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Honorable Lowell Weicker, Jr., Chairman

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Mr. Chairman, members of the Subcommittee and distinguished guests.

It strains the credulity of most people in our society when they're told that a method of service delivery that has existed for over one hundred years has not been working and should be abandoned. In fact the value of large custodial congregate care environments for people with mental retardation was challenged and found wanting by the very people who first suggested it, most especially by Dr. Samuel Gridley Howe, its pre-eminent advocate. In 1874, twenty-six years after he encouraged the opening of the first institution for people with mental retardation, Howe had this to say in his report of the Superintendent to the Trustees of the Massachusetts School for Idiotic Children:

> Now the danger of misdirection in this pious and benevolent work is that two false principles may be incorporated with the projected institutions which will be as rotten piles in the foundations and make the future establishments deplorably defective and mischievous. These are, first, close congregation and, second, life-long association of a large number of idiots. Whereas the true sound principles are separation of idiots from each other and diffusion among the normal population. For these and other reasons, it is unwise to organize establishments for teaching and training idiotic children upon such principles as will tend to make them become asylums for life. Even idiots have rights which should be carefully considered. At any rate, let us try for something which shall not imply segregating the wards in our classes, removing them from our sight and knowledge, ridding ourselves of our responsibility as neighbors, and leaving the wards closely packed in establishments where the spirit of pauperism is surely engendered and the morbid peculiarities of each are intensified by constant and close association of others of his class. (U.S. Department of Health, Education, and Welfare, 1976).

For over a decade we have been trying to get community residential alternatives to replace our outdated institution system. We have not been terribly successful. One reason for our lack of success is that funding streams in this country support existing programs, and secondly, a body of mythology has developed about who people with mental retardation are, and what they need.

On a professional level, I worked for many years in a large Iowa institution, as Executive Director of a smaller, private community-based institution (also in Iowa), and as Director of two major divisions in a totally dispersed community program in eastern Nebraska. I have, therefore, worked in every model of residential and support services that exist today for children and adults with mental retardation. Those experiences, combined with my travels to other countries as a member of the International Relations Committee of the National Association for Retarded Citizens, qualify me, I believe to make the following observations:

1. Unequivocally, there is no better place to serve citizens with mental retardation than in their home communities, preferably in their natural homes. Few if any resources can be made available in congregate care residential environments located many miles from one's home that could not have been made available in the person's home community. For example, when people need tertiary medical care in our institutions, they are referred to hospitals in the community. This historic problem has not been identifying or creating resources, but paying for them.

2. Some people have to leave their homes. The sad reality for many families when that happens is that they must send their loved ones hundreds of miles away to get the same services that could have been provided in their home community _if_ small residential alternatives had been available. It is true that congregate care has existed for 130 years and has served about 2 - 3% of our citizens with mental retardation, but the reason it exists is because no other choices are available. Unfortunately, the existence of such service systems over time is then used to justify their perpetuation, indeed their growth, into the future.

3. When we take children and adults far away from their home towns and keep them in those distant residential alternatives for long periods of time, they usually remain there. Very few people return to their homes. Worse, the home communities lose a sense of ownership for them.

Clearly, there are times when children and adults with mental retardation must have alternative residential services. For example, death or serious illness of one or both parents, divorce in the family, old age of the parents, emancipation of young adults with mental retardation ---all of these, as well as combined disabilities (physical or behavioral) may require a person to leave his/her home. If we are to avoid a custodial, terminal approach to services, people must be kept close to home and given intensive help to make service provision as short as possible. If we don't the maxim "out of sight out of mind" would prevail.

4. It has been said that mentally retarded people should "live with their own kind." It has also been said that mentally retarded people should be placed in large, congregate living environments in order to be educated or trained. The two statements contradict one another. People with mental retardation, like the rest of us, learn through imitation of the people around them. If we are to help people with mental retardation reach their maximum potential and lead lives which are as nearly normal as possible, we must place them in settings where they are surrounded by role models who are as nearly normal as possible. They cannot be exposed twenty-four hours a day, seven days a week, year in and year out, and avoid imitating the behavior of other people whose behavior is considered "deviant" by society. Under such circumstances, when people with mental retardation are <u>not</u> with their own kind, are not with the rest of us in society, how can appropriate learning occur?

   While our goal should never be to make mentally retarded people "normal," or like everybody else - because that is regimentation - it should nevertheless be our goal to make available to them the same conditions of everyday life that are available to the rest of us.

What are some of the assumptions we make about our fellow citizens with mental retardation? First, we assume that the institutions in which they live are the repository of highly specialized, technological medical services. While most institutions do employ some medical professionals and para-professionals, and while they may employ some ancillary personnel under the direction of the primary care physician on the staff, the reality is that they have few if any tertiary care medical specialists on staff. Most institutions have one or two primary care physicians and the residents of those facilities are transported many miles from the facilities to receive specialized medical care.

Another commonly held belief is that all of the residents of institutions in America are medically fragile, near death, or severely behaviorally disordered. As Dr. McGee has pointed out, there is no one living in our institutions today--no matter how severe their mental retardation or associated disabilities--who does not have a twin (in programmatic terms) being served successfully in a community based program. More importantly, the needs associated with mental retardation requires a medical environment. These are not sick people. This is not a medical problem. This is an educational problem.

In that regard, I call to your attention another assumption, which is that children and adults with mental retardation require an artifical environment of some sort in which to receive training and education, and that such an environment has been demonstrated to be effective. We have virtually reams of research which tells us that learning through imitation and role modeling are extraordinarily powerful avenues of learning, particularly for people with severe or profound levels of retardation who do not have the usual ability to learn through reading or understand very abstract concepts. People with severe mental retardation may have related physical disabilities such as a hearing or vision loss, or sensory-motor deficit. This makes it difficult for them to receive information and their severe level of mental retardation restricts their ability to comprehend the information they receive. What they <u>can</u> do is imitate us. However, when we isolate them from normal models in an environment where most of their models are people who do not behave normally, and are surrounded by sights and smells and sounds which don't even approximate a normal home, place of work, or recreation setting, how can we expect them to become more like the rest of us, to join the human family?

The next assumption was prominently evident in the recent Supreme Court Pennhurst decision. A key element in the high courts' decision was the presumed inordinate cost of providing appropriate treatment in the least restrictive alternative (see for example pp. 4367 and 4369 attached opinion). Such an assumption stems from the commonly held belief that all children/adults with mental retardation present medical problems (the image of a profoundly handicapped child curled into a fetal position comes to mind), that these are no economies effected when someone moves into a community program, that the severity of the condition is lifelong, and that there is no cost to provision of services in our state institutions. Relative to the latter, the supreme court refers to .."the high cost (for the states) providing "appropriate treatment' in the 'least restrictive environment..' and 'the fact that Congress granted to Pennsylvania only $1.6 mission in 1976, a sum woefully inadequate to meet the enormous financial burden of providing "appropriate' treatment in the "least restrictive' setting, confirms that Congress must have had a limited purpose in enacting section 1010." With all due respect, where does the court believe the burden of maintaining people in institutions lies now?

The all too frequent supposition seems to be that the $30 - 40,000 per year it costs to maintain each resident in our institutions, is not real because it isn't paid with state dollars.

The failure of Title XIX funds to follow the person from the most expensive to least expensive services has forced us to offer only the most expensive form of service - that offered in our institutions.

The savings realized by encouraging families to maintain their handicapped member, the use of existing housing rather than massive construction costs, the use of community YMCA's hospitals, churches, and the economies that derive from letting local agencies provide services have been undermined by the infusion of Title XIX into institutions and the predictable reluctance of states to shift state dollars to develop community alternatives. Even in my state, Kentucky, where Governor John Y. Brown, Jr. and Secretary of Human Resources Dr. Grady Stumbo totally support community programs (see attached press release), our community dollars are outnumbered 6 to 1 by institution dollars, despite a ratio of 8 community clients to every institution client. Thus we face the dilemma of institutions being at capacity with nowhere for their residents to go because no community alternatives exist. Let the money follow the person. We must let the states develop alternatives to 24 hour, seven day a week residential care located hundreds of miles from the family's home.

Another assumption frequently made is that a significant number of people are receiving residential services in institutions. At its peak no more than 3% of all persons with mental retardation have been living in our institutions. As noted above, however, our resources support the most restrictive, comprehensive services rather than more individualized forms.

I must confess to a personal motive for wanting to accelerate our adoption of a "support, not supplant, the natural home" philosophy. I have attended a number of meetings involving representatives from other countries over the past few years as a member of the United States parent's group, the National Association for Retarded Citizens. Their International Relations Committee has hosted a number of significant conferences in which western nations, including our own, have been made to look rather foolish by the so called "third world" or underdeveloped" nations. In nearly every one of the western nations, the movement today is to abandon the large congregate residences of the past and provide more support to families in their own homes, and to communities at the local level so that people with mental retardation do not have to be sent hundreds of miles away from home to receive adequate services. The less developed countries obviously have not had to worry about doing away with such a system since they were never able to afford it in the beginning. The great peacemaker Ghandi, probably said it best when in response to some newspaper reporters he was asked what he thought of western civilization. He is reported to have replied: "I think it would be a good idea."