

Noon Open Microphone Testimony
Pages 96-163

I WOULD LIKE TO ASK THE NEXT GROUP OF FOUR, FROM THE OPEN MIC
SESSION TO PLEASE COME UP.

SECRETARY ALLEN, I UNDERSTAND THAT YOU MIGHT HAVE JUST A
COMMENT

OR TWO BEFORE WE TRANSITION INTO THIS NEXT SEGMENT.

>> I DO.

THANK YOU FOR CATCHING ME ON MY WAY OUT.

NO, I JUST WANT TO MAKE A COMMENT.

96

AND I BELIEVE, FROM WHAT WE'RE HEARING TODAY IT'S A VERY
CONSISTENT THEME.

AND THAT IS THAT WHAT PEOPLE ARE ASKING FOR IS NOT FOR
GOVERNMENT TO HELP IN THE SENSE OF DOING THE WORK FOR THEM,
BUT

SIMPLY TO GET OUT OF THE WAY SO THAT THEY CAN MAKE CHOICES
AND

DECISIONS FOR THEMSELVES, AND THAT WE BRING THE RESOURCES TO
BEAR ON THAT.

AND IT'S A MESSAGE THAT IS VERY CONSISTENT.

AND I WANT TO THANK THOSE WHO PARTICIPATED IN THE MORNING
SEGMENT, FOR SHARING YOUR THOUGHTS.

AND I LOOK FORWARD TO WORKING WITH YOU THIS AFTERNOON TO GET
MORE COMMENTS IN, THAT WE CAN HAVE THE RECORD VERY FULL AND
COMPLETE.

AND I ALSO WANT TO THANK THE MEMBERS OF THE DIAS FOR STAYING
THROUGHOUT THE AFTERNOON AND THE REST OF YOU WHO WERE HERE
FROM

THE FEDERAL GOVERNMENT.

TO
FOR THOSE WHO ARE NEW HERE THIS AFTERNOON, WHAT I WOULD LIKE
VARIOUS
DO LASTLY, IS ONCE AGAIN HAVE THOSE REPRESENTATIVES FROM
FEDERAL DEPARTMENTS TO PLEASE STAND SO THAT YOU CAN IDENTIFY
THAT THERE ARE MANY HERE IN THE AUDIENCE FROM THE VARIOUS
DEPARTMENTS.
SO IF YOU WILL STAND ONCE AGAIN...
THIS IS YOUR GOVERNMENT.
THESE ARE YOUR EMPLOYEES.
THEM
AND I WANT YOU TO TAKE ADVANTAGE TO TAKE TIME TO TALK WITH
AS YOU GET A CHANCE.

97

OFFICE
WE REPRESENT, NOT ONLY HHS BUT LABOR, EDUCATION, AND THE
OF PERSONNEL MANAGEMENT, VETERAN'S AFFAIRS.
I CAN GO DOWN THE LIST AND GET MYSELF IN TROUBLE BECAUSE I
FORGET SOME OF THEM, BUT WE'RE HERE.
WE WANT TO HEAR FROM YOU.
SO TAKE ADVANTAGE AND TALK TO THESE INDIVIDUALS.
THANK YOU.
THE
>> IF I MAY, BEFORE WE TRANSITION TO THIS NEXT SEGMENT OF
AGENDA, I THINK WE'VE HIT A RHYTHM IN TERMS OF BEING SURE TO
HAVE PEOPLE THAT JOIN US AT THE DIAS INTRODUCE THEMSELVES SO
ARE
THAT THE PEOPLE PROVIDING TESTIMONY WILL KNOW TO WHOM THEY
SPEAKING.
CAN WE ASK THE PEOPLE WHO HAVE JUST JOINED US AT THE DIAS TO

INTRODUCE THEMSELVES VERY BRIEFLY.

IF YOU WOULD HIT THAT MIC.

>> MY NAME IS CHRIS CLARK.

I'M IN THE OFFICE OF INTERGOVERNMENTAL AFFAIRS WITH THE
SMALL

BUSINESS ADMINISTRATION.

>> YES, MR. SOLOMON?

>> MY NAME IS ROD SOLOMON.

EXCUSE ME.

I'M THE DEPUTY ASSISTANT SECRETARY FOR POLICY, PROGRAM, AND
LEGISLATIVE INITIATIVES.

IN HUD'S OFFICE OF PUBLIC AND INDIAN HOUSING, WE HAVE PUBLIC
HOUSING AND THE VOUCHER PROGRAM.

>> PLEASE.

98

>> YES.

MY NAME IS JOSEFINA CARBONELL.

I'M THE NEW ASSISTANT SECRETARY FOR AGING AT THE DEPARTMENT
OF

HEALTH AND HUMAN SERVICES.

>> THANK YOU FOR JOINING US.

LET ME TAKE A MINUTE.

WE'RE NOW MOVING TO THE OPEN MIC SESSION, AND WE WILL RUN
THIS

SESSION FOR ABOUT THE NEXT AND A HALF.

IT WILL RUN IN A FASHION VERY SIMILAR TO THE PUBLIC
TESTIMONY

SEGMENT THAT WE JUST CONCLUDED, WITH -- IS MY MIC --.

>> ONE MORE INTRODUCTION.

>> OH, I'M SORRY.

EXCUSE ME.

PLEASE, THANK YOU.

>> HI.

I'M BILL MCKINNON.

I'M THE ACTING EXECUTIVE DIRECTOR OF THE PRESIDENTIAL TASK
FORCE
ON EMPLOYMENT OF ADULTS WITH DISABILITIES.

>> THANK YOU VERY MUCH.

AS I WAS SAYING, THIS SESSION WILL RUN IN A FASHION VERY
SIMILAR
TO THE ONE THAT WE JUST COMPLETED, WITH THE EXCEPTION AND I
GUESS THE ADDITIONAL CHALLENGE, THAT THE PEOPLE WHO WILL BE
PROVIDING TESTIMONY OVER THE NEXT HOUR OR SO SIGNED UP THIS
MORNING.

WE HAVE ASKED THEM TO LIMIT THEIR COMMENTS TO TWO MINUTES A
PIECE.

99

AND I THINK THAT REALLY WE DON'T HAVE A HECK OF A LOT OF
WIGGLE
ROOM IF IN FACT WE WANT TO HEAR ALL OF THE VOICES THAT HAVE
EXPRESSED AN INTEREST IN SHARING THEIR VIEWS.

SO, MS. JOHNSON, WE'LL START WITH YOU.

AGAIN, WE WILL BE USING THESE LIGHTS.

THEY WILL FLASH YELLOW WHEN YOU'VE GOT ONE MINUTE LEFT, AND
THEN
FLASH RED.

AND I WILL ASK YOU TO BE SURE TO TRY TO HIT THAT MARK, IF
YOU

WOULD.

MS. JOHNSON?

>> MY NAME IS JAY JOHNSON.

NATIONAL I'M A FORMER MEMBER OF THE BOARD OF DIRECTORS OF THE

ALLIANCE FOR THE MENTALLY ILL.

REPORT I SERVED ON THE PLANNING BOARD FOR THE SURGEON'S GENERAL

ON MENTAL HEALTH.

AND A I'M HERE TODAY AS A PERSON WITH A PSYCHIATRIC DISABILITY,

DOMICILIARY THE FATHER WHO SPENT HIS LAST TWENTY YEARS IN THE VA

SERVICE WITH A PSYCHIATRIC DISABILITY, AND A BROTHER WITH 100%

CONNECTED DISABILITY IN THE VA SYSTEM.

BE I SPEAK FIRST OF THE INSTITUTIONAL BIAS WITH WHICH WE ARE
CONFRONTED AND HOW WE CAN CHANGE THAT, WHICH MUST ACTUALLY

DONE IN ORDER TO REALLY MAKE PROGRESS HERE

WE HAVE TO CHANGE THE ASSUMPTIONS UPON WHICH WE WORK.

STATE I COME FROM A STATE WHERE APPROXIMATELY 80% OF THE FUNDS FOR
PEOPLE WITH PSYCHIATRIC DISABILITIES ARE LOCKED UP IN THE

HOSPITALS.

100

ELUDED THIS SPEAKS TO THE IM EXCLUSION, WHICH A PREVIOUS SPEAKER

TO IN THE POSSIBLE USE OF THE 1915 C OR 1915 WAIVER PROGRAM.

IMD I'M GOING TO SPEAK OF THAT IN TERMS OF IF THAT WAIVER, THE

EXCLUSION, WERE REMOVED, THE CONDITIONS AND THE KIND OF

CHARACTERISTICS THAT WOULD HAVE TO TAKE PLACE IN THE STATES;
THAT ALL STATE FUNDS SUPPLANTED BY THE IMD OR OTHER
INNOVATIVE
MECHANISM SHALL BE ALLOCATED FOR COMMUNITY SERVICES FOR
PEOPLE
WITH PSYCHIATRIC DISABILITIES AND SERVICES THAT THEY NEED
AND
WANT, AND THAT HAVING AN APPROVED MEDICAID WAIVER FOR THOSE
SERVICES -- AGAIN, IF WE WOULD TAKE A FORM OF 1915 OR
WHATEVER.
BUT SOMETHING REALLY NEEDS TO BE DONE ABOUT THIS DISABILITY
DISCRIMINATION.
THESE WAIVERS SHOULD ENABLE INDEPENDENT CHOICE AND
SELF-DETERMINATION BY FACILITATING CONSUMER CONTROLLED AND
SELF-DIRECTED SERVICES.
NOTHING COULD BE MORE IMPORTANT.
THIS NEEDS TO INCLUDE PEOPLE WITH PSYCHIATRIC DISABILITIES
AND
THEIR DEFINED NEEDS WITHIN THE MEDICAID DEFINITION OF
PERSONAL
ASSISTANT SERVICES.
AND WE'VE HEARD SOME DISCUSSION ABOUT THE NEED FOR A LIVING
WAGE
AND GOOD CONDITIONS FOR PEOPLE WHO HAVE THOSE RULES.
AND ALSO THE MEDICAID REHABILITATION OPTION WOULD HAVE TO BE
IN
PLACE.
WE WOULD ALSO LIKE TO SEE MEDICARE BEGIN TO LOOK AT FUNDING
PEER
DEVELOPED SERVICES, PEER SUPPORTED SERVICES, PEER DELIVERED
SERVICES, BECAUSE THERE'S SO MUCH EXPERTISE THERE THAT
REALLY

CAN'T BE FOUND ANYWHERE ELSE.

>> MS. JOHNSON, ARE YOU DONE?

>> YES, I AM.

>> THANK YOU SO MUCH.

OF
>> LET ME AGAIN EMPHASIZE, I KNOW TWO MINUTES IS NOT A LOT

TIME TO GET ALL THE IMPORTANT POINTS OUT ON THE TABLE.

THIS
LET ME ENCOURAGE, NOT ONLY THE PEOPLE WHO ARE PRESENTING IN

THERE
OPEN MIC, BUT ALL OF YOU, I AGAIN WANT TO REMIND YOU THAT

OUT
ARE COMPUTERS OUT IN THE REGISTRATION AREAS, THERE'S STAFF

YOUR
THIS TO ASSIST YOU, IF YOU WOULD LIKE TO SUPPLEMENT ANY OF

REMARKS WITH ADDITIONAL WRITTEN TESTIMONY.

I WOULD ENCOURAGE YOU TO PLEASE DO THAT.

I KNOW THAT THIS IS CHALLENGING.

MR. COMPTON?

SCHIZOPHRENIA.
>> MY NAME IS BILL COMPTON, I AM DIAGNOSED WITH

I MENTION THIS BECAUSE I BELIEVE THE GREATEST BARRIER IS
DISCRIMINATION THAT CAUSES US TO DISGUISE OUR ILLNESS.

RETURN,
I LUCKILY THOUGH, AM EMPLOYED AS THE DIRECTOR OF PROJECT

OPERATED
THE NEXT STEP, A CONSUMER-RUN MENTAL SELF-HELP PROGRAM,

UNDER THE AUSPICIOUS OF THE MENTAL HEALTH ASSOCIATION, LOS
ANGELES, CALIFORNIA.

PRINS HAS OVER 2,000 MEMBERS.

WE CONSIST OF THREE PROGRAMS: NUMBER ONE, A NETWORK OF 86

FACILITIES

SELF-HELP CLUBS WHICH MEET WEEKLY AT MENTAL HEALTH

TWO,

AND COMMUNITY CENTERS LOCATED THROUGHOUT THE COUNTY; NUMBER

TWO CONSUMER-RUN

102

AND

PEER RECOVERY CENTERS LOCATED IN LONG BEACH AND PALMDALE,
CALIFORNIA, WHICH OFFER A WIDE MENU OF SELF-HELP ACTIVITIES

THE

OPTIONS FOR MENTAL HEALTH CONSUMERS IN RECOVERY; AND THREE,

CALL

FRIENDSHIP LINE, WHICH IS A PHONE LINE, THAT CONSUMERS CAN

365 DAYS A YEAR WHEN THEY WANT SOMEONE TO TALK TO.

WHEN I BECAME THE DIRECTOR OF PRNTS IN 1994, I CREATED 27

ENTRY-LEVEL POSITIONS DESIGNED FOR PEOPLE WHO ARE LIVING ON
MENTAL HEALTH BENEFITS.

ARE

TODAY, WE HAVE 92 CONSUMER EMPLOYEES, 19 OF WHOM NO LONGER

ON BENEFITS.

CONSUMERS

OUR PROGRAM HAS BENEFITED FROM THE EXPERTISE OF THESE

WHO HAVE SERVED AS ROLE MODELS FOR OTHERS.

AND

IN CLOSE OF MY TESTIMONY, YOU WILL FIND THE RESULTS OF THIS
SURVEY ADMINISTRATOR TO OUR CONSUMER EMPLOYEES BOTH IN 1997

IN 2000.

MOTIVATED;

IN BOTH SURVEYS OUR MEMBERS OVERWHELMINGLY SAY THAT THEY ARE
NUMBER ONE, PROUD TO BE WORKING; NUMBER TWO, THEY ARE

AND NUMBER THREE, THEY FEEL BETTER ABOUT THEMSELVES.

BEEN

I HAVE ALSO NOTED THAT IN ONLY A FEW CASES HAVE OUR MEMBERS
RE-HOSPITALIZED SINCE THEY HAVE STARTED WORKING.

I SUPPORT THE NEW FREEDOM INITIATIVE BECAUSE WE AS PERSONS
LIVING WITH A MENTAL ILLNESS WILL BENEFIT GREATLY FROM THE
OPPORTUNITY TO HAVE A REAL LIFE.

AS A PERSON WHO HAS LIVED IN GROUP HOUSING AND ON SOCIAL
SECURITY BENEFITS, I CAN ATTEST THAT THAT IS NO LIFE AT ALL.
IF YOU SMOKE CIGARETTES, AS MANY OF MEMBERS DO, YOU HAVE NO

103

RELEGATED

MONEY FOR CLOTHING OR PERSONAL ITEMS.

MOST OF US DO NOT ENJOY SUCH A LIFE, BUT IT HAS BEEN

AND

TO US BY THE LACK OF OPPORTUNITIES IN EDUCATION, EMPLOYMENT,
HOUSING.

AMERICA SHOULD BE ABOUT SELF-DETERMINATION.

WE

IF WE ARE GIVEN THE OPPORTUNITY TO LIVE REAL LIVES WITH REAL
JOBS, CARS, NOT PUBLIC TRANSPORTATION, AND HOMES OF OUR OWN,

WILL FEEL BETTER ABOUT OURSELVES AND DECREASE THE FINANCIAL
BURDEN OF OUR LIVES ON THE AMERICAN TAXPAYER.

PROGRAM

WE WELCOME THE OPPORTUNITY AFFORDED TO US BY THE BUSH
ADMINISTRATION, AND WE'LL OFFER OUR SUPPORT SO THAT THIS

BECOMES A REALITY.

AT

BUT I MUST MENTION THAT WE NEED FUNDING FOR THIS PROGRAM TO
BECOME A REALITY, A PROGRAM OF OUTRESOURCES IS NOT A PROGRAM

ALL.

THANK YOU.

>> THANK YOU, MR. COMPTON.

MR. HECK, BEFORE WE GO TO YOU, IF I CAN ASK THOSE OF YOU WHO
ARE

HOLDING WHITE CARDS WITH THE NUMBERS 9 THROUGH 16, THE NEXT
GROUP THAT WILL BE PRESENTING DURING THE OPEN MIKE SESSION,
IF

YOU COULD ASSEMBLE IN THE BACK, PLEASE, WE WOULD MUCH
APPRECIATE

IT.

MR. HECK?

>> GOOD MORNING.

MY NAME IS RANDOLPH HECK.

I COME ALL THE WAY FROM THE STATE OF HAWAII.

104

I TOO AM A MENTAL HEALTH CONSUMER SURVIVOR.

AND THERE ARE MANY OF US IN THE UNITED STATES WHO ARE LIVING
LIVES OF QUIET DESPERATION.

THERE JUST AREN'T ENOUGH SERVICES FOR US BECAUSE WE ARE FOUR
TO

FIVE PERCENT OF THE GENERAL POPULATION.

THE FEDERAL PERFORMANCE PARTNERSHIP BLOCK GRANT FUNDS FOR
MENTAL

HEALTH ARE MUCH SMALLER THAN BLOCK GRANT FUNDS FOR SUBSTANCE
ABUSE.

THIS DISPARITY IN FUNDING IS A BARRIER TO EXPANDING SERVICES
FOR

PEOPLE WITH POOR MENTAL HEALTH, ESPECIALLY TO THOSE IN RURAL
OR

FRONTIER AREAS WITH FEW SERVICES.

AND OUR GENERAL HEALTH ALSO TENDS TO BE POOR.

HEALTH WE NEED TO INTEGRATE THE MENTAL HEALTH FUNDS WITH PRIMARY
CARE.
A LOT OF US SMOKE AND MEDICAID COVERS SMOKING CESSATION,
PHARMACEUTICALS AS WELL AS SUPPLIES AND CLASSES.
PREVENTIVE CARE IS MUCH LESS EXPENSIVE THAN REMEDIAL CARE.
MENTAL POOR PHYSICAL HEALTH IS A BARRIER FOR PEOPLE WITH POOR
HEALTH AND FEDERAL PRIMARY HEALTH CARE FUNDING SHOULD ALSO
HAVE INTEGRATION WITH MENTAL HEALTH CARE AS A GOAL.
POPULATION, THERE SHOULD BE MORE MEDICATION EDUCATION FOR OUR
NURSES AND WE CAN USE THE ALLIED HEALTH PROFESSIONALS SUCH AS
AND PHARMACISTS THAT CAN HELP US OUT WITH THAT BECAUSE OUR
SIDE MEDICATIONS OFTEN HAVE POWERFUL SIDE EFFECTS AND DISABLING
AND EFFECTS, AND WE NEED TO KNOW ABOUT THESE AS SOON AS POSSIBLE
THEM, BESIDES FINDING OUT ABOUT THEM IN THE HARD WAY OF GETTING

105

PROVIDERS YOUR PHYSICIAN OR M.D. SHOULD BE DOING THIS, BUT THESE
OFTEN JUST DON'T HAVE THE TIME.
APPROPRIATE SO THESE SERVICES SHOULD BE REIMBURSED THROUGH THE
FEDERAL FACILITIES AND FUNDS.
PREVIOUS ALSO, WE NEED GOOD JOBS, MEANINGFUL WORK, AND AS OUR
SPEAKER POINTED OUT, JOBS ARE JUST VITAL TO OUR POPULATION,

FEELING GOOD ABOUT ITSELF.

THE EXISTING TAX CREDIT SHOULD BE INCREASED WITH A GOAL TO
RETAIN PEOPLE ONCE HIRED, NOT JUST SIX MONTHS.

TO
SO I THANK YOU FOR THIS OPPORTUNITY TO TESTIFY AND I DO WANT

ASK THE FEDERAL GOVERNMENT HOW MANY FEDERAL PRISONERS ARE IN
JAIL RIGHT NOW AND NOT GETTING MENTAL HEALTH TREATMENT,
INSTEAD

BEING INCARCERATED?

FIVE TIMES AS MANY PEOPLE ARE INCARCERATED THAN ARE IN STATE
MENTAL HEALTH TREATMENT FACILITIES.

THANK YOU.

>> THANK YOU, MR. HECK.

MS. ROBINSON?

>> I NEED SOME HELP WITH ADJUSTING THE MICROPHONE.

OKAY.

IS THIS WORKING FOR EVERYONE?

CAN EVERYONE HEAR ME?

>> YES, MA'AM.

>> MY NAME IS MS. MARTINA ROBINSON.

I'M A GRADUATE STUDENT OF THE UNIVERSITY OF MASSACHUSETTS
AMHERST, WHERE I HAVE BEEN A T.A. FOR THE PAST THREE
SEMESTERS

106

AND HAVE A SUMMA CAMLAUDE 4.0.

PART
I CAME TO MASSACHUSETTS NOT OUT OF CHOICE, OR ANY JOY ON MY
BECAUSE I HAD TO GO THERE IN ORDER TO RECEIVE THE NECESSARY
SERVICES.

I NEED TO ADVANCE MYSELF IN TERMS OF PERSONAL ASSISTANCE AND
WHEELCHAIR REPLACEMENT SERVICES.

I HAD TO LEAVE A JOB I LOVED AND HAD CREATED AT THE
PENNSYLVANIA

COALITION ASSISTANCE WITH DISABILITIES.

I HAD TO LEAVE MY FRIENDS AND MY COMMUNITY AND EVERYONE I
HAD

EVER KNOWN IN MY LIFE JUST TO MOVE TO A PLACE WHERE I COULD
MYSELF BETTER MYSELF AND BECOME THE SORT OF PERSON THAT I EXPECT

TO BE AND OTHER PEOPLE EXPECT OF ME.

THIS OCTOBER I AM TEACHING A DANCE CLASS TO OTHER CHILDREN
WITH

DISABILITIES SO THAT THEY CAN INCREASE THEIR SELF-ESTEEM AND
WELL-BEING.

I WOULD VERY MUCH LIKE TO GO BACK HOME TO PENNSYLVANIA AND
CREATE THIS PROGRAM IN A LONG-STANDING FASHION, BUT I DON'T
THINK THAT WILL BE POSSIBLE GIVEN THE PRESENT SITUATION IN
PENNSYLVANIA.

SO THEREFORE I THINK WE SHOULD POSSIBLY ESTABLISH A PROGRAM
THAT

WOULD ALLOW ME TO USE THE MONEY THAT THE FEDERAL GOVERNMENT
WILL

SPEND ON ME IN AN INSTITUTION TO LIVE WHEREVER I CHOSE AND
WHATEVER MANNER I CHOSE TO LIVE THERE.

THIS WOULD SAVE THE STATE MONEY AND WOULD INCREASE MY
ABILITY TO

BETTER MYSELF AND ALSO INCREASE THE ABILITY OF DISABLED
PEOPLE

TO EDUCATE OTHER DISABLED PEOPLE, ESPECIALLY YOUNG CHILDREN

INSTEAD

BECAUSE WE WOULD BE ALLOWED TO LIVE WHEREVER WE NEEDED

OF IN CONCENTRATED COMMUNITIES IN CALIFORNIA, NEW YORK, AND MASSACHUSETTS.

BECAUSE THAT'S WHERE THE SERVICES ARE.

SO I THANK YOU FOR THIS CONSIDERATION AND I HOPE YOU WILL CONSIDER MY COMMENTS.

MUCH

>> THANK YOU VERY MUCH, MS. ROBINSON, AND THANK YOU VERY

FOR YOUR TESTIMONY, ALL OF YOU.

US

I WOULD LIKE TO ASK THE NEXT FOUR TO PLEASE COME IN AND JOIN

IN THE FRONT. AND AS WE TRANSITION THERE, BEFORE WE GO TO

THE

MS. CHESSER, I BELIEVE THAT WE HAVE SOMEONE JOINING US AT

INTRODUCE

DIAS AND I WOULD LIKE TO GIVE HIM THE OPPORTUNITY TO

HIMSELF.

>> GOOD AFTERNOON, MY NAME IS JOHN WODATCH.

OF

I'M THE CHIEF OF THE DISABILITY RIGHTS SECTION AT DEPARTMENT

JUSTICE.

>> THANK YOU VERY MUCH.

>> MS. CHESSER?

>> HELLO.

MY NAME IS JUDY CHESSER.

I'M THE DIRECTOR OF PUBLIC POLICY FOR UNITED CEREBRAL PALSY.

UNITED CEREBRAL PALSY IS ONE OF THE LARGEST NATIONAL

ORGANIZATIONS REPRESENTING PEOPLE WITH DISABILITIES.

ONE

WE HAVE OVER 100 AFFILIATES IN 43 STATES AND WE SERVE OVER

MILLION PEOPLE WITH DISABILITIES DIRECTLY.

IMPLEMENT

WE APPLAUD THE PRESIDENT FOR HIS EXECUTIVE ORDER TO

108

OLMSTEAD AND FOR THE NEW FREEDOM INITIATIVE.

THE OLMSTEAD SUPREME COURT DECISION, AS YOU KNOW, PROVIDED
THAT

PEOPLE WITH -- SERVICES FOR PEOPLE WITH DISABILITIES MUST BE
PROVIDED IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR
NEEDS.

YET ONE OF THE MAJOR BARRIERS TO ACHIEVING THIS GOAL IS THE
MEDICAID REIMBURSEMENT SYSTEM, WHICH GIVES MUCH GREATER
REIMBURSEMENT FOR DIRECT SUPPORT WORKERS IN INSTITUTIONAL
SETTINGS RATHER THAN WHEN THEY ARE COMMUNITY-BASED.

AND WE ARE VERY AWARE OF THIS AT UCP BECAUSE MANY OF OUR OWN
AFFILIATES PROVIDE DIRECT SUPPORT WORKERS OR DIRECT CARE
ATTENDANTS.

CARE THE CURRENT MEDICAID SYSTEM GUARANTEES OFTEN INAPPROPRIATE

IN STATE INSTITUTIONS AND YET THAT WOULD BE A MUCH LESS
EXPENSIVE CARE IF WE COULD PROVIDE IT IN THE COMMUNITY-BASED
SETTING.

AN THE MEDICAID REIMBURSEMENT RATES ARE LOWER AND TO GIVE YOU

EXAMPLE, IT'S ABOUT \$9 AN HOUR IN THE COMMUNITY.

WHEREAS IT'S ABOUT \$20 AN HOUR IN INSTITUTIONS.

THAT AND THE MOST RECENT STUDY THAT WE KNOW OF THAT'S AVAILABLE

WAS DONE BY HHS IN 1999 JUST TO GIVE YOU AN IDEA OF WHAT THE
HOURLY RATES ARE, IN CALIFORNIA IT WAS \$5.24 AN HOUR; MAINE,
\$6.25 AN HOUR; MICHIGAN, \$6.50 AN HOUR.

IN AND THE AVERAGE SALARY FOR A DIRECT CARE WORKER AT THAT TIME

1999 WAS \$16,000 AN HOUR -- EXCUSE ME. \$16,000 A YEAR.
THESE REIMBURSEMENTS RATES -- WE WISH -- \$16,000 A YEAR.

109

THEM THE REIMBURSEMENT RATES MUST COVER NOT ONLY SALARY, BUT OF
COURSE FICA, BENEFITS, LIABILITY INSURANCE AND TRAINING.
OUR UCP AFFILIATES HAVE MUCH COMPETITION WHEN WE ARE PAYING

EITHER SUCH LOW HOURLY RATES AND WE ARE GIVEN A CHOICE BETWEEN

MIGHT TRYING TO AUGMENT IT BY CURTAILING OTHER SERVICES THAT WE

PROVIDE OR STICKING WITH THE MEDICAID REIMBURSEMENT RATE, IN
WHICH CASE WE CANNOT RETAIN OR RECRUIT WORKERS, WE ARE
COMPETING

THEMSELVES. WITH FAST FOOD RESTAURANTS AND STATE INSTITUTIONS

ME. WE HAVE A HUNDRED PERCENT REIMBURSEMENT TURNOVER -- EXCUSE

AND ONE HUNDRED PERCENT TURNOVER RATE IN MANY OF OUR AFFILIATES

25- TO 35% VACANCY RATES --

>> MS. CHESSER, IF YOU COULD SUMMARIZE, PLEASE.

>> I WILL.

>> THANK YOU.

>> THIS IS A CRISIS.

IN 1998, THERE WERE 256,000 DIRECT CARE WORKERS.

BY 2000, THE ESTIMATE IS THAT WE WILL NEED 374,000.

THERE ARE THREE AT LEAST APPROACHES TO REMEDY THIS.

INSTITUTIONAL

THERE IS A LEGISLATION TO CREATE PARODY WITH STATE

WORKERS, WHICH WE OURSELVES HAVE DRAFTED.

THERE IS A MICASA BILL, WHICH IS S-1298, WHICH HAS BEEN
INTRODUCED BY SENATORS HARKEN AND SPECTER.

TO

AND ANOTHER BILL WAS INTRODUCED BY SENATOR DURBAN WHICH IS

PROVIDE \$4 BILLION IN STATE GRANTS TO HELP COVER HEALTH
INSURANCE FOR DIRECT CARE WORKERS.

SUBMITTED

AND WITH THAT, I THANK YOU VERY MUCH AND WE HAVE ALSO

110

A FORMAL STATEMENT FOR THE RECORD.

THANK YOU.

>> THANK YOU VERY MUCH.

MS. GOLDEN, I'M SORRY, WE WENT OUT OF ORDER.

PLEASE.

>> HI, MY NAME JACKIE GOLDEN.

I'M THE EXECUTIVE DIRECTOR FOR INCLUSION RESEARCH INSTITUTE.

BUT MAINLY I'M A PARENT OF A YOUNG MAN WITH SIGNIFICANT
DISABILITIES.

MY SON JOSHUA IS 20.

HE HAS ANGELMAN SYNDROME.

WANTS A

AND EVEN THOUGH HE HAS SIGNIFICANT DISABILITIES, MY SON

LIFE AND HAS DREAMS.

OVER

I WANT TO FOCUS ON A FEW KEY BARRIERS THAT WE HAVE PASSED

THE LAST 20 YEARS AND DUE TO HIS FAMILY'S INPUT AND MAJOR

THAT EFFORTS ON OUR PART, HE HAS OVERCOME A LOT OF BARRIERS EVEN
YOU KEEP PUTTING DOWN IN FRONT OF HIM.
FOR INSTANCE, THE FIRST BARRIER HIT AT AGE EIGHT, HE WAS
FORCED INTO AN INSTITUTIONAL SETTING BECAUSE OUR SYSTEMS WILL NOT
PAY FOR FAMILY SUPPORTS AT HOME.
WE DO NOT PAY FAMILY MEMBERS FOR THE ABOVE-AND-BEYOND CARE.
FAMILIES CANNOT WORK, THEY CANNOT CARE FOR THEIR CHILDREN
WITH THE SUPPORT OF THE FEDERAL GOVERNMENT.
THEY ARE FORCED INTO AN INSTITUTIONAL BIAS.
THIS IS WHAT HAPPENED TO JOSHUA.
THE OTHER THING IS WE FACE COMPLEX REGULATIONS.

111

FOR INSTANCE, THE SOCIAL SECURITY ADMINISTRATION, WE DIDN'T
QUALIFY FOR SUPPORT AS WE MADE \$300 OVER THE LIMIT.
MY \$300 KEPT US OUT OF THE SUPPORT WE SO DRASTICALLY NEEDED AS
SON WAS GROWING UP TO MEDICAID.
HE WAS DENIED THESE SERVICES.
SO THEREFORE HE WAS DENIED HEALTH CARE AS WELL.
THE SUPPORT STAFF ISSUES THAT WE HEAR ABOUT IS A CHRONIC
PROBLEM.
YET, WE DON'T PAY -- NOT ONLY DON'T WE PAY OUR SUPPORT STAFF
NEED ADEQUATE FUNDS, WE ALSO DON'T PROVIDE HEALTH CARE THAT THEY
AS WELL.
I ALSO WANT TO HIGHLIGHT THE FACT THAT JOB OPPORTUNITIES ARE

REALLY LACKING FOR INDIVIDUALS SUCH AS MY SON.
WE ARE DEVELOPING A MICRO-ENTERPRISE AND YOU CAN IMAGINE,
I 'LL
I
DIRECT THIS TO THE SMALL BUSINESS ADMINISTRATION, THAT WHEN
CALLED THEIR ONE-STOP AND ASKED THEM FOR OUR DREAM FOR OUR
CHILD
TO OWN A MICRO-ENTERPRISE, THEY ASKED ME WHAT THE SMALL
BUSINESS
ADMINISTRATION WEBSITE WAS.
AS A PARENT, I FIND THAT REALLY OFFENSIVE THAT MY ONE-STOP
COULDN'T TELL ME AS A PARENT WHERE TO GET THE SERVICES AND I
WAS
INFORMING THEM.
THIS IS A LOT OF BARRIERS WE FACE WITH THE FEDERAL
GOVERNMENT AS
WELL AS OUR STATE GOVERNMENT.
PARENTS ARE OFTEN EDUCATING THE EDUCATORS AND THE SERVICES
THAT
ARE SUPPOSED TO BE PROVIDING SUPPORT.
THANK YOU.

112

>> THANK YOU, MS. GOLDEN.
MS. LIPMAN?
>> MY NAME IS JOYCE LIPMAN.
MY 34-YEAR-OLD DAUGHTER ELISE HAS SIGNIFICANT COGNITIVE
DISABILITIES.
AND ALTHOUGH I HAVE A MULTITUDE OF ISSUES, PARTICULARLY
EMPLOYMENT, TODAY I AM GOING TO FOCUS ON THE ROADBLOCKS THAT
WE
ARE ENCOUNTERING IN TRYING TO GET ELISE A SECTION 8 RENTAL

VOUCHER.

SITUATION THE ROADBLOCKS THAT I FEAR MORE AND MORE PEOPLE IN HER

CONTROLLED WILL RUN INTO AS WE CREATE NEW MODELS FOR CONSUMER

HOUSING FOR PEOPLE LIKE ELISE.

ASKING AS A MOTHER AND AS AN ADVOCACY LEADER IN MARYLAND, I AM

FOR YOUR HELP IN BREAKING DOWN THE REGULATORY BARRIERS.

HERE IS WHAT'S HAPPENING TO US.

ELISE IN LINE WITH THE NEW SELF-DETERMINED WAYS OF DOING THINGS,

AND HER ROOMMATE BARBARA RENT THEIR OWN HOUSE IN KENSINGTON,

MARYLAND.

BETWEEN THEM, THEY MAKE ABOUT \$200 A MONTH AT THEIR JOBS.

THEY RECEIVE SSI OR SSDI AND SUPPORT MONEY FROM THE MARYLAND

DEVELOPMENTAL DISABILITIES ADMINISTRATION.

WHEN THEIR FULL-TIME CAREGIVER CAROLYN LIVES IN THEIR HOUSE EVEN

SHE'S OFF DUTY.

SLEEPS ON WEEKENDS, SOMEONE ELSE ASSUMES THE RESPONSIBILITY AND

BEDROOMS. THERE FRIDAY AND SATURDAY NIGHTS, THUS WE NEED FOUR

FOR A HOWEVER, THE RULES SAY THAT ONLY ONE BEDROOM IS NECESSARY

CAREGIVER.

WEEKEND STAFF WOULD THEN HAVE TO SHARE CAROLYN'S ROOM, HER

HOME, OR SLEEP ON THE COUCH, SO MUCH FOR NORMALIZATION.

WITH TO ADD TO THAT, HOW DO YOU RECRUIT GOOD STAFF, ESPECIALLY
THE CRISIS THAT MS. CHESSER SPOKE OF, AND TELL THEM THEY CAN
HAVE NO PRIVACY?
WE ARE TOLD THAT THE COSTS ARE OUTSIDE THE GUIDELINES.
AS MANY OF YOU KNOW, RENTS IN MONTGOMERY COUNTY ARE SKY
HIGH.
WE MANAGED TO FIND A LITTLE HOUSE WITH LOTS OF LITTLE ROOMS.
THAT MEANS AN EIGHT BY ELEVEN LIVING ROOM AND A KITCHEN YOU
CAN'T TURN AROUND IN.
THE MONTHLY RENT IS \$1,370 PLUS UTILITIES OF ABOUT \$250.
OTHER CHOICES DON'T EXIST; WE LOOKED.
ELISE AND BARBARA REALLY NEED FINANCIAL HELP, SO WE WERE
VERY
EXCITED WHEN ELISE'S NAME CAME UP IN THE LOTTERY FOR ONE OF
THOSE RARE SECTION 8 VOUCHERS.
BUT TRY AS THEY MAY, HOC CAN SEEM TO FIND A WAY AROUND THE
REGULATIONS.
AS MARYLAN> THANK YOU VERY MUCH.
MR. CHEKASE?
>> THANK YOU.
IS THIS ON?
MY NAME IS ROBERT CHEKASE.
I'M ONE OF THE CO-FOUNDERS OF THE AMERICAN INDIAN
REHABILITATION
RIGHTS ORGANIZATION OF WARRIORS.
WHAT I'M ABOUT TO SAY COMES FROM MYSELF, BUT IT ALSO COMES
FROM
OTHER NATIVE AMERICANS WITH DISABILITIES THAT ARE IN INDIAN

COUNTRIES.

NATIVE THE INDIAN COUNTRY NEEDS THE ACCESS AND OPPORTUNITIES FOR

OWN AMERICANS WITH DISABILITIES TO LIVE INDEPENDENTLY IN THEIR

COMMUNITIES.

INDEPENDENT ONE SUCH VITAL LINK TO COMMUNITY-BASED SERVICES IS

VARIOUS LIVING CENTERS, WHICH PROVIDE OUTREACH, EDUCATION, AND

OTHER SERVICES.

AND INDEPENDENT LIVING CENTERS -- INDEPENDENT LIVING SERVICES

INDEPENDENT LIVING PHILOSOPHY IS A COMMUNITY-BASED,

COMMUNITY-DRIVEN PROGRAM.

COUNSELING, INDEPENDENT LIVING FULL CORE SERVICES ARE INFORMATION AND

REFERRAL, PEER COUNSELING, INDEPENDENT LIVING SKILLS

AND ADVOCACY, BOTH SYSTEMS AND INDIVIDUAL ADVOCACY.

THERE ARE OVER 300 INDEPENDENT LIVING CENTERS IN THE UNITED

STATES AND ITS TERRITORIES.

INDIAN THERE ARE TWO INDEPENDENT LIVING CENTERS THAT RESIDE ON

RESERVATIONS.

THERE IS A LACK OF OUTREACH AND SERVICES.

AND IN SOME INSTANCES, THERE ARE NO SERVICES.

THE ISSUES THAT COME UP ARE THE VAST DISTANCES, THE LACK OF

CULTURAL AWARENESS AND NOT ENOUGH MONEY TO GET OUT TO THE

RESERVATIONS.

NECESSARY INDEPENDENT LIVING SERVICES CANNOT ONLY PROVIDE THE

PEOPLE SERVICES, BUT CAN BE AN EMPLOYMENT MECHANISM TO EMPLOY

WITH DISABILITIES ON THOSE RESERVATIONS.

115

IT WILL ALSO LEAD TO BEING SELF-EMPOWERED.
PEOPLE HAVING THE TOOLS AND THE KNOWLEDGE TO HELP THEMSELVES
AS
WELL.
WHAT INDIAN COUNTRY NEEDS IS ACCESS TO INDEPENDENT LIVING
PEOPLE DOLLARS SO WE CAN DO THE OUTREACH, SO WE CAN ASSIST OUR
WITH THE PERSONAL CARE AND SERVICE ISSUES OF TRANSPORTATION,
HOUSING ISSUES, EMPLOYMENT ISSUES.
WE ALSO NEED TO BE ON THE STATE'S BOARDS AND COUNCILS.
HOW WE NEED TO BE AT THE TABLE BECAUSE THE STATE PLANS DETERMINE
AND WHERE SERVICES ARE DELIVERED IN THOSE STATES.
THE LAW AND FEDERAL REGULATIONS REQUIRE REPRESENTATION FROM
INDIAN COMMUNITIES ON THOSE BOARDS AND COUNCILS.
AND BUT SOME OF THE STATES ARE OUT OF COMPLIANCE WITH THESE LAWS
REGULATIONS.
WE NEED STATES TO COMPLY WITH THE LAWS AND REGULATIONS THAT
AFFECT -- IMPACT TRIBAL PEOPLE WITH DISABILITIES.
ON WHERE IS THE ACCOUNTABILITY WHEN WE CAN'T GET REPRESENTATION
OUR THE BOARDS AND IN COUNCILS THAT DEVELOP PLANS AND EXCLUDE
PEOPLE, YET COUNT OUR HEADS FOR THE DOLLARS?
SUMMIT ON I WOULD LIKE TO SAY FINALLY THE INDIAN COUNTRY NEEDS A
WELL DISABILITY TO ADDRESS AND PRIORITIZE DISABILITY ISSUES AS

AS WORKING WITH THE FEDERAL AND STATE AGENCIES TO BETTER
COORDINATE WORKING AND CONSULTATION WITH TRIBES.

INTO I WOULD JUST LIKE TO ADD ONE MORE THING ABOUT -- IS I RAN
THIS MYSELF FROM JUST WORKING IN THE DISABILITY FIELD WHEN I
MAKE TRIED TO CALL SOME OF THE FEDERAL AGENCIES, WHEN I TRIED TO

116

ANY CONTACT WITH THOSE AGENCIES, I AM NOT GETTING -- RECEIVING
KIND OF ANSWERS BACK FROM ANYBODY.

FROM I JUST WISH THAT WHOEVER IS THERE ON THAT END WOULD LOOK AT
DOING INDIAN DISABILITY ISSUES -- JUST LOOK AT THEM PLAIN BECAUSE
EVERY ONE OF THESE SIGNS HERE THAT THE SERVICE DOLLARS COME
ARE NOT MAKING IT TO THE RESERVATIONS OR OUR PEOPLE ARE
WITHOUT.

THANK YOU.

>> THANK YOU VERY MUCH FOR YOUR TESTIMONY.

PLEASE MAY I INVITE THE NEXT FOUR FROM THE OPEN MIKE PANEL TO
COME AND TAKE THEIR SEATS?

CARDS AND THEN LET ME ASK THE REMAINING PEOPLE WHO HAVE WHITE
COME TO WITH NUMBERS ON THEM ON THIS OPEN MIKE SESSION TO PLEASE
THE BACK OF THE ROOM, PLEASE.

MS. NESCAART?

>> THANK YOU VERY MUCH.

GOOD AFTERNOON.

SPEAKING ON BEHALF OF LOU GALANCAR AND REPRESENTING THE
COALITION TO PROMOTE INDEPENDENCE FOR PEOPLE WITH
DISABILITIES,

WE NEED YOUR HELP.

A SERIOUS BARRIER TO INDEPENDENCE IN THE MEDICARE PART B
PROGRAM

EXIST FOR MEDICARE BENEFICIARIES WITH DISABILITIES THROUGH
THE

CMS AS WELL AS THE DURABLE MEDICAL EQUIPMENT REGIONAL
CARRIER

OVERLY RESTRICTIVE INTERPRETATION OF IN THE PATIENT'S HOME
CRITERIA INCLUDED IN THEIR MEDICAL COVERAGE POLICY.

THIS RESTRICTIVE INTERPRETATION LITERALLY MAKES PEOPLE WITH

117

DISABILITIES PRISONERS IN THEIR OWN HOMES AND ARE PREVENTED
FROM

LEADING WHOLE AND PRODUCTIVE LIVES IN THE COMMUNITY AND
WORKPLACE.

IN OUR WRITTEN ANALYSIS PREPARED AND SUBMITTED TO YOU, WE
EXPLAINED THAT THE MEDICARE PROGRAM STAFF AND CONTRACTORS
INTERPRET A PHRASE IN THE MEDICARE ACT REQUIRE THE
REASONABLENESS AND NECESSITY OF ITEMS OF DURABLE MEDICAL
EQUIPMENT TO BE BASED SOLEY ON AN ASSESSMENT OF THE
INDIVIDUAL'S

NEEDS FOR THE DEVICE ARISING WITHIN THE FOUR WALLS OF HIS OR
HER

HOME.

AS A RESULT OF THIS INTERPRETATION, MEDICARE WILL DENY
BENEFICIARIES ANY MOBILITY DEVICE IF THEY ARE ABLE TO
AMBULATE.

HOWEVER, UNEVENLY OR INSECURELY WITHIN THEIR HOME.

IF AN INDIVIDUAL IS ABLE TO NEGOTIATE THEIR HOME ENVIRONMENT
WITH A CRUTCH, CANE, OR WALKER, THEY WILL NOT BE ELIGIBILITY
FOR
ANY TYPE OF WHEELED MOBILITY DEVICE.
AND FOR THOSE BENEFICIARIES UNABLE TO AMBULATE, MEDICARE
WILL
APPROVE ONLY A STANDARD MANUAL WHEELCHAIR, EVEN IF THEY ARE
ONLY
ABLE TO PROPEL SUCH A WHEELCHAIR ACROSS THE SMOOTH, FLAT
FLOORS
OF THEIR HOMES.
BUT IN NONE OF THESE CIRCUMSTANCES DOES MEDICARE CONSIDER IN
THE
CONTEXT OF MOBILITY AIDS BENEFICIARY'S FUNCTIONAL ABILITY TO
ACCOMPLISH THE FULL RANGE OF THEIR DAILY ACTIVITIES.
WE EXPLAINED IN OUR SUBMISSION THAT AN EXCLUSIVE FOCUS ON
THE
FOUR WALLS OF ONE'S HOME TO DECIDE THE REASONABLENESS
NECESSITY
OF DME IS NOT SUPPORTED BY ANY INDICATIONS THAT THIS IS WHAT

118

CONGRESS EVER INTENDED.
NOW, HERE IS SOMETHING YOU CAN DO NOW, WHICH IS A WIN-WIN
FOR
EVERYBODY THAT PROVIDES AN IMMEDIATE RESPONSE.
REQUEST THAT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES
IMMEDIATELY UNDERTAKE TO REPLACE THE USING THE PATIENT'S
HOME
INTERPRETATION THROUGH ADMINISTRATIVE RELIEF.
YES, ADMINISTRATIVE RELIEF IN THE FORM OF A PROGRAM
MEMORANDUM
AND ITS PLACE SHOULD BE A STANDARD OF MEDICAL NEED FOR

TO WHEELCHAIRS AND OTHER MOBILITY DEVICES THAT ALLOWS A PERSON
BE PRODUCTIVE IN THE COMMUNITY AND WORK FORCE.
PLEASE INCLUDE THIS IN THE RECOMMENDATIONS THAT YOU NEED TO
BE ABLE TO GIVE TO PRESIDENT BUSH.
WE APPRECIATE THAT.
THANK YOU.
>> THANK YOU VERY MUCH.
MR. ALLEN, BEFORE WE TURN TO YOU, I JUST WANT TO REMIND
PEOPLE,
I THINK YOU ARE ALL AWARE OF IT.
WE ARE CONTINUING HEARING TESTIMONY ALL THROUGH THE LUNCH
HOUR.
WE WILL BE GOING INTO THE AFTERNOON.
WE DO NOT HAVE ANY BREAKS SCHEDULED.
SO I WOULD ENCOURAGE YOU IF YOU NEED TO STEP OUT, THERE ARE
REFRESHMENTS IN THE CORRIDOR.
THERE IS A FOOD COURT.
PLEASE TAKE CARE OF YOURSELVES.
WE HAVE GOT A LONG DAY AHEAD OF US.
MR. ALLEN.

119

>> THANK YOU.
GOOD AFTERNOON.
THE CEREBRAL PALSY COUNCIL IS A COALITION OF PRIVATE
PROVIDERS
OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES.
FOR THE COUNCIL'S MEMBERS AND MANY OTHER PROVIDERS, THE
GREATEST

BASED BARRIER TO OFFERING FURTHER ACCESS TO HOME AND COMMUNITY-

LIVING IS BY FAR THE UNAVAILABILITY OF DIRECT CARE WORKERS .

WAGE MEDICAID PAYMENT THAT ALLOWS THE PROVISION OF AN ADEQUATE

ACCESS FOR DIRECT CARE WORKERS IS NEEDED TO ASSIST PROVIDERS IN ATTRACTING AND RETAINING QUALIFIED EMPLOYEES AND ENSURING

DISABILITIES. TO HIGH QUALITY SUPPORT SERVICES FOR PERSONS WITH

PROGRAMS . OVER THE LAST SEVERAL YEARS, THE PREFERRED CARED SETTING FOR MANY INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES HAS SHIFTED FROM STATE INSTITUTIONS TO HOME- AND COMMUNITY-BASED

RESTRICTIVE AT THE SAME TIME, MANY STATES HAVE RESTRICTED MEDICAID REIMBURSEMENT, MOVING FROM A COST BASED TO A MORE

PAYMENT STRUCTURE THAT HAS SEVERELY HINDERED PROVIDERS IN COMPENSATING DIRECT CARE WORKERS .

THE MARKET FOR PERSONS WHO PROVIDE DIRECT CARE SERVICES IS EXTRAORDINARILY COMPETITIVE .

IN SOME STATES THE AVERAGE MEDIAN WEEKLY WAGE IS AT A LEVEL DEEMED POOR ENOUGH TO QUALIFY FOR CERTAIN TYPES OF PUBLIC ASSISTANCE .

AS BECAUSE OF LOW WAGES COMBINED WITH POOR BENEFITS, THIS WORK FORCE CAN BE EASILY DRAWN TO OTHER AREAS OF EMPLOYMENT SUCH

THE FAST FOOD AND HOTEL INDUSTRIES .

FAR FURTHERMORE, DIRECT CARE WORKERS IN STATE FACILITIES EARN

MORE THAN DIRECT CARE WORKERS IN PRIVATE PROGRAMS.
THE CURRENT MEDIAN WAGE FOR PRIVATE DIRECT CARE WORKERS IS
LESS
SAME
WORK.
STATE DIRECT CARE WORKERS ALSO ARE MORE LIKELY TO RECEIVE
BENEFITS AND ADVANCED TRAINING AND THUS ARE LESS LIKELY TO
MOVE
ON TO OTHER EMPLOYMENT THAN PRIVATE DIRECT CARE WORKERS.
THE DESIRE AMONG MANY INDIVIDUALS WITH DEVELOPMENTAL
DISABILITIES TO MOVE OUT OF INSTITUTIONS AND OUT OF THEIR
PARENT'S OR OTHER RELATIVES HOMES WHEN THEY REACH ADULTHOOD
AND
TO INTEGRATE INTO THE COMMUNITY IS STRONG.
CURRENTLY, HOWEVER, MANY PROVIDERS ARE PREVENTED FROM
ACCEPTING
PROVIDER
THESE INDIVIDUALS INTO THEIR PROGRAM SOLELY BECAUSE THE
IS NOT SURE THEY CAN HIRE AND KEEP THE NEEDED SUPPORT, STAFF
REQUIRED TO PROVIDE PROPER CARE.
TO SUSTAIN HIGH QUALITY CARE IN HOME- AND COMMUNITY-BASED
SETTINGS, PRIVATE DIRECT CARE PROVIDERS MUST BE GIVEN THE
RESOURCES TO FAIRLY COMPENSATE THEIR EMPLOYEES.
THANK YOU.
>> THANK YOU, MR. ALLEN.
MR. LOVIN?
>> HI, MY NAME IS KEN LOVIN.
I REPRESENT REST CARE, WHICH PROVIDES SERVICES TO OVER
17,000
PERSONS WITH DISABILITIES, OR DEVELOPMENTAL DISABILITIES IN

STATES.

121

DEVELOPED
ADVOCATES,
FEDERAL,
VERY
SURPLUS IS
PRIMARILY
DEMAND
PERSONAL

LIKE COUNTLESS OTHER PROVIDERS, WE HAVE OVER THE YEARS
SERVICES IN RESPONSE TO THE DEMANDS OF POLICY MAKERS,
FAMILIES, AND CONSUMERS.
AND HAVE BEEN SUBJECT TO OVERSIGHT AND FUNDING FROM THE
STATE, AND LOCAL GOVERNMENTS.
NOW THAT WE ARE IN THE MIDST OF UNPRECEDENTED SYSTEMS CHANGE
INITIATIVES, I WANT TO STRESS THAT MOST D.D. PROVIDERS ARE
WILLING TO EMBRACE AND PARTICIPATE IN THESE SYSTEMS CHANGE
INITIATIVES AND FURTHER TO HELP SECURE NECESSARY FUNDING AND
SUPPORTS FOR ALL DESIRED SERVICE OPTIONS.
THE NUMBER ONE CRISIS OR THE NUMBER ONE OBSTACLE IS FUNDING
CRISIS.
MOST D.D. PROGRAMS ARE UNDERFUNDED.
MANY STATE BUDGETS ARE IN CRISIS AND EVEN THE FEDERAL
GONE MISSING.
THERE IS TREMENDOUS SHORTAGE OF DIRECT CARE WORKERS,
DUE TO INSUFFICIENT FUNDING AND THERE IS TREMENDOUS UNMET
DUE TO NEW DEMOGRAPHICS AND MANY CLASS ACTION LAWSUITS AND
LITIGATION.
CERTAINLY, FURTHER EXPANSION OF CONSUMER DIRECTED AND
ASSISTANCE SERVICES WILL HELP MANY.

BUT WHILE THIS IS A FOCUS OF MOST POLICY MAKERS, LET'S NOT FORGET THOSE THOUSANDS THAT ARE RECEIVING EXISTING SERVICES WHICH NEED FIXING AND LET'S BE CAREFUL ABOUT STARTING NEW PROGRAMS WITHOUT SHARING THE PROPER FUNDING AND SUPPORTS THAT ARE THERE.

122

AND FINALLY LET'S NOT TAKE SERVICES AND SUPPORTS FROM ONE GROUP TO SUPPORT ANOTHER GROUP.

THANK YOU VERY MUCH FOR THE OPPORTUNITY.

>> MS. MILLER?

>> HELLO, MY NAME IS FATIMA MILLER AND I'M VERY NERVOUS, SO PLEASE BEAR WITH ME.

I HAVE BEEN A RESIDENT OF FAIRFAX COUNTY, VIRGINIA, FOR 22 YEARS.

THAT'S ABOUT 20 MINUTES AWAY FROM OUR NATION'S CAPITAL.

I CONSIDER MY LIFE AS THE ANALOGY OF AN ELEVATOR, UPWARD CLIMB.

I GOT MARRIED, I WAS A HOMEOWNER AND I WAS CONTINUING MY EDUCATION FOR MY PH.D.

I WAS ALSO A TAXPAYER.

IN 1997, I WAS DIAGNOSED WITH MULTIPLE SCLEROSIS, AND TO ME THE

ANALOGY WAS THAT THE CABLE FROM MY ELEVATOR WAS SEVERED AND THE

ELEVATOR BEGAN TO DROP AND GO INTO A DOWNHILL CRASH.

AND AS I WAS WATCHING MY LIFE PASS BEFORE ME GOING DOWNWARD VERY

FAST, I KEPT LOOKING FOR PROGRAMS TO HELP ASSIST ME FROM THAT

WAS FALL, FROM THAT DROP AND IT WAS ALMOST AS IF ALL I COULD DO
HOLD ON TO THE WALLS OF THE ELEVATOR AS I WATCHED IT GO.
WORK MY HUSBAND ABANDONED, MY DISEASE PROGRESSED, I COULD NOT
ANY LONGER.

I LOST MY HOME, AND I AM IN FRONT OF YOU TODAY AS A HOMELESS
PERSON.

OTHER WHAT I AM ASKING FOR YOU TO CONSIDER TODAY IN HOUSING AND
BEGIN AREAS OF THE DISABLED COMMUNITIES NEEDS IS THAT WE WOULD

123

TO ENFORCE THE RULES AND REGULATIONS THAT WE ALREADY HAVE IN
EXISTENCE.

TODAY, FAIRFAX COUNTY HAS 2,000 PEOPLE DISABLED ON A WAITING
LIST.

UNITS. THERE IS A SURVEY THAT THERE IS 400 THAT ARE ACCESSIBLE

ONLY 14 THEY ARE NOT ACCESSIBLE FOR INDIVIDUALS IN A WHEELCHAIR,
ARE.

ARE THERE IS IN FAIRFAX COUNTY 10% OF OUR COMPLETE POPULATION
INDIVIDUALS THAT ARE DISABLED.

AND THAT'S A POPULATION OF OVER A MILLION THAT ARE 10% DISABLED
WE ARE IN NEED OF HELP.

ENFORCE WE WOULD LIKE TO SEE OR I WOULD LIKE TO SEE HUD START TO
THEIR OWN RULES AND REGULATIONS, SUCH AS THE FAIRFAX HOUSING

OF ACT, THE 504 REGULATION PUBLIC HOUSING AUTHORITY TO MAKE 5%
THE HOUSING STOCK ACCESSIBLE TO INDIVIDUALS.
THESE ARE THINGS THAT ARE ALREADY ON THE BOOKS.
IN AND WHAT'S HAPPENING NOW IS THAT THE DISABILITY COMMUNITY IS
GO A POSITION WHERE THEY HAVE TO BE OUR WATCHDOGS AND HAVE TO
THESE INTO PRIVATE SITUATIONS OF SUING INDIVIDUALS TO TRY TO GET
ACCESSIBILITIES.
EXISTENCE, AND IF HUD WOULD ENFORCE WHAT THEY ALREADY HAVE IN
PEOPLE THAT WE WOULD BE ABLE TO GET MORE ACCESSIBILITY AND MORE
OFF THE WAITING LIST.
THANK YOU.
>> THANK YOU, MS. MILLER.
WELL. AND THANK YOU, THE OTHER PANELISTS, FOR YOUR TESTIMONY AS

124

TESTIMONY I WOULD LIKE TO INVITE THE NEXT FOUR PEOPLE PRESENTING
TO PLEASE JOIN US IN THE FRONT AND, MS. GILLY, BEFORE WE GO
TO YOU, LET ME JUST DO A QUICK CHECK.
TO IS THERE ANYONE AT THE DIAS THAT HAS NOT HAD AN OPPORTUNITY
INTRODUCE HIMSELF OR HERSELF?
WE ARE OKAY?
GREAT.
MS. GILLY, PLEASE.

>> I'M BARBARA GILLY.

I'M CO-CHAIR OF DISABILITY HOUSING ADVOCATES OF NORTHERN VIRGINIA.

I'M ALSO A RESIDENT OF ALEXANDRIA, VIRGINIA, WHERE I HAVE LIVED SINCE 1976.

I'M THE MOTHER OF FOUR CHILDREN, ALL GROWN, AND THE GRANDMOTHER OF TWO.

IN THIS PART OF MY LIFE, I HAVE MADE IT MY MISSION FOR MY GRANDCHILDREN TO NOT HAVE TO SEE PEOPLE WITH DISABILITIES CRAWLING AROUND ON THE FLOOR, CRAWLING UP AND DOWN THE STEPS OF INACCESSIBLE HOUSING.

SO MY REMARKS THIS MORNING -- I HAVE ALREADY SENT IN EXTENSIVE WRITTEN REMARKS.

MY REBEL REMARKS THIS MORNING ARE KIND OF LIMITED TO THE DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT.

WE STRONGLY URGE THAT A PROGRAM OF TARGETED VOUCHERS AND CERTIFICATES BE OFFERED TO INDIVIDUALS IN INSTITUTIONS OR IN JEOPARDY OF INSTITUTIONALIZATION.

125

TIMING IS OF THE ESSENCE WHEN AN INDIVIDUAL IS TRYING TO LEAVE AN INSTITUTION AND TO COORDINATE A HOUSING SEARCH WITH ALL THE OTHER ELEMENTS OF TRANSITIONING FROM A NURSING HOME OR OTHER INSTITUTIONS.

MANY INDIVIDUALS WHO REQUIRE HOUSING AND HOUSING SEARCH

A ASSISTANCE NEVER RECEIVE THE ASSISTANCE THEY REQUIRE TO GAIN
HOME.
AFTER AND I CAN TELL YOU THAT MY PHONE RINGS OFF THE HOOK, DAY
LOOKING DAY AFTER DAY, OF THESE VERY SAME INDIVIDUALS WHO ARE
FOR HELP.
WE ENCOURAGE HUD TO FUND HOUSING COUNSELING PROGRAMS WITHIN
HOUSING AUTHORITIES THAT ALLOW THEM TO FUND AND WORK CLOSELY
WITH INDEPENDENT LIVING CENTERS AND OTHER AGENCIES SERVING
PERSONS WITH DISABILITIES TO MORE EFFECTIVELY LINK PEOPLE TO
HOUSING.
WHO SOMETHING NEEDS TO BE DONE ABOUT PUBLIC HOUSING AUTHORITIES
REFUSE TO LIVE UP TO SOME OF THE RESPONSIBILITIES THAT THEY
HAVE.
SOME I HAVE BEEN A TAXPAYER SINCE 1974, AND I WOULD LIKE TO SEE
OF MY TAX DOLLARS GO BACK TO SERVING PEOPLE WHO HAVE A
DISABILITY.
WE THEREFORE STRONGLY URGE HUD TO CONTINUE FUNDING ACCESS
HOUSING 2000, PROJECT ACCESS VOUCHERS.
WE ALSO STRONGLY URGE HUD TO CHANGE THE 232 PROGRAM TO
DISABILITIES, GUARANTEED LOANS FOR REAL HOMES FOR PEOPLE WITH
INSTEAD OF NURSING HOMES AND OTHER INSTITUTIONS.

HUD'S SECTION 811 FUNDS SHOULD BE USED FOR INTEGRATED,
AFFORDABLE, ACCESSIBLE HOUSING, NOT SEGREGATED HOUSING.

HUD NEEDS TO PAY FOR MORE HOUSING OPTIONS THAT PROVIDE ACCESSIBLE, INTEGRATED, AND AFFORDABLE HOMES FOR PEOPLE ON A SUPPLEMENTAL SOCIAL SECURITY LEVEL OF INCOME.

DESPITE
IN MY LIFE, PROBABLY THE MOST DIFFICULT THING FOR ME IS

THAT
THE NUMBER OF FRIENDS THAT I HAVE, DESPITE THE LARGE FAMILY

I HAVE, THE PROBLEM WE ALWAYS RUN INTO, IF WE WANT TO GET TOGETHER, WE HAVE DO IT AT MY PLACE BECAUSE MY PLACE IS ACCESSIBLE.

THINK OF WHAT THAT WOULD BE LIKE IF YOU COULD NOT VISIT YOUR FAMILY AND FRIENDS BECAUSE THERE WASN'T A RAMP, BECAUSE YOU COULDN'T USE THE BATHROOM.

AND YOU ALWAYS GOT TO PROVIDE THE TURKEY AT THE HOLIDAYS.

AFTER A WHILE, YOU GET A LITTLE BIT TIRED OF THAT.

THAT
AND I DON'T WANT MY GRANDCHILDREN GROWING UP WITH THE IDEA

IT'S OKAY TO EXCLUDE PEOPLE WITH DISABILITIES SIMPLY BECAUSE THEY USE A WHEELCHAIR OR SOME OTHER ASSISTIVE DEVICE.

THANK YOU.

>> MS. MCBORDER?

>> GOOD AFTERNOON.

THE
I'M SELINE MCBORDER, DIRECTOR OF PUBLIC POLICY FOR APSEE,

ASSOCIATION FOR PERSONS AND SUPPORTED EMPLOYMENT.

RIGHT
APSEE IS A NATIONAL ORGANIZATION THAT ADVOCATES FOR THE

CARRY
FOR PEOPLE TO CHOOSE INTEGRATED EMPLOYMENT OPTIONS IF THEY

A WHOLE BUNCH OF LABELS, AND RIGHT NOW THEY DON'T HAVE THAT

CHOICE.

I AM FROM THE SOUTH AND I WOULD REALLY PROBABLY GIVE YOU MY
NAME
THAT
UNDER TWO MINUTES, SO I'M GOING TO READ TO YOU FROM A BOOK
APSEE HAS JUST PUBLISHED.

IT'S A LITTLE PUBLICATION CALLED "CHOOSE WORK."

AND WE CHOSE THAT TITLE TO EMPHASIZE THE POINT THAT PEOPLE
SHOULD HAVE THE RIGHT TO CHOOSE WORK.

IT'S VERY SHORT.

AND THERE ARE COPIES OUT ON THE TABLE AND WE ACTUALLY HAVE
PUT
YOU
COPIES IN THE MAIL TO THE NEW FREEDOM INITIATIVE PANEL, SO
ALL WILL GET YOUR OWN COPY.

AND IF YOU WOULD LIKE, I'LL AUTOGRAPH IT.

"IF OUR NATIONAL POLICY STATES THAT DISABILITY IN NO WAY
DIMINISHES THE RIGHT TO PURSUE MEANINGFUL CAREERS, WHY IS IT
AND
THAT MOST PEOPLE WITH DISABILITIES CONTINUE TO BE SEGREGATED

EXCLUDED FROM THE COMMUNITY WORK FORCE?

STATE
WHILE FEDERAL POLICIES OF THE U.S. ELOQUENTLY AND CLEARLY

INTEGRATED COMPETITIVE EMPLOYMENT, INDEPENDENCE AND
INCLUSION AS

THOSE
ITS GOALS, THE REALITY IS THAT MOST PEOPLE, PARTICULARLY

ONE
WITH HIGH SUPPORT NEEDS, CONTINUE TO BE EXCLUDED FOR EVERY

FOR
PERSON WORKING IN INTEGRATED SETTINGS THROUGH SUPPORTED
EMPLOYMENT AND OTHER SUPPORTS, APPROXIMATELY FOUR TO FIVE

EVERY ONE PERSON IN INTEGRATED EMPLOYMENT.
APPROXIMATELY FOUR TO FIVE PEOPLE REMAIN IN SEGREGATED
PROGRAMS."

THIS IS DOCUMENTED BY A NUMBER OF RESEARCH STUDIES.

128

"WE KNOW THAT GIVEN THE PROPER COMBINATION OF SERVICES AND
SUPPORTS, PEOPLE CAN WORK AND ASSUME VALUED ROLES IN THEIR
COMMUNITY.

QUALITY OF LIFE FOR PEOPLE IN SUPPORTED EMPLOYMENT IS BETTER
THAN THAT OF PEOPLE IN SEGREGATED SETTINGS.

AND, AGAIN, ALL OF THESE STATEMENTS ARE DOCUMENTED BY
RESEARCH.

DESPITE THE GROWING BODY OF EVIDENCE SUPPORTED INTEGRATED
EMPLOYMENT FOR PEOPLE WITH DISABILITIES, MORE PEOPLE
CONTINUE TO

ENTER SEGREGATED SETTINGS.

APSEE BELIEVES IT IS TIME TO SHIFT THIS TREND AND EXPAND THE
OPPORTUNITIES FOR PEOPLE WITH DISABILITIES TO BE INCLUDED IN
THE

WORK FORCE AND BUILD CAPACITY TO MAKE THIS VISION A REALITY.

THE AVERAGE WAGE IN SHELTERED SETTINGS IS BELOW MINIMUM
WAGE.

\$2.46 AN HOUR.

AVERAGE WEEKLY EARNINGS \$64.

AVERAGE EARNINGS OF PEOPLE IN INTEGRATED EMPLOYMENT ARE
CONSISTENTLY 250 PERCENT TO 300 PERCENT HIGHER THAN THOSE IN
SEPARATE SETTINGS.

WORKSHOPS AND THE ACTIVITY CENTERS ARE LIMITED IN THEIR
ACCESS

OF TO DIFFERENT TYPES OF WORK, WHILE THERE ARE MANY THOUSANDS
THEIR OCCUPATIONS THAT PEOPLE WITH DISABILITIES CAN PURSUE IN
INTERESTS. COMMUNITIES BASED ON THEIR OWN INDIVIDUAL SKILLS AND

FEDERAL HOWEVER, APPROXIMATELY 80% OF STATE FUNDING AND 90% OF
FUNDING SUPPORT SEGREGATED SERVICES.

LET ME GIVE YOU THOSE NUMBERS AGAIN.
SEGREGATED 80% OF STATE FUNDING, 90% OF FEDERAL FUNDING SUPPORT

129

SERVICES, LEAVING LIMITED FUNDS TO SUPPORT PEOPLE TO WORK IN
THEIR COMMUNITY."

>> MS. MCBORDER, IF I COULD ASK YOU IF YOU COULD WRAP UP,
PLEASE.

>> SURE.

SURE.

>> THANK YOU.

>> ABSOLUTELY WILL.

COMMUNITY THIS INFORMATION WILL BE MADE AVAILABLE TO YOU.
WE SIMPLY ASK YOU AS YOU ARE EXPLORING THE BARRIERS TO

FOR TO TAKE A HARSH LOOK AT EMPLOYMENT AND WHAT EMPLOYMENT MEANS
PEOPLE WITH SIGNIFICANT DISABILITIES.

AND WE FEEL VERY STRONGLY AS YOU MOVE PEOPLE OUT OF INSTITUTIONS

AT WE STRONGLY SUPPORT THIS MOVE THAT YOU HAVE TO TAKE A LOOK
WHAT'S HAPPENING TO THEIR DAILY LIVES.

WHERE DID THEY WORK?

ARE WE GOING TO MOVE PEOPLE OUT OF INSTITUTIONS TO SPEND A DAYTIME OF INSTITUTIONAL -- IN INSTITUTIONAL SETTINGS?

ARE WE REALLY GOING TO ALLOW THEM TO CHOOSE WHAT THEIR LIFE LOOKS LIKE?

AND SO WE LEAVE YOU WITH THAT CHALLENGE.

I'M APSEE HAS ACTUALLY SUBMITTED IN-DEPTH RECOMMENDATIONS, AND SURE THAT THAT WILL BE MADE AVAILABLE TO YOU.

>> THANK YOU VERY MUCH.

>> THANK YOU.

>> MS. KELLY?

130

>> THANK YOU FOR THE OPPORTUNITY TO COMMENT.

MY NAME IS MARY KELLY.

I'M THE DIRECTOR OF GOVERNMENTAL AFFAIRS FOR THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS OR NADDC. THE MISSION OF NADDC IS TO PROVIDE SUPPORT AND ASSISTANCE TO MEMBER STATE COUNCILS ON DEVELOPMENTAL DISABILITIES IN ORDER

TO

PROMOTE A CONSUMER AND FAMILY CENTERED SYSTEM OF COMMUNITY SERVICES, SUPPORTS, AND OTHER ASSISTANCE FOR INDIVIDUALS

WITH

DEVELOPMENTAL DISABILITIES.

WE ARE PLEASED OF THE ATTENTION THAT IS BEING GIVEN TO THESE ISSUES AND WE ARE EAGER TO SEE THE GOVERNMENT FULLY SUPPORT

THE

IMPLEMENTATION OF OLMSTEAD.

PLACE,
AFTER THE LISTENING AND INFORMATION GATHERING HAS TAKEN
ACTION
THE GOVERNMENT MUST MOVE BEYOND WORDS AND FOCUS ON TAKING
-- ACTION THAT WILL RESULT IN REAL, SUSTAINABLE CHANGE.
CHANGE
POLICIES MUST CHANGE, PRACTICES MUST CHANGE, FUNDING MUST
AND ATTITUDES MUST CHANGE.
SEGREGATION, ISOLATION, AND DISCRIMINATION ARE PROHIBITED BY
LAW.
OWN IT
BUT LAW IS ONLY AS GOOD AS THE COMMUNITY'S WILLINGNESS TO
AND ENFORCE IT.
WE AS A COUNTRY MUST COMMIT TO LIVING WHAT WE SAY WE
BELIEVE.
PEOPLE WITH DISABILITIES ARE STILL TOO OFTEN LIVING LIVES OF
SEGREGATION, ISOLATION, AND DISCRIMINATION.
PEOPLE WITH DISABILITIES DESERVE ACTION.
THEY DESERVE TO LIVE FREE OF THE SHACKLES PLACED ON THEM BY
131
AND
IGNORANCE, FEAR, AND MAYBE SIMPLY PUBLIC INERTIA.
WE KNOW THE BARRIERS AND I THINK WE KNOW WE WANT TO CHANGE
THANK YOU FOR ANOTHER OPPORTUNITY TO COMMENT ON THEM.
I'LL BE BRIEF BECAUSE WE HAVE ALREADY SUBMITTED WRITTEN
COMMENTS.
OF COURSE WE KNOW A MAJOR BARRIER IS THE INSTITUTIONAL BIAS.
WE MUST REVERSE THIS.
COMMUNITY SERVICES SHOULD NOT BE A WAIVERED SERVICE, BUT A
MANDATORY SERVICE.

PERSONS

THE ENTIRE SYSTEM MUST BE REDIRECTED TO BE CENTERED ON

WITH DISABILITIES AND THEIR FAMILY.

FOR

SYSTEMS MUST BE STRUCTURED IN SUCH A WAY AS TO FULLY ALLOW

SELF-DETERMINATION BY PEOPLE WITH DISABILITIES.

FUNDING SHOULD GO TO THE CONSUMER OF SERVICES.

LAWS

WE MUST DO A BETTER JOB OF ENFORCING EXISTING CIVIL RIGHTS

END TO

AND DO WHATEVER IS NECESSARY TO ENSURE QUALITY AND PUT AN

ABUSE.

WE MUST ASSURE THAT THERE IS AN INFRASTRUCTURE OF SERVICES

INDIVIDUALS.

AVAILABLE TO MEET THE INDIVIDUALIZED NEEDS OF ALL

SUPPORT

WE NEED TO IMPROVE WAGES, BENEFITS, AND JOBS OF DIRECT

WORKERS.

WE DESPERATELY NEED ACCESSIBLE, AFFORDABLE HOUSING.

WE NEED TO MAKE IMPROVEMENTS IN EMPLOYMENT, EDUCATION,

TECHNOLOGY, AND TRANSPORTATION.

BUT BEYOND ALL OF THESE CRITICAL POLICY CHANGES, WE NEED

LEADERSHIP AND PERSONAL EMPOWERMENT.

132

LEADERSHIP ON THE PART OF GOVERNMENT AND PEOPLE WITH

DISABILITIES CAN CHANGE THE STATUS QUO.

TRUE LEADERSHIP HAS THE WILLINGNESS AND STRENGTH TO ACT EVEN

WHEN NOT EVERYONE IS COMFORTABLE WITH CHANGE.

DIFFICULT DECISIONS WILL NEED TO BE MADE.

THESE DECISIONS WILL NEED TO BE IMPLEMENTED AND ENFORCED.

WE MUST HAVE THE WILL TO CHANGE TO SET PEOPLE FREE.

THANK YOU.

>> THANK YOU, MS. KELLY.

MS. SPYERS?

>> HELLO, MY NAME IS THEA SPYERS.

AT I'M THE FORMER DIRECTOR OF THE OFFICE OF DISABILITY POLICY

HUD.

I AM NOT WITH HUD RIGHT NOW, DESPITE WHAT MY NAME TAG SAYS.

I JUST WANT TO FOCUS ON A COUPLE OF THINGS.

SOME THINGS HAVE ALREADY BEEN SAID, SO I WON'T REVIEW THEM.

DOUBLE BUT ONE OF THE MAJOR THINGS IS I BELIEVE THAT THERE IS A

STANDARD IN CIVIL RIGHTS WHEN IT COMES TO PEOPLE WITH
DISABILITIES.

IF ALL OF US UP HERE WERE OF COLOR AND WE WERE TALKING ABOUT
SEGREGATION BASED ON COLOR AND HOUSING AND THAT WE WERE ALL
SEGREGATED IN THE COMMUNITY BY OUR COLOR AND GROUP HOMES AND
ASSISTED LIVING FACILITIES, I THINK PEOPLE WOULD UNDERSTAND,
THEY WOULD SAY, OKAY, WE GET IT.

HOMES, YOU NEED INTEGRATION INTO THE COMMUNITY, INTO YOUR OWN

INTO OTHER FACILITIES.

133

THAT'S WHAT WE ARE SAYING.

WE DO NOT WANT TO BE SEGREGATED.

HOMES, WE DON'T WANT TO BE IN MINI-INSTITUTIONS, WHICH ARE GROUP

ASSISTED LIVING FACILITIES AND THE LIKE.

THOSE ARE INSTITUTIONS.

OLMSTEAD DID NOT SAY REMOVE PEOPLE FROM INSTITUTIONS AND DE-INSTITUTIONALIZE THEM IN LITTLE INSTITUTIONS IN THE COMMUNITY.

OLMSTEAD SAID TO DE-INSTITUTIONALIZE IN THE LEAST RESTRICTIVE

SETTING AND THAT IS NOT IN MINI-INSTITUTIONS IN THE COMMUNITY.

WE NEED THE CIVIL RIGHTS COMMUNITY AND OUR DEPARTMENTS TO STOP

TURNING THEIR HEAD WHEN IT COMES TO THE SEGREGATION THAT IS HAPPENING IN GROUP HOMES, THE PROHIBITED INQUIRIES, THE SPECIAL

TERMS AND CONDITIONS THAT ARE IMPOSED.

ALL THE THINGS THAT ARE PROHIBITED BY FEDERAL FAIR HOUSING LAWS

AND CIVIL RIGHTS LAWS THAT ARE HAPPENING IN THE MINI-INSTITUTIONS IN OUR COMMUNITY WHERE PEOPLE WITH DISABILITIES ARE BEING FORCED TO LIVE.

WE NEED THOSE LAWS ENFORCED AS SOME OTHER PEOPLE HAVE SAID. ALSO JUST VERY QUICKLY, WE HAVE TO STOP LINKING SERVICES WITH

HOUSING WHEN IT COMES TO PEOPLE WITH DISABILITIES.

JUST AS IT WOULD BE ILLEGAL TO REQUIRE PEOPLE WHO NEED TO LEARN

ENGLISH AS A SECOND LANGUAGE TO LIVE IN SPECIAL FACILITIES OR

GROUP HOMES SO THAT -- BECAUSE THAT'S WHERE SERVICES ARE OFFERED

TO TEACH PEOPLE ENGLISH.

WE HAVE TO STOP MAKING PEOPLE LIVE IN CERTAIN FACILITIES WHO

NEED PARTICULAR SERVICES.

WHERE

SERVICES HAVE TO BE LINKED TO THE INDIVIDUALS NO MATTER

THEY LIVE SO THEY CAN CHOOSE TO LIVE IN THE COMMUNITY.

THANK YOU VERY MUCH.

>> THANK YOU, MS. SPYERS.

AND THANK YOU TO THE OTHER MEMBERS OF THE PANEL FOR YOUR
TESTIMONY.

IF I CAN INVITE THE NEXT FOUR INDIVIDUALS WHO ARE GOING TO
PROVIDE TESTIMONY TO COME UP TO THE FRONT AND ANY OF THE
REMAINING OPEN MIKE INDIVIDUALS WHO HAVE WHITE CARDS WITH
NUMBERS ON THEM, IF YOU WOULD MOVE TO THE BACK OF THE ROOM,
PLEASE, I WOULD MUCH APPRECIATE IT.

DIAS

BEFORE WE GO TO MS. CRUISE, I WOULD LIKE TO GO BACK TO THE
AND INVITE THOSE OF YOU WHO HAVE JUST JOINED US TO PLEASE
INTRODUCE YOURSELVES TO THE GROUP, PLEASE.

THE

>> HELLO, I'M DEWAYNE JENOT, DIRECTOR OF HEALTH POLICY FOR
INDIAN HEALTH SERVICES.

>> THANK YOU VERY MUCH.

MS. CRUISE?

>> MY NAME IS TONYA CRUISE.

I WORK FOR THE TOPEKA INDEPENDENT LIVING RESOURCE CENTER IN
WICHITA, KANSAS.

I AM AN INDEPENDENT LIVING SPECIALIST.

COALITION

I'M ALSO A MEMBER OF THE DISABILITY RIGHTS, ACTS, AND
FOR HOUSING, WHICH IS DRAC.

I REPRESENT CONSUMERS ACROSS KANSAS.

I'M HERE ON THEIR ADVOCATION.

LAST I AGREE WITH EVERYTHING THAT'S BEEN SAID BY AT LEAST THE

THREE AND MANY OF THE DAY.

TESTIMONY WHAT I WOULD LIKE TO SAY IS YOU HAVE HEARD A LOT OF

HOPE TODAY FROM A LOT OF PEOPLE, FROM AGENCIES, FROM PEOPLE WITH

DISABILITIES, FROM PEOPLE ADVOCATING, FROM PARENTS AND I

THAT YOU REALLY DO GET THE MESSAGE.

WORKING FOR THIS TO BE AN HISTORIC EVENT AND EACH OF YOU TO BE

TOGETHER AND SITTING BESIDE EACH OTHER AND HEARING THESE

TESTIMONIES AND PEOPLE TAKING YOUR PLACES, I WOULD HOPE THAT

TAKE THIS WILL BE A REAL, PHYSICAL, APPARENT UNION THAT YOU WILL

SERIOUS.

IN THERE IS A SAYING THAT SAYS AND THIS AT ONE TIME WAS HANGING

SAYS, THE HUD OFFICE IN FRONT OF THE SECRETARY'S OFFICE AND IT

"THERE IS NOTHING ABOUT US WITHOUT US".

IN AND IF YOU CANNOT AND DO NOT TAKE HEED TO THESE TESTIMONIES

BEEN WRITING, IN PERSON, IN E-MAILS INTO WHAT YOU ALREADY HAVE

REVIEWING IN YOUR PROGRAMS, EACH OF THEM, IT IS ALL ABOUT

EQUALITY.

IT IS ALL ABOUT ACCESSIBILITY.

IT IS ABOUT SEGREGATION.

WHAT IS THAT?

IT IS ABOUT CHOICE.

WHOSE CHOICE?

IT IS ABOUT COMMUNITY LIVING.

WHOSE COMMUNITY, WHO IS LIVING THERE AND WHO IS MAKING THOSE

136

CHOICES?

PEOPLE WITH DISABILITIES ARE PEOPLE FIRST.

THEY ARE PEOPLE WHO ARE REAL AS YOU AND I.

MANY OF YOU UP THERE AS I DON'T HAVE AN APPARENT DISABILITY
TODAY.

TOMORROW, WE COULD.

WE COULD EACH BE IN THESE SHOES.

LISTEN

SO RATHER THAN LISTEN AND DO NOTHING, I SUGGEST THAT WE

AND WE TAKE IT SERIOUS AND WE HAVE ACTION AND REMEMBER.

DOING

AND WHEN YOU SAY WHAT ARE WE HERE FOR TODAY, WHAT ARE WE

TODAY, KNOW, "THERE IS NOTHING ABOUT US WITHOUT US."

AND IT'S ALL POSSIBLE.

AND BESIDES THAT, IT'S THE MILLENNIUM.

IT'S TIME FOR CHANGE.

THANK YOU.

>> THANK YOU, MS. CRUISE.

MR. FORSIGHT?

>> MY NAME IS LEN FORSIGHT, PARENT OF A BRAIN-INJURED SON.

I LIVE IN PALMYRA, VIRGINIA, JUST OUTSIDE OF
CHARLOTTESVILLE.

I WOULD LIKE TO POINT OUT THE LACK OF COMMUNITY LIFE,
FINANCIAL

ASSISTANCE FOR TRAUMATICALLY BRAIN-INJURED INDIVIDUALS.
MY SON GREG IS TOTALLY DISABLED WITH A TRAUMATIC BRAIN
INJURY.
HE WILL NOT WORK AGAIN, NEVER.
COLLEGE GRAD, COMPUTER SCIENCE.
HE HAD IT ALL GOING UNTIL THE ACCIDENT.
HAVING APPLIED FOR VIRGINIA MEDICAID, GREGORY WAS DENIED DUE

TO

137

THE MEAGER \$330 A MONTH CLIP LEVEL.
THE COST OF CARE FOR A BRAIN-INJURED PERSON IS HUGE.
MR. VAN DEWATER, THE \$330 IS A JOKE.
IT MIGHT JUST AS WELL BE \$3.30.
IT WILL NOT MAKE IT.
HIS DISABILITY INCOME IS FULLY UTILIZED FOR PARTIAL ROOM AND
BOARD SERVICES AT THE JOHN-JANE BRAIN INJURY CENTER IN
CHARLOTTESVILLE.
THIS LEAVES GREG IN DIRE NEED OF FINANCIAL ASSISTANCE FOR
DOCTORS, MEDICATIONS, DISABILITY SERVICES, AND SUFFICIENT
ROOM
AND BOARD.
THE LADY BEFORE ME SPOKE ABOUT THE DISCREPANCY OF
MASSACHUSETTS
VERSUS PENNSYLVANIA.
VIRGINIA IS PROBABLY NO BETTER OR PERHAPS WORSE THAN
PENNSYLVANIA.
I HAVE FOUND NO AGENCY IN VIRGINIA THAT IS FUNDED FOR
COMMUNITY
LIFE FINANCIAL ASSISTANCE.

VIRGINIANS

I HAVE GONE TO THE VIRGINIA DEPARTMENT FOR RIGHTS FOR
WITH DISABILITIES.

THEY DENIED ME ANY HELP.

I DON'T GET IT.

I DON'T GET IT.

WHAT ARE THEY THERE FOR?

BRAIN
AT THE PRESENT TIME AS I MENTIONED, GREG IS IN JOHN-JANE

INJURY CENTER IN CHARLOTTESVILLE.

IT'S AN EXCELLENT FACILITY.

138

IT FAR BEATS AN INSTITUTION BY A THOUSAND MILES.
THEY HAVE BEEN VERY COOPERATIVE, THAT IS, FINANCIALLY
SPEAKING.

BECAUSE HIS DISABILITY INCOME WON'T EVEN COME CLOSE TO THEIR
EXPENSES.

A
HOWEVER, IF NO FINANCIAL ASSISTANCE IS AVAILABLE, THEY HAVE
HIGH RISK OF CLOSING THEIR DOORS THIS YEAR.

AND
THE PROBLEM -- THERE WILL BE DISABLED PEOPLE ON THE STREET

JANE
THE COST TO VIRGINIA WILL FAR EXCEED THE COST AT THE JOHN-
CENTER.

IN SUMMARY, I HAVE THREE POINTS -- I'M SORRY.

I MADE ONE, FAR EXCEED STATE COST.

THE SECOND ONE IS PRESIDENT BUSH'S ORDER SIMPLY HAS NOT BEEN
IMPLEMENTED IN VIRGINIA.

BEING
AND THE THIRD IS WHEN YOU LOOK AT ALL THE AREAS CURRENTLY

NOT TO FUNDED, LONG-TERM CARE FOR THE TRAUMATIC BRAIN INJURED IS

BE FOUND.

OF AS I GO AROUND TO THE STATE AGENCIES, THERE ARE MANY TYPES

DISABILITIES BEING FUNDED.

DOES HE GREG DOESN'T FIT THE DEVELOPMENT DISABILITY AREA, OR NOR

FIT SOME OF THE OTHER TYPES OF AREAS:

DRUG REHAB, ALCOHOL REHAB, A LOT OF PROGRAMS, BUT FOR A
TRAUMATIC BRAIN INJURY, TBI, IT DOESN'T EXIST.

THANK YOU FOR YOUR TIME.

>> THANK YOU, MR. FORSIGHT.

MR. ALLEN?

>> HELLO, MY NAME IS JEREMY ALLEN.

139

I'M HERE WITH POWERS, POWELL, & BURVILLE, A LAW FIRM HERE IN
TOWN.

MEDICAL AND IT LOOKS LIKE MY ROLE IS GOING TO BE TO HAMMER HOME THE
POINT ABOUT MEDICARE PART B REIMBURSEMENT FOR DURABLE

EQUIPMENT.

HOSPITAL SECTION 1861 AND OF THE SOCIAL SECURITY ACT REQUIRES THAT
DURABLE MEDICAL EQUIPMENT BE USED IN THE PATIENT'S HOME AS
OPPOSED TO A NURSING -- SKILLED NURSING FACILITY OR A

IN ORDER TO QUALIFY FOR MEDICARE PART B REIMBURSEMENT.

IN EVEN THOUGH THERE IS NO GEOGRAPHICAL LIMIT ON THE USE OF DME

INTERPRETED

THE SOCIAL SECURITY ACT, CMS IN THE PAST NARROWLY

PATIENT'S

THIS CLAUSE TO APPLY ONLY WITHIN THE FOUR WALLS OF THE

HOME.

WILL

SO THE PRACTICAL IMPLICATIONS ARE THAT SAY MEDICARE PART B

PAY FOR A STANDARD WHEELCHAIR FOR SAY A YOUNG MOTHER TO USE

INSIDE HER HOME, BUT WON'T PAY FOR A ULTRA LIGHT-WEIGHT

WHEELCHAIR THAT MIGHT HELP HER INDEPENDENTLY TRANSFER TO AND

GROCERIES

FROM HER CAR SO SHE CAN TAKE HER KIDS TO WORK OR BUY

HELP

OR GO TO WORK OR RENT A MOVIE OR DO ANY OF THE THINGS THAT

INTEGRATE YOU INTO THE COMMUNITY.

IN 2000, MEDICARE COVERED ONLY 21% OF CLAIMS FOR ULTRA

LIGHT-WEIGHT WHEELCHAIRS AND 35% OF CLAIMS FOR POWER

WHEELCHAIRS.

NEW

THAT'S DEPLORABLE AND IT RUNS IN DIRECT CONTRAST WITH THE

REDUCING

FREEDOM INITIATIVE IS SUPPOSED TO BE ABOUT, WHICH IS

BARRIERS TO COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES.

140

DISABILITIES

SO AS A COUPLE OF FOLKS HAVE SAID BEFORE ME, A GREAT WAY TO

REMOVE AN IMMENSE DAUNTING BARRIER TO PEOPLE WITH

ISSUE

TO COMMUNITY LIVING IS TO MODIFY -- IS FOR CMS AND HHS TO

MEDICARE

A PROGRAM MEMORANDUM THAT WOULD EXPLICITLY STATE THAT DME IS

COVERED UNDER PART B IF IT ALLOWS DISABLED AND ELDERLY

BENEFICIARIES TO MEET THE NEEDS ARISING OUT OF THEIR DAILY
ACTIVITIES TO PARTICIPATE IN THE COMMUNITY.

MORE TO
THERE ARE VERY FEW ADMINISTRATIVE REMEDIES THAT WOULD DO
REDUCE BARRIERS TO COMMUNITY-BASED LIVING FOR PEOPLE WITH
DISABILITIES THAN THAT.

THAT
AS A CORRELATE, I ALSO THINK THAT A CREATION OF A TASK FORCE

OTHER
STUDIED SOME OTHER BARRIERS TO ASSISTIVE TECHNOLOGY UNDER

MEDICAID,
FEDERALLY-SPONSORED HEALTH INSURANCE PROGRAMS SUCH AS

ALSO BE
PROGRAMS LIKE THE V.A., THE DEPARTMENT OF DEFENSE SHOULD

ASSISTIVE
UNDERTAKEN SO WE CAN FIND OUT WHAT THE BARRIERS ARE TO

TECHNOLOGY FOR -- IN THESE OTHER HEALTH PROGRAMS AND TRY TO
REDUCE THEM.

OF
I THINK THESE ACTIONS WOULD GO A LONG WAY TO OPENING A LOT

DOORS FOR PEOPLE WITH DISABILITIES TO BETTER ACCESS THEIR
COMMUNITY.

SO THANKS FOR YOUR TIME.

>> THANK YOU, MR. ALLEN.

MR. MAXSATA?

>> GOOD MORNING.

MY NAME IS BRANDON MAXSATA.

COMMUNITY
I'M THE EXECUTIVE DIRECTOR OF THE AMERICAN CONGRESS OF

SUPPORTS AND EMPLOYMENT SERVICES.

WE ARE A NATIONAL NONPROFIT ORGANIZATION OF PROVIDERS OF
TO VOCATIONAL REHABILITATION AND COMMUNITY SUPPORTS COMMITTED
FOR MAXIMIZING EMPLOYMENT OPPORTUNITIES AND INDEPENDENT LIVING
INDIVIDUALS WITH DISABILITIES.

I COMMEND THE PRESIDENT'S NEW FREEDOM INITIATIVE AND HIS
SUBSEQUENT EXECUTIVE ORDER AND YOUR PRESENCE HERE TODAY TO
LISTEN TO US.

EDDIE I AM HERE TO ECHO THE CONCERNS OF SOME OF MY COLLEAGUES --
ALLEN, MARTHA FORD, AND JUDY CHESSER.

I WANTED TO TALK TO YOU ABOUT THE ISSUE OF QUALITY.

I DON'T THINK WE SHOULD DISCRIMINATE WHEN IT COMES TIME TO
QUALITY AND YET THAT'S EXACTLY WHAT WE DO WHEN MEDICAID
DIRECT REIMBURSES -- PAYS ITS REIMBURSEMENT RATES FOR PRIVATE
INSTITUTIONS.

I THINK IT'S AN ISSUE OF PARITY, AN ISSUE OF FAIRNESS.

BUT THE UNDERLYING ISSUE IS QUALITY.

WE DISCRIMINATE BECAUSE OFTEN THE SERVICES THAT INDIVIDUALS
WANT IN COMMUNITY-BASED SERVICES THEY CANNOT GET THESE QUALITY
SERVICES BECAUSE THEY CAN'T FIND THE STAFF, THEY CANNOT PAY
THE STAFF, THEY CANNOT RETAIN THE STAFF.

MY COLLEAGUES HAVE ALLUDED TO THE FACT THAT OFTEN FAST FOOD
DO JOINTS WILL PAY MORE IN TERMS OF SALARY AND BENEFITS THAN WE
OUR TO PEOPLE WHO ARE CARING FOR OUR LOVED ONES, OUR BROTHERS,
SISTERS, OUR PARENTS, OUR GRANDPARENTS.

THIS IS AN IMPORTANT ISSUE.

142

TO

IT'S PROBABLY ONE OF THE MOST PRESSING ISSUES THAT WE NEED
FACE.

SO I WILL LEAVE MY REMARKS AT THAT AND BRIEF.

BECAUSE I KNOW YOU HAVE A GOT A LONG DAY AHEAD OF YOU.

THANK YOU.

>> THANK YOU, SIR.

AND THANK YOU TOO TO THE PANEL FOR YOUR TESTIMONY.

I WOULD LIKE TO ASK THE NEXT FOUR INDIVIDUALS PROVIDING
TESTIMONY TO PLEASE JOIN US.

THE

AND BEFORE WE MOVE TO MR. SNYERSON, I WOULD LIKE TO INVITE
MS. KINNEY TO INTRODUCE HERSELF TO THE GROUP, HAVING JOINED
DIAS.

YOU MIGHT WANT TO HIT THAT.

THANK YOU.

>> GOOD AFTERNOON.

MY NAME IS PAT KINNEY, AND I'M WITH THE OFFICE OF PERSONNEL
MANAGEMENT, VERY PLEASED TO BE HERE.

>> THANK YOU VERY MUCH.

MR. SNYERSON?

MAKE

>> MY NAME IS ROBERT SNYERSON, AND I AM THE NATIONAL -- THE
CO-CHAIR OF THE NATIONAL COALITION ON SELF-DETERMINATION.

I AM HERE TODAY IN PLACE OF NICKLAUS DUPREE WHO COULD NOT

IT BECAUSE OF THE SUPPORT MEANS THAT HE NEEDS.

MORNING

HE SPECIFICALLY GAVE ME A PARAGRAPH TO READ TO YOU THIS

AND I WILL JUST READ IT.

MR. DUPREE HAS A RARE FORM OF MUSCULAR DYSTROPHY.

143

THE

HE WRITES, "ONE SERIOUS BARRIER TO COMMUNITY LIVING IS THAT

BASED

FEDERAL GOVERNMENT DOES NOT MANDATE HOME- AND COMMUNITY-

SERVICES.

WHIM

IT IS JUST AN OPTION THAT CAN TAKE OR LEAVE, FUND OR CUT A

ACCORDING TO THE FISCAL SITUATION.

BECAUSE

HOWEVER, STATES HAVE NO PROBLEM STRIPPING CITIZENS OF THEIR

FREEDOM AND SEGREGATING THEM IN FAR AWAY INSTITUTIONS

THIS IS A REQUIRED SERVICE.

THIS IS ABSURD AND MUST BE CHANGED.

AMONG

THE CIVIL RIGHT TO LIVE, WORK, AND PLAY IN THE COMMUNITY

DISABILITY

FAMILY AND FRIENDS REGARDLESS OF COLOR, RELIGION, OR

SHOULD NOT BE OPTIONAL FOR THE STATES.

JUST

IN THIS FREE COUNTRY, NO CITIZEN SHOULD BE DENIED FREEDOM

POWER

BECAUSE STATES DO NOT HAVE THE RESOURCES OR POLITICAL WILL

SERVICES

TO ADEQUATELY FUND OR SET UP HOME- AND COMMUNITY-BASED

PROGRAMS.

THANK YOU VERY MUCH.

>> THANK YOU VERY MUCH.

MS. MCGINNIS?

>> THANK YOU FOR THE OPPORTUNITY TO BE HERE.

FIVE YEARS AGO, I WAS WORKING, I WAS A STATE EMPLOYEE.

I WAS A CORRECTIONAL OFFICER.

THEY

WHEN I WAS DIAGNOSED WITH MENTAL ILLNESS, THE FIRST THING

DID WAS BAR ME FROM THE PROPERTY.

THE NEXT THING THEY DID WAS EVERY FRIEND I HAD THEY TOOK.

THEY SAID I WAS A SECURITY RISK, THAT NO ONE COULD VISIT ME,

144

HARM

CALL ME, SEE HOW I WAS OR ANYTHING ELSE; THAT I MAY WANT TO

MY CO-WORKERS.

I NEVER THREATENED ANYBODY.

I NEVER WANTED TO HARM ANYBODY.

MY LIFE HAS BEEN RUINED.

PTSD,

I HAVE STRUGGLED WITH ANXIETY DISORDERS, MAJOR DEPRESSION,

AND A NUMBER OF OTHER THINGS DAILY.

I

A WEEK OR SO LATER, THEY CALLED ME UP, WANTED TO TALK TO ME,

WORKED IN A MINIMUM SECURITY PRISON.

I WAS NOT WELCOMED THERE.

CRIME.

THEY WANTED TO TALK TO ME IN A LOCKED, SECURED PRISON

ENVIRONMENT, EVEN THOUGH I HAD CREATED OR COMMITTED NO

I COULD NOT FIND LEGAL HELP.

THE STATE WOULD NOT HELP ME BECAUSE IT WAS A CONFLICT OF

INTEREST FOR THEM.

I WENT TO CONGRESSMEN'S OFFICES, I CALLED SENATORS.

I STILL DO NOT HAVE HELP.
AND ON A DAILY BASIS I WONDER IF THIS TIME NEXT YEAR I WILL
BE
ABLE TO CONTINUE LIVING IN THE COMMUNITY.
WHEN I ASKED FOR THE DISABILITY FORMS, THEY SENT ME FORMS
NUMEROUS TIMES TO WITHDRAW MY RETIREMENT CONTRIBUTION.
I AM ON A STATE DISABILITY PROGRAM RIGHT NOW.
AT THE END OF AUGUST OR AT THE BEGINNING OF AUGUST OF NEXT
YEAR,
SECURITY
THAT WILL BE CUT BY WHAT I WOULD BE GETTING ON SOCIAL
IF I WAS GETTING SOCIAL SECURITY.
I AM RIGHT NOW TRYING TO DOWNSIZE ON MY MEDICATION BECAUSE I
145
DON'T KNOW COME NEXT AUGUST WHETHER I WILL BE ABLE TO HAVE
MEDICATION AT ALL.
I AM TRYING TO MAINTAIN SOME STABILITY.
I HAVE SERIOUS SIDE EFFECTS FROM THE MEDICATION AND I HAVE
BEEN
LABELED A CRIMINAL, SIMPLY FOR HAVING THIS DISEASE.
I HAVE SAT HERE THIS MORNING AND I'VE WONDERED WHETHER I WAS
GOING TO TELL MY STORY OR I WAS GOING TO TELL THESE FACTS
AND
THESE FIGURES.
BUT I BELIEVE THAT WE NEED MORE PEOPLE TELLING THEIR
STORIES.
WE HAVE HAD ENOUGH PEOPLE TELLING THEIR FACTS AND FIGURES.
THE FIRST TIME I APPLIED FOR SOCIAL SECURITY, I HAD WENT
INTO
PSYCHOMOTOR RETARDATION; I COULD NOT COMPLETE THE FORMS.

GET MY

THEREFORE, I DID NOT GET SOCIAL SECURITY BECAUSE I DIDN'T
FORMS BACK.

MANY

THE SECOND TIME, I DIDN'T HAVE SENSE ENOUGH TO KNOW THAT I
NEEDED IT AND NOBODY THAT I HAD CALLED, AND I HAD CALLED SO

CALLING

PEOPLE THAT MY TELEPHONE HAD GOTTEN DISCONNECTED FROM

LONG DISTANCE BUREAUCRATS BEGGING THEM TO HELP ME.

I HAVE APPLIED AGAIN LAST WEEK.

OF

THE WOMAN TELLS ME THAT BECAUSE I HAVE BEEN ABLE TO WORK
PART-TIME IN THE THREE OR FOUR YEARS SINCE I HAVE BEEN OUT

AND

WORK, THAT SHE CONSIDERS THAT SUBSTANTIAL MAYBE AND GAINFUL

GAINFUL

THAT I MAY NOT QUALIFY THIS TIME, WHILE I HAVE MADE NO

-- HAD NOTHING ABOVE THE SGA THIS YEAR.

BUT I HAVE TRIED TO HELP MYSELF.

WITHOUT THE HELP OF ALL THESE PROGRAMS THAT YOU PEOPLE HERE

146

HELPING

REPRESENT AND THE ONLY JOB I FELT COMFORTABLE IN WAS A
PART-TIME, 16-HOUR A WEEK JOB THAT I HAVE RECENTLY LOST

NO

ANOTHER CONSUMER WHO WAS MENTALLY RETARDED BECAUSE OF SOME
FEDERAL GUIDELINE THAT STATES THAT WE HAD TO FILL OUT A FORM

LIKE THE AREA PROGRAMS AND OTHER FOLKS, STATING THAT WE HAD

MENTAL AND PHYSICAL DISABILITIES THAT COULD ENDANGER OUR
CLIENTS.

HAVE

WHEN THE TRUTH IS MY CLIENT HAS BEEN TERRIFIED BECAUSE I

CHOSE HAVING BREATHING PROBLEMS AND PANIC ATTACKS AT WORK, SO I
NOT TO GET THE FORM FILLED OUT RATHER THAN LIE.
I TALKED TO THIS WOMAN FROM THE SOCIAL SECURITY
ADMINISTRATION
LAST WEEK, AND IT WAS VERY PITIFUL THAT A WOMAN IN ASHVILLE,
NORTH CAROLINA THAT WORKS FOR THE SOCIAL SECURITY
ADMINISTRATION
KNOWS ABSOLUTELY NOTHING ABOUT THIS NEW FREEDOM INITIATIVE
BECAUSE I ASKED HER WHAT SHE THOUGHT BECAUSE I KNEW THAT I
MIGHT BE COMING HERE.
AND SHE HADN'T THE FOGGIEST IDEA.
NOW, I HOPE COME NEXT AUGUST THAT I'M STILL LIVING IN MY
HOUSE.
I'M VERY, VERY THANKFUL.
I WAS ONE DAY FROM BEING EVICTED BECAUSE THE STATE WHEN I
FILED TO EEOC, THEY FILED A -- I FILED A COMPLAINT, THEY HELD MY
PAYCHECK FOR SIX MONTHS SO I COULDN'T GET A LAWYER.
I'M VERY THANKFUL TO BE HERE.
I NEED SOME HELP.
I NEED SOME ASSISTANCE.
I HOPE THAT I CAN REMAIN IN THE COMMUNITY AND I HOPE I CAN
GET
THE ASSISTANCE I NEED IN ORDER TO CONTINUE TO LIVE IN THE
COMMUNITY.
COME NEXT AUGUST, I'LL BE LIVING ON LESS THAN \$300 A MONTH
IF I

DOOR DO NOT GET THIS ASSISTANCE AND I WILL LITERALLY BE ON THE
FUNCTION STEP OF SOME FACILITY SAYING TAKE ME, I CAN NO LONGER
AND TAKE CARE OF MYSELF.
I HAVE GOT FACTS AND FIGURES THAT I LEAVE OUT HERE.
CRISIS, I IF IT WAS NOT FOR NOMI, WHICH I DID FIND IN ONE OF MY
WOULD HAVE NOBODY TO TALK TO.
THERE IS NO PROTECTION ADVOCACY IN NORTH CAROLINA.
ME. IN NORTH CAROLINA, THEY TALK ABOUT ME, THEY DON'T TALK TO
HOSPITALS ARE CLOSING, RURAL AREAS HAVE NO SERVICES.
WHETHER I JUST LIKE I DID NOT KNOW UNTIL FRIDAY EVENING FOR SURE
WOULD BE HERE OR NOT BECAUSE AN AIRPLANE TICKET FROM A RURAL
RALEIGH, AREA IN NORTH CAROLINA COST \$300 MORE THAN ONE FROM THE
RESEARCH TRIANGLE AREA.
COULD >> MS. MCGINNIS, I APOLOGIZE FOR INTERRUPTING, BUT IF YOU
WRAP UP, PLEASE, SO WE --
>> OKAY.
>> THANK YOU VERY MUCH.
>> BUT ON BEHALF OF MYSELF AND ALL THE REST OF CONSUMERS OUT
THERE, MANY OF US WANT TO LIVE IN THE COMMUNITY.
I WANT TO CONTINUE TO LIVE IN THE COMMUNITY.
BE I WANT TO CONTINUE TO HELP OTHER CONSUMERS AND I WILL NEVER
JUST ABLE TO WORK OTHER THAN MAYBE JUST A FEW HOURS A WEEK AND I
DON'T KNOW WHERE THESE PROGRAMS AND MYSELF FIT IN TOGETHER.

THANK YOU.

>> THANK YOU, MS. MCGINNIS.

MS. MALONEY?

>> HI.

I'M JUSTINE MALONEY.

AND I AM THE WASHINGTON REPRESENTATIVE OF THE LEARNING
DISABILITIES ASSOCIATION OF AMERICA.

PROFIT
THE LEARNING DISABILITIES ASSOCIATION IS A VOLUNTEER, NON-
ORGANIZATION THAT ADVOCATES ON BEHALF OF INDIVIDUALS WITH
LEARNING DISABILITIES, THEIR FAMILIES, AND THE PEOPLE WHO
SUPPORT THEM.

IT MAY SEEM, WHEN YOU HEAR THE TERRIFIC NEEDS OF MANY OF THE
PEOPLE WHO HAVE TESTIFIED TODAY, THAT THE NEEDS OF PEOPLE
WITH
LEARNING DISABILITIES ARE MINOR.

AND MY RESPONSE TO THAT IS, IF YOU'RE DROWNING, IT DOESN'T
MATTER WHETHER YOU'RE 50 FEET FROM SHORE OR 500 FEET FROM
SHORE,

YOU WILL DROWN IF YOU DON'T GET THE HELP THAT YOU NEED.
SO WE REALLY APPRECIATE THE PRESIDENT'S INITIATIVE, REACHING
OUT
BEYOND THE INSTITUTIONALIZATION TO LOOK AT THE BARRIERS TO
INDEPENDENT LIVING ACROSS THE BOARD FOR ALL PEOPLE WITH
DISABILITIES, INCLUDING THOSE WITH SO-CALLED MILD
DISABILITIES.

I THINK FOR PEOPLE WITH LEARNING DISABILITIES, THEIR
GREATEST
BARRIERS ARE, FIRST THE PERCEPTION THAT LEARNING
DISABILITIES
ARE A MILD DISABILITY.

LIKE ALL DISABILITIES, IT OCCURS ACROSS A WHOLE RANGE OF SEVERITY, FROM MILD TO SEVERE.

149

DEPEND AND THE POINT AT WHICH YOU DROP FROM MILD TO SEVERE MAY
OPERATING. UPON THE EXTERNAL CIRCUMSTANCES UNDER WHICH YOU'RE
VERY SO THAT A YOUNGSTER IN SCHOOL WITH A GOOD PROGRAM THAT IS
STRUCTURED MAY DO FINE.
IS AND THEN WHEN HE OR SHE GETS OUT INTO THE REAL WORLD, WHICH
MUCH LESS STRUCTURED, THEY MAY FALL APART.
THEY MAY NOT GET THE HELP THEY NEED.
DISABILITIES, THE OTHER ASSUMPTION IS THAT PEOPLE WITH LEARNING
ONLY. THAT HAVE LEARNING DISABILITIES, IS AN ACADEMIC PROBLEM
FOR ANY OF YOU WHO HAVE MET SOME OF THE FOLK WITH SEVERE
LEARNING DISABILITIES, YOU KNOW THAT THAT'S NOT SO.
LOOK SO I WOULD BEG YOU, AS YOU LOOK AT THESE THINGS, WHEN YOU
THE AT THE NEEDS FOR ALL PEOPLE WITH DISABILITIES, YOU CONSIDER
NEEDS NEEDS OF THOSE WITH INVISIBLE DISABILITIES BECAUSE THEIR
ARE JUST AS GREAT.
AND AND WE WOULD BE VERY HAPPY TO PROVIDE INPUT AND INFORMATION
EXAMPLES TO YOU AS YOU LOOK AT ALL OF THESE NEEDS.
THANK YOU VERY MUCH.
>> THANK YOU, MS. MALMSEY.

MS. HILDABRAND?

>> GOOD MORNING, OR GOOD AFTERNOON.

MY NAME IS NAN HILDABRAND.

I'M A MEMBER OF CAPILLARY ADAPT AND A FORMER CENTER FOR
INDEPENDENT LIVING DIRECTOR.

HOME THE CENTER I DIRECTED WAS ALSO A LICENSED MEDICARE/MEDICAID
HEALTH PROVIDER.

150

ADAPT, I FROM THESE EXPERIENCES AND MY CURRENT ROLE IN CAPILLARY
HAVE THESE COMMENTS TO OFFER.
SOME OF THE MAJOR BARRIERS TO TRANSITIONING PERSONS OUT OF
NURSING HOMES OR DIVERTING THEM FROM ENTERING THEM RISE OUT
OF A WIDE GAP IN THE SAFETY NET FOR PERSONS WITH DISABILITIES.
PROVIDERS THESE INCLUDE WIDESPREAD SCARCITIES IN ATTENDANTS AND
SERVICES OF ATTENDANTS, LACK OF ACCESSIBLE INTEGRATED HOUSING, POOR
AND SERVICE LINKAGES OF PEOPLE TO RESOURCES OF ATTENDANT
THROUGH AND HOUSING THAT DOES EXIST, ANTIQUATED EMPLOYMENT PROGRAMS
LIVING. SHELTERED WORKSHOPS, AND THE LACK OF SERVICES AVAILABLE
OFFER WE SUPPORT REGULATORY CHANGES THAT ENCOURAGE PROVIDERS TO

ATTENDANT PROGRAMS, SUCH AS A RELAXING OF THE 75 HOUR
ATTENDANT
LICENSING
TRAINING RULE; THE ABOLITION OF A CERTIFIED NURSE AID
TO SEPARATE THE ATTENDANT LABOR SUPPLY FROM THE SUPERVISION
OF
THE NURSE PRACTICE ACT; THE DEVELOPMENT OF A STANDARDIZED
TRAINING CURRICULA MORE APPROPRIATELY FOCUSED ON THE NEEDS
OF
PEOPLE WITH DISABILITIES; THE REVISION OF THE MEDICARE HOME
BOUND RULE TO MEAN THAT WITHOUT SERVICES THE PERSON IS HOME
BOUND, THAT IT'S SIMPLY AN ELIGIBILITY CRITERIA, THAT THE
PERSON
WOULD NOT BE HOME BOUND WITH SERVICES; AND ALSO THE REVISION
OF
MEDICARE SUPERVISORY REQUIREMENTS TO EVERY NINETY DAYS TO
SIX
MONTHS OR AS NEEDED INSTEAD OF EVERY TWO WEEKS; AND A
FUNDING
LEVEL THAT ALLOWS ATTENDANTS TO MAKE A LIVING WAGE.
WE URGE HEALTH AND HUMAN SERVICES TO SUPPORT MI CASA, SENATE

151

BILL 1298.
WE URGE HEALTH AND HUMAN SERVICES TO TEAR DOWN THE WALLS OF
LAGUNA HUNDA.
FOR HOUSING AND URBAN DEVELOPMENT, WE STRONGLY URGE THAT A
PROGRAM OF TARGETED VOUCHERS AND CERTIFICATES TO INDIVIDUALS
IN
INSTITUTIONS BE MADE AVAILABLE TO THEM IN A TIMELY FASHION.
AT THIS POINT I WOULD LIKE TO SUPPORT THE TESTIMONY OF
BARBARA
GILLEY IN THE INTEREST OF TIME, BUT TO URGE HOUSING AND
URBAN

DEVELOPMENT TO TAKE A VERY, VERY STRONG LOOK AT HOUSING
PROGRAMS, TO ENFORCE EXISTING REGULATIONS, REFORM 232811
PROGRAMS, TO SUPPORT ACCESS 2000 RENEWAL TARGETED VOUCHERS,
AND
TO WORK TO DEVELOP PROGRAMS THAT MORE APPROPRIATELY ASSIGN
RESOURCES TO PEOPLE WITH DISABILITIES AND HOUSING
AUTHORITIES
ACROSS THE COUNTRY.

WE ASK THE DEPARTMENT OF EDUCATION TO STOP USING FEDERAL
FUNDS
FOR SHELTERED WORK WHICH VIOLATE OLMSTEAD'S MOST INTEGRATED
SETTING REQUIREMENTS.

WE STRONGLY BELIEVE THAT PEOPLE WITH DISABILITIES ARE
ENTITLED
TO A FAIR DAY'S PAY FOR A FAIR DAY OF WORK.

WE ASK THE DEPARTMENT OF EDUCATION TO ADD A FIFTH CORE
SERVICE
IN THE CENTER FOR INDEPENDENT LIVING, WHICH REQUIRES THEM TO
PROVIDE INSTRUMENTAL SUPPORTS AND SERVICES TO GET PEOPLE OUT
OF
NURSING HOMES AND OTHER INSTITUTIONS.

WE ALSO ASK THAT INDEPENDENT LIVING CENTERS BE FUNDED
SUFFICIENTLY TO PERFORM THIS, AND ALL OF ITS CORE SERVICES.
THANK YOU.

152

>> THANK YOU, MS. HILDABRAND.
AND THANK YOU TO THE PANEL FOR THEIR TESTIMONY.
IF I CAN ASK THE REMAINING INDIVIDUALS WHO ARE GOING TO BE
PRESENTING DURING THIS OPEN MIC SESSION TO PLEASE COME DOWN
AND

TAKE THE SEATS AT THE FRONT.

THE
LET ME ALSO AT THIS TIME ASK THE FIRST EIGHT, THE GROUP WITH
BLUE CARDS, WE'RE GOING TO BE -- AFTER WE HEAR THE REMAINING
TO
TESTIMONY IN THIS OPEN MIC SESSION, WE'RE GOING TO THEN MOVE
THE PUBLIC TESTIMONY SEGMENT.

THAT
SO I WOULD ASK THOSE OF YOU WHO ARE HOLDING BLUE CARDS, FOR
FIRST GROUP OF PRESENTERS IN THAT SEGMENT, TO PLEASE
ASSEMBLE IN
THE BACK.

AND AS WE'RE MAKING THE TRANSITION BEFORE WE MOVE TO.
MR. THISSEL, LET ME GO TO THE DIAS AND ASK MS. MANSKE TO
INTRODUCE HERSELF.

>> I'M JILL MANSKE.

VETERAN'S
I'M THE DIRECTOR OF SOCIAL WORK IN THE DEPARTMENT OF
AFFAIRS, VETERAN'S HEALTH ADMINISTRATION.

>> THANK YOU VERY MUCH.

MR. THISSEL, PLEASE.

>> HELLO.

MY NAME IS ROBERT THISSEL.

I LIVE IN ROBINSVILLE, NEW JERSEY.

COMMITMENT
I WOULD LIKE TO THANK THE BUSH ADMINISTRATION FOR ITS
TO FULL IMPLEMENTATION OF THE OLMSTEAD STAFF DECISION.
THANK YOU FOR THIS IMPORTANT CHANCE TO TALK TO YOU ABOUT THE

BARRIERS TO BEING AN INDEPENDENT ADULT WHEN YOU HAVE A

DISABILITY AND RELY ON FEDERAL PROGRAMS FOR SUPPORT.

AS YOU CAN SEE, I NEED A LOT OF SUPPORT.

I HAVE SINCE BIRTH.

BECAUSE OF MY DISABILITY, I WAS INAPPROPRIATELY PLACED IN
DEVELOPMENTAL CENTERS, NURSING HOMES, AND GROUP HOMES
INSTEAD OF
BEING WITH MY FAMILY.

THESE PLACES DID NOT HELP MY INDEPENDENCE AT ALL.

THEY MADE ME MORE DEPENDENT.

I WAS DEPRIVED OF THE LEVEL OF EDUCATION I MIGHT HAVE
ATTAINED.

DISCOURAGED FROM, OR (INAUDIBLE) FOR MAKING INDEPENDENT
DECISIONS AND DENIED THE TECHNOLOGY I REQUIRED FOR
INDEPENDENT

MOBILITY AND COMMUNICATION, THE POLICIES OF THE FEDERALLY
FUNDED

SUPPORT SYSTEM CAUSED MANY OF THESE PROBLEMS.

LIMITATIONS AND (INAUDIBLE) IMPOSE UNNECESSARY OBSTACLES,
MAKING

ME MORE DEPENDENT ON PAID HELPERS JUST TO HELP ME FIGURE OUT
THE
RULES.

THE CURRENT SYSTEM PROMOTES DEPENDENCE AND MUST CHANGE IF
PEOPLE

WITH SIGNIFICANT DISABILITIES ARE TO JOIN OTHER AMERICANS IN
FULL ENJOYMENT OF THE AMERICAN DREAM.

I LOOK FORWARD TO THE NEW FREEDOM THAT THIS INITIATIVE
PROCLAIMS.

>> THANK YOU SIR.

MR. PALERMO?

>> GOOD AFTERNOON.

>> REACH OUT.

THE MICROPHONE IS RIGHT AHEAD OF YOU, ED.

>> GOOD AFTERNOON.

MY NAME IS ED PALERMO.

I WAS RECENTLY IN AN INSTITUTION FOR NINETEEN YEARS.

CHANCE
I COME BEFORE YOU TODAY TO SAY THAT PEOPLE SHOULD HAVE A
OWN,
TO GET OUT OF THE INSTITUTION AND LIVE IN HOMES OF THEIR

WORK AT A JOB, AND JUST LIVE AS HAPPY AS THEY COULD LIVE.

THEY CANNOT DO THAT WITHIN THE FOUR WALLS OF INSTITUTIONS.

I WENT TO JOHNSTONE, WHICH WAS AN INSTITUTION -- IT IS NOW
CLOSED -- IN 1970.

I WAS SIXTEEN YEARS OLD.

I AM NOW 47 YEARS OLD.

I LIVE IN AN APARTMENT.

I LIVE IN ROBINSVILLE, NEW JERSEY WITH MY ROOMMATE.

I'M WORKING, I'M HAPPY, AND I'M TRAVELING.

I RECENTLY WENT HAWAII AND JAMAICA.

I AM HAPPY TO BE OUT OF THE INSTITUTION, AND I WOULD BE MORE
HAPPY IF THESE PEOPLE THAT ARE IN INSTITUTIONS CAN BE OUT AS
WELL.

THANK YOU.

>> THANK YOU VERY MUCH.

MS. FRASIER?

>> THANK YOU ALL.

IS THIS OKAY?

I CAN HEAR MYSELF NOW.

TODAY. I THANK YOU ALL FOR GIVING US THE OPPORTUNITY TO BE HERE

155

FOR MY NAME IS COLLEEN FRASIER.
I RUN A CENTER FOR INDEPENDENT LIVING, A PROGRESSIVE CENTER
INDEPENDENT LIVING IN NEW JERSEY.
WE'RE A SMALL CENTER.
WE GET ABOUT 200,000 A YEAR TOTAL TO RUN OUR CENTER.
WE HAVE IN ONE OF MY COUNTIES -- I HAVE TWO COUNTIES.
WE HAVE 33 NURSING HOMES IN ONE OF MY COUNTIES.
PART OF OUR TASK AND COMMITMENT IS TO GET FOLKS WHO WANT TO
LEAVE THOSE NURSING HOMES OUT.
NOT EVERYONE WANTS TO LEAVE.
I DON'T UNDERSTAND THAT,
BUT THAT'S THEIR CHOICE.
JUST TO GIVE YOU A PICTURE OF THE MAGNITUDE OF THE PROBLEM -
-
I'VE BEEN LISTENING TODAY AND I DIDN'T WANT TO REPEAT WHAT
EVERYONE ELSE IS SAYING.
CHANGE IS NECESSARY, OR YOU GUYS WOULDN'T BE SITTING HERE
SPENDING ALL THIS TIME LISTENING TO US.
WHAT WE NEED TO LOOK AT IS THE ATTITUDINAL BARRIERS.
AND I KNOW YOU CAN'T WRITE A LAW TO CHANGE THAT, HOWEVER,
YOU CAN CHANGE YOUR BEHAVIOR TO CHANGE THAT.
AND I THINK THAT THAT IS VERY IMPORTANT.
WE HAVE, FROM NEW JERSEY -- WE CAME DOWN, THERE ARE TWELVE
OF US THAT CAME DOWN.

SPEAK. THERE ARE SEVERAL OF US THAT HAVE HAD THE OPPORTUNITY TO
TO DO WE WERE ASSURED -- AND I KNOW THAT YOU DON'T HAVE ANYTHING
THIS WITH THIS, BUT THIS IS AN EXAMPLE OF THE ATTITUDINAL

156

BARRIERS THAT WE HAD.
WE SEARCHED FOR A HOTEL THAT HAD FOUR HANDICAPPED ACCESSIBLE
ROOMS.
WE WERE ASSURED THAT WE HAD THAT.
WE DID NOT.
HAVE THE PUBLIC BATHROOM THAT IS HANDICAPPED ACCESSIBLE COULD
BEEN USABLE.
WE'RE VERY ADAPTIVE, IF YOU KNOW WHAT I MEAN.
WE ARE VERY ADAPTIVE.
WE COULD HAVE USED THAT.
THE ICE MACHINE WAS BLOCKING PARTIAL ACCESS.
PROBLEM, SO IT ISN'T WHAT THE RULE SAYS THAT'S NECESSARILY THE
ALTHOUGH I COULD GO ON FOR HOURS ABOUT RULES.
BUT IT'S THE ATTITUDE ABOUT THE RULES.
PERFORMS THIS BUILDING WOULD NOT PASS RSA'S INSPECTION THAT IT
UPON MY FACILITY EVERY THREE OR FOUR YEARS, OKAY.
WE COULD NOT PARK HERE TODAY.
WE WERE ALMOST LATE FOR THE BEGINNING TESTIMONY BECAUSE WE
TO COULDN'T PARK UNDERNEATH THE BUILDING WHERE WE WERE DIRECTED

FOR PARK BECAUSE WE HAD HIGH-TOP VANS THAT ARE REQUIRED FOR USE
PEOPLE WHO SIT IN THEIR CHAIR IN THEIR VEHICLE.
YOU NOW, IT'S SMALL THINGS LIKE THAT, YOU GET UP IN THE MORNING,
SHOWER, PLAN THE TWO HOURS IT'S GOING TO TAKE YOU TO GET YOUR
AND AND GO TO THE BATHROOM, BRUSH YOUR TEETH, AND GET DRESSED,
ALL THAT.
YOU PLAN THAT IN.

157

IN THE PLAN THE EXTRA FIFTEEN MINUTES IT'S GOING TO TAKE TO GET
AND OUT OF THE CAR.
THIS ANY OTHER LITTLE BARRIER THAT'S OUT THERE THAT YOU ARE --
WAS PLANNED FOR PEOPLE WITH DISABILITIES TO COME AND SPEAK.
AND HIGH TOP VANS WERE NOT A CONSIDERATION.
IT'S THAT KIND OF THING, WHEN YOU'RE IN YOUR PLANNING AND
CAUSE LOOKING AT STUDIES, PLEASE LOOK AT THE SMALL THINGS THAT
THE BIG PROBLEMS.
ONE OF THE PEOPLE BEFORE TALKED ABOUT GETTING A REPLACEMENT
WHEELCHAIR.
BY HE COULD BE TOTALLY INDEPENDENT DURING THE DAY, GET AROUND
HIMSELF, IF HE HAD A POWER CHAIR.
THE REGULATIONS AND ALL THE RULES AND THINGS -- HE'S BEEN
WAITING FOR TWO YEARS FOR THAT CHAIR.
HE CAN'T GET A JOB.

HE CAN'T DO ANYTHING REGULARLY.

HE CAN'T MAKE PLANS, BECAUSE HE DOESN'T KNOW WHETHER HE HAS
SOMEONE TO PUSH HIM.

SO THOSE ARE THE KINDS OF THINGS WE NEED TO FOCUS -- I HEARD
OF PEOPLE TALKING TODAY ABOUT CONTINUUMS AND COMPONENTS
THE SYSTEM.

I I THINK WHEN YOU LOOK AT THIS NEW FREEDOM INITIATIVE -- AND
REALLY HOPE IT'S MORE THAN AN INITIATIVE, I HOPE IT'S AN
ACTUALITY -- WHEN YOU LOOK AT THAT, FOCUS ON THE INDIVIDUAL.
THAT PERSON KNOWS WHAT THEY NEED.

PLENTY AND THE PERSON WHO DOESN'T KNOW WHAT THEY NEED, THERE ARE

158

DON'T OF EXPERTS OUT THERE TO TELL US, IF THAT PERSON SAYS, I
KNOW, I NEED AN EXPERT.

WE NEED TO DO THAT.

AS I SAID, I REALLY HOPE THAT WE DON'T JUST INITIATE THIS
PROCESS, THAT WE ACTUALLY ACCOMPLISH SOMETHING WITH IT.

LISTENING, AND I HOPE, IN CLOSING, THAT TODAY IS NOT JUST FOR

AS BUT TODAY IS FOR HEARING WHAT PEOPLE WITH DISABILITIES NEED
CHILDREN, ADULTS, AND THE AGING IN AMERICA TODAY.

THANK YOU.

>> THANK YOU VERY MUCH FOR YOUR COMMENTS.

I WOULD LIKE TO THANK ALL THREE OF YOU FOR YOUR
COMMENTS.

AND I WOULD LIKE TO INVITE THE FIRST GROUP, FIRST FOUR
PRESENTERS FROM THE -- HOLDING THE BLUE CARDS FOR THE PUBLIC
TESTIMONY TO PLEASE COME ON DOWN.

JUST

AS WE TRANSITION OVER TO MR. DE MIRANDA, I WOULD LIKE TO
TAKE A MOMENT, PLEASE, AND GIVE MR. NADEL THE OPPORTUNITY TO
INTRODUCE HIMSELF PLEASE.

>> HELLO.

AND

I'M MARC NADEL, THE ASSOCIATE COMMISSIONER FOR DISABILITY

INCOME ASSISTANCE POLICY AT THE SOCIAL SECURITY
ADMINISTRATION.

>> THANK YOU VERY MUCH.

MR. DE MIRANDA?

>> MY NAME IS JOHN DE MIRANDA.

ON

AND I'M THE EXECUTIVE DIRECTOR OF THE NATIONAL ASSOCIATION
ALCOHOL, DRUGS, AND DISABILITY.

159

OR

OUR ORGANIZATION IS FORMED TO HELP THE MORE THAN 5 MILLION
PERSONS WITH DISABILITIES WHO ALSO HAVE A COEXISTING ALCOHOL
DRUG PROBLEM LIVING IN OUR COMMUNITIES.

WE ALSO WORK TO INCREASE UNDERSTANDING OF ADDICTION AS A
DISABILITY.

AT

1998 WE MET WITH THE PREVIOUS ADMINISTRATOR OF THE SUBSTANCE
ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION WHO STATED

ACT

THAT MEETING THAT, IN HER OPINION, SAMHSA DID NOT HAVE ANY
RESPONSIBILITY TO ENFORCE THE AMERICAN'S WITH DISABILITIES

OF 1990.

THE STATES, SHE STATED, WERE THE ACCOUNTABLE JURISDICTION, DESPITE THE BILLIONS OF DOLLARS SUPPLIED TO THEM THROUGH THE FEDERAL BLOCK GRANT MECHANISM.

WE DISAGREED.

SHORTLY AFTER THIS MEETING, MR ORGANIZATION RELEASED THE FINDINGS OF A STUDY THAT LOOKED AT FOUR STATE, ALCOHOL, AND DRUG SERVICE SYSTEMS.

OUR FINDINGS INCLUDED BLEAK PROSPECTS FOR THE INDIVIDUAL WITH THE DISABILITY IN NEED OF ACCESSIBLE TREATMENT OR YOUTH WITH DISABILITIES REQUIRING ACCESSIBLE PREVENTION SERVICES.

OUR REPORT, THE ACCESS LIMITED REPORT -- AND I WILL LEAVE A COPY SHOULD, RESPECT TO ITS PROGRAMS AND CONTRACTS.

ARMED WITH THIS INFORMATION AND THE LACK OF A FEDERAL RESPONSE, WE APPROACHED THE NATION'S LARGEST HEALTH CARE PHILANTHROPY, THE

160

RECEIVE ROBERT WOOD JOHNSON FOUNDATION. AND WE'RE GRATIFIED TO A MAJOR GRANT TO CREATE DEMONSTRATION PROJECTS IN FOUR STATES TO IMPROVE ACCESS TO CARE.

OHIO, OREGON, FLORIDA, AND NEW JERSEY HAVE ALL WELCOMED OUR

TRAINING AND TECHNICAL ASSISTANCE, WHICH IS CURRENTLY UNDERWAY.

IN JULY OF THIS YEAR, WE WROTE THE ACTING SAMHSA ADMINISTRATOR,

DR. AUTRY, WHO WAS HERE THIS MORNING, AND URGED HIM TO ADOPT OUR

RECOMMENDATION IN FOUR AREAS.

THESE ARE:

THE AFFIRMATIVE DUTY TO COMPLY WITH EACH TITLE OF THE AMERICANS

WITH DISABILITIES ACT SHOULD BE REQUIRED OF ALL RECIPIENTS OF

FUNDS FROM SAMHSA AND THE SUBSTANCE ABUSE CENTERS, INCLUDING EACH SINGLE STATE ALCOHOL AND DRUG AGENCY RECEIVING FEDERAL BLOCK GRANTS.

CURRENTLY SAMHSA DOES NOT REQUIRE THIS CERTIFICATION ON ITS GRANTS BUT DOES REQUIRE CERTIFICATIONS OF COMPLIANCE WITH A WIDE

VARIETY OF FEDERAL LAWS, INCLUDING THE CLEAN AIR AND WILD AND

SCENIC RIVERS ACT.

SECOND RECOMMENDATION WAS TO EXPLICITLY INCLUDE PEOPLE WITH COEXISTING DISABILITIES IN KEY SAMHSA ACTIVITIES.

WE ASKED THAT THE PEER REVIEWS AND GUIDELINES FOR APPLICATIONS

FOR SAMHSA FUNDING, SPECIFICALLY INCLUDE PEOPLE WITH DISABILITIES RATHER THAN SEVERAL VAGUE TERMS, LIKE CULTURAL DIVERSITY, COMMUNITY INCLUSION.

BUT WE WOULD REALLY LIKE TO SEE THE TERM, PEOPLE WITH THOSE DISABILITIES, AS A SPECIFIC TARGET POPULATION, REPEATED IN

DOCUMENTS.

CREATE
AND FINALLY SAMHSA SHOULD SEEK AND REALLOCATE FUNDS TO
OPPORTUNITIES FOR STATE AND LOCAL JURISDICTIONS TO IMPROVE
PEOPLE
ACCESS TO COMMUNITY TREATMENT AND PREVENTION SERVICES FOR
WITH DISABILITIES.

ACCESSIBLE
IT IS LONG PASSED TIME FOR DEDICATED FUNDED TO CREATE
PROGRAMS.

LOOKED AT
ONE OF THE FINDINGS OF OUR STUDY WAS, IN CALIFORNIA WE
THE TREATMENT DIRECTORY.

WE CHOSE FIFTEEN PROGRAMS AT RANDOM THAT ALSO, THEY HAD A
TELECOMMUNICATIONS DEVICE FOR THE DEAF.

WE CALLED THOSE FIFTEEN PROGRAMS ON A TDD.

ONLY TWO WERE ABLE TO RESPOND TO US.

INDICATED
WE'RE PLEASED TO RECEIVE A PRELIMINARY RESPONSE TO OUR
CORRESPONDENCE JUST LAST WEEK FROM DR. AUTRY, WHICH

IN
THAT SAMHSA AND THE SUBSTANCE ABUSE CENTERS ARE INTERESTED

DISABILITIES
WORKING TO IMPROVE ACCESS TO CARE FOR PEOPLE WITH

WHO HAVE A COEXISTING ALCOHOL AND DRUG PROBLEM.

WE'RE AVAILABLE TO ASSIST IN THIS EFFORT.

IN
AND SOME BOARD MEMBERS FROM MY ORGANIZATION WILL BE SPEAKING

A FEW MINUTES.

THANK YOU.

>> THANK YOU VERY MUCH.

MS. CROCKETT?

>> GOOD AFTERNOON.

MY NAME IS BERTHA CROCKETT.

162

AND I PROVIDE PERSONAL CARE FOR JENNIFER SHEEHY OF THE WHITE
HOUSE.

SHE I KNOW WITHOUT MY HELP SHE COULDN'T DO THE IMPORTANT WORK
DOES TO MAKE CHANGES THAT BENEFIT ALL OF US.

I ALSO WORK TWO OTHER JOBS JUST TO LIVE IN AN APARTMENT IN
MARYLAND AND SUPPORT MY SON.

I WORK IN A NURSING HOME AS A CERTIFIED NURSE.

WITH AND I KNOW THAT ACTIVE PEOPLE SHOULDN'T HAVE TO LIVE THERE
DISABILITIES.

ADVANTAGE AND THE GOVERNMENT SAYS THAT PEOPLE LIKE ME WILL TAKE
OF THE SYSTEM THAT PAYS TO PROVIDE CARE FOR PEOPLE LIKE
JENNIFER.

I DON'T DO THIS BECAUSE I WANT TO GET RICH.

I DO IT BECAUSE I CARE ABOUT PEOPLE.

AND THE JOB IS VERY IMPORTANT.

DENTAL IF THIS WORK PAID A LITTLE MORE AND GAVE ME HEALTH AND

DO BENEFITS, I COULD GO TO SCHOOL AND TEACH PEOPLE LIKE ME TO

MONEY THIS JOB AND SUPERVISE OTHERS, AND AT THE SAME TIME SAVE

AND GO TO -- YOU KNOW.

I LOOK FORWARD TO YOUR SUPPORT.

AND THANK YOU FOR LISTENING.

>> THANK YOU VERY MUCH, MS. CROCKETT.
AND THANK YOU BOTH FOR YOUR TESTIMONY.
THAT CONCLUDES THE OPEN MIC SESSION.

To view the other parts of the listening session, click on the links below.

[Welcome by Deputy Secretary Allen and other Federal Staff](#) - Pages 1-29

[AM Testimony](#) - Pages 29-96

Noon Open Microphone Testimony - Pages 96-163

[PM Testimony](#) - Pages 163-251

[PM Open Microphone Testimony and Closing Remarks by Secretary Thompson](#) - Pages 251-302