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ABSTRACT

This document is a transcript of hearings conducted in Hartford, Connecticut, before the United States Senate Subcommittee on the Handicapped on the effects of deinstitutionalization of the mentally retarded. The bulk of the testimony was given by Connecticut officials and leaders in the mental health field. They presented evidence and case histories about the progress that has been made in closing mammoth state hospitals and placing the former residents in apartment and group homes in communities throughout the state. They indicated that many of the former hospital patients had made good adjustments and were being accepted by the community. In opposition to the state's official deinstitutionalization policy, parents of more severely retarded children testified that they want some larger facilities for the mentally retarded to remain open. They are involved in lawsuits to stop the state from closing some of the intermediate-sized facilities which they feel are the only realistic living arrangements for their children. They fear that deinstitutionalization would lead to ridicule and abandonment in a community setting. (The hearings were a prelude to eventual consideration of reauthorization of Title IX legislation.) (KC)

CARE FOR THE RETARDED, 1981

HEARINGS

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

NINETY-SEVENTH CONGRESS

FIRST SESSION

ON

OVERSIGHT ON THE EFFECTS OF DEINSTITUTIONALIZATION OF MENTALLY RETARDED CITIZENS

APRIL 14 AND 15, 1981
HARTFORD, CONN.

Printed for the use of the Committee on Labor and Human Resources

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TUESDAY, APRIL 14, 1981

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, D.C.

The subcommittee met, pursuant to notice, in the Judiciary Committee hearing room, State Capitol Building, Hartford, Conn., Senator Lowell Weicker, Jr. (chairman of the subcommittee) presiding.

Present: Senator Weicker.

Senator WEICKER. In recent weeks the Senate has shown itself to be willing to recognize the special needs of citizens with disabilities. As chairman of the Senate Subcommittee on the Handicapped, I am pleased with these early indications of support.

However, it must also be noted that at no time in the brief history of Federal support for education and training programs for handicapped children and adults has there been as strong a challenge as there is today to substantially reduce Federal funding and monitoring of such programs.

It is now more important than ever that a record be compiled of how a system of services for retarded people is set up and how it is working. I look to these 2 days of hearings to establish such a record.

These hearings are intended to seek the views of parents and professionals alike on the opportunities for mentally retarded people and what action might be taken by the Congress to improve or expand needed services.

I am very pleased that a wide range of persons concerned and committed to meeting the needs of retarded citizens have accepted an invitation to share their outlooks with us. The issues we will deal with today and tomorrow are extremely important.

Many of us are becoming aware that the needs, aspirations and sensitivities of individuals who are mentally retarded are similar to those of other people. It was not until 1972, less than 10 years ago, that a Federal court established the right to an appropriate public education for all retarded children.

In 1973, with the passage of the Developmental Disabilities Assistance and Bill of Rights Act, Congress accepted the principle that all retarded persons have the potential for learning and growth and established the right to habilitation that is least restrictive of the person's personal liberty.

The strength of research and developing technology continues to raise our expectations concerning the abilities of retarded people and what they can achieve. It is my hope that the next 2 days of

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testimony will challenge our vision about people and the concepts of independence and dignity.

At this time, the Chair would like to enter into the record statements by Senator Orrin Hatch of Utah, chairman of the full committee and Senator Harrison Williams of New Jersey, and to also acknowledge the presence of Nancy Zollars of Senator Williams' staff, and Chris Lord of Senator Hatch's staff.

[The prepared statements of Senators Hatch and Williams follow:]

PREPARED STATEMENT OF SENATOR HATCH

Senator HATCH. As we know, all persons residing in the United States are guaranteed basic human and civil rights by the U.S. Constitution as upheld by the Supreme Court. Unfortunately in the past, the application of these rights has not been universal for all, particularly the handicapped.

Even though the individual rights of people were guaranteed by the Constitution, this has not always prevented discrimination against specific segments of the population. History has witnessed and documented much discrimination. Originally, the handicapped were thought incapable and removed from society. Thus, the basic principle of due process was denied along with their opportunity to live as normally as possible.

During the 1970's, a new dawn arose in America. The individuals with characteristics that differed from those typical of the rest of the population became the focus of the "handicapped movement." People began to recognize the handicapped person's contribution to society. The disabled were allowed to exercise their rights in a responsible manner nd live in their respective communities. Deinstitutionalization and normalization became a viable alternative because Federal, State, and local governments joined with private citizens to access support services for handicapped persons.

However, in the midst of all this change, the availability of appropriate housing and services for handicapped citizens has presented a major obstacle in pursuit of their right to choose a place to live and be provided with services in his or her community. Because of this oversight, the provision and protection of the rights of persons with handicapping conditions has become a relevant undertaking in the legislative process of this country and throughout the world.

During the past few years, a number of innovative and effective provision for rights and services has been enacted along with legislative mandates for their enforcement. Our disabled citizens have gained much visibility and support. As a result, many previously "closed doors" have been opened for the handicapped. I am proud to have played a significant role in this movment.

In the process of becoming recognized, the handicapped population of America has asked to be granted the following: The right to services in the local community; the right to vote; the right to open communication; the right to acquire and dispose of property; the right to marry and have children; the right to have a fair trial for any alleged offense; the right to engage in leisure time activities; the right to receive such special training, rehabilitation, guidance, counseling, and education as may strengthen his/her ability to exercise these rights with a minimum of abridgment; and the right to choose a place to live in the least restrictive environment suitable to individual needs.

I am pleased that these field hearings have been organized to address the most important of these rights—the right to achieve maximum growth and skill development through placement in appropriate housing, educational, and social service programs. I commend my colleague, Senator Lowell Weicker, for his perceptiveness and determination to address the needs of the mentally retarded. Together, we must all accept the challenge and assist in the national effort to improve the lives of our country's largest minority, America's 40 million disabled persons.

PREPARED STATEMENT OF SENATOR WILLIAMS

Senator WILLIAMS. It is a great pleasure to welcome the distinguished witnesses to these Subcommittee on the Handicapped hearings in Hartford, Conn. While I cannot be present personally, I have anticipated these hearings with great interest and expectation. It is a great credit to our distinguished subcommittee chairman, Senator Weicker, that the first hearings of the subcommittee in the 97th Congress are for the purpose of exploring the issue of deinstitutionalization of handicapped people. I am hopeful that these 2 days of hearings will provide a sound basis for the development of clear and comprehensive national policy on the issue of deinstitutionalization.

This subcommittee has a distinguished history in forthrightly expressing the needs and protecting the rights of handicapped citizens. The Education for All Handicapped Children Act has received bipartisan support in the Congress and national support across the country. This law has resulted in thousands of children receiving appropriate education in public schools, often for the first time. The Rehabilitation Act and amendments is designed to train handicapped people, with the most severely handicapped people having a priority for this service, to work and live independently. Both these laws are particularly germane to recall today because the services they provide have actually prevented the institutionalization of many people. These Federal laws also insure that services will be availnble when people emerge from institutions to live in community homes.

This subcommittee also authored the Developmentally Disabled Assistance and Bill of Rights Act. This law helps to define the right to "appropriate treatment, services, and habilitation * * * designed to maximize their developmental potential * * * in the setting least restrictive of the person's personal liberty."

Our subcommittee therefore comes to this hearing with n substantial investment in the issue of deinstitutionalization, and ready to learn what the experts and parents gathered here can teach us about further needs and further action we can take to continue our commitment to protect the rights of this minority population and provide the services they require to lead full, productive lives.

Senator WEICKER. As the first witness before the committee, I am delighted to have with us the Governor of the State of Connecticut, the Honorable William O'Neill.

STATEMENT OF HON. WILLIAM O'NEILL, GOVERNOR OF THE STATE OF CONNECTICUT

Governor O'NEILL. Good morning, Senator. It is my pleasure to welcome you and your subcommittee home to your State of Connecticut, and to give you brief opening remarks for your hearings.

I share your concern for these special people. We in Connecticut are proud of our State's pioneering role in the development of effective services for mentally retarded persons.

We have come a long way from the days when placement in a training school was regarded as the only alternative available to parents of handicapped children.

In the 1960's, it was our State which first developed the regional service system that ultimately became a model for the Nation. This regional system recognized and responded to a wide range of needs and capabilities of our retarded citizens.

I can point with pride to a growing range of services available to retarded people in Connecticut—training schools for the most severely handicapped; the regional programs which include special daytime services; and array of residential programs within the regional center facilities, group homes, community training homes, supervised apartments, and independent living.

The efforts of our State to provide this range of residential and program options to retarded citizens are an excellent example of the innovation and progress that are part of the Connecticut heritage.

However, our job is not at an end. We must continue to expand these responsive programs so that they can be made available to each and every person who needs them. This is a challenge for all of us at the Federal, State, and private sector levels.

First, it is a challenge to the Federal Government to continue to provide funds to help in the development and operation of first-class residential programs, primarily through the medicaid program.

There are further challenges to the Congress to maintain the identity of programs for the developmentally disabled within the Federal bureaucracy, and to develop national standards and funding formulas to support the development of a wide range of services for mentally retarded persons, no matter where they live.

Next, the State of Connecticut will be challenged to continue to improve and expand services to its retarded citizens in the face of massive cuts in Federal dollars coming to our State, and in the face of our own limited tax revenue forecasts.

In spite of the discouraging fiscal situation in our State, the budget I proposed for fiscal year 1982 includes an increase in the budget for the Department of Mental Retardation from $87.7 million in the current fiscal year to nearly $94 million next year.

This is an increase of more than $6 million or more than 7 percent. The recommendation for additional funding includes:

Funds for 100 new positions to allow the opening of the new Bridgeport Regional Center and the Clifford Street Transitional Living Facility in Hartford;

Continued funding of 173 additional positions to improve the intermediate care facility program. These were originally added to the Department's current-year budget by the Finance Advisory Committee last December; and

Capital funds for the renovation of several cottages at the Southbury Training School so that they can be certified as intermediate care facilities to provide more individualized programs to residents.

There is one final challenge—to the service providers and advocates of Connecticut. They must work together to develop innovative ways to finance and deliver the additional services that are needed by retarded citizens.

In this period of fiscal retrenchment, it is not enough to point out needs and advocate solutions that require massive spending by the State and Federal Governments. We must now explore public-private partnerships more fully and, whenever possible, pool our efforts and our resources to improve the quality of life for retarded persons and handicapped citizens in our State.

It is a privilege for me to endorse this public hearing as an educational and fact-finding project. I sincerely hope that it leads to further constructive dialog among all parties for the benefit of our retarded citizens.

Senator, thank you very much for the opportunity to appear before you this morning.

Senator WEICKER. Governor, thank you very much for your testimony.

Governor O'NEILL. Thank you.

Senator WEICKER. The next witness to appear before the committee will be the Congressman from the Fourth District of Connecticut, the Honorable Stewart McKinney.

Good morning.

STATEMENT OF HON. STEWART B. McKINNEY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CONNECTICUT

Mr. McKINNEY. Mr. Chairman, I appreciate the opportunity to appear before the Subcommittee on the Handicapped to express my views on the current level of care and services for the mentally retarded in Connecticut and the Nation.

Over the past two decades, the policy of institutional custody for the mentally disabled in this Nation has been virtually eliminated in favor of complete treatment and rehabilitation in the community.

As you know, this transition has occurred with the goal of universal community care in mind. Today, however, it is clear that this noble goal has produced a fragmented, uncoordinated, and even harmful mental health delivery system which mandates placement of many patients in community settings and encourages frustration and anger on the part of all those affected.

In the next decade, therefore, it is my hope that we can bring about a moderation of the emotional rhetoric on this matter to provide mentally disabled citizens the option of choosing the most appropriate and beneficial form of treatment.

In 1963, President John F. Kennedy presented what was to become a national objective for the treatment of our Nation's retarded citizens: The transfer of the mentally disabled from large State institutions to small community treatment centers.

This approach has been applied primarily in the four areas of public social policy: Adult criminal justice, juvenile delinquency, mental health, and mental retardation. In all four areas, policies and programs are carried at Federal, State, and local levels.

Treatment of the mentally disabled, as designed by the Kennedy administration, was a massive reform in the delivery of services. The Kennedy goals were threefold: To move treatment centers from State hospitals and training schools to community facilities; to prevent the causes of mental retardation; and, to intensify efforts to discover the causes of mental retardation.

Upon the recommendation of the Joint Commission on Mental Illness and Health, the core of that plan became the community mental health center. The community mental health center was designed to provide a broad range of services intended to replace State institutions.

Specifically, the community mental health center goals were: Prevention of unnecessary hospitalization; curtailment of the length of hospital stays when it has been required; and the assimilation of patients into the community for rehabilitation. Both the representation of social reform and the realization of budgetary savings earned Kennedy's program swift, bipartisan support in Congress.

The refinement and expansion of the Kennedy plan has continued in a rapid yet uncoordinated manner since the enactment of the Community Mental Health Centers Act 17 years ago.

In subsequent years, five Presidents have endorsed the concept and goals of the program. Federal initiatives helped solidify this approach as the dominant theme in the care of the retarded.

In later years, other Federal programs, such as medicaid, supplemental security income, vocational rehabilitation and developmental disabilities, have been enacted or amended to allow more mentally disabled persons to live and be treated in their communities.

In addition, Federal district court decisions have mandated that States direct their rehabilitation efforts into the community treatment centers and away from State institutions.

In *Wyatt* v. *Stickney*, a Federal district court in Alabama ruled that the mentally retarded had a "constitutional right to treatment in the least restrictive setting necessary" and in *O'Connor* v. *Donaldson* the Supreme Court ruled that a State cannot constitutionally confine a "nondangerous person who is capable of surviving safely in freedom without offering treatment to the individual."

I wholeheartedly endorse the aspirations and objectives of the community mental health center movement. I do so in the belief that, where feasible and appropriate, community care is the most proper and humane form of treatment for the mentally disabled.

However, upon examination of the current status of community care facilities and programs nationwide, it is clear that the implementation of these original goals has verged upon disaster.

This serious lack of progress in attaining national objectives for the mentally disabled is causing hardship, injury, and in some extreme cases, even death.

There are three basic faults with the current treatment delivery system for the mentally disabled. First, there is a critical shortage of community treatment centers. Second, discharged patients are not being rehabilitated in the community and thereby causing unnaturally high readmission rates to State hospitals. Finally, the use of nursing homes as a substitute for community care facilities or hospitals is highly unsatisfactory.

The appalling shortage of community rehabilitative facilities is the primary shortcoming of the current community treatment of the mentally disabled. As a result of Federal initiatives, rapid discharges of patients from State hospitals into the community took place from 1955 to 1975, causing a 65-percent reduction in the census of residents at State hospitals.

Unfortunately, Mr. Chairman, the broad spectrum of community services needed to suitably care for the newly discharged patients has not been established. As a result, patients were abandoned to a neglected and uncertain existence.

A 1977 General Accounting Office report on the mentally disabled—defined therein as the mentally ill and the mentally retarded combined—stated:

> Many mentally disabled persons have been released from the institutions before sufficient community services and facilities were available and without adequate planning and followup. Others, enter, remain in, or reenter institutions unnecessarily

While many mentally disabled persons have been released from institutions and placed in group homes, foster care homes, and supervised apartments, with a satisfactory range of services, others have not fared as well.

The General Accounting Office report described many community residences as "overcrowded, substandard, and dirty facilities without provision being made for needed services." Importantly, the Government Accounting Office report found that these problems occurred in "all of the States we reviewed. Studies done by others identified this problem in other States."

In extreme cases, Mr. Chairman, the poor condition of a boarding home due to a lack of Federal and State minimum standards, and inadequate support staff has lead to death for some residents. In 1980 and early 1981, a total of 64 residents of several New Jersey boarding homes perished in fires. According to preliminary reports of the U.S. House of Representatives Committee on Aging, "most victims appeared to have been recent residents of State institutions for the mentally impaired or retarded." We cannot allow patients to be discharged to facilities of such poor quality which may endanger their health and well-being.

The second glaring weakness of the current method of community care is the significant increase in readmissions to State hospitals. According to a 1978 Scientific American article,

> * * * admissions to State hospitals increased from 178,000 in 1955 to a peak of 390,000 in 1972 and had declined only 375,000 by 1974. Moreover, a growing proportion of these admissions were readmissions, with about one-half of the released patients readmitted within a year of discharge.

While the Department of Health and Human Services no longer collect admissions data from State institutions, a study conducted by the National Association of Superintendents of Public Facilities for the Mentally Retarded stated:

> The primary reason for the readmission was a lack of community services such as living accommodations, comprehensive services and followup. The failure to adjust to community living and community rejection were also cited as factors.

This readmission syndrome reached the absurd in Nebraska where 12 patients had been released and readmitted a total of 127 times and 1 patient has been readmitted 27 times. I point this out only to present the lack of comprehensive, coordinated and effective nationwide community rehabilitation system.

Finally, the use of nursing homes has, in effect, transferred patients, not to a community setting, but from one institutional warehouse setting to another institutional warehouse setting.

The National Center for Health Statistics showed a 48-percent increase in the number of nursing home residents with mental disabilities from 1969 to 1977. One of the prime goals of the Kennedy reforms was to place patients in small, community-based homes.

However, a study by the Department of Health and Human Services concluded that:

> * * * more than 50 percent of the nursing home residents were in facilities with 100 beds or more and about 15 percent were in facilities with 200 beds or more.

In addition, numerous incidents of questionable practices have emerged concerning the unsupervised care received in skilled nursing facilities and intermediate nursing facilities. The 1977 Government Accounting Office Report stated:

> * * * many of these are not staffed or prepared to handle the developmental or psychiatric needs of the mentally disabled. Some did not meet safety or patient care standards. Some were so large, in effect, that persons were moved from one institution to another.

The net effect of this policy is not a community environment conducive to rehabilitiation, as President Kennedy outlined, but another form of an institutional environment with substandard levels of care.

Clearly the appalling lack of necessary community services, the extraordinarily high hospital readmission rates, and the extensive use of improperly administered nursing homes indicates that the goal of rehabilitation in the community has not been accomplished.

Because the responsibility for the mentally disabled is generally fragmented and unclear many have suffered needlessly. I am very concerned that under the guise of community care many States are using a poorly written Federal policy and the potential for budgetary savings to clear institutions of patients and "dump" them in the community where they are without even minimal services.

In short, we have moved from institutional warehousing to community warehousing. Since this policy can no longer be tolerated, we must act to restore the use of State hospitals when community facilities are unavailable. This option, if not the most desirable, is certainly more humane than allowing the mentally disabled to be released to a life of uncertainty, unspeakable squalor, and possible death.

Mr. Chairman, I want to reiterate my conceptual support for the community mental health center reforms. Where appropriate and feasible, they represent the best possible care for the retarded.

However, premature implementation of total deinstitutionalization is irresponsible, immoral and a disservice to those retarded citizens it intends to serve.

While analyzing this issue my goal will be to allow specific treatment for an individual to be determined not on the basis of ideology, but according to that individual's need for services.

While individuals should not be placed inappropriately in institutions, neither must they be dumped indiscriminately into the streets. The States should maintain a full range of high quality comprehensive community and institutional services in order to best meet the needs of the mentally disabled.

With this in mind, I have solicited comments from mental health directors, professional associations, parent groups and other interested parties to determine what is necessary to achieve this solution in an equitable manner.

My statements today are not for the purpose of criticizing any group or any organization but to point out how far we have strayed from our original intentions. Nor is it my purpose to suggest a radical deviation in our national policy for the mentally disabled.

Rather, it is my hope that the community mental health system can continue in a more rational and reasonable manner, providing the greatest possible alternatives for mental health care and services.

While it cannot be said that we have failed completely, it can be suggested that the way we are proceeding is unsatisfactory. We can do better and for the sake of those we serve, we must.

Senator WEICKER. Congressman, thank you very much for a very thoughtful statement. Both you and I are coming home today, in effect, being here in the State capital and the State legislature. Both of us have seen the prominant rôle played by the State of Connecticut over the years in the matters that are the subject of our attention today.

I wonder, while we have you here, as to whether or not you might comment on the funding situation, at least as you evaluate it, as it arises in the House of Representatives.

I know that we went through this exercise in the Senate and, unfortunately, whatever directions we go in, it all costs money.

I know the original budget, as it came before the Senate, was, in real terms, a 10-percent reduction. Thanks to Chairman Hatch and others on the committee, we were able to restore some of those funds, not all of them.

Now, the matter lies in the lap of the House, and I was wondering whether you have any ideas as to what direction, from a funding point of view, is going to be in the House.

Mr. McKINNEY. I think in the pragmatic world of today, the direction is going to be down. The House, will restore some funding but I think that the funds are going to be less available from the Federal Government in years to come.

The States' effort is going to—and I congratulate Connecticut. Connecticut's care and treatment of its mentally disabled citizens is an exception. I got interested in this because of the horrors I saw in Washington, D.C., as ranking member of the District of Columbia Committee.

But I think it is all the more reason why the dollars are going to have to be spent more carefully, and there is a direct correlation, Mr. Chairman, between the proper care in the best circumstances and the amount of money that is spent in searching for the best possible treatment.

If you put those people in community facilities who are best served, you are using the dollars best, and those who cannot really be very well served in the community setting who are in an institution, are using the dollars best in that course.

So, there is a correlation between what is going to happen in Washington, which is obviously a reduction in funds; the question is how can we make it least harmful. I think we have to be very careful that we take care of people in the best possible setting for their particular illness.

Senator WEICKER. I am glad to have your comments because I think it really just accentuates the point of these hearings, which is that in a time of reduced funding what is necessary is that we all work together and we can't have people going off in different directions.

We all want to achieve the same end result but, whereas in the past, this particular segment of our society could look upon the Nation as a whole as having an open and giving heart, it is not so.

I think we are talking about an entirely different arena and it impresses upon me and, I hope, others the necessity to get the most out of the dollars that are there, but more particularly, to present ourselves as a united group.

That doesn't mean to say that we all don't have different ideas, but as a united group, not one that is sparring among ourselves.

Mr. McKINNEY. I agree. The real thing here is how can we serve the most the best for the least amount of money. Everybody is broke. Here in the two chambers of this building they are dealing with a $40 million State deficit.

In Washington, D.C., even with the President's budget, the new debt ceiling, I gather, is going to be $1,070 billion. I can't even say it.

So, the problem is how do we do the best job possible for the mentally disabled. That, really, is the whole issue.

Senator WEICKER. Thank you, Congressman. It is good to have you with us.

Mr. MCKINNEY. Thank you, Mr. Chairman. It is good to see you.

Senator WEICKER. At this time the committee will have presented an overview and history of present services by Gareth Thorne. Commissioner Thorne will have members of his staff from the State department of mental retardation office and the regional center to share part of his presentation time.

Commissioner Thorne, I will let you handle this in any way that you deem most appropriate.

I might add that during the course of these hearings, because this is not my hearing, it belongs to everybody in this room, if there are those that either have questions or have a point they want to get across, if they will so put it in writing and give it to a member of the staff I can assure you your particular question or your particular point will be made during the course of the next 2 days.

Commissioner Thorne.

STATEMENT OF GARETH THORNE, COMMISSIONER, STATE DEPARTMENT OF MENTAL RETARDATION, STATE OF CONNECTICUT, ACCOMPANIED BY LYNN GRAVINK, DEPUTY COMMISSIONER; ROGER McNAMARA, SUPERINTENDENT, MANSFIELD TRAINING SCHOOL; MICHAEL BELMONT, SUPERINTENDENT, SOUTHBURY TRAINING SCHOOL; DANIEL O'CONNELL, SUPERINTENDENT, HARTFORD REGIONAL CENTER; EVERETT O'KEEFE, SUPERINTENDENT, JOHN DEMPSEY REGIONAL CENTER; GEORGE DUCHARME, SUPERINTENDENT, TOLLAND REGIONAL CENTER; AL DODSON, DIRECTOR OF EVALUATION AND STAFF DEVELOPMENT; GEORGE MOORE, SUPERINTENDENT, CENTRAL CONNECTICUT REGIONAL CENTER; BILL DOWLING, SUPERINTENDENT, NEW HAVEN REGIONAL CENTER; TOM SULLIVAN, SUPERINTENDENT, SEASIDE REGIONAL CENTER

Commissioner THORNE. Senator Weicker, I am very delighted to be here today. Thank you very much for asking myself and allowing me to bring along members of my staff.

My comments will be very brief. My thought was that it would be much more important for you to hear from people who were actively engaged in providing services within our various facilities and monitoring such services in our central office.

So, I am going to make a few comments. Also, I will show a few slides just simply to set the pace. You have a copy before you of these plates that will be shown on the screeen so that it will be easier for you to see them, and I am sure at that time we will have to ask them to shut the television lights off.

One of the things I want to open my comments with is that I think that Connecticut is extremely fortunate to have a collection of exceedingly capable professional people to operate its various services and give direction to the department's program.

You will be hearing from some of these people today and I am sure you will be very pleased to hear what they have to say.

With me, to my left, is Marilyn Gravink, who is the deputy commissioner for the department of mental retardation and she will be sitting with me here this morning. We will bring witnesses, probably singly and sometimes in groups of three, to the table so that we can expendite our program.

To start off, I would just like to comment that Connecticut, back in the early days of thinking about where to go with reference to the mentally retarded, gave some very significant thought at a time when there was a transition in the middle fifties up to the early sixties from the concept of institutionalization as the principal form of programing, to the concept of returning people to the community who could be returned to the community and a concept of retaining in the community those people who could be retained in the community for appropriate services.

As a consequence, Connecticut underwent an evolution of change of service location, to some extent, earlier than most States went. This was part of a movement, however. I think the Senator needs to understand that throughout the country there was a movement and it was somehow and in some way related to the civil rights movement as well, where there was more attention being given to handicapped people and minority people.

So, it was part of a whole process in this country in the evolution of change.

The other thing is that we need to bear in mind that prior to the early sixties in this State and in most States the only place where an individual could receive an education, who was mentally retarded, was within a training school, and that is where they got the name training school.

So that we saw the population of "institutions" or "training schools" in the middle fifties and the early sixties a much different population of people simply because many of them were there for the educational purposes because such services were not available in the public school programs.

So that the change of the training school population also came about partly due to the fact that the public schools began to offer special education for handicapped people in the early sixties throughout the country.

Just for the purpose of giving us a quick overview and to set the stage, this is the state of the art in 1960 as far as the State of Connecticut was concerned.

[Slide projections shown.]

We had two facilities—those are green squares—located in two corners of the State: Southbury and Mansfield Training Schools. But this was the time, in 1959, when a new law was passed in Connecticut enabling a new office of mental retardation be created within the health department, which then later became the department of mental retardation in 1975.

Basically, from that beginning we went to 1960, when the decision was, through very careful planning, to divide the State into 12 regions. The purpose of dividing the State, and this was an administrative decision and the boundaries were, in that sense, artificial—there were not staff available for each of these regions, but the idea was to break the State into workable populations, populations where whatever may follow from this concept would be within a reasonable distance of the services that would be envisioned.

And, so, it was predicated on dividing it into regions where services, when established, would be available to people within 20 minutes.

Then, by 1965, and there is one triangle missing. The red triangles represent regional centers and there should be one there for New Haven. By 1965, the concept of the regional program began to evolve into reality and actual construction was beginning on the Hartford region and the New Haven region. The Seaside region had already been established.

The basic thing to keep in mind is that at this time while these regional programs were beginning to evolve, also the department evolved a philosophy and principles of operation of regional programs, of which you have a copy in your materials, Senator.

It is the basic philosophical statement of the department as it relates to services for the mentally retarded. Important to keep in mind is that this philosophy that was articulated in the early sixties has not changed significantly since that time simply because, it is our belief, the philosophy very clearly spells out a system of services that would be appropriate, providing many options, for mentally retarded people.

Also, we felt it very important to be consistent over an extended period of time to allow the establishment of a solid base of service delivery systems. Rather than hopping from one thing to another, develop an idea and stick with it and bring it to its full fruition.

So, by 1970, we saw now that the service programs were beginning to expand so that additional regional centers were open and by this time we saw the emergency of group homes that had been established in the mid-sixties now as a viable resource for providing services to the mentally retarded and allowing many to stay near home.

The regional centers, as you will hear very shortly from other people, the services they offer were the mainstay of this program.

By 1980, at this point in time, the department offered the array of services that are shown by these various symbols, ranging all the way from the training schools, the regional centers, the group homes, supervised apartments, special school district locations, and some new capital programs that were authorized.

These are the funded and staffed programs of the department at this point. And you will notice in the regions there are clusters. In other words, the symbols are seen in every region, showing that the variety of services available is coming along. We would rather see a more rapid pace obviously, but within the funding we feel very comfortable with how we are moving at this rate.

Also, aside from the services the department offers directly, we fund other programs partially or totally and regulate those programs. In this particular 1980 depiction you see not only the services provided by the department but also services that it funds through grant-in-aid and through other funding.

This is very important because part of the concept of the regional system was that the department would catalyze and stimulate the growth of services by the private sector, particularly the nonprofit sector and the communities would come into ownership, as it were, of their own programs.

This particular slide shows the department services direct, the ones it funds and has direct involvement with.

The next slide should actually be superimposed on the previous slide, but in trying to do that I found there were so many dots and marks that you couldn't tell what it was. This slide we feel is a very important slide because it tells the continued involvement of the community based residential type facility and it shows the evolvement of the group homes which are the larger green circles and the little red dots that look like measles are the evolvement of the community training home program, which there are now in excess of 240 such facilities.

This is the backup residential program operated through the private sector, funded and regulated in great part by the Department of Mental Retardation and Department of Income Maintenance and a very important aspect of providing an appropriate place for people to live at home and not have to become institutionalized.

We give grant-in-aid to the various States in the amounts shown here. Some areas of the State—this is a grant-in-aid program which received almost $1 million in grant-in-aid to help them establish community-based services. I won't go over this total chart. You have a copy of it amongst your materials.

But it shows the activities of the State in providing basic grant-in-aid funding through community services programs operated by the department.

Then, more recently, the 605 project which the State now funds directly, services and workshops and so forth for more severely disabled persons. This amount, last year, was $4.4 million allocated to the department and dispersed to eligible recipients.

Basically, we have worked on the whole concept of the evolvement of services throughout the State. I am quickly running through just to show you how these things have grown by the department through the years.

Then, in 1974, we published our own book, the institutionalization booklet in which we outline the goals of the department which, again, are very similar to those of today.

With that, Senator I would like to begin to call the witnesses and if it is all right with you I will arrange to do that.

Senator WEICKER. Any way you deem fit.

Commissioner THORNE. Thank you, sir.

The first witness that I would like to call is Mr. Roger McNamara, who is the superintendent of the Mansfield Training School. Mr. McNamara will speak to the committee on the training schools.

Senator WEICKER. Roger, why don't you step up here. I had the pleasure of being with Roger for an hour or so yesterday afternoon. It is nice to have you here at the hearing this morning.

Mr. McNAMARA. I must confess that I have written at least three speeches for today and discarded all three. It is difficult to compress the amount of history and philosophy that is attendant to the issues, particularly with the training schools.

I would like to also say that I am here on behalf of Mike Belmont, superintendent of the Southbury Training School, and hope that my remarks reflect his views as well.

A theme has begun to develop this morning. I think that theme is, in an era of shrinkage of available dollars how are we going to achieve our goals? I hope one way of achieving our goals is through such a forum as this because recently I have realized that conflict costs more money, a great deal more money than working together cooperatively to achieve our goals.

The conflict itself consumes money that could otherwise be devoted to mentally retarded citizens across the State of Connecticut.

I am also thankful for this opportunity to speak directly to some issues. The first issue I would like to discuss with you is that the training schools have been struggling for years. They are responsible for serving, right now, approximately 2,000 individuals who range in age from 8 years to 80 years, for people with so-called borderline intelligence to persons with catastrophic disabilities.

We have been struggling with political, economic, social, clinical, and legal problems, and struggle to respond to needs and problems of so many people with other problems as well, including blindness, deafness, emotional disturbance, communication disorders, chronic brain dysfunctions.

I would like to try to develop a perspective that problems often discussed as institutions have been deemed the problems in the field of developmental disabilities, but the true problem is larger than a collection of buildings constructed in a certain fashion, located in a specific area of the State that identifies them as an institution.

Certainly there are problems in architecture, problems in staffing, supervision of staff, problems in the level and extent of training programs available for clients and for employees. But I worry very much that we become distracted by problems that are really symptoms, symptoms of greater problems: Public understanding, public support, public sacrifice for handicapped people.

The training schools have been overwhelmed by their responsibilities. Despite their overextended condition, some people have prospered; people have been successfully treated and people have left the facilities for a new life because of the assistance by concerned staff.

Lest there be any doubt in your mind, sir, and to the committee, Mr. Belmont and I, the superintendents of the training schools, are not resisting meaningful, constructive change. In fact, we are insisting on it, proselytizing for it whenever we can.

Deinstitutionalization is an ugly and, because I happen to be a student of the English language, I know that it is an illegimiate word. The phrase community living arrangement is a euphemism for "home." We need more homes, more apartments, schools, jobs, and training programs.

As more homes are created and services are expanded and we don't need to deinstitutionalize developmentally disabled persons, the staff of the Mansfield and Southbury Training Schools will automatically, reflexively, instinctively, if you will, seek out those opportunities for their clients without an order to relocate people from institutions to improved circumstances elsewhere.

The training schools can and should become smaller, clinically manageable, highly specialized facilities. They should be able to offer emergency, short-term care and strengthen a continum of care and habilitation for Connecticut's special citizens. The continuum of care approach appears to offer the most opportunities to people because of the variety of options for individuals and their families.

The generic services of communities must be expanded. General practitioners in all fields must be oriented to the needs of developmentally disabled people. Neighbors must become more accepting and supporting of the fellow citizens with individual differences, and all this will require planning, education, advocacy and, I hope, continual evaluation so that as we gather experience and data we begin to understand where to emphasize programs and services.

The questions that are most sensitive these days, the ones that defendants in lawsuits are advised to avoid are: Must training schools exist; could all mentally retarded persons, especially the severely and profoundly retarded, live safely, comfortably, happily, and meaningfully in the average community in the State of Connecticut?

Unfortunately, these are questions that polarize parents, professionals, and advocates, inflame emotions and distract from what should be our true tasks. The severely and profoundly mentally retarded people can live in communities and they can be safe, happy and productive if they are well supervised, are provided all the habilitative services they need and support services when they have difficulties.

Change is a process. It requires planning, thoughtful planning so we can avoid some of the travesties that have occurred in the mental health field. If we are vigorous, if we are aggressive in community development and we emphasize the security, dignity and opportunities that people living at the training schools should have, in my opinion, the problem will resolve itself.

But, as you said, only if we are creative and cooperative in improving programs and expanding services in the community.

I would like to add this one last thought and that is, as we pursue the dream—and I think we are all trying to pursue the same dream—some of us must articulate a concern that sometimes is unpopular: Is our society healthy enough, stable enough to be trusted to react to, support, and accept developmentally disabled people?

I think that is a matter of conjecture but planning and support, education and advocacy should certainly promote the health and compassion of our society. It is a process. It is not a matter of closing facilities. It is a matter of creating opportunities.

Thank you.

Senator WEICKER. Thank you very much, Roger.

Commissioner THORNE. We are going now to talk about the regional program evolvement and the regional program operation, which is at the heart of the Department of Mental Retardation Service plan and its philosophy.

To present, we will have Mr. Daniel O'Connell, the superintendent of the Hartford Regional Center, followed by Mr. Everett O'Keefe, superintendent of the John Dempsey Center in Putnam.

Mr. O'CONNELL. Good morning, Senator. I am Dan O'Connell. I am a Connecticut native. I have been employed by the State of Connecticut for 18 years. The last 6 years I have been employed as superintendent of the Hartford Regional Center of the Department of Mental Retardation.

I am pleased to have the opportunity this morning to talk to you about some of the services and programs available on a regional basis.

My purpose is to discuss the programs and services of the Hartford Regional Center as an example of the many services which are available within the State of Connecticut, within the Regional System of the Department of Mental Retardation.

I am not submitting this to you as a model, although there are many who feel that it could more than adequately serve as such. What I am suggesting, however, is that the Hartford Regional Center serves to illustrate a variety of activities which have been longstanding within the Department of Mental Retardation and the Office of Mental Retardation.

Admittedly, from region to region you may find that services and programs are packaged differently. You may also find that regional programs are in differing stages of development, depending on their own historical background.

The basic objective orientation which I will share with you is consistent throughout all regional programing of the Department of Mental Retardation and consistent with our own department's plan, project challenge.

My purpose, obviously, is not to duplicate the written material which you have before you. I am hoping possibly to elaborate on it and clarify it, and possibly help you see a regional program in a slightly different perspective.

The major point which I wish to make this morning is that the Hartford Regional Center is much, much more than a residential facility that happens to be located in Newington. It is much more than that.

It is that. And it is a very good residential facility located in Newington, but the Hartford Regional Center really is responsible for much more than that. It consists of a very comprehensive system of programs and services, both residential and day services, which exist as part of a network of human services in operation throughout the Hartford region.

The Hartford Regional Center is very well integrated into the community. It is very well integrated into other professional agencies serving handicapped people in this region. It enjoys tremendous support, both community and professional support, and it also is responsible for meeting the needs of mentally retarded persons on a daily basis. Approximately 600 persons are served throughout this network on a daily basis.

For instance, one service which I would like to explain to you and elaborate upon are the residential alternatives available to persons who need care or assistance in meeting the residential needs of their life in the Hartford region.

The backbone and the basis for the residential program is the Hartford Regional Center residential services located in Newington. This has a capacity for 96 persons. It is a totally certified

ICFMR, intermediate care facility, title XIX certified, has been since 1975, offers a very intensive habilitation and training program, has all of the necessary support services of occupational therapy, physical therapy, psychology, speech services, and so forth, that persons with various handicaps would need.

The Hartford Regional Center residential program consumes approximately 42 percent of the funds allocated to the facility. The next step in a continuum of residential alternatives which exist to people in this region—and this is somewhat typical of what you would find in other areas of the State—is a series of group homes that which throughout Hartford.

Obviously, if you are talking about group home living you are talking about people who are more capable of independence, more capable of self-direction, require less supervision, and require less intensive type of programing. In the Hartford region there are nine group homes with a total capacity of 132 mentally retarded persons.

The homes vary considerably. We have two homes: The J.C. House I in Newington, which was given to us by the Greater Hartford J.C.'s in 1970. Eight adolescents live in that home. We have a similar J.C. house in Glastonbury. There are two adult homes which we operate. Also we have five adult homes which are operated on a private basis in this region, but the basic model is the same; a family oriented, normal home living environment in which people are given varying degrees of independence and support to live in the community.

The next step, if we go from the regional center and talk about people who are capable developmentally are moving into the community group home, the next step in that continuum is the supervised apartment living program.

Hartford is particularly fortunate to have three apartment houses, well integrated discretely throughout the community which serve a total of 59 persons. The apartment houses are typical efficiency apartments which you would find in Hartford. There is either one or two mentally retarded persons living as a team in the apartment. There is one apartment unit in each building which is occupied by staff who serve as a backup to the persons living in the apartment; a resource, a counseling and support system.

Mentally retarded persons pay the portion of their own rent which they are capable of and the agency supplements the difference. The persons engage in very normal community living The interesting thing about the apartment living program—and this is remarkable—is that it was started by Mansfield Training School in 1969.

The group homes which I have just listed in the Hartford region began in the early sixties. The first apartment house opened by Mansfield Training School in Hartford was in 1969. Two others came in 1973 and 1974. So this is a longstanding, very successful program which has been operating in this area for some time.

The fourth step on that continuum which has only recently been available in this region is the ability to provide retarded people who are living in apartments and ready for the next stage of independence, subsidized apartment living. This is subsidized housing available through section 8 of the Housing and Urban Development program. We have a staff member working full time locating housing and arranging for subsidized placement of mentally handicapped people. Presently we have 19 persons placed in that program.

The Hartford Regional Center has a very active community training program in which there are 32 community training homes. Approximately 32 persons are placed in community training homes. We also have a very active respite program in which persons are given respite services or relief at the Hartford Regional Center.

Ten or twelve persons a week are given respite services at the regional center as well as respite homes located throughout the community.

To accept this approach, it is imperative that you accept a basic premise about mentally handicapped people, and that is they are different. They are different from one another to the same extent that you and I are different.

They have differing needs: they have differing abilities, they have differing personalities, likes, and dislikes and it is incumbent upon us to provide a system which accommodates those differences and treats individual people as individuals.

I wish I had time to elaborate upon the host of other services and programs available throughout the Hartford region. There are education programs; we have adult vocational programs, but all are based on the single premise of individuality of the people who we are committed to serve.

I understand fully well that these are very difficult days in public administration and I understand that we are in a period in which possibly a new consensus may be forming concerning the public policy for treatment of handicapped people in the future.

In this particular region, as it serves to illustrate other regions throughout the State, we have a program which has been immensely successful; the base is sound; it is firm and we are very confident that we can continue to build on those successes, allowing adequate public support.

Thank you very much.

Senator WEICKER. Mr. O'Connell, let me ask a question, and I am going to ask this of the witnesses that follow. I suppose I should have asked Roger McNamara the equivalent question.

Is your facility so constituted, so equipped, so staffed that you could take everybody out of Mansfield or out of Southbury and have them develop and progress at your type of facility?

Mr. O'CONNELL. I wished you had asked Roger that question. [Laughter.]

Senator WEICKER. My question to him would be the opposite. In other words, are there those in his facility that should logically be in another type of facility, one such as yours?

Mr. O'CONNELL. Let me begin to answer the question this way. There are about 193 persons from our region who are currently residents of Mansfield Training School. That is the primary population for which the Hartford Regional Center is designing programs; designing services to respond to those people originally from our geographic area. I could give examples of what we anticipate as the future and the need to provide more intensive, more structured programing for those people.

I would say, as the regional center is currently structured and staffed, it would be extremely difficult to provide adequate, comprehensive programing for all persons. I think that there obviously is a level of need and handicap which requires higher staff ratios, more intensive programing and more intensive structure

I think, most certainly, that our system, and our structure could accommodate that. I think it would take more resources. I guess this is what I am saying to you. I think it would take additional resources, but that the structure, in time, could accommodate those persons as well. That certainly has been our objective in what we have been working on for the past several years.

Senator WEICKER. I think you have answered the question. But the structure, the present facilities could not; is that correct?

Mr. O'CONNELL. It would take additional resources.

Senator WEICKER. That is the second point, that it would take substantial additional resources.

Mr. O'CONNELL. Yes.

Senator WEICKER. Thank you very much.

Commissioner THORNE. The next person will be Mr. O'Keefe from the John Dempsey Regional Center, superintendent.

Mr. O'KEEFE. Good morning, Senator.

Senator WEICKER. Good morning.

Mr. O'KEEFE. I am Everett O'Keefe, the original superintendent of the Dempsey Regional Center. I am in my 17th year as superintendent.

The John Dempsey Regional Center was established on November 9, 1964, as the fourth regional center in the State. It was developed in the rural, economically deprived area of Connecticut. The original service towns were the 10 towns of northeastern Connecticut.

During our initial years, it was determined that we should also service the towns of Hampton, Scotland, and Chaplin so that now we service 13 towns.

Prior to our agency's development in 1964, the only programmatic offerings for the mentally retarded in northeastern Connecticut was a 2-week day program in recreation and a 2-week overnight program in recreation offered by the Association for Retarded Children.

This organization had been founded in 1953. In the initial years of our operation we surveyed the area of northeastern Connecticut to ascertain and prioritize the programs that were most needed.

The original program that we determined was needed was a community-based psychological and medical diagnostic service. Originally, the center, when I was asked to go out to be superintendent, was told that there were 60 mentally retarded clients to be serviced in northeastern Connecticut.

Over the 17 years of our operation we have over 1,500 clients who have passed through our agency seeking services. Presently, there is an active caseload of 323. Over the years, our agency, because of its location, has provided many needed services to other clients who are handicapped.

The regional center developed and has continued to develop as a function very integral to the community. The immediate positive response which the regional center in Putnam has received has come from the communities that it services.

There are many reasons, which I am sure you are aware, of why we have received such total cooperation and such a beautiful marriage between the communities we service and our agency.

First of all, as I am sure you aware, our area is depressed, we lack public transportation—I know you can't cure any of these, I am aware of that—but we are the largest human service agency in our area. The citizens of the area have known much devastation over the years through flood, through the loss of industry and the area consistently seems to have the highest unemployment rate in the State.

Today, in 1981, our regional center has become the focal point for a multitude of services for the mentally handicapped. These services have followed the philosophical trend established by the department wherein the programs have been brought to the clients and their families within the community.

There are, today, over 40 infants and young severe and profoundly retarded children in daily programs at the regional center and also in the homes. Twenty-five miles from our agency there are 20 children receiving therapeutic and academic programs within their local community.

The residential population of the agency has grown from zero to 56. We presently have 17 in a group home 10 miles from our agency and we have been working very diligently in developing apartment programs.

Today we have 25 clients in apartments located in three different areas. This has allowed us a great deal of mobilization. We have not expanded our buildings in the past since 1970, but we have been able to mobilize our clients because we have developed what I consider a unique apartment program, not unique to us but unique within the State.

At the present time, and somewhat in answer to your question, I can't unload Mansfield. I have to be honest with you, Senator, but we have taken 11 clients from the large training schools in the State, who are presently in our apartments and 14 of the 25 have come from our own community programs.

In July of this year, and also thinking according to the economy, as was mentioned earlier, our center is going to open its third group home. This further illustrates what I think has been a beautiful and continual marriage between the communities and ourselves.

The home is being purchased by the Association for Retarded Citizens of Quinebaug Valley. It is being funded through Farmers Home Administration. They have a 5-percent mortgage for 40 years. The home will be staffed and run by our regional center.

This will be the first time the Farmers Home has entered into this type of agreement in the State. Our adult programing has always been enlarging. On our own agency grounds we have three workshops where there are 93 clients employed. In Moosup, Conn., 25 miles from our agency, there are 43 clients in programing.

In order to develop community oriented programs for the adult retardees, we have developed what are known as work crew programs. Every day we have several, perhaps 10, crews going out to work in the communities where they provide services to local industries, to restaurants, to stores, private schools and private homes.

In 1979, through a developmental disability grant, we were able to open up a greenhouse and truck farm. The past previous fiscal year, our workshops and satellite workshops have brought to the clients over $150,000.

The agency's service and program growth has consistently developed through the dedicated assistance and cooperation from the Department of Mental Retardation, the Association for Retarded Citizens of Quinebaug Valley and the citizens of the services communities.

Thank you, Senator.

Senator WEICKER. Thank you very much, Mr. O'Keefe. I would also say that one of the other reasons was that the Governor of this State captured the conscience and commitment of the State in this area. That was John Dempsey. That also might be one of the reasons why your situation has worked out as well as it has.

Mr. O'KEEFE. I have always said we mention John Dempsey and God in that sequential order in Putnam.

Senator WEICKER. I know this: I started off in the State legislature in 1963. It certainly was John that brought to my attention this whole area, as a legislator, as indeed he did to the whole State. I think, in any event, it is going to take that kind of leadership at all levels of authority in order to once again prick the conscience of the citizenry as a whole.

Again, I ask you the same question I asked Mr. O'Connell as to whether or not your facility is prepared to take on all residents from your area in either Mansfield or Southbury?

Mr. O'KEEFE. We could presumably absorb some clients but we are not built, as far as our buildings are concerned at the present time, to handle some of the multiacting out clients and some of the other clients that are at Mansfield.

We are able, as I mentioned, in this new group home which will have six clients, some of these clients will be coming from Mansfield Training School to our agency. But, no, we couldn't. And we have a good service agency, the same as Dan told you. We have all types of programs.

As you are well aware, we are limited to time. I think each one of us could go on forever if we had an opportunity, in addressing our own areas. But our area has accepted clients from Southbury Training School. As I mentioned, 11 of these clients went into our group home and are now out in the apartment program.

The evolution is there as we begin but, no, we couldn't, Senator.

Senator WEICKER. Thank you very much, Mr. O'Keefe.

I wonder if I might at this juncture ask Mr. McNamara, Mr. Belmont, who I saw in the back of the room. I wonder if I might ask you both a question in reverse, as to whether or not you have clients in your facilities at the present time who could be in the types of facilities described by Mr. O'Keefe and Mr. O'Connell were such facilities available?

In other words, are there persons in your institutes who you feel should be elsewhere were such a facility available?

Mr. McNamara. I think the answer to your question are unquestionably yes. As a matter of fact, it has only been 2 or 3 weeks since we transferred a client to the Hartford Regional Center.

We have such a large group of people with varying needs and problems. I think there are unquestionably groups of people who have extraordinary medical and behavioral problems that require specialized, highly individualized treatment. If you are to transfer such clients you must develop or relocate staff with the expertise simultaneously. Because people with these problems have been with us, we have developed technologies to respond to them, the technology has to be transferred as well.

Senator Weicker. Maybe I should rephrase my question. Do you have those at your facilities now who could be transferred to these facilities that have been described, the state of the art being what it is today at those facilities?

Mr. Belmont. Yes, in my opinion. Very obviously from the Southbury Training School.

Senator Weicker. The answer is yes?

Mr. Belmont. That is correct.

Senator Weicker. Then what is preventing that transfer of these types of people; lack of facilities?

Mr. Belmont. Lack of beds. I hate to use that term, Senator, but that is the reality of life. When the regional centers do have a bed available for us they do contact us and we do have residents at the Southbury Training School who can benefit from those services that they have.

Mr. McNamara. Also, being redundant, it is not just beds; it is expertise; it is a program designed for people. We have about 965 people at Mansfield. We have referral lists which include literally hundreds of people that could live in a variety of facilities. Our initial goal is to reduce the facility to 450 people.

Mr. Belmont. We also, through our clinical staff at Southbury Training School, probably have an active list of about 250 residents that we have approved for placement just as soon as the bed and the services become available.

Senator Weicker. Thank you very much. I think you have answered the question.

Please proceed, Mr. Thorne.

Commissioner Thorne. The next part of our presentation, Senator, is going to relate to community interaction and talking about interaction with local government, nonprofit organizations and so on, which is very much a part of our service.

To present will be Dr. George Ducharme, who is the superintendent of the Tolland region and Mr. Al Dodson, who is our director of planning and evaluation in the central office.

Dr. Ducharme. Good morning, Senator. Thank you for giving me this opportunity to share with you some thoughts of my work with persons who are mentally retarded. My name is George Ducharme. I live in Granby, Conn. I was born and raised in Willimantic, Conn.

In 1964, I ventured up Route 32 to seek summer employment at Mansfield Training School. That first experience 17 years ago has brought me to this moment as superintendent of the Tolland region of the Department of Mental Retardation.

My message to you this morning is simple, straightforward and personal. The work of community interaction, coordination, and program development being accomplished today in the Tolland region in eastern Connecticut has taken its shape from experiences and a philosophical base I began to learn 17 years ago.

I present to you a process which has and is evolving a solid set of community resources, homes, jobs, educational opportunities, recreation options and other support services for persons with mental retardation and their families.

This process, evolution if you will, is not unique to the Tolland region. It began, as you have heard, many years ago, when public and private advocates joined together to create community options.

The process began in 1966, when Fran Kelly, former superintendent of Mansfield Training School asked me to establish a day camp program using Mansfield Training School resources both for training school residents and community children. This is now the Spring Ledge Day Camp in Willimantic, Conn.

It continued in the establishing, as an employee of the Hartford Regional Center, of a strong community liaison for vocational development in the Hartford region from the year 1978 to the year 1981.

The Harc Shop, the Favarh vocational program in Avon and the North Central Connecticut Sheltered Employment Cooperative were formed during this period.

Working as community services director in the central office of the Department of Mental Retardation from 1971 to 1977, tremendous strides in developing private sector—Association for Retarded Citizens, Easter Seal, Goodwill, and private agency services for children and adults—took place.

The Shoreline Association struggled to hire its first executive and began to blossom. All association programs grew as we worked in partnership with and as program consultant to local ARC units, this in keeping with the stated mission and long tradition of my OMR/DMR Community Services predecessors.

Now I work as superintendent within a newly created Tolland region since 1977. The impetus is the same, to move folks, or better, to keep people in the community in the mainstream of life in Connecticut using resources available to all citizens; doctors, hospitals, schools, parks, workplaces. And, when not available, to create services, in partnership with community groups as State resources allow.

Above all, as a public employee, it is my job to be the strongest advocate possible for persons with mental retardation and their families in my area.

The principles I present which make communities in Tolland Region vibrate with life are perhaps phrased differently, applied differently and have more debate on fine points today, but that are, in my opinion, the same key principles to solid community development presented years ago.

The key principle is local ownership of the program, of an idea, of a service. The key element from which all community development flows is the person who is mentally retarded and that person's family.

The ultimate goal of community development is community helping all of its members reach full potential. I underline "all." What we as professionals in DMR do, as charged by law, to develop a comprehensive array of services for all mentally retarded, is to coordinate, to create options, to work in partnership with, to synthesize, to be the catalyst for, to make others winners, to listen and to communicate.

We do this in order to bring every State, Federal, municipal, and private resource possible together so that persons with mental retardation may emerge as a whole and fully functioning person in his or her own community.

The process of making this occur solidly, not just in surface flash, in each of the 15 towns of the Tolland region, or, in fact, the 169 towns of Connecticut, is plain hard work and time consuming.

The Yankee spirit of individuality translates itself into individual town personalities, desires and services. What works in Manchester may not necessarily work in the same manner in Stafford and Willimantic, in my area. Therefore, the keys of listening to each community, finding its leaders and natural resources, whether they be churches, industry, government, civic clubs, and translating those universal needs and desires of persons who are mentally retarded into that specific community's language is our job.

Here are some specific examples where the skills of keeping perspective, communicating, listening, judging the proper action moment—Piaget called it the teachable moment—coordinating and synthesizing have worked in the Tolland region.

The Tolland region is located in eastern Connecticut. It has 15 towns Its largest town is Manchester, with 50,000 citizens. Its smallest is Union, with 500 citizens. The resources available are plenty: associations for retarded citizens, three; four sheltered employment settings; the Mansfield Training School; the main campus of University of Connecticut and other major resources.

Ways of communication include a leadership forum of all local organizations, a sheltered employment cooperative in eastern Connecticut and a strong active and informed advisory committee. These are the first and continue to be the key listening posts for me of organized efforts to help persons with mental retardation in our area.

More basic than this, however, is listening to persons themselves and parents and advocates, be they our own social workers or parents of the local organizations. The results of listening to the pulse of the individual communities, as represented by people referred to above, have been the following:

The creation of a private, nonprofit housing corporation entitled "March, Inc.", helping to serve persons in the Manchester area and ultimately in the region in areas of housing.

The coalition here included the town of Manchester government leaders, three local churches—an Episcopal Church, a Lutheran Church, and a Catholic-church community—the Developmental Disabilities Council, the Manchester Association for Retarded Citizens, Statewide Corporation for Independent Living, and ourselves.

After playing the catalytic role to enhance the creation of this agency, we now participate as a working partner and consultant.

As a major entity of March, a respite program has evolved, having won funds from the Hartford Foundation for Public Giving with much support from our regional staff.

Second, the establishment of a workplace. The Hockanum Industries Sheltered Employment setting in Vernon had a similar coalition of Vernon town leaders, the Talcotville School Parents Association, Tolland Area Association for Retarded Citizens, and our effort.

Through consultive and coordinative efforts of the Tolland region, citizens of the greater Vernon area now have job opportunities there for 20 people. and able to be expanded very shortly;

And, finally, a homemaker/health aid service in the Willimantic area has brought together social workers from our area, the Manchester Community College, the Association for Retarded Citizens in Manchester, and two homemaker/health aid agencies so that we might now expand their services by inservicing their existing personnel and aids to serve the mentally retarded.

The point of these examples, and many others which could be made, is to illustrate the synthesizing, catalytic role of community development assumed by the Tolland region of the department of mental retardation.

In conclusion, the process continues. The movement of people into the community is constant. The job of DMR regional staff is to continue this movement and solid community development.

I hope these brief comments will assist you to clearly see the progressive role the department of mental retardation has taken in 20 years. The current work of community organization in the Tolland region is a natural progression of the principles and practices of the regional concept which seeks to move and keep persons with retardation in their own community.

Thank you very much, Senator.

Senator WEICKER. Thank you very much.

Are you prepared in your region, with the facilities you presently have, to take care of either the catastrophically disabled or the catastrophically retarded?

Dr. DUCHARME. No, we are not, Senator, with the resources we have, as you posed your question.

Senator WEICKER. What do you estimate it would cost to get the necessary resources to handle those two situations?

Dr. DUCHARME. In dollars? I don't know, Senator. In time? A great deal and a lot of community support. I do not have the dollar figure in my head to give you. I think that would not be my position to accurately give at this time.

What we do have is the ability, I think, to mobilize the resources that are there, whether they be the university, the three hospitals we have, the mental health community, to cooperatively work together to establish units that could help to retain in our community people who are catastrophically disabled.

One of the features which I think is important to a partial solution of this is that the individuals who are at the Mansfield Training School now, whom I met in 1964, were then 30 or 40 years of age and are now 50 years of age, had not the opportunity of what we term "early intervention."

This particular program and particular system of interaction with families and with children early in life to eliminate the catastrophic problem is something which will be discussed later. The cost of that program is an element of intense concern and the desire for us to move everyone into the community is constant.

We have 89 individuals living at Mansfield Training School now who come from the 15 towns that we serve whom we would love to move and are planning to move every single one home, if appropriate. But, as Roger indicated, there are certain types of programing that are needed, or perhaps will be needed, on a short-term basis, at least, in a residence, in a place like Mansfield Training School, just as when I have certain illnesses which I may contract which cause me to go to a hospital or a particular unit to be helped.

I hope that I have answered your question.

Senator WEICKER. Thank you very much.

Mr. DODSON. Senator Weicker, I am Al Dodson. My position with the department is as director of planning, development and evaluation.

Dr. Ducharme presented the interaction of one DMR agency with the private sector. In a very brief amount of time I will try and highlight both how other regions utilize this interaction and how DMR as a whole currently relies upon and provides support to other public and private agencies, and how it plans to expand upon this partnership.

First, at the center of this concept of utilizing and supporting other public and private agencies are the objectives of the community services component of Project Challenge. Those four principles are: One, to utilize those services that are available to the general public; two, to assist and support the development of community services for individuals who are mentally retarded by appropriate agencies and then to develop services where program or resource gaps exist; three, to coordinate the delivery of community services to those people who are mentally retarded; and, four, to assure the quality of those existing programs.

Some examples of the departments utilizing services that are available to the general public are the use of supervised apartments, some of which are funded through HUD section 8, municipal and private recreation programs, medical-dental services, often funded by title XIX, the use of competitive employment situations, the use of Farmers Home loans, the use of homemaker-health care aids and visiting nurse associations, assisting in supporting the development of community services where gaps exist are evident throughout the State.

Many regions have housing consortiums that plan and implement the development of alternative residential accommodations. At least two regions hold monthly meetings with ARC executive directors to discuss regional needs. Another region is cooperatively opening a group home, as Everett mentioned, with a local ARC.

Since the very beginning, one of the core pieces of community development has been the department's grant-in-aid program. Also, many regions enter into vocational consortiums which plan for the development and the utilization of vocational programs to meet the needs of the retarded.

A number of years ago the commissioner formed a developmental team which is a part of the central office that is involved in staff development and parent training. That has been constantly made available to the private sector and utilized by many parents, many ARC groups, many private and public organizations working with handicapped individuals.

Currently, the assurance of quality in residential and vocational programs existing in the private sector have been addressed by the licensing division and the community service division of the department.

To aid in the expansion of community services and to expedite the deinstitutionalization process, the commissioner established a planning and evaluation unit utilizing existing central office staff and also staff that had been developed through the legislative process.

This unit is charged with assisting regions in the development of community services and compiling a statewide community services plan. The reason I emphasize "assist" was pointed out in George's talk. Each region may have its unique needs and its differing resources, but we also need to remember that ownership is the key, ownership at the regional level, ownership of municipalities and, in fact, ownership at the neighborhood level as well.

As George mentioned, and as Dan and Everett illustrated, there are not only differences in needs of different communities but different regions of the State have differing needs and differing resources. It is very difficult to compare affluent lower Fairfield County with its many, many vocational opportunities for handicapped individuals with that of the northeastern part of the State that is economically depressed and, in fact, the only vocational opportunity existing for the handicapped at this time is the John Dempsey Regional Center.

The planning and evaluation unit is currently involved in compiling a statewide community needs profile. This profile is multifacted and involves the superintendents of each region, service providers within each region and throughout the State, and intends in the very near future to involve consumer groups.

What we are finding is that an array of services does exist in Connecticut. We are not in any way claiming that that array is available throughout the State in each and every area, or that we are meeting all the needs of the retarded.

What we are saying is that the continuum of services exist that may not be apparent. However, these services need to be expanded so that they can be made available throughout the State and we can meet the needs of each individual.

This expansion in an era of great fiscal concern will necessitate establishing a partnership among the State, the Federal Government, municipalities, and private service providers, both generic providers and specialized providers.

Samples of these expansions were included in a proposal recently submitted to the legislature that included an expansion of the community services program, an expansion of the supervised apartment program and a proposal to expand the number of community services directors so that each region throughout the State had a director of community services.

If this plan is accepted, and we have every reason to be optimistic, it will allow for 380 people to be placed in community training homes within a 3-year period, it will approximately double the number of people placed in HUD section 8 supervised apartments within the next 2 years and it will allow us to concentrate on development of those services that we know now are needed for those people in the training school, people residing in regional centers and those people residing at home.

The success of programs in Connecticut for people who are mentally retarded is a direct result of a partnership between the public and private sectors. This is not a partnership built merely on dollars as it is in many States but also on mutual effort and work of many, many people.

The department recognizes that the future of persons who are mentally retarded is intimately linked to efforts to work in partnership with all facets of private and public community resources.

DMR is looking to continue its cooperative efforts and, in fact, expand partnerships so that the needs of mentally retarded citizens of Connecticut are fully met.

Senator WEICKER. Thank you very much.

Commissioner THORNE. Senator, we will have a presentation now by three people. The subject is going to be options of residential services other than training schools and regional centers. This will give you more detail on certain specific programs that we are emphasizing now.

The first presenter will be Mr. George Moore, who is the superintendent of the Central Connecticut Regional Center, followed by Mr. Bill Dowling, who has a slide presentation on community training homes, and then, finally, Mr. Tom Sullivan, who is superintendent of the Seaside Regional Center. Mr. Dowling is superintendent of the New Haven Regional Center.

Mr. Moore.

Mr. MOORE. Good morning, Senator.

The next segment of our presentation will focus upon residential alternatives which have been developed in the past 20 years. Given the time available, we will attempt to highlight the issues and reflect the optimism which we feel regarding our commitment to ongoing growth.

As you know, today's department of mental retardation is the result of an evolution which began with the Mansfield Training School in 1917, the Southbury Training School in 1941, and the office of mental retardation in 1959. Throughout this history, there have been consistent efforts to improve upon existing services and broaden the options which are available to handicapped persons and their families.

It is imperative, however, that we recognize the fact that there are still many obstacles which must be overcome in order for us to reach our goals. A few of these include: limitations in the funding abilities of the State and National Government; the need to minimize bureaucratic constraints related to utilizing moneys once they are appropriated, availability of appropriate medical and other professional staff to support persons who have complicated medical or behavioral difficulties; and community or parental resistance.

It is our belief that realities such as those described above must be recognized, not accepted. The mission of the Department of Mental Retardation, from its earliest beginnings, has been to overcome obstacles and develop a continuum process which assures that all mentally retarded individuals should live in the least restrictive environment which is commensurate with their needs.

During the rest of my presentation I will emphasize the role which group homes and supervised living apartments play in this continuum. Bill Dowling, to my right, will then give an overview of the community training home program, and Tom Sullivan will reflect the role of transitional living facilities.

Since 1964, when Mansfield Training School opened the State's first group home, the department alone and in conjunction with the private sector, has continued its efforts to develop these alternatives.

Today, the department operates 27 group homes with a capacity to serve 323 residents. In addition, the department revised its regulations for licensure of privately operated facilities in 1975. Since then, the department has worked closely with the State Department of Income Maintenance to develop a rate system which reflects the true cost of services.

Since 1975, this process, as well as the active consultative role of the licensing section and regional staffs, have contributed to an overall upgrading of client care as well as the opening of 23 additional privately operated group homes, which adds to a total of 523 individuals who are served in 35 group homes.

Clients who were initially placed into group homes tended to be those who were highest functioning mentally, physically and emotionally. As we have expanded resources, we have been able to accommodate an increasingly varied type of clientele.

Our population now includes people who function in the severe range of mental retardation and who have emotional, physical and/or behavioral difficulties.

Nevertheless, we have a long way to go to meet the needs of individuals who can be accommodated in group homes but for the lack of resources.

In addition to persons with handicaps previously mentioned, it also includes many adults who presently live at training schools, health care facilities, or at home with their parents.

We believe that there should be an increasing emphasis by parents, professionals and society at large to see group homes and supervised apartments as resources to be affirmatively accessed at the time of adulthood rather than as a reaction to a stress or crisis situation.

In other words, mentally retarded individuals should be brought up to move away from home and toward independent living situations in the same manner as their nonretarded peers. This would reinforce the family's ability to emphasize their handicapped child's individuality and independence from birth forward and minimize the image of the handicapped child as a burden.

The pattern of growth which we have seen in the development of group homes is equally evident in the area of supervised apartments.

In the past 10 years we have increased our capacity in this area to the point where we serve 216 individuals.

Efforts in this area have been dramatically assisted by the section 8 program which is administered by the Federal Department of Housing and Urban Development. Accommodations are provided in a variety of settings, ranging from DMR—owned buildings, to apartments which are clustered together, and those which are spread throughout the communities.

In accordance with client needs, staffing patterns range from 24-hour coverage by live-in or shift staff, to periodic supervision on a daily, weekly or monthly schedule.

Apartment programs are particularly exciting because both the physical setting and financial necessities reinforce the need for an active partnership between client and staff, and show the client immediate rewards for independent functioning.

Clients may qualify for a driver's license or learn to access public transportation on their own. They may eat at home or go to a restaurant. They are faced with the same choices and dilemmas regarding rights and responsibilities as are faced by the rest of us.

While the choices are often limited and difficult, we witness the development of emotional maturity at this level of care which is difficult to duplicate in other environments.

For a minute I would like to give an overview of how these levels of service operate in my region. The Department of Mental Retardation, through the Central Connecticut Regional Center, operates two group homes in Meriden. In addition, there are two group homes in the Middletown area which are operated by a private corporation and one on-grounds group home operated by Durham Hill, a private school in Durham.

Recently, a group of associations for retarded citizens has formed a consortium to develop and manage group homes throughout the region. They now have 1 group home open in Bristol and expect to open 3 more within the next year and 10 to 12 over the next 5 years.

It is my hope that future group home development in the region will occur in the private sector. In this framework, State-operated group homes would continue to focus on serving persons whose behaviors and/or self-care skills are not being met or are marginal in terms of the private facilities.

In addition to the above, we presently have three distinct levels of section 8 apartment programs. The Eastwood apartment program serves 16 severely retarded adults in 8 two-bedroom units which are located on the second and third floors of a small apartment building in New Britain.

Residents require 24-hour staffing, centrally prepared meals and staff assistance with most of the day's decisions. None of the clients are competitively employed but each receives vocational training from activity programs run by the private sector in the community.

The Newbrite program is comprised of three two-bedroom units which are located on one floor of a large apartment building in downtown New Britain. The facility is staffed by a live-in staff person and clients receive assistance in the afternoons and evenings.

This assistance involves training to develop community skills, meals, housekeeping, personal hygiene, medical, and dental care for the clients. There is a shared responsibility between the clients and staff.

The most independent program, Baybury Apartments, is comprised of three two-bedroom apartments which are distributed throughout a large apartment complex in Middletown. In this program, staff are onsite each day but only for a part of the day. Staff efforts are focused upon assisting clients in budgeting their money, shopping for food, and recognizing options for leisure type activities.

Some clients are employed competitively while others are in workshop programs aimed toward competitive employment.

It is difficult in the short time given us to give a description which accurately reflects the scope and opportunity which has been made available to our clients through these programs.

I can tell you that the opportunities have helped these people to recognize and appreciate the self-respect that is realized through their participation in decisions which affect their own lives.

It is our belief that we have only begun to tap the potential associated with these levels of care. Further development will most certainly be affected by the willingness of taxpayers at the State and national levels to participate in the financial investment related to helping handicapped people to help themselves.

I would like to thank you for the opportunity I have had to make this presentation.

Senator WEICKER. Thank you very much. Commissioner Thorne, or anybody who would like to respond, I have a few questions here.

What is the total budget for group homes and what percent of the total budget does this represent?

Commissioner THORNE. Senator, I don't have that figure with me right now. We would be very happy to provide that for you. We have the material here. We are looking.

Senator WEICKER. The next question would be, what is the budget for supervised apartments or section 8 housing programs, and what percentage of the budget does this represent?

Commissioner THORNE. Again, this is a comingled program with HUD financing, with residents of the apartments personal funds and with State contributions. The State's contribution is principally, in that program, in the form of cost for staff and, in some instances, helping to subsidize.

Again, those figures we could get for you. I don't have them with me.

Senator WEICKER. I will just finish these questions. Any one you can answer, fine. Otherwise, for the record, what is the budget for community training home programs?

Commissioner THORNE. The boarding house budget is in excess of $1 million a year for subsidizing community training homes. That is comingled with SSI payments that the individuals have so that, again—and if the person does have their own personal resources, it involves that too.

We can get you precise figures on that, Senator.

Senator WEICKER. And, lastly, the estimated cost per year for clients in each residential program: institution, regional centers, group homes, training homes, supervised apartments, section 8?

Commissioner THORNE. We could develop that information too, keeping in mind that the cost of services comes from many different sources of people who are in the community so that we have to trace down the various locations of costing. We would be very happy to provide that information.

Senator WEICKER. Proceed.

Commissioner THORNE. The next presentation will be by Mr. Dowling who will be talking specifically about community training.

Mr. DOWLING. Good morning, Senator. My name is William Dowling. I am the superintendent at the New Haven Regional Center.

I have been in the field of social services for 15 years, one-third of which has been working with mentally retarded individuals. The common thread through my service has been the use of foster homes to provide community residential programs for those in need of such a program.

I am very happy to have the opportunity to share the department's community training home program with you. My comments will be somewhat abbreviated from the prepared text in order to allow time for a brief slide projection show which I think will be very helpful to your understanding of the program.

The community training home program is one of an array of residential services provided by the department. This program provides individualized care, and specialized training in private homes for one to four individuals.

They may reside in the home as family members or they may be there briefly as part of the department's respite program. The respite program, as you know, provides temporary relief to family members from the constant care of a handicapped child or adult. This allows the family the needed relief from that care in order to maintain the handicapped member in the community as long as it is appropriate.

The training home program—the term itself reflects the increased professionalism of this program is a modification of the traditional foster care program—has been evolving over a number of years in the department. Back in the fifties, and even before, the training schools used the boarding out home concept to provide community living arrangements for those it thought appropriate.

In the sixties, with the development of the regional concept, additional emphasis was given to the foster care program. And in the 1970's, with the assistance of developmental disability grants, two regional centers laid the framework for a more sophisticated foster care program.

It was in the seventies also that the commissioner authorized the creation of the respite and community training home task force in 1976. The purpose was to develop a community training home program and a community respite program in all of the regional centers throughout Connecticut.

At this point I think it would be helpful if I presented the slide show which is used by the New Haven regional center as part of its recruitment efforts for community training homes.

[Presentation of slide show:]

COMMUNITY TRAINING HOME AND RESPITE HOME TAPE

Unlike Angie, some mentally retarded individuals do not have their own families always available to provide care for them. Carolyn is 20 years old. In order to best meet her human needs she lives in a Community Training Home. Community Training parents provide care on a long-term basis, and act as substitutes for or a supplement to the individuals natural parents. They provide an opportunity for a mentally retarded individual to know the joy of being part of a family, to grow and develop with the experience of knowing others who are interested and concerned about them. In her home, Carolyn's community training parent works with her on skills that will help her to become as independent as possible. She practices basic cooking and housekeeping, and hygiene skills. During the day, Carolyn participates in a work training program where she is taught outdoor maintenance. She also learns cleaning skills that may someday qualify her for a job in the community. When a mentally retarded person needs a placement in a community training home, the home is chosen on the basis of which family can best meet this persons needs. Such factors as family composition, skills of the family members, and family preference are taken into account in making the choice. Before an individual is placed in a home permanently a series of respite placements are arranged with the community training family. In this way, the family and the mentally retarded individual can experience what sharing a home together would be like. On this basis, they and the agency, make a decision about whether the placement will be successful. By the time the individual is placed permanently, he or she and the family know each other well and the foundation for longer term relationships has already been layed. Some families choose to become community training parents while others feel that making a commitment to short-term respite care better suits their life style. Whichever their choice, the preparation for these roles is essentially the same. The first step is a general meeting with the program coordinator. She and the family discuss the problems and explore their participation in terms of both the agency's and families needs. There follows a series of meetings between the family and the program coordinator which serve as a mutually evaluation process. Together they explore the interfacing of the family and the program This evaluation becomes a part of the formal home licensing process. The family also participates in a training program. Through it they are introduced to some of the special needs of the individuals with whom they will become acquainted. They also acquire some of the skills they will need. During this time all families in training provide short-term respite care as a way of becoming more familiar with the agency, the clients, and their own future roles Community Training Home parents and respite parents emerge from the sessions as an Integral part of the agencies network services. In this capacity they receive payment for the care they provide and are expected to perform their roles well. To assist them in their task the program coordinator and a social worker provide ongoing support between the home and the agency If assistance is needed in a particular area, with an individual that is placed, the social worker can arrange for input from specific professions; such as, physical therapist, psychologist, nurses, or behavior specialists, as well as from other community agencies. Community Training parents and respite parents make a unique contribution to the lives of mentally retarded individuals. Together they and the agency work to insure that the human needs of those individuals are met in the best possible way They are the ones who have made it possible for Angie, Carolyn, and many others to be people in the mainstream of everyday life; working, playing, being part of their community, being part of a family that provides companionship, support and love. When you share a little bit of your world you can make a difference in somebody's life.

Mr. DOWLING. Presently, Senator, there are approximately 280 such community training home beds in the department's program. About one-third of them are for long-term placement. The rest are used for the respite program.

The department projects that were the money available right now, approximately 380 individuals could benefit from community training home living. Of this number approximately 320, would come from the existing residential programs such as the training schools and regional centers. The remaining 60 are estimated to be those on our urgent waiting list who are in need of an alternative to their present situation and this alternative could be a community training home program.

The community training home program that the department envisions in its budget request would also allow approximately 1,000 respite days to be provided in the community by each regional center. This would be a tremendous increase in a very valuable service to the community.

Right now it is the lack of funds that is the primary obstacle to the realization of this program. There is some optimism at this point since the department's proposal has received a favorable response from the Hospital and Health Care Subcommittee of the Appropriations Committee and they will be voting on that, in the next day or two.

The community training home program is one component of the department's mental retardation residential services. It has a potential for continued growth and increased importance. The department is very clearly committed to developing this potential.

Thank you.

Senator WEICKER. Thank you very much, Mr. Dowling.

Mr. SULLIVAN. Good morning, Senator. My name is Tom Sullivan. I am superintendent of the Seaside Regional Center. I would like to speak briefly on the concept of a transitional community living facility.

There are two major concepts that I would like to address in this presentation that I feel best represent some of the experiences we have had at the Mystic Educational Center, which was formerly known as the Mystic Oral School.

Since this program was started by the department, through the cooperation of the State department of education, back in December 1979.

The first concept that I would like to address is the concept of the "transitional facility." If I can borrow Mr. Webster's definition, transition is defined as a passing from one condition, form, stage, activity and place, et cetera, to another.

The key factors in the Mystic program focus upon the movement process from institution to community. Every client selected for the program participates in the planning and decisionmaking process, in conjunction with the staff, that will enable him or her to eventually live in the community.

The Mystic program, then, is not a goal unto itself. Rather, it is a means to an end, that end being community placement. So, in a sense it is a bridge.

When 50 residential and five respite beds were made available to the department back in 1979, our planning focused primarily upon establishing a program that would best meet the needs of a large number of the department's higher functioning clients who live in our larger residential facilities throughout the State.

Over the years, our experiences have indicated that the successful community placements of institutionalized individuals is best insured through a well-planned program which provides the individual with a gradual progression through more independent, or, if you will, less restrictive living situations as that individual acquires previously unlearned skills.

In most cases, the sequence of living units usually takes place on the grounds of the two training schools. When the individual is ready for community placement, he or she is placed in an appropriate community residence.

Most of these placements have proven to be quite successful. I have to note here that Representative McKinney, earlier in his statement, pointed out a concern about returns of people from the community to the institution, the problem of recidivism.

We, likewise, have experienced these problems to some degree. We found with some of these clients, in their transition from the institution to the community, that the pressures, stresses and expectations were entirely too much for them to handle.

As a result, they oftentimes returned to the institution. When the Mystic program was developed it was felt that this facility could become a viable stepping stone for these and other individuals who are ready, for all practical purposes, for community living.

Through a very close working relationship between the Mystic staff and the staff of the two training schools and the regional centers, 26 clients from the training schools and 24 clients from five different regional centers, several of whom were critical cases, were transferred into the Mystic facility.

With the current population of 50 clients, there are seven individuals who previously had been placed from training schools into community settings and were later returned to the training schools for a variety of reasons. Once again—this problem of recidivism.

A few of these individuals failed several times in a variety of settings. The staff at Mystic have concentrated very hard in providing a supportive environment and program for these individuals and, of the seven, two currently are in public school programs and three are working today in the community in various work groups. I would like to state that since the opening of the program back in December 1979, not one individual has been returned to an institution.

Obviously, all the 50 people aren't there because of recidivism problems. Many of them have been selected because they were found by the staff at the training schools and regional centers to be pretty much ready for community placement, but they needed some work and some training in specific areas of need.

I am most pleased to report that in early May, next month, eight of our school age children who are now living in Mystic will be moving into our newest group home located in Norwich. We have been concentrating on teaching them some of the skills they will need to succeed in this home.

There are many other success stories I could relate to you but in the interest of time I won't. In summation by the end of this month, 20 percent of the original population of 50 clients will have been placed into the community directly from the Mystic program.

What must be pointed out, in addition to living successfully in a community, one must be able to provide for themselves to some extent. Once again, we are talking about work. I think this is particularly true in our New England work ethic society. People must succeed and feel good about themselves and their ability to work.

So, we place a great deal of emphasis on our vocational training programs. There are seven adults now living in the program who previously were not employed in the community who are now working, individually, in the community for at least minimum wage in a number of work situations, many of them for over 1 year in the same job.

In addition, we have several adults who are being trained in group work programs to work in the community in janitorial subcontract type work cleaning restaurants, motels, community churches, and so forth. A total of 63 percent of the adult population living in Mystic is now working in the community.

As a transitional facility, Mystic has been very successful. The proof of the pudding is the successful community residential and job placements that have taken place and the individual improvements that we see.

Another transitional facility, the Clifford Street program, a 20-bed ICFMR facility, is currently undergoing renovations and will be opened next year by the Hartford Regional Center.

I would like to just briefly refer to a second major concept that I would like to present, and that is the concept of deinstitutionalization. Very briefly, this is a popular buzz word which is often frequently used without much thought in terms of its far-reaching effects.

Deinstitutionalization is often assumed to simply represent the concept of moving people from the institutions into the community. I have given a few examples of how it works in Mystic.

However, there is another edge to the sword of deinstitutionalization which quite often is underplayed or ignored, but equally significant, and that is the aspect of preventing people from moving into institutions.

The Mystic program has concentrated a great deal on this and through a number of programs—vocational programs, respite programs in which we have placed 60 people in weekend, overnight emergency respites over the last year, and a number of other services, such as recreation, we have proven quite successful.

Also, the special school district program services severely and profoundly retarded people living in the community in a number of towns in southeastern Connecticut, notably Groton, Stonington, Mystic, and that area east of the Thames River, which previously was unserved by a major type of facility in our region.

I think one of the things we are observing, which is very encouraging, is the absence of residential placements of youngsters. I mentioned respite programs. I mentioned early intervention programs. I like to think because of some of the successes we are having with these youngsters, we are observing here and throughout the State in all the regional centers, a decline or almost nonexistence of residential referrals for the youngsters ranging from 6 months to 6 years to 16 years.

Our residential population is getting older, but our referrals of youngsters are not that prevalent. In fact, we haven't had any in the past year or two for full-time residential placement. I think a lot of it has to do with respite and some of the Special School District Early Intervention programs that we offer.

In closing I would like to state that I hope I have conveyed to you the optimism which I and the Seaside staff have regarding the Mystic program. I have shared a few success stories and I can say with honesty there have been no failures.

In addition to preparing clients for community living successfully, the very fact that a major facility is located in this part of our region, is gradually preparing the community for our clients. We have to face this responsibility of preparing the surrounding communities to accept and to see these individuals as neighbors and friends.

In some cases many of us professionals prepare the community "by the book" through our formal presentations, media exposure and public relations. I think the best public relations people we have are those clients, and the more exposure they get in the community and the community has to them, we are finding that this is perhaps the best type approach we can take to readying the community to those programs we are planning on setting up.

In a sense, it is education through "osmosis."

Finally, the bottom line in determining the effectiveness of this program is the successful community placement. This has been proven true. I feel that there is indeed a viable and important place for a transitional facility such as Mystic in the continuum of treatment and care for the mentally retarded providing such a program does not become an end unto itself but a means to an end, and that end being community living.

Thank you very much.

Senator WEICKER. Thank you very much.

Commissioner Thorne, I have some questions prior to the next panel which we might take up at this time. There are over 300 retarded persons who are currently on waiting lists for residential services. How does the Department of Mental Retardation decide who has priority for an apartment, versus group home, versus Mansfield Training School?

Commissioner THORNE. The department has an admission and referral body that meets as often as necessary, at least once a month, to discuss all of the referrals for placement that come before that body. That would be admissions for people who are inappropriately placed within a department's facility where there is a consideration that it is very necessary to move from where they are to some other place.

That committee then establishes a priority based on the need of the client and then, as soon as a bed is available the client is moved into that particular bed.

Senator WEICKER. Then is it not true that the individuals placement is based more on what services are available rather than an individualized need?

Commissioner THORNE. I would say all the placements that are made are based on individualized needs. That is why we go through the complicated exercise of looking at the total picture of the individual as to what his needs are.

Within the system itself we are constantly rechecking and rebalancing it with our various team type programs, but also, the admissions and referral group would review this so that the object is, of course, to place the person in the most appropriate environment.

We recognize that there are times when that is not available and it is simply because of a lack of resources.

So, placements are not arbitrary. We don't admit people directly to training schools, for example, unless there is some type of an emergency situation that would warrant such an admission. All admissions are made directly to regional centers usually, or to group homes or community training homes, whatever might be the most appropriate situation of that person.

Senator WEICKER. The U.S. Department of Health and Human Services funded a national study. Connecticut was reported to be among the five States with the largest number of persons in institutions compared to the population of the State. I suppose the question here is why we have lost our position as a progressive leader in the field of mental retardation?

Commissioner THORNE. I question the statistics very much because it is just not the case. I have questioned their statistics before. The definition of what they term as institution, and so forth, is certainly subject to a great deal of interpretation.

I know at our National Association of State Directors and Commissioners we discussed this study and the fact that all of the States were concerned where they got their figures from and nobody could really identify specifically how they arrived at their statistics, so I would question their statistics and I would be very happy to discuss that with them.

Senator WEICKER. From 1974, the Department of Mental Retardation placed over 700 retarded persons in nursing homes where they received no program and have become victims of neglect and abuse.

I first want to ask why, and then, what efforts are being made on behalf of these persons to locate them in appropriate community living alternatives?

Commissioner THORNE. To begin with, persons have been placed in nursing homes in the State of Connecticut for 30 or 40 years, or whatever the case might be, as long as they have been in existence—not only by States but by families or whoever it may be.

So that, it is something that didn't occur just overnight. It has not been an uncommon source in any State for placement of mentally retarded people. We placed, in this State, people in nursing homes basically for two reasons:

One, the unavailability of beds for people at the time that there was a critical need for beds for individuals. In other words, where the family had collapsed, where there was not any other resource available other than the training school and it was full. There were people in training schools that, in the minds of the staff of the training schools, could be more appropriately served in nursing homes as a lateral institutional transfer.

There was never any intent on the part of the department to consider that such placements as non-institutional. It is a lateral institution transfer. As a consequence, none of those people were ever discharged. Those people were followed and are constantly followed, and all have been reviewed by our intermediate care facility investigators to determine the appropriateness of each placement and a plan of discharge or a new placement plan has been written on these persons which we will implement as soon as it is feasible to move them into settings, particularly ICFMR type settings as these are evolved, providing, however—and we have to keep in mind, Senator, that a great deal of the future of ICFMR is dependent entirely on the Federal Government and whether it caps that program.

It certainly appears that is what they are going to do. So the future for intermediate care type facilities for people who have severe chronic disabilities certainly, from that perspective, has more of a bleak outlook than I would like to think.

Senator WEICKER. Unlike most States around the country, Connecticut continues to move retarded persons from large facilities like Mansfield to other highly structured settings with 20 or more persons. Is this an unnecessary step to develop community residential services.

Commissioner Thorne. In our opinion, and that opinion is not a light opinion—this is the opinion of the professional people that work within our department—because the policy in relationship to appropriateness of placement, and the type of program, is a decision that is made among the professionals in the department as a matter of course. These are professional decisions based on what is the most appropriate environment for the types of clients involved.

It is our opinion that for many clients, because of the severity of their handicap and the intense needs that they have for day-to-day, round-the-clock service, that some congregate services are more appropriate simply because we are better able to amass the clinical staff, the treatment staff, which is in short supply, to those types of settings.

We understand full well in the field as professionals that there are contrary points of view and we recognize that, but we do not necessarily accept those contrary points of view.

It is our opinion, based on our experience, that the people have responded effectively and well in such settings, certainly as an interim step to a more or less structured setting.

Senator WEICKER. I have two questions that have been asked by persons here at the hearing. Sharon Johnson asks: Could you ask how many barrier free group homes now exist? Isn't this problem a significant detriment to moving a large number of people out of Mansfield and Southbury?

Commissioner THORNE. Barrier free group homes, which are required under Federal acts principally, makes it difficult. I understand that even recently there has been some difficulty in getting a change established for small group homes in terms of the Federal Government. HCFA's interpretation that we have to have certain fire protection within such facilities is going to make it even more difficult to establish group homes of a smaller nature in the community.

Again, a barrier free environment, in our interpretation, does not have to be the total home as long as there is available acceptable space in that home for a handicapped individual and that the program the home offers is available.

Furthermore, we feel that with the spectrum of services within any region, if there are barrier free group homes available within that region that should be sufficient so that not every home has to be barrier free in totality.

We have been attempting to evolve a system of barrier free group homes. We have a capital appropriation in one particular region where it is our intention to build six such facilities.

The planning and full design for two of these facilities has been completed by the architects and by public works. These facilities are ready to go to bid. They are the prototypes of what we would consider to be appropriate type facilities to be constructed throughout the State. We do have funds, not sufficient to build a total network, but sufficient to start, hopefully, at least, four to six in the Waterbury area, two or so in the New Haven area, one in the Manchester area, and so on.

The problem with this is the enormous cost per bed because a barrier free group home, by Federal law, in order to qualify certainly as an ICF, must be built in accordance with institutional standards, which makes the per-bed cost in excess of $100 a square foot, the reason being that it must meet the fire safety codes of institutional standards because of the fact that people in these facilities might be nonambulatory or might be very severely handicapped people.

This is going to be a substantial barrier to the creation of large numbers of facilities. It is simply the cost and the regulations that are behind the cost.

Senator WEICKER. Attorney John Jatar of Connecticut Legal Services says: Senator Weicker, ask Superintendents McNamara and Belmont the question, given the state of the art today, are there any residents of the training schools who could benefit from a program as described by Superintendents O'Connell and O'Keefe?

There is a further question which needs to be asked: Are there any residents of these institutions who could not benefit from these community programs; who are they and why couldn't they benefit from them?

Commissioner THORNE. Is that to be asked of who, me or——

Senator WEICKER. Of you or any part of your operation, whether it is Roger, Mike, or yourself or whoever can respond to it.

Commissioner THORNE. I will respond to this and they certainly would be happy to try. I think that we do have people residing in the training schools who are in the most appropriate environment for their needs for the reasons I have so stated prior, that there is concentration of staff, or expertise. It is very difficult to come by. These people have very extensive needs.

Either they are behavioral problems or they are problems of physical disability on many fronts. They are multiple handicapped. They need intensive 24-hour care. The question in this field, and it still is a question, and there still isn't even a substantial proof to this question, is whether or not such persons would benefit, truly benefit, from a smaller facility in terms of their own personal intrinsic benefit, what they gain from it.

Our observations of the profoundly handicapped, multiple, handicapped persons are empirical. The individuals are not able to speak for themselves to give us some measure of what they think of such a situation. From a research scientific point of view in the field there exist today many counteracting points of view as to what is the most appropriate environment for such people.

We do feel and we do sustain in the State of Connecticut the idea that the training schools have an effective and important role to play in the treatment program and the developmental program for very profoundly handicapped people who have not succeeded in any other type treatment setting that they have been in, and the training schools have thereby become the point at which they must receive their services.

Senator WEICKER. Fine. Mr. Thorne, why don't you continue to proceed with your presentation. We are a little tight on time.

Commissioner THORNE. Yes, I understand and, as a consequence we are going to drop two people from our presentation.

Senator WEICKER. I don't want to in any way shut anybody out. If you feel that is necessary, handle it any way that you want.

Commissioner THORNE. We want to in deference to your time. It is very important that Deputy Commissioner Gravink give her presentation because it relates to our planning, it relates to the future, some facts about that, how we arrived at that.

I would appreciate it if I have the opportunity to put her on now and then we will look at the time when she is through and if you have time I would like for you to hear briefly from at least one of the other presenters.

Senator WEICKER. Go right ahead.

For the information of those at the hearing, we will be recessing probably in 15 to 20 minutes and the afternoon's testimony will start off with the presentation by CARC, and then various panels after that.

Go right ahead.

Ms. GRAVINK. I can say good afternoon, Senator

My name is Lynn Gravink and I am Deputy Commissioner of the Department. Throughout the presentations this morning we have attempted to describe in some detail various aspects of the department's programs.

You have heard how these various programs interrelate to provide a continuum of services. I would like to describe for you how this all comes together on a statewide basis and just how far along we are in the development of what the original law that was passed in 1969, called for: a "complete comprehensive and integrated statewide program for the mentally retarded."

From the very beginning—in fact, before 1959—there has been a continuing planning effort. Although these plans varied slightly in emphasis, each plan challenges Connecticut to consider the varying individual needs of their retarded people and to provide the appropriate services.

Each calls for the communities to respond to make the generic services that are available to all its members also available to the mentally retarded. It was this planning that resulted in Connecticut being the first State to develop a regional approach to the service delivery.

As a department of State government, Connecticut DMR has the longest history in the country of providing a continuum of services in a variety of settings to persons who are mentally retarded.

That experience has demonstrated that mentally retarded persons indeed have a very vast array of needs, and that those needs can be matched with a variety of appropriate service delivery models.

We have seen mentally retarded persons improve and grow in training schools, regional centers, group homes, community training homes and in independent living situations when they have the necessary services and support systems available.

We have seen others fail in the same setting when that right matchup doesn't occur. It has been pointed out this morning that until 22 years ago the only services provided by the State of Connecticut to its mentally retarded citizens emanated from the two training schools.

Today there is indeed a full array of services provided by the public and private sectors. There are still shortages of some services in some areas but the base is there and it is on that base that we continue to build and develop.

Let's look at what has happened in those 22 years, since it is an evolving system and will continue to evolve in the future.

First of all, with the advent of mandatory special education, increased community acceptance, supportive parent groups, aggressive placement programs sometimes assisted by Federal grants, the population of residential facilities began to change.

When I first went to work at the Southbury Training School 26 years ago, approximately 70 percent of the residential population was mildly or moderately retarded. Today, more than 70 percent are severely and profoundly retarded.

The few higher functioning residents who still reside there have complicating medical, emotional, or other handicapping conditions that have, so far, precluded community placement.

Over the years this greatly affected the character of the training school. At the same time, the supportive services that mentally retarded persons and their families needed if they were to live in community settings became more evident and the role of the regional programs began to emerge.

They became what we often refer to as "the first line of defense", handling all initial referrals, providing counseling, day programs, respite care, recreation, and a variety of residential alternatives which we have heard described this morning.

The training schools were then able to reduce their populations from what was a combined total of over 4,000 in the early sixties to a combined total of 2,280 today.

During the seventies, with the Federal assistance of ICF MR program, we began to improve the environment and the program in the training schools for those more seriously handicapped individuals who now live there. Connecticut's regional program, developed on a region-by-region basis, so that, particularly in the beginning, services were not evenly available across the State.

This, too, has begun to level off in recent years and as the currently-authorized construction is completed all regions will have very similar capability of meeting the needs of the mentally retarded at the local regional level.

Currently, all regions have the basic nonresident services available, including social service evaluation, special school district (which you would have heard about today if time permitted but we will tell you about tomorrow), all either provide or have available in the region adult day services.

In each region there are DMR group homes and community training homes. All have some respite capability. Most have some supervised apartments and in all but two there is a campus-type facility available for the seriously handicapped person who needs the clinical or program services close at hand.

As a result of the community service update of Project Challenge, which was done in 1977, regional centers have identified community service teams with the task of considering local service needs and planning for them within their local regions.

A statewide profile of these needs is currently being prepared as part of the planning required by the 1980 legislature.

Through the years, the department has refined and revised its planning to meet the changing times and to take advantage of new opportunities. The department's current plan, which is known as Project Challenge, was updated during 1978, and circulated to many organizations and individuals for comment.

These comments and recommendations were then incorporated into the document that was published in July 1979. It is this 5-year plan that the department is currently operating under.

It proposes what was felt at that time to be feasible, given the experience of the preceding years, the economic situation at that time and the public attitude toward human services in general and the mentally retarded in particular.

I would underscore that it is a 5-year plan. It did not specifically address a more distant future. Those were and these continue to be times of uncertainty economically and attitudinally.

Full implementation of that plan would allow us to meet most of our current needs and there would be in place an array of services that could be further built on it in the future.

Basically, that plan calls for the continuous reduction of the population of the two training schools in an orderly way and upgrading of the remaining units at the training schools; the acquisition and construction of a large number of group homes, including those that would accommodate multiply handicapped persons; creating residential units near programs and clinical services in those regions where a regional center campus type facility does not currently exist; expanding the number of community training homes and supervised apartments; and encouraging and supporting the private sector to participate as well, primarily through the development of group homes.

Now, 2 years into the 5, the implementation of that plan is underway and we furnished in your packet of material, a chart that would describe the residential facilities that are currently available, authorized, and those that the plan would provide.

In some areas we are on schedule. In others we are behind. The supervised apartments and the community training homes are moving ahead while the development of new group homes is lagging.

I have attempted to briefly describe our progress and our current plan for the next few years. Let me describe now some of our current most pressing needs.

First, we have a serious need for more residential accommodations.

All of our regional centers and group homes are filled to capacity; 205 mentally retarded persons, nearly all severely and profoundly retarded, many with complicated problems, are living with their families and urgently need a residential placement. In every case, their situations are truly difficult.

Another 80 are in private facilities, including residential schools, skilled nursing facilities, group homes or children's nurseries and they, too, urgently need a setting more appropriate to their current needs.

The remaining, all adding up to the 300 that you referred to on that urgent waiting list, are people within our own facilities who need to be shifted from one setting to the another, and the total group all meet a definition of "urgent" that includes certain specific criteria. There are others who are less urgent, but these are the cases that we feel right now need to be relocated.

At the same time, we need to further reduce the two training schools by moving out those persons who are now ready for a more appropriate placement and to phase out those buildings that are out of date. These additional accommodations need to be of various types but most could be group homes.

Second, as our group homes and other community placements are available more support systems need to be in place: adult functional education, work activity programs, sheltered workshops, medical-dental services at title XIX rates, habilitation therapies, mental health services, leisure activities, and one of the most critical and currently most expensive services, transportation. Community programs just don't function without transportation services being available.

Third, we have a need for some facilities and programs for persons with very special needs. This has been commented on earlier. There is a need to provide a setting for intensive programing for the seriously disturbed, assaulted, and self-abusive client.

There are a number of mentally retarded persons with complicated chronic medical problems. The elderly retarded need some special attention. Educational settings are needed for seriously disturbed retarded children not eligible right now under the law for the special school district which we operate, and who consequently are now being sent to private residential schools, either in State or out of State, at a very great cost to the local public school.

Gradually, as space and staff becomes available, we have begun to develop some of these specialized programs at the training schools and regional centers but until more residential accommodations become available for those who are ready for community living, the very specialized programs cannot expand.

Fourth, we need a backup system for these expanded community residential facilities. Parents and foster parents need respite. Disturbed or ill clients are not always able to be coped with in group homes. Emergencies hit families that require immediate assistance and over the years in our existing homes we have encountered ice storms, power failures, flooded basements, and even fires that required immediate relocation for short periods of time.

If we double or triple the number of group homes, community training homes, and apartments that our plan calls for we must have some backup services in place. Again, we would expect that regional centers and training schools can provide some of these backup services but we need first to relocate those that are ready into the community.

The department has attempted to move in an orderly and planned way on a statewide basis over the last 22 years. From the beginning of the regional program we have been moving from the large training schools toward the community.

There have been setbacks and delays along the way. Money for the development of new facilities, and programs has been scarce, particularly in recent years. Neighborhood resistance has slowed the opening of group homes in some areas.

Bureaucratic procedures at both Federal and State levels make the process exceedingly slow, even when dollars are available. And parents who feel secure and comfortable with their sons and daughters living in a training school or regional center are frequently unwilling to accept a group home or community training home placement.

I hope to be able to expand on some of these problems tomorrow.

These and other barriers were identified in our 1979 Project Challenge. They have not all been solved but progress has been seen in several areas. We frequently become impatient and frustrated but the progress in the lives of the individuals, as we see them move through the many programs, encourages us.

We continue to evaluate our progress, to make adjustments, to explore new alternatives and to present our needs before the executive and legislative branches of government, both State, local, and Federal.

We are thankful for the opportunity that we have to do this again today. We hope, also, that we are beginning to reach the general public who must accept the handicapped people into their midst and must support the appropriate levels of service through their government.

Thank you.

Senator WEICKER. Thank you very much.

Commissioner, I intend to recess these hearings until 1:45 this afternoon. Is there anything that you would like conclude on as far as this aspect of your presentation, knowing that you are going to have the opportunity, or many of your people are, to be back here tomorrow?

Commissioner THORNE. I just want to, again, thank you, sir, for the opportunity for our staff to appear this morning. I am certain you already know this is a very complex and complicated problem. The service network is very deeply involved on many, many facets and, of course, there are many points of view but we do appreciate the opportunity to give you an overview of what the department is doing, and you will be hearing from other staff members tomorrow.

Thank you, sir.

Senator WEICKER. I might conclude on this point: I think you mentioned in your opening remarks the parallel between civil rights, individual rights, the rights of the disabled, handicapped, et cetera.

Indeed, if the rise in awareness occurred at the same time, the decline is taking place at the same time. I am talking about the attitude of the Federal Government and the Federal legislators.

I want everybody in this room to fully understand in what kind of context we are operating. No matter how good the concept, no matter how much we all might finally arrive at a consensus of what the best care consists of, I think none of us will deny that whatever road we take it is going to cost money.

I do not pretend to be an expert in the field in which many of you in this room have acquired your knowledge either through professional training or in a personal sense, but I am, I think, very knowledgeable in the area of politics and government.

What is being now proposed at the Federal level I am sure will have its impact at the State level. Let me assure you, there is only one word to use: It will be "brutal " I am not talking about a slight cutback. We are talking about very, very harsh cutbacks.

I just hope that as this dialog evolves you will all understand that. That is my battle to fight, but I can't fight it with any chance of success if indeed those who I am fighting it for, on whose behalf I am fighting it, are in disarray themselves.

The committee will recess until 1:45.

[Whereupon, at 12:35 p.m. the subcommittee recessed, to reconvene at 1:45 the same day.]

AFTERNOON SESSION

Senator WEICKER. The next two witnesses are Robert Perske, president of CARC, and Mr. Thomas Nerney, the executive director of CARC, and any and all persons that you have with you, if you would be good enough to introduce them to the committee and the hearing room, please proceed in whichever way that you deem appropriate, and it is nice to have you here.

STATEMENT OF ROBERT PERSKE, PRESIDENT, CONNECTICUT ASSOCIATION OF RETARDED CITIZENS, AND THOMAS NERNEY, EXECUTIVE DIRECTOR, CARC

Mr. PERSKE. I am Robert Perske, sir, and I will turn it over to Tom Nerney, so he can set the protocol.

Mr. NERNEY. It is a pleasure to introduce to you, Mr. Chairman, our distinguished panel of experts gathered here from around the country today. This is truly a nationwide issue and we congratulate you on your leadership in holding these hearings on community services as one of your first actions of the subcommittee.

The Connecticut Association for Retarded Citizens has complied with your request to present testimony on the capabilities of retarded persons to live in the community. Tomorrow parents from the Connecticut Association for Retarded Citizens will present a view familiar to you of what families want and what families know about retarded sons and daughters.

I am pleased that Senator Williams and Senator Hatch are represented here today by staff. Senator Williams, as former chairman of the full committee, sponsored significant legislation on behalf of retarded people.

Senator Hatch, taking Senator Williams' place as chairman, has been our new ally in the recent budget considerations for programs with persons with handicaps.

I would like to introduce once again, Mr. Robert Perske.

Mr. PERSKE. Specifically, sir, you asked us to outline opportunities for persons with retardation in the community to show how these opportunities can be advanced and how to help you build a record for future activity, and we will do that.

Professionally, I am a writer on assignments with three basic interests: One, inspiring healthy attitudes toward persons with handicaps; two, writing about remarkable relationships between them and persons with handicaps; and, three, describing outstanding community-based services for people with handicaps.

I usually write for the regular citizen. Therefore, I submit for the record the following books produced in part or in total by me for your record: "Report to the President," "Mental Retardation," "The Leading Edge," "Service Programs That Work," "New Life in the Neighborhood," a trade book describing how persons with retardation can help make a good community better, improving the quality of life, "An International Symposium on Normalization and Integration," "Childhood Retardation Today," "The Adult Tomorrow and International Year of the Child Symposium," and "Listen, Please," a report on outstanding face-to-face and self-help programs from across Canada.

I know you are busy and in the interest of efficiency, each document contains a quick guide for 5- to 10-minute browsing so that you can get the ideas that are in the documents. That will be turned in to you, sir.

For hundreds of years persons with retardation were belittled and isolated because of horrendous myths, pseudoscientific diagnoses, adamant refusals to support them in community settings. Today we know better because of the changing attitudes and the massive amounts of technology that we now have so that it is now possible for persons with retardation to be valued, to be accepted and to grow up in neighborhoods in our Nation.

It can now happen as never before in the history of humankind. One of the reasons for that is we recognize them as people with developmental disabilities, not that they have bad blood, that they are contagious, or that somebody has sinned, or somethings, all of the myths of the past, but they are developmentally disabled, which really means that each of us come into this world as a tiny bundle of forces and each force plays its part like a musician in a gigantic orchestra so that between the years of zero to 21 you and I develop from a baby to a full-grown adult, and we usually do it with the ease and skill of a soaring eagle.

Nevertheless, 1.4 of our population has a monkey wrench thrown into the works and we now can identify those barriers and we see them as heroes because they have to work from here on out like a bird with short wings in order to accomplish the same things that we accomplish.

We now know about barriers to development and ways that we didn't know 10 years ago. They are developmental. They long to achieve just like the rest of us in society. Therefore, it behooves us individually as good neighbors and collectively as a government to do everything we can to help these people with their development.

Here are a list of initial concrete suggestions for helping them with their developmental barriers. I will go through them rapidly. Support the family, don't supplant it. Provide in-home training and support as needed. Provide in-home and in-the-community respite care as needed. Provide specific financial aid, helping families to overcome specific debts caused by family members with mental retardation.

Next point: Know that we have reached a turning point with families. In the production of the report to the President in 1977 we found that we were at a turning point with families. Up to that point we had provided more incentives for persons to send their children away from the home than to keep them there.

Now, we think that there are more incentives starting to come on to the scene socially and economically so that we can support the family, support the person to stay in the home. This is a turning point because many of us who worked as professionals in the fifties and sixties were utterly brilliant about breaking up moms and dads from their kids. That day is fading rapidly.

Next point: View other residences as a last resort and only after it is clear that some other residence is needed, whether it is the natural family home or a natural adult home, only then should they go to another residence.

Next point: Develop residential alternatives in a person's own community. To take a person out of a community when they have a problem and send them miles and miles away can be devastating and it can cause regression right there.

To take them away from everything that they knew to be familiar.

Let residential alternatives be family scaled because growth is maximized in families and not in regiments. Therefore, we recommend that nobody move anywhere from institutions and from homes until they move into family-scale homes of six or less. We have some States here who are willing to testify today that they would go for three or less, or four or less.

Next point: Craft residences according to crucial needs. For years we had a slot in the residential service and we shoehorn somebody in there whether they need it or not. Now we look at a person's individual needs and then we craft a residence around them.

Next point: Let formal education take place in regular public schools. I have seen evidence that is emerging from across the Nation showing that persons with retardation, even those with severe or profound handicaps, fare better in public schools than in separated schools.

Next point: Let them become adults. At the International Year of the Child Symposium on Persons with Retardation, key persons from all over the world refused just to talk about childhood retardation because they had enough of the "eternal child" and the "eternal adolescent".

They felt that these people should be helped to become full-fledged adults as much as they could and to be treated like adults. This came through so clearly when the British journalist, Ann Shearer, spoke for all of us when she said:

> Mentally retarded persons are all too often caught in a half world between childhood and adulthood, fitting into neither, frozen into a continuous state of becoming prepared to enter adult life, yet not able to reach it.

The last point: Those with severe or profound handicaps belong in community settings too. Ten years ago this notion would have been unthinkable but in this hearing my colleagues who follow, Dr. Lew Brown, Dr. Tom Bellamy, Karen Green, Bob Carl, Linda Glen, Sister Barbara, and many others will be trying to make this point.

So, these suggestions set the stage for the speakers who follow. But before they begin speaking, I would like to call your attention to one more point. We now have evidence that twice in this century we tried to improve civilization by culling these people and sending them out of the mainstream of life.

We did it with the eugenic scare in 1912 through about 1940, and that is when our institutions became filled to overflowing, and that is still part of the problem that we are trying to solve.

Also, in the 1930's the German Nazi Party attempted to make a super-race by killing persons with retardation and we are having massive evidence come to us daily showing that the early genocide machinery was perfected in institutions for the mentally retarded that was used on the Jewish community later.

So, we are smarter now and we see people with handicaps as having weaknesses and strengths like we have weaknesses and strengths so that now we know that everybody figures in everybody else's survival and those people we once rejected may be the very ones who hold the key for improving the whole civilization.

I believe that and I am willing to do anything I can to help you see why I believe that way.

I will turn you back to Tom.

Senator WEICKER. Thank you very much, Mr. Perske.

Mr. NERNEY. For our first witness we would like to call Dr. Lew Brown, professor of studies in behavioral disabilities at the University of Wisconsin and also the president of the Association for the Severely Handicapped.

Dr. Brown is a teacher and he is accompanied by two of his associates.

STATEMENT OF LEW BROWN, PROFESSOR, BEHAVIORAL DISABILITIES, UNIVERSITY OF WISCONSIN AND PRESIDENT, ASSOCIATION FOR THE SEVERELY HANDICAPPED, ACCOMPANIED BY ALLISON FORD, TEACHER, MADISON PUBLIC SCHOOLS AND JAN NISBET, PHYSICAL THERAPIST, MADISON PUBLIC SCHOOLS

Dr. BROWN. Thank you. I would like to introduce my two associates, Miss Allison Ford, who is a teacher in the Madison Public Schools, and Miss Jan Nisbet, who is a physical therapist in the Madison Public Schools.

I would like to make one unfortunate announcement. I notice that there are photographers. We do not have permission from the parents of these children to present these slides for pictures of their children in such a body, so I would like very much to ask the people with cameras to please refrain from taking pictures of the slides.

Senator WEICKER. The Chair will request that there be no pictures taken of what it is that Dr. Brown is now presenting on the screen.

Dr. BROWN. For the past 12 years we have worked with the University of Wisconsin in an attempt to train teachers of severely handicapped children and with the public school system, and that is a metropolitan school district.

I would like to take a few points to try to communicate to you some of the more critical characteristics of our school program as it exists now. Many of the points I would like to make up front are points that are relatively new to us and we think are improvements on those made in the past.

One is that we operated a program for the past 7 or 8 years that excludes no one and rejects no one. In the past, prior to that point, the Madison district would say, "I am sorry, you are too retarded to come to this school" or, "We tried you out and you didn't work in our school" and you would have to go someplace else.

There was a philosophical commitment not to do that again and, as a result, we gained, in a very short period of time, a tremendous amount of experience and expertise.

Another characteristic is that we used to operate a segregated school, a school for only retarded people and that is closed now. Now, all our students are in what we call regular schools, schools with nonhandicapped people and approximately 90 percent of them are in what we call chronological-age-appropriate schools.

That is, your school placement is a function of your chronological age, not your intellectual disability or intellectual level. We think that there are critical, significant and valuable advantages of operating such a service system.

Another characteristic that is extremely important to us is that we think that no more than 1 percent of the population can be called severely handicapped and so no environment should contain more than 1 percent of the population severely handicapped.

If we look at what we have done in the past, we have placed our students in institutions, in large segregated schools away from people with no interactions with nonhandicapped persons, and the results generally have been catastrophic.

So, what we are saying is that if a child lives in a neighborhood he or she goes to a school in that neighborhood, or a school as close as possible to that neighborhood.

Another characteristic is that we used to think how big should a class be, we used to think how big should a school be, how big should a school bus be. We used to think about classrooms, facilities, buildings, buses. Now we are thinking, more and more, primarily because of the influence of Public Law 94-142 and the parent involvement that it mandated, about individual people.

So, the issue is not how big should a home be, how big should a school be, the issue is what should be the life space of a child. How many minutes a day should this child be stimulated? How many minutes a day should this child be left alone? What should this child be taught and why? Where should this child be taught and why?

All those questions that we somehow never get around to getting to. What I would like to do now is take a couple of minutes to talk specifically about what we think are the critical needs for interactions between severely handicapped people, meaning the lowest functioning 1 percent of our population intellectually and nonhandicapped persons, particularly the highest functioning people in our society.

This, Senator, is a slide of two students and they are in a regular playground. This is different than we used to operate. In the past we had playgrounds that only contained handicapped students.

Then we said, when we went to regular schools, let the normal kids go out and play first and then we will go. This is a telling slide for us because of several points. One is, when our students went out there for the first time the nonhandicapped students noticed them right away. We didn't notice them very much but they noticed us right away and they were very cautious.

They wouldn't play on the tires on the side that the children were and after about 2, or 3, or 4, or 5 days the presence of those students became insignificant. They didn't look at them. They knew they were there. They didn't focus on them. They didn't gawk at them. They didn't tease them. They didn't step on them. They avoided them.

This is Rose Mesina and she is a physical therapist in our system, and this student is severely multiple handicapped. The other students in that room are nonhandicapped and there is an art teacher there. This is an art class.

Because this child goes to a regular school in his neighborhood he can now interact with nonhandicapped persons in a wonderfully individualized activity in a very habilitative way.

This student is called various things in various places. If he was living in an institution, or something, he would be in an environment with only children of a similar functioning level. He is not ambulatory. He has severe difficulties keeping his head up. But his friends know. They are normal people in his neighborhood.

These are the people that are going to upgrade the group homes when he gets older. These are the people who are going to be the nurses at the medical clinic. These are the people who are going to be his teachers and these are the people who are going to take care of him for the rest of life, we think.

Because we are in regular schools interacting with nonhandicapped people we get different things that we don't get when we operate in environments that contain only handicapped people.

One of the things we get, Senator, is the eye. The eye is the look in the face of a nonhandicapped person that expresses warmth, that expresses understanding, that says, "Hey, we are together. Hey, let's interact." The eye is the basis of the interaction, all the interactions that follow.

This is a student who is currently dying of leukemia, and these are his friends. One of the things we are trying to avoid is this: This is the situation where one of our adolescent students is learning to use a picture book to shop in a regular grocery store.

There is a little young woman on the side there who is calling out to her mother: "Look, Mommy, look, look." The tragedy here is that this child did not have the opportunity to grow up with people who look differently than she is. She has not had the opportunity to interact with people who are severely handicapped.

This is a desegregated kindergarten which was initially funded by your early childhood demonstration program in the Office of Special Education and now it is a regular part of the Madison School District.

In our community, sir, severely handicapped children go to school with nonhandicapped children from birth.

The student in the middle here has spinabifida which is a severe neurological disease—in his case it is a severe neurological disease. The two students on the right are helping him. They are not just in his physical presence. They are not just tolerating him in the environment. They are physically helping him.

And, more significantly, sir, they are learning how to help him. They are learning that they don't sit him down on the mat and bring him a glass of water. They are learning how to help him crawl over to the water fountain and climb up. They are learning that it is OK to have a barrier for a handicapped person in a public place and that people actually use these barriers.

This is an art teacher in a different school. This young woman in the middle lives in an institution. We have 100 people who live in an institution in our community who come to our schools during the day. This is her nonhandicapped sponsor.

This is another eye, Senator. Fascinating things happen when handicapped people interact with nonhandicapped people. Here is a student that has a handle brace screwed into her skull in an attempt to straighten out some of his spinal column.

And here is a nonhandicapped person and her task, her mission, her objective is to get this kid involved in activities, not to leave him alone while he is waiting for physical therapy, not to leave him in a ward in a dayroom doing nothing, not to leave him alone but to get him involved.

Teachers can't do this. Teachers say you can't give that eye. We don't have the physical skills necessary to maintain this kind of involvement for hours and hours a day.

These are nonhandicapped students breaking their backs doing everything they can to involve a student with severe seizures and severe physical disabilities in a recreational leisure activity on the school grounds.

This is a child who is deaf, who has serious vision problems and many, many autistic-like behaviors. One of the things we have done in the past is put these children on wards with children of similar kind, in schools with only other children that have severe behavior problems and what do we get?

As adults we get adults with severe behavior problems. The thesis now is, our position now is, and the data are overwhelming, that the more you expose these children from birth to nonhandicapped people the less and less likely it is they will develop these skills.

Here is another student who lives in an institution and comes to a regular school for her education. And she anticipates the speed of moving objects. She is in a public roller skating rink. Ten years ago it couldn't be done. Today, unfortunately, in many places they say it couldn't be done. They say she can't benefit. Well, she does.

This is a fifth grader and Sylvia, the young student on the right, is 8 years old. One part of Sylvia's program is to learn how to act in public places, to learn how to use community environments.

She has severe articulation difficulties so she is learning how to interact with anonymous people to order her food, the food, incidentally, that she chooses. The person on the left is in the fifth grade and she is a friend of Sylvia's and that is a part of Sylvia's curriculum in the public school, and that can happen because Sylvia lives in the neighborhood and goes to school in the neighborhood.

And that can also happen because that student knows her, knows her family, knows where to go.

One of the things that people say when we say children should go to school, severely handicapped children should go to school with nonhandicapped children is that, yes, you are always talking about these cute little kids but what happens when they get older? And what about the really multiple handicapped?

I am sorry if this slide doesn't depict as well what I would like for it to, but that young girl is very stiff. The student is obviously fearful. He has severe spasms. And she is learning how to feed him. I don't know what she is going to be when she grows up. She might be a parent of a severely handicapped child. She might be a nurse. She might be a physician. She might be an engineer. She might be any number of things.

But she is learning how to handle that student but she is very stiff. See her elbows? See her fingers. This is another student learning to interact with Roy, a fellow in the room next door to her, and she is also very stiff. This is a behavioral characteristic that we see in many, many situations where nonhandicapped students start to learn how to interact with severely handicapped students in regular schools.

This is the difference, Senator. See the boy with the baseball cap and the student in his lap? He is looking at something that the teacher is doing. There are nonhandicapped students and handicapped students in that room.

He doesn't know that that kid is handicapped. He is rubbing his body. That child is a part of him. And that, physically, emotionally, and psychologically is our objective.

This is Todd. Todd is sponsored by a third grade at this point in the normal elementary school. Todd has no arms and no legs. Todd spends maybe 25 to 30 percent of his day interacting with nonhandicapped peers. I wish we had the time to discuss with you some of the situations that arose from parents of non-handicapped children because Todd is in that room, the attitudes and barrier changes on the part of teaching staff in the regular school. It is because Todd, who is retarded, has no arms and no legs and goes to a regular school.

This is a slide of children who grew up in community schools. You can't find the severely handicapped students but they are there. This is a recess period and they are out rousting about in the playground.

This is a student who comes from an institution ward and this is what he does. We go back to the institution ward and we watch him on weekends. This is what he does. He walks in circles. He self stimulates. He looks at his fingers. And he comes to school. After school he goes back to the institution ward. This is what he does.

The chief concept here, Senator, is the developmental twin, someone with the same intellectual endowment as he who grew up in a neighborhood school with a normal family or a surrogate normal family is going to be different than that child and we now all know this.

I would like to switch gears for a moment to talk about what happens, some of the things that happen as our students become older. We operate an extensive vocational training program that starts when students are 11 or 20 years of age because we only have them until they are 21.

I would like to share with you some of the things that they do. This is at a Red Cross distribution center. Incidentally, Senator, these are the students who, years ago with their developmental equivalence, people would have said: "They can't work, they can't learn, they can't make a penny, they can't even try. They should be deprived of the opportunity to try."

This is a Moose Club and the student is learning to be a bus person in a Moose Club. This is a public hospital in Madison and this student is learning to unpackage things from boxes as they come in.

This student is deaf and blind. He lives, tragically, in an institution ward. He comes to school and this is his vocational experience. It is in a general hospital in the city of Madison.

In an analysis of this pharmacy, which is placed in a hospital, the pharmacist was spending many, many minutes per day unpackaging things as they came in. A deaf, blind student is particularly qualified to function in this way and he is doing extremely well.

Some of the severe behavior problems, the self mutilation, the self stimulation, the scratching, all those things are gone now.

This is a student learning to be a chambermaid in a Howard Johnsons. This is the Madison Civic Center and they are in the mail room. This is a laundry in a hospital. This is a student who for many, many years was laid out on a mat. People thought he couldn't do anything, indeed, deprived him of the opportunities to learn to do things.

I doubt very seriously if he is going to make any money as a custodian when he finishes school but the point to be made here, sir, is that he is trying. You should see him. He can't go to the closet and get the broom, but you put the broom in his hand and you watch him move his wheel chair. If you put something on the floor he will get it.

This is a student as a bus person in a restaurant. Two students working in the laundry of a nursing home. This is Madison General Hospital and these students work in the area of the hospital concerned with sterilizing instruments that were used in operations.

This student works in a newspaper. This is a county garage. This is an interesting student because he currently lives in an institution. They are trying hard to get him out.

If you looked at his behavior file you would find that he bites people, grabs people, climbs up on walls, runs into doorways, breaks glass. In the institution he is a terrible behavior problem.

Here he is eating his lunch in a cafeteria of a public hospital. The differences are astounding, sir. Environments are critical. Here he is working. So, from a life of waste to a place where he can interact in public places and actually make money is the point. I am sorry, my time is up.

Senator WEICKER. Thank you very much, Dr. Brown. I have two questions. What is your opinion of how we are doing under Public Law 142 insofar as this Nation educating its handicapped students?

Dr. BROWN. I think fantastically on a number of fronts. One is when we started 10 years ago when this movement really started in a major way, our students were excluded from school. Now everybody, almost everybody goes to school.

In the past, 100 percent of our people went to segregated school, retarded, handicapped only schools, maybe 85 percent. All over this country people are going to regular schools.

People used to tell me when we first started developing teacher training programs that you can't get good people to work with these kids, you can't get talent, you can't get creativity, ridiculous. Wrong; absolutely not. The brightest people in education, indeed, the brightest people in our society now know what severely handicapped people are because we are in regular environments. We are in environments with other people.

All over this country the most talented people—applications for programs—the grade point averages—any dimension you want to think of, we are getting the talent that we need to succeed.

When we had these people locked up in corn fields and remote places we couldn't get good people to work with them. They would come, look, see, "no, I don't want that". It is different now. When our programs—and 94-142 gave us that. There is no doubt about it.

You demonstrated with the early childhood research that we can get these kids an education. We call it educationally prevent. We can prevent severe behavior problems. We can prevent scissored legs. We can prevent self stimulation. We can prevent attitudes and values from developing both in parents and children and nonhandicapped people that we never thought we could before.

So, you go right down the line of what the research and demonstration on early childhood education, vocational preparation, which was funded as a result of 142 and the acts that preceded. Tremendous progress.

This country is so excited. The other issue is parents used to be told by professionals: "We will take over. We will take care of it. We will do it." No more. No more. That requirement that every parent has a right to participate in the educational program of their children has had astounding results in the quality of life and the quality of education.

So, when you take the talent, the demonstrations, our task now is to pull it together. It is no longer do we have to demonstrate that severely handicapped people can live in communities. No longer do we have to demonstrate that they can work. No longer do we have to demonstrate that they can interact and benefit from interactions with nonhandicapped people.

That has all been done. That is being done all over the United States. What we have to do now is pull it all together—a little bit here and a little bit there. Now, our task is to come up with comprehensive community services for everybody.

Senator WEICKER. Can all severely handicapped students be served in regular public schools?

Dr. BROWN. No doubt about it, sir. The only way to answer the question is to come see. We could sit here and argue and talk, but you should see. These I have shown you I think are the most severely handicapped persons you are going to find.

Kids who used to have tubes in them, they don't have tubes in anymore. Kids who used to eat their hands, they don't eat their hands anymore. Kids that do all these things that you hear about, within an institution in the middle of a corn field someplace because these kids can't be served in regular schools, no.

We are putting in millions and millions of dollars in oil transporting these kids to and from segregated schools when they can be taken by their brothers and sisters, when they can be wheeled by their neighbors at no cost at all, because people feel these kids can't go to regular school.

But, you take almost every State in this union and I can point out a program to you where severely handicapped people are functioning extremely well in regular schools.

Other advantages: We are not preparing the future parents of severely handicapped children. We are not, as long as we keep these kids out of regular schools. We are not preparing future nurses, future physicians, future teachers as long as we keep severely handicapped children out of the schools.

Where is the talent in the future going to come from to take care of these children? It is going to come from those regular schools and the sooner we get to that dedication and creativity the better off we are going to be in the long run.

And that is the least restrictive environment. That is what the clause in Public Law 94-142 has given us, that children should grown up with nonhandicapped people whenever possible. That is access.

Senator WEICKER. Would you like to qualify your statement to the extent that all severely handicapped students could be served in regular public schools assuming that there is adequate funding?

Dr. BROWN. No, sir. I think it is cheaper.

Senator WEICKER. In other words, you feel that the job could be done for the most severely handicapped even in the absence of rather substantial funding?

Dr. BROWN. I know school districts that plan to build school buildings but they couldn't get the money and they couldn't afford the transportation costs so they started serving their kids in the regular schools. The kids are doing better.

So, you don't want to put your money into ceramic tile, stainless steel, oil, bricks and mortar. There are buildings all over this country half empty. What you want to put your money into is talent, curriculum development, research, demonstration.

Senator WEICKER. I don't argue that point with you. I just wondered whether or not it would be sufficient to rely on the volunteer assistance either from without or within the classroom to take care of these situations which clearly require more of a one-on-one type proposition in terms of professionals.

Dr. BROWN. Well, sir, I think every child deserves the one-to-one attention of attentive and sophisticated adults. But to say that these children need one-to-one all day long is not so. In fact, it is counterproductive.

When we get down to issues of curriculum, clearly these people need to learn to interact with each other. Clearly they need recreation and leisure skills. Clearly they need to function in group settings, and they can.

The old assumption that these kids should be with only experts so they can have one-to-one instruction, we used to believe that, sir, and then we started counting the number of minutes per day that these kids actually got touched by someone else, rubbed by someone else—miniscule in relation to when we started putting these kids with normal kids.

Senator WEICKER. All right, then, my last question would be if what you say is so, why don't we go to what it is that you are suggesting?

Dr. BROWN. I think we are. I think that was the force of the law. I think States all over this country—we could sit here for a long time—I am thinking of California, Oregon, Washington, Minnesota and Alabama. We are. Clearly we are going that way.

We know now these kids can survive. They can flourish much better.

Senator WEICKER. I am not arguing that point with you. For instance, would you suggest that the institutions devoted to the care of retarded would prefer to keep themselves in the business at the expense of the welfare of their clients?

Dr. BROWN. I think there is an element of that. I think we have monuments. I think the people who have made decisions personally and professionally are hard to change. I think there are many other reasons for that.

I think people are committed to jobs and, in many cases, legitimate professional judgments. I just think they are wrong. When you talk about the individual development of a person—take any person no matter where he or she lives. Let's talk about that person and what life space is most habilitative for that person.

Anything that you can do in an institution we can do in a community. And, not only that, sir, we can do things in a community that can never be done in an institution. I tried to show you some of those things.

Senator WEICKER. I have no further questions.

Dr. BROWN. Thank you, sir.

Senator WEICKER. Thank you very much for a very good presentation.

Mr. NERNEY. Senator, I would like to introduce Dr. Thomas Bellamy, associate professor of special education and rehabilitation of the University of Oregon. Dr. Bellamy is also a member of the President's Committee on Mental Retardation.

Senator WEICKER. It is my understanding, incidentally, that, am I correct, Tom, that your witnesses all come here at their own expense?

Mr. NERNEY. All of our witness have volunteered. sir.

Senator WEICKER. They all volunteered to be he. I think that is certainly proof of their commitment to the cause which they serve.

This is Dr. Bellamy of the Center on Human Development of the University of Oregon. Dr. Bellamy, it is good to have you here in Connecticut and please go right ahead.

STATEMENT OF THOMAS BELLAMY, ASSOCIATE PROFESSOR OF SPECIAL EDUCATION AND REHABILITATION, CENTER ON HUMAN DEVELOPMENT, UNIVERSITY OF OREGON

Dr. Bellamy. Let me, first of all, say that I sincerely appreciate the opportunity to be here. I understand that the impetus for the hearings comes from Connecticut but I think the issues that you are raising are nationwide ones that many of us have devoted a great deal of attention to. I appreciate being included.

Senator Weicker. Not at all. You are entirely correct. These hearings are hearings of the U.S. Senate and even though they are being held here the principles that we are discussing here will be taken in the context of being nationwide.

Dr. Bellamy. Although I must admit that as I listened to your opening comments this morning it occurred to me that a letter of support for you might have sufficed as well as an airline ticket. [Laughter.]

The focus of my presentation is on the potential that severely and profoundly handicapped people have for community living, have for participating in a life and the work of the communities that they live in.

I am focusing on adults because I think after H. 21, after entitlements to public school and children services run out that the final test of our success and the final cost accounting really has to be made. I am focusing on severely handicapped people because I think this is the group, because of the extreme difficulties they present both to their families and to parents that serves to bring into focus the most critical issues that we are facing in terms of policy and program design.

What I would like to do is to try first to frame a bit the issue that I think we are all addressing. Second, to look at the record that has been compiled since the three laws that your subcommittee is responsible for have been on the books and earlier with the national commitment to deinstitutionalization.

And, finally, to look at some of the work that I have done at the University of Oregon as an illustration of the points that I am making.

The basic human issue that is raised in any discussion of alternative strategies is what sort of life is appropriate, affordable, reasonable, desirable, what have you, for people with handicaps. What represents a quality adult living for those individuals?

In a broader context, our society has answered that question for the rest of us several times. We are, as a society, willing to enter major conflicts to protect our life, our liberty and our pursuit of happiness.

Those same values, those same issues apply equally well to individuals with handicaps. And the real issue that we have to deal with is how those get operationalized in day-to-day living. What is the framework available for that? How much of it is built on the experience that we have had in the last 10 years in providing services, how much of it deriving from the concept of normalization?

We believe that the opportunity for continued growth and the opportunity to participate in ongoing community life, the opportunity for a safe and healthy environment and the opportunity for productive work represent the goals which we are striving for and represent a framework which might provide a basis for national policy or for explicit national goals in the fields of mental retardation and severe handicapping conditions.

On the basis of our experience so far, where are we? The first and, I think, most powerful thing that has come out of the last 10 years is a very clear demonstration of the potential of severely handicapped individuals, all severely handicapped individuals to develop skills to continue to grow, to overcome major behavior problems that no one ever thought possible a very short time ago.

I think that it is important to reflect on why that has happened. As community services were confronted with problems that we had never dealt with before as a result of either the Development Disabilities Act, or Public Law 94-142, or sections 515 and 504 of the Rehabilitation Act—as these pieces of legislation confronted community service providers with problems that were unfamiliar to us we developed solutions and strategies and technologies that raised the level of expectation of individuals themselves, of their families, and of the professionals far beyond what had ever occurred before.

Technology development occurred in a very real sense because of the challenge that those pieces of legislation presented to community services.

We now are thoroughly convinced that every severely handicapped person has the potential to develop the skills needed for daily living, for participation in community life and so forth.

The question must arise, does this really apply to everybody? I think the answers to that are, first, a resounding yes, but underneath that a level of complexity that bears some attention.

I believe that if our experience in several States bears out nationwide, and there is very little reason to believe that it wouldn't, for every person now served in a restricted environment in a segregated school, in a segregated adult program, in an institution, we will find an functional twin somewhere else who has benefited incredibly from integrated community services.

But the honest second answer of that is that most of us who are involved day-to-day in service delivery confront some very bewildering people. The job of technology development is not over but if we establish policies that take those bewildering people out of our programs the job of technology development will stop, or at least the impetus for it will.

The real test of all this though comes not in what someone can learn but in what sort of life they have. And I think it is here that the dramatic potential of integrated community situations becomes very clear.

People in small community programs, adults who are severely handicapped in small community programs, can and do travel independently in their neighborhood, can and do select and purchase items from local stores, can and do take work breaks in downtown coffee shops, can and do work outside their home, attend church independently, jog with nonhandicappped peers, and on and on

I submit that the services that we provide are only half the picture. The other half is the opportunities that our society provides to everyone. It is only at the point that those intersect that we really achieve the outcome for adults that our whole service network is designed to solve.

It is the proximity to those opportunities and it is the flexibility in staffing and facilities and so forth in community services that allows severely handicapped people to enjoy the fruits of their labor.

Rather than endure treatment as eternal children preparing continuously for some distant goal of participation or mainstreaming, people with severe handicaps in community programs have the opportunity to use the skills that they have in ways that enhance the quality of their life and contribute to the quality of those around them.

There is a great deal of data that I won't go into that suggests that, in fact, this skill development does occur more rapidly in small community settings, that community settings over and over again have been associated with improved health status, with increased family contact, with increased participation in the planning process that determines individualized programing, and so forth.

But, let me turn to work. The importance of work is chronicled in our history, at least, given your comments earlier today, by every civil rights group that has advocated for itself in this country.

We have moved very quickly in the literature of every one of those groups from an emphasis on equality to an emphasis on work opportunity. Given our demonstration that severely handicapped individuals can learn the skills necessary for work, they, too, join the rest of us in society whose options really depend on the status that is provided by our employment and the opportunities that are provided by our wages.

Let me very briefly describe some of my research. We began at the University of Oregon 8 years ago to try to solve what we thought was a very pressing and difficult problem.

In national statistics we have something like 100,000 people who are served in programs called adult day programs, developmental centers, day activity programs, programs for people that presumably have no work potential.

And faced with fairly clear data that that wasn't necessary, that those individuals did have work potential, we set about trying to design an alternative to that, an alternative that would allow individuals to work at the level that they were capable in a structured, supported community situation.

The people that were included in the program in a group, gradually from 3 or 4 people to a total of 15, were all considered severely or profoundly retarded, all considered, in fact, at the outset too handicapped to be served in the State's day activity programs either in the institution or in the community.

They represented extreme behavior disorders. The files were full of things like: "Let's don't try this person on any other work situation," and that sort of thing.

We live in a situation that is not blessed by the best economy and we went as far as 5 and 600 miles away to identify a market for electronics work and began the process of teaching nonverbal, severely and profoundly retarded individuals who had extreme behavior problems to assemble such tasks as oscilloscope cam switch actuators, cable harnesses, chain saw components, circuit boards, computer printer frames, transformer coils, power supply units, and so forth.

Last year, those 15 people earned a combined wage of $18,371, something like four times the average for their much more capable counterparts in work activity centers in the country, something like three times the national average for all people who are called mentally retarded in sheltered workshops.

And, I think, perhaps more significantly, that program now has been completely replicated in communities in six Western States. It is not dependent on the extra resources available to the university or anything else. It is clear what we have done is take only a very small slice of the possible work opportunities that severely handicapped people could benefit.

But, I think the results of taking that slice and doing it systematically speak for themselves.

The way I would suggest we deal with this data are to affirm that severely handicapped people do have potential but to be honest that not everyone who has been served in community settings in the last 5 or 10 years have enjoyed these kind of benefits.

I think the policy and program issue that we are faced with now is where to attribute those difficulties. The data seems clear; we cannot attribute those difficulties to either the readiness or the potential of handicapped individuals.

If we honestly look at the results of the last decade we must attribute the difficulties to the service system itself and to the ability of that system to adapt to developing technologies and to put together the complex set of interlocking community services that are needed.

I think as we attempt to deal with a continuing need for program development in times of less than abundant resources it is important to take a look at all aspects of what we have done before.

I am convinced that one of the critical things that must be solved is that, let's call it an underlying idea of readiness that seems to pervade an awful lot of Federal and State programs right now; our services are designed to prepare a person, to prepare a person so well that he or she can participate without any further support in the mainstream of community life.

Let me tell you what that does to severely handicapped people. It sentences them to indefinite preparation, getting ready in institutions for regional centers, getting ready in regional centers for group homes, getting ready in institutions for day activity programs, getting ready in day activity programs for workshops, and on and on and on.

In fact, what it does is sentence people to programing in the least efficient environment for what we know about severely handicapped individuals is if we want them to participate somewhere, we start there, we provide the support and we withdraw that support as we can.

Let me conclude quickly. We do have the technology to allow severely handicapped people to participate in the mainstream of community life. We have the potential to allow them to affect the rest of us.

But, the personal results are probably even more impressive. This individual entered our program in Oregon after something like 30 years in a State institution. He has been called schizophrenic, autistic, profoundly retarded, nonverbal, dangerous, and several other things.

After a few years in the programs he is now competent on something like 25 separate electronics assembly tasks, has earned more than $100 a month for the last 3 or 4 years, not without support. He threw a television through a plate glass window in the group home not too long ago, but those are difficulties that, in fact, qualified staff have been able to deal with. He doesn't need to be segregated because of one behavioral incident in 5 years.

Another individual spent almost as long in an institution. He has Down's syndrome, is nonverbal, was characterized by a loud high pitched screaming in the institution ward hour upon hour. He now is the individual I referred to earlier that jogs independently, goes to church by himself, buys things at a neighborhood store, and so forth.

That concludes my testimony.

Senator WEICKER. Let me ask one basic question with a few parts. I have seen quite a few slides here this afternoon but I haven't seen yet the kind of severe, catastrophic situation which I have seen in bed.

Point No. 2: I heard the term "families" mentioned in supporting the family. What if the family doesn't want the individual? What about the situation of the older person who doesn't want to leave?

And, then, lastly, what about the community that doesn't want to involve itself?

Dr. BELLAMY. I will defer part of those, if I may, to people who come after me who might be able to address some of them better than I.

Senator WEICKER. In other words, what I am saying, I suppose, is I don't think you have to convince me either as to the goal or what is the most desired result. I just think we are dealing with certain fact situations that don't necessarily lend themselves to what we would like to have done.

Dr. BELLAMY. Let me answer that in a roundabout way. There is a person who is very active politically in the State of Oregon who is an adult, was one of the people who returned from an institution through our program.

That person had had no family contact for several years. And, in fact, today has family contact every few months or something like that I discussed that once with the family and essentially said this. It is very abnormal in our society for adults to have daily contact with their parents. It is very abnormal in our society for parents and families to make all the decisions for an adult. That, in fact, what was happening is that we were providing an opportunity for that individual to live with fewer restrictions and providing an opportunity—no more than that—for the family to take advantage of the fact that there were fewer restrictions, there was no coercion for that kind of contact.

What we found is that it has happened over and over again voluntarily. The other side of that, and I think a point that needs to be made in relation to your comments just before lunch, is that we are faced with hard choices, that the sort of brutal budget decisions that have to be made will force us to deal with some issues that we would prefer not to deal with.

We have two parallel service systems, both designed to do essentially the same thing by the original founders, one fairly segregated and one quite integrated. To the extent that we choose to maintain investment in both, we would probably do a mediocre job of everything.

To the extent that we are able to choose one or the other, then we can offer some security to parents who now have children of school age that something might be available as adults.

The point is that overuse of institutions creates further overuse because in times of fiscal crisis we won't be able to have the community opportunities for people after they leave school unless we make some of those hard decisions now.

Thank you.

Senator WEICKER. One last point, however. All of us in this room are sitting here trying to determine the way to go. Maybe there is not so much debate upon that as there is, when do we go and, yet, the other side of the coin is that in this time of restricted resources, as much praise as I have heard for Public Law 94-142, make no mistake about what is going to happen and what already is happening, which is we are going to find out how we can fudge on Public Law 94-142 as between the persons who share our concern and those who are, according to the world, "normal".

So, there really is another fight, is what I am saying, that I see taking place and I make no mistake about it because these funds. you see, come to pass by virtue of what we call politics and politics involves itself with majorities.

Dr. BELLAMY. It is an interesting phenomenon that in each of the communities that has experienced some of the kinds of programing that we described today a consensus has emerged that has become incredibly supportive of that. Perhaps it is a fault of all of us that we fear the unknown a bit but I think if we take time to look at the situations around the country where we have programs of the kind that would show it, they have had a political impact as well as a personal and social.

Senator WEICKER. Dr. Bellamy, thank you for coming all the way from Oregon. I appreciate it.

Mr. NERNEY. Our next witness is Karen Green of Glenwood, Iowa. Karen has been a consultant for 22 States and the Government of Canada, especially in the field of providing services to persons of profoundly handicapping conditions.

Senator WEICKER. It is very good to have you here.

Tom, I am beginning to get a little concerned. I am telling you what our problem is as I see it coming down the road here. And I am at fault too. Obviously I enjoy these discussions between various witnesses. But the hearings were scheduled originally to close at 3:30. I don't intend to do that. We will keep going till 4 o'clock but I think that is going to be——

Mr. NERNEY. We will speed it up.

Senator WEICKER. Please believe me when I say, far from wanting to cut anybody off, I can sit here well into the night and, indeed, I will be back here at this stand tomorrow. I don't intend to foreclose anybody but just understand what the constraints are.

Please, Karen, go right ahead.

STATEMENT OF KAREN GREEN, CONSULTANT, TRAINING OF DIRECT CARE STAFF

Ms. GREEN. Senator Weicker, I thank you very much for the opportunity to share information about the needs of the catastrophically involved persons that we have spoken of.

I have been in the field of mental retardation for the last 16 years and am a little hesitant to mention that I have, for all of that time, worked with people who are both severely and profoundly retarded, who have medical complex needs and largely in the last several years, who are also, in fact, adults who had been institutionalized for very long periods of time.

I am currently a full-time consultant and I travel approximately 150,000 miles a year helping individuals move severely and profoundly, multiply handicapped young people and adults out of institutions into small community settings where, I will be very straightforward, I think they belong.

First of all, it probably is helpful and, again, in describing individuals who are severely and profoundly retarded and multiply handicapped, it is very difficult because literally the only thing that strings these individuals together is the diversity of their need.

Persons who are identified as "severely and profoundly retarded" are usually awarded the label at birth or in early infancy. And truly, persons who acquire this diagnostic description do present problems in mobility, self-care, language, health, and many other areas.

Unfortunately, the diagnosis itself can become a major obstacle to developmental growth, because it often means a diagnostic dead end instead. Many medical and behavioral professionals are woefully ignorant in the area of developmental disability. The diagnosis is frequently interpreted as being synonymous with hopelessness rather than a temporary means to identify obstacles that can be removed one by one. So the helper's door slams shut. Self-fulfilling prophecies such as these have denied service access to hundreds of thousands of persons who are classified "severely physically and mentally handicapped." In many places, an individual's mental retardation is an acceptable rationale for denying services—such as corrective surgery—which "normal" youngsters receive automatically. We know how to solve a majority of the clinical problems presented by the seriously handicapped. Often we simply choose not to provide the service.

> The very factors which cause an individual to be labeled as severely/profoundly handicapped also can prevent that individual from receiving programing of sufficient intensity and duration to enable acquisition of essential skills. A great deal of information is known about what types of medical, therapeutic, and educational interventions can assist the handicapped individual in skill acquisition. However, institutionalized handicapped persons can frequently be found not to have had surgical procedures which would help them walk or have not received regular therapy services because they are too low to benefit. [Bricker & Campbell.]

Many maintain that persons with severe physical and mental disabilities must always be cared for in large group settings. It is for this very population, some believe, that larger single purpose institutions should always be with us. A growing number responsible professionals now believe that the more complex the developmental problem, the smaller the setting should be.

When disability strikes early enough in life, such trauma dramatically impairs the young person's developmental sequence. An individual injured in adulthood may have to "relearn" sitting balance, but memory or previous movement and how the body feels in space may make that a conquerable task with short-term help. Consider the case of Mark, a young child whose story illustrates the scope and nature of what the helpful service continuum should be.

MARK

Mark was born on April 5, 1974, in a small town in a large Western State. When he was born his condition was apparent right away. Hydrocephalus is a condition in which there is an accumulation of fluid within the skull. The head enlarges because fluid accumulates in the iner chambers--ventricles—of the brain, causing pressure on the soft unknit bones of the skull.

Mark's parents were told by their doctors that he would not survive early infancy, and that they should take him home and care for him as best as they could until his "time" came. They did not know, nor, were they told, that a relatively simple surgical procedure could arrest or even reverse the accumulation of cerebrospinal fluid on the brain. Because Mark seemed so damaged, the doctors assumed that surgery would be a waste of time. Mark's parents moved within a few months to another State. This happened to be a State which had developed a very comprehensive community service network for persons with developmental disabilities. But Mark's parents did not search for services at first. They had no reason to believe such effort would do any good. mark was not supposed to survive his first year of life.

LACK OF EARLY INTERVENTION COSTS A LOT

Mark had severe brain damage and a number of other physical problems resulting from this significant birth defect. Mark could not move his head without assistance, and his muscles were very floppy. The weight of his elevated head pressing down on the spinal column was sure to cause serious, abnormal back curvature if poor body posture was not aggressively interrupted. This deformity, called scoliosis, also "scrambles up" the lungs, heart, and digestive system because of excessive pressure on those organs. Such compression on the lungs makes breathing difficult, and impairs sucking, swallowing, and chewing.

It became easier for Mark's mother to let gravity do the work of swallowing while he lay reclined with his neck tilted back. She hadn't enough hands to hold him correctly and manipulate the spoon at the same time. Without instruction, she had no idea how to assist Mark to suck and swallow correctly.

AREAS OF MAJOR LIFE ACTIVITY

Mark had "substantial functional limitations" which would surely persist throughout life. The impact of so much stress at such a crucial period of life left little energy for the hard work of leap-frogging developmental milestones. When so much goes wrong with a little person's neurological system at such an early age, the growth sequence can be devastating. Mark was referred by the welfare department to the community service agency, and was evaluated for services. He was quickly admitted to a very small community residential program for severely handicapped children. Mark was also evaluated by a team of developmental specialist to determine in what other ways he needed help. The process of preparing Mark to return to live in his own home required almost 18 months. Initially, sores on Mark's head were infected and very difficult to heal. He required 3 months of treatment before he could be subjected to a shunt procedure. After surgery, the staff began to experiment with various types of adaptive equipment to facilitate a broader range of developmental growth. This required close cooperation between the physical and occupational therapist, a special adaptive equipment, and the residential staff.

The agency which provided Mark's residential services also administered a range of other specialized services which made planning efforts for Mark much easier. The interdisciplinary team which evaluated Mark before his entry into the residential service unit consisted of a group of specialists; and occupational therapist, a physical therapist, a pediatric nurse, a speech clinician, and a psychologist. One member of the team was assigned to translate and implement the special services Mark required with the residential staff and Mark's parents. Parts of the program were taught directly to the staff as such activities fit naturally into the pattern of the everyday living schedule.

One of the first priorities for all involved was to work on developing independent swallowing and sucking with Mark. He had previously been fed in a reclining position with gravity doing most of the work of swallowing. He had only been able to swallow thick liquids at first. Moving into a more upright position allowed the staff to introduce Mark to a diet with more texture. The staff used straw draining to initiate an independent sucking pattern, and allow Mark to graduate to a more sophisticated pattern of eating. Such preventive measures also protected Mark from accidentally sucking fluid into his lungs while he ate.

The physical therapist also taught the residential staff to exercise Mark. They learned how to relax muscles before mealtimes; how to exercise his joints and muscles so they would not freeze into permanent disuse. Within a few months, the program planning team was able to establish other developmental goals as well, and Mark's parents were ready to begin preparing to take Mark home.

Going home meant that Mark's parents had to learn some new skills, such as lifting and carrying, exercising and relaxing techniques, and how to feed Mark properly. This was not a quick or simple process. Much of developing Mark's program consisted of trial and error, and try and try again. One of the biggest staff challenges of working with a child like Mark is remaining flexible and admitting when an approach or technique doesn't work. The staff and family don't ask "if" we can complete the task, they ask "how" can we complete the task, and then, do it.

Mark is now going to an integrated preschool during the day. He and several other handicapped children attend a community preschool for nondelayed children. Mark has the extra help he needs in the preschool setting. A resource teacher is provided by the same community agency that provided Mark's other services. He has learned to suck and swallow independently and is now eating a regular diet with relative ease. He is learning to chew. Because his body is growing and his head condition has stabilized, his appearance looks less distorted now. His parents are doing well at managing Mark at home. Mark is not cured, and he is still severely retarded. But he is valued. He is growing and changing and getting better at a lot of things.

I would like to introduce to you a friend of mine who now lives in an apartment in a large eastern city. She is characteristic of another type of individual that many maintain that the institutional system must always be maintained for. Ruth spent the first 26 years of her life lying flat on her back either in a bed in the institution or on a mat on the floor. If we needed a diagnostic "label" for Ruth, we would probably describe her as spastic quadriplegic, cerebral palsey with multiple flexion contractures of all joints, bilateral hip dislocations, and a severe kypho-scoliosis of the spine. Now for most persons, all that hodgepodge of labels provides is an enormous scare and an intense desire to run in the other direction. Ruth came into the world with damage to the motor centers of her brain which caused a short circuit in the ability of her muscles to lay down increasingly complex patterns of movement that the ordinary child evolves in the first 15 months of life, and perfects over the first 5 or 6 years.

She didn't arrive with the deformities I've just described. Her joints and muscles looked the same as any other child's, and her sense of hearing, sight, taste, and smell were largely intact. What happened is that certain types of movement caused Ruth to experience muscle spasms. There were no services to help Ruth's mother learn how to handle her in ways that would prevent this increasing spasticity from occurring. Pulling on an arm or tugging on a leg began to send her head in the direction that caused the body to tighten even more. It became easier to leave Ruth in her crib lying on her back for longer and longer periods of time. Gravity began to squash her chest, interfere with her moving on her own, and causing her to become stiffer with each passing week.

In the early 1950's, we didn't know very much about how to help persons like Ruth, and her family was advised to give her up quickly before they became too attached. In the days when Ruth entered the institution, there were often 50 children in a ward and only 1 or 2 staff to care for them. There was no choice but to provide 3 basic meals per day in the quickest way possible, and little else.

Joanne was left to lie on her back 24 hours per day. By the time she was 7 or 8, lack of movement and the effects of lying in one position forced her hips out of their sockets, her arms and legs to freeze in a bent position, and her back to collapse in an "S" curve. By the time she was 26 years old, she had only two independent movements left in her body. She could not turn, sit or move at all without total support. She could not participate in dressing, toileting, feeding, or any other activities. She could turn her head slightly to the left and she could blink her eyes. In 1972, her institutional file described her as a profoundly retarded, spastic quadriplegic with multiple deformities. The recommendation for "treatment" was "long-term custodial nursing care." She was perceived as a candidate for a geriatric nursing home as her "form" of community placement.

However, Ruth was lucky. The facility in which she lived happened to believe that all persons, regardless of their degree of disability had a right to live in the community in as normal for their age as possible setting, and it was up to the staff to figure out how to make that possible.

Several staff members noticed that Ruth consistently blinked at a furious pace whenever anyone came near her. One day a speech therapist asked, "JoAnne (Ruth), are you trying to tell us something when you blink your eyes?" A speech therapist began to work with her, and taught her to respond in a manner that would indicate yes or no. She too received the special equipment necessary to assume an upright position. She learned to use a special communication device driven by her lateral movement.

In 1979, Ruth moved into an apartment in a neighboring city. She still has only two independent movements in her body. She still has contractures and spinal deformities and dislocated hips. But now she has a specially adapted wheelchair, a personal care attendant, transportation and a day program. She lives with another friend who is almost as handicapped as she is. Across the hall, in another apartment, are two men with similar handicaps, and similar services.

For all these persons we would have thought these things impossible only 10 years ago. But in an era with the technology to place a man on the moon, is it so difficult to conceive that a person who is incapable of independent movement might be able to live in an ordinary home. There are few persons so handicapped that services provided to ordinary citizens cannot accommodate their needs. Some extra services need to be woven into the framework of ordinary community life, such as the provision of equipment to assist in movement, the modification of transportation to allow handicapped persons access to the larger world.

It has been our experience that the severely handicapped can be served by persons with ordinary education and training where they live, work or go to school, so long as these staff persons have regular access and support from professional specialists to help them eet their clients' individually identified needs. This is perhaps part of the magic of small living situations where two or three persons with severe disabilities are served by a minimum number of staff. There are fewer persons needs to meet; fewer special handling techniques to learn, and the handicapped person has a greater chance to feel trust and security in the persons upon whom he or she may be totally dependent.

We have tried in many institutional settings to approximate normal homes and family patterns. We have spent enormous sums of money to fabricate schools and work settings in isolation from the essential elements that give severely handicapped persons the incentive and models to achieve independence. Children learn from other children and the same life experiences that other children experience. Adults need peer models and demands and a few hard knocks to feel good about their lives.

It has been my fortunate experience to work with catastrophically impaired persons in community and institutional settings throughout most of the United States and Canada. I have worked with such persons in schools, in their natural homes, and in group residential settings. I have seen them achieve in work settings, and where creativity supports are provided, in integrated, competitive employment. There are some characteristics of service systems which seem to help persons develop and change:

One, the agency uses the assessed needs of clients to design services.

Two, the agency has a sufficient array of services to meet those assessed needs.

Three, services come from generic agencies whenever possible. Clients and their families should have guarenteed access.

Four, there is a coordinating system which insures that needed services are delivered and maintained.

Five, there is a strong quality control mechanism which evaluates services and indentifies problems.

Six, programs are dispersed and integrated and provide for continuity of service.

These features imply that many existing community systems must come together to plan and coordinate their unique service. Client centered planning, or asking what does the individual need to grow and develop, should be the vehicle around which all services are built.

The common demoninator that binds these creative service providers together is the unyielding belief that all humans, regardless of age or disability, retain the capacity to move along the development continuum given the right kind of help. When that development does not occur, the person with the handicap hasn't failed, we have.

WHAT DOES THE CLIENT NEED

Persons with developmental disabilities are still being put away in institutions. Families and professionals still believe that there are "Treatment Temples." If an institution/agency has a concrete building, there must be magic inside. Responsible professionals must dispel such myths and acknowledge the superiority of the family setting. There is no group home or institution that can ever replace a nurturing home. Parents must hear that they have the best magic and support should be provided to make that a reality.

Provide concrete services across developmental continuum. We expect normal children to grow, and they do. At 5 they go to school, at 6 their teeth fall out, and at 10 they go to camp for a week and survive without us when we wish they couldn't. They are milestones, schools, churches and dentists for children without labels. Children with spastic limbs and crossed eyes pose for posters and must appeal to charity for second hand wheelchairs.

Handicapped children who can go to to school at the same time other children do and have doctors and other typical services to tend to their needs in a helpful way seem to keep homes to live in as well. When handicapped children have access to the same services as other children during their growing up years, with extra services provided as they are needed, they seldom have to be removed from their own homes.

We have been far less than creative in providing services in the homes of severely handicapped children. In-home support services such as homemaker services, parent training, special devices, and trained babysitters can do much to keep natural homes viable for children with extra special needs. We should not ask if the child can remain in natural community settings. We should ask how the child can remain in natural community settings. We should ask how the child can remain there, and then the mechanisms to make that possible.

Senator WEICKER. Let me ask you this question: If a young lady or young man had the same condition today would the same treatment apply in the sense of being put on the mat and left there?

Ms. GREEN. In some places but decreasingly so because the technology that has been evolving over the last 7 or 8 years in the field—we cannot only prevent this from happening in the first place but we can do very much to improve the situation of individuals.

For instance, if you have hip dislocations, joint contractions and those kind of things, we know how to surgically repair those persons and make them more mobile. We know how to literally apply daily management techniques so that we can reduce the frequency of catastrophic infections that these individuals acquire because they don't get to move.

We have been able to demonstrate in places all over the United States that even the most severely physically handicapped—I have seen persons whose chests had literally been flattened by gravity over time can be made more mobile. We have been able to change the shape to mobilize those individuals, to pull them out into disperse community settings.

One of the points I want to make the most is that—this is the same lady, by the way, 2 days later. I don't know if it is particularly obvious to you because we try and do this very subtly, but she was provided with a piece of special adaptive equipment.

It doesn't take very much imagination to make a person more attractive if you try really hard. She still has only those two independent movements in her entire body. She has a slight lateral head turn and she can blink her eyes. But the fact is, in this particular institutional facility in which she lived a decision was made that she had the right to live in a community and so then the process was to make it possible for her to go there.

My speciality over the last several years has been in teaching ordinary persons without special clinical skills to handle, manage, program, and make it possible for persons like Ruth to live in very small settings.

The advantage to Ruth in those kind of situations is that in particular she is devastated by multiple handlers. That is, having too many people laying their hands. She has some very specific needs. She has some very specific requirements that have to be taught to only two or three individuals.

Where we have gotten into trouble and where we have watched these individuals regress over time, and the paradox of the increase in staffing patterns in institutions, by the way, is that we literally multiply the number of individuals who lay their hands and impose themselves on this person who is totally dependent on others.

The advantage that we gain clinically from moving people out into very small settings is that we limit the number of people we have to train to her very specific needs. We limit the number of environmental impositions. This lady still has a startle reflex so that every time something clashes in the environment she startles and her muscles tighten.

The magic about living in a house is that it is generally carpeted and there is generally smaller rooms and fewer people there and so you don't have to deal with those same environmental kinds of management issues we do here.

My point is that over time we are not going to see, I hope, persons with the devastating levels of disability of Ruth and other kinds of persons because one of the things that I see the most consistently with the early intervention programs that are now progressing and with the kinds of handling and retaining more seriously handicapped persons in their homes is that we simply aren't seeing this level of severe disabilities.

So, this is a population of individuals who, to some degree, are sort of passing. The only disturbing part of that is that I am often stumbling into pediatric nursing homes where children are being slipped into horizontal positions, again being left to lie on their backs in the supposition that these children are too handicapped to learn and that all they need is a bed in a corner someplace.

I find that enormously distressing because we will again produce a population down the road that will have the problems that Ruth does when we know how to prevent them.

Senator WEICKER. I agree with you that that is going to happen, unless you are willing to go ahead and put your money out on the table and take the more expensive road, which is what you are describing here. It is far easier, if you have no hope for the future, or no goals to set for yourself, to drop somebody in bed.

Ms. GREEN. That is right.

Senator WEICKER. That is going to be very much at issue in the months ahead.

Ms. GREEN. I know. And the paradox is that caring for persons in a horizontal position does not necessarily prove to be that much less expensive.

Senator WEICKER. You are probably right on that point, too. There is no question about it. My whole argument on the raising the budget—I might add, in which Senator Hatch joined me and we sat down and discussed it—it was, here is an administration that is dedicated to productivity. If you want to have productivity, the money spent in this area produces citizens who actually can be put back in the mainstream and, in some ways, as has been testified here, earn money as compared to the cutting back and having persons that lie in bed.

Philosophically, those of us that are pushing for the additional funding in this area are in tune to the philosophy of the times but funding, that takes another direction.

Ms. GREEN. Sir, this is the population that most people maintain that the institution will always have to be kept around for. Again, my position relative to that is you then begin to say, because people don't get better in congregate care settings that all we have to do is pile in more staff, and more staff, and more staff, and so the expense keeps going up, and up and up.

I will frankly tell you that what these individuals need is not one-to-one or all kinds of staffing persons but what is needed are staff adequately trained to handle persons like Ruth, who are seriously handicapped. It is not the quantity. We tended to substitute quantity for quality in a lot of ways and that has driven up costs tremendously.

Senator WEICKER. You say you have been seeing these pediatric nursing homes on the increase. Why is that?

Ms. GREEN. The United States is very interesting in terms of how it locates services. You never see pediatric care facilities in States where the ideology and the commitment is to developmental continuance.

I see these facilities primarily in States where there is no articulated philosophy about how a person should be served. I won't name the cities.

Senator WEICKER. What do you think is going to happen then under a block grant philosophy?

Ms. GREEN. It scares me a lot.

Senator WEICKER. Thank you very much.

Mr. NERNEY. I am now going to ask four persons: Sister Barbara Eirich, director of the Community Resource Center for the Developmentally Disabled in the Bronx, N.Y.; George Gunther, who is the superintendent of the institution for retarded persons in the State of Rhode Island; Mrs. Lavasseur, the immediate past president of the Ladd School Parents Association of that institution; and, Rachael Rossou, who is a mother of the Alpha Omega Family here in Ellington.

STATEMENT OF BARBARA EIRICH, DIRECTOR, COMMUNITY RESOURCE CENTER FOR THE DEVELOPMENTALLY DISABLED, BRONX, N.Y.; GEORGE GUNTHER, SUPERINTENDENT, DR. JOSEPH H. LADD CENTER, RHODE ISLAND; EILEEN LAVASSEUR, PARENTS ASSOCIATION, DR. JOSEPH H. LADD CENTER, RHODE ISLAND; AND RACHAEL ROSSOU, PARENT, ALPHA OMEGA FAMILY, ELLINGTON, CONN., A PANEL

Sister EIRICH. I want to thank you, Senator, for having the hearings and for my being able to participate in the hearings.

I am the director of the Community Resource Center for the Developmentally Disabled, an organization formed in New York City, formed out of concern for the needs of the young folks who are presently and have been at Willowbrook Developmental Center.

We presently sponsor two residential settings, both of them located in the heart of the community it serves. The Community Resource Center had its early-day sponsoring from Elite Community Youth Program, which is a child care agency formed with board administration.

The staff members and young people served and families all came from the South Bronx. We have replicated that in a spinoff project and the special service unit first started in 1976, as a forerunner, and kind of gave birth to Community Resource Center.

I believe the focus of my attention and statement this afternoon is to really state that multiply handicapped individuals, severely handicapped, whom I heard you refer to as catastrophic, who might have been in bed are individuals that we care for in the community setting.

We have an apartment setting in the South Bronx. We have two separate apartments that we rent. We rent space in a 500 apartment complex. The community has very much accepted us. The young folks, their families come from the neighborhood.

The community planning boards, the local tenants association, the neighbors, if you will, have been most supportive. Our young people were taken from the backwards of Willowbrook back in 1976 and at that time when we moved in to accept the youngsters, if we did not have a State representative from the central office with us we were not allowed to see these young people, the backward individuals.

They are nonambulatory. Many do not have speech, and unable to feed, dress and toilet themselves. And with all of the handicapping conditions that they have, the community accepted us with open arms. They have continued to do for us in subtle ways of acceptance, of communication and so forth.

In East Harlem we opened a unit back in February of 1980. The individuals selected in that project also are considered to be hardcore backward individuals, nonambulant individuals with lower levels of retardation, multiple medical problems that needed control and management and perhaps the most challenging of all were those with self-abusive behaviors, self-abusive to the point where a person will bite themselves and have raw skin and be bleeding on both upper extremities constantly from self abuse.

Within 6 months time, this individual, and several other individuals, with very, very unusual and extremely unacceptable behaviors moved into operating in acceptable behavior fashion. They have learned to handle a number of self-help skills, which is self feeding, and toileting and learning to dress themselves and are participating in activities.

We have found community acceptance. I think that part of the reason that we have had the community acceptance and the community support is that we basically are from the community. Our young folk, their families, our staff, we are from the local area. And I would just want to share that the community is not rejecting us; the community is accepting us with open arms and I think that is the message that I would like to leave with you, that it is possible for very, very handicapped persons to be brought back home, to be brought to their local community to be accepted and to be cared for.

Senator **Weicker**. Thank you very much, Sister.

Ms. **Lavasseur**. Good afternoon, Senator Weicker. I am honored to be here today representing Rhode Island.

My name is Eileen Lavasseur and I am 77 years young. I am on the board of directors and represent Ladd Center Parents Association. I am a parent of a retarded daughter, age 41, now living at the Ladd Center. I have been going to Ladd Center every week since 1954, and have seen many changes, all for the good.

When I first went to Ladd there were 1,200 residents. Now, I understand, there are about 580. Many have gone to group homes, apartments and a few at home to their parents, and some made lives of their own and doing very well.

My opinion and experience with group homes is now altogether very different to how we used to feel. We were formerly opposed to group homes because we thought the supervision was not good or the staff did not have enough experience with these kinds of residents.

We have visited and monitored these homes throughout the State, and knowing most of the residents, they are very happy and contented knowing they have finally got their wish in living a family life.

In my opinion, group homes and apartments are the best thing that has taken place for our institutions. I sincerely hope some day soon they may find a group home for my daughter, Marion.

Thank you.

Senator **Weicker**. Thank you very much.

Mr. **Gunther**. Mr. Chairman, my name is George Gunther. I am the chief administrative officer of the Dr. Joseph H. Ladd Center in the State of Rhode Island.

To assist you, I think it is important to place my testimony in the perspective of being the chief administrative officer of an institution for 600 severely and profoundly mentally retarded persons, but also as the parent of a 22-year-old severely retarded woman who is one of the 600 clients at my facility.

I have been at the Ladd Center for 11 years. During that time improvements have been accomplished. In 1970, the budget for over 1,000 clients was $5.5 million. Today, the budget is over $20 million for 596 persons. However, only $16 million is spent at the institution and $4 million is spent in community-based programs to which 400 Ladd Center clients are transported every day, Monday through Friday, and 30 older retarded citizens who were institutionalized for over 30 years live in community-based section 8 apartment programs staffed by Ladd Center employees.

I will have another seven of these apartment programs open by September 1.

The development of a network of group homes and apartments now gives parents a choice beyond either staying at home or going into the institutions large wards and buildings which have caused many of the problems that long-term institutionalized persons exhibit.

Ladd Center will be reduced to a population of 500 by July 1, 1981. This shift of clients from the institution to the community requires fiscal responsibility by reducing the institution manpower and moving them to community programs through agreements with AFSCME and closing old buildings in institutions and reducing operating costs.

Today, at Ladd Center only 750 of my 1,055 employees are at the exodus site in the institution. The balance are working in different places throughout the State of Rhode Island.

The decentralization of clients in this manner has been supported by the Governor of Rhode Island, the General Assembly, the unions, many unions. Of 1,055 employees at Ladd I am the only person not in a union. And the parents are all supportive.

It is important for this committee to consider the fact that right now today, 400 of 600 severely and profoundly retarded clients leave Ladd Center every day and travel to 20 different locations to learning centers throughout the State and return for dinner and to sleep.

These clients can live somewhere else with the necessary supervision to insure their safety and to meet their program requirements to help them learn. The future for the mentally retarded person who is institutionalized is grounded in the orderly transfer to small group homes and apartments where all of their needs will be met in that setting rather than the institution or necessarily at home.

The future for a mentally retarded person who is now at home but may need to leave that home some day, for whatever reason, will not be a life in an institution but a home in their own neighborhood.

The approach I have described is not theory. This transfer has been done, is being done and will continue to be done.

Thank you for this opportunity.

Senator WEICKER. Let me ask a couple of questions. When do you foresee the closing of the Ladd Center?

Mr. GUNTHER. I think the Ladd Center can be reduced to approximately 100 to 200 clients by about 1983 or 1984. Beyond that, it will become a little bit more difficult to place clients because we will be into the construction business and constructing small homes that meet all of the life safety codes that are required for residences that do not have self-preservation characteristics.

So, it will slow down a little bit. Also, I might add, Senator, and this is something that perhaps people don't think about too much, when you have a large facility, such as I have, or Southbury or Mansfield, that I am familiar with, and you have many buildings spread out over 700 acres of land, powerhouses with miles of steam lines, sewage treatment plants, security, fire departments and everything else that goes with these places, when you bring the population down to 100 residents the budget office will order that place closed and will give you plenty of money to get to someplace that will be a lot more economical, not only more humane.

That would be because you cannot afford to run a huge complex like that for 100 people, even if you wanted to.

Senator WEICKER. I suppose what I am trying to say is I don't see any disagreement with what you are saying and what I have heard from the superintendents of our own institutions in the State of Connecticut.

What we are really talking about is the matter of timing here. You mentioned, I don't know the term, self-preservation?

Mr. GUNTHER. Yes, self-preservation characteristics.

Senator WEICKER. Characteristics. What are you going to do with these people?

Mr. GUNTHER. We are placing people in the community right now who do not exhibit "self-preservation characteristics." All you have to do is make sure that: No. 1, there is sufficient supervision; and, No. 2, that they are in a ranchhouse that meets what is called the institutional fire code.

In other words, it is sprinklered and you make sure you have an exit here and an exit there. It might add another $15 or $20,000 to the cost of the facility to meet the stricter code. It is just a method but it usually requires construction.

Right now, for example, in the State of Rhode Island we operate 28 group homes. We own 55. The rest of them are in some process of being opened. They can open rather quickly because you just remodel them for the limited code, called a board house code in our State.

But when you go to the more stricter code, new construction is more economical. Then you have to buy land, site that land and get into the construction business. It just takes longer.

Senator WEICKER. And the 100 to 200, you are saying that the only problem there is you have to build the facility for them?

Mr. GUNTHER. At least one of the things I get involved in all the time are when people are trying to figure out where can retarded people best be served. It is not a geography issue.

The kinds of retarded people that are being served in Rhode Island could be served at Southbury, and the kind of people in Southbury can be served in Fort Lauderdale. It is a question of what do they need, providing that kind of supervision in that kind of an environment.

It can be really provided anywhere because indeed it is being provided somewhere now.

Senator WEICKER. I don't disagree with what you are saying. I am just wondering whether or not the public is willing to make the commitment that is required in the sense of what you are advocating.

One impression I don't want to get across to anybody is that for some reason or other this is going to be a cheaper way out. I don't think it is. I think it is going to be far more expensive.

Mr. GUNTHER. No, sir. No one that I know of—at least we don't—promote it as being a cheaper way out. We promote it as being the best thing, the best kind of life for that retarded person. However, there are millions and millions of dollars, which, with a little creativity can flow from that institution as the clients flow to assist in paying for these services in a proper location.

Senator WEICKER. I certainly hope we are all right in what it is that we wish for those that are trying to help and also, that we are going to be right and that our fellow citizens are going to come to fore to provide it. I think that is rather a big question mark at this point.

Ms. ROSSOU. There are so many things I want to say.

Senator WEICKER. Don't rush.

Ms. ROSSOU. As a footnote on that, the Alpha Omega Family ran into difficulty because we had more than three children that are not ambulatory and not capable of self-preservation, which gets us in immediate conflict with the Federal fire and safety code.

We went before the legislature last year and Connecticut has on the books the statute for permanent family residence, of which we have been licensed as the first. They are coming up now with their formulated regulations to encourage more permanent family residences.

What it means is that they are taking a commonsense approach to the State fire and safety code. We opted for egress in our house. Every bedroom where there is a youngster in a wheel chair the youngsters can transfer to their chair and go out with a patio type door.

You can't have both containment, like you have at a New Britain Memorial, with the metal doors and the enclosure and egress. They are both fire approved safety ways of handling a preventative situation, but they are mutually exclusive.

This is just one example, Senator, and I would love to go into more detail with you through the help of our local fire people and the Department of Children and Youth Services and the State Legislature in Connecticut how Alpha Omega was able to resolve this.

Senator WEICKER. Let me say one thing about legislators that I am finding out at this time in Washington, D.C. They are perfectly willing to write all good things on the books. Then comes the time to pay for them. And you know my famous quotation: "Everybody likes to go to heaven but nobody wants to die," as far as the Congress of the United States is concerned. [Laughter.]

That is one of the difficulties we are having right now. What if they legislate this and all good things are going to happen. I don't think they are I know just the amount of time all of you people spend in terms of time—never mind the other man-hours that are required of professionals; never mind the construction that is required. As I say, in terms of commitment or whether in terms of resources, our good intentions in this instance are going to cost us dearly, and I think they should.

Ms. ROSSOU. I would really have to take issue with that, Senator.

Senator WEICKER. Do you think you are going to be able to do this inexpensively?

Ms. ROSSOU. No. I can only speak for the Alpha Omega Family. I am not familiar with Mansfield, Southbury—I can only speak for ourselves.

Our Charlie was at New Britain Memorial for 10 years, Eddie for 5 years, Simone 5 years, David for a year, and Ellen at one of those nursing homes for 6½ years. The cost is tremendous and where their rates continue rising and ours hasn't.

I think last year it was almost $200,000, a little hair over that that they had figured was saved by our being in existence last year.

Senator WEICKER. I don't think—and I have to speak for myself on this—that you can equate the benefit derived in dollar terms because I don't think we are going to make sense on that count. I can tell you right now, if I can build one driveway instead of 100 driveways, that is cheaper, 1 utility system rather than 100 utility systems, that is obviously cheaper.

So, what I am saying is in those terms I can't justify the goals that all of us are trying to drive to, but I don't think that is what is important. In my way of thinking it is to achieve that goal. I tell my friends down in Washington that if you believe in this then be prepared to go ahead and fight for it, be prepared to go ahead and pay for it.

And I do believe in it. I think there are many reasons that support the arguments that all of you are making here. I don't think this is what you are trying to do, any of you, but I don't want to give the impression that for some reason or another this is going to be an easier way out in any sense of the word.

I think it is the better way to go. That could very well be.

Ms. Rossou. But in some situations it also is cheaper. A case in point. There are two youngsters right now at New Britain Memorial. The rate there is $80-something a day, and there are two approved foster homes trying to get these youngsters and they are in the midst of difficulties.

It has the doctor's support and the social worker's support. I know a very limited little sphere. I can't magnify this.

Senator Weicker. You speak for yourself and your own experience. That is the most important thing, quite frankly. That is life. I am delighted to hear from you. I just enjoy discussing these things with you just as if we were sitting in your living room. There is no difference here. Go ahead.

Ms. Rossou. We were asked to chat about community acceptance, and to me community acceptance is a matter of the heart and I think for some of us it is love at first sight and in other situations it takes time for a love affair to gently blossom.

And I believe that in the Alpha Omega family in the community of Ellington we have been able to witness both. This morning, Carl and I and the people from the junior high were over at the high school and we were getting the finishing touches on setting up a program for Eddie for next year.

There is just so much I wish I could put in a capsule about our whole family and each of the youngsters, where they are from, where they are and where they are going.

Just very, very briefly, Eddie had been at New Britain Memorial for 4½ years because there was not an alternative within Connecticut for Eddie. Eddie is a multiply handicapped little fellow. He needs auditory training, he needs large books. He is visually impaired. Two of his cranial nerves are paralyzed. He was born with one leg. He has two fingers. He has very severe asthma. He was born without a tongue. He is a multiply handicapped little boy.

That tells you what he doesn't have. What he does have is an incredible love for 18 wheelers. He is not very goal oriented. He gets on his bike and he never goes anywhere. He just experiences the wind, and the motion and the speed and he loves it. And I get grayer because he doesn't see very well and he just barely misses trees, but that is all part of Eddie and that is part of the life and the risk that he needs to be fully alive and he is fully alive.

And some of the comments that guidance counselors from the junior high were making this morning at the meeting at the high school were he was quite emphatic that the fact that Eddie had earned the right to be at the junior high and he had earned the right to be at that high school and he also had earned the respect of every single teacher in that junior high.

But, as I said, there is so much I could show you. When Eddie came home he bounced, he pawed, he hit his head against the wall. He opened and closed doors for 6 weeks. It wasn't until our little Susan, who was 1½ and very chubby and cuddly and kept squeezing him and if he saw you coming he would paw and he would hold on for dear life. But if he didn't see you coming he would arch his back and scream because he just hadn't had physical closeness.

After 6 weeks of Susan hugging him he would scream. The more he would scream the more Susan would hug. After 6 weeks he was opening and closing the door and he closed the door on Susan's finger and Susan screamed. And before I could do anything Eddie went like this, and I stood and just cried because I knew if Susan could reach Eddie we could reach Eddie, and it was going to be all right.

We learned more from our son. He is really the whole reason for the Alpha Omega family. When we saw that little boy just turn into a regular ordinary kid, we thought there are other kids out there that just need a family, to be in the community.

There are medical anomalies. They are tremendous. There are youngsters who have grand mal seizures. Nine of our children are incontinent. Most are in wheelchairs. Simone is 30 pounds. She can't sit. She is in a little infant's seat that sits inside—she has brittle bones. She had almost 200 fractures being born.

She controls her electric wheelchair with her elbow. She has already been approved for seventh grade to go into the junior high. Her one comment was that she hopes the aide doesn't go with her when she goes to the dances. She wants to get in trouble at junior high.

Some of our children learn very slowly. Some of our children are profoundly retarded. They range from being academically talented to profoundly retarded. As I said, there is so much.

I think when you talk about trying to teach a child to read you have to have a group of similar level of youngsters. But we are interested in our family teaching them to accept one another, everybody to give to one another.

In our neighborhood wheelchairs are as common as eyeglasses. Our youngsters were in scouts and activities. Simone manages a basketball team. It is just very ordinary. Our church, when you have a community acceptance, no one asked them—they put in an elevator It cost all kinds of money, and it has brought all kinds of elderly people. Eleven families came back to the church because they had disabled people who couldn't attend the church and they stopped going.

There is so much goodness out there that a lot of times people don't know how to help but they want to. I would like to take 1 second to tell you about our little Ben. I know there is a lot about people getting jobs and going into the community.

Three of our children will not be able t , and Ben is maybe the best example of that. He was born with a brain stem that lets him breath and suck and that is all there is. He doesn't have a brain, or a midbrain, and he doesn't have any vision, or hearing, or balance, or memory. But what he does have—he is a little over 2—he has an incredible presence about him, Senator.

And we see in this little boy—we know how he has touched our lives—about once a week—and Dr. Gaum, the neurosurgeon, cannot explain it—but about once a week, all on his own, Benjamin laughs, and it takes him a half an hour. And he holds his head up and he opens his beautiful blue eyes and he chuckles. And he just chuckles, and he just chuckles.

And everything in the house stops and whoever sees it first will say: "Ben is laughing," and everybody comes and truly, it is his moment and it is magnificent. Again, I have learned so much from Benjamin.

We parent children sometimes we get so messy. Do we want the children to succeed for our benefit or for their benefit and whose goals are we really after, and all this, and here is little Benjamin that is totally at his potential right now. He has already reached it, and to survive is success and to be alive is magnificent.

As far as impact on people—a good friend of mine is a medical student down at Yale. She is my age and went back to school and is in medicine at Yale. She spent a day with us last year. She wanted to sit in the corner and just write notes about Benjamin, and she wrote about, like, our 14-year-old son has a permanent which, culturally, that is a little hard—that is a different generation, boys with permanents—and he tells me he has to keep his permanent because every time he passes Benjamin he takes his hair and poofs and Ben kind of smiles.

What this does to a 14-year-old soccer player is tremendous. Karen is writing all these notes down and she took them back to her ethics professor at Yale. About 3 weeks later I get a note from her saying that she had just heard her second lecture from the Yale University Medical Center on Benjamin, that her ethics professor had the philosophy and spirituality to believe that little Benjamin should be treated and should be in a family and in a community but that he never had a person to put his philosophy on before and now he does.

And the final line of her letter was: "Isn't it magnificent, the child who cannot learn is teaching."

Senator WEICKER. Thank you very much.

Mr. NERNEY. Before we get finished—I think it may come up with this panel—the question raised about cost is a good one. I would add that there are some distinctions that probably should have been made: One is the new capacity in institutional settings that has been going on for a long time; and the other is that severely and profoundly retarded persons do not necessarily have to go into capital intensive buildings.

There are families out there willing and waiting to take one or two persons and train to work with them. We wouldn't suggest that that is a more expedient way to serve people because it is, so far, less expensive but what we say is it is a necessary way for some people because it is a much more humane way.

I would like to introduce the last panel very quickly. Linda Glenn, who is the top mental retardation official in the State of Massachusetts, Catherine Weinberg, who is with her. She is the deputy, Robert Carl, who is the top public official in mental retardation of the State of Rhode Island and Charles Fulner, who is the assistant to Edward Lewis, who is the top community public official in the State of Kentucky.

STATEMENTS OF LINDA GLENN, COMMISSIONER OF MENTAL RETARDATION, STATE OF MASSACHUSETTS; ROBERT CARL, COMMISSIONER OF MENTAL RETARDATION, STATE OF RHODE ISLAND; AND, CHARLES FULNER, DEPUTY DIRECTOR, DIVISION OF MENTAL RETARDATION, STATE OF KENTUCKY, A PANEL

Commissioner GLENN. Good afternoon. I do come to you, as the other two witnesses have, as administrator and State bureaucrats. You have heard from a lot of program people today and I think I have heard some of your issues that I have to be concerned with too that are not necessarily program issues.

I do want to do something though I hadn't planned on. Karen Green's presentation, where she showed Ruth, is in my State. It is something we have been doing, repeatedly taking people that are severely handicapped out of the facility.

Karen didn't mention two punch lines, one of which I certainly have to be interested in as administrator and program people don't necessarily have to. The other one is more a program issue.

Ruth, it wasn't mentioned, even though she was multiply handicapped, bedridden at the institution, needing total care and costing probably $40,000 or $50,000—because even if I gave you an average cost in my institutions which is, right now, about $40,000, the range within it would range from $5,000 to probably $80,000. She was on the higher end.

Ruth now costs substantially less, probably only about $30,000 in that situation in the community, probably less. She is also now married. She has written her own autobiography and she is attending the University of Massachusetts.

Now that is from a person that when you walked through a ward you would have thought didn't have any capacity, didn't have any capability of learning because they are laying there looking at a white wall in the deformed conditions that they are in, and that is what we see all the time.

And you asked her if that is other places too. Yes: every institution I go into, even my own institutions, there are people who are laying around, you don't know if it is just somebody locked in their body You don't know how intelligent they are, what capacity they have or any human feelings they may have independent of intelligence.

I just wanted to let you know that punch line.

Senator WEICKER. I agree with what you say. And certainly as far as I am concerned, I would have a very difficult time ascertaining the capabilities of that individual. I don't pretend any expertise. But, on the other hand, I can't believe the professionals that we have here in the State of Connecticut who are in charge of the institutions can't make those determinations.

Commissioner GLENN I have not been through the Connecticut institutions and I cannot speak to the capacity of your administrators here.

I do have some comments on what I heard this morning, however. I have been administrator for about 15 years. I have run a large service system, one of the largest in Nebraska, in eastern Nebraska, that served about 1,400 people. For 5 years I have been in charge of mental retardation in Massachusetts where I serve about 11,000. I have got eight State facilities, probably similar. I think some are larger than any you have in Connecticut.

If I leave you with two things it would be to leave you with my learning experience from two of the things that there is controversy in this field about. One, and I sort of heard it this morning, is people believe they can't develop services fast enough in the community to really replace the institutions, and if you want to go on costs, you can't really get a lot of heavy costs, like George Gunther was talking about, until you close the facilities and really get rid of those fixed costs.

And you talk about humane reasons, but even on the cost reasons. They are learning now on the mental health side that closing facilities can save a lot of money in the budget in Massachusetts for the fiscal year 1982 budget.

So, I want to break down that argument. It can be done. It can be done rapidly. It can certainly be done more rapidly than I heard their plans for placing 360 people in 3 years. I think that is ridiculous.

The second is that the argument that you have to have institutions for certain people. I found that it is absolutely not true, in both my experience in Nebraska and my experience in Massachusetts.

The experience in Nebraska was interesting because we decided in 1969 not to develop extra institutions because there was an overflow at the Beatrice State Home. That State was lucky it only had one institution that it had to try to get rid of.

From 1969 to 1976, I believe, or even less than that, we got it down, I believe, from 2,300 to 1,000 by building systems of community care. My own agency that eventually served 1,400 people in 5 counties around Omaha, decided in 1972 it wasn't going to continue to discriminate against the most handicapped. It was going to not just continue to take the mildly retarded and the moderately, and then the severely and then any persons with multiple problems.

We decided to reverse that, to take out the absolute most difficult both medically complex, multiply handicapped, profoundly retarded and to take out the most severely behavioral involved. That is the other that institutions try to justify themselves with, that people cannot handle, either the community folks or staff, people with extreme self-abusive behavior or abusive to others behavior.

So, we started taking them out. The success rate was unbelievable. It was 100 percent with those people. The lack of success was with a few people. We stopped admissions but we did have a couple, I believe 7 over a 3-year period, readmissions to the institution because the community just couldn't tolerate the behavior. It was the mildly retarded people.

The same thing is happening, that mildly retarded people have gotten in trouble with the law and really had overlays of emotional difficulties that, my best professional guess, were caused by their lengthy periods of institutionalization. The same thing in Massachusetts.

I was surprised. I had this view of Massachusetts being very liberal, service-oriented, innovative—at least that is what the professions run around telling people in the field.

But, when I got there in 1976 I was appalled. The State had relied on institutions almost exclusively for the mentally retarded and didn't even allocate any State funds until, I believe, 1974 or 1975, and then it was a piddling $990,000.

They made no commitment to develop alternatives. The institutions were terrible. So, I had a dual job. I had to go in and try to at least keep those institutions in some level of compliance because they were receiving the Federal medicaid funds, so I had to spend a lot of time trying to clean the institutions up and, at the same time, I had to try to develop and assist the system in developing the community services, and do it fast.

We were going to start losing revenue if we didn't get thousands of people out of the institution, and we had enough court suits around that we had to do it right. There could be no dumping.

I think one guy was talking about dumping this morning and I think he had mental health exposure. They have had the mental health patients confused with the mentally retarded. Anyway, in this short period of time we phased down the institutions from about 7,000 to about 4,000.

We have got 3,000 people in community residential services of all types. We have 4,500 to 5,000 in day training services. The whole statewide system of the early intervention services that have been spoken of serve about 2,500 zero to 3-year-olds, and about 3,000 in respite care and a whole system of case management and quality control systems.

It can be done and it can be done right and a lot faster than I heard the plans this morning for the State of Connecticut. We have been able to prevent the admissions and the readmissions. Admissions are down from what used to be, in 1975, about 200-plus a year. I think our track record in the past 3 or 4 years is fewer than six or seven that have had to go in for short-term emergency.

And a lot of the myths that people put up, or the issues they raise about why it can't be done, in my opinion and experience are just bogus, absolutely aren't there. The community acceptance? I just did a study of why some of my programs that were supposed to start this year were delayed in getting started, and I expected, just because everybody theoretically thinks about acceptance, that a lot of the issues would be zoning fights they are going through, or problems with communities not letting them in.

I didn't find that. Out of the 4 or 500 programs that were supposed to start there were about 72 reasons for delay for programs. Four of those had anything to do with community resistance.

Second, client preparation—I believe that has been addressed earlier today. When somebody says to me a client is not prepared to go to the community, my first reaction can only be, aren't his bags packed? You don't have to do things to individuals to move them from one setting to another to get more learning opportunity in that other setting.

And the third is cost.

Senator WEICKER. How many do you have in institutions in Massachusetts right now?

Commissioner GLENN. I have a little over 4,000 left in institutions for the mentally retarded.

Senator WEICKER. Why don't they have their bags packed?

Commissioner GLENN. We are developing the services.

Senator WEICKER. How long will it be until you close the institutions in Massachusetts?

Commissioner GLENN. We have a commitment from the State that they signed a plan that would allow me to take an additional 3,000 people out of the institution between now and 1985, and there is also a signed commitment to the plaintiffs in a couple of cases that they will continue to depopulate after that.

They have not been wanting to go on public record of when they are going to close an institution yet, but they have got a phase down plan for every single one of them.

Senator WEICKER. We have, at the present time, in the State of Connecticut, as I recall, it is just under 2,000. Am I correct on that number?

Mr. NERNEY. 3,000.

Senator WEICKER. I am just trying to get the relative number. Please go ahead.

Commissioner GLENN. There was a study just completed by the National Association of State Coordinators also that if you put Connecticut beside the other States for what population level they will have at the end of their plan for placements. It ends, I guess, in 1983 or 1984. They will still have a substantially more institutionalized population than the average of the country and about three times as many at the end of that plan as compared to in our plan in Massachusetts.

The other point, besides the fact that it can be done, that I wanted to make is the institutions really cannot do it. I have thrown money at these institutions. In New York I have sat on the Willowbrook Review Panel that was set up by Judge Judd back in, I believe, 1974 and watched us just throw money into the institution.

Willowbrook has gone from, when I first saw it, I believe $4,500 per person. Now it must be close to $6,000 per person. And you don't see a lot of measurable change. It is less crowded, people are better clothed, there is somewhat better food, and some of the quality of life issues and there is some more activity. But you cannot say, looking at it as a professional, how relevant that activity is. It is not that relevant.

We have seen the things that are really the most powerful for the development of people. You have heard a lot about it today. I found it cannot happen in the institutions, not with people segregated, not with the kind of turnover people have and the lack of continuity for the numbers of individuals that interact with the person that Karen talked of. I have seen that in my institutions. We have almost doubled the number of staff. I put 4,000 more staff in just since I have been there; doubled the budget; doubled the cost.

I just did a survey last week of one of my institutions that is the second highest cost institution, and I was trying to find out the day program issues, were people getting day programs. Were they getting any substantial part of their day in programing, and I found out that only 39 percent of my clients in that institution are getting programing in the day and most of that was being provided by the Department of Education, not by the institution.

I will close with—I could talk a lot longer about the power of institutions and how it robs people of opportunities but I think you have heard that.

One other State's director who could not be here asked me to give you a written statement however.

Senator WEICKER. I would be delighted to have it included in the record.

Commissioner GLENN. This is Dr. Jennifer House, who is deputy secretary of mental retardation in Pennsylvania. She runs the State of Pennsylvania programs.

I would also like to submit for the record a summary. I heard somebody talking about research earlier. One of the most recent pieces of research has come from Pennsylvania, a study on the people that have come out of the Pennhurst State Hospital since Judge Broderick's decision which showed that the growth in all categories of the people that left the institution was very significant, whereas, the matched sample that did not leave the institution, there was no significant change.

Thank you.

[The following was received for the record:]

PREPARED FOR SENATOR LOWELL WEIKER AT THE REQUEST OF
TOM NERNEY, CONNECTICUT ARC, 15 HIGH STREET, HARTFORD, CONNECTICUT

Dr. Jennifer Howse,
Deputy Secretary
Office of Mental Retardation
Department of Public Welfare
Harrisburg, Pennsylvania

April 8, 1981

STATEMENT OI PENNSYLVANIA'S

COMMUNITY MENTAL RETARDATION PROGRAM

The Pennsylvania Community Mental Retardation System was initiated with e passage of the Mental Health and Mental Retardation Act of 1966.

Through the passage of this Act, Pennsylvania, a State with approximately elve million people and large urban and rural areas, developed a strong commitnt to the provision of community services to mentally retarded people based on normalization principle and the developmental model. Guiding principles in formation of our system included services to prevent out-of-natural-home idential placement and deinstitutionalization with an emphasis toward placement the least restrictive environment.

In Pennsylvania, Mental Retardation services are administered by the fice of Mental Retardation in the Department of Public Welfare. The most sig- icant program components in Pennsylvania's community MR system include the munity Living Arrangements program and the Family Resource Services program; t recently, the Office of Mental Retardation has begun the active use of tle XIX funding for community services.

The Community Living Arrangements program was developed in 1972 to provide ontinuum of professionally staffed community residential services as alternatives institutionalization. These services emphasize the development of small home-like egrated living arrangements that are both flexible and structured to meet the ried needs of individuals requiring community living support. Over 95% of the [illegible] house three or fewer clients. The Community Living Arrangements program served almost 8,000 people since its inception in 1972, and its budget has grown om $1.9 million in 1972 to over $52.0 million today.

Pennsylvania previously maintained 14,000 people in State Centers for the ntally Retarded. That number has been sharply reduced over the past nine years. ay approximately 7,000 people reside in State Centers, and over 3,000 previously itutionalized children and adults have returned to their natural homes with all essary support services.

Pennsylvania provides the following type of services available to mentally arded persons and their families through the Family Resource Services program: ite Care, Family Aides, Homemaker Services, Recreation; Transportation; In-Home rapy; and Family Education/Training.

The thrust of Family Resource Services has been to provide the support vices necessary to aid the family in maintaining a retarded child or adult at me, and, thus, prevent institutionalization from ever taking place. In addition, ily Resource Services offers several support services necessary to assist the institutionalized mentally retarded person in making the adjustment from an itutional to community lifestyle. Thus, within the mental retardation component the County MH/MR Plan, the FRS Program serves both as an alternative and as a plement to the Commonwealth's Community Residential Services Program.

Currently, over 18,000 mentally retarded people and their families e benefitting from Family Resource Service programs. Pennsylvania's current get for Family Resource Services and other support programs is currently ver $33 million.

The Governor's proposed budget for Mental Retardation services for iscal Year 1981/82 is a further reflection of Pennsylvania's commitment to mmunity services; for the first time, more State dollars are recommended for mmunity programs than for State centers. An important ingredient in next ar's budget includes approximately $10 million for new community residential grams, with special emphasis on ICF/MR development in settings of four to eight ersons, and for further expansion of the Family Resource Services program.

In summary, Pennsylvania has developed the structure for a quality munity services system, and currently serves clients in community programs th the same characteristics as any clients in State Centers. This includes ople with medical problems, the non-ambulatory and those with severe behavioral roblems. Pennsylvania's program clearly demonstrates that all mentally retarded ople can benefit from community programs, and the Legislative support received, rticularly since 1972, has enabled the office to maintain a commitment to mmunity services.

Thank you for your interest in Pennsylvania's efforts toward developing comprehensive community-based mental retardation system.

2 B Sunday, April 5, 1981 Philadelphia Inquirer

From Pennhurst to group homes, improvement seen

By Julia Cass
Inquirer Staff Writer

A study comparing the progress of 70 residents of the Pennhurst Center for the Retarded with that of 70 former residents who were transferred into group homes in the community found overwhelmingly that those who were moved had improved in skills while those who remained in the institution had not.

The study, recently completed by Temple University's Developmental Disabilities Research and Evaluation Group concluded that the 70 who were transferred "have benefited substantially from relocation to smaller less segregated, around-the-clock supervised community settings."

A second study, conducted by the Office of the Special Master for Pennhurst, also found that the skills of Pennhurst residents improved when they were transferred from the large state institution in Spring City, Chester County, into more home-like settings in the community.

In addition, the second study, which surveyed all of the community living arrangements — group homes and apartments — in the region, found that retarded people were receiving good supervision and health care.

Pennhurst has become the focus of such studies because in March 1978, U.S. District Judge Raymond J. Broderick ordered that community living arrangements be established in Bucks, Chester, Montgomery, Delaware and Philadelphia Counties for the 1,000 Pennhurst residents so that the institution eventually could be closed.

In a suit filed by the Pennsylvania Association for Retarded Citizens against the state and the five counties, Broderick ruled that retarded people could not be taught to live up to their potential in large, isolated institutions such as Pennhurst and that confining them there was unconstitutional.

The U.S. Supreme Court is to decide soon whether to uphold Broderick's ruling. Its decision will have far-reaching consequences because similar suits have been filed against institutions in 17 other states.

Because Pennhurst is a test case, the Temple study stated, it was important to determine "whether relocation of clients from large, segregated institutions into small, community based facilities actually enhances developmental growth."

The Temple study, part of a five-year evaluation for the U.S. Department of Health and Human Services, attempted to answer that question by comparing 70 retarded people at Pennhurst with 70 who had been moved into the community since 1978.

The two groups were matched on the basis of sex, level of retardation, length of time institutionalized, age, IQ and 1978 scores on a test called the Behavior Development Survey.

The test looked at three areas of adaptive behavior: personal self sufficiency (toilet training, use of table utensils, dressing, bathing), community self sufficiency (eating in public, telling time, money handling, food preparation) and personal social responsibility (care of clothing, initiative, awareness of others, participation in group activities).

The test also studied maladaptive behavior such as violence, rebelliousness, running away and hyperactivity.

In 1978, all 140 of the research subjects lived at Pennhurst and were tested there. Two years later, in the fall of 1980, the Temple researchers retested the 70 who remained at Pennhurst and the 70 who had been transferred to see if there was a difference in development.

The researchers found the report stated that "the 70 clients who have been placed [in the community living arrangements] have, on the average, made significant gains in all three areas of adaptive behavior. Their matched 'twins' who remained at the institution have made no significant progress in adaptive behavior."

The researchers also found that "in the maladaptive-behavior domain, there were no significant changes for either the movers or the stayers."

The report did not attempt to explain the reasons why the movers improved and those who stayed did not, except to state that there was a sharp difference in the number of services the two groups received.

It found that the average number of hours a week that those in the community spent in various programs was 31.5; for those at Pennhurst it was 14.1. The report added that "one cannot be certain that deinstitutionalization itself caused the different developments for the two groups."

The Temple researchers — James Conroy, Joelle Efthimiou and James Lemanowicz — also attempted to determine, within the community group, what variables seemed to contribute to developmental growth.

They discovered that age and length of time institutionalized seemed to have no effect on development. Sex and level of retardation were significant, however. The researchers found that men improved much more than women and that those with more severe retardation showed greater relative gains than those who were more mildly retarded. The report did not attempt to account for those differences.

For its study, the Office of the Special Master — which was created to supervise implementation of Broderick's decisions about Pennhurst — [illegible] visited the community living arrangements and day programs of 140 of the people who left Pennhurst and looked at the sort of health care and recreational activities available to them.

The office also conducted in-depth studies of six randomly selected former Pennhurst residents who had been moved into the community.

The master's report details the "significant" but slow, painstaking progress the six have made since leaving Pennhurst. For example Ms. S., 42, a retarded woman with epilepsy and cerebral palsy who was a resident of Pennhurst for 28 years, now gets in and out of bed by herself for the first time in her life using equipment designed and built in her new community living arrangement, the report states.

Mr. P., 67, who is severely retarded, has begun to address people by name rather than by functional labels such as "the lady who cooks for me." A resident of Pennhurst for 50 years until he moved into a group home, he also has learned to shave, cut up food and take his dentures out at night.

According to the master's report, none of the 140 people who left Pennhurst was readmitted to the center or any other state institution for the retarded. In groups ranging in size from one to eight, they live in apartments or family-sized houses and have 24-hour staff supervision. In the community, the average was one staff member for two residents, compared with one staff member for eight residents at Pennhurst.

The study determined that only one person was not receiving an annual medical exam, that 85 percent had been to a dentist since being transferred and that, in several instances, former residents' health had dramatically improved. Some were fitted with dentures or eyeglasses that they had needed but had never been given in the institution.

Senator WEICKER. For as little as I know about the Pennhurst case, I wouldn't disagree at all with whatever it is that is coming out insofar as the capacities of those that are no longer in institutions. I don't argue that.

On the other hand, as to whether or not those that are left at Pennhurst have been well served by that decision, I think that is probably up in the air because what, in effect, was happening, and if there is no capital money going in there at all, as I understand it, and the ones that suffer from that are the ones that are there.

I think that raises the issue because I think what we are all trying to find here—your group, the State of Connecticut—how do we transition? What is the time factor involved? I want to make sure that nobody gets hurt by whatever it is that we do. I am not so sure that was achieved in the Pennhurst decision the way it now stands.

Dr. CARL. I would first like to express my profound appreciation to you and the other members of the subcommittee for providing this forum for all of us to discuss these issues of such marked national interest and of such personal interest to the many retarded citizens throughout Rhode Island.

I would like to briefly introduce myself by pointing out that my experience includes more than 15 years in the field of mental retardation, 9 of which involved the operation of State or public institutions for retarded persons in three different States.

I worked in Massachusetts originally and was one of the first of those professionals to discover Ruth many, many years ago. I am quite familiar with the experiences that Miss Glenn and others have referenced regarding the terrific loss of opportunities for so many people.

I have been a State institution superintendent in Ohio, deputy commissioner in Ohio and am now the State director of retardation services in Rhode Island. I facilitated the opening of over 80 small community residences in these States so I feel I know both sides of the aisle in retardation services.

In my professional opinion, sir, there is no real legitimacy to the institution versus community debate. How, under what auspices and what timeframe we open community programs are issues to be discussed. We would like to briefly discuss some of the similarities and differences that I believe are transparent when one compares Rhode Island and Connecticut.

I would like to briefly outline the past 27 months since I started in Rhode Island. To set the stage, let me note that I was hired in Rhode Island after over a year of front page newspaper exposes of an institution that in my opinion was then significantly better than the present operations of the State facilities in Connecticut, the recent firing of the superintendent and newly assigned duties to several members of the retardation bureaucracy.

Groups were split, some promoting lawsuits to force the development of new community programs to close institutions, some opposing community directions. Parents, professionals, staff public officials, and the citizenry at large were confused, were demoralized.

Some wanted to spend millions to upgrade our State institution. We only have one. Others threatened to sue if the State took one step in that direction. So what did we do?

First, we scrapped the multimillion-dollar institutional renovation and developed a short-term fixup of over 200 beds to be used on an interim basis only until we could move the client into small, high quality residential settings throughout Rhode Island.

Next, we obtained legislative support for the development of the activity sides for over 400 of the institutionalized persons. This insures a minimal quality of services and adequate preparation for community living. At least people will begin to get an exposure to that.

And, more importantly, our staff got an exposure to the notion of getting people up, and out and into the community, a continuation of our medicaid funding and establishing an anchor point in the community for these people.

At the same time, we committed ourselves to small, usually two, three, or four persons living arrangements and rejected placement in nursing homes and other inappropriate long-term care settings

We developed a plan to reduce our population from the over 700 persons then at the institution to no more than 100 people by 1984. Concurrently, we prepared plans to take care of over 300 persons in the community who were "at risk" of being institutionalized.

We negotiated agreements with AFSCME and other labor unions to guarantee no layoffs by obtaining their support to move State personnel into the community to operate some of these service settings.

Over 60 percent of the electorate—two State bond issues were passed providing almost $10 million for the construction of group homes and other facilities in little Rhode Island all in the past 2 years.

So what have we accomplished with these plans? Our institutionalized population has been reduced from over 730 persons to less than 600 as of this testimony. Another 100 persons will leave for community placements before July 1981.

Only three persons have been returned to the institution in the last 27 months. Three persons have been admitted to the institution. Plans calling for placing at least 100 to 150 persons per year into a range of comprehensive residential options in fiscal years 1982, 1983, 1984 have been accepted as our State's avowed public policy.

We have placed almost 75 persons who are at risk of being institutionalized into community living arrangements thus avoiding the unnecessary institutionalization and its accompanying heartbreak for the parents who struggled so long to take care of their children in their own homes.

Over 400 persons of the remaining 590 at our institution leave every weekday for community-based programs. Transportation, not inactivity, has become our major nightmare. Over 200 persons from the institution attend local churches every Sunday in several communities throughout Rhode Island.

We still have 600 certified, federally certified, thereby medicaid funded, beds at our State institution, so all of our clients have received services which meet State and Federal requirements even during this transition period. Our total number of group homes or what we like to call family style homes, has increased from 8 in

1979 to over 40 operational today with another 15 scheduled to be open before July of 1981.

We open local services for local folks to keep them out of institutions and to bring them home in every community in Rhode Island. Over 75 persons have moved into apartments, some semisupervised, some ICFMR certified, with another 60 ICFMR apartment units scheduled before July to open before July 1981.

Thirty of these new apartment residents are long-term institutionalized elderly retarded persons. They have an average length of stay of over 30 years per person in State institutions.

Day programs have expanded from about 800 persons statewide in work activity centers and very little opportunities for institutionalized persons to over 1,600 retarded citizens from all kinds of living arrangements participating in a vast array of developmental and vocational programs.

We started a statewide respite care program, our first sheltered manufacturing plant and a statewide monitoring system to complement our licensure and health department reviews.

A 5-year plan updated annually was published in 1979 and we are just initiating an automated data system and a comprehensive case management program, something we call service coordination.

I am not talking theory, Senator, nor dreams. I am talking about what can happen when persons such as the Governor of Rhode Island, Governor Garrahy, and other elected officials support a commitment to dignity and quality of life, as has been done in my home State.

Our experience shows that much is possible with good planning and hard work. Nothing that goes on in an institution cannot be replicated, often improved upon in an appropriate community setting for any individual who lives in any State institution in America.

Senator, I have been in many, many States, I have worked in many, many States and I have been in over 30 State institutions for the retarded in the last 5 years. This might mean a lower per person cost. With some careful planning and monitoring we can guarantee better per person quality of services in community settings.

There is no need to debate the relative merits of community services versus institutions. The time is now, the technology and know-how is available now. All that is lacking, or is not happening is the imagination and the will.

I would like to present to you several copies of some brochures and a recent advertisement which appeared in the Providence, R.I., Sunday Journal, R.I.'s statewide newspaper. This should serve to demonstrate the pride we in Rhode Island take in our public policies for serving retarded citizens and their families.

Thank you very much for this opportunity, Senator.

Senator WEICKER. Thank you.

Mr. FULNER. Senator, my name is Charles Fulner and I am the deputy director for the division of community services for mental retardation in the State of Kentucky, and I am speaking for myself and my boss, Dr. Skarnulis, who couldn't be here today. But he has submitted some written testimony.

I think my colleagues have more than established that the job can be done in the community, so instead of rehashing some of those points, in the interest of time I thought I would simply submit a written statement talking about my experience working in the State of Michigan where they reduced their institutional population by some 40 percent in 4 years, and of some of the things we are planning to do in Kentucky to take those first steps toward operating without State institutions.

Senator WEICKER. How many people do you have in the institutions in Kentucky at this time?

Mr. FULNER. 1,040, and our intent is in the next 18 months to move 200 of those individuals to community-based residential alternatives.

Senator WEICKER. What is the population of Kentucky?

Mr. FULNER. Approximately 3.4 million.

Senator WEICKER. What is the population of Rhode Island?

Dr. CARL. 935,000, Senator.

Senator WEICKER. And you have 600?

Dr. CARL. We have 590 persons today.

Mr. FULNER. In all fairness I should point out that there are approximately 600 additional individuals in nursing homes whom we also have to move out.

Senator WEICKER. Then you have approximately 1,600.

Go on.

Mr. FULNER. What I thought I would do instead is summarize some of the very basic principles that we have heard expressed over and over this afternoon about what makes up a good residential system, and then talk very briefly about how those principles interface with the Federal policy and Federal regulations regarding financing care for persons with mental retardation.

I think if you look at all the programs around the country you would see that there are perhaps eight basic principles that make up a good residential system or from which you would design as guidelines.

The first principle, and one that we are just beginning to do in Kentucky, is that all family and individual support services should be made before any alternative residence is sought, that we ought to do those things that keep persons in their own families before that family burns out.

The second point is that all residences should be made as small as possible. The smaller the residence the less hard it is, the less segregated the people are who live there and the more individual attention those people can have.

The third principle is the principle of individualization of those programs. The specific reasons for requesting and then providing residential services should be identified and some solutions to those problems must be actively and creatively sought as part of that residential program.

Before anyone even is removed from her or his home, or goes into a specialized residential program, I would suggest that a date for reevaluating that program be arrived before admission so it is not a dumping thing that went on earlier that many of the speakers referenced earlier in the day.

The fifth thing is that a residence should be as close as possible to the community, the neighborhood or the home where the person will live upon completion of this specialized residential program, and that those people living in special residences will leave those residences and move into places that are appropriate to their age group as they progress.

The sixth point is that partial residential services should be available. Too often, what we simply assumed is that if a family need for its family member to receive residential services that it has to be 7 days a week, 24 hours a day.

Something we are going to be trying in our State is partial services, perhaps 1 day a week, 4 days a week, 5 days a week, providing some relief for the family to rebuild itself.

The seventh principle is that family involvement should be encouraged. Too often, we try to move families aside so the professionals will do the job, and we have encouraged families to divorce themselves from their family member.

Lastly, the residential systems personnel, like those of us sitting at this table, ought to be evaluated and rewarded according to their ability to integrate individuals with mental retardation in the community and to remove the stigma and the separateness of the services we provide to those people.

One of the things that has happened is many of the States have attempted to use Federal dollars, particularly under the ICFMR program, to provide community-based services is that they found a number of road blocks.

Some of my predecessors spoke about those road blocks, some of the fire safety and institutional language that goes into the Federal regulations governing Federal financial participation. If anything comes out of the approach to going with block grants for the medicaid program, I would suggest that some modification of those regulations that govern participation under the ICFMR program be made to encourage the development of community services and the financing of community services and to discourage the continued use of that funding source for institutions.

Clearly, community programs do emphasize building independence and they do cut down on an individual dependence on an existing service, whereas, the same cannot be said for the institutional programs.

So, as we need to manage in time of less financial participation by the Federal Government I would suggest that we be given the opportunity to use that money, what is left, in more creative ways according to the principles that I have summarized.

Thank you, Senator.

Senator WEICKER. Thank you very much.

[The prepared statement of Mr. Fulner and Mr. Skarnulis follows:]

STATEMENT OF CHARLES FULNER, DEPUTY DIRECTOR, DIVISION OF MENTAL RETARDATION, STATE OF KENTUCKY

First, I'd like to express my appreciation to Senator Weicker and other members of the subcommittee for providing us with an opportunity to discuss important issues regarding services for persons with mental retardation.

Eight years ago, I began working at Oakwood, an institution for mentally retarded persons that had just been opened by the Kentucky Department for Human Resources. The facility was featured on national television in 1973 as a new hope in the field. It was an institution that would train people to live in the community and then place them within three years of their admission. As that facility's admission officer, I quickly learned that like most States, Kentucky was only providing parents with two choices—to either go it alone by keeping their children at home with little or no support from community resources or to place their children in a distant institution and accept whatever level of care is provided there. Most parents I met did not want to place their children in an institution or even desire 24 hours a day, 7 days a week care. They wanted some occasional respite or some assistance in toilet training or some time to rebuild their family lives after devoting almost exclusive attention to one member for many years.

Unfortunately, the State had decided to first construct a new facility and then to develop the community-based system to serve its residents leaving that facility. As a result, there was almost an immediate clogging of the original plans for people to flow through the facility because there was no place for the residents to go. There wasn't that same strong commitment to building a community-based system that there had been to build an institution and to this day, a large number of Oakwood's residents are waiting for the creation of placement opportunities in their home communities.

Later, in 1976, I went to work for the Michigan Department of Mental Health, joining the Department's task force that had been assigned the responsibility for developing a statewide program of community-based services for persons with mental retardation to parallel the remodeling and downsizing of its institutions. The task force focused on the development of three program types. the first was specialized group homes of 4-8 beds (mostly 6) funded through the ICF/MR program that would primarily serve severely and profoundly mentally retarded persons, most of whom would have a second handicapping condition like epilepsy, blindness, deafness of cerebral palsy or who would be particularly deficient in selfcare skills. The second type was a less specialized set of group homes also 4-8 beds, funded by SSI and State dollars that would serve individuals with less intensive needs. The third type which was the preferred model for children, was specialized family foster care, individually-tailored placements with families who were paid to provide both a home environment and to teach certain adaptive behavior skills. The use of nursing homes as a placement source was abandoned for all practical purposes.

In the last 4½ years, each of those placement programs provided approximately one-third of the placements that reduced Michigan's institutional population from 6600 in 1976 to 4300 today. (Some apartment and independent living programs also contributed.) The return rate of these individuals has been minimal, and the State Auditor General's review has repeatedly found the community system to be programmatically sound.

The placement system worked because the State chose to emphasize community placement. It chose to earmark approximately 10 percent of its annual MH/MR budget in a special line item reserved for community placement. It used its state lease system to secure real estate rather than build group homes itself It recognized start up costs as a legitimate first year operating expenditure, emphasized normalization as a guiding principle, and built in quality assurance measures from the beginning.

Meanwhile, back in Kentucky, when Governor John Y. Brown took office in December 1979 and shortly thereafter appointed Dr. Grady Stumbo as his Secretary for Human Resources they had to decide whether or not to rebuild the Department's Oakwood institution in rural Dawson Springs. Dr Stumbo's investigation indicated that the State offered too few alternatives in the community for persons with mental retardation, forcing families to choose institutions when they didn't really want that, and maintaining a State obligation to finance expensive long term care. He decided to rectify that situation. Instead of remodeling a 176 bed facility, he decided to develop a commuity based program throughout the State and build an 80 bed institution with 48 beds for long-term care and 32 for evaluation and respite With the support of Governor Brown, he hired new staff last November and directed them to place 200 new neighbors out of state institutions by the end of his term in 1983. As of March 1, when I rejoined the staff there, 40 people have been placed in individualized settings throughout the State.

Under the leadership of Dr. Skarnulis we are developing our community program based on 8 guidelines, which we think are crucial for assuring both permanence and quality of service. They are:

I. All family and individual support services should have been made available before a residence is sought

II. All residences should be as small as possible.

III. Individualization. A specific reason(s) for requesting residential service should be identified and solutions to that problem(s) must be actively and creatively sought

IV. A date for re-evaluating the residential program should be arrived at before admission.

V. A residence should be as close as possible to the community, neighborhood, or home where the person will live upon completion of the program. People living in special residences will leave those residences for programs appropriate to their age group.

VI. Partial residential services should be available. Rarely is 24-hour, seven-day-a-week residential service needed. Often one day per week, a few hours per day, or a specified block of time will suffice.

VII. Family involvment should be accommodated and encouraged. Service systems should not assume responsibility for parental functions which can continue to be met (e.g., providing transportation, managing medical/dental clothing needs, relating to school staff, etc.). It is not appropriate for staff to supplant the family by performing these functions.

VIII. Residential systems personnel should be evaluated and rewarded according to their ability to assist individuals to acquire new skills and become more integrated with the community at large.

I would suggest, Senator, that if Medicaid funding is capped, that the federal regulations governing participation in the ICF/MR (Intermediate Care Facilities for the Mentally Retarded) program be modified. As presently written and applied, they do not encourage the development of the kind of small programs that would reflect the service guidelines I've just outlined. In fact only 23 states use ICF/MR funding for facilities for 15 beds or less and only a few attempt to do so for settings of 6 beds or less. In Kentucky we are anticipating a long uphill battle with the federal Department for Health and Human Service simply because our community program is not institutional enough.

Unfortunately current regulations provide states with a strong financial incentive to rebuild old facilities or construct brand new institutions. The fact that 46 states obtain ICF/MR reimbursement for institutional program vs. 23 for community-based programs give evidence that the federal government is encouraging the several states to continue institutional programs. It is especially ironic in these conservative political times, that federal regulations favor a program delivery model that promotes dependency on the part of its clients and will require increasingly larger investments of public funding in the future, rather than a community based model that would promote the independence of its service recipients, and would judge itself on the basis of how well it promotes the integration of its client into the economy and community at large.

Basically, it is our contention in Kentucky that 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.

When people do have to leave their home it should be for as short a time as possible, as short a distance away as possible, and in preparation for a return to a setting that is as close as possible to what is normal for non-handicapped persons of the same age.

Lastly I want to quote Samuel Gridly Howe, a 19th century reformer and early champion of institutions. Speaking in 1866 at the laying of the cornerstone of the Batavia, New York, State Institution for the Blind he said:

* * * Society, moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wished to less. * * * Our people have rather a passion for public institutions, and when their attention is attracted to any suffering class, they make haste to organize one for its benefit. * * *

All great establishments in the nature of boarding schools, where the sexes must be separated, where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine and formality, and restraint, and repression of individuality, where the chores and refining influences of the true family relation cannot be had, all such institutions are unnatural, undesirable, and very liable to abuse. We shold have a few of them as possible, and those few should be kept as small as possible. The human family is the unit of society. (U.S. Department of Health, Education and Welfare, 1976.)

DEPARTMENT FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT 40601

FOR HEALTH SERVICES
sion for Community Services
Mental Retardation

April 3, 1981

Subject: Residential Alternatives for Persons with Mental Retardation

Senator Lowell Weicker
Chairman
Sub-Committee on the Handicapped

Dear Senator Weicker:

This letter is being written as supportive testimony to be considered by the sub-committee members in their deliberations on residential alternatives in the United States today. As Director of Kentucky's community programs for children and adults with mental retardation, I am extremely concerned that those services be safeguarded and improved upon. 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

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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 not 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.

Senator Lowell Weicker
April 3, 1981
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I have enclosed a copy of a press release which we issued recently supporting the more extensive use of our state's resources in development of community alternatives. The Commonwealth of Kentucky would be very appreciative of whatever help could be provided by your committee to aid in this endeavor. Thank you.

Sincerely,

Edward R. Skarnulis

Edward R. Skarnulis, Ph.D.
Director
Division for Community Services
for Mental Retardation

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PREFACE

In the eleven months of the Brown Administration that I have served as Secretary of the Department for Human Resources, no one issue has been as complex or as emotional as various aspects of our Mental Retardation programs. Within this highly critical area, the largest single issue has been whether or not to rebuild the Outwood institution in Dawson Springs. At the same time, Kentucky is far away from having an adequate community based program in each city and county in the Commonwealth for our forgotten mentally retarded children and adults. I have frequently talked about the need for all of us to rapidly develop a program at the local community level for what I have frequently called "our new neighbors"--those who have been largely forgotten, almost always misunderstood, and for whom we have done too little. We are trying to restructure our systems to rectify this oversight. I have recruited new managers in our retardation programs. The Governor has flown with me and inspected our institutions. The issue is if we continue to devote the majority of our time to institutional programs or to the immediate development of our vitally needed community programs. The issue, however, is not as simple as that. While we move to community programs for mentally retarded persons, we desperately need to reform our institutions, to alter their mission, to provide temporary facilities, to actively and expeditiously move to community programs. Simply put, the issue of whether or not to rebuild Outwood is not an "either-or" decision, but a "both-and" one.

Many of our retarded citizens live at home with their parents or other family members. When a parent or loved one dies, there are no choices other then sending one of our citizens to an institution. There are not adequate supports to them in their homes and few community residential alternatives for them. Private facilities are often beyond the means of a family's resources or to our general fund resources--even with Federal supports. The program I am about to announce today is the culmination of many months of intensive deliberation and of the most serious talks within the Administration, of long prayer and often agonizing soul searching. Nothing has touched my heart so much as my visits to our current institutions or to the handful of existing alternatives we have in the cities and towns of Kentucky. I can tell you that the Governor was touched deeply by his involvement in this decision. The decision on Outwood is not so much the culmination of a problem but the beginning of a solution. If, by the end of this Administration, we have begun to develop a new mental retardation service for "our new neighbors," my time in Frankfort will have been worth it and we will have made some small progress in our service to people.

STATEMENT

The Commonwealth of Kentucky will build five residences for 10 mentally retarded persons in a new program at the Outwood State Hospital in Dawson Springs to replace the current facility in Christian County.

The new facility will focus upon evaluation services and a new respite care program and will be a departure from traditional institutional services for mentally retarded citizens in Kentucky.

The new program will resolve a three-year deadlock over whether to rebuild the Outwood facility, which involved a court suit brought by the Kentucky Association for Retarded Citizens (KARC) dismissed earlier this year and which sought community-based services as opposed to institutional care for mentally retarded children and adults.

The original rebuilding of Outwood called for an $11.5 million effort to serve 176 people. The new plan calls for an expenditure of $8.1 million. Each cottage will serve 16 persons and will cost an estimated $132,783 each. There will be two service buildings at $109,600 each and a Resident Life Center at an estimated $3.2 million. Site improvements will cost an estimated $681,000, and contingency factors will add $1,797,000 to the project. The new facility will offer a wider range of services for client needs.

The new replacement at Outwood will also be accompanied by plans for the development of a major thrust in community-based programs for mentally retarded persons throughout the Commonwealth. There are currently 104,000 mentally retarded citizens in Kentucky of which only 1,702 are currently in institutions--1,047 in public or state operated facilities and 655 in private institutions or nursing homes.

Over 98 per cent of Kentucky's retarded citizens are already in the community, but there is a shortage of community-based services for the mentally retarded--specifically group homes and other residential services. Omaha, Nebraska (with a population of 500,000) offers over 250 residential places run by an agency specializing in mental retardation. In contrast, Louisville (with a population of over 700,000) has only 22 residential places run by a specialized agency.

The decision to build a small facility at Outwood in Dawson Springs is not a decision in favor of institutional care for mentally retarded persons at the expense of the rapid development of community-based alternatives. It is a recognition that there is a severe shortage of services for the severely disabled in the Commonwealth and that funds for the facility have already been approved by the Kentucky General Assembly.

A systematic program for "community alternatives" for our mentally retarded citizens in Kentucky is currently being designed by the Bureau for Health Services in DHR under the direction of Dr. Edward Skarnulis, a nationally recognized leader in the field recruited from Nebraska earlier this year. Dr. Skarnulis is working with KARC, and Kentucky's network of locally based mental retardation programs and groups. The new community-based program will be completed in its design stage my mid-1981 and specific funding will be sought to support the plan, both from federal sources and from the 1982 Kentucky General Assembly.

The new Outwood program is designed with several goals in mind:

1) to improve institutional conditions for mentally retarded persons;

2) to move Kentucky to the forefront in the reform of traditional institutional services;

3) to avoid placement of individuals into institutions;

4) help families avoid the need for placement wherever possible by providing them with necessary services or equipment;

5) to move toward the active development of comprehensive community-based programs.

Institutions for mentally retarded persons offer some unique and intensive medical and social programs, but they are also expensive in that they duplicate some resources already available at the community level--local hospitals and clinics, gymnasiums, swimming pools, school facilities, etc.

Re-integration of our mentally retarded neighbors into the mainstream of community life is made more difficult by the lack of movement from an institution back to a community setting. The new Outwood facility is being designed to expedite and encourage deinstitutionalization of these mentally retarded persons.

It is important to note that no current facilities offer 24-hour, seven day a week treatment and training programs inside existing institutions.

The new community-based program being initiated will include a Community Support System. It will consist of an organized network of caring and responsible people committed to assisting a vulnerable population in meeting their individual needs and developing their potentials without being unnecessarily isolated or excluded from the community.

The community support system will serve a population consisting of individuals with a persistent disorder that seriously impairs their functioning in unassisted daily living situations, in normal employment, or in personal or living situations--but for whom a long-term, 24-hour care in an institution, hospital or nursing home would either be unnecessary or inappropriate. It may demonstrate, as some other states have, that we have underestimated what can be done for even severely handicapped individuals given adequate community resources. We may be surprised at how far people can grow and develop.

One of the five cottages at the new Outwood would be dedicated to diagnostic and evaluation of people. A new program will identify specific needs of each person and design both a corrective plan and a specific placement. Individuals would remain in the diagnostic and evaluation unit for a period as brief as two weeks and not to exceed six weeks. As with each of the five residences in the new development, there will be sixteen people within the evaluation unit.

A second of the five residences at the new Outwood will be devoted to respite care. The respite care residence will be a supervised living environment for those community or home based individuals when parents or other regular guardians may require to be away from their home. Stays in the residence will normally be for a two-week period.

The three remaining residences will be for individuals at Outwood for longer periods--but with a focus upon eventual community placements. The three residences will accommodate 48 ment and women.

Architects will complete the final drawings of the new Outwood plan and the next step will be to issue or sell the bonds authorized by the General Assembly. Construction could begin as early as spring of 1981 and actual construction could be completed by mid-1982.

There are currently 200 individuals at Outwood. When completed, from 125 to 175 persons will be transferred to community placement and/or other existing facilities within the Commonwealth's institutional network. This will not be a easy task. The following action plan is something we will begin working on.

ACTION PLAN

1) Plans for appropriate community placements will begin immediately. The longer we delay, the more traumatic such relocations will become.

2) We will immediately begin contacting the families of residents of Outwood to determine which families would be willing to accept their sons or daughters home, given necessary resources and support. The rule of thumb would be that no greater support can be provided than would be provided using existing per diems ($50 per day) at Outwood. Such support would have to include a day program, medical assistance, recreation, etc. We may contract with a group like the Kentucky Association for Retarded Citizens to enlist their aid in making such contacts and conducting such interviews to parents of the residents at Outwood.

3) A team of trained staff from the Division for Mental Retardation will be assigned to immediately begin evaluations of residents at all facilities for the purpose of encouraging community placement plans where residents are not being moved. Any vacancies created by these moves would be filled by Outwood residents. All existing community residential resources will be

earmarked for occupancy either by Outwood residents or residents of one of the other facilties. Vacancies created by movement of other facility residents into these community residences would be earmarked for Outwood residents.

4) Community groups that have indicated their willingness to support the deinstitutionalization program will be contacted immediately and given specific instructions on how they can he helpful. Specifically, a group calling themselves supporters for Outwood deinstitutionalization has been formed in Louisville and have agreed to move no fewer than two persons per month out of that facility. The Seven Counties MH-MR agency has accepted a grant of $50,000 for moving three children from institutional settings into their community, demonstrating that children that are the most severely or profoundly retarded can be served adequately in a community environment. These three children would cost $75,000 if they stayed in Hazelwood. They have said they will serve 20 more as soon as we give them the money. We have received assurances from colleagues in the academic community at the University of Kentucky, Department of Special Education, that they will do whatever is necessary to provide us with technical or programmatic expertise. This would be very helpful in training community employees for service delivery. We are currently interviewing a gentleman from the state of Michigan who helped to develop that state's very progressive Title XIX regulations which might lead to continuation funding for any residential programs started using the $600,000 allocated by the Legislature this session.

5) In order to avoid "dumping" of people into inappropriate locations, we have been in contact with two professionals who would be willing to help us to develop a state plan of action which would timeline out community residential alternatives development over a period of three to five years. The Division for Community Services for Mental Retardation can provide the expertise necessary to develop appropriate standards for community programs and, by contracting with local associations for retarded citizens, we can ensure more than adequate monitoring of such systems. It is crucial to note that the dispersal of people throughout communities necessitates development of a management system and outside monitoring components, that will prevent programmatic deterioration and the rise or decline of appropriate environmental standards. However, it is also significant to note the <u>visibility</u> of people in communities makes them much more likely to be spotted when abuse or neglect occurs. This has been a historical problem with isolated institutional invironments.

6) One of the tendencies is to view deinstitutionalization as an all or nothing proposition. If we break the challenge down into component parts, however, it is far less overwhelming. For example, if each comprehensive care center were willing to establish two residential places per month for one year, a commitment already made in Louisville, we would be serving all 276 Outwood residents in the community at the end of nine months. Another example: The Macomb-Oakland Regional Center in Michigan created places for 700 people in five years. In eastern Nebraska, a division Dr. Ed Skarnulis administered, created 110 new places for institutional and community residents in six months.

7) Clearly the techology is available to deinstitutionalize Outwood.

8) Use of existing housing (the time lag in building new residences can be as much as a year or more) must be a priority.

9) We might have to consider moving people into homes that accommodate no more than one, two or three individuals with handicaps. This is necessary if we are to cut down the time requirement for group licensing, certificate of need, fire marshal requirements, and zoning requirements. If we are required to go through those mechanisms we will be delaying nine months to a year and a half the opening of any single residence.

10) Except for group homes, our objective will be use housing provided by the residential employee. Displaced homemakers, professional people who are employed in other jobs, and graduate students are all candidates for employment as trained professional staff. Many of these people would never be willing to stay away from their own homes and spend evenings or weekends or holidays in agency-owned residences.

11) The use of private residences, not agency owned, also reduces the potential for neighborhood reaction and opposition. Since no zoning exceptions are being requested, since the people providing the service are well known to their neighbors, and since such a method of service provision is viewed by others as temporary the opposition is reduced and the likelihood of the persons return home is increased.

12) We must avoid the dangers of traditional foster home placement and this essentially has to be done in the recruitment and selection of personnel, paying them professional levels of wages, and insisting that they comport themselves as professionals and that they engage in an on-going in-service education training program.

13) The natural parents, whenever possible, will be intimately involved in every phase of this residential placement. They will help to recruit, to screen, and in some cases (where services are provided in their own homes) may even be involved in signing the paycheck and supervising the person hired.

14) All residences are dispersed widely and therefore need "monitoring". For this purpose an assistant residential manager will be hired for every cluster (approximately six to twelve residences) and it is the job of this assistant manager to personally monitor and evaluate each of the residences on an on-going basis. As noted earlier, a contract with the local parent association for retarded citizens could also provide such safeguards.

SUMMARY OF DECISIONS

(1) Build a new type of structure for a new program at Dawson Springs. This construction effort will have 80 beds total.

16 beds for diagnostic studies
16 beds for respite care
48 beds for chronically ill

The proposed structure would cost approximately 8.1 million dollars.

(2) Second aspect of decision is to begin to develop a major thrust in community-based programs for mentally retarded children and adults. A systematic program for community alternatives is now being developed in Health Services. The plan will avoid inappropriate or ill-planned mass releases.

Mr. NERNEY. Senator, I would like to add one comment with regard to some facts and figures that don't appear to be too clear. The number of persons in institutions in the State of Connecticut for mentally retarded persons is approximately 3,000. It does not include any of the folks that happen to be in nursing homes. We have counted approximately 1,000 mentally retarded persons at skilled nursing facilities, general ICF's and homes for the aged.

In addition, we do have the facts, figures, and costs per capita of the portion of the budget that the Department of Mental Retardation spends on community programs, institutional programs, and we would be happy to provide all that data to your committee.

Senator WEICKER. Fine. Thank you very much.

I want to thank all those who have taken the time to express themselves here today. The committee will recess until 10 o'clock tomorrow, but I personally want to say that I think I have heard an intelligent, reasoned discussion of a very tough subject. To my way of thinking, it can only mean that after all is said and done, we are going to be working together and not apart.

I think it must be obvious that we each fight for what we believe in. Certainly, there is more goodness in this room than anybody could possibly calculate. Now, let's, for God sakes, use our heads to make it come out right.

The committee will stand in recess until 10 o'clock tomorrow morning.

[Whereupon, at 4:10 p.m. the subcommittee recessed, to reconvene at 10 a.m., Wednesday, April 15, 1981.]

CARE FOR THE RETARDED, 1981

WEDNESDAY, APRIL 15, 1981

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Hartford, Conn.

The subcommittee met, pursuant to recess, in the Senate Chamber, State Capitol, Hartford, Conn., Senator Lowell Weicker, (chairman of the subcommittee) presiding.

Present: Senator Weicker.

Senator WEICKER. The Senate Subcommittee on the Handicapped will reconvene its hearings. We have a great number of witnesses this morning. I would only like to remark at the outset so it would save both you and I embarrassment, that I would appreciate it if each witness would restrict themselves to the 10 minutes alloted in order that everybody might be heard.

It is my intention to have as many people express themselves on this matter of deep concern to each one of us without in any way trying to restrict a complete exchange of views. I think that can best be achieved if we try to remain within the time restraints that I have indicated.

Our first witness will be Dr. Fierri, the chairman of the Governor's Council on the Mentally Retarded. Dr. Fierri, welcome.

STATEMENT OF DR. FIERRI, CHAIRMAN, GOVERNOR'S COUNCIL ON THE MENTALLY RETARDED, STATE OF CONNECTICUT

Dr. FIERRI. Thank you.

Senator Weicker, and members of your staff and committee, I appreciate the opportunity to express myself. Having spent some time with your staff members this past winter, they are very efficient and I am glad to have their interest.

I have been asked today to comment as a parent and as a member of the statewide Council on Mental Retardation, and I would like to add to that on my own, as a dentist of 30 years in practice and somewhat of an expert in the rendering of care medically and dentally in the community, I would like to touch on that as something that might be underemphasized during these hearings or possibly overlooked, so I will add that to it.

First, as a parent, I would like to be as brief as possible because no matter how superficially you would get into the description of this area we would have great trouble in not personalizing it in some way.

I have a 22-year-old son who is a moderately retarded boy. He has been through a private sector facility, then in the State system at the Hartford Regional Center. He later went into a training home on campus there at the Hartford Regional and then eventually into a group home and when he ran out of educational time, I was called one day and it was suggested to me that he be sent down to the Mystic Oral School in a new program that would emphasize vocational training for young adults and did I mind his going there.

I said absolutely not. His maturation there has been very evident. I am very, very pleased with it. So here is a boy going from a group home into a larger setting for a specific purpose, and even though that facility was—later on, on the advice from an advocate group—to not continue in that larger setting, I can't help but think we have got to take a closer look at such programs.

As a parent, I have been in the community, my community being Bristol, and very hardworking in their particular efforts to get community services in place have played a hard role there—and I have no one else to say it for me so I will have to say I have been fairly successful at getting great people and resources involved in that community, and so, in a few years we have taken giant steps forward and I have had the opportunity of dealing with the parents at that level.

And as a council member, as have other council members, have received many calls from many parents so that our sensitivity to the poignancy of this problem is pretty acute. We have to admit that, depending on who you are talking to, with a parent that certainly you are trying to impress them with your views. It pays to be the last person to talk to them because the poor things are at the mercy of their fears, and I include myself in that category, and it is very hard to keep from thinking of the worse things rather than ignore positive things, so we have to keep all that in mind when we try to describe things from the standpoint of the parent.

One of the things I am beginning to bristle at after 10 years of direct involvement from the council level, is the fact that none of us are professional in the view of some of the hierarchy in all of the segments of the advocacy groups and of the professionals. We are supposed to be too emotional, we can't be objective, and it was the late Governor Grasso that pointed out to me when I was describing to her at one point the possibility of changing the composition of the council to include maybe younger and more professionally oriented council members and she wondered why.

She said, doesn't the parent component in there, having brought people up under trying circumstances have anything to offer? We are not that complicated, are we, and so forth. So that, you see, you have these various viewpoints as to what a parent's role is, and so forth.

We are, unfortunately, in one of the most crushing areas that any parent can find themselves in. So we have to apologize for that system of pressures and emotions.

In dealing with my community groups I find that no matter how much work you do in the community, if you get a label for being an institutional person they are quick to remind you of that, which is what I want to direct myself to now, speaking, let's say, from the standpoint of a council member for 10 years and its chairman for 8 years.

I have been a chairman under the original Meskill administration that put me on the council and subsequently under Governor Grasso's term and a half and now under this present administration. It got me directly involved in the governmental process.

So often as I describe the dilemma that we find ourselves in to the various advocates I will find some very intelligent and well-meaning people say, "Well, you know, that is all political stuff and it is very nice but we have got to get down to the real things, the philosophies of these things".

I have to say I don't agree with that at all. It is insulting to hear someone say that to me because I am politically oriented and I feel that when we have to deal with a process with elected officials, and with revenues and with limits of our resources we have to take into account the other areas of life.

I don't like to talk about human services. Let's talk about the areas of life that everyone needs resources for, and we have to be careful that we don't end up with an image of grasping clutching kinds of people, so I consider the person who has the best of intentions who has just said this to me, and I say, I understand him but he doesn't understand me, so we go on from there.

The council, when I arrived, the agency, rather, had a budget of about $26 million and today we are over $90 million, so I have been aware of what it has taken to move this along in a very competitive area. As a former member of our legislature I am sure you recall the enormous efforts made to get this system in place.

We feel that every gain made has been hard worked for and certainly earned and here we are now approached $100 million, and when anybody says to me that we shouldn't be political, or whatever semantics used in there, I just have to say that they are the naive people and we do have to consider the dilemmas we get into economically and respond to them in the best possible manner.

The matter of working toward a solution of the various viewpoints in this very complex area leaves—I am sure at the end of all this there will be no clear cut picture because there is just no way that anyone can be expected to convince the other end of the spectrum that everything is fine up here, just come up to this end or that end.

In the early seventies we had the problem as council members of going out, literally by ourselves, to convince the training school parent associations there was nothing out there in the community they should be fearful of, that we should move as many people who belong out there as possible and not move those that we thought at the time weren't appropriate.

So, we had that experience in the early seventies when we had to get in there and do some hard fighting. At that time the great concerns of the advocate groups were that there would be proper staffing ratios in place, that there were not to be 10, 15 of 20 clients for 1 aide, and so forth. These ratios had to be down to where they were reasonable and good.

And that was the big battle at that time. So our efforts to get people in the community were overshadowed by such things. We had to get in and do some hard fighting and we were not appreciated by the training school parents at that time.

They were also advocating that there is nothing wrong with being big, big is good. Now we have the other end, we have smallness is good and maybe it is the only good, so that after 10 years of this the only thing I can think of on some days is that old expression that old general sweeping statements are false, including the one that I just made, and that is the situation we find ourselves in.

How we can find the resource to get everything done and keep everybody happy in some degree, a contentment to these parents and give the best possible aide and programing to the retarded individual. Along the way, the deep emotional investment that people make in their early positions has to be looked at.

They have become so solidified to that early position that they find great difficulty in moving away from that at a time that would best serve the interest of the retarded if we would all take a look at what we said originally and see whether or not—I think everybody says things every day that they wish they hadn't said—and be able to come back and say, "Well, I was wrong here or there and let's take another look."

It doesn't seem to be taking place. It seems that the end in many cases justifies the means. In other words, I have heard experts from my neighboring State at one point a few years ago make a statement that maybe we would have to sacrifice the care of the institutional people for one generation to obtain the desired result in the community.

That is a form of the end justifying the means. I heard that maybe we can't do thus and thus because it would affect the outcome of litigation and that is baloney as far as I am concerned because, again, that is the end justifying the means. We are going to have to put an end to anything that takes that kind of direction. The realistic motives that we ought to be trying to inspect right down the line and doing a good bit of analysis has to take place.

These are the kinds of things that the council has, with its composition of about half the members being parents and the other half being very interested people, come up with.

Along the way the matter that I mentioned earlier of dentistry and medicine and the need for a good system to be in place for these people. I think a few minutes should be spent on that.

I have been practicing dentistry for 30 years. I know the difficulties involved and there are some great people practicing dentistry that "a labor of love" is all you can describe it to be to where this very kind of work emotionally and physically is done to people that truly don't understand everything that is happening to them.

So that the notion that it can be done better this way and that way on a service that is present in everybody; a look has to be taken at the sustained service in a community is what we would like to see. But I find, as a practitioner with several men in my office, that I have forced them to do work on people that after an hour of real struggle by good qualified specialists in the area, with the title XIX fee structures being as low as they are, we simply lost the dentists and certainly not the client along the way.

Medically speaking, I have been a director of the Bristol Hospital for 15 years and I had to finally go into the staff, as a member of the executive committee, and insist that they find 1 person in that 100 people that service that hospital, that would take the time to go out there and officially be responsible for the care of these people, and I had to apply great pressure to get that person.

I am not saying it can't be done. It can be done and it can be pointed to. There are great people like Dr. Tannenbaum, who is just marvelous at this sort of thing. There are great people who have tried this for a period of time but on a sustained basis, it is a very difficult thing to come by.

So I don't have an answer there but I think it should be remembered that these services are essential to everybody. They are very painful without them and they are painful with them. They have got to be provided for and fees have to be put up that can allow service to be rendered.

With that background I just want to say there are no simple solutions to this whole problem except that we have to be ready to reconsider our positions.

With that, I realize your time is——

Senator WEICKER. Thank you. Not my time, everybody's time. But, Dr. Fierri, thank you very much for a very expert and personal testimony.

Is there anybody that knows of somebody in the room that is either deaf or hearing impaired that would like to have the services of an interpreter at this time?

[No response.]

Our next witness is Dan Reinhardsen, a parent representing the Development Disabilities Council. It is nice to have you here.

STATEMENT OF DAN REINHARDSEN, CHAIRMAN, ADVOCACY COMMITTEE, GOVERNOR'S COUNCIL FOR THE DEVELOPMENTALLY DISABLED

Mr. REINHARDSEN. Thank you, Senator, Mr. Doyle. I am here today representing the Governor's Council for the Developmentally Disabled for which I serve as chairman of the Advocacy Committee. I am also here as a parent of a 29-year-old retarded son.

Before stating my position, Senator, I would like to publicly thank you for your efforts to retain Federal funding for the handicapped population. I am sure that in these days of economic crunches this has not been easy. The pressures have been great but your support is appreciated and applauded by all the parents of the handicapped.

Senator WEICKER. Thank you very much.

Mr. REINHARDSEN. I appreciate the opportunity of appearing before you today because, like you, I am deeply concerned about the litigation brought by the Connecticut Association for Retarded Citizens and other organizations against the department of mental retardation.

The basis, very simply, of this litigation is the question of deinstitutionalization. There is no question that many, if not most, of the handicapped persons now residing in our large State institutions, namely Mansfield and Southbury, could be better served in small community-based homes.

My own son, for a short time, was a resident of Mansfield. He also resided, again for a short time, at Seaside Regional Center. At the present, he is a resident of a community-based home for five handicapped persons, operated by a private association, the Shoreline Association for Retarded and Handicapped.

To say that his life today is better than when he resided in an institution is a great understatement. He is able to enjoy a full and productive life with dignity. He is able to participate in local social and recreational programs which enrich his life and many other handicapped persons are enjoying these same advantages in group homes throughout our State and many more now in institutions should be enjoying these opportunities.

There can be little argument that deinstitutionalization is necessary and most desirable. At the same time, however, there are a number of parents of severely handicapped that believe sincerely that their handicapped children are better served in an institutional setting.

Parents of these handicapped are very concerned that the current litigation, if successful, will eventually close down our large institutions. Members of the Governor's Council, which I have had the privilege of serving on for a number of years, are sympathetic to both sides of the litigation.

Representatives of both CARC, via local ARC's and the department serve on the council. The council has tried to maintain a neutral position in the hopes that it might serve as the catalyst to bring parties together to settle these problems in the best interest of the population that they both serve.

Unfortunately, we have not been successful in this attempt and it is for this reason that I appear before you today. Both CARC and the department of mental retardation are composed of many dedicated individuals with similar goals. Their primary objective, I am sure, is to provide the finest program and life styles for the handicapped of our State.

However, the present litigation is creating barriers to this objective and the ones who suffer the most are the very ones that we are trying to serve. Communication between both parties have almost completely broken down. A large amount of time, energy, talent and money is being spent developing a case for or against the litigation.

Staff members of the institutions cannot properly do their jobs when so much of their time must be devoted to prepare a defense. CARC staff, I am sure, is devoting so much time to litigation that other programs must suffer.

By coming before you today on behalf of the council, Senator, it is our sincere hope that some way can be found to bring the parties involved together, to sit down as reasonable individuals and to work out a solution which will best serve all of our handicapped citizens.

For an example, one area where CARC and the State might have worked together to overcome their differences would have been the completion of Project Habitats. Project Habitats was a statewide survey undertaken by CARC in May of 1979, and stopped when CETA funds were withdrawn in October of 1980.

This project would have determined the number of handicapped persons residing in the State and enumerated them by type of disability. Additionally, the study would have measured their program needs, would have developed the programs that are currently available in the State.

This study, if completed, would have given the State and private agencies a reliable data base upon which to plan housing programs for the handicapped persons and to target financial resources for them.

Some allocation of funds must be made to allow everyone the opportunity to have the program and the life style best suited for them. A lengthy and expensive lawsuit need not be our only alternative, and I assure you that the council stands ready to assist in every possible way.

For just a moment, Senator, I would like to speak not as a representative of the DD Council but simply as a parent. For 29 years my wife and I have experienced the frustrations of many parents of handicapped children. We were told years ago that our son could not make it in normal society.

And yet, we have had the thrill of seeing Steve grow and mature. We have seen the joy that he brings to all that come in contact with him, particularly his family. He has taught us a great lesson, that handicapped people can lead a productive life and contribute to their community and, most important, can give love without hesitation.

Through the years in working with the handicapped we have learned the true meaning of compassion, of patience and of pleasure in simple things. Before education became mandatory in this State and school systems, by and large, rejected the idea of special classes, I can remember well the spirit of cooperation in my own town of Guilford when parents and educators sat together and decided that handicapped children had the right to an education.

We didn't need arbitration or a court case to make this possible and, frankly, I don't think we need it now. We should learn from our handicapped the importance of working together. There are no religious, wealth or color lines in the minds of the handicapped.

Rich or poor, white or black, Jew or Christian, we have seen the handicapped working and playing together and enjoying it more. At a public beach some years ago where we had taken our son for a swim we overheard some people say, "Why do they bring that child here?" I don't think that would happen today with the educational programs that have been developed in this State.

Some say we should have gone further. I am sure we should have. But we have come a long way. We must not let all the progress that has been made in Connecticut be sidetracked by different groups working against one another instead of cooperating and striving toward our common dream.

Thank you very much for the opportunity of presenting the council's and my own personal views.

Senator WEICKER. Thank you very much, Dan, for a very eloquent statement.

I have given additional thought, even as I drove home late last night back to Mystic, as to what can be done and I can only assure you that even after these hearings close down it is my intention to maintain contact with your groups and individuals involved to see that we can arrive at a conclusion of this matter in a way that is satisfactory, maybe not 100 percent satisfactory to everybody.

As I learned when I started out my law career in Greenwich, Conn. in talking to an elder jurist one time, he turned to me and said, "Lowell, a good decision is one that leaves everybody a little bit unhappy." I think that is probably the way it goes.

But I do know this: It is going to really be a very difficult fight to obtain the necessary resources to help all those that are involved in this controversy in today's climate. And I am not so sure—and I say this to all my friends in the room that appeared yesterday and that are appearing here today—that I intend to expend that kind of personal energy and political capital if after we achieve that goal everybody is going to squabble about what it is that has been attained in the way of funding.

Maybe it is that we are going to have to arrive at some sort of a legislative resolution of this matter in terms of where the money goes. I hope that wouldn't be the case. But I think you have correctly pointed out that in a time of limited resources, especially monetary, a great deal of money has been expended already in this problem, which would have been far better spent in a positive effort toward the young and old men and women involved.

That isn't to say that litigation isn't a proper avenue. I am a lawyer. Sometimes it takes that to get people off their backside. I have no criticism in that regard. But I don't think that this is a matter that can be better settled in the courts than can be settled by reasonable men and women either in the matter of personal contact or in the legislative context.

Those decisions are tailored by the many far better than one man or one woman who sits in judgment on all of us, especially when that one man or one woman probably doesn't have that personal experience that almost everybody that has appeared here has had in addition to their professional expertise.

Again, I commend you not only for your statement but for your efforts, and I want to say to those that did testify yesterday that you gave me a whale of an education. I think, if anything, I came into these hearings slightly tilted against the stance of those who testified yesterday afternoon and I can tell you honestly that I came away from yesterday afternoon with a greater appreciation of their point of view.

But I can't appreciate, because of the circumstances of the time, a squabble that goes on ad infinitum, and I think we all feel the same way. So, thank you very much, Mr. Reinhardsen.

Mr. REINHARDSEN. Thank you, Senator.

Senator WEICKER. Is Senator Rogers in the room?

Senator Rogers has been delayed so we now have Mr. and Mrs. Mario Janazzo, is that right? Did I pronounce that correctly?

Mr. JANAZZO. Marco.

Senator WEICKER. Marco Janazzo. I apologize. Believe me, nobody gets their name mispronounced more than I do, so I have a great deal of appreciation for the fact of pronouncing other people's names correctly.

Mr. and Mrs. Janazzo are both parents, I gather, of a child in Southbury.

Mr. JANAZZO. Yes.

Senator WEICKER. The committee will be delighted to hear from you. Go right ahead.

STATEMENT OF MR. AND MRS. MARCO JANAZZO, PARENTS, SOUTHBURY, CONN.

Mrs. JANAZZO. I will speak first, Senator.

Senator Weicker, my name is Fanny Janazzo. I am President of Parents and Friends of Connecticut Retarded Citizens, Inc. This parent organization was formed because of the suit against the State of Connecticut by Connecticut Association for Retarded Citizens and its other plaintiffs regarding deinstitutionalization of Mansfield and similar institutions.

CARC and its other plaintiffs do not represent the majority of the parents for the well being of all retarded citizens by placing all classes of the retarded into group family type homes within the community.

The organization I represent believes that there is a certain percentage that can live in a community type environment but State-operated facilities, such as Mansfield and Southbury are needed to care for the retardates, which deinstitutionalization would be detrimental to their safety and well being.

The national policy of deinstitutionalization has affected the mental health services by stopping improvements and/or growth in institutions, stopped hiring very badly needed personnel for the care and education of the retarded, stopped instituting new programs and thousands of dollars spent on lawsuits.

The severely and profoundly retarded need constant attention, care and direction. Their best care is in an institution where they have around-the-clock care and continuity of care.

All facilities are provided for them on the grounds; medical, educational and recreational. Their surroundings are always the same so that they do not have to make any adjustments. They are not frightened or frustrated. It is a safe and happy environment for them.

The institution is their community, not the community where even the normal can't cope. All the insitutionalized retarded came from the community. They could not make it into the community, our community. Parents with normal children are allowed the privilege of deciding whether to send their child to a boarding school, private school, or public school. Why can't the retarded child's parents have the input as to where they want their children?

The majority of the parents whose children are in institutions would like to have them upgraded, make them modern, decent, progressive, healthy, well equipped and staffed. Build up their community where they can live in luxury for their needs by their standards, not our standards.

Their needs and wants are not like the normal. If they could have remained in the community not one parent would have experienced the pain and agony of placing their child in an institution. They will never be adults, even though they get to be 100 years old.

Mainstreaming is wishful thinking and to place the severely and profoundly retarded in the community is cruel. Anyone who has a severely and profoundly retarded child suffers the accompanying agony of knowing that that child is a misfit in society geared for normal people.

Senator Weicker, I am a mother of a Downs Syndrome 22-year-old severely and profoundly retarded child, my only child. I placed my son James at the Southbury Training School when he was 16 years of age. He attended a day care and then attended the Gengras Center for Exceptional Children for 11½ years, one of the finer schools in Connecticut.

I tried to socialize him by keeping him out in the open, taking him everywhere. He was never, ever closeted. However, that is not to say that society has accepted him. It hasn't. So-called society has spurned him, stared at him, laughed at him and been frightened of him, among other things.

My son, with the mentality of a 2-year-old does not know enough to cover himself when cold, not able to turn on a faucet to get water and, as a matter of fact, does not even know he is thirsty or sick. A group home will only lead to frustration, unhappiness, sickness and eventual death for him.

The severely and profoundly retardates need the four sheltered walls that now house them and to destroy the concept of institutions is to destroy the retardates themselves.

Senator Weicker, may I add, on Thursday, April 9, 1981, I attended a human rights meeting at the Southbury Training School to hear their guest speaker, a doctor from St. Francis Hospital in Hartford.

He stated that two mildly retarded people were scheduled to have medical treatment where anesthesia was required. The doctors waited and waited. These people are living in a group home and whoever drove them to the hospital left them off at the front door. They finally were found wandering on the grounds. The doctors couldn't work on them because they didn't know whether they had breakfast, medication and so forth.

What I would like to point out, Senator, is what if these people were severely or profoundly retarded, like my son?

Thank you very much, Senator.

Senator **Weicker**. Thank you very much.

Mr. **Janazzo**. I might run a minute or so over, Senator.

Senator Weicker, I sincerely thank you for the opportunity to make this statement. My name is Marco Janazzo and I speak to you today in a twofold capacity. I speak for my 22-year-old son, Jimmy, whose home away from home has been the Southbury Training School for the past 6 years, and I speak in my capacity as the president of the Southbury Training School Home and School Association.

The association is now in its fourth decade of service. In this capacity, I represent an association of parents, relatives and friends deeply concerned about and deeply involved with the 1,300 mentally retarded citizens of the Southbury Training School. Our feelings go deep. Our feelings are honest. Our convictions have a solid foundation of many, many years of experience.

Senator, we are not talking about children. Nine out of ten residents at the Southbury Training School are over the age of 21. Hundreds are over the age of 40. Our children, now grown, have found a home at the Southbury Training School. They have found acceptance. They have found friends. They have found excitement.

They have found laughter. And, yes, because Southbury is real and fully human, they have found disappointment.

That the training school is something less than perfect is hardly sufficient reason to condemn it. Very few of our children can adequately express themselves in words. Perhaps, most of all, they have experienced at Southbury a sense of their own worth, a sense of their own dignity.

A full range of services must be made available for the 45,000 retarded citizens in Connecticut. Any person who can prosper in a life in the community setting is entitled to that opportunity. Any person who could prosper in an institutional setting such as the Southbury Training School is entitled to that opportunity.

The institutions continue to be a vital, critical component in the continuum of care that our retarded citizens need, that continuum of care, which is their birthright. A popular phrase these days is "cost effective". We are led to believe that community programs will be cost effective as compared to the high cost of an institutional program.

We are light years away from resolving that particular problem.

It is a complete fallacy to compare an institutional budget with a community program unless all of the services that an institution renders are also rendered in a community, personal, educational, recreational, medical, dental, social services and so forth.

No valid comparison can be made unless the comprehensive array of institutional services are made available in the community and the cost accounted for. A highly visible institutional budget cannot be compared with the costs that are far less visible because they will be spread out in a variety of service agencies.

There is no inexpensive way to meet the needs of seriously handicapped people. At any rate, we, the parents of the citizens of the Southbury Training School are sure of one thing: Our children are not up for sale. For the most part, the residents of the training school are severely and profoundly retarded.

Many are capable of learning the basic skills of living. They are capable of improving their behavior. They are capable of a happy life with appropriate supervision. They are very dependent people and they will be dependent people all their lives.

If the needed services are to be duplicated in the community, contention about cost will likely disappear. Senator, the issue is the person and what is best for him. I would like to conclude with two recommendations. I ask that you speak to the parents of the Southbury Training School and hear from them in their own words what they feel about the Southbury Training School and what it means in the lives of their children and in their lives.

Second, I would ask that you visit the Southbury Training School and plan on spending several hours there, see with your own eyes, talk with the people yourself. And after you have visited the training school and seen its strength and its weakness, you tell me, Senator, if the Southbury Training School has nothing to offer and that the Southbury Training School is not needed.

Once again, when all is said and done, with all its good, with all its bad, the Southbury Training School, which is called an institution, is itself a caring community.

Thank you.

Senator WEICKER. Thank you very much, Mr. Janazzo.

I have, just as recently as a couple of days ago, been at Southbury for several hours. I also paid previous visits to it. Let me say this: I share much of the feeling you have expressed here today as to the quality of care, the extent of the care that is given at Southbury. I also want to make clear to you that your experiences, as both of you have recounted them here this morning, are the best kind of testimony in the sense of your personal involvement.

I also want to make clear that I think what we are trying to achieve is a continuum of care to make sure that the appropriate care is given each individual. So I can assure you that I don't come into this with any prejudices. As a matter of fact, as I indicated earlier, if anything, I would say I started off the hearings with maybe a slight prejudice against those on the other side of the fence from you.

But I think as everybody speaks their heart and their mind, it becomes clear there is a very tight knot here. There has to, and I underline "has to," be a way out of it. I think that way is far better achieved as among ourselves as in court. That much I do believe.

Thank you very much.

Mr. JANAZZO. Senator, may I have 1 more minute, please?

Senator WEICKER. Sure.

Mr. JANAZZO. Yesterday, Senator, there was an expert here from the State of Massachusetts who talked about Hitler's deinstitutionalization and his method of dispersing the problem and that was the gas chambers or whatever methods they had.

Senator, I would like to know what is going on in the State of Massachusetts. I have here in my possession a document that states that in 1960 they had 10,096 residents in their institutions and in 1979, they had in the community 5,590.

In front of U.S. District Judge Joseph L. Tauro in the Federal court they were only able to find 2,000; 3,590 of these retarded who were deinstitutionalized are lost. They have disappeared from the face of the Earth.

And when asked what has happened to these people they said, they maybe starved to death, froze to death, died for lack of medical attention, and so forth. Here is also the testimony of Professor Ricci, and I would like to read just one little paragraph, if I may.

This is Benjamin Ricci before Senator Bakman's committee, December 3, 1979. "Deinstitutionalization is a convenient way to disperse the problem. The Department of Mental Health"—now that is a little different than Connecticut— "is bankrupt in leadership. Our next series of tragedies will involve those who just could not hack it on their own in the community, as some area directors are quick to point out that our clients, meaning my son, and your daughter and relatives have a right to be murdered, to be raped," and then he goes on to say, "at long last there seems to be a constitutional amendment which is in order."

Senator, I would like to leave this with you. It is the full document. I don't want to take any more time, but someone also mentioned about the Alabama case. Here is the Alabama case. And the testimony here yesterday was not fair and that is why the parents are angry.

We are angry because we are not represented by attorneys. We do not have the civil liberty, legal aid, Justice Department backing us up on this.

Senator WEICKER. As I said before, I think you have made a very good presentation as to your feelings in the matter. Believe me, they carry just as much weight with the committee as those who testified yesterday. What I want to do is try to hear positively from both sides.

You are just going to have to leave it up to the committee to try to weed out fact from fiction and go ahead and rely on those parts of the testimony that carry the most weight. But I did publicly compliment those that presented their case yesterday. I think they did it in a very positive sense.

And, quite frankly, I think your testimony here today is a good beginning as Dan Reinhardson and Dr. Fierri present the other side of this matter. So let's leave it at that. Thank you very much.

Mrs. JANAZZO. Thank you, Senator.

Mr. JANAZZO. Thank you.

Senator WEICKER. Next we have Mr. and Mrs. Irving Sloan, also parents of two children at Southbury and aren't one or both of you the chairpersons of the parents organization?

STATEMENT OF FRANCES SLOAN, OFFICER, SOUTHBURY TRAINING SCHOOL FOUNDATION AND PRESIDENT, CONGRESS OF ADVOCATES FOR THE RETARDED, AND IRVING SLOAN, PRESIDENT, SOUTHBURY TRAINING SCHOOL FOUNDATION

Mrs. SLOAN. I am an officer of the Southbury Training School Foundation and I am also president of the national organization, Congress of Advocates for the Retarded, and Mr. Sloan is president of the Southbury Training School Foundation.

Senator WEICKER. I am delighted to have both of you here. I know I have had the pleasure of your visit down in Washington and I am delighted to give you this opportunity that you might say many of the things that probably you said to me in private for the public record.

The floor is yours.

Mrs. SLOAN. I will speak first because I think Mr. Sloan will leave you with a better impression.

Mr. SLOAN. I don't believe that.

Senator WEICKER. He is not going to admit to that.

Mrs. SLOAN. Senator Weicker and committee staff, I am Frances Sloan. I speak to you as a concerned parent of two sons. The fact that my children are retarded enhances my love for them and my devotion and responsibility to them. Consequently, their living environment and care are of the utmost importance to me.

Many years ago, before placing my children in Southbury, as an officer of the Cerebral Palsy Society of New York City, I made a trip from Maine to Florida investigating residential facilities.

It was apparent that Southbury Training School was the finest school in the whole east coast. Today, after having seen many more schools in the United States and abroad, I now feel that it is the finest school of its kind in the world.

Most important, at this large facility a complete community is provided for the residents. In brief, this is a normal environment for them. They ride bicycles safely on the drives. They walk hand in hand in the country atmosphere. They attend church. They swim in a modern swimming pool. Their nutrition is guided by a weekly published diet which is specially arranged when needed. They are trained vocationally. Medical and dental care are immediately available. They attend school. They receive music lessons and therapy. They celebrate holidays with pageants and parades. They take trips to the movies and circus, the "Ice Capades."

But, above all, they are surrounded by love reflected down from the top staff. They are comfortable in familiar, safe surroundings. The alternatives are bleak; confinement in, for the most part, housing in undesirable areas, restriction upon restriction, unsafe to walk out of the door, medical and dental treatment consists of any convenient clinic wholly unprepared to treat retarded persons.

Isolation prevails in a community that rejects them, danger stalks them, even to a much greater degree than it does us so-called normal people in daily living. Persons who have spent many years in familiar surroundings are thrust into strange places, strange faces without the ability to understand the sudden transition and are dependent upon the whims of one or two people as compared to a supervisory staff in the larger facility.

We feel that no person who can benefit from what the community offers and from public education should be in an institution. But we also feel that the more severely and profoundly retarded need the protective atmosphere and perpetuity of care that the larger facility offers.

There is a need for a full range of services for the retarded. An upgraded and improved residential facility must be a part of these services. When community placement and services can provide living conditions and therapies commensurate with Mansfield and Southbury, then, and then only, should they be considered desirable habitations for our retarded people.

At the moment, community placement encompasses very little to meet the vast problems of the severely and profoundly retarded. Improvements and sufficient financial support are imperative to preserve the larger facility. They must be preserved to be there and ready to receive back the great percentage of those who have not been able, and will not be able, to live in the community.

In the State of Connecticut we are fortunate in our commissioner and our two superintendents in Mansfield and Southbury; knowledgeable and the real experts in the field, based on many, many years of experience. It is to these men and the directors of the regional centers that planners for the retarded should turn for guidance.

It is because of these men that Connecticut has been and will continue to be a leader in the world of the retarded. We suggest to the committee the following: That you set up standards that determine the eligibility of a person to be designated expert and that his life preparation, his number of years of service in the field, and proven positive accomplishments be considered essential criteria.

And as an aside to that, Senator, I would be perfectly willing to testify under oath, and others should too, because yesterday I heard great discrepancy in description of conditions in States from the reports that I get from my parent members.

Also, at the same time I will remark on the slides. You know, when you take a still—I have a child of 33 who has a mentality of about 18 months. I could put him in a chair and put a broom in his hand and say, "See, he can sweep the floor." My attitude is, "show me."

Two, that the committee be shown the real audited facts and figures involving the economics of the community placements and the larger facility.

Three, that in your considerations you be constantly aware that the highest mental age level that a retarded person can reach, according to our experts, is the sixth grade, or 11 years of age.

Also, bear in mind that this development is not well rounded, does not generally include abstract thinking, nor the ability of judgment, nor self-defense.

Four, that in your consideration of this issue you be impressed by the fact that this litigation has been forced upon the parents and that we speak for ourselves from our hearts, and that we do not have professionals and paid workers to speak for us.

We also respectfully request that the phrase "most integrated, least restrictive" be more clearly defined in the developmental disability regulations. As president of the national organization, Congress of Advocates for the Retarded, I represent thousands of parents of the retarded across this land and the thoughts I express here are the thoughts and opinions of these parents.

Our opinion is important because it is shared by thousands of parents who have experienced and lived with retardation most of their lives. Our opinion is important because we are the most closely concerned. Our opinion is important because as parents our autonomy is constitutionally guaranteed.

Thank you.

Mr. SLOAN. Senator, I am happy to see you in Hartford. We parents of the retardeds in the training schools are actually in a situation where we felt nobody really cared.

My name is Irving Sloan. I am the president of the Southbury Training School Foundation and have been for the past 8 or 9 years. I speak as the parent of two retarded children who have resided at the Southbury Training School since 1957.

By legal proxy, our parents, guardians, and friends of the retarded residents in Southbury have stated that the CARC does not represent them in the litigation brought to close Mansfield and that the Southbury Training School Foundation represents them.

The number of proxies in our possession total 1,000, which is a significant number out of 1,300-some-odd residents. They know that if the philosophy is established and Mansfield is closed, Southbury will surely be closed also. Our parents are frightened but they are willing to fight and they will fight to a conclusion. There will be no compromise, make no mistake about it.

And in the end we will prevail. No other solution makes any sense. The concept of mass deinstitutionalization is not only wrong, it is stupid. In my opinion, anyone who advocates closing the schools is either vicious, uncaring, and disinterested or is ignorant of the mental level of the retarded.

So-called experts are brought in from other States to support their positions. Why do they have to come from other States when we have experts here in Connecticut who have spent all their adult lives on the problem, such as Commissioner Gareth Thorne, Superintendent Michael Belmont, Superintendent Roger McNamara, and parents such as Mrs. Frances Sloan and myself, Mr. and Mrs. Marco Janazzo, Mr. and Mrs. Jack Devine, Frank Powers, and parents of 1,000 residents who signed legal proxies from Southbury, and also the 600 who signed legal proxies from Mansfield, and also include the regional centers who side with us?

Persons without compassion are interjecting themselves into a situation they know nothing about and do not understand. The commissioner of mental retardation is constantly harrassed. The superintendents are subject to all sorts of interrogatories and abuses, legally and verbally, by person who are our adversaries.

Funds which should be allocated for the retarded are being spent for attorneys' fees and litigation. These legal expenses are grossly unfair. Our parents are taxpayers. As such, their money is used to educate and maintain their children, then the government allocates their tax funds to the legal services and the protection and advocacy boards and other organizations who seek to destroy a concept that parents desire when, in actuality, they should be fighting our cause along with us to save these schools.

Finally, we have had to hire our own attorney, at considerable expense, to defend our position. Another one of our adversaries is the Department of Justice. Under bill S. 10, procedures were established by the Senate for the Justice Department to instigate proceedings to correct deficiencies in these types of facilities.

However, they entered this case and now our parents must all consider our Government as opponents, and have found that the Department of Justice does not provide justice for all, as our Constitution states. Our funds cannot match the finances and expertise of the Justice Department.

We cannot understand how the U.S. Government has millions of dollars to throw away on projects of litigation such as we are involved in, and in the end commonsense will prevail.

I have personally heard from many parents of residents in Mansfield. They think it is a fine school. They love the place and the personnel and only want to see it improved. Anyone that wants to leave it should go elsewhere, but Mansfield should be left to its own devices and be improved.

The parents and guardians of our retarded can have no peace in our lifetime because Congress has ordained that all citizens be educated in the least restricted, most integrated setting.

My children would be completely isolated in the community. The State is being forced to divert funds from the institution for the lawsuit and for group homes. In reality, more funds should be made available to the large institutions for therapy and upgrading.

It makes more sense and could be monitored easily. Hundreds of group homes in Connecticut would be ridiculous. Our children are innocents and they are being used as pawns in a game of chess.

Congress must do something to stop this hatred that exists on both sides and to protect our parents from fear for the lives of our loved ones. Parents have rights and self-serving advocates have no business in interfering in these rights.

In conclusion, let me tell you about a conversation I had with a highly respected person in New York State. I asked if parents of a retarded child kept a child home until he was 25 or 30 years of age in New York State and could no longer care for him or her, could no longer diaper this adult retarded child or person, could no longer handle him physically or mentally, what solution would they have for the child? Where would they put him?

The answer was their only solution was to go to the George Washington Bridge with that child and the three of them should jump. If this case does not conclude properly, that will be the Connecticut solution.

Thank you.

Senator WEICKER. Thank you, Mr. Sloan. The only question I would ask you is whether or not your rather dim view of deinstitutionalization is not brought about by the assault on the institution which you feel is best for your children?

In other words, you have some rather harsh comments to make about a concept which most of the testimony up to this point would support. That doesn't mean to say that most of the testimony has supported closing Southbury. That is the other side of the coin, and I don't think it has. But I just wanted to find out, if we can, in some sort of a dialog here as to whether this dim view is based on experience or based on your own expert's view of the deinstitutionalization concept, or whether as a matter of your own heart you don't feel it is brought about by the fact that those that advocate that concept are not engaged in an assault on a concept in which you believe.

Mr. SLOAN. We do believe in a full range of services for the retarded. Those that can benefit substantially, not marginally, in group settings should be allowed to go there. But I think that the large institution has a real place. It is a real school. It is a real community.

And the parents have the right of placing the child where they feel it is best for their child. For the child itself, if he can graduate into a community the institution can be upgraded. Southbury has been a training school for many years. They have been proud of their graduation record. It can be improved and should be improved.

But to destroy it, is all wrong.

Senator WEICKER. So, in other words, when you talk about the large institution, you aren't really referring to the buildings as much as you are a place where all services are available?

Mr. SLOAN. Right, with a school, with a center, a community.

Senator WEICKER. Do you foresee, over a period of time, that the population of a place like Southbury would decline as these new concepts are brought onstream?

Mr. SLOAN. No; I think there is a need for Southbury and other schools forever. Closing Mansfield makes no sense at all. The lawsuit makes no sense at all. Mansfield is needed. And the parents don't want their children to go into the communities.

I don't understand where the profoundly retarded children are going today. The parents can't keep them home unless they jump off the George Washington Bridge. That would be the solution because there is no place for them, and the place is a place like Mansfield, but not a big building that is a blight on the horizon.

We are talking about nice places. I have seen nice places, group homes in Missouri, beautiful. I saw it in Massachusetts in the Fernald School. The main school is a terrible place but they have ICF cottages on the grounds that are beautiful. In other words, it can be done and should be done. But isolating them in the community is wrong.

Mr. **SLOAN**. That is another concept, Senator. You see, most of these large institutions have very ample grounds. Why could not some of the ICF cottages be built on those grounds where the residents could have the advantage of good medical and dental care and it might even prove a great saving and education right there?

I think that might be a practical approach that could be considered.

Senator **WEICKER**. Again, I thank you for your testimony. Incidentally, I think there is another aspect which you have not alluded to at all here, but if I am not mistaken, hasn't the parents' group at Southbury—and I am sure maybe the same is true of Mansfield, but it was mentioned to me—also given a great deal of their own resources to the school?

Mr. **SLOAN**. One of the things that makes Southbury so unique is an organization—the Southbury Training School Foundation—we are just one aspect of the parents' desire to keep the school and keep it well.

The Southbury Training School Foundation is a vehicle for parents primarily to leave their estates and resources for the upgrading and benefit of Southbury, which makes Southbury a unique thing by itself.

But, aside from that, the parents of Southbury, they don't all come from lower Fairfield County, feel that from time to time they make a donation for various purposes. They speak to Mike Belmont, or the former superintendent, and say, "What does the school need?" And parents would donate $1,000, $500, $200, whatever they can.

They run all sorts of functions, affairs to upgrade the facilities. And, of course, the State should be doing a lot of these things but the parents didn't want to wait for the State to do it and they did it themselves.

Senator **WEICKER**. Thank you very much.

Next, Mrs. Kathryn Jetter and Mrs. Mary Lea Johnson, parents of children in Mansfield.

Ladies, it is a pleasure to have you here and you proceed in any way that you care to.

STATEMENT OF KATHRYN JETTER, HAMDEN, CONN., AND MARY LEA JOHNSON, PARENTS

Mrs. **JETTER**. Thank you. I am Kathryn Jetter, a parent. I live in Hamden. Thank you for this opportunity, Senator Weicker.

I am a parent of a 25-year-old daughter. As a result of viral encephalitis at the age of four she was left with uncontrolled epilepsy and moderate mental retardation. She was placed in an excellent program after second grade in Sharon, Penn.

Her father, being an engineer, was transferred to Pittsburgh. For 2½ years she was in a large regional school which was utter disaster. At age 11½ we enrolled her in a private school which accepted her on a temporary basis because she was already beyond their age limit.

After much searching we found that in the United States of America there were only two schools who would accept an epileptic, moderate retarded female that was 11½ years old. Hence, our move to Connecticut because we had already heard Mr. Smickle and he had been out in the Pittsburgh area and were reading about the available programs.

We located in Hamden. The school system promptly excluded her. We had enrolled her in a private school, which was Stonegate. After much pressure, Hamden School District finally paid the educational cost and we paid the balance for a 5-year stretch.

At age 18, again they excluded her but we did not contest this. We again contacted the New Haven Regional Center for help and over a period of time they arranged a placement in Mansfield Training School.

There has never been a choice of services for our daughter. Mansfield Training School offers the care, especially the medical, that is required. Her first placement in the Star Building was very good. The second placement was a poor custodial care and then the awakening for our daughter.

Our daughter moved to Manchester Cottage, an ICF/MR group home for 16 residents on the grounds. Daily programs are provided on a limited basis due to insufficient staff and funding. At 25, she is now, for the first time in her life, included in Special Olympics, adult education, group outings, dinner dances, shopping, to just name a few.

The team work of the medical staff and the other professionals in observing and investigating, plus the consultations have gained the best seizure control ever in her life.

We have our daughter home every other weekend and major holidays. On our visits to the cottage we have noted great improvement and advances in the conduct of some much lower functioning residents. Many have become more verbal with appropriate greetings, expressions of pleasure and appreciation for special attentions or gifts, appearing properly dressed and displaying good manners.

It is a happy time for us going into our daughter's cottage, which she refers to as "home". Our communities are not ready, nor have they been educated to accept the handicapped as human beings with equal rights. The support services that exist are limited and overcrowded.

Both of us are active board members in the Greater New Haven area of the various organizations for the handicapped. We are not against the concept of community living for the handicapped. Before this can be accomplished, though, there has to be acceptance by the community who will provide living facilities with trained staff, medical facilities, not relying on hospital emergency rooms with 2, 3, and 4 hour waits.

Vocational opportunities, recreational, social activities and transportation—these all exist and are available for the so-called normal person.

Jack Devine is the president of the Mansfield Parent Association and is out of town. He has asked me to just give five brief inserts taken from hundreds and hundreds of letters which have been received by him from parents at Mansfield. I also noted in doing this that the majority of the parents at Mansfield are in the retired group, many on fixed incomes, aging, poor health and lack of transportation.

No. 1, our daughter has resided in Mansfield Training School for 40 years. My husband is 86 years of age, suffering from advanced Parkinson's disease and I am 82, in poor health. We are very much concerned.

No. 2, an aged mother with advanced arthritis had a relative type a letter sharing her deep concerns for her son. The last time she was physically able to travel was in 1979, at which time she was deeply impressed with the solicitude of the staff, his obvious affection for them and left feeling a complete satisfaction that her son was receiving kind, able professional treatment.

No. 3, I do not believe any one form of care is best for all.

No. 4, we are not against group homes. In fact, we support the concept for those who can function in them. We also agree that the improvements are needed at Mansfield but we still feel very strongly that the needs of the severely, profoundly, and multiple handicapped retardees can best be served at Mansfield.

No. 5, many residents, like our son, are not sufficiently independent to survive in the community centers and would simply fall through the cracks of such a system. For these totally dependent people, the training school must survive. If there are deficiencies in the present system, better to correct them than throw away hard-won benefits of the last 15 years. A society can be judged by what it does for its weakest members.

Thank you.

Senator WEICKER. Thank you very much.

Mrs. Johnson?

Mrs. JOHNSON. Good morning, Senator. I am Mary Lea Johnson. My husband and I have a 23 year old profoundly retarded son that has lived and learned in Mansfield since 1963. He was then 5.

When we placed Rick there was only one place to do this and that was at Mansfield. The regional centers were just barely off the ground, after 2 years of him being at Mansfield I tried to place him in the Hartford regional to bring him closer to our home, which is in Southington, but was told that he was not the type of a child that could be taken into their program.

Now that these regionals are off the ground there are better programs and if Rick were the right age, he might go into them. I am not going to take your time telling you of the fight we are having to keep our son and other parents' sons and daughters in the larger institutions, or to tell you about Rick's life, but I would like to say just a few words about the moneys for programs.

At the State level we have the Protection and Advocacy Board which was formed by the State and funded by the same to help all handicapped. They don't even want to hear us as parents because the Connecticut Association for Retarded has told them that they are speaking for all the retarded.

CARC is a nonprofit private group that is receiving Legal Aid help to fight for the removal of all clients at the institutions. The parents group at these institutions are bitterly opposed to CARC's actions and no longer support CARC.

CARC did not have the courtesy to return six phone calls that I made to them 2 years ago to ask help on a question I had. And then, just recently I had to pay the State to become a guardian of my son so that I could speak for him because he has no speech.

I know that State and Federal moneys are hard to come by in these times. All we want is programing for all retardeds and not to rob Peter to pay Paul, or to use State and Federal moneys for only part of these programs.

Thank you, Senator.

Senator WEICKER. Let me ask you a question because I don't understand. You say that there is a State board—the part of your letter that refers to——

Mrs. JOHNSON. The Protection and Advocacy Board?

Senator WEICKER. Right. How does this operate? This is a State——

Mrs. JOHNSON. This was formed by the State and funded by the State to help retarded or help the handicapped, I should say.

Senator WEICKER. And this board no longer functions because of this lawsuit?

Mrs. JOHNSON. Oh, yes, they are functioning but——

Senator WEICKER. Who sits on the board?

Mrs. JOHNSON. I don't really know that. I know that this board was formed by former Governor Grasso to help the handicapped in the State.

Senator WEICKER. And just to make the point clear, you say that, in effect, they will no longer speak for you as parents, this board won't?

Mrs. JOHNSON. They don't recognize us as parents of retarded, that we can speak for our sons and daughters.

Senator WEICKER. They recognize what, only CARC?

Mrs. JOHNSON. Yes. They are for deinstitutionalization.

Senator WEICKER. Again, thank you both very, very much for putting another piece of the puzzle into place. I know it is a great effort on your part to be here but I greatly appreciate it. Thank you very much.

Mr. and Mrs. William Zitko, or Mr. Zitko. And is Judge Barell here? Judge, it is nice to have you. Mr. Zitko, it is nice to have you. Please proceed in whichever way you deem appropriate.

STATEMENT OF WILLIAM ZITKO, PARENT, HARTFORD REGIONAL CENTER

Mr. ZITKO. Senator Weicker and members of the committee, I wish to thank you for this opportunity to speak today. As someone mentioned before, to take your time to come down here and listen to us parents, how we really feel, I appreciate it.

My name is William Zitko and I am a resident of Meridan, Conn. We have a son, our only child, who is severely and profoundly retarded at the age of 24 right now. He is ambulatory, unable to talk, who needs constant medication and will never overcome his seizure problems, according to his medical records.

He has resided at the Hartford Regional Center for 14 years and prior to that, the Seaside Regional Center for 6 years. In 1959, it was difficult to find services to evaluate your child. Community Day Care in Meridan wouldn't accept him because of his retardation severity.

We took him to Kennedy Memorial in Massachusetts for evaluation where the doctor stated we were fortunate that we were living in Connecticut because they are in the best field of retardation and I still believe this today.

I have held presidency between these two facilities for 7 years as well as vice president and executive positions for another 13 years.

As a parent of a retarded I consider myself a professional because who knows their child better. I have seen much progress over these past 20 years and what I was unable to obtain in the early years is now available for those parents who need these services, such as the early intervention program.

The Hartford Regional Center houses approximately 96 residents, and under their supervision, group homes, apartment dwellings, and the newly acquired community transitional training center to provide the necessary training for those ready to go into community living.

In all, approximately 320 retarded citizens are in housing facilities under the jurisdiction of the Hartford Regional Center. What does the Hartford Regional Center provide? It provides a contract between the parents and the center showing the programs outlined for the year for each resident with the goals they wish to achieve, workshops for residents and persons residing within the community, work activity programs, education at the Beach Park School for those 21 and under, full recreation, field trips, social activities, two swimming pools, medical facilities at the Newington Home for Crippled Children right across the street, dental care at the Dempsey Medical Center, and a staff that is compassionate and dedicated to their work and a campus type living environment free from the hazards of everyday community life.

I invite you, if you have not already, to tour our facility, and I am sure you will be astounded as to what you will see. We, the parents, have raised over $80,000 for the benefit of the center over these years so that our residents may have a fuller measure of life.

We have worked and struggled hard to obtain what we had set out to achieve, and with God's help, we do not intend to lose it. Let me make one thing perfectly clear, Senator. I believe very strongly that there should be a variety of facilities throughout our State to accommodate all types of retardation and for those who wish and can function properly, to live in a community type setting.

I believe it is a sin to deny a person these rights, but it is a worse sin to say that everyone must be mainstreamed out of the facility and live in the community. Somewhere within our great Nation a movement started to deinstitutionalize, close all the large facilities because the residents' constitutional rights, by not living in the least restrictive environment, have been violated.

They should all live in small, individual homes within the community. Is someone or persons throughout this country trying to achieve power or personal recognition with total disregard to the human lives which may be in jeopardy?

Senator, the least restrictive environment for one person is not the same for another. I know my son possibly, as well as other parents' relatives, could not exist in a community dwelling since he would be more confined in this type of environment than the campus type living at the center.

Yet, another mild retarded may live and work in a community and cope with everyday living and he should be given that opportunity. But there are persons who have been living at training schools for 30 to 40 years, happy, content, suddenly to be uprooted and placed in a dog-eat-dog world of living when they don't want to.

Elderly parents, secure with the thought that if they pass away knowing their relatives will be well taken care of, are suddenly burdened with worries of where are they going to go now.

Let the person choose for themself and if he or she can't speak, then their legal parent or guardian be given that authority.

Senator, what may be the remedy for some is not the cure for everyone. Before the placement of all retarded are ever made into the community, community services and backup services should be made readily available. Obstacles to overcome are medical services. Every physician, dentist, and hospital, they are not equipped to handle all retardeds.

Monitoring of facilities scattered throughout our State would be phenomenal. And what happens to the safety of the severely retarded when power outages occur? The community residents must be educated to accept their fellow beings which they rejected 40 to 50 years ago.

Will these people have the same care; the recreation and safety from crime provided them in a community as on the campus? Will the community accept them as one of their own, respect them, socialize with them, give them jobs and love them?

And, lastly, if a retarded doesn't fare in the community, where could they go back to if the facilities have all been closed? The State of Connecticut has implemented their project of various facilities, maintaining the training schools and regional centers with addition to group homes, specialized homes, apartment dwellings, foster homes, and transitional training centers.

We are not perfect. There are improvements that have to be made at these facilities so that residents may live in a dignified manner of which they are entitled. In order to accomplish this, we need the financial help and the support of both State and Federal legislators.

In closing, Senator, you have provided us, as parents, an opportunity to speak out on a vital issue concerning all of us and how this State should act. I am sure that with your wisdom and concerned dedication for the rights of all the handicapped and retarded, you will steer us in the right direction.

My wife and I will never see our son married, nor will we have the joy of grandchildren. But one thing we will know is that our son received, and with the grace of God, will continue to receive the best of care within our facilities because we are those chosen few, fortunate to live in a State that has been and will always remain the forerunner in the field of retardation.

Thank you very much, Senator.

Senator WEICKER. I think you raise a very good point. I can't speak with any great deal of expertise as to the status of care in the State of Connecticut at the present time, but I can say this, and I think it ought to be pointed out, having heard how every other State in the Union is so terrific; Massachusetts, Rhode Island, and Kentucky, certainly my office, from the time I went to Washington as a Congressman in 1968 and right up to fairly recently, was besieged by those that want to know if they move into the State of Connecticut whether their children would receive the care that we give here.

So I think that point should be made. I know there has been a good deal of negative comment but there also happens to be a great deal of feeling outside the State of Connecticut that the care given here is not as inadequate as was portrayed in some of the previous testimony.

STATEMENT OF HON. HERBERT BARELL, BOARD MEMBER, ...RTFORD REGIONAL CENTER AND PARENT

Judge BARELL. Thank you for inviting us, Senator.

I am here basically as an advocate for my son. My son is at the regional center, some 19 years old. He was at home until he was 16, and the choice of the regional center was a particular choice made by me and my wife because it offered what I deemed was appropriate for my child, a structured environment.

I said I am here as an advocate for my son because I think I learned early in life that if you don't advocate for yourself, or you don't get involved in problems in the community, then nobody else will speak for you many times. And, so, in the course of my involvement I have served on various committees.

I was a member of the North Central Regional Advisory Board. I am currently on a board at the Hartford Regional Center. I was formerly on the Advisory Committee for Special Education for the State. I served on a committee with such people as Dr. Solnet from Yale, Dr. Graferdino, dealing with children's problems in the State. I have had consultations with regard to my son at Albert Einstein Center in New York, Children's Hospital in Boston as well as here in this State.

In the course of time I have helped develop programs. I helped organize the first League for Autistic Children in the State a good number of years ago. I helped organize a school that will help teach behaviorally disturbed children and I have been an advocate for a number of years since I first discovered my son's problems.

I mention this because I specifically used this knowledge in order to obtain what I call the best appropriate services for my son, not to say that there was not need for improvement even within the Hartford Regional Center. There certainly is and I know Bill Zitko and I and a number of other parents are continually working with the superintendent and the staff to improve the quality.

It seems to me from my observation there are certain things that are coming through in these hearings, that there is a need for a full range of services for the retarded, anywhere from the institution to the community service.

What is perhaps more important is what do you mean by an institution? What do you mean by community services? Because, if you mean institution as a warehouse then I am dead set against it. But I don't think that is what you are hearing here today.

If you mean community service to mean that somebody is dumped in some sort of group home without backup services, then we don't need that type of community service. What we need is a full spectrum of services, depending on the individual.

Retarded people are no different in some respects than normal people. They need different things. You can't lump retarded people into some class by themselves that either should be totally institutionalized or totally community based.

I think that anybody who aspires to the theory that you treat them all alike would be the same type of person that treats all American citizens alike. And we do know that retarded people differ, have different problems, different needs and unless we recognize the differences and treat them differently then we are going to talk around in circles.

Two: Beware of experts bearing gifts of philosophies that solve all the problems of the world. A long time ago I had a long talk with an eminent man in the field by the name of Carl Feneshal—when it was unfashionable to teach kids with behavioral disorders.

And he said to me, "Herbert, whatever you go through in life with your son," and I suspect he spent a lot of time with me because I was a parent, he said, "beware of people that offer facile solutions, one solution for a problem. Whatever may be the vogue today may change tomorrow."

I have been through the—at that time we were discussing, for example, behavior modification techniques. I became an expert on it. But we soon came to realize that different children need different things and I suspect any expert that will say before this committee that this is the only solution to a problem.

I think essentially what everybody is really alluding to here is that there is only so many dollars available in a community at this point in time and that what we are dealing with is a fight for dollars.

Senator WEICKER. I think you have hit it right on the nose.

Judge BARELL. And I am concerned because, as you have indicated in the introduction, I am a judge so I am well aware that a lawsuit sometimes can be brought, and is necessary to be brought, to start something going. But, do we have to become so polarized that we can no longer have a dialog and a talk.

And I know that the courts cannot solve this particular problem. But even after that case should be decided by the judge these same people are going to have to sit down on how to implement the decision, so why not start talking now.

I see the zealots on one side and on the other side saying they cannot sit down and talk, and it seems to me that some of our advocacy units would be better advocates if they would start bringing together some of the sides to have some intelligent discussion.

Senator WEICKER. I think that is good testimony from both of you. In my own experience, just in the very small experience, which is nothing compared to all of you in this room, this past fall, Sonny, my 2-year-old, started his early intervention, as conducted by the public school system in Virginia, and they grouped all the children by age.

Now, and this gets to the point that you were making, the problem with that was Sonny is actually pretty garrulous, physically 100 percent, thank God, and doing very well, and he would be grouped, just because of the age factor, either with very autistic children or those children that would say nothing.

Obviously he was different. This is what you are saying. Each child, each person is different and it calls for a different solution. You can't use one common denominator for them all. It is impossible. You can't use Southbury and Mansfield as the denominator any more than you can use the home environment, or that which comes closest to home, for everybody.

That much I don't subscribe to, I can tell you right now, as far as the testimony that is given, that everybody is going to thrive under the same set of circumstances. They are not and nobody should know that better than this group of Americans where the whole emphasis of our Nation has always been individuality. It is in this group of citizens as much as it is for any one of us.

On the same token, do I think we ought to proceed with the most modern techniques and continue to progress? I think the fact that you are the parents of children in a regional center, that represents a progression from what just used to be strictly the institution.

I think it interesting that you sit here and testify on behalf of the institution along with the other forms of care. It is a good presentation by both of you. Thank you very much.

We now have Linda Berry and with Linda is Janice Chamberlain. Is that correct?

I see my old friend, Dr. Cohen. Dr. Cohen and I served in the legislature together. You are looking younger and handsomer. I am getting older and uglier. How are you, Dr. Cohen. Nice to see you.

All right, Linda, have a seat. It is nice to have you here. Janice, how are you?

Ms. CHAMBERLAIN. Good.

Senator WEICKER. You just do it any way you want.

STATEMENT OF LINDA BERRY, MENTALLY RETARDED CITIZEN, ACCOMPANIED BY JANICE CHAMBERLAIN

Ms. CHAMBERLAIN. My name is Janice Chamberlain. Thank you for inviting us here. This is Linda Berry.

We are here today—Linda is an example of a woman who has used the whole gamut of services, going from an institution to a supervised group home, and I think it would be a good idea for you, Senator Weicker, and everyone else to hear a story about how this woman has used the services provided by Hartford regional center and how they have benefited her.

Also, as a client of the system, I think it is important that she have a chance to say something too. Feel free to ask any questions. I think that would be helpful.

Senator WEICKER. OK, Linda. Can you get that microphone close to Linda?

Ms. BERRY. This one?

Senator WEICKER. Yes, that is the one.

Ms. BERRY. I was living at home for a long period of time and my mother felt as though I was ready to be moved to the center. She told me that I was ready to move to the Hartford regional center. At that time I was on medication for wrist biting and temper tantrums.

What they had done was, I was out for a long period of time there. They decided they were going to try it for a week without the medication, see how it would go without it. Eventually I was able to manage myself without the medication.

Ms. **Chamberlain**. They used a behavioral program as a substitute for the medication.

Ms. **Berry**. I was on a behavioral program.

Senator **Weicker**. And where was this, Linda?

Ms. **Berry**. At the Hartford regional center.

Ms. **Chamberlain**. The Hartford regional center.

Ms. **Berry**. They felt as though I was ready to come off of it [Medication].

Ms. **Chamberlain**. What are some of the other things you did at the regional center?

Ms. **Berry**. I was doing other activities, like I was able to study in the workshop program. Like they were able to get me started right away in the workshop program. Then, after I was done in the workshop I was helping other wheel chair patients, feeding and making beds for them. Then, they felt as though I was ready to be moved out to move to a group home for teenagers in Glastonbury.

Ms. **Chamberlain**. JC–3.

Ms. **Berry**. Which is a JC–3 home.

Ms. **Chamberlain**. JC–3 is a group home that was originally started by the Hartford regional center.

Senator **Weicker**. So Linda now went from home to the regional center to the group home.

Ms. **Chamberlain**. The JC-3, right. And JC-3 was for younger individuals, younger women.

Senator **Weicker**. How old are you, Linda?

Ms. **Berry**. Twenty-one.

Ms. **Chamberlain**. What are some of the things you learned at JC-3 or did at JC-3?

Ms. **Berry**. Laundry skills, working on money and time programs, cooking skills. They felt I was ready to be moved again to another home in Hartford called Marshall Street, where I am now living.

Ms. **Chamberlain**. How did you feel about that? Were you asked if you wanted to move?

Ms. **Berry**. Yes; I was asked if I felt like I was ready to and I said, "Yes."

Senator **Weicker**. What was the difference between JC-3 and her new home in Hartford?

Ms. **Chamberlain**. At Marshall Street group home, there are 15 women in the house and they range—(they are older than 18)—in age from 22 to 70. One of the differences I see, is that in Hartford (nobody drives a car); they can use public transportation and they are taught how to use public transportation to get to their sheltered workshops, to competitive job situations, to go downtown shopping, to go out to the West Hartford Mall shopping, and take the bus to go visit friends and relatives in nearby towns. I think Hartford is a much more accessible town for people like Linda.

The other thing was, too, because it is an adult group, from this standpoint, she can work at the group home in a kind of structured, supervised apartment-type setting, which is on the third floor with staff and three other women who would also be placed there with her and in that type of situation she would be able to learn how to cook and plan menus, go out shopping for food which later would ready her for possibly a supervised apartment.

What are some of the things you do——

Senator WEICKER. That is what I was going to ask Linda.

Linda, what do you do at your new home?

Ms. BERRY. Laundry skills, taking out the garbage and things like that.

Ms. CHAMBERLAIN. Household chores.

Senator WEICKER. We all do that, even U.S. Senators. I can tell you right now. [Laugher.]

Ms. CHAMBERLAIN. What program are you involved in right now?

Ms. BERRY. I am doing the money program with Joanie now. Once I have got that down then she is going to be going to a time-telling program with me.

Senator WEICKER. Linda, do you go outside the home here in Hartford? Do you go shopping, or do you go see a movie, or can you move around pretty much the way you want to?

Ms. BERRY. Yes; I can.

Ms. CHAMBERLAIN. What do you like to do on Saturdays?

Ms. BERRY. I walk to the civic center a lot on Saturdays.

Senator WEICKER. And where do you go, to the shops in the civic center?

Ms. BERRY. Yes.

Ms. CHAMBERLAIN. And Thursday nights?

Ms. BERRY. Thursday nights I go swimming with recreation.

Senator WEICKER. Where do you go swimming?

Ms. BERRY. I go to the Hartford High School.

Senator WEICKER. You say, originally you went from your home through these various stops. Do you go back home and visit?

Ms. BERRY. Yes.

Senator WEICKER. How often do you do that?

Ms. BERRY. Not very often.

Senator WEICKER. Do you have a lot of friends your own age?

Ms. BERRY. Uh-huh.

Senator WEICKER. Are they with you in the home or do you visit friends that you have had at your other homes also?

Ms. BERRY. I visit friends at the other home, too, sometimes and I do have friends at my home.

Senator WEICKER. You told me when you started off your story originally you were on medicine, is that right?

Ms. BERRY. Yes.

Senator WEICKER. For behavioral correction. Are you on medicine anymore?

Ms. BERRY. No.

Ms. CHAMBERLAIN. Linda still sometimes, when she becomes very frustrated, she will bite her hand, or something, and right now, the way we deal with that in the group home is that a staff person will take Linda aside and have her sit down, relax for a little while, and then talk out the problem—what seems to be bothering her—in a short counseling session.

Senator WEICKER. Well, you are doing very well here, Linda. You are a good witness.

Ms. CHAMBERLAIN. I think she is doing better than I am.

Senator WEICKER. I think you are doing better than the committee. I have no further questions, Linda. I just want to thank you very much for coming and visiting with us.

Ms. BERRY. Thank you.

Senator WEICKER. Maybe we will meet again in a year's time and you can tell me how everything is going.

Ms. BERRY. Yes.

Senator WEICKER. What do you want to do? Do you have something you especially want to do in the way of skills?

Ms. BERRY. Eventually I want to be able to go to my own apartment, a supervised apartment.

Senator WEICKER. That is a good idea. When you say "go", do you mean live by yourself?

Ms. BERRY. Yes.

Senator WEICKER. Is such an opportunity available to Linda?

Ms. CHAMBERLAIN. The step before that would be in a supervised apartment. What I mean by a supervised apartment is that she would have her own apartment space and there would be staff people there 24 hours to help her out with different skills, money problems, paying rent, telephone bills, that type of thing.

From that point on there is one more step—section 8 moneys pay for apartments that individuals like Linda could move into and there would be one person almost acting as a social worker that would come in every week or so to help that person out. That is a possibility.

Senator WEICKER. Well, Linda, maybe sometime in the next couple of weeks do you think you could walk down and visit my office in the Federal Building? Would you like to do that? Why don't you go down there and see what is going on around there. Check up on them and let me know whether they are working or not. OK? [Laughter.]

It is nice to see you, Linda.

Ms. BERRY. Thank you.

Senator WEICKER. Thank you very much, Janice.

Ms. CHAMBERLAIN. Thank you.

Senator WEICKER. Next we have Jeanne Sandahl of CARC. Sit right down, Jeanne. The floor is yours.

STATEMENT OF JEANNE SANDAHL, PARENT, CONNECTICUT ASSOCIATION OF RETARDED CITIZENS

Mrs. SANDAHL. I am not too used to microphones so if I misuse it please tell me.

Senator WEICKER. Go right ahead. Keep that microphone close to you, that is all.

Mrs. SANDAHL. I am especially grateful to be here today as a parent because it gives me a chance to thank you, Senator Weicker, for helping to restore vitally needed funds for the handicapped in the Federal budget.

I am a member, too, of the Connecticut Association for Retarded Citizens, which has a membership of more than 10,000 people, representing, also, people in institutions who have no one to represent them, and some of their parents and siblings.

We are all most grateful for your interest. I am speaking today for the 41,000 retarded children and adults in Connecticut who are not served by our State institutions. These are the stepchildren of the DMR system. They are forgotten and neglected because of Connecticut's single-minded preoccupation with institutional structures.

Because resources are limited, little is left to serve the huge majority of retarded persons in our State after the institutions are served.

I would like to tell you about a few of the families I have been talking with recently. Take the Sam Teitlemans of New Haven, who have a profoundly retarded teenager at home. Ruth is virtually a prisoner in their home, has been for many years, because she has almost sole responsibility for Phillip's care. The only relief she gets is one weekend a month of respite care at the regional center, and funds for respite care are severely cut back in the new DMR budget.

Ruth really needs a trained home health aide. True, there is a tiny token program way up in Tolland, but it meets only a fraction of the statewide need. And a comprehensive program would also provide work activity or functional educational centers for Phillip.

The Teitlemans are determined that one day their son will live in a group home in New Haven though he is severely retarded. If they wait for State help, though, that day may be far off.

Or, take the Rusgrove family of Bristol. With tremendous love and determination they have kept their 30-year-old, severely retarded son at home all these years. Mr. Rusgrove would literally rather see him dead than in an institution. Their son is growing older. A group home in Bristol would be the happiest solution, but in a capital request of over $10 million, DMR allots only $150,000 for group home construction—1½ cents for every DMR dollar. All the rest is for institutional renovation.

Senator Weicker, you asked for a reasonable compromise between the two points of view being voiced today. I leave it to your judgment. Is 1½ cents out of a dollar a reasonable compromise, or is the department of mental retardation virtually totally committed against progress in the community?

In addition, as I have learned recently, serving on a committee to set up a private New Haven group home, our State throws every possible roadblock in the way of group homes, redtape and Byzantine regulations that make the struggle one against enormous odds.

Other States don't do this. The Macomb-Oakland region in Michigan, an area about the size of Connecticut, has 1,700 people in group homes. They are good ones, beautifully supervised. And Michigan is now planning 200 more such homes in the near future.

Once our State was No. 1 in the field of service to the retarded. Not any more.

Then there are Judy and Barry Bosworth in East Hartford. They have a 16-month-old daughter with Down's syndrome. They have no intention of ever giving her up to an institution. But in this

State, says Judy, those who raise a child at home get the short end of the stick.

Many more parents would elect to keep their children home if the State offered a reasonable range of services in the community. Judy wants the future to include a group home or a supervised apartment. She sees little likelihood of this possibility unless the State takes a conscious turn in that direction now.

Its present powerful fixation on institutional service makes that unlikely.

And consider Bob Roth and Judith Lerner, a young Hartford couple who have a 15-month-old daughter with Down's syndrome. They are deeply committed to a life in their community for their child. It deeply disturbs Bob that the necessary long-range community-based support services for his child and for thousands of others do not appear to be even contemplated in the DMR budget.

Bob can't understand why DMR is so overwhelmingly committed to bricks and mortar, the most expensive form of care for retarded people, when the $43,000 or more per capita cost at institutions in ICF cottages particularly, could be stretched much further in the community.

It also concerns Bob that there is an almost total lack of innovation in the DMR budget. If we are unwilling to try out new forms of doing what institutions are so patently failing at, what hope is there for improvement?

Nor, says Bob, is there any sign of independent evaluation of our present course. Why not get in some independent experts and reassess it. Bob Roth, by the way, has made an independent critique of the DMR budget and would like permission to have it included with CARC's testimony in the record along with the CARC response to Project Challenge, if that is all right with you, Senator. Can we include those in the minutes of the meeting?

Senator WEICKER. Absolutely.

[The following was received for the record:]

Testimony of Robert Roth, Before the Appropriations Committee, General Assembly, State of Connecticut, February 24, 1981

My name is Robert Roth, and I am a resident of Hartford. I am an attorney licensed to practice law in Connecticut and in California, and I spent five years working on the reform of psychiatric institutions before working for the last five years in energy conservation planning. I am also the father of a 15-month-old child afflicted by Down's Syndrome. I'd like to share with you some perspectives that I think it's important to keep in mind as you consider the Department of Mental Retardation's budget.

First, I'd like to make it clear that, although I am in favor of creating a community-based support system for our mentally retarded citizens, I don't believe this should be done at the expense of achieving the maximum quality of care possible for the present residents of existing State institutions. Except for major new capital expenditures, which I would oppose, we need to provide, and I believe that ethically we <u>must</u> provide, the most favorable prospects possible for personal development and eventual return to the community, for any person whose only present option has become institutionalization.

My primary personal concern with the development of community-based support systems, then, is with the future. And I feel I must ask some rather disturbing questions about how that budget is going to translate, in the long run, into a community-based support system.

Perhaps the most comforting thought that my wife and I had as we adjusted to what we'd been told about our daughter's affliction, was that our conventional stereotype of the retarded person was outmoded and inaccurate. It was not true, we've been told by a wide variety of professionals, that retarded individuals have to reside in institutions. There are some who feel that no retarded citizen need be consigned to live in an institution; as you know, the neighboring states of Massachusetts and Rhode Island appear to have made long-term commitments to deinstitutionalizing their entire system of services for their mentally retarded residents. So I am given an image of what is possible. But this image doesn't appear to be reflected in either the proposed budget nor in any projections that I can personally make from it. The necessary community-based support services appear to be neither available nor contemplated in this budget.

Several observations, then, which to some extent only lead to more questions, occur to me.

First, it appears that out of a population of some 48,000 retarded individuals in the State, based on what Commissioner Thorne has called a conservative estimate, DMR programming totalling roughly one hundred million dollars appears to plan to provide services to only several thousand of them -- perhaps five thousand, perhaps seven thousand. So my question here may be obvious: What about the other 40,000 persons afflicted by retardation, and their families?

Second, I have the impression from my work in the assessment of psychiatric institutions, that institutional arrangements are easily the most expensive means to provide services.

Yet the State system is primarily institutional, and appears slated to remain that way. Along those lines, I have put together some very fragmentary data that is extremely disturbing. These figures relate to the Waterbury Regional Center, and Cottage 7A at the Southbury Training School. With the effort to bring these facilities up to ICF/MR standards, per capita cost is going to skyrocket. Commissioner Thorne estimates the present per capita cost per year per client of the Department at $20,000. But according to figures that are part of the Certificate of Need Application on file with the Commission on Hospitals and Health Care, bringing the Waterbury facility up to ICF/MR will mean per capita operating costs of about $43,000 per year. At Cottage 7A, which presently houses just over 60 residents but could house less than half that number on an ICF/MR basis, the comparable figure is $60,000 per person per year. Please let me know if you see some mistake in my figures, or in my analysis of them. And I have to conclude, under present assumptions, that we _must_ spend this money, for ethical as well as other public policy reasons. But if these figures are right, then please consider what this means for the future provision of services for mentally retarded persons in Connecticut.

Third, I am struck by the apparent lack of innovation in the budget. The Department seems to be asking for more and better of the same. To the extent that we're contemplating a reduction in the size of the Training Schools, that's because we intend to expand the regional centers, which are in effect a form of mini-institution. The portion of the budget allocated to innovative community-based services appears to be infinitesimal.

And finally, I would ask what independent source, or sources, do we have to enable us to be sure that the budget submitted by the Department will provide effective services, offers some reasonable prospect of achieving the degree of deinstitutionalization that is both possible and desirable, or that the State is making the most and best use of available expertise to develop more effective networks of community-based services in the community? I am suggesting that there is wide disagreement among the experts as to what is possible, that the Department's budget, as distinct from its philosophy, appears to opt substantially for the institutional end of the continuum, and that we need to develop some basis for public policy decisions that incorporates a greater diversity of perspective.

As I said earlier, I support the desire of all the other parents in the State to have the best care possible for their children. I am therefore supportive, in general terms, of the proposed DMH budget. But I don't think there is any way for an institution to provide the kinds of support and stimulation which will enable any individual to achieve their maximum developmental level. My extensive experience with psychiatric institutions, my studies of the literature, and my gut feelings as a person and father all lead me to want my daughter to be in a position to live out her life in the company of other people of all kinds. So I am depressed when I try to project this budget into the future, where it appears my daughter would benefit from, and indeed will require, services which may not exist in the community. The proposed budget does not appear to provide much room for hope in this respect.

CONNECTICUT ASSOCIATION FOR RETARDED CITIZENS, Inc.
15 High Street, Hartford, Connecticut 06103

CARC Testimony on Project Challenge Update - Residential Services Component

Presented at Public Hearing held by Dept. of Mental Retardation,
December 7, 1978 — Cedarcrest Hospital, Newington, CT.

I am Luella Horan of Guilford, President of the Connecticut Association for Retarded Citizens, Inc.

Before I start my remarks on the Plan itself, I would like to express my regret about the timing of this Public Hearing. Starting tomorrow, many leading authorities in the field of mental retardation from across the country will begin arriving in Hartford for a long-planned National Symposium on Residential Services for Handicapped People. It would undoubtedly have been valuable to seek the input of these acknowledged experts while we were fortunate enough to have them in Connecticut.

Also, I would like to express our concern and sensitivity to the fears of the parents of retarded people now living at the large training schools. It is regrettable that the Department's plans, as they progressed, could not have been shared in small group settings so that the shock of the institutional number reduction could have been addressed; explanations and detailed plans could have been presented to these parents to help alleviate some of the fears and anxieties they now feel.

The Connecticut Association for Retarded Citizens is in full agreement with the Department of Mental Retardation's statement published in the original Project Challenge in 1973. I would like to read that statement now:

> "...Historically, it is not too many years past that society's most enlightened answer to the problem of what to do for the mentally handicapped population was to develop large, complex institutions, in most cases far removed from the eyes of the general public, and allegedly to provide a decent life for these persons within their own closed community. Such a solution did not work, but indeed brought into the lives of these people a dehumanizing process which further reduced their functioning, and this is the <u>principal issue</u> that the DMR long-range plan addresses itself to.
>
> "There is no simple answer to planning a future for more than 45,000 mentally retarded people in Connecticut but the courts of the land, and the people who have given great thought to this issue — not only the parents, but the professionals as well, have strongly indicated and pressured a course of action which ensures the rights of the mentally handicapped person <u>to live in partnership with his fellow beings</u>. To make any other decision would be to turn away from this central issue and to thereby seek an expedient and demeaning process for avoiding a major social and legal responsibility."

The original Project Challenge defined, on pages 6 through 9, some 45 clear, well-stated goals. The majority of these goals were family and community oriented, and, unfortunately, most of them have not been implemented.

Does the 1978 Project Challenge update adhere to the original philosophy? Are the new goals as desirable and clearly-defined as the original ones? We submit that the answer to both questions is "no."

The Connecticut Association for Retarded Citizens calls upon the Department of Mental Retardation to re-affirm its support of the philosophy it so articulately expressed in 1973, and to commit its energies and resources to implementing the goals it defined so well at that time.

Representatives of CARC served on the DMR Task Force charged with developing this Plan and attended all meetings. However, our opinion, when it differed with the Department, was not adopted. We submitted two minority reports, neither of which was adopted as a part of the Plan. These reports are attached to our testimony. When we were in disagreement, we were told that as CARC members of the Task Force, we would have the opportunity to comment in writing and at a Public Hearing on those issues of concern to us, and we will do so today.

First, however, I would like to stress that we are in agreement with that aspect of the Plan that encourages community living for retarded people. We also support the recognition of the private, non-profit sector as providers of residential programs. We think more detail should have been provided on the use of the private sector, such as the legal accountability for residents, funding mechanisms, etc., such information would have, among other things, answered some of the parents' concerns about the security for their children.

I will highlight briefly some of our major concerns with this Plan:

1. The Plan, by the implication and design, will keep about 2,000 persons in institutions and nursing homes, even if the Plan were successful; and, in order to do this, the Plan calls for the expenditure of many millions of dollars for construction at the institutions, including eight new buildings on the grounds of Mansfield Training School.

2 There is an implicit assumption in the Plan that less severely handicapped persons have the right to live in community settings, but that more severely handicapped persons do not sh[illegible] in these same basic rights.

3 The Plan not only calls for hundreds of retarded persons to remain in nursing homes, but also allows for the continuation of such placements.

4 In point of fact, the number of people who will live in the community and the number who will remain in institutions and nursing homes under this Plan appears to be determined by the expedience of obtaining Federal dollars rather than by individual assessments of the retarded persons involved.

5 Time constraints placed on the members of the Task Force prevented individual assessments of retarded people now residing within the system in order to determine what an appropriate residential setting would be for them in the future.

6. Time constraints placed on the Task Force members also prevented members from determining the number of retarded people living in the community who would need residential placements in the next five years. Even without this necessary data, however, it is apparent that this Plan does not provide any real expansion in the number of available places for people to live.

7 There is no emphasis on maintaining a retarded child in his natural residence, the family home, by providing services to the child and support services to the families such as parental subsidies, respite care, family counseling, etc.

8. There is too little emphasis on the next best residential placement, the foster or adoptive home — again with services to the child and training and support services provided to the alternative family.

9. The Task Force, probably again due to unrealistic time constraints, did not include many State and local, private and public agencies and officials who will ultimately need to cooperate in its implementation.

10. The steps in this Plan are not tied to definitive timelines or to actual dollar impact. This was not done in the original Project Challenge Plan in 1973, or the Update in 1976, and may at least partially account for the fact that the majority of recommendations in those two documents have not been implemented.

In closing, may I point out that there are in Connecticut between 50,000 and 100,000 retarded children and adults, many of whom will require a supervised living arrangement for at least a portion of their lives. DMR facilities now house fewer than 4,000 retarded persons at a cost that exceeds 90% of its entire budget. How can the very options that we all seek be implemented, unless the funds which DMR has to use are allocated in a more equitable manner?

We urge the Department and other State agencies involved to realize that an acceptable Plan would have to address the entire population of mentally retarded persons, and insure that every placement, whether from the institution or from the home, would be to a normalized, home-like environment where parents could rest assured that their sons and daughters would receive the care and training that would enable them to grow and develop and to be secure in the future as citizens of the communities of our State.

December 7, 1978

Mrs. SANDAHL. Now let's consider what the residents of our State institutions get for that $43,000 that it costs to keep them there in the ICF program, for example. Let me say I believe there are some wonderful people working in those institutions, but I also have seen over the years how often the very nature of the situation has consumed its brightest and best staff.

The turnover rate of 50 percent of staff in the first year speaks for itself. Frustration and limitation are built into those million-dollar behemoth "cottages," as they call them.

My 33-year-old profoundly retarded son has spent 26 years at Southbury in various levels of purgatory. I have learned that it is not the rolling hills, not the Georgian architecture, not the rug on the floor that counts. It is what is going on when you walk, unannounced, into that place at, say, 10 a.m. on a Tuesday morning, and it is usually nothing.

Peter has logged years in 40 resident wings where clothes were an exception and 1 staff person might be seated at the door. In such cases, there is little or no staff interaction with the residents.

You could count on the fingers of one hand the months he spent in school over 26 years. At Southbury, they lose a teacher and they hire a fire marshal. Peter's parents pay taxes in New Haven. Why can't he use the services of New Haven firemen? He, too, could live in a group home.

I have numerous friends whose sons and daughters have regressed after a few months in the large institutions. One couple I know found that their two sons, both ambulatory when they went in, lost the use of their legs within a couple of years after entry. The father figures that even though his sons are in an ICF facility they get 6 minutes per meal to eat because that is all the staff time available to hand-feed them.

Several times broken bones have not been explainable. When complaining to the medical staff, the parents were told to take their children home if not satisfied. Many children there lose speech. Others lapse into spaced-out states or fall victim to self-mutilation, as my son has done at times, due to lack of stimulation and boredom. Others are maintained on doses of psychotropic drugs and chemical restraints.

We have been luckier with our 31-year-old daughter, Tina, a victim of Down's Syndrome. She went to live in the New Haven Regional Center at 17. Her life has been much more active, though her abilities are no greater than Peter's. She lives in a "cottage" of 17 persons. Every day she goes out to an activity class of some kind. Trips are frequent and the world cheerfully trails in and out of the center. We infinitely prefer the regional center to the training schools but it would be cheaper and Tina could have the same services if she lived in a group home. Then some of the 41,000 other retarded persons in our State who need more services might share some of the resources.

You can tour Southbury's hilltop cottages and hospital and see many deformed, contractured bodies. The staff do their best, but you heard experts yesterday say that mass institutional care is never going to do what is needed for those people.

Individual training homes and intimate special-care facilities, like Omega House, can keep these people from getting into that state, and to think it would even be cheaper.

Many say, what are we going to do with people who are institutionalized? The State has a heavy investment in those stately buildings, the sewage plants, the laundries, greenhouses, staff homes, and so on. There are parents who are firmly convinced there is no other safe depository for their children.

But I am not so much concerned with the present status as with the lack of clear direction for change in the future. Almost a decade ago Governor Meskill promised that within 2 years our State would have 100 group homes. Today, there are only 27 State-run homes and 35 private facilities.

If we get one out of the current budget it will be a miracle. Meanwhile, these are the hard facts. Only 4 or 5 percent of mentally retarded persons are in Connecticut institutions today but 70 to 80 percent of the current budget goes to support those persons, and of the $66 million in rebuilding and bonding dollars spent by DMR to date, only $6 million has gone for community facilities, and over half of that is really going to perpetuate institutions, as in the building of "group homes", if you can call them that, on the grounds of the Hartford Regional Center because there happens to be land there. That is a travesty on the community concept.

Finally, even if Project Challenge should ever be fully implemented, which is by no means certain, the net decrease in our institution population will be only to 2,800 persons, and there will still be all those people in nursing homes around the State. That will still leave Connecticut with a very high rate of institutionalization--three times the national average.

And worst of all, the provision of 120 new beds at Mansfield, and the ICFing of numerous institution cottages will perpetuate for perhaps another whole generation this regressive and far from least-restrictive environment for hapless retarded people.

Fifteen years ago my husband was mental retardation planner for the State of Connecticut. He and countless committees drew up plans for comprehensive services to the retarded persons in our State. And chief among those plans were newer, more human-scale environments for those persons.

He quoted Robert Frost, saying, our State had "Miles to go before we sleep." In my opinion, Connecticut has been sleeping for the last 15 years. Many other States have passed us and left us in the dust.

I would like to quote part of another poem by Frost,

THE ROAD NOT TAKEN

I shall be telling this with a sigh
somewhere ages and ages hence.
Two roads diverged in a wood and I,
I took the one less traveled by
and that has made all the difference.

Somewhere we have taken the wrong turning. The future of retarded and handicapped persons surely lies closer to us, not farther away on rural hillsides. Bringing them back into our hearts and communities involves risks, sure, some to us and more to them. But any full life involves risk. If they are to spread their wings to their widest possible extent we have to give them every opportunity to grow.

Let's go back to where we somehow got off onto that wrong turn and set out again once more.

Senator **WEICKER**. Thank you very, very much, Jeanne, for very eloquent testimony.

Next, we have Jim Rebeta, the Parents and Friends of the Retarded, Bridgeport, Conn.

All right, Jim, I am going to try to keep you to the 10-minute rule, if I can. I haven't done very well at it this morning so I am not going to lower the boom on you, but we do have a couple of more witnesses and we are going to have to recess the hearing at 12:30, so I would appreciate it. Do the best you can. I am not going to stop you.

STATEMENT OF JIM REBETA, PARENTS AND FRIENDS OF THE RETARDED, BRIDGEPORT, CONN.

Mr. **REBETA**. Senator Weicker, Mr. Doyle, my name is Jim Rebeta of Trumbull, Conn. I am the parent of a 32-year-old mentally retarded daughter who has had experience in various facilities in the States of Massachusetts, Missouri, New York, and now, of course, in Connecticut.

She is a member of the Kennedy Center Workshop in Bridgeport, a client there and also is a member of Maridot Manor, one of the group homes that is operated and run by the Parents and Friends.

For myself, I have been on the board a number of years of Parents and Friends and am entering my third term as president, and I say that not to illustrate any degree of expertise but merely to add some perspective to my remarks.

Thirty-two years of experience with a retarded child and also experience in four different States and 7 years here in Connecticut. Allow me to be bold enough to suggest that first and foremost, we need to effectively identify the problems of the retarded in Connecticut.

I know that we have a marvelous program here. We certainly are not behind any of the other States with which I have had personal experience, but, nevertheless, I do indicate that we do need to identify the problems.

We do need to evaluate the needs of the retarded and to formulate a realistic and all-encompassing program of action for the retarded if we are ever to seek a viable solution.

I know that my comments will shock some people and infuriate others who feel that they know the problem and they have the solutions. However, when I can hear the so-called experts point out and advocate educational mainstreaming of all retarded and deinstitutionalization across the board, elimination of all institutions, then I know we are far from knowing the problems of the retarded and we are far from really having the answers, as well intentioned as these experts and professionals may be.

You will note that I introduced myself as a parent of a mentally retarded daughter. I did not say that I am the parent of a developmentally disabled person. This is a beautifully sounding rights defending term that has been concocted and is being used and I can't help but feel that is just symptomatic of our problem today.

It is beautiful sounding and, just like some of the solutions that are being advocated, they are solutions that really have not been tested. Again, I say, our basic need is further study and evaluation and, really, the identification and determination of the needs of the retarded. Otherwise, we are merely going to continue to provide band-aids where perhaps major surgery is needed.

And I would like to use the example of our own Kennedy Workshop, if I may, to illustrate this point. When we receive clients there, and we have 240 of them now, we start out, regardless of where they may have been—the public schools, at home, in the institutions, at a regional center, wherever—and put them through a 3-month period of evaluation and testing.

I say 3 months because that is the minimum. It may often go to 6 and 8 months, depending upon the attention span of the client. As you know, in many instances the client can only take about 10 minutes of review, consultation, and testing, and the interest span is gone. It is over, it has been reached and we have to call it off there and come back the next day. And that is the reason why we feel that under no circumstances will we ever know the problems and the needs of the individual retarded client without this kind of evaluation.

For anyone to sit down, regardless of how talented and how professional, and think that in 1 hour, perhaps 2 and the filling out of one form, they can automatically know the needs of this individual is just another indiciation of some of the problems that we have.

So, we do need to take time and have patience with the retarded. I would be remiss if I didn't point out that we need to discuss funding and basically stability in funding because, hopefully, some degree of stability would come from these hearings and from the evaluations of which I speak, because today there is too much time spent by our staff in second-guessing the authorities, too much time spent in interpreting the various regulations that are changed quite often, and also too much time in determining just what it is that is expected of us in terms of compliance.

And, of course, the adequacy of funding is another point. It certainly should not be on the basis of the loudest voices or the most professional presentations but should be on the basis of investment in people and also a determination of the needs that are required, and not necessarily—and this may be of some interest to you—it doesn't necessarily need to be in ever-increasing amounts or larger amounts than before but we do need to learn how to spend our money and the available funds more wisely.

And, again I say, evaluations and studies are needed to determine the overall needs as well as the personal needs of the clients. In terms of institutions, I feel the basic need here is to make certain that we have qualified staffing and that we eliminate the abuses that, incidentally, are held up as examples as to why we should eliminate the institutions, and also the development of effective programs of education and training for these individuals.

It may be shocking to the audience to know that within the last 2 weeks I have been in receipt of a memo at one school in Connecticut, a memo to the staff saying that from this point on—that is, just 2 weeks ago in the year 1981— that school will no longer use bar soap in the mouths of the retarded, nor will liquid soap be squirted down the throats of the retarded from that point on as corrective devices and as a means to stop any extraordinary conduct on the part of the individuals. This is the year 1981 and those practices are still continuing.

And, yet, I do not advocate that we eliminate this school or close it by any means, but rather that we stop this kind of nonsense, get qualified people who don't have to resort to such tactics in order to keep control over their clients.

Senator WEICKER. This is a normal public school or private school? I am not trying to get a name here.

Mr. REBETA. A public school that has a number of classes for the retarded. Obviously the staff people involved were not up to the problem and apparently had heard somewhere or read somewhere that this was a practice that could keep the retarded under control. Of course, what they may have read may have been something that was vintage 50 or 60 years ago.

Again, I would emphasize the need for further study and evaluation on the part of an unbiased panel, a panel that involved all facets of interested people in this community and interested people in terms of this problem so that we get to know basically what the problems are and we get to come to grips with what the real needs are and then determine whether or not the institutions are the answer, and what size institutions and how we can use some of the other recommendations that have been offered at these hearings and use them most wisely.

I personally feel that there is room for all of the facilities that we have mentioned, community training, the group homes, the regional centers, the large institutions only because of the needs of the individual.

I understand from the signals I am getting that I have stayed within the 10 minutes. Thank you very much.

Senator WEICKER. I certainly have to thank you very much. I appreciate it.

Next, Mrs. Erlich of the Easter Seal-Goodwill Group in New Haven.

And then, we will conclude after Mrs. Erlich's testimony with Bob Holzberg. You will be following Mrs. Erlich's testimony.

Welcome, Mrs. Erlich, and please proceed.

STATEMENT OF MRS. ERLICH, COCHAIRMAN, PARENT GROUP, WORKSHOP ACTIVITY PROGRAM, NEW HAVEN EASTER SEAL REHABILITATION CENTER

Mrs. ERLICH. Thank you, Senator Weicker.

I was asked to come here because I am the cochairman of a parent group for the workshop activity program at the New Haven Easter Seal Rehabilitation Center, but I speak more personally as a parent of a 27-year old son who is mildly retarded and also cerebral palsied and who, until 3 years ago, lived at home and now lives in a group home.

For the past 9 years, Seth has been, at least 5 hours every day, at the rehab center in some sort of a workshop setting, first as part of his educational services from the New Haven School System and now as part of the work activities program.

There are about 155 people in the program and they do all kinds of minor assembly work and perform rather simple tasks. They learn these tasks. They earn according to their productivity and they learn how to perform in a regular kind of work.

Many of them live at home. Some live in group homes. Those who can use public transportation to get to work and, the most important thing, they feel they are part of the community.

Of course, you know about the threat to the budget of workshops such as ours, and that means that these clients—and they are very well aware of it and may someday not have a place to go, not have a place to work, and not have a place to feel as if they are worthy of something.

As a matter of fact, right now there are too many people on waiting lists who can't get into the workshops because there is no room and no money to accommodate them. Personally, for my son the workshop is a place to learn, to socialize, but it is also a place of great frustration.

Most of the work that they get to do requires small motor control and this is where he really is in big trouble. But, despite endless frustration he keeps perservering and his failures, as well as his successes, are a very real proof of the need for such workshops and the need to develop even more expanded programs in them.

There should be exchanges of staff and services with workshops around the State and even around the country. There should be ways of developing products that the workshops can produce, or services that they could perform that will insure them of work and a place to go when they can't get things from the outside industry.

Until 3 years ago, as I mentioned, Seth lived at home and I think he was reasonably happy. But since then he has been a resident of Friendship Gate, a group home in Hamden, Conn., that is incorporated by a group of private individuals who are interested in this kind of service.

Friendship Gate has changed his life and ours. It has helped him develop beyond anyone's expectations. He is his own person. He makes his own decisions, his own mistakes and his own achievements.

As a parent, I believe that group homes, as well as large institutions and anything in between, are all needed. Whatever is most appropriate for that individual is what should be available to him.

Of course, it would be an ideal situation if we could have all of these facilities. group homes for those who can benefit, respite facilities for people who live at home but whose family need to place them temporarily for short stays, regional centers and places like Mansfield and Southbury, which serve those who are best helped by those programs. In other words, let the facility fit the need and not the client fit the program.

Senator WEICKER. Mrs. Erlich, thank you very much. You summed up the feelings of a good many of us in this room. Thank you.

Next, Bob Holzberg of the State Office of Protection and Advocacy, accompanied by Sharon Johnson.

STATEMENT OF ROBERT HOLZBERG, ATTORNEY, STATE OFFICE OF PROTECTION AND ADVOCACY, ACCOMPANIED BY SHARON JOHNSON, PUBLICIST, STATE OFFICE OF PROTECTION AND ADVOCACY

Mr. HOLZBERG. Good afternoon, Senator. I am Robert Holzberg, for the record, and with me is Mrs. Sharon Johnson, who is our publicist.

First of all, thank you for the opportunity to appear here. I want to begin by clarifying a comment or statement that was made earlier by one of the previous witnesses concerning the Governor's council which purportedly was not providing representation on behalf of the Friends of the Training School.

I think the lady had in mind the advocacy office. I would like to take this opportunity to explain that. We are involved in an amicus capacity in the Mansfield lawsuit. That decision came after our board of directors studied the matter and considered the options over a long period of time. Indeed, I dare say, many complained that we were vacillating.

In any event, after careful consideration a decision was made in terms of the lawsuit. Because of that we feel, and I am sure you will appreciate this, Senator, as an attorney that it would be inappropriate at the same time to be representing the opposite position.

I hasten to add, however, that we have no difficulty in representing any person who is retarded or handicapped pertaining to issues which are not involved in the Mansfield suit.

Senator WEICKER. I find that rather difficult, counselor. It seems to me that everything is involved in the Mansfield suit.

Mr. HOLZBERG. To the extent that this suit calls for a—let me put it this way: There are issues involved in the care of persons while they are at the institution; for instance, obtaining certain services, or being denied trip privileges. We feel comfortable in serving as an advocate.

However, when we were called upon to represent a parent in their quest to have the training schools remain open, or continue in perpetuity, we feel that is in conflict with the plaintiff's position and the amicus brief we had filed.

Senator WEICKER. Who made the decision that your office should take that position?

Mr. HOLZBERG. We have an advisory board, sir, and it was they that after a careful consideration of the differing viewpoints made the decision. And, by the way, I believe it is a fair cross-section of the community.

Senator WEICKER. Does the public law that set up your operation permit for this type of an operation where there very well might be a conflict of opinion within the group that you are meant to serve?

Mr. HOLZBERG. Yes, sir. In fact, I was going to get to that. I think it was finally their judgment that it would be an abdication of our responsibility were we not to take a position. The Developmental Disabilities Act which, of course, charters us authorizes us to get involved in representing, advocating, and investigating matters pertaining to handicapped citizens.

We have a State law which is roughly analogous to that and it also authorizes us to get involved in lawsuits. Unfortunately, it is impossible, I guess, to be all things to all people and, based on our judgment, the judgment of the advisory board, the most fruitful position for the office to take was in its amicus role.

I understand it is a very delicate, sensitive issue but we feel that it is something we have to do and it would be remiss to sort of sit on the sidelines given the allegations which were raised.

We also are prepared——

Senator **WEICKER**. Where does this leave the parents, as far as the council is concerned, that have a point of view that the institution should stay open even if for limited purposes? Where does it leave them?

Mr. **HOLZBERG**. I guess they are in the position where they are now where they retain Joel Klein from one of the large Washington law firms.

Senator **WEICKER**. I think what bothers me is that you are partially funded, if I am not mistaken, by Federal funds.

Mr. **HOLZBERG**. That is correct, sir.

Senator **WEICKER**. Why don't they have the same right to representation in this matter.

Ms. **JOHNSON**. If I could attempt to answer that, Senator, not being an attorney but I was with the office at the time that we made the decision to enter the lawsuit as an amicus and both our State and Federal mandate discuss very succinctly the fact that we are established to represent handicapped and developmentally disabled persons.

We based our decision, our board's decision, to enter the lawsuit on perhaps approximately 18 months of research that was done by in part contacting other protection and advocacy offices. There are 54 P. & A. offices across the country and territories and doing quite a bit of research into the types of programs that you saw yesterday, the types of slides, the types of evidence that was given yesterday.

Based on that, and based on also the fact that many of our staff had been former employees of either mental health or mental retardation institutions, based on the experiences they were able to give to the office and to the board, and based on the experiences that many of the parents on our advisory board had had in the social service system in Connecticut, that is precisely how we entered the lawsuit as an amicus on the side of the plaintiffs.

Senator **WEICKER**. I still don't understand where that leaves these people who have their children in the institution and want their children in the institution. They are, in other words, specifically covered by the public law which sets up your institution. Where do they go? You are telling me they go to the private sector. That is not what the law contemplates.

Mr. **HOLZBERG**. Senator, I think it is a very difficult question and I want to preface my comments by that.

Senator **WEICKER**. I am not going to get into the legalities now but I think it is manifestly unfair that a law that was meant to serve all is only serving a few. What I am saying to you is I think you probably should have stayed out of this.

Mr. **HOLZBERG**. There was much——

Senator **WEICKER**. I am not saying you should have taken their side. And I am deeply concerned that we have this commitment from Federal funding which is geared toward an entire group and you are using it now to favor a portion of that group against another element within the group.

That was not contemplated by the Federal law. It was contemplated in the sense of representation of the entire group, vis-a-vis the rest of society.

Mr. HOLZBERG. May I respond to that, Senator?

Senator WEICKER. There is no point in expanding these hearings to get on to this point but I think I am, just on the basis of fairness, regardless of my personal feelings—when we made this commitment it was to assure that there would be an advocacy outlet for the parents of these people.

And what you are telling me here today is that a portion do not have that outlet.

Mr. HOLZBERG. I am afraid that the problem is accentuated because of the intense emotion and the difficulties of the losses sustained.

Senator WEICKER. I am not emotional, I am just talking about the fairness of the proposition.

Mr. HOLZBERG. It seems to me that that problem arises even in issues which are not as, shall I say, provocative as this, or as difficult to resolve. Yet, there are always going to be those who wish something that will be an opposing point of view. I am not sure how that is resolved practically so that——

Senator WEICKER. I think we would both agree that probably if you want to take a head count—and I don't think a head count is particularly important as are the equities or the legalistics that are involved here—but if we want to take a head count there is probably a pretty close division here in the sense of numbers. Numbers shouldn't be the issue anyway.

I just don't see how you got into the middle of a situation that obviously is of concern. I might add this: I very well might have my own ideas that indeed the State should press forward with the newest forms of treatment, of housing, of programs. I am not even arguing that point with you.

I just feel there is something manifestly unfair when you have been put into place to serve all that you decided to serve only a segment of all. That is what bothers me.

Ms. JOHNSON. If I can just interject, we do believe that we serve all developmentally disabled and handicapped people. We do not serve—we were not mandated to serve the parents. I really think that is an important distinction.

Senator WEICKER. Well, I will tell you, we are going to have this out. I have got reauthorization hearings coming up and I will see you both then. I will want a damn good reason as to why this is going on. As I said, and I want to repeat, if anything, I would say that I have been deeply impressed by the testimony of yesterday. I am not going to say that I haven't been.

But I also understand, I think, the situation of those that have testified today and those, I might add, who have been in the middle of all of this have indicated to me, those that really have no ax to grind or, indeed, have children in circumstances that are best served by the group testifying that it requires all parts of the spectrum to be in play.

And all of a sudden, this board is coming up here saying, "We are going to close the institutions". I haven't heard any testimony to that extent, none. What kind of testimony did you hear?

Mr. HOLZBERG. First of all, the position of the amicus brief was not to close the institutions. I think that is not an accurate representation of what the lawsuit is. I appreciate your concerns.

I guess I have a few more minutes left.

Senator WEICKER. You have enough there. I am not going to take away from the time of your presentation but I want to repeat that I am going to do everything I can in those reauthorization hearings to make certain that the advocacy function is one that is executed on behalf of all those within this particular community, all those, in the sense of the retarded and their parents and legal guardians.

For the advocacy office to go ahead and choose up sides on an issue such as this within the community, I do not think fulfills the intent of the law. I am beginning to understand why it took 18 months to come to a decision. I suggest that anytime you get into something that takes that long to decide, chances are you shouldn't be in it in the first place.

Anyway, go ahead and proceed and we will cover the matter at the reauthorization.

Mr HOLZBERG. I will summarize very briefly. I submitted earlier a written statement and I will just rush right through it.

I begin with this problem of appropriate—by briefly describing what it is we do in our office. In addition to this lawsuit we have represented, by our calculations, well over 500 retarded persons and their parents on a variety of matters.

What I would like to do is sort of distill those experiences which we have gleaned from representing the various retarded citizens and highlight different problems which have appeared to us. This is, by no means, an exhaustive list. There are certainly many other problems and needs, but some of the more recurring problems which we have seen.

I have divided my testimony into two parts: The needs and problems of those retarded citizens in the community, and the latter half of my testimony will deal with the needs and problems of the retarded citizens in the institutions.

We have identified three major problems of the community treatment. One has to do with what we believe to be the inappopriate placement large numbers of retarded citizens in nursing homes. You heard yesterday the figure, which I believe is accurate. There are presently 700 retarded persons who have been placed, either by a family or by the State Department in nursing facilities. We believe that the large majority—and I think the Department would agree, too, based on their own assessments—the large majority of these people should not be there primarily because they are in need of habilitation programs and the nursing facilities, unfortunately, are ill equipped to provide those sorts of services.

One suggestion which might be fruitful is to take a look at the title XIX of the medicaid regulations to determine if and when retarded persons are placed in nursing facilities they ought to be guaranteed a certain level of services above and beyond the basic nursing services. I am speaking about habilitation programs now.

The second problem in the community has to do with what we believe is the current fragmentation of the service delivery system. As you are aware, Senator, there are a myriad of services which a retarded person may need, ranging from educational to habilitative to housing, advocacy, et cetera.

In assembling these services the retarded person may have to deal with a multiplicity of State, local and private service providers. And it has been our experience that even a sophisticated consumer will often have difficulty negotiating his way through the system.

This is made doubly difficult by the fact that a retarded person may not be that sophisticated and may have to endure various forms of discrimination. What we would suggest is a more intensive program of case management to assist the person in assembling the various services that he needs.

In Connecticut right now there is a model project to help elderly persons locate alternatives to nursing homes. This has proved to be very cost effective and has helped to reduce the placement in nursing homes. We think the same principle can be applied to retarded persons so that they get the appropriate assistance and liaison to assemble the required services that they need.

Finally, I would like to simply point out that we think that there is a need for additional services in terms of family support. It has been our experience that too many times families are placed in the cruel—are presented with the cruel option of having to keep their child at home in situations which pose great stress and exhaustion, or place them in the insitution, and were there more support services the family unit could be kept intact, and in this regard we suggest two possible programs.

One is a service subsidization program which would allow parents who have disabled children to get small subsidies to help them assist in the care of their child which is in excess of the cost it would take to raise a nonhandicapped child.

And, finally, although Connecticut has made a beginning in respite care, we think more of that is needed. I am going to stop here, Senator.

Senator WEICKER. I thank you very much. I am just deeply disturbed by what it is that the Office of Advocacy has done here. You are supposed to be representing a minority and now you have left a minority within the minority to fend for itself.

Just out of curiosity, what are you going to do now if several of these parents have children or wards in the institutions which are proven incapable of being served outside those institutions? What are you going to do on their behalf if they come to you and say, "We want the help to keep our——

Mr. HOLZBERG. Do you mean if that is the final decision?

Senator WEICKER. No, that is the situation.

Mr. HOLZBERG. If that is the situation then we will do all within our power to insure that they receive the best possible program and services in the institution. If that is the final word, we will obviously live by it and we will do our best within that context.

Senator WEICKER. Who is going to render that decision?

Mr. HOLZBERG. I assume it may be rendered by the local district judge——

Senator WEICKER. I am talking outside of your lawsuit. It seems to me that you have already made a decision within your advocacy group as to which should or shouldn't be.

Mr. HOLZBERG. Are you suggesting that professional opinion should change in some way or there should be more unanimity of opinion that——

Senator WEICKER. I have heard no professional opinion around here that doesn't see a particular need for the institution. I am not saying the need, but a need. What happens to those people? They are now precluded, because of this action of your entering in an amicus, from using your office. Do you think that was contemplated by those of us who set up the program?

Mr. HOLZBERG. If I can back up, Senator, I am not trying to deflect your question, but I don't think it is entirely accurate to say that they are precluded from using our office.

Senator WEICKER. You are the one that told me that.

Mr. HOLZBERG. Insofar as they request that we represent them on the other side of the lawsuit. Perhaps I didn't make that clear. We are fully prepared and fully willing and able to represent them on any other matter. We are not saying, don't call us, don't come to us, we can't help you anymore.

We are just saying that having filed an amicus brief we are now precluded from representing you as defendants—intervenors. Short of that, we are fully prepared, willing and capable, I believe, of rendering vigorous and effective advocacy.

Senator WEICKER. Of course, the only thing that means anything to these people is you can't represent them.

Mr. HOLZBERG. On that particular issue.

Senator WEICKER. That issue is the issue. That is everything.

Mr. HOLZBERG. In some ways it is but there are a host of subsidiary issues which come up on a day-to-day basis.

Senator WEICKER. As I said, without taking their part in this matter at all, just as an element of fairness, as an element of—as a recognition of the intent of the Congress I don't think this was contemplated.

Obviously they have got their own attorneys.

Mr. HOLZBERG. Right.

Senator WEICKER. But if we thought everybody had to go out there and get their own attorneys we wouldn't have set up the Office of Advocacy.

Mr. HOLZBERG. Sir, if I could just make one more point.

Senator WEICKER. I am glad they can afford an attorney, but what if they couldn't afford an attorney in this situation?

Mr. HOLZBERG. I know that sometimes the numbers don't mean anything but I just have to point out that this is not merely a Connecticut problem. This is not to suggest that your concern is not appropriate but the entire protection advocacy system, with the exception of 9 offices, 45 offices have filed a brief, an amicus brief in the Supreme Court independent of this case, the one from Pennsylvania, so it is not a problem that is indigenous to Connecticut or to our office.

Senator WEICKER. Again, counsel is correct. John tells me that we are going to be considering all 50 when we reauthorize. We will be. I am going to make damn sure any reauthorization, should this type of situation arise, that counsel is going to be available—you people wired yourself in, they didn't. They didn't, they were put into this corner.

They were put into this corner by persons who disagree and that is the right of those who disagree to hire their counsel and go to court. I am not disputing that. But now, the apparatus, the mechanism that was set up to guarantee them their legal rights was denied them because that apparatus has become part of the suit filed by others. To me, it just totally subverts the whole intention of the advocacy portion of the legislation. As I said, without trying to judge the merits of the situation I just think it is patently unfair.

Mr. HOLZBERG. May I just make one more comment? One thing, do not walk away with the impression that our office, or indeed the other 45 States, you will hear this at the hearings and I don't have to take up much time—has done nothing but be involved in this lawsuit. We have provided very important, I think, and useful advocacies for a——

Senator WEICKER. Now look, you are a lawyer and so am I. Do you think—let's move away from this case. Do you think, under the circumstances these people now are going to come to you when, in effect, you are the counsel on the other side of the largest case in their lives but they are going to come to you on other matters?

Mr. HOLZBERG. We have received requests for assistance, sir, and it may be that there has been a chilling effect. That is entirely possible.

Senator WEICKER. I think that is the understatement of the year. I would say that is very chilling. I don't think it would encourage me. And, as I say, I don't want to attempt to judge the merits at all and, indeed, it probably is true, the State should be pressing its advance in this area to a far greater extent. Maybe that isn't even the fault of the State. Maybe it is the fault of the fact that nobody wants to fund any of this.

I think when Judge Barell made his comments that what we are really talking about here is a battle over funding, I think he put his finger right on it. But, as I say, my concern is with the original intent of the law as it related to your particular function.

And this is no law, as obviously it is not your decision individually, but I very much question as to whether or not this is what was intended, but this is what we can go into in the hearings in Washington.

In the meantime, I did not mean to give you a difficult time.

Mr. HOLZBERG. That is OK.

Senator WEICKER. You keep doing, obviously, what you have to do on behalf of your board and I will consult with my board down in Washington and whoever has the votes will win.

Mr. HOLZBERG. That is the way it works. Thank you.

Senator WEICKER. The hearing will recess until the hour of 1:45.

[Whereupon, at 12.45 p.m. the hearing recessed, to reconvene at 1:45 p.m. the same day.]

AFTERNOON SESSION

Senator WEICKER. The hearing will come to order and we will have as our first witness for this afternoon's session Senator William Rogers.

STATEMENT OF HON. WILLIAM F. ROGERS III, A SENATOR FROM THE 32D DISTRICT OF THE STATE OF CONNECTICUT IN THE CONNECTICUT STATE LEGISLATURE

Senator ROGERS. Good afternoon, Senator Weicker and Mr. Doyle My name is William Rogers. I am State Senator from the 32d District.

I appear this afternoon—incidentally, I apologize for not being here this morning.

Senator WEICKER. You lead the same life I do and you can't be in two places at the same time, so I appreciate that. You go right ahead, Bill.

Senator ROGERS. Thank you.

I appear not as a parent of a retarded child but as in eight other categories: as a resident of the town of Southbury for 35 years, one who has lived close to the Southbury Training School—part of my property abuts Southbury Training School property;

One who has known all the superintendents, including Mr. Rossell, who was the first one; one who has come to know hundreds of the employees of the Southbury Training School; and, one who has been in the cottages and the hospital time after time, informally and otherwise, and I think I am one who knows the Southbury Training School intimately.

I appear also as one who was a member of the Southbury Training School Board of Trustees for 4 years under Governor Meskill. I appear as one who knows the dedication and, yes, the real love shown by the staff and the employees to the mentally retarded in Southbury.

And, finally, as one who has seen individual clients improve to a condition which has allowed them to return home or to active life in their own community.

I agree totally with Commissioner Thorne's ongoing policy of placing each retarded in the highest type of environment that that retarded can assimilate. But, to demand arbitrarily that all of our mentally retarded, including the severely and profoundly retarded, be placed in individual homes of four to six per home, is, to put it mildly, unconscionable and simply cruel.

The plaintiffs are vague as to how the retarded will benefit more by such placement. I question three specific areas where such placement will be highly detrimental. total safety, continuity of care when the parents have deceased—and that, incidentally, is of great concern to the parents who are growing older and having had children there, some of them for 30 years or longer, and, third, community acceptance.

The last alone is a terrible problem. We have all seen that problem and some results that have come about in certain of our larger cities with total opposition from the neighborhood.

Senator, this case is now estimated to be costing the State of Connecticut approximately $4 million and we haven't seen the end of it.

My testimony is short. I will conclude only by saying how sad, sir, how very sad. The plaintiffs must not prevail. Thank you very much.

Senator WEICKER. Thank you very much, Senator. I appreciate your taking the time to share your thoughts with us.

For the balance of this afternoon we have three panels and the time situation is such that I am going to allocate a half hour to each one of the panels. At this time I also want to find out whether or not there is anybody who has not been heard by the committee, who might not have been scheduled in the formal sense that would like to have 5 minutes before this committee, the idea being that I don't want anybody to leave here feeling that they have been precluded from expressing themselves.

Is there anybody that is in that category? If so, don't hesitate to speak up.

Why don't you come down, and, sir, why don't you come up and make your comments while the other witness is coming down. Then we will move directly to the panels.

If you would, have a seat and identify yourself for the record.

STATEMENT OF FRANK POWERS, WEST HARTFORD, CONN., MANSFIELD PARENTS ASSOCIATION, PAST PRESIDENT

Mr. POWERS. My name is Frank Powers. I live at 217 Somerset Street, West Hartford. I am a past president of the Mansfield Parents Association. I am on their executive board and I am their legislative chairman.

Senator Weicker, I appreciate the opportunity to speak before you and your panel and for the record. I do want to say one thing. Many items you have read in the newspaper have been negative toward our school and I want to make a quote:

There are more good things happening daily at Mansfield and there are more good people, dedicated people working at Mansfield than not. There has been much said today, and you know the picture very well.

I am going to be brief. I am going to say that I think that the department of mental retardation, regardless of the harassment by the press and by professional lobbying groups because of their theories and philosophies, I think we have the be. . department in the United States. I haven't seen any better.

I have been very active in trying to improve the quality of life at Mansfield. I have been very successful and all the times that I have been successful the same group that you have been hearing about today, Connecticut Association for Retarded Citizens, have opposed all the efforts that we ever had to improve Mansfield.

Mansfield has improved since 1973. I think we have an excellent commissioner. I think we have excellent staff people and I think that it is a shame that we have to be involved in a difference of opinion to the point of litigation.

Where our problems should be resolved is right in these halls and not by a judge to mandate the eviction of 1,100 people into a community that is not ready for them, and even if the community was ready for them I doubt very much whether the remainder of people that we have after the deinstitutionalization process since 1967 that has been going on at Mansfield, I doubt the people we have left can function in the community in an independent way, in a way that they deserve to be taken care of.

I thank you very much, sir.

Senator **Weicker**. Thank you very much, Frank. I appreciate your testimony.

I believe there was one other person that indicated that they cared to testify. Step right up, tell me who you are and fire away.

STATEMENT OF LUELLA WARREN, PARENT, GUILFORD, CONN.

Mrs. **Warren**. I am Luella Warren and I live in Guilford, Conn. I have a 21-year-old daughter who has Down's Syndrome. I have other roles but I will not relate to those in any way.

Our daughter has been fortunate enough to have been able to live at home all of her life. She has also had the opportunity to be with her own sisters and brothers and with those people who live in our neighborhoods. I have fought for the opportunity for her to be able to go to public school.

Many times I was almost persuaded to put her in a segregated school where they told me the program was better and she would benefit more from it. But I felt, if she is going to live in our society she needed exposure to it. Therefore, she went through all of the different public school programs, many of which were very inappropriate for her, but she survived.

She happens to be a very surviving kind of person who has a delightful personality and a great sense of humor, which I feel are parts of her that would not have been developed if she had not had the opportunity to be with so-called normal people.

We are a local association, was one of the first in the State to open our own first group home. We also have a fairly large sheltered workshop situation in which we made every effort not to follow the stereotype of what is expected of retarded people, that is simply bench work.

We have a horticulture program, food service program. We have a ground maintenance program, sewing. We opened two restaurants and through these efforts the community has come to know our people and to appreciate their abilities. They also recognize the differences but they are accepting them as individuals which I think is one of the greatest achievements that we have been able to make.

Instead of "the retarded", "the handicapped", or "the whatever", they are people who are different and who need certain kinds of help and services. The Department of Mental Retardation has been very helpful to our association through its developmental team. They come down and help establish programs.

They have helped us in trying to open our group homes. We now have three with three more that are going to be coming into being within the next few months. You know about the HUD process. You know how long that takes. One is on the ground, one is up and the other one will be by June.

I think that one of the sad things that I listened to in the last 2 days—and I fully appreciate the pain and anguish that these older parents are experiencing and their fear of what will happen "when I am no longer here". I have gone through this for so many months and I really do understand it.

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They did not have—their children did not have the opportunity that my daughter had to go to the school and have the training and the help that she needed. She didn't always have it. She didn't go to school till she was 8 so she missed a lot of that stimulation, which I understand your son is going to experience. Therefore, his limitations need be much less than what a child who did not receive that would be.

So, these older parents have these older individuals living in what they consider a very safe environment. Perhaps it is safe for some of them than for others; I am sure you are aware of things that happen in those large congregate settings which cannot be avoided.

One of the things that I don't think has come through clearly today about the litigation process—it seems to be clear cut, institution or community, and it isn't that, at least not in my estimation.

What the lawsuit hopes to accomplish is to give every retarded or handicapped person who is confined in an institution or anywhere else an opportunity to develop to the best of his ability or her ability in the environment which will be least restrictive of his or her freedom.

These people are actually—maybe the parents think that they are safe and sound and it gives them peace of mind, but what about the individual who has known nothing else and will never know anything else unless change comes about. I just wanted to make sure that you understood that the goal of the lawsuit is not to close Mansfield. It is to create the best possible life for each individual who now happens to live there.

Senator WEICKER. The only question that I would have—and you correct me if I am wrong—and, again, I have nothing except something that sits in the back of my mind as to having been told and I can't even say by who, is it true that attempts were made to settle this lawsuit, which attempts were almost successful except for the insistence by the CARC that there be a clause in the settlement that would indicate the closing of Mansfield?

Mrs. WARREN. Absolutely untrue. I don't know where you heard it. It is absolutely untrue. There have been efforts made, through the DD Council—Dan was very correct in that—that he wanted to have CARC and DMR sit down and discuss the various components of the lawsuit.

Senator WEICKER. Let's hope that people can sit down and talk. I don't know what would preclude anybody from sitting down and talking.

Mrs. WARREN. I can't either.

Senator WEICKER. I don't understand that at all. There is nothing in there that I know of as an attorney, never mind as a U.S. Senator, that insists this go to a conclusion in the courts.

I think, No. 1, you made a very good presentation here. I think I am aware, as you are, as to both what the problems and the opportunities really are and I think that as long as everybody understands there are problems that have to be solved along with the opportunities that have to be pursued, this thing could be settled.

Mrs. WARREN. You were right, though, about the funding too. I guess everybody is aware of that problem. And I think what the people in the community are frightened about, these parents who have been able to keep their child at home or somewhere close by, that what they envision down the road when their time comes is all that will be left is the institution for their child.

That would be just disastrous.

Senator WEICKER. I would agree with that point.

Mrs. WARREN. I have talked with educators just recently and they say, what is the good of all of this education we have been giving these children up to age 21 and then there is nothing available for them after that. And as far as services in the community, the most crying need of any family is respite care. And you just try to get respite care. You cannot get into the system unless there is a really dire need.

The New Haven Regional Center has been most helpful. They have started a training program for foster parents, or for what we call community home training parents. We are trying to think of nice words, respite. But there the funding stream is pretty limited.

But if we could train people in the community to take handicapped individuals into their home for even a matter of hours, a weekend, a week, so these parents could have some kind of relief that would be one of the biggest gifts that could be given to the people that do live and keep their people in the community.

Senator WEICKER. Well, as was testified, of course, that very area is one of the ones that would suffer from the program cuts.

Mrs. WARREN. I understand and I think this would be——

Senator WEICKER. I really mean it. I can't emphasize again that which I do know something about which is that these cuts are coming and I need everybody out there in the field right now to be fighting the Federal Government's budget cuts. Never mind half the team back home playing a ball game between themselves.

Mrs. WARREN. Of course the bottom line is the community rejected people in the past and that is why people had to go to institutions, because there was nothing else. Now, with the educational system that we have had people are not rejecting them in the community anymore. They are accepting them as part of the fabric of the community and they are better because those people live there.

Senator WEICKER. With this one caveat, that if the budget cutting goes the way it is going now, which is not just in the area of the disadvantaged but also in the normal educational process and all of a sudden the "normal" sector has to make choices.

I hope that same generosity and spirit is there that exists now. I am afraid I have already seen some examples that make me rather doubt that that is going to be the case.

Mrs. WARREN. I can see where if regular education is cut that people in special education should expect it also. I am not unfair enough to think that special kids have to have all the special treatment. That isn't fair.

Senator WEICKER. No, but I am a great believer that the strong take it on their shoulders first and the weak last, and that is not the way things are working in Washington right now.

Thank you very much.

Mrs. WARREN. Thank you for the opportunity.

Senator WEICKER. We have as the first panel on the subject of group homes and independent living, Lars Guldager, director of the Oak Hill School and president of the Corporation for Independent Living; Dan O'Connell, superintendent of the Hartford Regional Center, Lynn Gravink, the deputy commissioner of the Department of Mental Retardation, and Ben Schwartz, program director of Goodwill of Bridgeport.

Lady and gentlemen, welcome and, as I said, you divide it up any way you want to but I would like to restrict each panel to a half hour's worth of testimony.

STATEMENT OF LARS GULDAGER, DIRECTOR, OAK HILL SCHOOL AND PRESIDENT, CORPORATION FOR INDEPENDENT LIVING; DAN O'CONNELL, SUPERINTENDENT, HARTFORD REGIONAL CENTER; LYNN GRAVINK, DEPUTY COMMISSIONER, DEPARTMENT OF MENTAL RETARDATION; AND BENEDICT SCHWARTZ, PROGRAM DIRECTOR, GOODWILL OF BRIDGEPORT, A PANEL

Mr. GULDAGER. Senator, my name is Lars Guldager. I am the president of the Corporation for Independent Living and also the superintendent of the Oak Hill School, which is conducted by the Connecticut Institute for the Blind.

Two years ago, a number of private agencies in Connecticut were quite upset due to the fact that it was very, very difficult to create group homes. It was an almost impossible task due to many reasons, one was funding, another was zoning. It was almost impossible for any small group of parents, such as a small ARC or small agency, to overcome these barriers.

Therefore, the CARC took the initiative to form the special corporation now called the Corporation for Independent Living. There were six agencies that started the corporation, CARC, Oak Hill School, Connecticut Committee for the Handicapped, Connecticut Society for Autistic Children, Connecticut Easter Seal, and UCP of Connecticut.

Those six agencies got together and formed a special corporation to develop housing for the handicapped, not just for the mentally retarded but for the mentally ill and for people with different types of other disabilities. Now, 2 years after the corporation was founded, I think that we can reflect on some great accomplishments.

We have an executive director. We have two consultants. We have a bookkeeper. In a 2-year period we formed a nonprofit housing corporation for the State of Connecticut. At this time we have 11 clients and are operating on 22 sites. We have created, in the 2-year period, 161 units which are serving 183 people. We have attracted non-State funds in the amount of $6 million to those projects.

We are still going full steam ahead and are getting involved in more and more projects related to housing for the handicapped in the State. At present, we are involved in developing a housing unit for 18 persons in Hartford with money lent to the corporation by Connecticut Mutual Insurance Co. We are operating these projects for small ARC's and small groups, basically using non-State funds.

For the first time in this State, Housing and Urban Development has gotten involved in housing for the handicapped.

I would like to just briefly mention one of these projects because I think that it gives an additional perspective to what we have been discusing for the past 2 days. The Oak Hill School, or the Connecticut Institute for the Blind, is involved in two projects under the Corporation for Independent Living, one is a group home for those who have self-preservation skills I think it is very important to understand that some people with self-preservation skills can live in a group home, a regular home similiar to what you and I live in, but, with 24-hour supervision. Those who do not have self-preservation have to live in a special group home. That means that if you have a severely and profoundly retarded person who obviously does not have self-preservation you have to go about the operation of your group home in a different way.

You have to have a specially constructed group home. You have to have special staffing. You have to have all of the services that have been talked about in the past 2 days but that are not available in the community.

You have to organize and coordinate those services around those group homes. Presently, the Oak Hill School is working on two such group homes in one of the neighboring towns of Greater Hartford. Each home will house for six people, all of whom are severely and profoundly handicapped. They will be living in a house that meets the institutional code.

What does that mean? That means that the house is being constructed of fireproof material. That means that it must have 8-foot corridors. How do you overcome 8-foot corridors? You build your bedrooms around the living area so that when the residents go out of their bedrooms, they go into a common area. In that way, you avoid having 8-foot institutional corridors.

The house has 3,000 square feet of living space and really fits very nicely into the community. What we did is we went out in Granby and got involved with a developer that had taken a piece of farmland and developed it into 50, or 60 lots. We bought a lot on each end of that development. We are going to serve the severely and profoundly handicapped in group homes right in the community.

In addition to group homes, we need day programs It has been mentioned that we have severely and profoundly mentally retarded people in nursing homes without day programs. That is not much better than having people sitting around doing nothing but living in a beautiful building and getting a nice menu every day. They need day programs.

These people should be doing something constructive from 8 o'clock in the morning until 4 or 5 in the afternoon, Monday through Friday. We are proposing to develop and implement a day program for severely and profoundly handicapped people so that they can live in a home like any other family and be transported to a day activity or work activity program which is on a much lower level than a sheltered workshop.

We are talking about people who would do meaningful activities instead of sitting, rocking in a corner. So, I would like to stress that although it won't be easy, it is possible to create group homes for severely and profoundly retarded people.

However, keep in mind that those group homes have to be specially constructed and staffed and the programing has to be developed according to the special needs of the residents. It is very possible and I would like to invite you, Senator, back here in another year and I will show you the two group homes.

Senator **Weicker**. I would very much like to see that.

Mr. **O'Connell**. To reintroduce myself, I am Dan O'Connell and I had the opportunity yesterday to talk to you about the continuum of services that exist throughout the Hartford region.

In anticipating this afternoon's presentation about some of the issues to be considered in addressing community alternatives I would like to run the risk of making three assumptions. They are dangerous assumptions and we really shouldn't make them but it will serve to facilitate our discussion.

Let us assume there is adequate funding for group homes, or alternative living, or whatever type of living you choose for community residences. The funding is established and it is secure. Let us also assume that we all agree upon an organizational structure, whether it is public, private, nonprofit, partnership or whatever; but we agree on that structure.

And let us agree that, for the sake of assumption, we agree upon a model; whether it is 2 beds, 4 beds, 12 beds, urban, rural, apartments, continuum, or whatever. We have three assumptions. there is money; there is an organization; and, there is a model we all agree to.

So, let's go do it. My point is there are some secondary issues, more subtle to be considered. No one in itself will probably be all that significant most of the time but cumulatively they have to be considered. I think it is wise for prudent and sensitive people to pay attention to these issues which impact on the development of community alternatives.

The first is that, by and large, those people who are most capable to live in the community have already been placed in the community When the concept of deinstitutionalization began years ago the people who were most ready to move out of facilities were moved out. That is a reasonable approach. Those who are left in institutions are the people who are definitely the more difficult to place. We have less experience with them. There are a great many unknowns about them and I think we have to recognize that; that our assumptions based on our previous experience may not hold true in our future experience.

Our assumptions about community acceptance in the past may not hold true in the future. And, most certainly, some of our current ideals may not prevail.

The second issue is that we in the field of working with handicapped people are not alone in our pursuit of community alternatives and alternative community residences. I have a publication dated last month from the Connecticut Association of Residential Facilities which describes many other disciplines in many other fields in pursuit of community housing.

Mental health in Connecticut, for instance, is into deinstitutionalization and halfway houses for emotionally disturbed people. They have some 27 facilities in Connecticut dealing with emotionally disturbed persons.

Juveniles and adolescents; abused, neglected; abandoned; emotionally disturbed, delinquent youth—we have approximately 45 homes in the community for this population.

Our own development disabilities programs deal with learning disabled, autistic, multiple physically and emotionally handicapped. There are 30 halfway houses for drug and alcoholism and, of course, corrections. There are 12 community facilities for criminal offenders.

The result, and the point I am attempting to make, is that we aren't alone in this activity. There is quite a bit of competition going on. Everybody is equally committed to their population and equally effective advocates. But with the limited funds and limited alternatives available, there is competition in the market of developing community alternatives.

Another result is significant confusion. There is public confusion about who is who; who is mental health, who is correction, who is alcoholism. And there is also political confusion about who is really paying what to develop community alternatives.

We have lost a clear identity in developing community living for handicapped people.

There is another issue which has to be dealt with, and that is the attitudes of the general public toward community housing for handicapped people? I have never had a neighborhood come forward and ask for the privilege of developing housing for handicapped people.

I think that occasionally it happens and I think there are very lucky and sophisticated neighborhoods who advocate this but, by and large, the general public's attitude is marginal or questionable at best. There is confusion. Handicapped people are not always welcomed in this sphere.

The general public is also on the horns of an economic dilemma. There are a lot of people who are having difficulty living in society as it is on marginal incomes, or unemployed. They really have a questionable commitment to a quality of life, somewhat at public expense, for handicapped people.

There is also, we are finding, neighborhoods in communities which are much more organized than they have been in the past. They represent their own interests well. They want to be dealt with regarding any changes in the neighborhood. The classic example took place in Hartford not too long ago.

Asylum Hill organized and kept MacDonalds off of Farmington Avenue. Years ago MacDonalds would have been an asset to Farmington Avenue. They organized and felt MacDonalds now would be a detriment to that neighborhood.

But there is another set of attitudes which have to be dealt with in this matrix and that is parental and family attitudes. There is a marvelous article which a member of Commissioner Thorne's staff has written for publication and the title says it all. It says: "Deinstitutionalization, Parental Jet Lag."

For years we have been giving a consistent message to parents regarding a partnership, that we are in this together and parents are going to be dealt with and included in planning for the child's future.

But, now, a new social trend is developing which defines handicapped people as people in their own right. They must be dealt with as individuals, and this at least displaces or dislodges, or raisies a very serious question: What is the role of parents in the future planning for their adult children?

This is especially true in Connecticut where the parents have had very active involvement. Additionally there is a whole series of support systems which are needed to develop community alternatives: a variety of day programs.

Dr. Galdager is a member of a professional organization in this area with me. If somebody said to us today that they could put 100 people in our community; they have the homes; they have the funds; we couldn't take them. We don't have room in our day programs for 100 handicapped people. I would say we don't have room for 50 handicapped people in our day programs.

This needs to be developed. It is time consuming. It is expensive and it takes planning. Very frankly, our public debate about the issues in our own field is not helping us in this pursuit today.

The whole issue of community support—you have heard Dr. Fierri talk about the dentists, the doctors, recreation, socialization, all has to be dealt with if you really want a handicapped person to have a normal life in a community. The administrative support and, of course, the specialized services for medically involved people with severe behavioral problems all have to be addressed.

I see, in essence, two dangers in the approach that we are currently taking. One, in our haste, in our sense of urgency I see a trend toward oversimplification. This is not a simple process. It has been with us for a long time. It is not insurmountable although I think some of these issues sometimes in some locations are insurmountable. There is a trend toward oversimplification.

The second factor is that we are getting into a numbers game. We are beginning to measure our contribution by the numbers of people we are placing, and numbers of people we are serving and not by how well we are serving them.

In an extreme form I guess that could be "dumping" and that is certainly something we have to be vigilant against. But the other end of that I guess we could be accused of being overprotective and paternalistic. There is a danger in thinking our purpose for existing is to place the largest number of people in the community. Our purpose must be to make the best placement possible.

I have just two final points. I think the situation calls for two components to prevail. We have to return to a sense of individuality. Behind these numbers, behind these statistics, are individuals and families, real people with feelings, personality, needs, likes and dislikes, and we have to return to recognizing that this is a human service business.

The second factor is that we have to regain our sense of sensitivity. We can't forget why we got into this field to begin with, and that is to help people. When we truly do that, our greatest attribute is a sense of sensitivity.

In the last 2 days I have been impressed by one common bond that has cut across all testimony before you. I think there is a strong commitment on every one of our parts to do what is in the best interest of the handicapped people. We may have different solutions and we may have different strategies on how to implement that, but the commitment is there.

I think that is quite a bit to work with. It is complex but it is not insurmountable. I thank you for the opportunity to present some of the subtler influences that are very definitely having an impact on our programs. Thank you.

Senator WEICKER. Thank you.

Ms. GRAVINK. Dan has discussed some of the specific problems that are faced, and I would like to discuss some of the things that are probably more involved with the system, whatever that system would be, and I think it affects us both at the public and private level.

Although as I list these and as I thought about them, it sometimes is overwhelming, and I think I want to say right at the outset that even with some of the very complicating and complex systems that are in place, we are operating—as a department—26 group homes and we have funds for around 9 to 12 more.

And I have to say 9 to 12 because we don't know exactly how many we can get for the money that has already been authorized. No doubt the overriding problem that we face—and I think this is true of both the public and private sector—is an economic one, and we addressed it in many ways during these 2 days.

It costs a lot of money to buy or build a house if we are doing it for ourselves. And when you add all the special features that Lars mentioned must be built into a home that is to serve the more complicated and handicapped person, it adds substantially to that cost.

Ironically, many of the bureaucratic procedures that were put in place to save money have actually, in many cases, cost money and that cost is often there because of the delays that some of those steps cause and, with inflation running at the pace it is, the additional cost is felt in that way.

Some of the things that we have to go through in order to open a group home. First of all, there is the initial authorization by the legislature for the money, and during the late seventies the dollars have become increasingly scarce from that source.

We asked for more than we have received, and sometimes we receive substantially less. Sometimes the money is available only for planning and acquisition. This is true particularly with the development of regional programs, including our decentralized regional programs, and we have to go back the next year to get money for construction or purchase and escalating costs sometimes make us go back more than once.

The prices of land and homes, as I have mentioned, have already escalated and the cost of rehabilitating facilities, although it may still be much less than construction, is expensive. Leasing has already proved to be so costly and problematic in other ways that we have been encouraged not to pursue this as a way to develop homes.

Just let me quickly list some of the bureaucratic steps that must be gone through after the money is authorized. We have ourselves, and with the Department of Public Works, looked at hundreds and hundreds of homes and sites and had to have them ruled out because they just weren't appropriate. Many of them were not suitable to pursue at all.

But they were available and they were on the market and they were investigated. When we find one that appears suitable there is the necessary engineering studies. These would have to be done if any of us were building a home, certain code compliances for the special type of home, three outside appraisals, environmental and urban impact statements that have to be filed, and then there is the certificate of need process that we go through with the hospital cost commission and the HSA's.

And, again, the way the law is presently written, this would apply to any facility that is going to receive title XIX funds, which means it applies also to private facilities that are going to be ICF/MR facilities.

The State properties review board is another step in the process. Their review sometimes takes two or three visits to a site and they frequently request more information, or further study after a site visit and this frequently delays the process. This was one of the steps that was put in place to save money for the State.

If there is to be construction there are two or three steps to the process of selecting an architect: Getting authorization from the bond commission to hire that architect; then the architect has his preliminary, basic, and final plans, each with a review step at the bureau of public works and within the department to make the appropriate changes. Frequently there are water and sewage investigations and negotiations that go on with local towns that any of us might have to do if we built a home.

Finally, the office of policy and management becomes involved about when it is appropriate to put a project out to bid and then to decide when it is appropriate to be placed on the bond agenda so that moneys can be available either for purchase or construction.

There are the necessary codes that must be complied with, fire codes, ICF/MR regulations, 504 regulations. Any of these may rule out a facility or a certain home for purchase, and certainly, as has been expressed earlier, does add to cost of construction.

There are zoning considerations. The State technically can be exempt from these but there are feelings that the State should not override the local zoning and we should attempt to at least comply with existing zones.

Lest we be overwhelmed with these steps, I should say that even though it sometimes seems discouraging we have learned to cope with many of these things and they become a matter of routine, and the more routine they become the less time that it takes.

And we are trying continually to streamline them. We have met with the Bureau of Public Works on several occasions and with the Office of Policy and Management to try and modify the process and to allow some of these things to run concurrently.

Whenever possible, we try to do some minor renovations in a facility ourselves and if costs fall below a certain level we can subcontract ourselves. We have had several meetings with the Bureau of Public Works regarding the use of a prototype design so that it would not—so a new design and a new architect would not have to be hired for each group home.

We more recently have been talking with the Bureau of Public Works, and it looks like we will be able to pursue this in our next development, the possibility of prefabricated modular construction. We have seen some of that developing now in the shoreline area which was just described by Mrs. Horan earlier.

This year we submitted legislation that might streamline the process for the certificate of need and that, we understand, has passed the Senate. We are hopeful that that will assist both us and the private sector because it would eliminate steps in the process for group homes below 15 occupants.

Senator WEICKER. We still have another witness to hear from, Miss Gravink. I think we are going to run a little overtime. Go ahead and try to wind it up.

Ms. GRAVINK. OK. I would just like to say we are looking at other alternatives about which we are very concerned because we understand funds will be cut at the Federal level. This would include the Farmers Home and some of the HUD section 8 possibilities.

Some of the other possibilities that we have found to be very productive include looking at surplus property from other departments. We have acquired homes and land from the Department of Transportation, from the Department of Environmental Protection and, also, more recently from one of the community colleges that is going to allow us to build a group home on their facility.

It is complicated and lengthy. We would like to be able to shortcut more but there are some solutions.

Mr. SCHWARTZ. Senator Weicker, my name is Benedict Schwartz. I am the director of human services for Goodwill Industries of Western Connecticut and I oversee the administration of Connecticut's only federally funded center for independent living under the Rehab Act.

I would like to thank you for two things. One, for the strong role you have played as an advocate in Washington for the handicapped, and I would also like to thank you for the fact that you have represented the Connecticut citizenry with a consistent personality and have not suddenly gone along with the tide and become an extreme right card-carrying fiscal conservative throwing caring to the wind.

And I want to say I really wish there were more like you in the Senate, very much so.

As we are all acutely and painfully aware, we are facing a number of complex dilemmas. As we talk about deinstitutionalization, as we talk about handicapped persons becoming more and more aware of the creative slice of life that historically they have not had access to and they are trying to gain more and more a piece of that slice of life we see resources to enable that shrinking.

One resource which I think is vital is the development of centers for independent living. When persons leave an institution and go into the community what are the resources in the community to help them live in a less restrictive environment, what are the resources available to help them live more independently and care for themselves to a greater degree.

And for persons who have never been in an insitution but who live in a community who are handicapped, what are the resources to help them to live more independently. One of the responses has been the development of centers for independent living around the country.

Connecticut's only center is located in Bridgeport and it is a collaborative effort of five cooperating agencies: Goodwill Industries of Western Connecticut, the Easter Seal Rehabilitation Center of Eastern Fairfield County, Parents and Friends of Retarded Citizens-Kennedy Center, the Office of Handicap Services of the city of Bridgeport, and Connecticut's Division of Vocational Rehabilitation.

And I want to say that represents something of a miracle in and of itself, that five agencies, three of whom historically have competed for funds and programing are working very closely together and planning ways in which they can collaborate on more and more projects, one of which is a transportation consortium which is now in place.

Another is a centralized case management system that they are looking at for all three agencies, trying to conserve resources and provide better services.

The center is an attempt on the part of the five agencies to provide both comprehensive, independent living services to handicapped persons and also to serve as a catalyst for increased consumer-based activity among handicapped persons in the greater Bridgeport area.

The programing of the center can be divided into three major areas of emphasis. One is what we call the Coordinated Services Delivery System. Essentially, this means that all of the resources in any of the agencies that can help the independent living functioning of a client are opened up so that a client can have partial service at the Kennedy Center, partial service at Goodwill, partial service at the Easter Seal Center.

The center becomes an umbrella that coordinates the relevant services of the agencies, advocacy from the Office of Handicapped Services, independent living training apartment use in Kennedy Center, OTPT services at Easter Seal Center, so that one client can be served at any of the agencies.

A second major area of emphasis is what we call the Community School for Living, and its main thrust is to be able to reach persons who are not part of the traditional workshop system or rehabilitation system, persons who have been deinstitutionalized and may be living on their own in the community, or who may be living with their families.

The community school develops programs that consumers themselves ask for. Recent programs. Banking, personal health care, how do you do your taxes, exercise groups and so on. One major component of the community school includes the development of peer counseling services where handicapped persons can help each other in terms of overcoming fears, becoming more assertive, learn how to be self advocates.

A third major area of the center includes the area of outreach and advocacy, helping handicapped persons to find housing, helping them deal with landlords, leases, helping them with their benefits, helping them deal with the social service maze and any other problem areas that may arise.

The center works with persons who live in group homes, persons who live with their families, persons who live in apartments. Clients are worked with on an individual basis, in small groups. They are taught survival skills, money management, cooking, shopping, housekeeping, grooming, and hygiene, how to use the transportation system, recreational opportunities are provided, camping trips planned, film festivals, informal social actions, a basis is provided and encouraged.

I think that a critical thing is the continuation of programs which will encourage persons to take care of themselves. The more someone is able to take care of himself or herself, that means the less outside resource is needed, obviously, to provide that care.

So, we thank you for the support that you provide and say keep up the good work and we hope you can make some converts of others.

Senator WEICKER. Thank you, Ben. Was the statistic correct that was quoted this morning where somebody said that under the Meskill administration the plan, or goal were 100 community homes? Was that the goal?

Ms. GRAVINK. Yes.

Senator WEICKER. How many do we have built now?

Ms. GRAVINK. We got authorization for staff and for leasing money for a total of 25 one year and 25 the other year. There were 50 that were authorized during that period of time and 17 got opened before the—of that group got opened.

Senator WEICKER. How many do we have in operation today?

Ms. GRAVINK. We have 26 that we——

Senator WEICKER. How many are going to be in the budget that is now being debated?

Ms. GRAVINK. It looks like none. The funds that we have now available are from a previous authorization.

Senator WEICKER. I don't know what people are arguing about here. Good luck to everybody on this lawsuit. I think it is going to be a very hollow victory one way or the other to maybe achieve something in principle and find that the big battle has been lost.

I want to repeat that again so that everybody can hear. A major battle on behalf of everybody is going on right now. Believe me, it is a crucial one. We are not talking about just this year's budget. We are talking about the shape of the Federal budget for the next, I would say, 5 years. Minimum, four.

I can assure you, the way I see that budget shaping up as it relates to this group, we won't even be halfway home to the Meskill goal by the end of the 4 years, so far as any Federal participation is concerned. And you can bet your bottom dollar that if I say that as far as the Federal budget is concerned and the various priorities, it isn't going to be any better in the sense of who gets what piece of the pie back at the State level, not in this area.

And I have no argument at all as to the end to be achieved as represented by the statements of the people that are on this panel. In any event, thank you very much.

The next panel will consist of Rod Rosta, Terry Roberts and Tom Fanning on the matter of community services.

Ms. ROBERTS. Ladies first?

Senator WEICKER. Do it any way you want to. There is a half hour, as I said before. Nobody seems to be able to stay within the limits. I don't expect you to but try the best that you can. You are no different than my colleagues in the Senate so I shouldn't apply any higher standard, I will put it that way, to the rest of the population. Go right ahead.

STATEMENT OF TERRY ROBERTS, SUPERINTENDENT OF SCHOOLS, DEPARTMENT OF MENTAL RETARDATION SPECIAL SCHOOL DISTRICT; ROD ROSTA, SUPERINTENDENT, WATERBUR REGIONAL CENTER; AND TOM FANNING, EXECUTIVE DIRECTOR, DATAHR, DANBURY, CONN., A PANEL

Ms. ROBERTS. My name is Terry Roberts. I am the superintendent of schools for the department of mental retardation special school district.

In 1977, the Connecticut Legislature did two very important things. First they removed all the exclusionary clauses from our education law here in Connecticut to open up a free appropriate education for the most severely and profoundly handicapped, and, secondly, created a school district within the department of mental retardation. The latter action was based on a previous set of steps that had been taken in DCYS and in the department of corrections.

Most of the children who required this very specialized kind of training were either residents of the department or were already being served by the department in some other capacity.

For example, in the department of mental retardation, without any educational mandate, we had, in fact, been providing programs for students since the early sixties. These were not run by special education teachers. They didn't have the sanction of the law but they were, in fact, programs for people who lived with us or who lived at home and came on a daily basis.

Because we had that base, it was not very difficult to start the school district. It was primarily administrative moves which had to be made. Our students already had individual program plans since 1972. We had teachers available. We had classrooms available, and so forth.

The children who are in the school district are the severely or profoundly retarded who must also match another set of criteria. They are children who are not mobile, or sit independently. They are children who do not respond to either oral or manual language. They are children who are continuously a danger to themselves or others and who are very medically fragile.

That leaves a lot of students attending other kinds of educational situations Right now, we have residents between the ages of 3 and 21, as the Federal law requires, 425 students attending our programs. Those students live with us. Some of them go to school right on campus. Some of them go off campus to have their classes in local public schools, closed public schools or a variety of kinds of settings.

Our input with them is to help them acquire the skills to move into different kinds of residential facilities or perhaps go home.

The State law also provided for the local education agencies, the public schools, to purchase services from the Department of Mental

Retardation when a severely or profoundly retarded child that met the criteria lived in their community. We have 200 of those children who come on a daily basis and go home each afternoon to their families.

By providing that 5-hour a day respite to those families, hopefully, those students will stay in their home community longer and may never have to come into an institutional setting.

The last group of students that are included in our program—and Mr. Rosta is going to speak about them in more detail—is our early intervention population, from birth to 3. We currently have 273 of those children and our average referral age is 1 month. We are picking up students very, very early. I hate to call them students when they are still babies in the hospital.

Senator WEICKER. Do you know what is happening to that program on early intervention at the Federal level?

Ms. ROBERTS. The State Department of Education funding is not coming through, at least that is what they have informed me.

Senator WEICKER. That is one of the programs slated for about half the funding that has been available in the past, even though—this is the irony of this budget—I don't think there is anybody in this room that wouldn't say that we are really moving ahead so far as success of early intervention is concerned. This has proven to be a success and, indeed, talk about something that is cost effective in the long run. It might prove to be some of the best money we ever spend.

Ms. ROBERTS. The only Federal funds we get for our early intervention program at all is that those students are counted in our title I enumeration, which obviously is under great jeopardy. The rest of the program is funded by general fund monyes from Connecticut.

Senator WEICKER. Get ready to go ahead and pick up the slack. That is what is going to happen.

Ms. ROBERTS. The other thing I would like to talk about in relationship to the special school district is that we do have about 210 children who live with us who go out to public school every day, to a local public school in the community. They have become the educational responsibility of that community and they simply live on our grounds. Some of the local schools are beginning to develop their own programs for the severely and profoundly retarded so that they don't have to buy the services and the children don't have to be transported.

The LEA's are also starting early intervention programs. That is one of the areas that is funded totally by Federal money and will be in great jeopardy.

There are two other kinds of things that I, as a superintendent of schools, need to talk about. We educate the profoundly retarded to age 21. We have students who had only 1 or 2 years of school because the Federal legislation was passed when they were in their teens. The department does not have the intense kind of programing for adults that the school, because of its very mandate, is able to provide.

That is creating some problems for us for people who are getting a taste of learning and that we are not able to follow all the way through at the same level.

You asked Dr Brown yesterday about 94-142. I have one other kind of reaction to 94-142. I think Connecticut probably would have started programs for all children without 94-142. We were well on our way to that. One of the things that is happening however, is that I see us not communicating like we used to because there are so many particulars to the guidelines and the regulations for 94-142.

We sit down with families and professionals and one of the first things that happens is we start talking about everybody's due process rights before we talk about what it is we are going to do for children.

Senator WEICKER. How would you like to see 94-142 taken off the books?

Ms ROBERTS. I would feel very confident that Connecticut would continue to support the programs for the special education——

Senator WEICKER So you would not object—you do not feel it would be a setback if it were taken off the books?

Ms ROBERTS. Of course, I don't get any 94-142 money so I am not a very good representative.

Senator WEICKER. Let me tell you, you just might have your wish come true because it is my understanding that the Administration very well might go in that area. It either gets a rather large debate—the problem is, from my point of view, which is obviously different, that Connecticut might do it all right.

I don't think you could give me that guarantee that that would happen in 49 other States. That is the difficulty.

Ms. ROBERTS. No, I could not.

Thank you.

Mr. ROSTA. Mr. Chairman and Mr. Doyle, my name is Rod Rosta and I am superintendent of the Waterbury Regional Center of Connecticut's State Department of Mental Retardation.

The Waterbury Regional Center is responsible for a 16-town service area in central Connecticut with a total population census second only to the New Haven region. The center has an active caseload of some 510 individuals at the present time.

The vast majority of the services being provided are noncampus residential in nature with but 48 individuals residing on grounds in the regional center facility. As is typical throughout our State's regional program concept, a wide array of services are provided, including information and referral, counseling and specialized therapy services, diagnostic services, early intervention programing, functional education, adult-work activity and vocational training, community planning and organization, public information and education, campus residential and respite placements as well as community alternative living situations and parent training.

I appreciate the opportunity of appearing before you today to talk to you about one of our programs, an extremely important and vital program which is provided by the Department of Mental Retardation through its 12 regional programs. It is my intent to share with you some local perspectives and experiences that we have had with the program in the Waterbury area, which experiences can be generalized to other DMR programs throughout the State which offer the same programing component as part of their normal service array.

Yesterday and this morning there was substantial testimony offered which focused on the issue of deinstitutionalization, its merits and drawbacks, as a philosophy and as an accepted national and State goal, the pragmatic realities of implementation, the different opinions on how it should be achieved and how quickly; and some of the emotionalism associated and surrounding the concept.

I would like to attempt at this point in time to put the horse back in front of the cart, as it were, and talk about a program that offers not only the promise but the reality of forestalling and, in many instances, eliminating altogether the need for institutional placement.

I speak of a program which reaches children and their families at one of their greatest times of need, a program which provides direct clinical and educational assistance to the child to help maximize his or her developmental potential while simultaneously providing support, guidance and specialized training to the child's parents

I speak about, of course, early intervention programing. One of the major goals of the Department of Mental Retardation, which has been articulated time and time again, is the prevention of institutionalization. In my opinion, and in the opinion of countless other professionals in the field, reaching that child and family early is essential in forestalling institutional placement.

As a trained psychologist, I had my beginnings in the field conducting basic and applied research on language acquisition and motor development in young children, investigating the processes in both normal and handicapped children. I have taught learning and development theory at the university level. I have served as director of education and clinical services at a private, nonprofit community mental health center which offered early intervention.

I served as executive director of the Governor's Planning Council on Development Disabilities in the State of Connecticut, which council provided startup funding for numerous programs around the State in early intervention.

Senator, I am convinced, both personally and professionally, that one of the greatest investments of resources that we can make, to restate what you just said a moment ago, is in the area of early intervention. We are investing in children and their families.

There is no substitute, in my opinion, for the child's natural family as the most appropriate nurturing source in these early years of life. We have a professional, indeed, a human responsibility to provide as much input, support, guidance and training as we can for families faced with the incredibly complex and difficult task of raising a handicapped child.

The investment made early most assuredly reduces the need and dependence of the child on greater, more costly levels of intervention later on, and clearly reduces the trauma, anxiety, guilt, confusion, and uncertainty which all too often becomes part of the reality faced by the parents at this time in their lives.

We began our program in Waterbury some 3 years ago with six infants. We currently have 65 infants and young children enrolled in our program currently. We utilize two basic programing modalities, one being a classroom situation, the other being a home-bound situation—a home oriented program.

The selection of the modality is based on the child's and family's needs as well as age criteria. Our program is fully integrated into the community with solid working relationships with hospitals, clinics, and physicians who serve as our primary source of referrals on the one hand and solid relationships with local nursery school programs and with the local school systems who assume educational responsibility for a number of the children at the completion of our program.

In addition to the educational/clinical services that we provide directly to the child, parents are involved in the training paradigm so that we, the professionals as it were, can transfer, in part, our skills to the parents so that they can work with their child at home.

If one looks at it in terms of the time and involvement with children I don't think you would find a professional who would deny the fact that it is the child's natural parents who spend the majority of the time with their child and, therefore, if we get the skills to the parents they are certainly going to be much more effective than the professional who may only see the child for 2 or 3 hours a day.

In addition to the specialized training offered to the families, they also participate in more therapeutically oriented activities which help to assist them cope more effectively in many instances with the respective situations.

In closing, Senator, I would just like to share with you a couple of brief comments that we received from some families that have participated in our program and whose children have since graduated In the 3 years we have been operational, we have graduated some 27 children from the program.

This is from a parent whose child graduated from our program last year. "Marnie is doing just beautifully. You can tell Lydia", who is our speech pathologist, "that she is starting to talk and put words together and pronouncing them very well. She just loves school and goes off every day on a bus. She is becoming quite an independent little girl and we are very pleased with her progress. Thank you all for the help she received in your program. I think it has benefited her greatly".

The second letter. "Cheryl was in Karen's class", Karen is one of our teachers "for only a few short months but in that limited time Karen helped Cheryl come out of her shell." Dr. Russman, who is a neurologist at Newington Children's Hospital, "saw Cheryl this week, 1 year after caring for her at Newington Children's Hospital. There she had been labeled as retarded with an atypical ego and autistic tendencies. He could not believe the improvements and I believe your school and Karen helped her get started. Thank you all.

For the sake of time I won't share the other ones.

This is a third communication from a mother whose child also graduated last year.

> Jody started school last year at Century Nursery School in a two-day program for three year-olds She was being seen at Wheeler Clinic for occupational therapy. This year. she is in the four year-old group which meets three days a week. She still attends Wheeler Clinic once a week. They just recently told me that Jody will be attending kindergarten next year. She is doing very well but will most likely

require ongoing special therapy for gross motor and fine motor work, which has always been her problem.

The mother sent us a picture of Jody.

A special thanks to all those at WRC who worked with Jody and made it possible for her story to be such a success.

Senator, I thank you for having the opportunity to speak with you today.

Senator WEICKER. Thank you.

Mr. FANNING. Good afternoon, Senator. My name is Thomas Fanning. I am executive director of DATAHR, a private, not-for-profit agency located in Danbury, which annually serves hundreds of mentally retarded and handicapped people. I am also president of the Connecticut Association of Rehabilitation Facilities, an organization consisting of over 30 community agencies serving thousands of Connecticut's mentally retarded and handicapped people each year.

I am extremely grateful for the opportunity to present some thoughts with regard to the importance of community programs for mentally retarded adults, including severely retarded persons.

Many of our mentally retarded citizens now benefit from long-term programing, not dead-end placement, but long-term, systematic, developmental programing responsive to individual needs.

In differing locales these programs might be called work activity, vocational therapy, adult day care or functional therapy. By whatever label, these services are critical to the continuing development of many thousands of our mentally handicapped adults.

We in Connecticut are deeply concerned about the future of these programs. I know that this is a concern shared by parents, families, and professionals throughout the country These programs and services are of immeasurable human value to mentally retarded persons and their families.

Through these programs, many men and women define their self worth. They produce, they earn, their lives take on added meaning Through these programs many men and women grow They develop skills. They increase their ability to care for and about themselves.

They become more independent. It is because of the human worth of these programs that we are primarily concerned. However, it is also true that community based programs are less expensive than many institutional alternatives. These are cost-effective programs.

Many, if not most, of the mentally retarded adults involved in these day care programs reside in the homes of the their natural families at correspondingly less cost. As individuals acquire skills they increase their ability to care for themselves.

As people grow in independence they require fewer programs and services, resulting in less cost. Finally, though the people I am talking of are severely handicapped, a substantial number, move from community based programs to jobs and to apartments and to independence. They can become taxpayers rather than tax users.

If these programs are truly effective in both human and financial terms, why are we concerned for their future? I believe there are two reasons, interrelated, that we worry. First, there is a lack of a strong commitment to community-based programs. And, second, there is not suffitient funding for these programs.

What do I mean when I say that there is a lack of a strong committment to community-based programs? Isn't the byword of the day deinstitutionalization? Doesn't this mean movement toward depopulating our institutions on one hand and preventing people from entering them on the other?

Absolutely. It does. But a commitment to deinstitutionalization does not necessarily mean an equal commitment to the development of community-based programs. While I have done no word count my guess is that much more has been written against institutions than has been written for community services.

While effective deinstitutionalization may require an equal commitment to the development of services in the community, merely lessening the populations of institutions does not.

Thus far, our society does not have a commitment to the development of community-based services as it does away from institutions.

The second cause of our concern, clearly related to the first, is funding. In Connecticut recently, funding was a problem of critical proportions. Since 1973, Title XIX medicaid moneys had been utilized to fund more severely handicapped persons who needed programing in community agencies for an extended period.

Connecticut felt that these services were eligible under medicaid law, as section 1901 of the law itself addresses both medical assistance and rehabilitation and other services. However, the Health Care Financing Administration of HEW issued an administrative ruling in 1979, stating that only "predominantly medical" services would be eligible for title XIX funding. The result in Connecticut could have been catastrophic to the services. However, our State, its executive branch, legislative branch, and administrative department took emergency steps to ameliorate the problems caused by the severely reduced title XIX funding.

Of an expected appropriation of some $9 million for these programs in Connecticut in 1981-82, $8 million of 100 percent State funding is needed to salvage these programs at bare subsistance levels. Believe me, we are very grateful to the State of Connecticut for the support that we have received here.

This experience, though, amplifies the need for an increased and concerted commitment to community based programs and the need for a funding policy which recognizes the value of these programs in both human and financial terms.

Regardless of the semantic argument as to medical assistance versus rehabilitation services versus habilitative services, points in dispute between Connecticut and HCFA, the common sense arguments weigh heavily in support of Connecticut's position.

Funds spent in community based programs for mentally retarded persons are well spent in the interests of the people served in our society. It might also be pointed out that title XIX funds may be used for these programs for an individual who happened to reside in an intermediate care facility for the mentally retarded.

It would only seem logical that they might be used for persons who received the same services but happen to live with their families at home. In these times of necessary fiscal restraint it would seem logical to utilize limited resources in a most cost-effective manner.

We need to increase our committment to community-based programs that would provide long-term services for mentally retarded persons, and we need to consistently fund these services adequately.

These services make the lives of thousands of our citizens meaningful and in many ways these citizens have been able to provide meaning to our society.

Senator, I would like to thank you for the opportunity to speak before you and also to second Mr. Schwartz' earlier comments on your efforts on our behalf.

Senator WEICKER. Thank you very much, Tom, and I thank each member of the panel for going ahead and supplying the committee with additional views of the situation. I would hope, as events proceed, that we will have the funding necessary to bring to reality the endeavors you are engaged upon.

Thank you very much.

The last panel will consist of John Kennedy, Roger McNamara, Steve Taylor, and Cathy Stevens.

I am delighted to have all of you here. Again, I am going to have to ask you to restrict your comments because I now have another commitment outside these halls coming up before 4 o'clock.

Senator Williams has indicated that he, through his able staff assistant who is here, he would very much like to hear the full testimony of Mr. Taylor, so why don't we let Mr. Taylor go first and then travel around any way that you want.

STATEMENTS OF STEVEN TAYLOR, UNIVERSITY OF SYRACUSE; JOHN KENNEDY, REGIONAL ADMINISTRATOR, HEALTH CARE FACILITY; CATHY STEVENS, DEPARTMENT OF MENTAL RETARDATION, LICENSING AND CERTIFICATION; AND ROGER McNAMARA, SUPERINTENDENT, MANSFIELD TRAINING SCHOOL, A PANEL

Dr. TAYLOR. First of all, I would like to thank you, Senator, both for the opportunity to present testimony today and for your effort and concern on behalf of the disabled. I can tell you that your concern does not go unnoticed in other parts of the country.

Senator WEICKER. Thank you.

Dr. TAYLOR. My name is Steven Taylor. I hold a Ph. D. in Sociology and while that qualifies me to present some facts and evidence relevant to the subcommittee's activities, that certainly doesn't qualify me to resolve the many difficult legal and moral issues that have been presented today.

I am also on the faculty of Syracuse University in Special Education and acting director of the Center on Human Policy.

I would like to, at some point, present for the record a copy of a report on title XIX that I recently completed with a team of researchers at Syracuse University.

Senator WEICKER. That report will be included in the record in its entirety at this point.

[Note. In the interest of economy, the report referred to was retained in the files of the committee where it will be available for research upon request.]

Dr. TAYLOR. Fine. Thank you.

As the previous testimony has indicated today, I think there is considerable controversy surrounding the issue of deinstitutionalization, and it is a difficult and painful time for many of us, with parents disagreeing with parents, professionals disagreeing with professionals, and researchers disagreeing with researchers.

Notwithstanding that controversy, I think there is an increasing body of professionals and parents who do support the concept of deinstitutionalization. For nearly two decades Federal policy has supported deinstitutionalization It is ironic that today the single most formidable obstacle to deinstitutionalization nationally is the title XIX medicaid ICF/MR program.

Somebody mentioned earlier today that perhaps the controversy between the institution and the community really reflects a battle for dollars. And if that is the case—and I am not sure whether it is—the community is clearly losing in that battle.

In 1978—that's the last year for which figures were available when we completed our report—the Federal Government made available $1.3 billion under the ICF/MR program, to somewhat over 40 States. Our review indicates that 95 to 98 percent of those dollars were going to institutions, not to community settings.

I certainly would not deny that as long as people have to live in institutions they deserve the most decent care possible within the institutional setting. The problem is that under the current ICF/MR program the Federal Government, by providing huge sums of money for institutions, provides a strong incentive for States to keep people in institutions and not to place people in appropriate community settings.

I could go into detail on some of the things we uncovered in our report about how eligibility criteria under the ICF/MR are manipulated by States to insure continued receipt of medicaid funds, but I won't go into that now. Just let me say that I am aware of children and adults who are admitted to institutions today against the best professional judgment of people at the institutions and they are admitted only because the funds are available for their care at the institution.

The other major impact of the medicaid program is to encourage the various States to invest scarce State dollars in institutional staffing and construction. The medicaid standards require States meet certain staffing levels within institutions. They also require States to meet certain physical environment standards. One study showed that in the period 1977 to 1980 alone different States invested $821 million in the construction and renovation of institutions.

It strikes me as difficult to understand, at least at this point in history, given this controversy surrounding deinstitutionalization, given the professional opinions supporting the rights of people to live in the community, that the Federal Government is forcing States to lock themselves into an institutional system. Even if we all agreed tomorrow that everybody should live in the community the States could not move people out because the only way they have to recover these construction costs is by continued receipt of medicaid funds.

In short, the conclusion of our report is that the ICF/MR program is out of control. Not only is it not guided by any underlying policy, it runs counter to current policies and trends in the field of mental retardation and developmental disabilities.

Another issue we looked at in our report was the general issue of cost effectiveness of services. To understand cost effectiveness, first you have to look at the cost of institutions and then you have to look at their effectiveness.

As of 1979, the average operating budget for ICF/MR certified institutions was $27,420 per person per year, somewhat over $15,000 of that being the Federal share. In New York State alone for the Governor's proposed budget for the upcoming fiscal year proposes a budget of $35,900 per person per year, enormous costs. What are we getting for these dollars?

We reviewed what are called medicaid deficiency reports, ICF/MR deficiency reports, to try to get a sense of what federally mandated inspections were finding at these institutions.

We reviewed reports from 44 institutions in 31 States. Let me say at the outset that our overwhelming conclusion was that the surveys, the monitoring reports, were grossly inadequate, focusing far more on policies and far less on the quality of life and programing at the institutions.

Notwithstanding that, we found massive evidence that even minimal standards are not being met at these institutions. In 33 reports there was clear evidence that residents were not receiving programing.

Violations, deficiencies concerning the barenness of the environment, lack of privacy, idleness, poor housekeeping, offensive smells were commonplace at the institutions. We found specific serious violations, of people's rights.

At one institution children were living in totally enclosed cribs. There were locked isolation cells for residents at a couple of institutions in violation of the standards. At many institutions we found inappropriate use of restraints. We often found people spending days being restrained and indications of inappropriate drugging.

My sense, and over the past 6 years I have studied or evaluated 23 institutions in 10 States, is that these deficiencies in these reports represent merely the tip of the iceberg. I have found conditions far worse at many ICF/MR certified institutions than are portrayed in these reports. At numerous institutions in ward after ward there is no toilet paper, no soap, no towels—the same things that we found 10 years ago for a lot less money.

I found, in many institutions, wards of 30, 40 children locked up in a room during normal programing hours. Public Law 94-142 is not implemented at many of these institutions, let alone the ICF/MR standards——

Senator **Weicker**. Tell me something. Why is not the thrust of those, let's say, here in the State of Connecticut—I know you can't speak for that—why isn't the thrust in creating these community settings rather than worrying about whether you are going to close down Mansfield or close down Southbury?

It seems to me that if you create the facilities out here then—whether the facilities are entirely adequate in the institution level, believe me, the higher up personnel are, I am sure they would be delighted to go ahead assuming the facilities are out there to receive them to start getting the population out of their institutions. Why don't we handle it that way, or why isn't it handled that way, that the emphasis should be on the creation of the various types of diverse and smaller type facilities which, if they are out there and if they are ready and waiting to receive the population of the institution?

Dr. TAYLOR. I certainly agree, and somewhere along the line somebody said something about closing down institutions. I think that is unfortunate because the goal, as you suggest, is not to close down institutions. The goal is to create the services in the community.

I think the basic problem is that there is not a flexible funding mechanism to do that. The basic problem underlying the ICF/MR program is that the dollars go to facilities, they don't go to people.

So, for example, is I were a parent of a child, if I keep my child in an institution I can get whatever it is costing—$100 per day with the Federal Government picking up 50 to 78 percent of that. If I keep my child at home I can't access those funds for support services and, also, it is very difficult to create community-based alternatives with ICF/MR funds.

So, I certainly agree with your comment. I think the basic problem is that the way the ICF/MR program is set up today is to provide disincentives to move people out of institutions and to create those services in the community.

And it also creates services at a far more intensive level than many people need. I can also say that many of the people I know who are living at ICF/MR certified institutions are not even mentally retarded. They have other disabilities and somehow were certified as medicaid-eligible. There are gross inequities in the system.

Something is wrong when we have to spend $25,000 $30,000 $35,000 per person per year and still have these kinds of conditions and very inadequate care at institutions.

The final general issue I want to address is the general monitoring of these ICF/MR certified institutions. As I suggested before, monitoring, for the most part, focuses on bureaucratic policies, it focuses on paper audits and very little direct observation of residents.

For example, I have been to two institutions; one in New York and one in Oregon that are very comparable institutions. I found at one of those insitutions a medicaid deficiency report was 11 pages long. At the other one it was 99 pages long. How is it possible when you have institutions that are identical, one surveyor finds 11 pages of violations and the next one finds 99 pages?

Even more disturbing, I think, than the hollowness of the surveys is the fact that very seldom are affirmative plans required to correct any deficiencies. So, for example, when you find, as we found in some reports, that people are lying in their own feces and urine, the response is to write a policy that people shall no longer lie in their own feces and urine, and that is accepted as a plan of correction and the moneys continue.

There is no accountability in this program and the question in my mind is how much is enough and when will the Government act to halt the expenditure of thousands of dollars of Federal funds for inadequate facilities?

In our report we do offer a series of recommendations. You can read those in our report. I am also happy to answer any questions.

Just let me say in concluding that personally I strongly support the policy of deinstitutionalization. I am convinced that retarded people can grow and thrive and develop in community settings. And community settings may be many things, not one thing.

As a social policy I support that. I am not sure whether social policy issues can solve the difficult mess we are in today. Professionals—and I consider myself a professional—10, 15, 20 years ago told parents to institutionalize their children.

Parents made very painful decisions to do so and today, many of us professionals turn around and say, we were wrong back then. We have to be sensitive to parents. We have to realize that what we develop as a social policy—and I strongly believe our social policy should be to support deinstitutionalization totally and the Federal role should be to support alternatives—cannot always tell us what to do with folks who live in institutions today and who have lived there many years. But the Federal Government must stop encouraging institutionalization. And States must show parents and others that deinstitutionalization can work.

Finally, one more comment if you will bear with me, Senator, a year ago I would have made different recommendations than I will today Let me say that what I feel is extremely important at this point in time is to retain the DD Bill of Rights Act. I think that is the one tool that parents and consumers can use to enforce their rights and we can't afford to lose that tool, and the clearly established rights to treatment, rights to least restrictive environment. Thank you.

Senator WEICKER. Thank you very, very much. I appreciate it. Even now we will start to run over and I would appreciate it if we could wrap this thing up within the next 20 minutes.

Mr. KENNEDY. My name is John Kennedy. I am the regional administrator of the health care financing administration in Boston, Mass.

Thank you for the opportunity to appear before the Senate Subcommittee on the Handicapped. As Chairman Weicker has requested, I will briefly describe the title XIX intermediate care facility for the mentally retarded program. I will confine my comments to the current statute and regulations which govern the program. In addition, I will outline current and emerging trends in the ICF/MR program as well as some data which you may find interesting relative to Connecticut.

I would like to apologize, Senator, I did not have an opportunity to prepare formal testimony today.

Senator WEICKER. Go right ahead and just speak off the top of your head. That is what most of us are doing anyway.

Mr KENNEDY. I do have a brief outline of the testimony which you may want. It may have some use.

Senator WEICKER. Fine.

Mr. KENNEDY. I will show it to my colleagues on the panel if they are interested.

Senator WEICKER. Get to the salient points and hit the things that you want to talk about.

Mr. KENNEDY. I feel like requesting equal time from the first presentation, Senator, but I will fulfill your request that I address some of the legislative background. I will try to go through this very quickly and hopefully will be able to have an opportunity to comment on some of the earlier remarks.

The legislative history for the intermediate care facility Program itself goes back as far as 1967. In those days it was not regarded a medical program qualifying for medicaid reimbursement under the medicaid Federal matching programs.

As a consequence of that, those in each States that were eligible for that benefit back in those days, 1967 and thereafter, were limited to those categorically needy eligibles which meant that the other eligibles, categorically needy were eligible but the medically needy were not eligible for the program.

In 1971, that was changed and the ICF program then became part of the medicaid program. At that same time, for the first time, legislation was introduced in the Senate that added the ICF/MR benefit for the mentally retarded in intermediate care facilities.

There was very little legislative history surrounding the introduction of that. I have noted there were some points that were made by Senator Bellmon, who introduced the amendment in the Senate, and it was at that time, that being the limited legislative history that was available, the four points that Senator Bellmon made when he introduced that amendment and I would just like to touch on them because I do think that they provide the framework for the later development of the program.

First of all, it, of course, enabled the Secretary to establish standards for facilities participating in the ICF/MR Program It made it clear that the purpose of these standards were to assure that the facilities that developed were not simply residential facilities, that the individuals accommodated in these facilities must need and actually receive help or rehabilitative services.

So there is a clear thrust in the direction of this being a health or rehabilitative benefit. Finally, as a protection, so to speak, there was a requirement or an amendment that related to making sure that whatever additional Federal moneys might become available that they would not displace State moneys that heretofore had been made available so that these Federal moneys as they became available, were in addition to a certain level that had already been available through the States.

So, this concept could be embodied in the notion of active treatment, and the legislation, when it passed, did contain a positive indication in the language of the statute that active treatment was a key element in what was anticipated would be the benefit.

It was with this framework that the department began to develop regulations implementing these directions and these concepts They were published first in 1974. The thrust was to provide a safe, healthy and normalizing environment which, through active treatment, would maximize independence of the individuals.

The regulatory provisions of the so-called conditions of participation relative to ICF/MR's can be viewed from four, probably different, perspectives. There is a section dealing with administrative policies and procedures relating to staff qualifications, experiential background and experience in the area of mental retardation.

There are a set of requirements dealing with residential living. To promote the notion of independence and of privacy, certain of the residential living standards were adopted requiring such things as no more than four persons per room, the minimum square footage per person, policies relating to behavioral modification and the use of restraints and things of that nature.

Finally, there were a group of regulations relating to professional and special programs and services requiring that the facilities either provide or have available under arrangement the appropriate medical, dental services, training, habilitation, nursing, food and nutrition services, physical and occupational therapy and recreational services.

Finally, there was a set of regulations that deal with health and safety and those involved the use of the life safety code and certain additional sanitation standards.

In addition, it was felt that as a part of the same regulations a special consideration should be given to facilities with 15 beds or less and these involved permitting contractual modifications, not having professionals on staff, registered dieticians are not required, exempted from certain of the more rigid standards in the life safety code, et cetera.

These regulations, published in 1974, originally contemplated that there would be full compliance with these standards by March of 1977 However, because of the problems which many facilities were having, particularly—and I think the early remarks about the bias in the direction of institutionalization, large institutions, has to be taken in the context of situations that existed at the time the original legislation was introduced in 1971-1972.

At that point in time there was a pattern for—and I think from the testimony that surrounded its introduction into the Senate—a clear indication that the objective was to begin to infuse Federal assistance on behalf of those patients that were in large State institutions.

And at that particular time there was not a great deal of other facilities or other locations for the provision of that kind of care, so I don't think really even from the standpoint of legislative history—certainly not from the standpoint of the way it was drafted, and certainly not from the standpoint of the way the regulations were drafted—that there was any statutory bias or, ultimately, administrative bias in favor of large State institutions.

But the fact of the matter was that at the time the legislation was introduced and got off the ground, that was the primary mode and the primary location of the patients who were to be served by this benefit.

Continuing, the active treatment provision, as I indicated earlier, was key to the conceptual part of this thing and it was effectively addressed through requirements relating to independent professional review as well as the facility is required to do an annual interdisciplinary review of the patients in house.

The certification process has been alluded to and facilities seeking participation in the program do require to be—must be certified by the State surveying agency. In Connecticut I believe it happens to be the department of mental retardation.

It has to be certified as in compliance with these standards. Since 1974, we have had 48 States participating in the ICF/MR program. Nationally there were about 1,000 ICF/MR's serving approximately 140,000 individuals. Three hundred of the 1,000 ICF/MR's, however, are public institutions. About 70 percent of these house more than 200 residents each.

Concurrently, however, from 1972 to 1979, there was a reduction in the residence of the public institutions, according to the studies available to us, of about 34,000 people. During that same period, 1972 to 1979, over 3,500 community residential facilities were established and 600 of these were ICF/MR's serving 15 or less patients.

Connecticut has approximately 46 ICF's in the program. Twenty-six, as we heard earlier, could be classified as small facilities and in the neighborhood of 15 or less. Expenditures have been increased substantially since 1953. In 1953 the annual expenditure was approximately $165 million. By 1978 it had crept up 800 percent to $1.3 billion.

In fiscal 1980 it is anticipated that the benefit expenditures will account for almost 10 percent of total medicaid costs or approximately $2 billion.

To touch on some of the situation in Connecticut, I will simply indicate there are approximately 46. Thirty-nine of these are State facilities, seven private facilities. We have in the State of Connecticut approximately a total of 1,307 beds. Ninety-four percent of those beds are in State facilities.

Of the 1,250 beds in State facilities, 706, or approximately 56 percent, are in Mansfield and Southbury. As a matter of fact, in the area of per diem rates in Connecticut, I will summarize very quickly to indicate that taking the three kinds of classes of facility in the State and the annual rate of expenditures, our data would suggest that for the large State institutions the average expenditure is 24 to $25,000 a year. For the regional centers housing smaller patient populations, the annual expenditure is in the neighborhood of $15,000 to $20,000 a year, and in the private facilities, of which there are only seven, the annual expenditures are in the neighborhood of $8,000 to $10,000 a year.

That is a quick overview. I would be glad to go into it further.

Senator WEICKER. That is fine. We have the statistics as you have presented them to the committee.

Why don't we let Cathy Stevens go here. You haven't had a chance to talk. I have heard Roger for 2 days running.

Mr. MCNAMARA. My staff feel the same way, Senator.

Senator WEICKER. Mine probably feel the same way so why don't we let you go.

Ms. STEVENS. I was going to suggest that if you wanted Roger to go, I am going to submit mine. I don't know if his is in.

Senator WEICKER. However you would like to do it.

Ms. STEVENS. I will skip parts of it.

My name is Cathy Stevens. I am director of licensing and certification for the department of mental retardation. As you have heard, the intermediate care facility program for the mentally retarded was developed to upgrade the quality of life for the clients in the institutions, notably by decreasing the number of clients, renovating the physical plant and increasing the number and quality of institutional staff in order to provide the active treatment.

In order to reduce the population of the institutions alternative placements were needed in the community. Many higher functioning clients needed additional skill training in group homes before they could move on to semiindependent apartment living.

Hence, group homes of 15 beds or less were included in the ICF/MR program The program has active treatment as its core component Part of active treatment involves the postinstitutional planning which forces the interdisciplinary teams to look to the future of each client's life; what skills does the client need to learn in order to move on to the next least restrictive environment either within the institution or the community.

The ICF/MR program has forced the professional and the administrator to become accountable for the planning, program delivery and active hands-on involvement. Professionals have been brought into the institutions and clients have been brought to the professionals in the community.

Neither system has been totally satisfactory due to the lack of knowledge and acceptance on the part of professionals in dealing with the mentally handicapped as well as resistance to complying with the documentation required by the regulations.

Lack of prompt payment for services rendered has not helped the situation either. Society is not totally prepared or accepting of the handicapped Revocation of licensure is a reality. Many providers are out to make a buck off the handicapped by whatever method possible, not necessarily in the best interest of the clients.

Many professionals resist participating in an interdisciplinary team process and resent being questioned by members of other disciplines However, experience has shown that interdisciplinary or multidisciplinary system greatly benefit the clients.

Documentation does not always guarantee quality control but, coming from a regulator's point of view as the director of both licensing and certification, the documentation and client's records, actual observations and interview with staff and clients provide the basis for determining compliance with the regs.

The intent behind the ICF/MR regulations was well founded. However, the regulations have often gone into too specific detail, such as specific requirements for a QMRP, which is a qualified mental retardation professional. In other instances the regulations violate the client's rights and give power and authority to individuals that only a court has the right to do.

I have worked on a task force with the National Association of State Mental Retardation Program Directors regarding the revised interpretive guidelines for small community-based ICF/MR facilities The interpretive guidelines have been an attempt to clarify or rectify the regulations but they are only guidelines and do not, in fact, have the force of regulations.

Until the regulations are rewritten, the ICF/MR program will continue to be criticized as a typical bureaucratic system. Many advocates feel that the program should be done away with and other advocates want eligibility to be so loose and the rates so increased that any handicapped person would be supported by taxpayer's money.

I have personally been caught in the middle, as a professional determining whether a facility truly needed the additional staff in order to provide active treatment, and as a taxpayer I have watched the cost of care escalate year after year.

The ICF/MR program has not been the sole cause of this escalation. Advocates and providers have wanted the department's licensing regulations and rates to be so flexible as to cover all areas of need for every client and at whatever cost was necessary.

If this were allowed then the providers would not have to adhere to the regulations. A five-client home and an eight-client home need the same number of shift staff to provide around-the-clock coverage. Smaller is not necessarily less expensive.

Shift staffing does not usually lend itself to a homelike consistent environment, yet, the rate of staff turnover and burnout necessitates shift staffing. No amount of training will compensate for being on duty or on call 24-hours a day, 7 days a week.

Title XIX payments in the State of Connecticut are based on a fee schedule and have limited provisions which do not necessarily allow for compliance with the regulations. Such fee schedule addresses doctors fees, dentists, speech therapy, et cetera.

The Title XIX ICF/MR regs were partially based on general ICF regulations. Surveyors trying to apply principles of normalization within constraints of the regulations often run into conflicts. Without a thorough knowledge of program and experience with the mentally retarded, the surveyor cannot adequately evaluate the quality of life within the home or the institution.

Surveyors should be qualified mental retardation professionals. This is required of the independent professional reviewers but not of the ICF/MR inspectors. Inspectors who have experience with mentally retarded look for adult day treatment programs, for quality of individual plans of care and for quality of life that someone unfamiliar with mentally retarded might overlook by just adhering to the survey booklet.

Modification of regulations through application may be accomplished when necessary. I prepared a short list of some of the areas that my staff and I feel should be eliminated or modified from the regulations and I would also be happy to serve on any committee regarding rewriting the regs.

And I would like to submit this.

[The material referred to follows:]

STAFF AREA RECOMMENDATIONS

ELIMINATE

(1) Verification of licensure when using community services.
(2) Inventory control system in group homes.
(3) All cross-referencing.
(4) Formal agreements with outside resources.
(5) Menus and food purchase records being kept for 30 days.
(6) W-299-300 EEG—too medical model.
(7) Autopsy.
(8) Record Personnel—ICF/MR not a medical facility with staff for this purpose
(9) W-511-528 content of records—repeat of many previous regulations.

REWORD OR COMBINE

(1) Training and Habilitation—combine with overall plan of care.

(2) Clarification of difference between health care and nursing care plans. Health care plan should be part of overall plan of care. Get away from medical model.

(3) W301-308—Medical case management and treatment goals—reword and incorporate into the overall plan of care.

(4) QMRP—make the requirements a little more flexible and also include residential living staff.

(5) W354-355 Formulary—only require in institutions with a pharmacy.

(6) Access to client's records and information is addressed in a couple different areas of the regulations.

(7) Financial affairs—needs to be reworded and combined.

Additionally, new survey booklets are needed to match the 1978 regulations. We currently use 3 separate books for each survey.

Senator WEICKER. Thank you very much Cathy. The statement, in its entirety, will be accepted in the record and, I might add, if assistance is looked for we will be glad to call upon you. I am sure that we will be.

Roger.

Mr. MCNAMARA. Senator, for the record, my name is Roger McNamara. In the interest of time, perhaps I will just make some flat statements and if people want to prove me wrong or question me later they can catch up with me at Mansfield.

I think a couple of things have to be said. First of all, I don't know if it was the impression Dr. Taylor was trying to create, but certainly it is not our policy or practice to admit people to capture Federal money, nor do we retain them in our facilities to continue to obtain the reimbursement. I don't think that is what he meant to imply, but for the record I want to make certain that our motives are well understood. We accept disabled persons to habilitate and to care for them.

As far as plans of corrections and surveys, let me just say that Cathy Stevens and her staff could just as easily be archeologists. I think they have microscopic vision. Surveys, therefore, have been detailed and comprehensive in accordance with the regulations.

There has been a trend nationally. The superintendents have been very concerned about the extent of the regulations and the fact that it becomes very difficult to operate an ICF/MR with the myriad regulations. I know that I could operate if "operate" is the correct term—my own household and satisfy the regulations. The program is an incremental one in nature. The regulations were written to allow you to add components over a given timetable.

Therefore, while an agency is obtaining conformance, there will be deficiencies. I think that in all of our facilities in Connecticut, it has been demonstrated that the deficiencies are being reduced. The benefits, the facilities—I could enumerate them. Let me just say that we have more staff and the programs they generate for our clientele.

We received 189 positions at the Mansfield Training School alone since 1975 and that includes direct care staff and professional staff. Active treatment has increased. We have not reached our full active treatment at Mansfield. We have requested additional positions for program centers, supervision and program development.

Despite what Cathy said, I think there is a dilemma in the decertification-certification process. If a State will respond to the threat of decertification and add the staff, the services and the community living arrangements necessary to implement the postinstitutional plans, fine.

If they will not, for whatever fiscal events that are occurring and a facility is decertified then there will be a loss of services to the clients and nothing is gained by decertification, except the State's reimbursement is affected. I think the regulations need to be inspected. I think they need to be reviewed. There is a great deal of effort that went into their writing and perhaps it is time to adjust the elements for optimum benefit for reasonable manageability

As I said earlier, the superintendents would testify about deregulating the ICF/MR program. Had they heard your comments the last couple of days about the probable cutbacks, I think they would accept the regulations and accept the money and services that it will purchase for their clientele.

Senator WEICKER. Who—and anybody can speak up on this point; I see Tom Nerney in back—CARC is what, the plaintiff in this suit; is that correct?

Mr. MCNAMARA. That is correct.

Senator WEICKER. And the defendant is what, the State of Connecticut?

Mr. MCNAMARA. No, the judge ruled that it had to be named defendants, Commissioner Thorne and myself as well as commissioners of other departments.

Senator WEICKER. But basically the State of Connecticut is representing you, is that correct?

Mr. MCNAMARA. That is true.

Senator WEICKER. Obviously the main purpose of these hearings was to get a very thorough overview of the situation here in the State of Connecticut, which is not atypical of that that exists across the country, and in that sense I think the hearings, at least to this particular Senator, have been extremely educational.

We do have a great deal of work to do on the committee in the months ahead both in the reauthorization hearings and also when it comes time to determine what the priorities of funding are going to be. Also, the conditions of funding as that develops.

In a narrower sense, and more specifically, as it deals with the situation in Connecticut, I would like to suggest the following, and this is not in any way a command but a suggestion.

I would like to digest what has been said here today, talk with my staff on it and I would hope that sometime within the next month CARC and the State of Connecticut would avail themselves of my offices in the sense of seeing whether or not anything can be accomplished by the route of talking.

I don't mean to substitute myself as a lawyer here but I honestly, after I get all through, I will bet you that I wouldn't disagree with 10 percent of what everybody has said, and under those circumstances I think the matter is far better resolved as between ourselves than the court of law. That is my opinion.

And there are some real problems that have arisen de facto by virtue of what is going on in the Congress of the United States right now. So I offer that for what it is worth. I am not in a position to tell CARC or the State of Connecticut what to do.

If there is any way I can be helpful, I will be more than glad to act in that capacity. I think we all understand the problem of the parents, of many of the children and adults of both Southbury and Mansfield. I don't think it takes any super intelligence to see what the difficulties are. I think they relate probably in the main to systems in the past that are no longer adequate, and yet there is still a human problem regardless of what science dictates, or leads us to.

I don't think that it really takes any particular genius—I am talking now from the layman's point of view, which is certainly what this Senator is—to see the direction in which care is going and should go. I won't dispute that. And I think I have accurately described to all of you what the situation is when it comes to the attitudes in Washington and, more particularly, the attitudes of Congress at this time.

I might add also that I think many times it does take action by the citizenry to get government to get off its backside and do the right thing, so I am not in any way surprised or dismayed by the fact that a lawsuit has been instituted.

Having said all that, I think I come away from these hearings certainly better equipped to handle my duties in the years ahead as chairman of the committee, and also the hopes that with that knowledge in hand maybe with the belief on all of your parts that there can be a fair resolution of difficulties and that we get on to that particular task.

The larger task that confronts all of us is to make certain that this Nation—never mind the State of Connecticut—this Nation must still demonstrate the conscience that has brought us to the point where probably among all nations we lead in the care of those that need our special attention.

This country, unfortunately, has become rather narrow in its vision and of a rather mean and questioning spirit so far as it regards itself and its citizens. In that fight, believe me, all hands are needed, so I would hope in both those regards, the general picture, that I could count on the support of those that are present and, the more specific situation, that thoughts other than those that dominate the scene at the present time might be given consideration by the various parties.

With those comments the hearing is adjourned and the record will remain open for any further statements that those interested care to make. Thank you very much.

[Whereupon, at 3:57 p.m. the subcommittee adjourned.]

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