

THE PARENTS GROUP
*Parents and Guardians of residents at
Western State School and Hospital*
333 Curry Hill Road
Canonsburg, Pennsylvania 15317

*WSSH
CCA FILE*

POSITION STATEMENT

(PRESENTED ON SUNDAY, AUGUST 11, 1974, AT THE HOST INN, HARRISBURG, PENNSYLVANIA
AT THE INVITATION OF THE AD HOC RESIDENTIAL COMMITTEE OF THE PENNSYLVANIA ASSOCIATION FOR RETARDED CITIZENS)

THE WESTERN STATE SCHOOL AND HOSPITAL PARENTS GROUP WAS OFFICIALLY ORGANIZED SEVEN YEARS AGO TO REPRESENT THE INTERESTS OF WESTERN RESIDENTS AND PARENTS OF WESTERN RESIDENTS. ITS BY LAWS WERE APPROVED AND ITS FIRST OFFICERS ELECTED IN SEPTEMBER OF 1967. IT WAS THE FIRST PARENTS GROUP OF ITS TYPE IN THE COMMONWEALTH. WESTERN'S RESIDENTS TOTAL APPROXIMATELY 650, AND THE PARENTS GROUP ACTIVE MEMBERSHIP EXCEEDS 200 AT THE PRESENT TIME. "ACTIVE MEMBERSHIP" INCLUDES THOSE WHO ATTEND AT LEAST HALF OF OUR GROUP'S MONTHLY GENERAL MEMBERSHIP MEETINGS.

OUR PARENTS GROUP HAS WORKED HARDER THAN ANY OTHER ORGANIZATION OR GROUP IN THIS STATE TO IMPROVE THINGS AT OUR INSTITUTION. WE HAVE DEFENDED WESTERN STATE SCHOOL AND HOSPITAL AGAINST ATTACKS FROM OUTSIDE FORCES AND PRESSURE GROUPS, AND WE HAVE COOPERATED WITH ADMINISTRATION AND STAFF IN THE CREATION OF AND IN THE SUPPORT OF ALL PROGRAMS DESIGNED TO MAKE THE BEST USE OF THIS UNDERSTAFFED, UNDERRUGGED, OVERTWORKED FACILITY, AND IN SO DOING BENEFIT OUR CHILDREN THERE.

WE WERE RESPONSIBLE FOR POINTING OUT THE DEFICIENCIES IN PREVIOUS ADMINISTRATIONS AT WESTERN WHICH IN TURN, LED FINALLY TO THE APPOINTMENT OF THE FIRST ECLECTIC, COMMUNITY-ORIENTED SUPERINTENDENT OUR INSTITUTION HAS EVER KNOWN. AND PERHAPS MOST IMPORTANT, WE HAVE DEVELOPED A POSITIVE AND EFFECTIVE RELATIONSHIP WITH THE EXISTING BOARD OF TRUSTEES THAT HAS TAKEN FIVE YEARS TO ACCOMPLISH. AT ONE POINT, WE EVEN ASKED THE FORMER BOARD OF TRUSTEES TO RESIGN AS A BODY BECAUSE OF THEIR INATTENTION TO SPECIFIC CONDITIONS AT WESTERN WHICH WERE EVEN WORSE THEN THAN THEY ARE NOW. IMPROVEMENTS THAT HAVE OCCURED HAVE PRIMARILY BEEN THE RESULT OF BETTER UTILIZATION OF EXISTING STAFF, EXPANSION OF VOLUNTEER PARTICIPATION, IMPLEMENTATION OF THE "RIGHT TO EDUCATION" CONSENT AGREEMENT THROUGH INTERMEDIATE UNIT #1, UNANNOUNCED VISITS BY PARENTS AND TRUSTEES TO VARIOUS SEGMENTS OF THE INSTITUTION, ADOPTION OF A PARENTS AND RESIDENTS GRIEVANCE PROCEDURE, AND ESTABLISHMENT OF A PARENTS/TRUSTEES LIASON COMMITTEE WHICH MEETS ONCE A MONTH TO DISCUSS THE MOST PRESSING PROBLEMS CONFRONTING THE INSTITUTION'S DELIVERY OF RESIDENTIAL CARE, EDUCATION, AND HABILITATION SERVICES.

THROUGH ALL THIS WE HAVE MAINTAINED AUTONOMY, IN THAT WE ALLOW NO ONE TO SPEAK FOR US OR OUR DEVELOPMENTALLY DISABLED RESIDENTS EXCEPT US AND OUR DESIGNATED SPOKESMEN. YET, IT IS DIFFICULT TO BE HEARD DESPITE ALL THE LETTER WRITING WE HAVE DONE. OVER THE YEARS WE HAVE MADE EVERY EFFORT TO OBTAIN MONEY AND STAFF AND CENTRAL OFFICE ACTION THAT COULD IMPROVE CONDITIONS AT OUR INSTITUTION. THESE CONDITIONS MUST BE IMPROVED FOR THERE IS NO LIKELIHOOD THAT WESTERN'S POPULATION WILL BE SIGNIFICANTLY REDUCED IN THE NEAR FUTURE. OUR POPULATION REMAINS STEADY AND THE PUSH IS TO ADMIT MORE. WE HAVE EVEN CONSIDERED A COURT SUIT TO BLOCK FURTHER ADMISSIONS AS A WAY TO DRAMATIZE THE PLIGHT OF THOSE THERE.

BUT WE HAVE BEEN UNABLE TO HAVE OUR POINTS OF VIEW PREVAIL AT THE CENTRAL OFFICE, LEGISLATIVE, OR STATE ADMINISTRATIVE LEVEL. THIS IS DUE IN LARGE MEASURE TO FRUSTRATION OF OUR EFFORTS BY SUCH ORGANIZATIONS AS THE PARC, WHICH HAS POSITIONED ITSELF POWERFULLY IN OUR STATE CAPITAL AS AN ANTI-INSTITUTION LORRY, WHICH PRESUMES TO SPEAK FOR US PARENTS AND OUR RESIDENTS AND FUTURE RESIDENTS. LET US STATE RIGHT NOW THAT PARC LORRY DOES NOT SPEAK FOR US, OR, TO OUR KNOWLEDGE, ANY OTHER RESIDENTIAL FACILITY IN OUR REGION.

YET, WHEN WE CALL OUR LOCAL SENATORS AND REPRESENTATIVES OR MUSTER UP ENOUGH MONEY TO PERSONALLY VISIT THE POWER CENTERS IN HARRISBURG AND APPRISE THEM OF THIS FACT, THE RESPONSE IS A VARIATION OF THE FOLLOWING WORDS: "WELL MAYBE NOT, BUT ALL MY COLLEAGUES HERE THINK SO; WE GET A STEADY FLOW OF INFORMATION AND RELEASES FROM THE PARC THAT INDICATES THAT THEY ARE ADVOCATING THE BEST INTERESTS OF THE MENTALLY RETARDED." THESE OFFICIALS TRULY BELIEVE THAT EVERY CHILD REQUIRING RESIDENTIAL PLACEMENT IS "MENTALLY RETARDED", AND THAT THE PRESCRIPTION FOR THEIR MELL BEING IS ONLY THAT DICTATED BY OR APPROVED BY PARC.

TELL THESE PEOPLE THAT ONLY ONE-THIRD OF THE RESIDENTS AT WESTERN HAVE "MENTAL RETARDATION" AS THE PRIME REASON FOR THEIR INSTITUTIONALIZATION, AND THAT EVEN THIS ONE-THIRD HAVE OTHER COMPLICATING LABELS AS WELL, AND YOU GET A BLANK LOOK. OR TELL THAT THE "RIGHT TO EDUCATION" AGREEMENT IS OFTEN INTERPRETED TO DESCIMINATE AGAINST EVERY CHILD WHOSE PARENTS OR GUARDIANS

WILL NOT ACCEPT A MENTAL RETARDATION LABEL AND SUBSEQUENT INAPPROPRIATE EDUCATIONAL PROGRAMS, AND THE LOOK IS EVEN MORE BLANK.

TELL THEM THAT THE COSTLY AND VICIOUS DICHOTOMY THAT EXISTS IN SEPARATE STREAMS OF MH AND MR BUREAUCRATS AND FUNDING IS BASED ON THE PARC SUPPORTED VIEWPOINT THAT "MENTAL RETARDATION" IS AN EDUCATIONAL PROBLEM. MENTAL ILLNESS IS A MEDICAL PROBLEM" AND THEY REALLY TUNE YOU OUT. THEY CAN NOT COMPREHEND THE VARYING SHADES AND ADMIXTURES THAT CRY OUT FOR MULTI-DEPARTMENTAL COOPERATION AND MULTI-DISCIPLINARY APPROACHES TO ALL DEVELOPMENTALLY DISABLED CITIZENS, SO THAT EACH CAN ACHIEVE SUCCESSIVELY HIGHER LEVELS OF DEVELOPMENT.

TELL THEM THAT THEY SHOULD USE THEIR POWER TO SEE THAT THERE IS FULL SEVEN-DAY-A-WEEK COVERAGE AT INSTITUTIONS LIKE OURS BY PROFESSIONAL STAFF AND NURSING ATTENDANTS, AND THEY SHUDDER.

TELL THEM THAT WE NEED MORE CARE PERSONNEL TO MEET AT LEAST THE MINIMAL JCAH STANDARDS FOR HUMAN DIGNITY AT WESTERN OR THAT HIGHER SALARIES ARE REQUIRED TO ATTRACT COMPETENT MEDICAL PRACTITIONERS TO INSTITUTIONS, AND THEY TELL YOU THAT THE DEPARTMENT OF PUBLIC WELFARE DID NOT SPEND TEN MILLION DOLLARS OF ITS APPROPRIATION LAST YEAR, OR THAT THE DEPARTMENT OF PUBLIC WELFARE STILL HASN'T FILLED ALMOST 500 ALLOCATED POSITIONS.
NOW, THE REALLY INFORMED BUREAUCRATS AND LEGISLATORS REALLY THINK THEY ARE SHARP WHEN THEY TELL YOU THAT WESTERN HAS THE BEST STAFF-RESIDENT RATIO OF ANY INSTITUTION IN THE STATE AND WHAT ARE WE COMPLAINING ABOUT.

TELL THEM TO PREPARE LEGISLATION THAT WOULD OVER RIDE LOCAL ZONING REGULATIONS THAT PREVENT ESTABLISHMENT OF COMMUNITY RESIDENTIAL FACILITIES, AND YOU ARE RIGHT ON THEIR TUFF. THEY TELL YOU SIMPLY THAT SUCH LEGISLATION WOULD BE RIDICULOUS, IT WOULD BE UNCONSTITUTIONAL.

TELL THEM TO RELEASE FUNDS FOR NEEDED CONSTRUCTION TO RELIEVE OVER-CROWDING, OR TO USE APPROPRIATE EMPTY SPACE AND TRAINED PERSONNEL IN MENTAL HOSPITALS TO ACCOMMODATE THE INSTITUTIONAL OVER-LOADS UNTIL THESE COMMUNITY OBSTACLES ARE OVERCOME, AND THEY TELL YOU "THE SECRETARY IS AGAINST IT AND SO IS PARC I UNDERSTAND."

TELL THEM THAT WE FAVOR ELIMINATION OF THE WASTEFUL MH/MR DICHOTOMY BY ESTABLISHMENT OF A SINGLE, SEPARATE DEPARTMENT OF STATE, WITH A MULTI-DISCIPLINARY ADVISORY BOARD, TO ADMINISTER ALL SERVICES FOR THE DEVELOPMENTALLY DISABLED, AND WE ARE TOLD BY EVERYONE IN STATE GOVERNMENT AND PARC, THAT THIS IS AN IDEAL THAT IS ENTIRELY UNREALISTIC. SO THE BILLIS THAT A FEW WELL-MEANING LEGISLATORS HAVE INTRODUCED IN BOTH HOUSES OF STATE GOVERNMENT NOW Languish IN COMMITTEE. THEIR POSITION IS UNTEAABLE BECAUSE IT IS EVEN MORE UNREALISTIC TO EXPECT THE NORMAL COMMUNITY TO LOVE OUR CHILDREN OF VARYING DEGREES OF HANDICAP - AND SOCIAL COMPATIBILITY; THEY PAY SO MUCH TO KEEP THEM OUT OF THEIR SIGHT; IT IS A PROBLEM THEY DON'T HAVE AND THEY DON'T WANT.

NOW, MANY OF US PARENTS IN OUR GROUP ARE MEMBERS OF LOCAL ARC CHAPTERS—
SUCH AS THE ALLEGHENY COUNTY CHAPTER WHICH HAS BEEN SYMPATHETIC TO SOME
OF OUR VIEWPOINTS—AND WE ARE NEVER ASKED TO HELP AS MEMBERS TO FORMULATE
THE STATE PARC LOPPY POSITION, SO WE ARE UNDERSTANDABLY RELUCTANT TO
BELIEVE THAT OUR POSITION—IMPLICIT IN FORGOING REMARKS WILL IN ANYWAY
PPEVAIL IN THIS PARC AD HOC COMMITTEE'S RECOMMENDATIONS. BUT WE ARE
PLEASED THAT PARC HAS SOUGHT OUR CONSULTATION AND OUR CRITICISM FINALLY.
IF WE CAN REACH ANYONE THROUGH THESE REMARKS WHO CAN IMPROVE THE LIVES
OF OUR CHILDREN, WE WILL CONSIDER THE TIME AND EXPENSE IN COMING
TO THIS MEETING QUITE WORTHWHILE. YOU SEE, AT THE TIME WE PARENTS
INSTITUTIONALIZED OUR CHILDREN AT WESTERN STATE SCHOOL AND HOSPITAL WE
THANKED GOD FOR SUCH A PLACE THAT WOULD ENABLE US TO RECONSTITUTE OUR
LIVES. WE ONLY WANT IT TO BE A BETTER PLACE, NOW. AS IT IS, OUR
RESIDENTS ARE SACRIFICIAL LAMBS IN SOME UNGODLY CELEMONIAL CONFLICT
THAT PITS LAPEL AGAINST LAPEL, AND DIGNITY AGAINST DOLLARS. AND THOSE
AT THE FOREFRONT IN THIS SACRIFICE SEE1 TO HAVE LOST SIGHT ENTIRELY OF
THE ONE REAL OBJECTIVE: INSTITUTIONALIZED CITIZENS WITH VARYING COMBINA-
TIONS OF DISABILITIES, AND THE PRESENT DEPLORABLE CONDITIONS UNDER WHICH
THEY LIVE AND ARE EXPECTED TO LEARN.

ONE LAST PARTING SHOT THAT ILLUSTRATES AN ALMOST INCOMPREHENSIBLE SENSE
OF PRIORITIES. THERE WAS A RIOT, A MAJOR ESCAPE, AND A GUARD KILLED
RECENTLY AT A STATE PRISON IN OUR REGION. WITHIN THREE MONTHS ENOUGH
MONEY WAS FOUND SOMEWHERE, SOMEHOW, TO BEGIN A FORTY MILLION DOLLAR
RENOVATION PROGRAM WHICH IS NOW UNDERWAY. WE PARENTS SUBMIT THAT
OUR CHILDREN DID NOT OPT TO BE HANDICAPPED. BUT THEY ARE, AND EVEN
THOUGH THEY ARE, THEY ARE STILL ABLE AND WILLING TO STRIVE FOR THE
NEXT HIGHER LEVEL OF ACHIEVEMENT. AND WE SUBMIT FURTHER THAT ELECTED

AND APPOINTED OFFICIALS OF THIS COMMONWEALTH WHO HIDE BEHIND THE DOLLAR SIGN AND EXPEDIENCY, WHO ARE INTIMIDATED BY THE LAWLESS INSTEAD OF MOTIVATED BY THE HELPLESS, IN DENYING THEM THIS OPPORTUNITY ARE THEMSELVES SOCIAL CRIMINALS.

THANK YOU FOR THIS OPPORTUNITY TO PRESENT THIS POSITION STATEMENT.

EXECUTIVE COMMITTEE

WESTERN STATE SCHOOL AND HOSPITAL PARENTS GROUP

HARRY L. GOLDBERG

PRESIDENT