

Testimony of:

Bette Rosse
3725-47th Avenue South
Minneapolis, Minnesota 55406

Phone: 612-724-9552 or 612-827-5641

Given:

on August 13, 1984,
before the United States Senate Finance Committee's
Subcommittee on Health,
Minneapolis, Minnesota

Summary of Principal Points:

- (1) Introductory comments are provided.
- (2) Locating small residences throughout each state allows many, many more mentally retarded people to maintain close contact with their families than does the use of large facilities.
- (3) Well-trained, competent, enthusiastic staff members are readily available to small community residences.
- (4) All mentally retarded people can live in small, community residences -- any needed services which are provided within the four walls of a large institution can be equally well provided within the four walls of a small community residence.
- (5) Using small community residences allows mentally retarded people to receive the special help, support and quality assurance which neighbors provide to neighbors.
- (6) Large, congregate institutions are unacceptable for governmental support as residences for mentally retarded people since other people -- those with choices -- do not ever choose to live in such settings.

I would like to introduce myself to you.

My name is Bette Rosse. I'm what many of you in today's audience call "a parent", which means not only that I have a child but that I have a mentally retarded child.

My only son, Scott, is now a young man. He is severely retarded, and he is also autistic, a second handicapping condition which means that in addition to all of the limitations of mental retardation, he also has profound communication impairments and he has severe behavioral problems -- aggression and self-injurious behavior. In order to lead his life fully, and to develop to his full potential, and to enjoy life, he has needed and, since there exists no cure for his condition, shall probably always need a lot of specialized services.

Six years ago we were contacted four families who had adult sons older than our Scott, and whose sons lived in state institutions. All four families were desperate, because their sons were deteriorating badly and at least one was in immediate danger of death through failure to thrive. Certainly none were showing evidence of enjoyment of life in those large, isolated living environments, and the families were eager -- maybe desperate is a better word -- to find another living situation for their sons.

Using all of our professional expertise, and all of our concern as parents, we began to design a Community residence and a program which would meet the needs of all of these desperately disabled people, that would provide them with care and supervision, but also with increased family contact, community involvement, and the chance they needed to grow and develop and acquire new skills and enjoy life.

Now both pride and satisfaction overwhelm me as I tell you that after a lot of hard work, my husband and I and other members of our non-profit corporation opened a new community group home named Shingle Creek Option. Our son and other sons and daughters went to live at Shingle Creek Option.

As we designed Shingle Creek Option, we knew we wanted it in the community, near all of the families whose sons and daughters were to live there. We wanted to be able to visit our sons and

daughters easily and frequently, and to keep them a part of our lives and to keep us in their lives, just the way things work out with our other sons and daughters.

I must digress here to point out that my son, and others like him, may have lots and lots of problems and they may lack a lot of skills, but they are still wonderful people, and precious sons and daughters. It does describe my Scott to say that he is severely retarded, and that he can exhibit certain aggressive behaviors, and that his self-injurious behavior is a real problem, but it also describes him to say that he's a good-looking young man who enjoys music and drawing and bicycling and cooking, and he's beginning to enjoy swimming.

All of us who worked on Shingle Creek Option knew that our potential residents had substantial needs for very specialized service. We were told by both our County and State personnel that such severely disabled people had not previously been moved out of state institutions and into the community. But we believed that our sons and daughters could be served well in the community. We saw institutions as four walls within which services are provided, and we felt these essential services could be provided within the four walls of a state institution or, at least equally well, within the four walls of a small, Community residence.

Fortunately, for the well being of the mentally retarded people we have the privilege of serving at Shingle Creek Option, we were indeed correct that all essential services can be provided in small settings.

We further believed that we could hire competent people to care for our sons and daughters and others at Shingle Creek Option, in the community.

And we have been able to provide a sensitive, totally competent service, fulfilling a dream that some still say is impossible! The atmosphere is cozy, homey, and gentle, and the quality of interaction between staff and resident is extraordinary, and all needed services are provided competently. Our residents -- each and every one -- are developing new skills which permit them to both participate constructively and to enjoy life. They are each continuing to grow -- as we knew they could -- if given just half a chance.

Those services which we have associated with the four walls of an institution can be moved to the four walls of a small Community residence, where each mentally retarded person can additionally live near family and in a small normalized setting.

My Scott's Shingle Creek Option is small, and in the Community, competently staffed, and located so that family involvement is encouraged. But more than that happens in the Community.

I'd like to focus for a moment on quality of service and freedom of the residents from neglect and abuse -- the critical issues in any service to the severely disabled among us.

A first advantage of a Community residence for quality and safety is that all residents are required to attend day programs which are away from their residential service, and under the direction of another agency. For some, including my son, the bus service back and forth is even provided by a third agency. For our severely disabled, non-verbal sons and daughters and friends and clients, this involvement of several agencies provides a good, daily check on the quality of care that each place is providing. Tragically, neglect and abuse can occur to the vulnerable anywhere, but with several agencies involved, it is far more likely to be detected and reported and corrected in the multi-agency system which exists only in the Community.

A second form of protection for these severely disabled individuals also exists only in our community residences -- that of independent licensing. In Minnesota, the Department of Human Services both licenses and operates the State institutions, but Community residences are operated privately and licensed by the State. Separating the responsibilities for operating and licensing obviously strengthens the checks that are available to ensure quality and safety.

A third form of protection in our Community is that many smaller residences can be closer to families and can involve families, so that the quality and safety of care are more frequently monitored by those who care most.

But let me tell you about a fourth form of quality and safety protection you may not have thought about before, and that I only learned about

through Shingle Creek Option:

Small Community residences are not isolated -- they are a part of their communities and neighborhoods. In just the two years Shingle Creek Option has been in operation, the Manager of the nearby convenience store stopped over to give us a donation collected by his employees for the use of our residents -- the employees had noticed our folks when they, accompanied by staff members, purchased items at this nearby store, and they wanted to do something to help out. Another time, the director of the city parks stopped by -- his staff had noticed that our adult residents and staff frequented a nearby park, and he wanted to know what equipment he might add to increase the enjoyment of the folks who live at Shingle Creek Option. And the elderly residents at a nearby town house complex wrote to offer their services as volunteers. Of course, all of these kindnesses were greatly appreciated. But it goes beyond help and appreciation. These people, our neighbors, cared enough to notice our residents, and to find out where they were from, and to think about how they could help, and to then provide the help -- then obviously these people, our neighbors, would also care enough so that if our residents were not properly cared for, they would figure out who to report that to. Being a part of a Community, being a neighbor and having neighbors means that there will be a check on quality and safety that is sincere and continuous and ongoing. To restate the fourth Community protection for quality and safety --I learned that the community, where small residences are neighbors and have neighbors, has a strength that will provide real protection to mentally retarded people now and in the future, the strength of many, many people watching and caring and doing, the strength which comes from being a neighbor and having neighbors, which large isolated institutions have never developed because their size isolates them.

The Hearing Announcement asked that testimony address the question "how can we provide the best care in the best way?"

I offer the answer that care can be provided in the four walls of an institution or a small Community residence, but the issues of the quality and safety of that care demand small Community residences.

I have one final point that I offer for your consideration:

There remains no question that all mentally retarded people can be served in small Community residences -- we know it can be done. We know that the critical issues of quality of care and freedom from neglect and abuse can be better addressed in the community, with State licensing separate from operation.

But there is a final issue of morality which must be stated.

Large institutions, either State or those in the community are not like our small Community group homes, and they are not like the homes you and I -- any of us here -- live in.

I can be sure that you and I -- all of us here -- undoubtedly live in very different ways, in very different homes. We have single family homes, large and small; and live in apartments; we live in lake homes; we live in town houses; we live in condominiums.

We live in many styles. What we do not live in -- those of us who have choices -- are large, congregate settings.

There are only two times in our lives that those of us with choices live in large, congregate settings -- in our college years, a time when most of us left dormitory living as quickly as possible; and the other time we -- those of us with choices -- lived in large congregate settings was in the Army, and then only briefly, because even the Army knew that people who have other choices would not stay long in a system which used large, congregate housing.

Although all of us here live in many ways, in many styles of housing, not one of us here beyond brief college and Army days ever chooses to live in large, congregate housing.

Why don't we ever choose large, congregate housing? Remembering my dormitory, I found it dehumanizing to have so few choices; I was bothered by the lack of privacy; I felt an isolation from the neighbors around the building.

It becomes a moral issue -- a matter of simple human and civil rights.

We, who are the able majority, cannot choose a style of living for the vulnerable minority of mentally retarded people that none of us ever chooses for him or her self. I cannot say that a life style that's not good enough for me *is* good enough for my son.

As a matter of morality, of fairness, of human and civil rights, we cannot choose by our funding large, congregate living arrangements for the vulnerable among us.

S. 2053 would make a positive difference in the lives of mentally retarded people!!!