

S. HRG. 100-817

**MEDICAID HOME AND COMMUNITY QUALITY
SERVICES ACT OF 1987**

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HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE

UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

S. 1673

MARCH 22, 1988



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MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454)

MY NAME IS NANCY WARD AND I AM THE MOTHER OF DIANNE WARD, SHE IS 26 YEARS OLD AND IS A RESIDENT OF FORT WORTH STATE SCHOOL, FT. WORTH, TEXAS. DIANNE HAS BEEN A RESIDENT OF STATE SCHOOLS FOR 16 YEARS, SHE WAS IN CORPUS CHRISTI STATE SCHOOL FOR 6 YEARS AND 10 YEARS IN FT. WORTH STATE SCHOOL. DIANNE IS PROFOUNDLY RETARDED, SHE FUNCTIONS AT A 16 MONTH LEVEL, HAS NO SPEECH, CEREBRAL PALSY, AMBULATION PROBLEMS, VISUAL DISORDER, BEHAVIOR PROBLEMS, MANY SEVERE MEDICAL PROBLEMS AND OTHER PHYSICAL DEFECTS. DURING MY PREGNANCY I WAS GIVEN PROVERA TO PREVENT A POSSIBLE MISCARRIAGE AFTER SURGERY FOR AN OVARIAN CYST. DIANNE IS THE YOUNGEST OF THREE DAUGHTERS. MY OLDEST IS AN ATTORNEY AND THE MIDDLE DAUGHTER IS AN ACCOUNTANT, THEY BOTH HAVE EXCELLED IN SCHOOL AND NOW IN THEIR CAREERS.

WHEN DIANNE WAS AGE 2, WE LIVED IN MIDLAND, TEXAS AND WE ENROLLED HER IN THE OPPORTUNITY CENTER AND CEREBRAL PALSY CENTER FOR SPECIAL TRAINING THAT INCLUDED SPEECH AND PHYSICAL THERAPY, SHE REMAINED THERE FOR 4 YEARS, WE THEN MOVED TO CORPUS CHRISTI, TEXAS. DIANNE WAS THEN ENROLLED IN THE OPPORTUNITY CENTER AND HAD PRIVATE SPEECH AND PHYSICAL THERAPY UNTIL SHE WAS 10 YEARS OLD. WITH ALL THE TRAINING DIANNE HAS HAD, SHE IS STILL UNABLE TO TALK OR WALK NORMALLY. SHE DID MAKE SOME PROGRESS, SHE CAN FEED HERSELF, BUT SHE IS STILL NOT TOILET TRAINED AND HAS NO SENSE OF SELF PROTECTION, SHE IS STILL LIKE A 16 MONTH OLD BABY EXCEPT SHE IS NOW 5 FT, 8 Ins. TALL AND WEIGHS 172 lbs. AND VERY STRONG. AT AGE 10, WE REALIZED DIANNE NEEDED SPECIAL TRAINING AND VERY PROTECTIVE CARE THAT WAS IMPOSSIBLE TO GIVE AT HOME SINCE SHE DID NOT REALIZE OR HAVE ANY FEAR OF DANGER, MORE THAN ONCE SHE WANDERED OUT OF THE HOUSE AND INTO THE STREET POSING A DANGEROUS SITUATION FOR HER, A HOT KITCHEN STOVE MEANT SHE COULD TOUCH TO TEST IT, SHE ALSO PUT INEDIBLES IN HER MOUTH AND SWALLOW THEM. SHE HAD TO BE WATCHED EVERY MINUTE, EVEN DOING THAT, SHE STILL HAD ACCIDENTS AND WAS INJURED. WE THEN DECIDED TO ENROLL HER IN THE CORPUS CHRISTI STATE SCHOOL SO SHE COULD HAVE SOME FREEDOM WITH SPACE TO WALK WITHOUT CONSTANT SUPERVISION, SHE REMAINED THERE UNTIL OUR TRANSFER TO FT. WORTH AND WAS THEN TRANSFERRED TO FT. WORTH STATE SCHOOL. DIANNE IS VERY HAPPY AND WELL TAKEN CARE OF, SHE CONTINUES TO MAKE PROGRESS WHICH I AM PROUD OF, BUT SHE STILL FUNCTIONS LOW EVEN THOUGH SHE HAS HAD MANY OPPORTUNITIES THROUGH INTENSIVE SPEECH AND PHYSICAL TRAINING AND CONSTANT ATTENTION AND LOVE FROM HER ENTIRE FAMILY.

I AM VERY CONCERNED ABOUT S. 1673/H.R. 3454) IF PASSED, THE LARGE INSTITUTIONS NEEDED BY MANY CITIZENS WILL BE CLOSED AND WILL LEAVE MANY PEOPLE LIKE MY DAUGHTER WITHOUT THE CARE AND PROTECTION SHE NEEDS JUST TO SURVIVE. THE LARGE FACILITY IS THE LEAST RESTRICTIVE ENVIRONMENT FOR MANY SEVERE AND PROFOUND PEOPLE WITH MENTAL RETARDATION.

THE CIVIL LIBERTARIANS AND DEVELOPMENT DISABILITY INDUSTRIALISTS WHO ARE SUPPORTERS OF THESE BILLS ARE BIASED AGAINST LARGE INSTITUTIONS AND HAVE PRESENTED MISLEADING OUTCOMES FOR MANY WHO HAVE GONE TO LIVE IN THE COMMUNITY AND THEY FAIL TO REPORT THE TRAGEDIES THAT HAVE OCCURRED IN SOME SMALL GROUP HOMES, THEY ONLY REPORT NEGATIVE INFORMATION ABOUT LARGE FACILITIES. MANY PRIVATE PROVIDERS SUPPORT THIS BILL BECAUSE THEY CAN SEE AN OPPORTUNITY TO INCREASE THEIR INCOME. BUT THE PRIVATE PROVIDERS WILL NOT TAKE PEOPLE LIKE MY DAUGHTER BECAUSE IT WOULD BE IMPOSSIBLE TO CARE FOR HER AND MAKE A LARGE PROFIT BECAUSE OF THE SPECIAL CARE SHE NEEDS. ^{NOT} SOME ADVOCATES AND ADVOCATE GROUPS WHO CLAIM TO REPRESENT ALL RETARDED PEOPLE DO ~~NOT~~ REPRESENT PEOPLE LIVING IN LARGE INSTITUTIONS WITH SEVERE AND PROFOUND RETARDATION. THESE SAME ADVOCATES AND GROUPS ARE IN THE COMMUNITY GROUP HOME BUSINESS, SO IT IS OBVIOUS THEY ARE ONLY INTERESTED IN THE PROFIT THEY CAN MAKE, THEY SHOW NO INTEREST OR CARE FOR THE MANY RETARDED PEOPLE WHO WILL BE DUMPED OUT OF THE LARGE INSTITUTIONS WHO WILL BECOME THE HOMELESS STREET PEOPLE, THE STREET PEOPLE POPULATION HAS INCREASED TREMENDOUSLY SINCE THE DEINSTITUTIONALIZATION MOVEMENT. IT IS SAD TO SEE SO MANY STREET PEOPLE WITH MENTAL ILLNESS AND RETARDATION SUFFERING FROM LACK OF MEDICAL CARE, FOOD, SHELTER AND PROTECTION, I WONDER WHAT KIND OF A SOCIETY WE HAVE BECOME. I WORRY ABOUT MY DAUGHTER BECOMING A HOMELESS STREET PERSON IF I AM UNABLE TO CARE FOR HER, AND IF I SHOULD DIE OR BECOME ILL THIS IS POSSIBLE.

THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454) DISCRIMINATES AGAINST ALL PERSONS NEEDING AND BENEFITING FROM THE PROTECTION AND CARE THAT CAN ONLY BE GIVEN BY A LARGE FACILITY WITH ALL THE SUPPORT SERVICES LOCATED ON THE CAMPUS. MEDICAL AND DENTAL CARE IS VERY DIFFICULT TO OBTAIN IN THE COMMUNITY BECAUSE MENTALLY RETARDED PEOPLE ARE NOT ALWAYS COOPERATIVE AND REQUIRE MORE TIME TO TREAT. PEOPLE WITH MENTAL RETARDATION ARE THE MOST HELPLESS, HOPELESS AND VULNERABLE MEMBERS OF OUR SOCIETY AND THE PASSAGE OF THIS BILL WILL BE UNFAIR TO THEM AND WILL HURT THEM GREATLY. THE LARGE INSTITUTION IS THE ONLY PROVEN, EFFECTIVE, EFFICIENT AND PROTECTIVE METHOD OF CARING FOR THE SEVERE AND PROFOUND MENTALLY RETARDED. THIS BILL ALSO DISCRIMINATES AGAINST THE FAMILY WHO WILL BE FORCED TO CARE FOR THEIR CHILD, IT WILL BE NECESSARY IN MANY CASES FOR BOTH PARENTS TO QUIT WORK TO CARE FOR THIS CHILD WITH SPECIAL NEEDS. THEY WILL NO LONGER BE TAX PAYING CITIZENS AND IT WILL BE NECESSARY TO GO ON WELFARE.

AS A TAX PAYING CITIZEN AND VOTER I WISH TO EXPRESS MY OPPOSITION TO THE MEDICAID HOME AND COMMUNITY QUALITY SERVICES ACT OF 1987 (S. 1673/H.R. 3454), I HOPE BEFORE ANY ELECTED OFFICIAL VOTES FOR THIS DISASTROUSLY BILL THAT WILL HURT SO MANY CITIZENS, THEY WILL MAKE AN EFFORT TO LEARN THE TRUE FACTS, NOT JUST LISTEN TO PEOPLE WHO STAND TO MAKE A PROFIT. MY DAUGHTER WILL NEED THE LARGE FACILITY FOR AS LONG AS SHE LIVES AND IT WILL BE NEEDED BY MANY CHILDREN IN THE FUTURE.

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