



# **Mental Retardation Association of Nebraska, Inc.**

*"Common Sense Advocacy for All Retarded Persons"*

Statement of

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Mental Retardation Association of Nebraska

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My name is Patricia Kelly Crawford. I'm from Lincoln, Nebraska. I serve as Governmental Affairs Chairman for Mental Retardation Association of Nebraska, as a Director for Congress of Advocates for the Retarded, and as a Director for Voice of the Retarded. For the past eleven years, I have been a member of the Nebraska Governor's Developmental Disabilities Planning Council, and have been appointed and reappointed by three governors.

The reason for all this activity is my son, Matt, now 27 years old, the middle of five children. He lived at home till he was 14; we had been aware for a few years that we were not meeting his needs in a home setting even though he went to a "school" every day and had attended nursery school from age 3.

I wish Matt could be here today to testify but because he has profound mental deficiency, he has no speech at all. He requires help and guidance for all life activities: eating, bathing, shaving, toileting. He functions, I believe, at about the level of an 18 month old child. His needs can only be met in a large facility where he has security, complete and comprehensive and intensive services, training, medical care, and immediate and continuing access to all the disciplines necessary to his care and training.

He has been a resident of the Beatrice State Developmental Center for thirteen years now--he is a happy guy because he feels secure. He lacks understanding of the

spoken word, unless it is a familiar statement or command, and because they have a rigid schedule, he knows what to expect next.

I will always remember Matt at about age 12, trembling, with knees knocking, literally, in the back seat of my station wagon. We were only going a short way to take his sister to a dancing lesson. I tried to reassure him, but he is so profoundly retarded he was not able to comprehend-- maybe he thought we were going to drop him off at a group home for 3 weeks while the rest of the family went on vacation as we had done the previous year. Matt typifies the resident of a large facility today.

We, parents and families, the members of Mental Retardation Association of Nebraska, strongly oppose HR 3454. On one hand, the bill is very generous with the intent of improving and expanding community-based programs. It aims to provide a vast array of services to a vast number of disabled persons. This we applaud and approve--always have-- but the bill has a dark side. While it gives to so many, it takes away from the most severely disabled Americans, those who need and rely on your help the most, those who have depended on Medicaid support since 1977. It takes away the choice of a continuum of services and substitutes a pseudo-choice of community based services.

Don't think for a minute that all retarded people are alike, that they all need the same remedy. We have tried

that already. For 80 years in Nebraska, the institution was the only place you could get educational and residential services for retarded people. Everyone agrees that that one remedy was not the answer for all. Let us not repeat the mistake and get rid of large facilities that have a good reputation for providing an array of services to the most severely and profoundly disabled Americans.

HR 3454 is a Trojan Horse to close institutions – the freeze on money to large facilities attempts to make this effort less likely to attract opposition. The authors of this bill are going through the back door in their Trojan Horse to achieve the ultimate goal—to close institutions.

Nebraska parents strongly oppose HR 3454 because it is a Trojan Horse which will close large facilities (over 15 beds) for the mentally retarded. An anti-institution bias pervades the entire bill. HR 3454 caps the Medicaid money received by the state for services for severely disabled individuals. With inflation factored in, the net result will be less money to spend for each person. There will be fewer staff and a decline in overall quality of care. Large facility residents are the most severely handicapped in the nation. They require the comprehensive and intensive care and the security found only in a large facility. The CPI is now 4%, a year. In five years that amounts to a 19.5% reduction; in 10 years, 33.6%; and by year 2000 that will be a 38.8% reduction in Medicaid money for services to individuals.

At the same time these institutions must comply with a maze of Federal rules and standards as well as exacting survey teams, or the facility will be decertified: the facility will not be eligible to receive Medicaid funds to render services for disabled individuals.

This bill also states that if the CPI rises above 67c, payments for persons in large facilities would be increased only to the extent that the CPI exceeded 67%. For example, if the CPI rose to 77%, the payments to those most severely handicapped Americans would only increase by 17%.

The practical effect of this most cruel freeze, this Trojan Horse, would be an actual cut in payments for services to real individual people.

There is a second cruel freeze in this bill--the freeze out of parents and legal guardians from the decision-making teams for our children. We now have the right to participate in planning life activities for our children. If you pass this bill, some bureaucrat will make the decision to include us, " . . . as appropriate". We are scared and we are outraged.

If HR 3454's Medicaid freeze were to become law, the truly mean and radical cuts in payments for individuals' services would cripple the ability of large facilities (over 15 beds) to properly care for the residents. They would have inadequate funds to strictly comply with HCFA standards and rules.

If you believe that old stereotype that these large facilities are warehouses, you are badly misinformed. HCFA allows no warehousing. Each individual has a program plan for each and every hour of each and every day. If this bill is passed, in a few years institutions would no longer be able to meet HCFA rigorous standards, would lose Medicaid certification, and be forced to shut down or depend on less reliable funding sources.

They could even revert back to the snake pits and warehouses of 20 years ago--God forbid!

There are two other provisions that would help to shut down institutions:

- 1) This legislation would also require the States to set forth specific objectives and a projected schedule over the next five years for transferring severely disabled persons residing in larger institutions to "more appropriate" residential settings.
- 2) The bill "restricts" admission to any facility larger than 15 beds--this means that any admission would be temporary until a spot in a small facility could be found.

The large facilities operated by Baptists, Catholics, Lutherans, and other charities will be subject to this law, too, only they will have to make up the deficit with donations, if able.

The wording in the bill, "transferring . . . persons

residing in larger facilities to 'more appropriate' residential settings" clearly reveals the bias against large institutions which pervades this legislation. HR 3454 would, as night follows day, result in the elimination of the option of choosing a large facility. Please kill HR 3454.

The parents and families of Mental Retardation Associates of Nebraska are very pleased to support HR 5233, the Medicaid Quality Services to the Mentally Retarded, Amendments of 1988. This bill makes sense. It gives the states the right to determine what services their mentally retarded citizens need, thereby increasing local control. In Nebraska we have 77,000 square miles of real estate and only 1.6 million people--lots of wide open spaces--rwhich means that sophisticated medical, dental and other services are bunched into two or three population centers. We have a well established community based Mental Retardation service system serving about 2300 persons and only 761 large facility beds.

HR 5233 does not discriminate against severely and profoundly retarded people who need the security and comprehensive and intensive care found in a large facility. A fellow like Matt can move about the large and beautiful campus at B.S.D.C. on his own, but move him into a community based program and he loses the autonomy he now has; in a community based residence he would need an attendant for any and every activity away from his residence.

The Waxman bill could expand Medicaid funding into community based programs and does not make the residents of large facilities pay the bill.

We urge you to advance HR 5233 with the following amendments. On page 12, line 1, put a period after the word unobtainable and delete the remainder of the sentence. The way it reads presently makes parents worry that someone might regard their participation as "inappropriate" and thereby eliminate potential disagreement on a matter of import to client and family. On page 26, insert after line 4, (D) Requirement of habilitation facility to re-admit client promptly, if transfer or discharge to new living environment fails. One example of failure is: lack of fulfilling the service needs of the client identified in the pre-discharge IPP. The rationale is this, if a parent or family were certain that their loved one could return to the institution if things do not work out, it would certainly act as a catalyst for families to try a community-based service.

We will always need large facilities for that segment of the disabled population who are multiply handicapped, and have severe or profound retardation.

It is very important that you understand how different the folks are who reside in a large facility. These are not the folks with mental retardation that you see on the bus with lunch box in hand, or in church on Sunday. They are not

able to get about on their own, some have severe behavior problems, many are multiply handicapped. Here are some hard facts. At the Beatrice State Developmental Center, our only state "large facility" (over 15 beds) for the mentally retarded, of the 470 residents, 84% need help bathing, 82% need help dressing, 66% need help toileting, 82% have no speech or are speech impaired. Seventy-three and a half percent have a mental age of near 0-2 years. In addition to mental deficiency, more than a third of the residents have been diagnosed as mentally ill. These figures are typical of large facility residents across the nation.

We, parents and family, support a broad range of services: in-home services, small facilities, and large facilities, so that each individual can be served in the most suitable setting. We cannot support the Medicaid Home and Community Quality Services Act HR 3454 because of the bias against large facilities (over 15 beds) for mentally retarded persons who sorely need comprehensive services. We support with enthusiasm HR 5233 and urge its passage.