

HI. I'M ED MATTHEWS. FOR THE PAST 5 YEARS I HAVE BEEN PRIVILEGED TO SPEAK WITH YOU ABOUT OUR FIELD AND THE THINGS THAT WE, AS PERSONS BEING SUPPORTED, AS FAMILY MEMBERS, AS STAFF AND AS FRIENDS AND ADVOCATES WE FIND MOST IMPORTANT

FOR 5 YEARS I'VE STOOD UP HERE AND TALKED @ MANAGED CARE, RATE CUTS AND IMploRED US TO SPEAK UP, CONVince OUR ELECTED AND APPOINTED OFFICIALS THAT PEOPLE WITH DEVELOPMENTAL DISABILITIES ARE JUST AS IMPORTANT TODAY AS THEY WERE IN 1972 WHEN THOSE BRAVE PARENTS WHOSE KIDS WERE AT WILLOWBROOK SIGNED A COURT PETITION AND SAID "THAT'S ENOUGH"

FOR 5 YEARS, I, AS WELL AS EVEN MORE ARTICULATE AND PASSIONATE PEOPLE HAVE STOOD HERE AND TALKED ABOUT THOSE THINGS THAT ARE TRULY IMPORTANT. WE'VE ASKED NOT TO BE FORGOTTEN. WE'VE ASKED THAT THE PROMISE BE CONTINUED. WE'VE ASKED THAT AS WE PASS THE TORCH TO THE NEXT GENERATION, THE FUNDAMENTAL PRINCIPLES OF A VALUED LIFE IN THE COMMUNITY FOR ALL NOT BE FORGOTTEN.

WHAT WE GET FROM STATE OFFICIALS IS THE PROMISE: "OF COURSE WE'RE NOT GOING TO FORGET THAT. IT'S THE PRINCIPLE THAT EVERYTHING WE DO NOW IS BUILT ON. THAT'S WHY OUR MANAGED CARE WAIVER IS THE PEOPLE FIRST WAIVER.....THAT'S WHY WE HAVE OUR TRANSFORMATION AGENDA WHICH WILL STOP THE WAREHOUSING OF PEOPLE IN INSTITUTIONS LIKE ICFS. THAT'S WHY WE ARE GOING TO INSURE (NOW CATCH THIS) EVERYONE WILL GET, THE RIGHT SERVICE, AT THE RIGHT TIME, AT THE RIGHT PRICE."

VERY SOON WE ARE GOING TO HAVE AN EVALUATION AND ENOUGH DATA TO PREDICT HOW EVERYONE WHO'S SCORE IS JUST LIKE YOURS IS GOING TO NEED. WE'RE GOING TO HELP YOU CREATE A LIFE PLAN. "

SERIOUSLY? BY THE WAY, THESE ARE GOOD PEOPLE. THEY BELIEVE THIS STUFF. IT'S ALSO TRUE THAT THERE ARE REAL ECONOMIC FORCES AT PLAY HERE. THERE

ARE SERIOUS POLITICAL FORCES AT PLAY HERE. WE'RE NOT GOING TO GET AWAY FROM THAT. WE CAN ALSO DO BETTER.

SO AS EVIDENCE THAT THE NEW ORDER HAS YOUR BEST INTERESTS IN MIND, THEY INTRODUCE.....THE FRONT DOOR. GEEZ WHAT A MESS! I WON'T BELABOR THE POINT. BEHIND THE FRONT DOOR COMES WORKSHOP CLOSURES, DOWNSIZING OF RESIDENCES AND ON AND ON. HERE'S THE THING FOLKS! THE PROCESS HAS BECOME MORE IMPORTANT THAN THE OUTCOME.... THE LABEL MORE IMPORTANT THAN THE LIFE.... THE COST MORE IMPORTANT THAN THE VALUE.

LOOK, WE'RE NOT GOING TO BACK TO THE WAY THINGS WERE. FOR 20 + YEARS, WE HAD GROWTH IN OUR SYSTEM RATE INCREASES, NEW AGENCIES POPPING UP TO SERVE UNMET NEEDS, FLEXIBILITY TO DO WHAT WAS NEEDED AND SOLACE FOR FAMILIES THAT THE PERSON THEY LOVE HAD A GUARANTEE OF A PLACE TO LIVE, SOMETHING TO DO AND FRIENDS TO SOCIALIZE WITH

MUCH OF WHAT WE ALL CREATED TOGETHER IS NOW LOOKED UPON AS BAD...OR AT BESTUNNECESSARY. SOMETIMES I FEEL THE SAME WAY THAT PEOPLE RUNNING DEVELOPMENTAL CENTERS DID IN THE '60S & '70S DID WHEN WE ALL CAME ALONG AND SAID... "GET OUT OF THE WAY, WE HAVE A BETTER IDEA." IT'S ALSO HOW WE ARE TREATED. AT THE HIGHEST LEVELS OF BOTH STATE AND FEDERAL GOVERNMENTS, ALL I'VE HEARD IS LOOK AT THOSE **VOLUNTARY AGENCY PROVIDERS, THEY NEVER WANT TO CHANGE AND WHEN WE ASK THEM TO THEY GO OUT AND SCARE PARENTS THAT THERE IS DOOM COMING." I'M SORRY, I'M SO TIRED OF LISTENING TO THAT BULL THAT I GET SICK. GROUP HOMES ARE YESTERDAY'S NEWS NO ONE WANTS TO LIVE IN THEM.NO ONE HAS CHOICE OH AND THEY'RE TOO EXPENSIVE.! DON'T WORRY WE'RE GOING TO GET YOU THE RIGHT SERVICE AT THE RIGHT TIME AT THE RIGHT PRICE.**

LOOK, I GOTTA ADMIT. SOME OF THIS WE BROUGHT ON OURSELVES. WE WERE THE 47TH STATE TO ADOPT THE HOME & COMMUNITY BASED WAIVER THAT WE NOW LIVE UNDER. WE WERE SUPPOSED TO CREATE MORE OPTIONS. WE DIDN'T. WE CALLED ICFs IRAs, DAY TREATMENT DAY HAB, AND GOT INCREASED

RATES TO DO IT. THAT CRITICISM IS FAIR. BUT HERE'S WHAT ISN'T. THOSE MODELS ARE NO GOOD, THEY ARE **ALL TOO EXPENSIVE. NOBODY NEEDS THEM.** TRUTH IS, THAT'S PURE AND UTTER NONSENSE. HERE'S THE THING. MANY PEOPLE CURRENTLY LIVING IN GROUP SETTINGS DON'T NEED TO, DON'T WANT TO. LET'S MOVE THEM OUT.

LET'S MAKE SURE THEY HAVE THE SUPPORTS THEY NEED TO BE SUCCESSFUL. BUT LET'S NOT LOSE OUR MINDS. LET'S NOT PRETEND THAT BY DOING SO, YOU'VE SOLVED ALL THE ISSUES. LET'S NOT PRETEND THAT EVERYONE CAN WORK. LET'S NOT PRETEND THAT EVERYONE LIVING ON THEIR OWN IS LESS EXPENSIVE. LET'S NOT PRETEND THAT EVERYONE CAN OR WANTS TO DIRECT THEIR OWN SERVICE. LET'S BE SURE THAT THOSE OPTIONS ARE NOT ONLY AVAILABLE, BUT LET'S BE SURE THEY ARE FULLY EXPLAINED AND MORE IMPORTANTLY FULLY UNDERSTOOD BY PERSONS SUPPORTED FAMILIES AND CAREGIVERS. THAT'S WHAT THE FRONT DOOR SHOULD BE DOING. NOW IT'S JUST DIRECTING FOLKS TO THE LEAST EXPENSIVE OPTION NO MATTER WHAT THE TIME

LET'S DO WHAT WE SHOULD HAVE DONE 20 YEARS AGO. I'M FINE WITH THAT. BUT LET'S NOT TREAT THE WORLD CLASS SYSTEM THAT HAS BEEN CREATED OVER 40 YEARS LIKE SOMETHING THAT HAS TO BE DISMANTLED. THAT'S THE FEAR OF EVERYONE HERE FOLKS. MANAGED CARE AND THE TRANSFORMATION AGENDA ARE ON A DOWNHILL COURSE TO DO THAT. WE HAVE THE POWER TO DO SOMETHING DIFFERENT. LET'S NOT KID OURSELVES THAT "THE RIGHT SERVICE AT THE RIGHT PRICE AT THE RIGHT TIME" IS SOMETHING THAT'S REAL, OR SOMETHING PEOPLE CAN RELATE TO. THE FACT OF THE MATTER IS THAT IT'S WHAT WE'VE BEEN DOING FOR 40 YEARS. WE HAVE TO WORK ON OPTIONS AND IN SOME CASES ON PRICE BUT THIS IS SURELY THE TIME.

I'M GOING TO TELL YOU A QUICK STORY ABOUT BOBBY WHO LIVED, IT WON'T SURPRISE YOU, IN A RESIDENCE SPONSORED BY UCP. HIS PARENTS WERE THE GREATEST PEOPLE. HE WAS MULTIPLY DISABLED, WITH LOTS OF PROBLEMS. LIVED AT HOME, BUT LIKE THOUSANDS OF OTHERS, BOB & KAY SIMPLY COULDN'T DO IT ANYMORE. THEY WERE THRILLED THAT HE WOULD BE WELL CARED FOR IN A GROUP HOME. THEY DIED WITHIN A FEW YEARS OF EACH OTHER, AND MANY YEARS LATER SO DID BOBBY. HE HAD TWO SISTERS WHO WERE REALLY NOT IN HIS LIFE BUT WHO DID PARTICIPATE IN HIS WAKE AND

SERVICES. HE WAS EULOGIZED NOT BY FAMILY MEMBERS BUT BY THE STAFF OF THE HOUSE. IF I STOP THE STORY THERE, MODERN ADVOCATES WOULD SNICKER AND SAY SEE, HE ONLY HAD PAID STAFF IN HIS LIFE HE HAD NO REAL RELATIONSHIPS YA DA DA YA DA DA YA DA DA.

WHAT LITERALLY “BLEW HIS SISTERS AWAY” WERE TWO THINGS

1) HE LIVED AS LONG AS HE DID BECAUSE HE WAS PRETTY MEDICALLY FRAGILE

BUT MORE

2) THE LIFE HE HAD, THE PLACES HE WENT, THE EXPERIENCES HE HAD, THE PEOPLE HE MET, THE FRIENDS AND RELATIONSHIPS HE HAD

THEY TOLD US THEY NEVER THOUGHT THAT COULD HAPPEN FOR HIM

OH, BOBBY LIVED IN AN ICF. BUT TO ME, AND I THINK YOU, HE GOT THE RIGHT SERVICE AT THE RIGHT PRICE AT THE RIGHT TIME.

COMMISSIONER DELANEY, WHO IS A GOOD PERSON, WHO IS MY FRIEND AND WHO DESERVES OUR SUPPORT IS, TO HER CREDIT, PUTTING A TRANSFORMATION PANEL TOGETHER TO HELP CHART THE NEXT FEW YEARS PATH. SHE SHOULD BE SUPPORTED IN THAT EFFORT. BUT, IF WE CAN ALL PLEDGE TO REMEMBER WHAT’S REALLY IMPORTANT HERE, US, OUR ELECTED OFFICIALS, OUR GOVERNMENT PARTNERS THEN WE WON’T HAVE TO WORRY @ TRANSFORMATION..MANAGED CARE OR ANYTHING ELSE. WE’LL SURVIVE AND THRIVE.

THE RIGHT SERVICE IS THE ONE YOU REALLY NEED AND THAT REQUIRES HUMAN JUDGEMENT AS WELL AS DATA, THE RIGHT TIME IS NOW, THE RIGHT PRICE IS DEFINITELY SOMETHING THAT WE CAN TALK ABOUT, BUT NONE OF IT CAN BE DICTATED BY A TEST SCORE.

KEEP THE FAITH! PEACE! GOD BLESS!