

**COMMENTS ON PENNSYLVANIA’S STATEWIDE
TRANSITION PLAN FOR HOME AND COMMUNITY BASED
SETTINGS (HCBS) IN VIEW OF THE CENTER’S FOR
MEDICARE AND MEDICAID SERVICES (CMS)**

“FINAL RULE”

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FIRST I WOULD LIKE TO POINT OUT THAT NOWHERE IN THE U. S. SUPREME COURT *OLMSTEAD V. L.S.* IS IT SUGGESTED OR IMPLIED THAT ALL DEVELOPMENTALLY DISABLED INDIVIDUALS MUST BE LIVE AND RECEIVE CARE AND TREATMENT IN COMMUNITY SETTINGS. IN FACT, IN CONCURRING WITH THE APPROPRIATE DIRECTION OF THE MAJORITY.

JUSTICE RUTH BADER GINSBURG SPECIFICALLY STATED THAT “FOR CERTAIN DEVELOPMENTALLY DISABLED INDIVIDUALS, CARE IN THE COMMUNITY IS NOT AND NEVER WILL BE APPROPRIATE AND THAT FOR OTHERS IN SOME TIME IN THEIR LIVES, INTENSIVE CARE IN AN INSTITUTIONAL FACILITY WILL ALWAYS BE NECESSARY.”

I POINT THIS OUT BECAUSE DEVELOPMENTALLY DISABLED INDIVIDUALS ON THE AUTISM SPECTRUM EACH PRESENT AN INFINITE COMBINATION OF CHARACTERISTICS IN VARYING DEGREES OF SEVERITY. EACH THEN REQUIRES INDIVIDUAL EVALUATION AND ASSESSMENT TO DETERMINE THE BEST LIVING SETTING WHEREIN APPROPRIATE SERVICES CAN BE PROVIDED. FOR SOME WITH AUTISM, THIS IS A LIFE-LONG NECESSITY.

I SAY THIS AS THE FOUNDER OF AMERICA’S FIRST GROUP HOME -- WITH DR. SIDNEY KAPLAN AND DIRECTOR RAY WEBB, OF THE ALLEGHENY

COUNTY EAST BASE SERVICE UNIT IN 1970 – AND NINE MORE GROUP HOMES SINCE. ALL ARE SERVING AUTISTIC AND DEVELOPMENTALLY DISABLED INDIVIDUALS TO THIS DAY. THIS INCLUDES MY OWN SON, NOW 57, CURRENTLY LIVING IN A GROUP HOME OPERATED BY ALLEGHENY VALLEY SCHOOL WHICH PROVIDES A COMPLETE CONTINUUM OF APPROPRIATE ICF/IID LIVING SETTINGS.

PRESENTLY, INDIVIDUALS LIVING IN GROUP HOMES, SUPPORTED LIVING ARRANGEMENTS, CONGREGATE COMMUNITIES AND FARMSTEADS NOW MAY RECEIVE LONG TERM SUPPORT SERVICES (LTSS) FUNDING VIA HCBS WAIVERS. UNDER THE CMS “FINAL RULE”, THAT COULD CHANGE. AND THIS CAUSES MINE AND THE FAMILIES I REPRESENT GREAT ANXIETY.

THE “FINAL RULE” THREATENS THIS OBVIOUS FREEDOM OF PARENTS’ RIGHT TO INFLUENCE AND THEN CHOOSE WHAT’S BEST FOR THEIR DEVELOPMENTALLY DISABLED SONS AND DAUGHTERS WHO OFTEN ARE JUDGMENTALLY IMPAIRED. THE RISK IS THAT THIRD-PARTY APPOINTEES, NON-TREATING PROFESSIONALS, SOCIAL ENGINEERS AND “ADVO-ZEALOTS” WILL MAKE THE DECISIONS FOR THE PARENTS AND FAMILIES – NOT BY DENYING THEM FREEDOM OF CHOICE, BUT INSTEAD BY TAKING AWAY THE CHOICES.

FOR EXAMPLE, FOR THOSE SETTINGS THAT ARE CONGREGATE (NOT “COMMUNITY ENOUGH”) AND PRESUMED INSTITUTIONAL BY THE ENFORCERS OF THE NEW CMS “FINAL RULE”, IT IS UP TO THE STATES TO MAKE THE CASE TO CMS THAT THESE GOOD PROGRAMS ARE IN FACT “COMMUNITY “TO THE FULLEST EXTENT APPROPRIATE -- THAT HENCE ITS RESIDENTS DESERVE HCBH FUNDING SUPPORT.

AND THOUGH, LIKE TODAY, THE STATE (PENNSYLVANIA) IS REQUIRED TO PROVIDE OPPORTUNITY FOR PUBLIC INPUT ON ITS RECOMMENDATION OF THIS “FINAL RULE”, ULTIMATELY I HAVE LITTLE CONFIDENCE THAT MY STATE WILL MAKE THIS “FREEDOM OF CHOICE” CASE CONVINCINGLY TO CMS. HERE’S WHY.

MY STATE, SINCE 1988, HAS BEEN SEVERELY DEFICIENT IN THIS REGARD. INSTEAD OF COMBINING AND IMPROVING ALL RESIDENTIAL CARE AND TREATMENT OPTIONS, PUBLIC AND PRIVATE, COMMUNITY AND INSTITUTIONAL, TO BETTER SERVE EVERYBODY, THEY CONTINUE TO ELIMINATE THE CHOICES, CAUSING THE TRAGEDIES AND SERVICE DEPRIVATION ACCOMPANYING RAPIDLY GROWING WAIT LISTS FOR APPROPRIATE LONG TERM ACCOMMODATION. INSTEAD IT SEEMS LOGICAL TO GO TO BAT FOR TRUE HUMAN SERVICE INITIATIVES THAT ARE

PROVIDING HIGH QUALITY CARE TO PEOPLE IN A CONTINUUM OF APPROPRIATE SETTINGS. THIS INCLUDES SUPPORT FOR SETTINGS THAT COULD CLOSE BECAUSE OF A NARROW VISION OF “COMMUNITY” -- PEOPLE WHO ARE WELL SERVED AND RECEIVE MEDICAID REIMBURSEMENT FOR THEIR CARE.

LOOK AT THE LEEWAY FOR MISINTERPRETATION: IF A PROVIDER IS ICFS/IID AND HAS ONLY IFS/IID ON CAMPUS (EVEN IF SCATTERED IN SMALL HOMES), THEY FIT THE “FINAL RULE”; IF ON THE SAME CAMPUS THERE ARE ICFS/IID AND HCBS-FUNDED WAIVER GROUP HOMES, THEN THE GROUP HOMES WILL HAVE TO CLOSE OR BE CONVERTED TO ICFS/IID. THE RULE ALLOWS FOR NO WIGGLE ROOM; IF A PROVIDER OPERATES HCBH GROUP HOMES OFF ITS CAMPUS, THEN THERE IS WIGGLE ROOM – MORE THE FARTHER YOU GET FROM CAMPUS, BECAUSE HCBS PROGRAMS NEAR (IN CLOSE PROXIMITY BUT NOT ON CAMPUS) TO ICFS/IID HAVE TO BE JUSTIFIED BY THE STATE AS BEING TRULY “COMMUNITY” ACCORDING TO THE CRITERIA IN THE NEW HCBS FINAL RULE.

IT IS DOWNRIGHT INHUMANE TO DISPLACE THESE INDIVIDUALS FROM THEIR CURRENT RESIDENTIAL SETTINGS AND FORCE THEM INTO

ALTERNATE HOUSING OF UNCERTAIN QUALITY OF CARE, TREATMENT AND LEARNING – AGAINST THE WISHES OF THEIR PARENTS AND FAMILIES.

I URGE THAT PENNSYLVANIA’S PUBLIC SERVANTS PRESENT A FAIR AND REALISTIC CASE TO CMS, DESPITE THE LONG STANDING “ANTI-INSTITUTION” ONE-SIZE-FITS-ALL MINDSET THAT HAS LONG DOMINATED PENNSYLVANIA’S DEPARTMENT OF WELFARE AND ITS SUCCESSION OF ADMINISTRATORS.