

# The Weicker hearings

Some of the nation's leading officials and authorities on mental-retardation programs, invited by CARC, testified at hearings held in April at the State Capitol by

the U.S. Senate Subcommittee on the Handicapped, chaired by Sen. Lowell Weicker, Jr. (R-Conn.)

## Labeling a child 'severe' creates obstacle to developmental growth

*The following testimony was given at the Weicker hearing by Karen Green, R.N., a consultant to 22 states and the Canadian government on programs for persons with retardation and other handicapping conditions.*

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.

Bricker and Campbell said that "The very factors which cause an individual to be labeled as severely/profoundly handicapped also can prevent that individual from receiving programming 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."

### The story of Mark

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 of 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...

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



Karen Green, R.N.

do any good. Mark was not supposed to survive his first year of life.

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.

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 persons' neurological system at such an early age, the growth sequence can be devastating.

Mark was referred by the Welfare Dept. 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 specialists 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 three 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, 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 — an 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 drinking to initiate an independent sucking pattern, and allow Mark to graduate to 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 non-delayed 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.

### The story of Ruth

A friend of mine who now lives in an apartment in a large Eastern city is characteristic of another type of individual that many maintain the institutional system must always be maintained for.

Ruth spent her first 26 years of 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 palsy with multiple flexion contractures of all joints, bilateral hip dislocations, and 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 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 five or six years.

She didn't arrive with the deformities I've just described. Her joints and muscles looked the same as

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# How service systems encourage development

*Continued from preceding page*

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 '50s, 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 one or two staff to care for them. There was no choice but to provide three basic meals per day in the quickest way possible, and little else.

Ruth was left to lie on her back 24 hours a day. By the time she was seven or eight, 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.

## A transformation

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 a setting as normal for their age as possible, 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, "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, but 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 and the modification of transportation to allow handicapped persons access to the larger world.



LISTENING are Sen. Weicker, right, and his staff aide, John Doyle.

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 meet 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:

1. The agency uses the assessed needs of clients to design services.
2. The agency has a sufficient array of services to meet those assessed needs.
3. Services come from generic agencies whenever possible. Clients and their families should have guaranteed access.
4. There is a coordinating system which insures that needed services are delivered and maintained.
5. There is a strong quality control mechanism which evaluates services and identifies problems.
6. 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 plan-

ning, or asking what does the individual need to grow and develop, should be the vehicle around which all services are built.

The common denominator 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 developmental 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.

## Creativity in home

Provide concrete services across developmental continuum. We expect normal children to grow, and they do. At five they go to school, at six their teeth fall out, and at 10 they go to camp for a week and survive without us when we wish they couldn't. There 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 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 there, and then provide the mechanisms to make that possible.



Linda Glenn, mental-retardation commissioner in Massachusetts.



Prof. Lou Brown



Sister Barbara Eirich



Linda Berry, resident of a group home in Hartford.

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# R.I. makes strong commitment to community

*The following testimony was offered by Robert Carl, state director of mental retardation in Rhode Island.*

The past 15 years of my professional career have been spent in programs serving retarded and other developmentally disabled citizens and their families, mostly in state service capacities.

My experience includes more than nine years with state institutions for retarded persons in three states, serving as an assistant superintendent and program director in Massachusetts; managing officer and superintendent of an Ohio institution; deputy commissioner in Ohio; and supervisor of four state institutions.

I have 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.

There is no real legitimacy to the institution vs. community debate. How, under what auspices, and what time frame are issues to be discussed.

I would like to briefly discuss some similarities and differences between Connecticut and Rhode Island. Let me 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 following over a year of front-page newspaper exposes in an institution, a recent firing of the superintendent, and newly assigned duties to several members of the retardation bureaucracy. The parents' groups were split—some promoting law suits to force the development of new community services and close the institutions, some opposing community directions.

Parents, professionals, and staff, public officials and the citizenry at large were confused or demoralized. Some wanted to spend millions to upgrade our state institutions; others threatened to sue if the state took one step in that direction.

So what did we do? First, we scrapped the multi-million dollar institutional renovation and developed a short-term fix up of over 200 beds to be used only until we could move the clients into small, high-quality residential settings.

Next, we obtained legislative support and funding for the development of day-activity sites for over 400 of the institutionalized persons. This insured quality services, an adequate preparation for community

living, and continuation of our Medicaid funding, and established an anchor point in the community.

At the same time we committed ourselves to small (usually four person) living arrangements, and rejected placements 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 service settings.

By a vote of over 60% 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 two years.

So what have we accomplished?

1. 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 placement before July 1981. Only three persons have been returned to the institution, although we are placing severely and profoundly retarded persons.
2. We have placed almost 75 persons who were at risk of being institutionalized into community-living arrangements, thus avoiding unnecessary institutionalization and its accompanying heart-break for the parents who struggled so long to take care of their children.
3. Over 400 persons of the remaining 500 at our institution leave every weekday for community-based day programs. Transportation, not inactivity, has become our major nightmare. Over 200 persons from the institution attend local churches in several communities each Sunday.
4. We have 600 ICF/MR-certified beds at our state institution, so all of our clients receive services which meet state and federal requirements even during this transition period.
5. Our total number of group homes, or what we call family-style homes, has increased from eight in

1979 to over 40 operational now, with another 15 scheduled to be open before July 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.

6. Over 75 persons have moved into apartments, some semi-supervised, some ICF/MR-certified, with another 60 ICF/MR apartment units scheduled before July 1981. Thirty of these new apartment residents are long-term institutionalized, elderly retarded persons. They have averaged over 30 years in the institution.
7. Day programs have expanded from about 800 persons statewide in work activity centers and very little activity 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.
8. 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.
9. A five-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.

No, I'm not talking theory or dreams. I'm talking about what can happen when persons such as Gov. Garrahy of Rhode Island and other elected officials support a commitment of dignity and quality of life, as has been done in my state. Our experience shows that much is possible with good planning and harder work.

There is nothing that goes on in an institution that cannot be replicated, often improved upon, in an appropriate community setting. Often, this will mean a lower per-person cost; with some careful planning and monitoring, we can guarantee better per-person quality of services.

No, there is no need to debate the relative merits of community services vs. institutions. The time is now. The technology and know-how are available now. All that is lacking where it is not happening is the imagination and the will.

## R.I. community care is not just a theory

*The following testimony was presented before the Weicker subcommittee by George Gunther, chief administrative officer of the Dr. Joseph H. Ladd Center in Rhode Island.*

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 the facility.

I have been at the Ladd Center for 11 years and during that time improvements have been accomplished. In 1970 the budget for over 1,000 clients was 5½ million. Today, the budget is over \$20 million for 596 persons.

Only \$16 million, however, is spent at the institution. Four million dollars is spent in community-based programs to which 400 Ladd Center clients are transported every day — Monday to Friday.

Thirty older retarded citizens who were institutionalized over 30 years each live in community-

based Sec. 8 apartment programs staffed by Ladd Center employees, and 100 will be served by September.

The development of a network of group homes and apartments now gives parents a choice beyond either staying at home or going into the institution's 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 of 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 there are 750 persons in institutions and 250 in the community. The decentralization of clients in this manner has been supported by the Governor of Rhode Island, the General Assembly, the unions (of 1,055 employees), and the parents.

It is important for this committee to consider the facts that right now — today — 400 of 600 severely and profoundly retarded clients leave Ladd Center every day and travel to 12 different locations throughout the state and return for dinner and to sleep. Those 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 in the institution or necessarily at home.

The future for the mentally retarded person who is now at home but may need to leave that home someday — for whatever reason — will not be a life in an institution but a home in his own neighborhood.

The approach I have described is not a theory. This transfer has been done, is being done and will continue to be done.

## Mother, 77, praises R.I. changes

The 77-year-old mother of a resident at Rhode Island's Ladd Center strongly supported community residential care in testimony before the Weicker subcommittee.

Eileen LeVasseur said she has been going to the Ladd Center to see her daughter, now 41, every week since 1954 and has seen "many changes, all for the good."

## Policy lack cited

U.S. Rep. Stewart B. McKinney (R-4) told the Weicker hearing that the lack of coherent national policy on care for retarded persons "is causing hardship, injury, and in some extreme cases, even death."

He said that "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."

Ladd's population, she noted, has decreased from 1,200 residents in 1954 to about 580. "Many have gone to group homes and apartments, and a few went home to their parents, and some made lives of their own and are doing very well," Mrs. LaVasseur said.

"Our opinion and experience with group homes is now altogether very different from 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."

Mrs. LaVasseur concluded: "I sincerely hope some day soon they may be able to find a group home for my daughter."



PARENT of a Ladd Training School resident, Mrs. Eileen LeVasseur, with George Gunther, school administrator.



# The potential of severely disabled adults

G. Thomas Bellamy, Ph.D.  
University of Oregon

I appreciate the opportunity to offer testimony today. Although I understand the impetus for this hearing comes from Connecticut, the issues to be addressed are generic ones that represent critical policy and program decisions. Consequently, I want to thank you, Mr. Chairman, and the subcommittee for providing a forum in which the issues can be discussed on the record.

The focus of my testimony is on the potential of severely handicapped adults to participate in the life and work of their communities. I will concentrate on adults because it is at that age, after entitlements to children's services run out, that evaluation of final service success must be made. The implied promise of school and other services is that, upon reaching adulthood, an individual will be prepared to partake in the responsibilities and benefits of community life. I will concentrate on *severely handicapped* adults because extreme service needs presented by this group bring into focus several basic issues relating to community services and government support.

## *Severely Handicapped People*

Definitions of severe handicaps differ widely, and rightly so. Disabilities handicap people differently in different aspects of life. An individual's condition may result in severe handicaps in school that do not affect work, in work that do not affect independent living, and so on. Labeling the condition tells only the beginning, especially for adults, who face multiple life demands. I will refer to people as severely handicapped who are typically labeled severely and profoundly mentally retarded, autistic, and multiply handicapped. Historically, these individuals have been most likely to be placed in institutions, denied access to school as children and to vocational rehabilitation as adults, and seen by families and service providers as creating extreme hardships.

## *Quality of Life*

The basic human issue raised by a discussion of alternative service strategies is what sort of life is appropriate or desirable for severely handicapped citizens. While each of us would no doubt emphasize slightly different things in defining quality of life, history suggests that the constitutional guarantees of life, liberty, and pursuit of happiness are so important that our society will enter major conflicts to preserve them. Like everyone else, severely handicapped people enjoy quality living only as these basic values are operationalized in the opportunities of daily living.

No single view of quality in adult living is likely to capture the richness and diversity of modern aspirations. Nevertheless, a growing worldwide consensus provides a useful framework for operationalizing fundamental aspects of quality living for individuals with severe handicaps. Deriving in large part from the concept of normalization, these include provision for basic health and safety, development of personal skills and independence, integration and participation in community life, and productive work.

## *Effects of Community Alternatives*

After more than a decade in which deinstitutionalization has been a professed national priority, where do we stand in efforts to provide opportunities for quality living to severely handicapped individuals? The decade saw repeated situations where community service providers were confronted with unfamiliar service problems and developed technologies to solve those problems, creating opportunities not previously thought possible for severely handicapped people. The cumulative result has been widespread demonstration of the potential competence, productivity, and community participation of people with severe handicaps. In the comments to follow, I will illustrate the depth of this contribution to quality of life. But first a reminder: The generation of severely handicapped individuals of whom I am speaking have not benefitted from the education available to handicapped children today. Thus, their success in community services may be only a fraction of that for which we should now be planning.

## *Community Living*

Residence in small community residences has been associated with several improvements in the lives of severely handicapped people. In the area of health and physical well-being, an expectation of any service system, an important report was recently completed in the state of Washington. All retarded residents released from state institutions in 1979 were studied after a year in the community. During this period, the health status of more than a third of these individuals had changed significantly, with improvements recorded in needed weight changes, chronic medical conditions, correction of previous misdiagnosis, and use of needed prosthetic devices. The records of individuals leaving the Pennhurst institution near Philadelphia is consistent with these

findings.

The record on development of personal independence is similar. For most severely handicapped individuals, the exercise of personal autonomy requires both programming for skill development and regular opportunities to use skills that have been mastered. Although a technology for teaching needed skills has been available for some time, several recent studies have observed more rapid development of skills needed for personal autonomy in small community residences. For example, a carefully designed effort is now underway to compare the progress of individuals leaving the Pennhurst institution with matched behavioral "twins" who have remained in the institution. Measures of both groups were taken over a two year period with a widely recognized behavior rating scale. Those in the community showed highly significant gains in personal self-sufficiency, community self sufficiency, and personal-social responsibility; those remaining in the institution showed no significant gains in any area. Successful skill development is so widespread in well-managed community programs that it is now commonplace to expect previously dependent severely handicapped individuals to contribute to and participate in daily activities in both home and community settings.

Improvements in personal skills contribute meaningfully to quality of life only when the environment affords opportunities to use them according to individual interests and goals. It is in this area that the dramatic potential of community-based services becomes clear. Development of skills in small programs can and does allow individuals to travel independently in the community, select and purchase personal items, work outside the home, attend church independently, jog with non-handicapped individuals, enjoy work breaks in downtown coffee shops, and so on. The proximity to community opportunities and the potential flexibility of community services allow severely handicapped people to enjoy the benefits of their skills. Rather than endure treatment as eternal children expected continuously to learn new skills, severely handicapped individuals in community settings have the opportunity to use the skills they have to enhance the quality and enjoyment of their lives.

Family contact represents another aspect of quality of life that is widely valued in our society. Here the data provide overwhelming and unmistakable support of small community programs. In the study of the Pennsylvania institution I mentioned earlier, the number of parents participating in individual program planning meetings - the basis of all individualized programming - increased from 11 percent in the institution to 75 percent after the same individuals were placed in the community. Visits with families tripled after leaving the institution, and the number having monthly outings with relatives increased by a factor of nine.

## *Work Potential and Opportunity*

The importance of employment in a quality adult lifestyle in our society is chronicled in the expectations of practically every minority group whose civil rights have been at issue. Now, with clearly demonstrated ability to learn needed skills, severely handicapped individuals have joined others whose participation in our society is determined in part by the status afforded by work and in part by the opportunities provided by wages.

To illustrate progress in the area of work, let me describe some of my own research. Eight years ago I began a small vocational program for severely and profoundly retarded individuals who had been excluded because of skill deficits and behavior difficulties from all day programming. This program grew gradually to serve fifteen individuals who today are representative of the least capable individuals served in day activity programs in institutional and community settings in the Northwest. At the outset a market for electronic work was identified and a structured program was designed to provide extended employment in small parts assembly. During the ensuing eight years, the fifteen individuals have learned such complex assembly tasks as oscilloscope cam-switch actuators, cable harnesses, chain saw components, circuit boards, computer printer frames, transformer coils, and power supply units. Their combined wages last year were \$18,371, more than four times the national average for their more capable counterparts in work activities centers. Not only can severely handicapped individuals learn the skills for remunerative work, but also can they earn significant wages when structured employment opportunity is provided. That program has now been duplicated in ten communities in six western states with similarly positive results. Parallel efforts in vocational preparation nationwide leave little doubt that severely handicapped individuals can become competent, productive workers.

## *Issues*

These community living and work successes, and the many additional studies they illustrate, make it clear that severely handicapped individuals have the potential for skill development, community integration, and productive employment. Not all efforts to provide for deinstitutionalized living have had such success, however. In fact, many severely handicapped adults now in community settings are so sheltered that they enjoy neither independence, nor integration, nor employment opportunities.

The experience of the last decade indicates, however, that these difficulties cannot be attributed simply to the presence of severe handicaps. Too many similar people have succeeded when needed services and opportunities were available. Instead of blaming the severely handicapped individual for lack of potential or readiness, we must look for barriers to success in the service delivery system itself. The process of designing comprehensive community services has proved complex, as has the task of adapting policies and programs to new service technologies. Experience with both the successes and failures of community services for severely handicapped individuals brings one important service design issue into focus. I believe it must be addressed if quality adult living is to be made more accessible to those with severe handicaps.

The issue is a broad emphasis on "readiness" that pervades many policies and programs affecting handicapped individuals. In essence, the readiness logic is that programs and services are needed to prepare an individual for later participation in work, community living, recreation, or other opportunities. Preparation continues until an individual is deemed "ready" for the next step, i.e. until the individual is expected to participate *without further support*. The result for severely handicapped individuals is all too often a sentence to indefinite preparation; in institutions, for example, getting ready for community living; in day activity programs, getting ready for work activities centers; and in sheltered workshops, getting ready for open employment.

Let me use the area of work to further illustrate the effects of this readiness strategy on severely handicapped people. The nation's vocational rehabilitation program is designed to provide services that equip a consumer so well that he or she can enter the labor market needing no further support from social services. To accomplish this, the program has developed an impressive array of evaluation, counseling, training, job development, and other services that have resulted in successful employment for many handicapped individuals, including some with the severe handicaps addressed here.

Despite the vocational competence demonstrated by severely handicapped people in structured employment situations, however, there is little evidence to expect many of these individuals to succeed in unsupported open employment. Neither incentives nor programs now exist for employers and social services to meet the additional needs for capitalization, training, supervision and support that severely handicapped individuals appear to require in open employment with current treatment technologies.

With limited prognosis for totally unsupported employment, severely handicapped adults frequently are denied all access to work opportunities. Instead of receiving the needed support to work in either sheltered or open employment, severely handicapped individuals typically are assigned indefinitely to prevocational or non-vocational programs where a regimen of recreation, training in daily living, and other activities is expected ultimately to develop readiness for work. The result is that severely handicapped people who with adequate support could be vocationally competent are excluded from work opportunities. The attached papers describe the national scope of this problem and suggest a framework for designing an alternative.

## *Conclusion*

The technology is now available to assist previously segregated severely handicapped individuals to participate in the life and work of a community. That participation will require ongoing support for many individuals, but it will also enable them to achieve a quality of life and a measure of contribution to society that has been thought impossible. The experience of the last decade shows that most of the limits previously blamed on severely handicapped individuals must be attributed instead to the availability and quality of support services. With a commitment to continued improvement in policies and programs to match the emerging technology of service, quality community living can be offered now to all of America's handicapped citizens.

## The Weicker hearings

# Pennsylvania stresses community services

*The following remarks were prepared by Dr. Jennifer House, deputy secretary for the Office of Mental Retardation in the Pennsylvania Dept. of Public Welfare.*

The Pennsylvania Community Mental Retardation System was initiated with the passage of the Mental Health and Mental Retardation Act of 1966.

Through the passage of this act, Pennsylvania, a State with approximately 12 million people and large urban and rural areas, developed a strong commitment to the provision of community services to mentally retarded people based on the normalization principle and the developmental model. Guiding principles in the formation of our system included services to prevent out-of-natural-home residential placement and deinstitutionalization with an emphasis toward placement in the least restrictive environment.

The most significant program components in Pennsylvania's community MR system include the Community Living Arrangements program and the Family Resource Services program; most recently, the Office of Mental Retardation has begun the active use of Title 19 XIX funding for community services.

The Community Living Arrangements program was developed in 1972 to provide a continuum of professionally staffed community residential services as alternatives to institutionalization.

These services emphasize the development of small home-like integrated living arrangements that are both flexible and structured to meet the varied needs of individuals requiring community living support. Over 95% of the settings house three or fewer clients. The Community Living Arrangements program has served almost 8,000 people since its inception in 1972, and its budget has grown from \$1.9 million in 1972 to over \$52 million today.

Pennsylvania previously maintained 13,000 people in state centers for the mentally retarded. That number has been sharply reduced over the past nine years. Today, approximately 7,000 people reside in

state centers, and over 3,000 previously institutionalized children and adults have returned to their natural homes with all necessary support services.

Pennsylvania provides the following type of services available to mentally retarded persons and their families through the Family Resource Services program: Respite care; family aides; homemaker services; recreation; transportation; in-home therapy; and family education training.

The thrust of Family Resource Services has been to provide the support services necessary to aid the family in maintaining a retarded child or adult at home, and thus prevent institutionalization from ever taking place.

In addition, Family Resource Services offers several support services necessary to assist the deinstitutionalized mentally retarded person in making the adjustment from an institutional to a community lifestyle.

Thus, within the mental retardation component of the county MH/MR Plan, the FRS Program serves both as an alternative and as a complement to the commonwealth's Community Residential Services Program.

Currently, over 18,000 mentally retarded people and their families are benefitting from Family Resource Service programs. Pennsylvania's current budget for Family Resource Services and other support programs is currently over \$33 million.

The Governor's proposed budget for mental retardation services for Fiscal Year 1981/82 is a further reflection of Pennsylvania's commitment to community services; for the first time, more state dollars are recommended for community programs than for state centers.

An important ingredient in next year's budget includes approximately \$10 million for new community residential programs, with special emphasis on ICF/MR development in settings of four to eight persons, and for further expansion of the Family Resource Services program.

Pennsylvania has developed the structure for a



**TESTIFYING** is Rachel Rossow of Alpha and Omega, Ellington.

quality community services system, and currently serves clients in community programs with the same characteristics as any clients in state centers. This includes people with medical problems, the non-ambulatory and those with severe behavioral problems.

Pennsylvania's program clearly demonstrates that all mentally retarded people can benefit from community programs, and the legislative support received, particularly since 1972, has enabled the Office of Mental Retardation to maintain a commitment to community services.

## Kentucky program based on 8 guidelines

*Following are excerpts from testimony before the Weicker subcommittee by Charles Fulmer, deputy director of the Div. for Community Services, part of the Kentucky Dept. for Human Resources' Bureau for Health Services. He also spoke for Ed Skarnulis, division director.*

Eight years ago, I began working at Oakwood, an institution for mentally retarded persons that had just been opened by the Kentucky Dept. for Human Resources. The facility was featured on national television in 1973 as a new hope for mentally retarded persons. It... 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, seven 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. To this day, a large number of Oakwood's residents are waiting for the creation of placement opportunities in their home communities.

In 1974 I left Oakwood to go to graduate school at the University of Michigan. As I was completing my degree requirements in 1976, I went to work for the Michigan Dept. of Mental Health, joining a task force that had been assigned to develop 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, or cerebral palsy, or who would be particularly deficient in self-care 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 four and one-half years, each of those placement programs provided approximately one-third of the placements that reduced Michigan's institutional population from 6,600 in 1976 to 4,300 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% 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 Gov. 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 Oakwood institution in rural Dawson Springs.

Dr. Stumbo's investigation indicates 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 community-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 Gov. 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.

We are developing our community program based on eight guidelines, which we think are crucial for assuring both permanence and quality of service. They are:

1. All family and individual support services should have been made available before a resident is sought.

2. All residents should be as small as possible.

3. Individualization. A specific reason(s) for requesting residential service should be identified and solutions to that problem(s) must be actively and creatively sought.

4. A date for re-evaluating the residential program should be arrived at before admission.

5. 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.

6. Partial residential services should be available. Rarely is 24-hour, seven-day-a-week residential service needed. Usually one day per week, a few hours per day, or a specified block of time is all that's needed.

7. Family involvement should be accommodated/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.

8. Residential systems personnel should be evaluated and rewarded according to their ability to assist individuals to acquire new schools and become more integrated with the community at large.

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Should Medicaid funding go the block grant route, the federal regulations governing participation in

*Continued on next page*

## The Weicker hearings

# Regulations biased toward institutions

*Continued from preceding page*

the ICF/MR (Intermediate Care Facilities for the Mentally Retarded) program should 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 of 15 beds or less and only a few attempt to do so for settings of six beds or less.

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 programs vs. 23 for community-based programs gives evidence that the Federal Govt. 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 clients into the economy and community at large.

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 Gridley Howe, a 19th century reformer and early champion of institutions. Speaking in 1866 at the laying of the corner-

stone of the Batavia, N.Y., 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 should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society.

# The once rejected may hold keys to improving our civilization

*Following is the text of an opening statement made by CARC president Robert Perske at the Hartford hearings of the U.S. Senate Subcommittee on the Handicapped, headed by Sen. Lowell Weicker (R-Conn.).*

You asked us:

- to outline opportunities for persons with retardation in the community;
- to show how these opportunities can be enhanced, and
- to help you build a record for future activity.

Professionally, I am a writer-on-assignments with three basic interests:

1. Inspiring healthy attitudes toward persons with handicaps.
  2. Writing about remarkable relationships between them and non-handicapped persons.
  3. Describing outstanding community-based services for people with handicaps.
- Therefore, I submit for the record the following books authored or edited by me:

"The 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 neighborhood better;" "Improving the Quality of Life," an international symposium on normalization and integration; "The Child with Retardation Today — The Adult of Tomorrow," and "Listen Please," a report on outstanding face-to-face and self-help programs from across Canada.

## The retarded valued, accepted

For hundreds of years, persons with retardation were belittled and isolated because of horrendous myths, pseudo-scientific diagnoses, and the adamant refusal to support them in community settings.

Today, we know better. Rapidly changing attitudes and massive amounts of technical breakthroughs now make it possible for persons with retardation to be valued, to be accepted, and to grow up in the neighborhoods of our nation. It can now happen as never before in the history of humankind.

Today, we recognize that persons with retardation have developmental disabilities. Today, we are aware that each of us came into this world as a small bundle, containing thousands of developmental forces. Each tiny component, like a single musician in a gigantic symphony orchestra, was designed to do its part at the right time. Together, these forces triggered the enlarging, strengthening, and deepening that enabled you and me to change from tiny babies into mature adults within approximately 22 years.

Most of us moved through this masterpiece of growth with the ease of a soaring eagle, but for approximately 14% of our population, some sort of "monkey wrench" was thrown into their developing systems, creating barriers to development which they must overcome or live with for as long as they live.

Therefore, they must work like birds with short wings in order to achieve the same tasks we accomplish like a bird with longer ones. Growth for them is like sucking a thick milkshake through a very thin straw — they must work for what they get.

Nevertheless, they are developmental, and they long to achieve like the rest of us. Therefore, it behooves us individually (as good neighbors) and collectively (as a government) to help them overcome or live with barriers to their development in every way that we can.

Here are some concrete suggestions for helping them with their barriers:

**Support the family, Don't supplant it.** Provide in-home training support. Provide in-home and in-the-community respite care. Provide specific financial aid, helping families to overcome specific debts caused by family members with retardation.

**Know that we have reached a turning-point with families.** In 1977, during the production of the Report to the President, it dawned on the President's Committee on Mental Retardation that up to this time, families received more incentives, economically and socially, for sending their child with retardation away. As a professional since 1950, I can recall how we were utterly "brilliant" at breaking up moms and dads from their children with retardation. Now, however, we are on the verge of providing more incentives for helping families keep such children in the home as long as they possibly can or until they come of age.

View other residences as a last resort. Only after it is clear that something other than the natural childhood or adult home is needed, should other residential alternatives be considered.

**Develop residential alternatives in a person's own community.** Moving people miles away from their home towns can be devastating. Such displacement-from-the-familiar can lead to regression instead of development.

**Let residential alternatives be family-scale.** Growth and development is maximized in small, intimate, close-knit settings — not in regiments. Therefore, I believe that no one with retardation should move from where they are — no matter whether they now live in institutions or family homes — until they move into family-scale residences containing six persons or fewer. (Some states now advocate a limit of three or fewer.)

**Craft residences according to crucial needs.** For years we "shoe-horned" people into already existing residences, paying little attention to a person's specific needs. Now, forward-thinking workers look closely at specific developmental barriers in a person's life, and then they create residences tailor-made for helping him or her to deal with those barriers.

**Let formal education take place in regular public schools.** Massive evidence is emerging from across the nation, showing that persons with retardation — even those with severe and profound handicaps — develop better in regular public schools when proper attitudes, support, and in-service training for teachers are available.

**Let them become adults.** At the International Year of the Child Symposium on persons with retardation, key persons from all over the world refused to focus on "The Child With Retardation" only. Instead, they talked about "The Adult of Tomorrow" — about their fullest possible adulthood, about their place in industry, about their sexuality, and about their being enabled to be advocates for themselves. It was a British journalist, Ann Shearer, who 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 enabled to reach it."

**Those with severe and profound handicaps belong in community settings, too.** Ten years ago, such a notion was unthinkable. In this hearing, my colleagues who follow (Dr. Lou Brown, Dr. Tom Bellamy, Karen Green, Dr. Bob Carl, Linda Glenn, Kathy Schwaninger, Charles Fulner, Sister Barbara Eirich, and many others) will present evidence to support this view.

These suggestions set the stage for the speakers who follow.

But before they begin speaking, I call one more point to your attention. Twice in this century, some people attempted to improve civilization by pushing persons with retardation out of the communities. In the early 1900's, in the United States, "eugenic societies" called for the identifying of every "feeble-minded" person they could find and for segregating them in out-of-the-way institutions. During that period, we filled institutions to overflowing. Then, in the late 1930s, the German Nazi party attempted to make a super-race by killing persons with retardation.

Today, we have mounting evidence, showing that the early genocide machinery that was used on Jewish communities, was first perfected in institutions for those with mental retardation.

We are smarter now. We see persons with handicaps as having weaknesses and strengths like all of us have weaknesses and strengths. We have learned that everybody has value and that everyone figures in everyone else's survival. Therefore, those persons we once rejected, may be the very ones who hold strategic keys for improving our civilization. I believe they do. And I am willing to do anything I can to help you see why I believe that way.

## R.I. razes old institution buildings

Rhode Island is razing old buildings at Ladd Center in Exeter, the state's institution for the mentally retarded.

The State Properties Committee has approved demolition of the first of five old buildings at the center and the transfer of six other buildings to the adjoining Veterans Cemetery.

Demolition of the Mann Building

was approved after the state's Historical Preservation Commission informed the Properties Committee that preservation of the 66-year-old dormitory was not warranted.

Four more old school buildings are being razed to reduce maintenance and heating costs under a program to move most residents to group homes.



## The Weicker hearings

# 'Let's go back to where we somehow got off the road — and set out once more'

*Following is the text of a statement made in behalf of CARC at the hearings of the Senate Subcommittee on the Handicapped by Jeanne Sandahl. Mrs. Sandahl is a former CARC secretary and former president of the Parents and Friends of Bridgeport.*

I'm 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'd like to tell you about a few of the families I've been talking with recently. Take the Sam Teitlemans of New Haven, who have a profoundly retarded teenager. Ruth is virtually a prisoner in their home and has been for many years, because she has almost sole responsibility for Philip's care. The only relief she gets is one weekend a month of respite care at the Regional Center. (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. It meets only a fraction of the statewide need. And a comprehensive program would also provide work-activity or functional education centers for Philip. The Teitlemans are determined that one day their son will live in a group home in New Haven. If they wait for state help, that day may be far off.

## Only \$150,000 allotted for group homes by DMR

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 homes—one and a half cents for every DMR dollar. All the rest is for institutional renovations.

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: Red tape and Byzantine regulations that make the struggle one against enormous odds. Other states don't do this. The Macomb-Oakland region of Michigan, an area about the size of Connecticut, has 1,700 people in group homes—good ones, beautifully supervised—and Michigan is planning 200 more such homes in the near future. Once OUR state was Number One in the field of service to the retarded. Not any more.

Then there are Judy and Barry Bosworth of 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 of institutions could be stretched much farther 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, how can we hope 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?

Let's consider what the residents of our state



**POINTS ARE MADE by Luella Horan, CARC's immediate past president.**

institutions get for the \$43,000 it costs to keep them in the ICF/MR program, for example. I believe there are some wonderful people working in the institutions. But I also have seen over the years how often the very nature of the situation has consumed the brightest and best staff. The turnover rate of 50% of staff in the first year speaks for itself. Frustration and limitation is 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's not the rolling hills, not the Georgian architecture, not the rug on the floor that counts. It's what is going on when you walk unannounced into that place at say 10 a.m. on a Tuesday morning: Usually nothing. Peter has logged years in 40-resident "wings," where clothes were an exception and one staff person might be seated at the door of the room. In such cases there is little or no staff/resident interaction. You could count on the fingers of one hand the months he has 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!

## Much more activity at regional center

I have numerous friends whose sons and daughters have regressed greatly after a few months in the large institutions. One couple I know found that their two sons, both ambulatory, 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's all the staff time available to hand feed them. Several times broken bones have not been explainable. On complaining to the medical staff, the parents were told to take their children home if they were not satisfied. Many children lose speech, others lapse into spaced-out states or fall victim to self-mutilation due to lack of stimulation and boredom. Others are maintained on doses of psychotropic drugs—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.

## Group home okayed in Windsor Locks

The State Dept. of Mental Retardation has granted a permit for a group home for retarded adults on S. Main St., Windsor Locks, and residents have moved in. The permit allows up to six residents.

Florence Quagliaroli, a neighbor, said there have been no problems with the residents, but she is still unhappy about having the building used as a group home. She said she doesn't plan

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 these 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 the 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 Gov. Meskill promised that within two 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.

## Great disproportion in allocating funds

Meanwhile, these are the hard facts: Only 4 or 5% of mentally retarded persons are in Connecticut institutions today, but 70 to 80% of the current budget goes to support those persons. And of the \$66,000,000 in rebuilding and bonding dollars spent by DMR to date, only \$6,000,000 has gone for community facilities—and over half of THAT is really going to perpetuate institutions, as in the building of group homes on the grounds of the Hartford Regional Center because there happens to be land there—a travesty of the community concept.

And finally, even if Project Challenge should ever be fully implemented, which is by no means certain, the net decrease in our institutional population will be only to 2,800 persons (and there will still be all those people in Uncas-on-Thames and in nursing homes.) 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 ICF-ing 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; many other states have passed us and left us in the dust. I'd 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 risk: Some to us, 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 the road—and set out once more.

to protest the group home to town agencies but will do so if there are problems.

Several neighbors registered objections with the Planning and Zoning Commission last year, when the plans for the group home were made known. They were told the town could not stop the home because no special zoning permit was required for its operation.

# Legislation

## State aid for education beyond age 21 is urged on Legislature

Following are excerpts from testimony by Luella Horan, CARC immediate past president and now chairman of CARC's Education Committee, on three bills before the Legislature's Education Committee.

HB 5994

House Bill 5994 would permit the State Dept. of Education to continue to reimburse local boards of education for special-education costs for students beyond the age of 21, provided that:

1. The student is moderately to profoundly mentally retarded;

2. The student was deprived of an education at a younger age, and

3. He can benefit from continued programming for up to two years beyond age 21, as determined by the local board.

It was not until 1978 that all of Connecticut's children were legally entitled to a free, public education. Until the state law was changed in 1977, certain children were specifically excluded from school, including primarily children with moderate to profound mental retardation. Some of the children who started school very late and are now approaching age 21 have had only three or four years of public education.

Because my own daughter could not

meet all the criteria for admission to school under the old law, she did not start school until age eight, and, as with many developmentally delayed students, she did not find her "stride" in learning until her late teens. She is now receiving, at age 20, for the first time appropriate basic living and vocational skills training. Her progress over the past year has been documented as remarkable.

Ideally, in the future, when students with severe disabilities are provided with early intervention programs and appropriate education throughout their school years, such a bill will no longer be necessary. Passage of the bill at this time, however, would provide a valuable vehicle to assure that certain students leaving the public school system would be more fully prepared for the real world. In addition, it would correct an inequity.

HB 5597

HB 5597 concerns special education in-service training programs for all teachers and administrators. Many teachers who are now seeing more handicapped children in public school than ever before have expressed a desire for in-service training to better equip them to identify and assist students with physical or mental

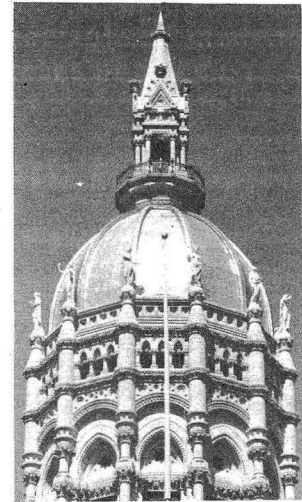
handicaps. Many teachers of "normal" children were trained and certified long before state and federal laws were passed that encourage integration and mainstreaming of handicapped children. These teachers now feel the need of further training.

Another benefit to in-service training is invaluable. When teachers learn more about children with handicapping conditions, they become more comfortable with them and their attitudes become more positive. This, in turn, aids in generating positive attitudes toward handicapped students by the non-handicapped students. From there, it is only a small step to peer-group education that is a powerful teaching tool and superb answer to unenlightened prejudice.

This should be basically a no-money bill, since programs can undoubtedly be put together using available, free community resources such as the Special Education Resource Center, college and university personnel, and non-profit associations of and for handicapped persons.

HB 5785

HB 5785 would increase the state reimbursement to the Oak Hill School for the outstanding educational program it provides for very severely



handicapped children—children with visual impairments who also have additional severe physical handicapping conditions.

In my nearly 20 years in the field of mental retardation, I have rarely been as impressed as I was when I spent time observing the truly remarkable programs at Oak Hill. There are simply no other programs in the state that can match them.

## Home economist backs CARC's clothing bill

*This statement in support of legislation permitting institution residents to wear their own clothing was made by Anita Malone, extension home economist with the University of Connecticut Cooperative Extension Service.*

"Although physical body type contributes to its development," says Marilyn J. Horn, "an individual's self-concept is derived largely from the social situation. Because the self is rarely presented in the social situation without some form of clothing, the boundaries of the body are often extended to incorporate one's clothes into the body-image. At every stage of development, clothing helps to establish the identity of the individual to himself and to others with whom he interacts. Positive attitudes expressed toward one's clothes tend to reinforce a generalized positive feeling toward the self, while negative responses contribute to the deprecation of the self. Clothing contributes to one's self-

esteem, self-respect, self-confidence and security."

Clothing is also operant in restoration of feelings of self-worth. Rather startling examples of this can be observed in the behavior of the mentally ill. During the last few years, doctors and other hospital personnel have taken increased recognition of the fact that personal appearance is one of the clues to mental health. Fashion therapy is the term now used to designate programs geared to helping patients improve their physical appearance.

"During the last decade," wrote Naomi Reich, "attitudes toward the clothing considered to be suitable for the mentally and/or physically handicapped living in the community or institutions have started to change. Correctly chosen clothing can improve appearance and promote greater comfort and easier dressing, which, besides saving the patient from unnecessary physical pain, may often

lead to the saving of many hours of the nurse's time. Although this is directed at institutions, where most of the research work has been done, it also applies to the handicapped person who is living at home."

Dr. Robert Shushan, executive director of the Los Angeles Based Exceptional Children's Foundation uses what he calls "therapeutic cosmetic intervention." He pays attention to making over the appearance of mental patients including not only their dress, but their hairstyling, eyeglasses and makeup. Attending to their appearance has resulted in much greater acceptance of the mentally retarded in positions out in the community.

Other recent studies have dealt with depression and its relationship to appearance and self-concept. An experimental group who had sought psychiatric counseling through a Women's Resource and Services Center were compared with a control

group from Virginia Polytechnic Institute and State University. The intensity of depression and ideal clothing and appearance self-concept was measured. At the conclusion of this study it was shown that a more depressed mood was related to a greater discrepancy between one's ideal and perceived clothing and appearance self-concept.

A professor emeritus from the University of Connecticut, Eleanor B. Hotte, conducted a course referred to as "Everyday Living Skills" at Mansfield Training Center, in which students worked with the retarded to help them learn dressing skills. She states the biggest problem in obtaining community acceptance of retarded persons is their lack of everyday skills. Retarded persons in institutions have no opportunity to learn what is appropriate. Having one's own clothing, appropriate to the person, is essential.

### 50 adults served by TEAM program

The TEAM program at the West Haven Community House provides services to 50 mildly retarded adults and their families in the West Haven area.

A program each Tuesday evening gives members opportunities for socializing, taking trips, and learning independent living skills.

A day program meets twice weekly, serving eight persons who are working on daily living skills such as transportation, health and safety, and nutrition and cooking. Individual and family counseling is provided.

The program staff includes coordinator Darleen Young and program worker Ann Horwitz as well as students and volunteers.

The program goal is to encourage TEAM members to develop their potentials and to live as independently as possible in the community.

For further information: 934-5221.



**FOES OF CUTS.** . . Bridgeport area sends large delegation to State Capitol to support Dept. of Mental Retardation budget in full.