAT'S GOING ON.

I WOULD LIKE SOMEBODY HERE TO TELL ME WHAT I NEED TO DO.

I CALL THEM AND THEY SAY OH, I DIDN'T EVEN KNOW THAT HAPPENED WHEN THERE WAS THE 6% CUT.

LET ME GET BACK WITH YOU.

I NEVER HEAR FROM THEM.

>> YES.

STANDS UP, PLEASE.

>> YEAH, AND I'LL JUST SAY SOMETHING, IN TERMS OF LEGISLATORS, THEY DON'T UNDERSTAND.

THERE'S A LOT OF THEM THAT HAVE GOTTEN SOME GOOD INFORMATION FROM SOME OF THE PROVIDER AGENCIES, FROM SOME

OF THE FAMILIES ABOUT WHAT'S HAPPENING BUT BY AND LARGE THEY DON'T UNDERSTAND.

IT'S VERY COMPLEX AND IT'S VERY DIFFICULT AND THE DEPUTY COMMISSIONER WAS BEFORE THE HOUSE AND SENATE BUDGET HEARINGS LAST WEEK.

A NUMBER OF THE LEGISLATORS ASKED SOME VERY, VERY GOOD QUESTIONS OF THEM BUT STILL IT'S SO COMPLEX, IT'S KINDS OF HARD.

SO I THINK PART OF IT IS YOUR STORY IS SORT OF EXACTLY WHAT YOUR STORY IS AND AS WHAT'S THE IMPACT THAT THESE CUTS ARE HAVING ON YOU.

AND THAT IT'S UP TO THAT DIVISION TO TAKE ITS RESOURCES AND USE IT WISELY AND MANAGE THAT BUDGET.

THERE'S A LOT OF MONEY IN THAT BUDGET.

AND THEY'RE NOT MANAGING IT WELL.

AND THAT'S THE PROBLEM.

IT NEEDS TO GET OUT TO THE LEGISLATORS IS THE PERSON IN CHARGE IS NOT MANAGING THAT MONEY WELL.

>> WELL, I -- I EVEN EXPLAINED TO THE LEGISLATOR MY SITUATION BECAUSE I DO UNDERSTAND THAT IF YOU DON'T DEAL WITH THIS EVERY DAY AND THAT IT DOESN'T INVOLVE YOUR LIFE, IT'S EASY TO NOT THINK ABOUT IT, TO NOT -- WHEN YOU SIT

THERE AND TELL THEM AND STILL GET NO RESPONSE.

>> WE HAVE THREE MORE QUESTIONS THAT HAVE COME UP.

THIS LADY AND LORI AND EVAN.

>> I'M SURE MOST OF YOU HAVE GOT EMAILS FROM ME.

[APPLAUSE]

>> LEGISLATORS ARE GETTING IT, THEY ARE UNDERSTANDING IT
AND YOU'RE HAVING TO BREAK IT DOWN IN REAL-LIFE SCENARIOS.

I'M AN ANALYST, I CAN TELL THEM POINT BY POINT BY POINT
WHAT I DEAL WITH EVERY DAY.

I'VE BEEN SUPPORT STAFF.

I'VE WORKED AS A SUPPORT STAFF.

SO I CAN GIVE THEM THAT STAND POINT OF IT.

BUT IF YOU'RE -- I GOT FIVE EMAILS FROM THEM TODAY, JUST
FROM WHAT I SENT OUT YESTERDAY.

THEY DON'T UNDERSTAND.

BUT YOU HAVE TO BE ABLE TO MAKE THEM UNDERSTAND YOUR POINT
AND MAKE THEM VALIDATE IT AND REPEAT BACK TO THEM WHAT YOU
SAID TO THEM.

BECAUSE A LOT OF TIMES THEY'RE DEALING WITH 500, 600
DIFFERENT BILLS THAT ARE COMING ON THE DOCKETS BUT I'M
TELLING YOU, THEY GET IT NOW.

I MEAN, THEY'RE EMAILING ME BACK, TELLING ME WE'RE WORKING

WITH COMMISSIONER NORRIS, WE'RE TALKING WITH HIM, WE UNDERSTAND THE BUDGETS, THERE'S DEFICIT THAT IS A PRIORITY FOR US.

I'VE GOT IT IN WRITING FROM FIVE, SIX, SEVEN DIFFERENT MEMBERS JUST IN A DAY.

SO THERE'S PROGRESS BEING MADE.

BUT THERE'S STILL MORE STEPS THAT WE HAVE TO TAKE.

AND YOU NEED TO INUNDATE THEIR AIR FORCES, CALL THEM, GO BY AND SEE THEM, MAKE APPOINTMENTS WITH THEM.

GET IN THEIR FACE.

PUT YOUR DAUGHTER IN THEIR FACE.

LET THEM SEE THE PEOPLE THAT THEY'RE CUTTING THE FUNDING FROM.

THAT'S A REALITY.

YOU KNOW, THE PROVIDERS ARE GRIPING ABOUT THE MONEY ISSUE.

THEY NEED TO BE LOOKING AT THESE FACES.

AND THAT'S WHAT THEY NEED TO SEE.

MAKE AN APPOINTMENT WITH THEM AND TAKE YOUR FAMILY MEMBER WITH YOU.

>> THIS GENTLEMAN HERE.

HE WANTED TO ASK A QUESTION?

>> OH, OKAY.

>> THANK YOU.

>> ONE LAST QUESTION.

THIS LADY HERE AND THEN WE'RE GOING TO GO -- WE'LL GO WITH THE ORDER THE PEOPLE SIGNED UP TO TESTIFY AND WE'LL CALL PEOPLE.

>> THANK YOU, GREGORY, FOR THAT.

THAT WAS SO GOOD.

I'M MARGARET FROM NEW HORIZONS.

I WAS WONDERING IF ANYONE HAD ANY INFORMATION ON WHAT DMRS'S INTENT IS COME JULY 1?

IT'S IMPOSSIBLE FOR US TO BUDGET IF WE DON'T KNOW WHAT THE REVENUE IS GOING TO BE.

>> I WOULD STRONGLY SUGGEST THAT YOU LISTEN TO COMMISSIONER STEVE NORRIS' TESTIMONY TO THE LEGISLATOR.

I THINK HE ANSWERS THAT QUESTION.

WHAT I HEARD HIM SAY WAS THAT HIS DESIRE IS TO REDUCE THE 6% FUNDING CUTS AND TO HAVE THOSE CUTS COME FROM THE SERVICE REDUCTIONS THAT ARE MADE THROUGH THE OTHER DESCRIPTIONS THAT I GAVE YOU.

AND HE SAID THAT THE 6% SERVICE CUTS IN HIS MIND WAS A TEMPORARY MEASURE UNTIL THESE OTHER PROPOSED WAIVER

AMENDMENTS TOOK PLACE, WHICH WOULD BE THE MEDICALLY NECESSARY WHICH WOULD BE PROTOCOLS, AND IF YOU RECALL I PUT UP HERE, HIS STATEMENT THAT THEY HAD 21 PROTOCOLS THAT HE WAS IN THE PROCESS OF IMPLEMENTING AND SEVEN HAVE BEEN IMPLEMENTED.

SO MY IMAGINATION WOULD BE THE OTHER 14 PROTOCOLS WOULD BE OTHER COST CUTTING MEASURES BUT THAT WOULD NOT BE THE 6.1% BUT WOULD HAVE THE SAME IMPACT BECAUSE THE PURPOSE IS TO REDUCE THE COSTS ACROSS THE BOARD.

WE ARE GOING TO GO TO TESTIMONY.

AND SARA IS GOING TO CALL PEOPLE AND THE -- WE HAD A MICROPHONE BEFORE BUT THE SOUND SYSTEM HAS GONE OUT SO THEY'VE GIVEN US THIS.

SO WE'RE GOING TO ASK AS YOU COME UP TO STAND UP HERE AT THE PODIUM AND WE'LL HOLD THIS OR PUT IT ON YOUR -- HOOK IT TO YOU OR HOWEVER YOU'D LIKE TO DO IT.

JUST BE SURE EVERYBODY CAN HEAR.

WHO'S FIRST, SARA.

TESTIMONY

>> MAX TICE.

>> I AM MAX TICE AND AS YOU HEARD A MINUTE AGO, I'M

BEHAVIORAL ANALYST AND I'M ALSO A PARENT OF A CHILD WITH DISABILITIES.

AND THE BUDGET CUTS HIT ME VERY HARD BECAUSE I REMEMBER WHAT IT WAS LIKE WHEN WE HAD NO SERVICES.

I HAVE A DAUGHTER WHO, WHEN SHE GETS EXTREMELY UPSET, WILL FIRST OF ALL, IF WE'RE DRIVING, IF WE'RE IN THE CAR, SHE WILL RIP OFF HER SEAT BELT AND THEN THROW OPEN THE CAR DOOR.

WE HAVE TAKEN ALL TYPES OF MEASURES TO STOP THAT AND TO STOP OTHER BEHAVIOR PROBLEMS.

THE BEST HELP THAT WE'VE RECEIVED WAS OF COURSE FROM DMRS. I REMEMBER THE DAYS WHEN THERE WAS NONE AND HOW FRIGHTENED WE WERE, HOW SCARED.

AND THEN DMRS CAME TO THE RESCUE.

BUT NOW LOOK WHAT'S HAPPENING.

ALL OF US ARE HERE BECAUSE OF THE FACT THAT EITHER YOU ARE A PERSON WHO IS DISABLED, YOU'RE THE PARENT OF SOMEONE WHO IS DISABLED, OR YOU ARE IN A CLOSE MANNER ASSOCIATED WITH THIS.

I AM HERE BECAUSE I AM A PARENT.

THOSE OF YOU WHO ARE PARENTS CAN SAY THIS, OUR SONS AND OUR DAUGHTERS ARE A PART OF OUR HEARTS AND WHEN ANYONE DOES

ANYTHING THAT WOULD TEAR INTO THE LIVES OF OUR SONS AND DAUGHTERS, THEY RIP UP OUR HEARTS.

THAT IS WHY I FEEL THE PASSION THAT I FEEL FOR THIS CAUSE. AND THAT'S WHY IF THE PROPOSALS THAT ARE BEING PUT FORTH CONTINUE, THEY ARE GOING TO HAVE A FIGHT ON THEIR HANDS.

[APPLAUSE]

>> I HAVE TO ASK THE QUESTION, WHATEVER HAPPENED TO HUMAN RIGHTS?

WHAT HAPPENED TO INDIVIDUAL CHOICE?

I CAME ON TRAINED AS A BEHAVIORAL ANALYST AND THAT'S ALL I HEARD.

HUMAN RIGHTS AND INDIVIDUAL CHOICE.

AND THE VERY PEOPLE WHO WERE TEACHING IT, THE VERY PEOPLE WHO WERE PUSHING IT, ARE NOW THE PEOPLE WHO ARE VIOLATING THE HUMAN RIGHTS AND DIMINISHING INDIVIDUAL CHOICE.

ONE OF THE THINGS THAT I'VE BEEN HEARING EVER SINCE THIS STARTED WAS A COMPARISON BETWEEN THE STATE OF TENNESSEE AND OTHER STATES.

THE ARGUMENT HAS BEEN MADE BY COMMISSIONER NORRIS AND PERHAPS OTHERS THAT TENNESSEE IS DOING MORE, SPENDING MORE MONEY ON THESE INDIVIDUALS THAN OTHER STATES.

I DON'T KNOW IF ANYBODY'S ASKED THIS QUESTION, BUT I THINK

IT'S A QUESTION THAT NEEDS TO BE ASKED.

TO WHICH STATES IS TENNESSEE BEING COMPARED?

WHICH STATES?

I WOULD LIKE TO KNOW WHAT THOSE STATES ARE.

AND I WOULD ALSO LIKE TO KNOW HOW THOSE COMPARISONS WERE MADE.

DID THEY LOOK AT THE OVERALL BUDGET OF TENNESSEE AND THEN GO TO ANOTHER STATE AND LOOK AT THE OVERALL BUDGET OF THAT STATE AND THEN JUST MAKE THAT GENERAL COMPARISON?

OR DID THEY BREAK THEM DOWN INTO THE INDIVIDUAL COMPONENTS SO THAT WE COULD START LOOKING AT THE INDIVIDUAL COMPONENTS AND MAKE A COMPARISON HERE AND THERE AND THUS BEGIN TO SEE WHETHER OR NOT SOME OF TENNESSEE'S FUNDING LABELED AS BEING TARGETED FOR THE DISABLED POPULATION WAS ACTUALLY GOING FOR OTHER THINGS?

AND WE MIGHT BE ABLE TO FIND AREAS WHERE CUTS COULD BE MADE TO STOP SOME OF THE CURRENT PROPOSALS.

THESE ARE QUESTIONS THAT NEED TO BE ASKED AND ANSWERED.

NOW, IF IT SHOULD TURN OUT THAT UPON ASKING THIS QUESTION AND GETTING THE ANSWER THAT IT TURNS OUT THAT IT'S RIGHT, TENNESSEE IS WAY UP HERE AND THESE OTHER STATES ARE WAY DOWN HERE IN WHAT THEY'RE DOING FOR THE DISABLED, THEN I

HAVE TO SAY THIS IS A SORRY COMMENTARY ON AMERICA.

[APPLAUSE]

THAT CLAIMS TO BE THE CHAMPION IN THE WORLD WITH REGARD TO HUMAN RIGHTS.

I WOULD ALSO SAY FINALLY THIS, THAT JUST BECAUSE SOME OTHER STATES MAY TURN THEIR BACKS ON THEIR NEEDIEST CITIZENS, THIS DOESN'T MEAN TENNESSEE NEEDS TO DO THE SAME.

THANK YOU.

[APPLAUSE]

>> LORI.

>> MY NAME IS LORI WIGGINTON.

LIKE I SAID EARLIER, I'M QUITE CERTAIN MOST OF YOU HAVE RECEIVED EMAILS FROM ME OR ARTICLES OR SOMETHING OFF OF THE WEBSITE THAT I DON'T OWN BUT I HAVE ACCESS TO.

I LISTENED TO MAX TALK AND YOU KNOW, I HAD AN UNCLE WHO DIED ABOUT SIX MONTHS AGO WHO WAS MENTALLY RETARDED.

AND THE ONLY REASON WHY I BECAME TO WORK IN THIS PROFESSION WAS BECAUSE OF HIM, BECAUSE OF THE RIGHTS VIOLATION AND THE THINGS THAT HAPPENED TO HIM ALONG THE WAY.

HIS OWN FAMILY MADE FUN OF HIM.

I CAN REMEMBER BEING TWO, THREE YEARS OLD AND WATCHING MY UNCLES MAKE FUN OF HIM, HIS BROTHERS.

AND MY MOTHER ALWAYS PULLED ME ASIDE AND SAID HONEY, YOU KNOW THAT'S NOT RIGHT.

YOU KNOW YOU DON'T MAKE FUN OF YOUR UNCLE.

YOU LOVE YOUR UNCLE.

AND BECAUSE OF THOSE STATEMENTS, I BECAME AN ADVOCATE FOR HIM, AT THREE YEARS OLD.

I WAS SITTING IN THE FLOOR ONE DAY AND ONE OF HIS BROTHERS DID SOMETHING REALLY HORRIBLE TO HIM.

AND I DON'T REMEMBER SAYING THIS BUT MY MOTHER SAID YOU TURNED AROUND AND SAID YOU NEED TO STOP IT.

AND AT THAT POINT IN TIME IN MY LIFE, AS A 3-YEAR-OLD, LOOKING AT ADULTS, WE LOOK UP TO ADULTS AND THAT'S HOW WE SET OUR STANDARDS.

THAT'S HOW WE LEARN.

AND, YOU KNOW, THE OLDER I GOT, THE MORE I LOOKED AND SAW, YOU KNOW, THAT'S WHAT HAPPENS ALL THE TIME.

AND I MADE A PROMISE TO MYSELF AND TO MY UNCLE THAT I WOULD ADVOCATE FOR PEOPLE JUST LIKE HIM UNTIL I COULDN'T DO IT ANYMORE.

AND WHEN THESE CUTS CAME AND THESE THINGS STARTED HAPPENING, I HAVE 14 PEOPLE ON MY CASELOAD THAT ARE JUST LIKE MY UNCLE, THAT HAVE DISABILITIES, MINIMAL

COMMUNICATION SKILLS, BEHAVIORAL PROBLEMS, THAT ARE LOSING SERVICES EVERY DAY.

OF THOSE 14 PEOPLE, I'VE HAD 8 DENIALS AND 8 APPEALS THAT I'M HAVING TO APPEAL, NOT ONLY BEHAVIOR SERVICES BUT OTHER SERVICES.

AND AS A FAMILY MEMBER, IT INFURIATES ME TO SEE THESE THINGS TAKING PLACE.

AND IF IT HASN'T INFURIATED OTHER FAMILY MEMBERS IN HERE, I DON'T KNOW WHAT WILL INFURIATE YOU AND MAKE YOU ANGRY.

IF THESE CUTS TAKE PLACE, Y'ALL, THESE INDIVIDUALS THAT WE SUPPORT ARE GOING TO ENDS UP BACK IN THE INSTITUTIONS THAT WE'VE WORKED SO HARD TO GET THEM OUT OF.

THE GROUP HOMES THAT THEY'RE SETTING UP ARE INSTITUTIONALIZED.

I MEAN, THEY ARE SETTING UP SMALL INSTITUTIONS ACROSS THE STATE.

WE CAN'T LET THIS HAPPEN.

THEY WERE ABUSED IN THE INSTITUTION.

I HAVE PEOPLE THAT HAVE SURGERIES BECAUSE OF ABUSE.

I HAVE PEOPLE WHO WERE TALKING BEFORE THEY WENT INTO THE INSTITUTION THAT WILL NOT UTTER -- HAVE NOT UTTERED A WORD IN 40 YEARS.

AND THAT'S NOT OKAY.

IT'S NOT OKAY.

AND I HOPE THAT THE PEOPLE THAT WE HAVE ELECTED INTO OFFICE ARE PAYING ATTENTION TO US AND LISTENING TO WHAT WE HAVE TO SAY.

BECAUSE IF THEY'RE NOT, WE'RE IN A SAD A STATE, Y'ALL.

WE'RE IN A VERY SAD STATE THAT WE ELECTED THESE PEOPLE TO SPEAK FOR US, FOR THESE INDIVIDUALS, AND THEY'RE DOING THIS TO THEM.

AND, YOU KNOW, IT'S FUNNY HOW DMRS IS UNDER FINANCIAL AND ADMINISTRATION.

THEY ARE SEEN AS NUMBERS.

THEY ARE NOT SEEN AS PEOPLE.

THEY ARE A DOLLAR SIGN FLASHING AT COMMISSIONER GOETZ'S HEAD BECAUSE HE IS AN ACCOUNTANT.

THEY DON'T HAVE SOCIAL SERVICES BACKGROUND.

NOW, COMMISSIONER NORRIS MAY, I DON'T KNOW HIS BACKGROUND BUT I KNOW THE PERSON DRIVING THAT DEPARTMENT DOES NOT.

AND THAT INFURIATES ME.

THEY'VE NEVER MET THEM.

OUR GOVERNOR SAID IN THE HEARING, WHY CAN'T WE JUST TAKE THEM TO GREEN VALLEY?

COULD THEIR PARENTS NOT COME VISIT THEM LIKE THEY DO ON A COLLEGE CAMPUS?

HOW MANY OF YOU KNOW THE FAMILY MEMBERS THAT ARE REMAINING OF THE CLASS MEMBERS OF CLOVER BOTTOM, THEY'RE IN THEIR 60s, 70s, 80s, THEY'RE ELDERLY AND THEY -- HOW CAN YOU EQUATE GREEN VALLEY TO A COLLEGE CAMPUS?

YOU SEND THEM BACK THERE WHERE THEY'VE BEEN ABUSED, MY GUYS WOULD HAVE SIGNIFICANT PROBLEMS.

AND THAT'S WHO RUNS OUR STATE.

AND THAT'S THE STATEMENT THAT WAS MADE IN THE BUDGET HEARING PRIOR TO THESE.

THAT OUR GOVERNOR WOULD SAY THAT ABOUT THESE PEOPLE.

THANK YOU.

[APPLAUSE]

>> CHARLES HALL

FIRST OF ALL, I THANK -- SHE MADE A GOOD THING ABOUT CLOVER BOTTOM.

I'VE BEEN OUT THERE ALMOST SINCE I WAS A KID, MY FOSTER DAD SENT ME OUT THERE WHEN I WAS A LITTLE KID.

I WAS SICK AND EVERYTHING.

I WAS KIND OF SICK FOR A LONG TIME AND THEN FROM THERE I WENT TO MANY PLACES, MANCHESTER, I JUST WENT TO THEM ALL.

I WENT TO JUST DIFFERENT ONES.

AND THEN I GOT -- WITH PEOPLE FIRST AND THE LEE ANN AND

I'VE KNOWN THEM A LONG TIME.

THEY DONE A GREAT JOB GETTING THINGS GOING FOR US.

AND WE SHOULD GET A PAT ON THE BACK FOR DOING A GREAT JOB.

AND I THANK THEM.

I NEVER MET THEM BEFORE.

I'D LIKE TO MEET THEM MYSELF.

I REMEMBER A LONG TIME AGO I MET MARY IN THE OFFICE.

HE GAVE ME A \$10 BILL FOR MY FIRST DAY.

[LAUGHTER]

>> AND I -- WE WERE TALKING ABOUT CLOVER BOTTOM AND ALL
THAT.

I SAID WELL, YEAH, YOU'RE A GOOD MAN AND EVERYTHING.

BUT WE GOT A NEW MAYOR NOW.

AND I NEVER HAD THE SENSE TO MEET THE NEW MAYOR YET.

BUT HOPEFULLY I'LL GET TO MEET THE MAYOR SOON.

I HOPE I CAN.

I'D LIKE TO.

BECAUSE LEE ANN HAS GOT SOME GOOD PROGRAMS GOING ON AT

PEOPLE FIRST AND ADAPT AND HAVE BEEN WITH US FOR MANY AGES,

FOR MANY DAYS AND MONTHS AND YEARS.

AND I'M WORKING REAL GOOD BEING ON THE BOARD FOR DIFFERENT ASSOCIATIONS AND PEOPLE FIRST ASSOCIATION AND THINGS.

SO I'M GLAD TO BE LIKE I AM.

AND I'M GLAD THAT I CAN BE LIKE I AM.

OF COURSE I MISS MY BROTHER JOHN.

MISS JOHN VERY MUCH.

HE DON'T EVER CALL ME.

I GET WORRIED ABOUT HIM.

I GET KIND OF WORRIED ABOUT HIM.

LAST TIME I SAW JOHN WAS HE CAME DOWN AND EVERYTHING AND WENT AND SAW HIM AND WENT TO A PARTY AND WENT TO A SERVICE AND WE HAD A REAL GOOD TIME.

AND THEN WHEN IT WAS TIME TO LEAVE, MY BROTHER HAD TO GO BACK ON THE AIRPLANE AGAIN AND GET BACK WHERE HE WAS GOING AT.

AND THAT'S THE LAST TIME I SAW JOHN.

AND I CRIED, TEARS COME DOWN MY EYES.

AND THINK ABOUT THE GOOD TIMES WE HAD TOGETHER.

AND THAT'S WHAT IT'S ALL ABOUT.

AND SO I WANT TO THANK -- AGAIN, I WANT TO THANK Y'ALL FOR SENDING ME HERE TONIGHT AND I THANK THE GOOD LORD UP ABOVE.

I'M A CHRISTIAN MAN, AND I'VE BEEN BAPTIZED A LONG TIME AGO

AT THE BAPTIST CHURCH AND CHURCH OF CHRIST, I'VE BEEN
BAPTIZED THERE.

I BELONG TO THE HOUSE OF THE LORD FOREVER.

SO I GOT -- I GOT TO GO BECAUSE I KNOW OTHER PEOPLE HAS GOT
TO TALK.

SO THANK YOU FOR LETTING ME BE A PART OF THIS TONIGHT.

APPRECIATE IT VERY MUCH.

THANK YOU.

THANK YOU, EVERYBODY.

AND THANK YOU ALL VERY MUCH.

THANK YOU.

[APPLAUSE]

>> MY NAME IS RUTHIE BECKWITH AND I AM THE LEGAL GUARDIAN
FOR A MAN NAMED THOMAS.

I HAVE BEEN THOMAS' LEGAL GUARDIAN CONSERVATOR FOR THE LAST
14 YEARS.

AND LAST NOVEMBER THOMAS SAID MY NAME FOR THE VERY FIRST
TIME.

IT'S BEEN A VERY SIGNIFICANT THING FOR THOMAS TO SAY MY
NAME.

LIKE MANY OF YOU ARE PARENTS AND I ALSO AM A PARENT OF
THREE FINE YOUNG MEN.

THE FIRST TIME YOUR CHILD, YOUR FAMILY MEMBER SAYS YOUR NAME, YOU KNOW THAT THEY KNOW YOUR EXISTENCE IN THE WORLD AND THAT YOU'RE IMPORTANT TO THEM.

THOMAS HAD A VERY LONG JOURNEY TO COME TO THE POINT WHERE HE SAID MY NAME.

I BECAME THOMAS' LEGAL GUARDIAN WHEN HE WAS 21.

HE WAS BORN A RUBELLA BABY, ONE OF THE LAST INFANTS AFFECTED BY RUBELLA EPIDEMIC OF 1973.

HE WAS BORN DEAF AND BLIND IN A HOSPITAL IN MEMPHIS.

AND HE WAS ABANDONED AT BIRTH.

HE WENT INTO FOSTER CARE WITH D.H.S. WHEN THEY PROVIDED FOSTER CARE SERVICES.

WHEN HE WAS A TEENAGER HIS FOSTER MOTHER COULD NO LONGER PROVIDE SERVICES TO HIM AND SO HE WAS PLACED BACK WITH D.H.S.

AND THEY FOUND HIM A REALLY NICE NURSING HOME TO LIVE IN MEMPHIS.

AND THERE HIS COUNSELOR FOR THE BLIND FOUND HIM TIED TO THE BED.

SHE BROUGHT HIM BACK TO NASHVILLE TO THE SCHOOL FOR THE BLIND AND WHEN HE BECAME 21 HE ENTERED THE DMRS SERVICE DELIVERY SYSTEM.

WHEN I FIRST BECAME HIS GUARDIAN HE WAS RECEIVING SERVICES IN HIS OWN HOME WITH A LIVE-IN COMPANION AND HE WAS DOING QUITE WELL.

WE HAD A LOT OF HOPES AND DREAMS FOR THOMAS.

HOWEVER, THOMAS GOT SICK AND DURING THAT TIME DMRS WOULD NOT GIVE HIM ANY ADDITIONAL SUPPORT SO HE WENT INTO THE HOSPITAL.

WHILE HE WAS AT THE HOSPITAL HIS PROVIDER ABANDONED HIM AND SAID THEY WEREN'T GOING TO TAKE HIM BACK.

SO HE STAYED IN THE HOSPITAL FOR THREE MONTHS AT THE WONDERFUL RATE THAT THE HOSPITAL CHARGES AND DMRS PAID FOR THAT SERVICE WHILE WE LOOKED FOR ANOTHER PROVIDER.

THOMAS CAME BACK OUT INTO THE COMMUNITY INTO A HOME WITH TWO OTHER GUYS AND AGAIN WE HAD REAL OPTIMISM THAT THOMAS WAS GOING TO REGAIN HIS LIFE.

HOWEVER, ABOUT TWO YEARS LATER THAT PROVIDER SAID THEY NO LONGER WANTED TO PROVIDE SERVICES IN NASHVILLE AND THEY GAVE US 30 DAYS NOTICE AND AGAIN WE WERE ON A QUEST FOR THOMAS' SERVICE PROVIDER.

THOMAS' THIRD SERVICE PROVIDER WAS PUT OUT OF BUSINESS BY THE STATE OF TENNESSEE, WHICH GIVES YOU AN IDEA OF HOW BAD THINGS MUST HAVE GOTTEN FOR DMRS TO ACTUALLY CANCEL A

SERVICE PROVIDERS CONTRACT.

IT WAS AT THAT POINT THAT THOMAS WAS ABLE TO FORM A MICRO BOARD AND MANY OF YOU IN HAD THE AUDIENCE ARE FAMILIAR WITH MICRO BOARDS BUT THEY ARE ORGANIZATIONS THAT ARE FOUNDED JUST TO SERVE AND SUPPORT ONE PERSON.

SO AT THE END OF 11 YEARS I HELPED THOMAS BECOME HIS OWN PROVIDER.

WHEN THOMAS BECAME HIS OWN PROVIDER HE BEGAN TO GET SERVICES.

WE REALLY BEGAN TO SEE AND REAP THE BENEFITS OF WHAT OUR WAIVER HAD BECOME AND THE KINDS OF SERVICES AND SUPPORTS THAT THOMAS COULD RECEIVE.

CULMINATING IN THAT REALLY WONDERFUL MOMENT LAST THANKSGIVING WHEN THOMAS WAS ABLE TO SAY MY NAME.

NOW I'M WORRIED THAT THOMAS WILL HAVE MANY THINGS CHANGE IN HIS LIFE THAT WE TRIED VERY HARD TO MAKE POSSIBLE FOR HIM.

THAT HIS GAINS IN LANGUAGE ACQUISITION WILL DIMINISH BECAUSE HE WILL NO LONGER GET THE SUPPORT FROM STAFF WHO HAVE BEEN TRAINED AND SENT TO SPECIALIZED TRAINING SO THEY KNOW HOW TO COMMUNICATE WITH HIM.

BEFORE THOMAS RECEIVED HIS SERVICES FROM THIS MICRO BOARD HE LIVED WITH TWO OTHER PEOPLE WHO COULD TALK SO THE STAFF

OF COURSE TALKED TO THE PEOPLE WHO COULD TALK AND THOMAS WAS TREATED ALONE.

HE WAS LEFT IN HIS BEDROOM AND TREATED LIKE A PIECE OF FURNITURE.

HE RECEIVED THERAPY SERVICES BUT THE THERAPISTS HAD NO DIRECTION FROM THE -- FROM THE PEOPLE WHO SUPPORTED HIM AND SO THEY WEREN'T ABLE TO MAKE PROGRESS WITH HIM.

HE RECEIVED SERVICES FROM UNTRAINED STAFF AND OF COURSE MANY OF YOU ARE FAMILIAR WITH HOW MANY STAFF AND KIND OF TURNOVER AND STRUGGLE THAT PROVIDERS HAVE IN TRYING TO KEEP STAFF WHO KNOW HOW TO WORK WITH PEOPLE IN GENERAL, LET ALONE SOMEBODY WHO IS DEAF AND BLIND.

HIS HEALTH ISSUES, WHILE HE WAS -- BEFORE HE WAS IN HIS MICRO BOARD WERE SIGNIFICANT AND BY THE TIME HIS MICRO BOARD WAS CREATED HE HAD SPENT TEN YEARS GAINING WEIGHT TO THE POINT WHERE HE HAD HIGH BLOOD PRESSURE AND DIABETES.

THOMAS NOW IS IN GOOD HEALTH.

HE'S COMMUNICATING.

HE'S LETTING PEOPLE IN HIS LIFE KNOW WHAT'S IMPORTANT TO HIM.

AND I REALLY WANT ALL OF US TO WORK TOGETHER SO THAT PEOPLE LIKE THOMAS AND OTHER PEOPLE WHO DON'T HAVE FAMILIES BUT

HAVE PEOPLE LIKE LORI AND MYSELF AND OTHER PEOPLE WHO LOVE AND CARE ABOUT THEM CAN CONTINUE TO LEAD THE LIVES THAT WE ALL ENVISIONED WHEN WE TRIED TO CREATE THE SYSTEM THAT WE HAVE NOW.

THANK YOU.

[APPLAUSE]

>> STEPHEN GLOWICKI.

>> CAN EVERYBODY HERE ME?

MY NAME IS STEPHEN GLOWICKI.

I'M A FAMILY MEMBER AS WELL AS A FRIEND TO MANY WHO ARE CERTIFIED WITH DMRS SERVICES AND I COULD PROBABLY TAKE UP THE REST OF THE NIGHT TO SPEAK ABOUT ALL OF THE MANY INDIVIDUALS THAT I KNOW AND CARE ABOUT THAT ARE BEING AFFECTED BY THIS.

I WILL NOT DO THAT.

I WILL JUST TELL ONE TOUCHING STORY ABOUT TWO INDIVIDUALS THAT ARE VERY CLOSE TO ME THAT I FOLLOWED FIVE YEARS THAT ARE DRASTICALLY BEING AFFECTED BY THIS.

ONE OF THE INDIVIDUALS THAT IS PARANOID SCHIZOPHRENIC, HAS PSYCHOTIC EPISODES AND BEEN KNOWN TO -- AND THE OTHER IS A MANIC DEPRESSIVE AND HAS SERIOUS BEHAVIORAL EPISODES THAT PUT THE OTHER INDIVIDUAL AT RISK OF HARM.

BOTH INDIVIDUALS WERE MOVED VERY FREQUENTLY FOR MANY, MANY YEARS UNTIL THEY FOUND EACH OTHER AND THE SITUATION WITH THESE TWO INDIVIDUALS HAS WORKED BEAUTIFULLY.

THEY'VE BECOME FRIENDS.

THEY UNDERSTAND THE OTHER SENTENCE THAT THE OTHER FACES WITH THEIR DISABILITY, AND IT'S BECOME -- IT'S BECOME A VERY GOOD LIVABLE SITUATION FOR THESE TWO GENTLEMEN.

NOW THEY ARE BEING FORCED TO CONSIDER ANOTHER ROOMMATE AND MOVE FROM THE APARTMENT THAT THEY HAVE MADE THEIR HOME AND POSSIBLY HAVE TO BE MOVED CONTINUOUSLY UNTIL THEY FIND ANOTHER SITUATION THAT HAS BEEN PROVEN TO BE AS GOOD AS THE CURRENT ONE THEY LIVE IN.

AFTER THE ICAPS WERE REDESIGNED THEY WERE REDUCED TO ONE STAFF PERSON AROUND THE CLOCK INSTEAD OF ONE STAFF PERSON AROUND THE CLOCK AND AN ADDITIONAL PERSON DURING PEAK HOURS WHEN THERE WAS A MAJOR CONCERN FOR BEHAVIORAL NEEDS.

WHEN ONE OR THE OTHER PERSON WAS HAVING BEHAVIORAL CONCERNS, THAT MIGHT HAVE JEOPARDIZED OR PUT THE OTHER PERSON IN DANGER, THEY HAD THE ABILITY TO LEAVE -- LEAVE THE HOUSE, THE ONE THAT WAS NOT HAVING BEHAVIORAL CONCERNS THAT DAY.

OR EPISODES.

NOW THEY'VE BEEN REDUCED TO ONE STAFF AND THE FIRST TIME THIS SECOND INDIVIDUAL THAT I DESCRIBED WAS THROWING FURNITURE AND WAS PUTTING HIMSELF IN DANGER AND THE OTHER INDIVIDUAL IN DANGER, IT WAS ONLY MANAGED BY ONE STAFF.

THAT STAFF PERSON IS TRYING TO HELP THE SECONDS INDIVIDUAL I SPEAK OF KEEP FROM HARMING HIMSELF AND THE OTHER INDIVIDUAL TAKES OFF DOWN THE LOAD ON FOOT.

THIS INDIVIDUAL DOESN'T KNOW HOW TO LOOK FOR CARS IN THE STREET.

THEY FOUND HIM THREE MILES AWAY FROM HIS HOME.

HE COULD HAVE DIED.

HE COULD HAVE DIED.

AND I DON'T -- I DON'T EVEN WANT TO THINK ABOUT HOW MANY OTHER INDIVIDUALS WE'RE PUTTING IN THIS KIND OF RISK.

AND I WILL FOLLOW THIS AND I WILL PROMOTE THIS TO AS MANY PEOPLE AS I KNOW AND THERE'S NO WAY THAT THIS CAN CONTINUE.

AND I'M SORRY I'VE GOTTEN SO EMOTIONAL ABILITY THIS.

THESE PEOPLE REALLY MATTER TO ME AND MANY OTHERS.

AND THE THOUGHT THAT RICKY WAS ABLE TO GET THREE MILES AWAY FROM HIS HOUSE WITHOUT BEING STOPPED, HE COULD HAVE DIED.

HE COULD HAVE DIED.

AND I DON'T KNOW HOW THESE PEOPLE CAN LIVE WITH PUTTING

THESE PEOPLE IN THIS KIND OF HARM.

[APPLAUSE]

>> PAUL.

>> I'M PAUL SANGUINETTI FROM SPECIAL NEEDS.

WE PROVIDE PRIMARILY PHYSICAL THERAPY.

WE HAVE IN THE PAST PROVIDED OCCUPATIONAL AND SPEECH
THERAPY.

I ALSO DO THE PAPERWORK FOR A COMPANY.

WE SUPPORT ABOUT 80 PEOPLE PRIMARILY IN PHYSICAL THERAPY
AND, THE CRUCIAL SUPPORT FOR ABOUT 120 PEOPLE.

SO WE SEE A LOT OF -- A LOT OF YOUR PEOPLE OUT THERE.

WE HAVE A CONTRACT WITH DMRS.

IT SETS RATES.

IT SAYS YOU WILL BE PAID SO MUCH AN HOUR OR SO MUCH A UNIT
TO PROVIDE THERAPY.

SO I DON'T QUITE UNDERSTAND WHERE THEY COME TO NOW AND SAY
OH, WE MESSED UP.

WE DIDN'T BUDGET CORRECTLY SO WE'RE GOING TO CUT YOU 6%.

IT JUST DOESN'T MAKE SENSE TO ME.

WE HAVE A LEGAL CONTRACT.

WE TYPICALLY BILL ABOUT 80% OF WHAT WE'RE APPROVED FOR.

THAT'S BECAUSE WE'RE MANAGING OUR CLIENTELE, WE'RE CUTTING

BACK WHERE-- YOU KNOW, WHERE WE'RE ABLE TO, PUTTING PEOPLE ON MONITOR THAT HAVE REACHED CERTAIN GOALS, AND SO WE'RE NOT THE PROBLEM.

WHEN THEY'RE OVERBUDGET IT'S NOT BECAUSE THEY'RE LOOKING AT SPECIAL NEEDS AND SAYING YOU GUYS HAVE OUT -- GONE OUT AND SPENT MORE THAN YOUR BUDGETED FOR.

WE CAN'T SPEND MORE THAN WE'RE BUDGETED FOR.

THE ONLINE BILLING SYSTEM WON'T PERMIT US TO BILL FOR MORE THAN WE'RE BUDGETED FOR.

WE AREN'T THE PROBLEM.

THE PROBLEM IS COMMISSIONER NORRIS IS UNABLE TO BUDGET PROPERLY.

[APPLAUSE]

>> YOU'RE PROBABLY AWARE THAT NOT LONG AGO WAIVER WAS OPENED UP AND MORE PEOPLE WERE RELEASED INTO THE WAIVER SYSTEM.

I DON'T THINK HE THOUGHT ABOUT THAT WHEN HE PUT A BUDGET IN PLACE.

HE HAS A BUNCH OF PEOPLE BEING RELEASED FROM CLOVER BOTTOM.

A LOT ARE HIGH MAINTENANCE PEOPLE.

THEY DON'T FIT INTO THE SAME SLOTS THAT PEOPLE HAVE BEEN OUT THERE.

HE IS EXPECTING US TO BE ABLE TO PROVIDE SUPPORT FOR THESE PEOPLE AND STAY WITHIN A BUDGET THAT HE CREATED THAT I STILL CAN'T FIGURE OUT WHAT HE WAS BASING IT ON.

THE THIRD THING IS THAT HE EXPECTED THE SELF-DETERMINATION WAIVER TO BE A MUCH BIGGER PERCENT OF THE NEW PEOPLE BEING RELEASED INTO WAIVER AND IT'S JUST NOT HAPPENING.

THESE PEOPLE ARE BEING RELEASED INTO WAIVER AND BEEN ON WAITING LISTS AND THEY NEED SUPPORT.

BASICALLY THE SELF-DETERMINATION WAIVER IS SET UP SO THAT THERE'S NOT ENOUGH FUNDING IN THERE TO PROVIDE THERAPISTS.

WE CAN GO IN AND DO A SITED ASSESSMENT, RECOMMEND IMPROVEMENTS THAT NEED TO BE MADE TO MAINTAIN THEIR SAFETY, AND THEN WE'RE OUT OF THERE.

WE CAN'T PROVIDE ONGOING SERVICES FOR SELF-DETERMINATION.

NOW, WE'RE IN A BUSINESS.

I'M NOT ALL THAT ALTRUISTIC THAT I CAN SAY WE CAN GO OUT THERE AND SAY, YOU KNOW, DO ALL THIS STUFF FOR FREE.

AND THE WAY I SEE IT, NORRIS HAS NO INCENTIVE TO FIX THIS PROBLEM BECAUSE ALL HE HAS TO DO IS SAY OH, THIS MONTH

WE'RE 8% UNDER BUDGET, WE'LL JUST PASS IT ON.

WE'LL JUST MAKE -- SUBTRACT THAT MONEY FROM WHAT OUR PROVIDERS ARE BEING PAID.

THERE'S NO INCENTIVE FOR HIM TO FIX THINGS.

THERE'S NO WAY FOR US TO REACT TO A BUDGET CUT BECAUSE HE'S MAKING IT UP AS HE GOES ALONG.

IN JANUARY WE KIND OF KNEW IT WAS GOING TO BE ABOUT 6.1%.

HE'S INDICATED THAT THERE MAY BE REDUCED IN THE FUTURE.

THERE'S NO GUARANTEE OF THAT.

HE CAN COME BACK AND SAY NO, THIS MONTH IT'S GOING TO BE 10%.

I MAY BE WRONG IN THIS BUT TO MY KNOWLEDGE THERE'S NOBODY WORKING IN DMRS THAT'S EVER BEEN ABLE TO MAKE A LIVING AS A THERAPIST.

THE ONLY ONE I KNOW THAT'S EVER TRIED IS HOLLYWOOD AND SHE QUIT BECAUSE SHE COULDN'T -- COULDN'T KEEP UP WITH IT.

THERE WAS TOO MUCH UNBILLABLE TIME INVOLVED.

THIS ISN'T A TYPICAL THERAPY BUSINESS.

THERE'S A LOT OF UNCOMPENSATED TIME.

WE ESTIMATE THAT ROUGHLY ONE THIRD OF OUR TIME IS BILLABLE, TWO THIRDS OF IT IS FREE.

I MYSELF HAVE GONE OUT AND REPAIRED WHEELCHAIRS, BUILT RAMPS, I SPENT ONE WHOLE MONTHS COMPLETELY REBUILD AGO BATHROOM FOR SOMEBODY BECAUSE THEIR FACILITIES WERE INADEQUATE FOR THEM AND THERE WASN'T ENOUGH MONEY IN THE

BUDGET TO HIRE SOMEONE TO DO IT SO.

I DONATED MY TIME.

NONE OF THAT FALLS INTO THIS NEAT LITTLE BOX THAT COMMISSIONER NORRIS SEEMS TO HAVE BASED ON HIS MEDICAL MODEL.

THESE GUYS WORK 8:00 TO 5:00 FIVE DAYS A WEEK AND THINK WE'RE ALL OUT THERE DOING IT TOO.

THEY DON'T REALIZE WE HAVE TO BE THERE 24 HOURS A DAY, IF NEEDED, ON CALL TO BE ABLE TO GO IN AND TRAIN OR FIX A PROBLEM, TAKE CARE OF STAFF TURNOVERS AND MAKE SURE THAT THE PEOPLE REMAIN SAFE.

HE EXPECTS US TO GET IN, TEACH \$8 AN HOUR -- I DON'T KNOW, I DON'T WANT TO OFFEND ANYBODY BUT ROUGHLY -- LOWER, \$6 AN HOUR, YOU KNOW, PERSONAL ASSISTANTS HOW TO BE THERAPISTS AND THEN GET OUT.

AND I JUST DON'T SEE IT HAPPENING.

I MEAN, SO FAR HIS EXPECTATION DOESN'T MEET UP WITH REALITY IN ANY WAY.

ONE OF THE THINGS WE'RE STRUGGLING WITH RIGHT NOW IS THIS 90-DAY APPROVAL.

ONE OF THE THINGS THAT WE ARE DEALING WITH IS DMRS REQUIRES US TO GIVE THEM A 21-DAY LEAD TIME FOR THEM TO PROCESS

THEIR PAPERWORK WHEN WE SUBMIT A REQUEST FOR SERVICES.

SO BASICALLY WE'VE -- AND YOU ALL KNOW THAT I.S.C.'S CAN'T REACT AT A MOMENT'S NOTICE TO TAKE OUR RECOMMENDATION, GET HIM INTO AN I.S.P., GET THINGS WORDED SO IT MEETS THE NEW PROTOCOLS, GET IT TO THE REVIEWERS WHO ARE PRETTY MUCH CLUELESS ON WHAT ALL THIS MEANS IN THE REAL WORLD, AND THEN HAVING THEM SIT DOWN AND SPENT WHO KNOWS HOW MUCH TIME WRITING FIVE-PAGE DENIALS TO DENY THE LAST NINE MONTHS OF THE SERVICES THAT WERE REQUESTED.

SO AS A RESULT, ONE OF THE THINGS THAT WE'RE FINDING OUT IS THEY'RE NOT GETTING US THE APPROVALS ON THE PORTION THAT IS APPROVED.

WE BASICALLY LOSE THE FIRST MONTH.

WE'VE ALREADY LOST THE LAST MONTH BECAUSE WE HAVE TO GET ALL THE INFORMATION IN THE I.S.P. TO ASK FOR CONTINUED SERVICES.

SO WE BASICALLY HAVE ONE MONTH TO GO IN, CONTINUE SERVICE, FIND OUT -- ONE MONTH?

TO GET THE SERVICES APPROVED AND FIND OUT WHAT'S -- WHAT THIS PERSON REALLY NEEDS TO CONTINUE SERVICES.

BASICALLY, YOU KNOW, WE'RE FIGHTING AGAINST A LOGISTICAL PROBLEM THAT'S A MANUFACTURED -- IT'S BASICALLY DONE BY

PEOPLE WHO ARE CLUELESS AND LEADING PEOPLE WHO HAVE NO IDEA
WHAT THIS POPULATION IS ALL ABOUT.

THERE'S NO EFFECTS TO THESE PEOPLE.

THEY CAN BE MAINTAINED SAFELY, BUT THEY'RE NOT GOING TO BE
CURED.

AND MEDICAL MODEL THAT TENNCARE IS WORKING UNDER DOES NOT
WORK FOR THIS POPULATION.

AND UNTIL WE CAN GET TENNCARE PEOPLE OUT IN THE FIELD
SEEING WHAT WE'RE DEALING WITH AND SEEING WHAT THE RESULTS
OF THIS POPULATION, THEY'RE NOT GOING TO KNOW THAT WHAT
THEY'RE TRYING TO DO IS GOING TO CREATE CHAOS.

ANYWAY, THAT'S MY SPIEL.

[APPLAUSE]

>> MY NAME IS PATTY ASPINALL.

AND THIS IS MY BROTHER, TODD FARR.

>> YOU WANT TO COME UP HERE WITH ME?

>> YES.

>> COME WITH ME.

MY NAME IS PATTY AND THIS IS MY BROTHER TODD.

I AM NOT ONLY HIS SISTER, I'M HIS P.A. AND HIS C.B. DAY
PERSON AND IN THE PAST I'VE BEEN HIS JOB COACH.

THE AGENCY I WORK HERE, ALTHOUGH THEY'RE TERRIFIC, SOME OF

THEM ARE PRESENT AND EVEN THOUGH I'M PAID STAFF RIGHT NOW,
I'M SPEAKING AS A FAMILY MEMBER.

[LAUGHTER]

>> I WANT THAT UNDERSTOOD.

I'VE BEEN WORKING WITH TODD NOW FOR SIX YEARS.

I AM FROM CALIFORNIA.

I THOUGHT THAT I UNDERSTOOD MY BROTHER TO FIND OUT THAT I
DIDN'T.

WE WOULD BE LOST WITHOUT A BEHAVIOR ANALYST AND WE HAVE
FOUND OUT RECENTLY THAT WE ARE.

>> KEVIN.

>> KEVIN.

WE LOST KEVIN IN DECEMBER.

AND KEVIN DID NOT RENEW HIS CONTRACT WITH DMRS DUE TO THESE
FUNDING CUTS.

SO WE ARE STILL WITHOUT A BEHAVIOR ANALYST.

TODD HAS RECENTLY LOST HIS MOTHER IN JANUARY AND WE
COULDN'T NEED A B.A. MORE THAN WE DO NOW.

WITHOUT OUR OCCUPATIONAL THERAPIST, OUR LIFE WOULD BE A
LIVING HELL.

LIKE I SAID, I'M FROM CALIFORNIA.

Y'ALL ARE ALL I THINK TENNESSEANS.

DO Y'ALL NOT STILL TAR AND FEATHER?

WHERE IS --

[LAUGHTER]

>> WE'RE SITTING HERE AND WE'RE GOING TO CALL OUR STATE
LEGISLATURE.

DOES ANYONE HAVE HIS PHYSICAL ADDRESS?

I MEAN, WE NEED TO DO MORE THAN JUST HAVE MEETINGS AND
FORUMS AND I REALLY APPRECIATE MARK AND I APPRECIATE STEVE
JACOBS FROM THE ARC.

HE HELPED US SET UP A PERFECT SETTING FOR OUR FAMILY AND
OUR FAMILY MEMBER, ESPECIALLY GIVEN WHERE WE LIVE WHICH IS
PRETTY RURAL.

AS SOON AS THAT WAS SET UP AND EVERYTHING WAS GOING WELL,
STEVE NORRIS CUT IT.

AS TO SPECIAL PERMISSION TO GET OUR DEFENSE PLEASE
GRANDFATHER US IN, WE DIDN'T EVEN GET A MEETING OR AN
APPOINTMENT.

WE WERE NON-HEARD.

NOW YOU'RE TALKING ABOUT CUTTING P.A. HOURS.

I AM HIS P.A. AND HIS SISTER.

IF I GO OUT TO WORK OUTSIDE THE HOME, WE HAVE NOT BEEN ABLE
TO KEEP STAFFING DUE TO BEHAVIORAL ISSUES.

WE NEED TO KEEP WHAT WE'VE GOT AND WE REALLY NEED TO ALL
WORK HARD TOGETHER.

I'M A LITTLE DISAPPOINTED THAT THERE'S NOT MORE OF US HERE
TONIGHT BECAUSE I KNOW THERE'S A LOT MORE OF US OUT THERE.
MAX, WHEN I HEARD YOU SPEAK, I HAVE HEARD FOR THE LAST SIX
YEARS OF MY DEPARTED MOTHER NOW SOME OF THE SAME SENTENCES
THAT SHE SAID FOR MANY, MANY YEARS.

AND NOW THAT TODD'S MOTHER AND FATHER ARE BOTH GONE, IT'S
LEFT TO THE SIBLINGS.

SO AS PARENTS, I'M ASKING YOU PARENTS TO ALL BE THINKING
ABOUT WHEN YOU'RE GONE, BECAUSE SOMEDAY YOU WILL BE, WHAT
HAPPENS NEXT?

DOES YOUR CHILD HAVE SIBLINGS?

DO YOU HAVE SOMEONE ELSE IN PLACE?

DO YOU HAVE A CONSERVATOR YOU'RE THINKING OF?

THESE FOLKS GO ON.

AND IN THEIR FACES THERE'S A LITTLE STRESS BUT THEIR
HEARTS, THEY'RE JUST BROKEN.

WE ALL REALLY NEED TO PULL FORWARD AND DO SOMETHING.

AND I KNOW WE CAN.

THANK YOU VERY MUCH.

IS THERE ANYTHING YOU WANT TO ADD?

>> THANK YOU.

[APPLAUSE]

>> THANK YOU.

>> I'M SORRY.

HI.

THANK YOU ALL.

[APPLAUSE]

>>

>> LINDA LEWIS.

>> I'M A P.W. FOR MY DAUGHTER AND I JUST WANTED TO GIVE A
LITTLE DESCRIPTION ABOUT WHAT WE GO THROUGH -- DO GO
THROUGH IN MY BROTHER'S LIFE DAY BY DAY.

THESE ARE PEOPLE THAT DIDN'T ASK TO BE BORN LIKE THIS BUT
THEY ARE ALL PEOPLE.

AND I HAVE BEEN AN ADVOCATE FOR MY BROTHER FROM THE TIME I
WAS A LITTLE GIRL.

AND SO MY HEART DOES GO OUT TO THEM.

MY BROTHER IS 49.

HE HAS A DIAGNOSIS OF DEMENTIA, DOWN SYNDROME AND
DEPRESSION.

HE HAS LIVED WITH ME, HIS SISTER, AND MY HUSBAND AND OUR
THREE CHILDREN.

ONE OF OUR CHILDREN WHO HAS M.R. AND SEIZURES.

FAMILY MEANS EVERYTHING TO JOHN.

HE HAS A VERY STRONG BOND WITH HIS NIECES AND NEPHEW AND IS VERY CLOSE TO THE NEPHEW WITH M.R. AND SEIZURE.

JOHN NOW REQUIRES CONSTANT SUPERVISION AT ALL TIMES DUE TO THE ALZHEIMER DISEASE.

HE IS STILL MOBILE BUT HIS GAIT HAS SLOWED DOWN.

HE DOES LOSE HIS BALANCE AT TIMES.

BUT -- AND HE'S AT RISK FOR FALLS.

HE DOES HAVE TO BE ASSISTED WITH HIS MOBILITY, BATHING, GROOMING, AND PERSONAL HYGIENE.

JOHN USED TO RESPOND TO VERBAL PROMPTS, BUT NOW REQUIRES TACTICAL PROMPTS, PHYSICAL GUIDANCE AND EVEN HANDS ON CONSTANTLY THROUGHOUT HIS DAILY ROUTINES.

THESE ARE SOME OF THE DAILY CHORES WHICH HE USED TO BE ABLE TO DO WITH NO INSTRUCTION.

HE LOVED TO DO HOUSEHOLD CHORES, BUT EVEN WITH ONE STEP DIRECTION HE REQUIRES CONSTANT REMINDERS NOW TO ACCOMPLISH THESE CHORES.

FOR EXAMPLE, HE WAS ASKED TO TAKE THE TRASH OUT OF HIS GARBAGE CAN WHICH IS IN HIS BATHROOM.

BUT IMMEDIATELY AFTER BEING ASKED HE WALKED INTO THE

BATHROOM AND JUST STOOD THERE.

WHEN ASKED WHAT HE WAS DOING, HE SAID I DON'T KNOW.

WHEN REMINDED OF HIS TASK, HE SAID I FORGOT, WHICH IS SOMETHING WE HEAR ALL THE TIME, SEVERAL TIMES A DAY NOW.

WE ALSO HAVE HIM HELP WITH SETTING FOOD ON THE TABLE AND GETTING THINGS OUT OF THE REFRIGERATOR FOR MEAL PREP WHICH IS PART OF A MENTAL EXERCISE WE DO WITH HIM.

FOR EXAMPLE, HE WAS ASKED TO GET EGGS OUT OF THE REFRIGERATOR.

INSTEAD HE GOT OUT MILK.

WHEN I REMINDED HIM ABOUT THE EGGS, HE SAID I FORGOT.

HE IS ALSO FORGETTING WHERE THINGS ARE KEPT.

FOR EXAMPLE, I USED TO GET SOME PAPER PLATES WHICH HAVE ALWAYS BEEN KEPT UNDER OUR COUNTER IN THE LAUNDRY ROOM.

INSTEAD HE WAS LOOKING IN THE PANTRY, A PLACE WHERE THEY HAD NEVER BEEN KEPT.

WE ARE ALSO SEEING A MORE CONFUSED LOOK ON HIS FACE WHEN WE TELL HIM IT'S TIME TO DO SOMETHING.

HE HAS TO THINK A WHILE BEFORE HE PROCESSES IT.

AND THEN HE MAY GO THE OPPOSITE WAY OF WHERE WE ARE TO BE GOING.

FOR EXAMPLE, IF I TOLD HIM IT'S TIME TO GO GET A SHOWER,

AFTER HE PROCESSES IT, HE MAY HEAD FOR THE LIVING ROOM
INSTEAD OF THE BATHROOM.

WHEN I REMIND HIM ABOUT IT, HE'LL SAY I FORGOT.

JOHN'S ABILITY TO STAY FOCUSED ON HIS TASKS HAVE DECLINED
GREATLY.

FOR EXAMPLE, HE USED TO BE ABLE TO VACUUM AT THE CHURCH
WITH NO INSTRUCTION, DOING BETWEEN THE PEWS AND THE AISLES.
BUT THE AISLES HAVE BECOME TOO OVERWHELMING FOR HIM AS HE
TENDS TO WANDER ALL OVER WHEN VACUUMING THEM AND MISSES
LARGE SECTIONS.

JOHN'S SLEEP PATTERN AT NIGHT HAS CHANGED, TOO.

HE IS UP AND DOWN AT NIGHT AND THAT IS WHY WE ARE ALWAYS
THERE TO ASSIST HIM BACK TO BED AS WE DON'T WANT HIM
WANDERING OUT THE DOOR AND GETTING HURT AS WE LIVE ON A
VERY BUSY STREET.

FURTHERMORE, RESEARCH CAN BE FOUND IN THE ENCYCLOPEDIA OF
GENETIC DISORDERS THAT STATES IF A PATIENT REMAINS ABLE TO
GET OUT OF BED IN THE LATE PHASES OF ALZHEIMER'S DISEASE
THEY MAY WANDER AIMLESSLY AND WANDERING MUST BE MONITORED
AT NIGHT BECAUSE SLEEPING PATTERNS MAY BECOME ALTERED.

WE HAD JUST HAD A NEURO COGNITIVE TEST DONE WHICH SHOWS
THAT HIS COGNITIVE DECLINE SINCE '03 AND SUGGESTS THAT WE

ARE IN THE MODERATE TO LATE STAGES OF ALZHEIMER'S.

I HOPE THIS WILL GIVE YOU A PICTURE OF WHAT WE GO THROUGH IN OUR DAILY LIVES AND I WISH THAT MR. NORRIS AND ALL HIS STAFF COULD SEE WHAT WE AS FAMILY MEMBERS AND P.A.'S GO THROUGH.

AND I WISH THAT THEY WOULD UNDERSTAND THAT THE CUTS THEY'RE TRYING TO DO, NOT ONLY HURTS THEM, BUT IT ALSO HURTS THE FAMILY MEMBERS.

THANK YOU.

[APPLAUSE]

>>

>> MICHELLE WALTER.

>> I THINK THIS NEEDS TO BE A WAKE-UP CALL TO ALL OF US THAT WE'RE GOING TO HAVE TO EDUCATE PEOPLE WHO BECAUSE OF THEIR BUSY LIVES HAVE NO IDEA WHAT WE GO THROUGH EVERY DAY. WE'RE GOING TO HAVE TO HOPE THAT FROM BEING EDUCATED THEIR HEARTS WILL OPEN UP AND THEY'LL SEE THAT, YOU KNOW, WE DON'T JUST SIT AROUND AND SIT WITH THEM ALL DAY. YOU HAVE TO BATHE THEM, DRESS THEM, FEED THEM, AND WHEN YOU HAVE TO DO THAT FOR SOMEBODY, IT TAKES A BIG PORTION OF YOUR DAY.

WE'RE GOING TO HAVE TO ALL BAND TOGETHER AND GET OUR

LEGISLATORS TO SEE, NO, WE'RE NOT GOING TO STAND FOR THIS.

THESE PEOPLE DIDN'T ASK TO BE THIS WAY.

MY DAUGHTER'S PROBLEMS ARE THE DIRECT RESULT OF THE DOCTOR

JUST NOT ANSWERING HIS PHONE CALLS.

AND IT'S NOT FAIR TO PUNISH HER FOR HIS MISTAKE AND TO

THROW HER OUT LIKE SHE DOESN'T COUNT.

THESE PEOPLE HAVE TO SEE THEY'RE HUMAN BEINGS.

AND YOU HAVE TO BALANCE YOUR HOUSEHOLD BUDGET.

WE HAVE TO PRIORITIZE.

THESE PEOPLE CANNOT TAKE CARE OF THEMSELVES.

THEY CANNOT GO OUT AND WORK AND MAKE A LIVING WAGE.

SO WE'RE GOING TO HAVE TO CHANGE OUR PRIORITIES AS A

SOCIETY.

AND IF THEY WON'T DO IT WILLINGLY, THEN WE'RE GOING TO HAVE

TO ALL STAND TOGETHER AND SAY YES, YOU WILL DO IT.

AND YOU KNOW, I KNOW IT'S SO FRUSTRATING.

MY DAUGHTER'S 26.

I'VE BEEN FEELING LIKE I'VE BEEN BANGING MY HEAD AGAINST

THE WALL ALL THAT TIME, BUT IF WE ALL STAND TOGETHER AND

EDUCATE PEOPLE AND GET THEM TO TRULY REALIZE THESE PEOPLE

CAN HAVE A GREAT LIFE AND THEY'RE A BLESSING AND WE DON'T

WANT TO HAVE TO MAKE THEM MOVE TO A HOME WHERE WE HAVE TO

VISIT THEM.

THEY SHOULDN'T BE ASKED TO DO THAT BECAUSE THEY HAVE PROBLEMS AND MORE CHALLENGES THAN WE DO.

AND I'M SORRY TO SAY I'VE VOTED FOR BREDESEN.

IF I KNEW THAT'S HOW HE FELT I SURE WOULDN'T HAVE.

BUT I THINK IT ALL COMES DOWN, YOU KNOW -- AND IT'S HARD TO REALIZE PEOPLE WITH THEIR BUSY LIVES THAT DON'T DEAL WITH THIS DON'T UNDERSTAND.

BUT WE'RE GOING TO HAVE TO MAKE PEOPLE UNDERSTAND.

AND WORK TOGETHER AND SAY WE CAN'T JUST THROW THESE --

BECAUSE OF MEDICAL TECHNOLOGY, A LOT MORE PEOPLE ARE BEING KEPT ALIVE WHO WEREN'T BEFORE.

AND MORALLY CAN WE JUST SAY THERE YOU GO, YOU'RE ALIVE, GO MAKE THE BEST WAY YOU CAN?

NO.

AND THAT'S NOT WHAT THIS COUNTRY WAS FOUNDED ON.

SO WE JUST ALL NEED TO ENCOURAGE EACH OTHER.

I THINK WE NEED TO ENCOURAGE DOCTORS TO DO MORE EDUCATION, MORE ADVOCACY AND GET -- ONE THOUGHT I'VE HAD IS GET PEOPLE, ESPECIALLY WHEN THEY'RE FIRST DIAGNOSED, PAMPHLETS BECAUSE IT CAN BE SO OVERWHELMING, YOU DON'T KNOW WHERE TO START.

SO YOU DON'T DO ANYTHING.

AND WE NEED TO BE AWARE OF THAT AND HELP PEOPLE WHEN WE CAN.

AND I JUST WANT TO THANK ALL OF Y'ALL FOR COMING AND JUST ENCOURAGE YOU.

WE CAN'T GIVE UP.

I KNOW THAT'S WHAT THEY WANT US TO DO, BUT IF I HAVE TO SUE THE STATE, THAT'S WHAT I'LL DO BECAUSE THE WAIVER WAS STARTED FOR THIS REASON BY A COUPLE WHO DID RESEARCH THAT IT'S A LOT CHEAPER TO KEEP THEM AT HOME AND THEY DO BETTER. SO THEY -- THEY DON'T HAVE A LEG TO STAND ON.

IT'S JUST GOING TO BE -- I FEEL A LOT OF TIMES THEY FEEL THEY CAN TAKE ADVANTAGE OF THE PEOPLE IN THIS COMMUNITY BECAUSE A LOT OF THEM CAN'T SPEAK.

A LOT OF THEM WHO CAN HAVE NO WAY TO GET THERE, DON'T KNOW WHAT TO DO.

SO I THINK WE SHOULD SPEAK UP FOR THEM.

THANK Y'ALL.

[APPLAUSE]

>> LYNN BECK

>> I'M HERE THREE REASONS.

I HAVE A GRANDSON THAT'S MENTALLY CHALLENGED WHO MOVED FROM

TEXAS BECAUSE TEXAS MADE -- TENNESSEE DEPOSE.

AT THE AGE OF NINE MONTHS, HE'S MENTALLY CHALLENGED.

I ALSO HAVE A HUSBAND WHO'S 82 YEARS OLD WHO HAS DEMENTIA
AND I WORK A FULL-TIME JOB.

SO I KNOW WHERE PEOPLE ARE COMING FROM.

I WORKED WITH TEXAS MEDICAID FOR FIVE YEARS.

I'VE BEEN HERE FOR SEVEN.

THE SEVEN YEARS I'VE BEEN HERE I'VE SEEN FROM ONE EXTREME
TO THE OTHER.

THE THING I DO KNOW IS NO ONE KNOWS ABOUT THIS PROGRAM.

WHEN MY GRANDSON WAS IN THE HOSPITAL I SAID LET'S GET HIM
ON THE MEDICAID WAIVER SYSTEM, THEY SAID WHAT'S THAT?

HOSPITAL DISCHARGE PLANNERS HAVE NO CLUE WHAT THIS PROGRAM
CAN DO.

THEY HAVE NO IDEA WHAT WE ACTUALLY DO FOR THESE
INDIVIDUALS.

I THANK GOD THE P.A. I HAD WORKING OUT THERE FOR ME AS AN
AGENCY.

BECAUSE THEY GO THROUGH 30, 40 HOURS OF TRAINING, THEY GET
PAID \$7.25 AN HOUR AT BEST, AND THEY GO FLIP HAMBURGERS AT
McDONALD'S FOR \$9.

SO YOU TELL ME HOW LONG WE'RE GOING TO RETAIN THOSE PEOPLE.

NOT VERY LONG UNLESS THEY HAVE AN INVESTED INTEREST IN THAT INDIVIDUAL.

FAMILY MEMBERS ARE VERY IMPORTANT AS WELL.

I'VE SEEN GOOD FAMILY MEMBERS THAT ARE WAY OUT THERE AND THEY WILL DO ANYTHING THEY CAN TO MAKE IT RIGHT.

AND I'VE SEEN OTHERS THAT REALLY DON'T CARE.

AND THEY JUST SIT, I'VE SEEN IT BOTH WAYS.

I'M A REGISTERED NURSE.

WE USED TO COVER NURSING CASES FOR FRIENDSHIP.

WE'VE CAN'T COMPETE WITH THE STATE -- WITH THE PRIVATE INDUSTRY WHERE YOU MAKE \$18.

WE'RE REIMBURSED \$23.75 PER HOUR AND WE ARE FOR-PROFIT AGENCY.

WE ARE NOT ABLE TO OFFER BENEFITS BECAUSE THE GOVERNMENT -- THE REIMBURSEMENT RATES ARE NOT THAT GOOD.

SO THE NURSING ARE NOT OUT THERE.

YOU HAVE A NURSING SHORTAGE AS IT IS.

BUT WHEN YOU CAN'T FUND NURSES IN THE MEDICAID WAIVER THEY HAVE TO GO SOMEWHERE.

TENNCARE WILL NOT COVER THEM CONTINUOUSLY.

WE GET CALLS ALL THE TIME, CAN YOU COVER ACCU CHECKS FOUR TIMES A DAY?

NO, I CAN'T.

I DON'T HAVE A NURSE THAT WILL GO OUTSIDE THEIR REALM EVERY FOUR -- ABOUT EVERY FOUR HOURS AND DO A TWO-HOUR CHECKUP. BESIDES, THAT I'M MY LAST 2308 LOW THAT INDIVIDUAL, ONE OF THE NURSES OUT THERE AND HANG OUT.

I HAVE PAID TWO FITTINGS, NURSE WITH THREE FITTINGS A DAY, TWO HOURS A WEEK.

CAN'T DO IT.

MY LICENSE IS ON THE LINE IF THAT PERSON HAS GRACE AFTER TWO HOURS.

NO NURSE IS GOING TO TAKE THAT LIABILITY.

OR THEY SHOULD NOT.

BECAUSE IT'S THEIR LIVELIHOOD.

I'M ALSO A THERAPY COORDINATE FOR FRIENDSHIP.

MOST WORKING INDIVIDUALS THAT HAVE THERAPY ARE MAINTAINED BECAUSE THEY HAD THERAPY.

IF WE TAKE THERAPY AWAY FROM THEM THEY'RE GOING TO CURL UP A LITTLE BALL LIKE THEY WERE WHEN WE STARTED.

SO WE HAVE TO GO BACK TO THE BEGINNING AND INVENT THE WHEEL AGAIN?

BECAUSE THAT'S WHAT WE'RE DOING.

WE'RE WAITING FOR THEM TO CURL UP IN A LITTLE BALL AND SAY

OKAY, WE'LL TAKE YOU BACK ON AND YOU CAN STRAIGHTEN UP FOR
A WHILE, MAINTAIN YOU NINE, TEN MONTHS, AND THEN WE'LL
DISCHARGE YOU AND GO IN A BALL AGAIN.

MY GRANDS SON CAN'T SPEAK BUT HE CAN SIGN.

IF HE DIDN'T HAVE SPEECH THERAPY WHERE WOULD HE BE?

THERE'S NO SPEECH THERAPY THAT WILL DO EARLY PREVENTION
CHILD DEVELOPMENT -- I'M SORRY FOR THE INITIALS BUT IT'S
FOR THE TENNCARE PRACTICE.

THERE'S NOT AN AGENCY OUT THERE THAT WILL COME TO MY HOME.
HE GOES TO VANDERBILT THREE TIMES A WEEK AFTER SCHOOL AND
HE GETS THERAPY FOR O.T., P.S. AND S.P.

NOW, I DON'T KNOW WHERE OUR KIDS ARE GOING TO GO BECAUSE
SOME OF THEM CAN'T GO THERE.

SOME DON'T HAVE A WAY TO GET THERE.

THERE ARE WAYS.

BUT YOU HAVE TO REALLY BE STUBBORN ENOUGH TO WORK WITH THIS
PROGRAM BECAUSE IF YOU DON'T YOU'LL CRY EVERY DAY.

YOU'LL CRY EVERY DAY WHEN YOU GO HOME.

WE JUST RECENTLY TOOK ON AN INDIVIDUAL FROM MIDDLE
TENNESSEE MENTAL HEALTH.

HE HAD BEEN INSTITUTIONALIZED FOR 32 YEARS.

WOULD NOT COME OUT OF HIS UNIT.

OKAY.

WE STARTED A PROCESS.

WE KNEW HE WASN'T GOING TO COME RIGHT AWAY.

WE HAD THREE MONTHS FOR P.A.'S TO WORK SIDE BY SIDE WITH THAT INDIVIDUAL.

HE DID COME OUT.

WE HAD A ROUGH TWO WEEKS BECAUSE HE WAS SEEING THINGS HE HAD NEVER SEEN BEFORE IN HIS LIFE.

BUT AFTER HE GOT ACCLIMATED TO HIS SURROUNDINGS, WE HAD HIM SPEAKING.

HE HADN'T SPOKEN IN 32 YEARS.

HIS FATHER CRIED BECAUSE HE WAS ABLE TO SEE HIM.

HIS FATHER IS 82.

HE SAID WONDERFUL.

NOT EVERYONE KNOWS -- IF WE WEREN'T OUT THERE TO TAKE ON THESE INDIVIDUALS, THEY WOULD ALL BE INSTITUTIONALIZED AND ALL WOULD BE IN DIRE NEED.

I DON'T KNOW ABOUT YOU.

WE HAVE TO DO SOMETHING HERE.

WE HAVE TO DO SOMETHING.

THESE PEOPLE DEPEND ON US AS AGENCIES.

WE'RE A FOR-PROFIT AGENCY.

WE'RE NOT A NONPROFIT.

SO IT'S VERY HARD FOR US TO TAKE ON A C.B. DAY.

C.B. DAY IS RATIOED AT FOUR PEOPLE PER P.A.

WE DON'T DO FOUR PEOPLE PER P.A. IN THE RES -- IN PRIVATE HOMES.

OURS ARE ONE ON ONE.

IT'S HARD FOR US TO GIVE THE KIND OF CARE THAT THEY'RE ASKING US TO GIVE AND NOT PAY THE P.A.'S ENOUGH MONEY TO DO IT.

NURSES AIDS MAKE MORE MONEY THAN THE P.A.'S AND THEY TAKE LESS TRAINING.

AND I DON'T KNOW WHAT IT TAKES FOR US TO DO BUT TO GO OUT AND SIT OUTSIDE THE COURTHOUSE MAYBE AND DO A LITTLE DEMONSTRATION MAYBE.

THAT MAY HELP.

MAY NOT.

OUR INDIVIDUALS ARE VERY IMPORTANT TO US AS NURSES BECAUSE OUR AGENCY IS RUN BY NURSING.

WE'RE THE ONE OF THE AGENCIES THAT HAVE NURSING IN THE HOME.

BUT WE DO BELIEVE IN TAKING CARE OF OUR INDIVIDUALS.

WE DO BELIEVE IN MAKING SURE THEY -- AND THAT'S ALL I HAVE.

THANK YOU.

[APPLAUSE]

>> HUGH

>> I WANT TO READ SOMETHING TO THE GROUP.

>> GOOD EVENING.

I'M GLAD TO BE HERE.

MY NAME IS HUGH.

I WANT TO READ SOMETHING TO YOU ALL.

AND I WANT SOME ADVICE ON THIS.

WHERE IT SAYS SOMETHING ABOUT DMRS IS REVIEWING ALREADY

APPROVED I.S.P.'S, LOOKING FOR PLACES TO CUT SERVICES.

LET ME ASK ALL OF YOU ALL, WHAT -- WHAT NEEDS TO BE DONE

ABOUT THAT?

ANY COMMENTS, SUGGESTIONS?

IDEAS?

AT ALL?

WHAT NEEDS TO BE DONE?

BESIDES LOOKING WHAT'S ON THE SCREEN TONIGHT.

WHAT DO Y'ALL THINK ABOUT THAT?

I'M GOING TO TELL YOU ONE THING, WHERE IT SAYS CUT IN

STERLING SILVERS, LET ME TALK ABOUT THAT FOR A FEW MINUTES.

THE WAY I FEEL, I WANT PEOPLE WHO NEED SERVICES TO HAVE

THOSE SERVICES.

THAT THEY NEED IN ORDER, NUMBER ONE, IS THEY NEED TO KEEP
THEIR HOME THEY LIVE IN.

THEY DON'T NEED TO GIVE UP THEIR HOME.

[APPLAUSE]

>> YOU AGREE WITH THAT?

HOW MANY OF YOU AGREE WITH THAT?

I DON'T WANT TO LOSE THEIR SERVICES.

AND THAT'S THE REASON I'M KIND OF GLAD SEE WHAT'S ON THE
SCREEN TONIGHT.

WE CAN READ IT TOGETHER.

CALL YOUR STATE LEGISLATORS, FILE AN APPEAL IF SERVICES ARE
REDUCED OR DENIED.

FILE A COMPLAINT WITH THE C.M.S., SIGN PETITIONS, YEAH.

SEE ADVOCATE HANDOUT.

I LIKE THAT.

I THINK THAT IS GREAT.

SO I'D LIKE TO SAY TONIGHT, THAT'S THE REASON I'M HERE.

I WANT PEOPLE TO HAVE SERVICES WHO NEED THOSE SERVICES AND
NOT GIVE UP THEIR HOME.

[APPLAUSE]

ANOTHER THING, I WANTED TO TELL YOU ALL, I HAD THE JOY OF

GOING TO LEGISLATIVE PLAZA WEDNESDAY.

I DON'T KNOW HOW MANY OF Y'ALL WENT.

I WENT.

AND THE COMMISSIONER WAS THEIR SPEAKER.

I ATTENDED THAT SESSION WITH HIM.

AND HE TALKED ABOUT ALL -- ONE THING CHARLES TALKED ABOUT
TONIGHT.

HE TALKED ABOUT THAT.

AND THEN HE TALKED ABOUT THE WAIVER CERTAIN SERVICES.

BUT THE WAY I UNDERSTAND IT, CERTAIN SERVICES ARE NOT BEING
GIVEN THAT NEED TO BE GIVEN.

AND I WANT THOSE SERVICES TO BE GIVEN TO OUR PEOPLE.

AND I DON'T WANT THEM LOSING THEIR SERVICES OR LOSING THEIR
HOME.

AND IF IT TAKES MONEY FROM THE STATE, LET'S SAY IT THIS
WAY, I'M GLAD THEY'RE TALKING ABOUT THAT TONIGHT ALSO.

IT'S NOT ON THE PAPER HERE, NOT ON MY PAPER, BUT I WOULD
LIKE TO SEE THE STATE GIVE OUT A LOT OF MONEY WHEREBY

PEOPLE CAN HAVE SERVICES WHO NEED THOSE SERVICES AND WHO

DON'T HAVE TO GIVE UP THEIR HOME AND WHO HAVE STAFF WHO

COME IN AND SUPPLY THEIR -- THEIR PART OF THE PROGRAM.

THAT'S WHAT I WANT TO SEE HAPPEN.

AND I'M -- I REALLY GLAD TO SEE NORM THERE DOING THEIR PART
AND ALL THESE OTHER PEOPLE I KNOW, THEY'RE DOING THEIR
PART.

SO I'M KIND OF -- I'M KIND OF GLAD TO BE HERE AND REALLY
TALK ABOUT THIS.

THIS IS REALLY ON MY HEART TONIGHT.

LET ME TELL YOU THIS, I WANT SOMETHING DONE FOR OUR PEOPLE.

I WANT Y'ALL TO HAVE THE SERVICES YOU NEED.

AND YOU KNOW WHAT THEY ARE.

YOU DON'T HAVE TO LIST THEM.

YOU NEED TO STATE STAY IN YOUR OWN HOME WHERE YOU ARE AND
NOT HAVE TO GIVE UP THE SERVICES AND LIKE I'M GOING TO TELL
YOU ONE THING, AS I WAS TOLD WEDNESDAY, IT'S A BATTLE.

AND BY GOLLY, WE GOT TO FIGHT IT.

[APPLAUSE]

>> IT'S A BATTLE.

WE HAVE TO DO IT TOGETHER.

AND BY GOLLY, WE BETTER START DOING SOMETHING IF WE WANT TO
SEE SOMETHING HAPPEN.

BUT THAT'S NOT ON THE PAPER BUT THAT'S WHAT I WANTED TO
SHARE WITH Y'ALL TONIGHT.

I WANTED TO SHARE THAT WITH EVERY ONE OF YOU IN THIS ROOM.

AND THAT'S WHAT'S ON MY MIND.

AND I WANT SOMETHING DONE.

AND I WANT TO SEE YOU -- KEEP YOUR HOME AND KEEP THE
SERVICES ROLLING.

AND GET THE MONEY AND LET'S GET THEM ROLLING.

[APPLAUSE]

THANK YOU ALL FOR HAVING ME HERE.

>> HAVE WE MISSED ANYBODY?

I WANT TO THANK EVERYBODY FOR PROVIDING A TESTIMONY.

IT'S VERY MOVING.

A COUPLE OF THINGS I WANT TO SAY AND SUMMARIZE AND WIND UP.

ONE IS THAT THE NEXT DMRS ADVISORY COMMITTEE MEETING IS
LISTED ON THE SCREEN THERE, MARCH 13 AT 8:30 AT CLOVER
BOTTOM.

AND THAT'S AN OPEN PUBLIC MEETING.

IT'S A COMMITTEE BUT IT'S OPEN TO EVERYONE THAT CAN ATTEND.

SEE DECISIONS.

I WANT TO THANK PEOPLE FOR COMING TONIGHT.

I REALLY APPRECIATE THAT.

ONE OF THE REASONS I PICKED TONIGHT, SPECIFICALLY MARCH 10,
THIS IS A VERY HISTORICALLY SIGNIFICANT NIGHT.

MOST PEOPLE DON'T KNOW IT, AREN'T AWARE, BUT TONIGHT MARKS

THE TENTH ANNIVERSARY THAT NAT T WINSTON -- AN INSTITUTION
IN EASTERN TENNESSEE WAS CLOSED.

AND IT REPRESENTS FREEDOM FOR THE PEOPLE WHO LIVED THERE
AND REPRESENTS THE REAL MILESTONE IN TENNESSEE IN THAT ALL
PEOPLE WHO LIVED IN THE INSTITUTION WERE OUT OF THAT
PARTICULAR PLACE.

TENNESSEE HAS THREE OTHER INSTITUTIONS CLOVER BOTTOM AND
ARLINGTON AND GREEN VALLEY THAT ARE NOW, FOR THOSE OF YOU
DON'T KNOW, THERE ARE NOW EIGHT STATES IN THE UNITED STATES
THAT HAVE NO INSTITUTIONS AT ALL.

[APPLAUSE]

>> HAVE MANAGED TO FREE ALL THE PEOPLE AND HAVE PEOPLE LIVE
IN HOMES OR WITH FAMILIES AND RESIDENCES.

AS A LADY MENTIONED EARLIER, MANY OTHER STATES HAVE PEOPLE
LIVING IN COMPANION MODELS AND FAMILY SETTINGS, SITUATIONS
THAT ARE NOT ONLY LESS EXPENSIVE BUT MORE HOME-LIKE.

AND BY THE WAY REDUCE EXPENSES ENORMOUSLY.

SO THAT -- THAT'S THE REASON THAT WE PICKED THIS EVENING AS
AN HISTORICAL MOMENT OF THE TEN-YEAR CELEBRATION.

AND OUR HOPE IS THAT AS TIME PASSES WE WILL HAVE CLOVER
BOTTOM BE ABLE TO SAY THERE'S AN HISTORIC MOMENT, NOBODY
LIVES THERE ANYONE, AS LIKewise WITH ARLINGTON AND GREEN

VALLEY.

THESE CUTS THREATEN THAT GOAL.

EIGHT OTHER STATES HAVE MANAGED IT.

NEW HAMPSHIRE THAT WAS ONE OF THE FIRST STATES TO HAVE
EVERYBODY OUT OF THE INSTITUTION.

WHEN THEY FIRST DID THAT, EVERYBODY SAYS OH, WELL, THAT'S
NEW HAMPSHIRE, THEY'RE SMALL.

ORR, WELL, THAT'S UP ON THE NORTHEAST.

THOSE DAMN YANKEES, I'M A YANKEE.

[LAUGHTER]

>> OR OH, WELL, THEY HAVE LOTS OF MONEY UP THERE.

THEY'RE NOT LIKE WE ARE.

OR SO ON AND ON AND ON.

AND SLOWLY THE SECOND STATE AND NEW JERSEY AND NEW MEXICO
AND HAWAII AND EACH TIME PEOPLE SAID OH, WELL, THAT'S THAT,
NOW THERE'S EIGHT, PEOPLE REALIZE OH, WELL, THAT COULD BE
US.

WHERE THERE GOES US.

I WANTED TO SHARE THAT WITH YOU ALL.

AN HISTORIC MOMENT THAT WE SHARE TOGETHER.

THESE ARE VERY DIFFICULT TIMES, VERY DARK TIMES.

THE CUTS THAT WE'RE EXPERIENCING POSE REALLY DARK DAYS AND

TIMES FOR PEOPLE, THE CUTS THAT ARE PROPOSED ARE EVEN MORE TROUBLING.

WE AS ORGANIZATIONS CAME TOGETHER AND ATTEMPTED TO PROVIDE A FORUM THAT PEOPLE CAN SPEAK UP.

THE TESTIMONY THAT PEOPLE HAVE GIVEN, THE ENTIRE TRANSCRIPT, YOU'VE SEEN IT RIGHT IN FRONT OF YOUR EYES, WILL BE DISTRIBUTED AS WIDELY AS WE CAN.

IF ANYBODY HASN'T PUT YOUR EMAIL ADDRESS ON THE REGISTRATION LIST, IF YOU HAVEN'T REGISTERED, PUT YOUR EMAIL ADDRESS, WITHIN A WEEK WILL GET A TRANSCRIPT OF THIS AND WE'LL THANK KARYN FOR TRANSCRIBING TONIGHT, THE INTERPRETERS.

SO THERE WILL BE A COPY OF THAT.

[APPLAUSE]

>> AND WE'LL DISTRIBUTE IT AS WIDELY AS WE CAN.

THE PURPOSE IS TO SHARE YOUR VOICES AND TO LET PEOPLE HEAR AND UNDERSTAND THE DRAMATIC EFFECTS THAT REDUCTIONS IN SERVICES ARE HAVING.

THESE ARE NOT JUST ABSTRACT.

I THINK YOU -- HUGH SPOKE REALLY WELL.

THESE AREN'T JUST PEOPLE IN AN OFFICE MAKING DECISIONS.

THESE ARE VERY CONCRETE IMPACTS ON PEOPLE.

THEY HAVE IMPACTS ON PEOPLE WAITING FOR SERVICES, HOPING TO
GET THEM.

AND RESULT IN PEOPLE BEING HARMED.

SO I WANT TO THANK YOU FOR COMING AND BEING WITH US.

WE'RE GOING TO DO ONE MORE IN MEMPHIS.

AND WE'LL BE DISTRIBUTING THIS AND WE DEEPLY APPRECIATE ALL
OF YOU COMING AND BEING WITH US.

BLESSINGS TO ALL OF YOU.

THANK YOU.

[APPLAUSE]