

STATEMENT
of
MEL HECKT
3/27/87

TO THE MINNESOTA LEGISLATURE'S SENATE FINANCE COMMITTEE, HEALTH AND HUMAN SERVICES DIVISION.

My name is Mel Heckt; I am a Minneapolis lawyer and father of Janice, age 35, whose home for the past 28 years has been the Faribault Regional Center. Jan is severely retarded, has psychomotor and grand mal seizures, severe scoliosis and severe behavioral problems, all of which are being expertly treated by FRC.

Jan lives with nine other women in a separate unit of a four-plex: It has a kitchen, dining area, living room, bedrooms and bath; she works part-time, goes to DAC, receives physical therapy, psychological counselling, nursing care, medical and dental care and drug monitoring by experienced experts. She frequently goes downtown for meals, treats, bowling and church. Every waitress at Wimpy's knows and likes Jan. They know she will order chicken and cherry pie a la mode. Some of her staff have been with her for most of her 28 years in the home.

From 1953-1985 I have been active in the ARC movement; in the past, I have served as president of Minneapolis ARC, Minnesota ARC, Regional vice president and secretary of NARC and member of the President's Committee on Mental Retardation. I have advocated for almost every community service in place today and for improvements in our State's regional treatment centers.

Regretably, I am convinced that the ARC, the MR Division and the attorneys for the Welch Class do not speak for my daughter today. They do not speak for 90 per cent of the mentally retarded residents of our 7 State and 52 community institutions. They want to destroy and close all of them and force their philosophy that small is best upon all of us who disagree. To accomplish their goal, they advocate the Chaffee Bill on the Federal level and the Commitment Law, the Public Guardianship Law, Waivered Services, Rule 185 and a proposed amendment to limit funding under Medicaid to residences for no more than six, they prefer 2, 3, 4 or 5 maximum size, on the State level. They want to force their dictatorial philosophy upon all of us whose loved ones now reside in facilities in excess of 15 residents. Ironically Jan lives with nine ladies.

They want to deny us the freedom to choose the State and Community Institutions as the most normal and least restrictive environment for our loved ones. We believe in their right to choose their own homes, foster homes or small group homes for their relatives.

WHAT IS THE PRESENT PLAN FOR THIS BIENNIUM?

400 persons who are mentally retarded will be forced out of seven regional treatment centers.

180 persons will be forced out of nursing homes.

400 persons will be forced out of community ICFMR's.

980

The ARC claims there will be no funding in the governor's budget for 160 of the 980. It also claims that 180 people will leave nursing homes, but there will be no increased funding in the SILS budget to pay for them. That there will be 380 on the SILS waiting list at the end of the Biennium. I assume these 340 mentally retarded people will become bag men and bag women. Some of the 380 on the SILS waiting list may have to join the bag people.

WHAT IS THE RESULT OF THIS PROPOSED NON PLAN?

400 people who are mentally retarded will be forced out of RTCS against their or their relatives will into community ICFMRS in order that 400 can be forced out of community ICFMRS against their or their relatives will into non-existent and unfunded SILS and in order that 180 can be forced out of nursing homes against their or their relatives will into nonexistent and unfunded SILS in order that the 380 from the community on the waiting list can be denied this service and in order that the 500 or more in the community who need small group home care or foster care or SILS or Respite Care can be denied same.

A far worse scenario or alternative will be to place those from RTCS and ICFMRS into community homes of three or four under waived services in order that the services they desperately need can be waived, forgotten and covered up.

If the ARC and MR Division of the Department of Human Services believe this non plan provides for a continuum of service, they are mistaken. It provides for a continuum of nonservice, inappropriate service and in some cases life threatening service. It has caused us relatives, parents and friends of the 980 to be forced out to be mad, frightened and fearful for the future welfare and safety of our loves ones.

As you know the State has met its quota of discharges of people from our State RTCS under the Welch Court Order. Yet some counties erroneously believe that they must continue to secure discharges either because of Welch or to secure their quota of waived, services funds.

Now, let me tell you how this inane system of Welch, waived services, screening teams and almost total power in the case manager and none in the parent and relative is threatening the life of Karen. She is 43 years old and a resident of the Faribault Regional

Center; her mother is 80 and lives in Austin, her uncle is a retired professor at the University of Minnesota who taught medical students.

Karen is profoundly mentally retarded. She suffers from hypothermia, osteogenesis imperfecta, scoliosis and seizures. She sleeps on a heated water bed to guard against death from hypothermia. She has two attendants help her out of bed to avoid breaking her fragile bone structure. Her mother and uncle are most pleased with the loving care given by her attendants and the expert and experienced care given by the medical and nursing staff of FRC.

The Mower County Case Manager and his hand-picked screening team are insisting that Karen be transferred to a house yet to be selected in Austin and live with three men. They claim they must meet a quota; that Karen is the only one available who does not have behavioral problems; that they don't want ambulatory residents because the neighbors would object to seeing these retarded people walking the streets. When the mother cried and protested her daughter being forced to live with three men, the Case Manager told her that Karen would not be interested in two of the men.

Her uncle and mother are totally opposed to this transfer. They are convinced that bussing Karen daily to a DAC will undoubtedly cause broken bones. That such bussing may very well kill her from hypothermia; that her seizures now under control may resume, and they doubt that any responsible physician would want to be responsible for her care. Her uncle was most unimpressed with the social worker who said they would be able to correct her disuse atrophied limbs - 43 years of disuse atrophy just won't be corrected.

The new philosophy is to hell with the parents and relatives . . . we the screening team know whats best . . . we don't need doctors and nurses to tell us . . .

I want to tell you of one other shocking case. The woman was 85 years of age. She has lived at the Faribault Regional Center for many years. Again an all knowing inexperienced case manager decides she should move to a home for four in Litchfield. The Judge and two attorneys travelled from Litchfield to Faribault to hold court. Finally, the Judge asked the elderly lady if she wanted to move to a house in Litchfield and the elderly lady who is mentally retarded said no, this is my home. Thank God the Judge and the old lady had more common sense than the case manager. Just look at the anxiety, the fear, the paper work, the unnecessary expense, all because the case manager erroneously believes small is always better.

I respectfully recommend the following:

- 1) Freeze the budget for regional treatment centers at present levels until a thoughtful and fair plan can be submitted and implemented.

- 2) Prevent the Department of Human Services from further depopulating our RTCS and community ICFMRS except where the parents or relatives request the move and the transfer is approved by the case manager and the ICFMR interdisciplinary team.
- 3) Lift or relax the moratorium on ICFMR beds, but do not pass S.F. 527 which limits new funding for new facilities to six beds.
- 4) Do not permit further decertification of beds at the regional treatment centers so that those who move or have moved to the community can return if they are demitted or if their community group home closes, or if the one year lease on the waived service home for four is not renewed or if the care is later on found to be of lesser quality than that previously received at the RTC.
- 5) Insist that Rule 185 be amended to clearly permit parents and relatives in addition to legal guardians of adult mentally retarded persons the right to appeal from decisions of the screening team and case manager. Study the feasibility of removing the screening team bureaucracy.
- 6) Amend the public guardianship statute to permit parents to act as co-guardians in order that they can be assured that the state will continue to have a legally enforceable duty to provide care, treatment and habilitation for profoundly and severely mentally retarded wards . . . a private guardian can only put the wards name on a waiting list.
- 7) Abolish the commitment law (or design a totally separate law) for profoundly and severely mentally retarded people. It makes no sense to have court commitment of these people to RTCS or to community residential facilities. Now we just commit to RTCS. Exceptions could be made.
- 8) Prevent waived services from being used to avoid necessary standards and needs of the individual.
- 9) Do not practice medicine by prohibiting faradic shock for all under all situations. Rather establish guidelines and safeguards. I know of one person who is probably alive today because it was used carefully under expert advice and procedure.

Thank you for the opportunity to appear before you. I am most grateful to past governors and legislatures which have made fantastic improvements in our State institutions over the past 28 years. I hope we will not destroy the Minnesota success story of providing so much for so many of our least fortunate members of society. Nebraska and Michigan do some great things for a few. Minnesota has done great things for many in need.

Mel Heckt
3550 Multifoods Tower
Minneapolis, MN 55402
333-3000