

Rights of the Mentally Handicapped Who Should Decide Where People Live?

by Roger Manus
and Barbara Blake

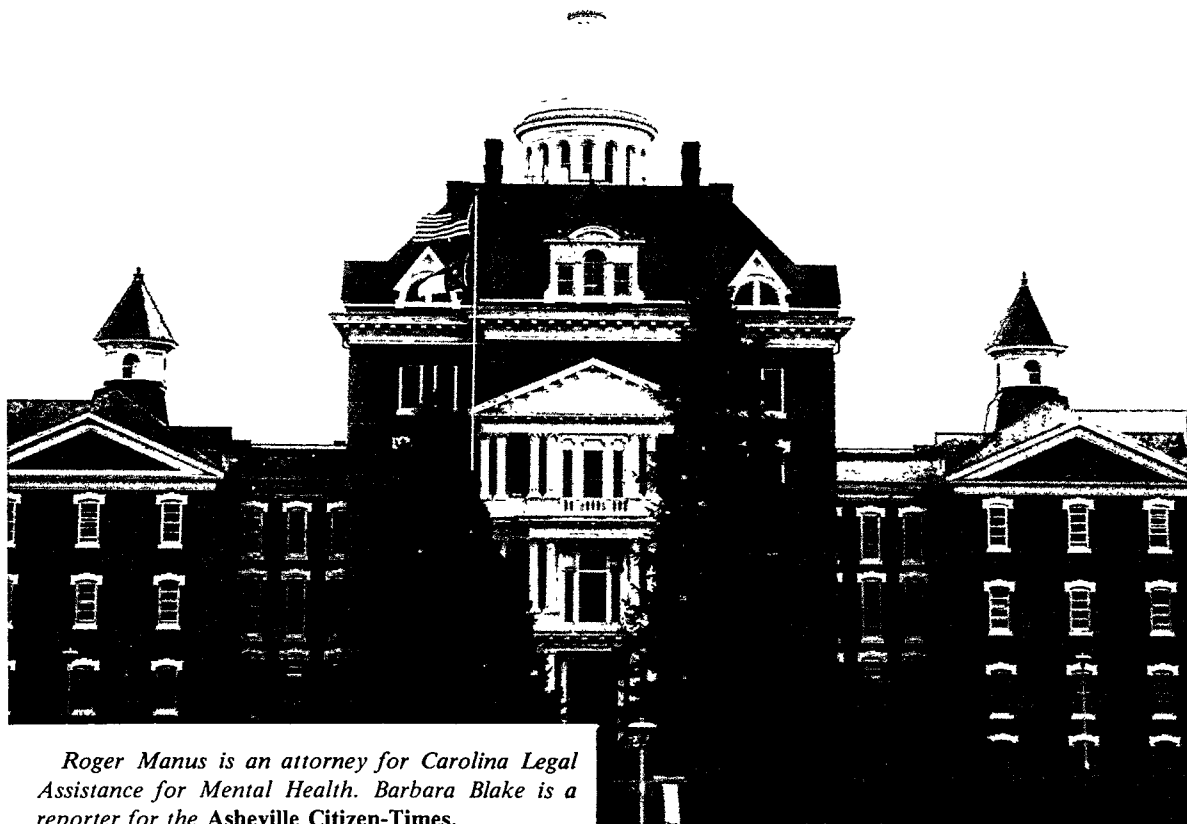
"Each handicapped citizen shall have the same right as any other citizen to live and reside in residential communities, homes, and group homes . . ." North Carolina General Statutes Section 168-9 (1975).

"My mother made all the decisions when I lived at home. Now I make my own decisions, a lot of them, and tough ones. I've got lots of friends in this big house. I feel more important living here." Richard Marcus Cohen, a group home resident in Asheville, N.C.

Broughton Hospital, Morganton

Richard Cohen is 23 years old and has "moderate" mental retardation. For the first 20 years of his life, his mother kept him at home, protecting him from many activities of normal children. He had a job as a dishwasher once, when he was living at home in Miami, Florida, but he got fired.

Almost three years ago, Richard moved to Asheville, where he got a job through Handi-Skills, an Asheville program for physically and mentally handicapped people. And he moved into the "big house" sponsored by the Buncombe County Group Homes for the Developmentally Disabled, Inc. Today, Richard is still working through Handi-Skills, sorting equipment for the Asheville Plastic Company.



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Photo Courtesy of N.C. Department of Human Resources

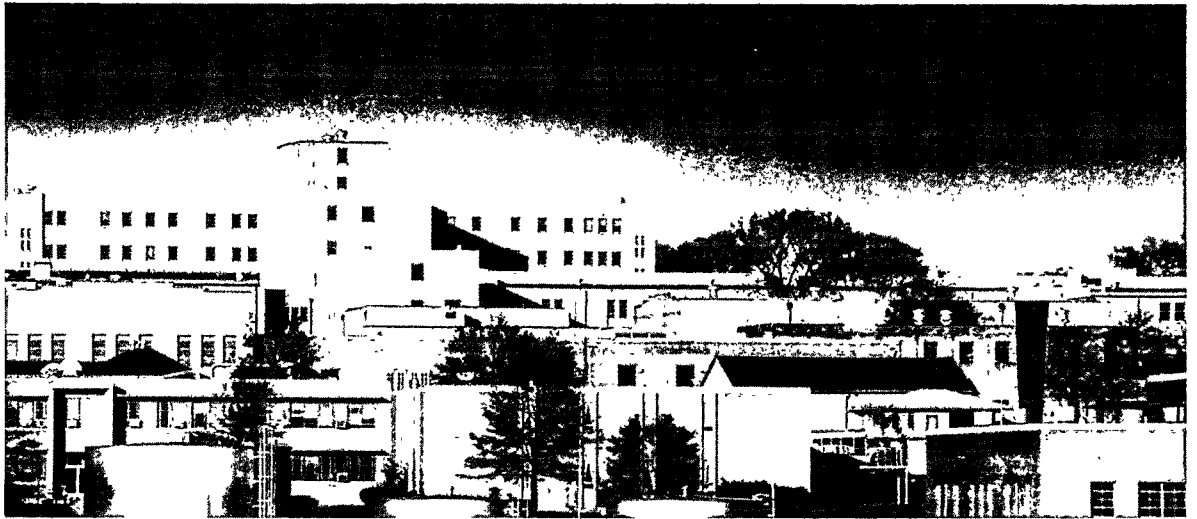


Photo by Paul Cooper

"We have breakfast together," says Cohen. "Then we go to our jobs. When we get home, we have dinner together. On my cooking nights, my specialty is meatloaf."

Across the state in a downtown Raleigh neighborhood, Doris Jones does most of the cooking for the seven women in a home sponsored by Community Group Homes, Inc. A Raleigh native, Doris has worked as a switchboard operator and a file clerk for Seaboard Railroad. Now 67, she has been living in the two-story frame house since leaving Dorothea Dix Hospital eight years ago.

"Most of the women come here from Dix," says Jones. "This is a place for a lot of people who don't really have any place to go. I went to Dix back when I was real depressed, you know. I couldn't talk to anybody without crying. They (the Dix staff) helped me find this place."

The group homes in Asheville and Raleigh are part of a nationwide de-institutionalization movement — an effort to bring some people with mental handicaps out of institutions and to help others avoid institutions in the first place. Most people with mental retardation and mental health problems — like Richard Cohen and Doris Jones — have spent most of their lives outside of institutions, often living with a family member in a sheltered or isolated situation void of many opportunities. And many other people have spent years in institutions because alternative facilities simply have not existed. Today, about 500 mentally disabled people live in group homes and supervised apartments in North Carolina. But over 1,000 more are waiting to move into a community setting.

Since the late 1800s, states have maintained special institutions for a large number of people who seemed to be mentally different.* At first, institutions were intended to shelter the residents from societal abuses. Reformers such as Dorothea Dix devoted their lives to helping provide a place for the "mentally afflicted," the term used in the 19th century. But by the early

Dorothea Dix Hospital, Raleigh

1900s, institutions began expanding for the opposite reason: to protect society, so the rationale went, from the sick, subhuman elements, the menaces to law-abiding citizens. Images of the mentally handicapped as diseased burdens of charity pervaded the society, creating a set of myths that persist today. Many human service providers in hospitals and in the community no longer subscribe to these myths, but little has been done to educate the general public about such false images. People still pity, fear, and resent people like Richard Cohen and Doris Jones, simply because they were once in an institution or have moderate retardation.

Such attitudes have fostered discrimination against handicapped people in employment, education, social services, and housing, all fundamental needs for an independent life. In the last 15 years, federal and state legislation has begun to help handicapped people overcome these barriers to community living. Employers that receive federal funds can not discriminate against the handicapped, for example. And North Carolina school systems must now serve children with special needs. (See box at the end of the article for a summary of existing civil rights legislation for handicapped citizens.)

In 1975, the North Carolina General Assembly voted to allow handicapped citizens the right to live in residential communities. The statute appeared to give group homes the right to exist despite what local zoning ordinances or restrictive covenants in private property estates may say. Since the law passed,

**The confinement of mentally different people actually began much earlier. Connecticut's first house of corrections, for example, was established in 1722 for "rogues, vagabonds, beggars, fortune tellers, diviners, musicians, drunkards, prostitutes, pilferers, brawlers, and the so-called mentally afflicted."*



Photo by Paul Cooper

nevertheless, people opposed to group homes in their neighborhoods have successfully blocked or delayed group home openings throughout the state.

"The statute is non-specific," says H. Rutherford Turnbull, an attorney at the Institute of Government who specializes in mental health law. "It is not clear how far the courts would give it precedence over local ordinances."

The "non-specific" nature of the statute became very obvious in Asheville last fall, when Buncombe County Group Homes for the Developmentally Disabled requested a zoning permit to build a second home in the middle-income Kenilworth neighborhood. Asheville's City Council had never considered how zoning and building code regulations might apply to group homes. No organized opposition had questioned the first home, the stone house where Richard Cohen lives. But the residents of Kenilworth mounted a campaign to block construction of the second one.

"I think it's a great idea, but I certainly do feel that the residents of Kenilworth need to have a lot more understanding of what the home is for," says Shirley Chamberlain, a resident who attended many of the Council meetings.

"They're afraid their property values will go down," says Cohen. "They think we might rob them or throw rocks in the windows."

Buncombe County Group Homes for the Developmentally Disabled held a meeting to explain the homes to the neighborhood. "We tried to talk

At the far right is the house owned by Community Group Homes, Inc., on S. Boylan Avenue in Raleigh.

frankly and openly about the program," says Dr. Raymond Standley, president of the group's board of directors, "to stop rumors and untruths from going around, to answer any questions."

But even those neighbors receptive to the group home idea didn't feel the meeting was enough. "The people in the community feel we have been dealt somewhat a low blow," says Marvin Chambers, a past president of the Kenilworth Residents Association and the parent of a retarded child. "The feeling seems to be that if someone had tried to educate the people as to what the intent of the home is, there would be a lot less bad feelings now. It's created a lot of animosity, and in my opinion, it does something detrimental to the whole program."

Some people, however, experienced in starting group homes say that a prior community education effort can be counterproductive. "It only emphasizes the differences of handicapped persons and makes them like second-class citizens," says Jean Stager, the mental retardation specialist for Durham County. "You or I didn't have to ask permission to move into a neighborhood. Such efforts more often only serve to heighten community apprehensions by making a big deal out of a very unremarkable occurrence."

The Asheville opposition is just one example of the difficulties group homes have had in finding receptive neighborhoods. Opposition has flared across the

state, from Raleigh and Knightdale to Burlington, Greensboro, China Grove, and Salisbury. Just outside of Chapel Hill, for example, a group of neighbors mounted a petition drive and a vigorous lobbying effort to force the Area Mental Health Board to withdraw its support of a proposed group home for children with mental retardation. The opposition group claimed to be concerned for the welfare of the group home children, afraid that the children would not fare well with neighborhood chil-

“You or I didn’t have to ask permission to move into a neighborhood.”

dren on the school bus, for example. But during a hearing before the Area Mental Health Board, other fears emerged. People opposed to the home said that they were scared their property values might go down and that they might not be safe. When the Area Mental Health Board remained committed to the home, the opponents filed a lawsuit. But the suit failed, and after several months of delay the group home was established.

Community resistance is usually based on a fear of property values going down or a fear of increased crime. But experts suggest that these concerns are groundless. Princeton professor Julian Wolpert, for example, studied 52 group homes in 10 communities, using “control” neighborhoods for comparison. His study, released in 1978, found that group homes have no negative impact on house selling or moving and that group homes were generally better maintained than nearby homes. The study concluded that “property values in communities with group homes had the same increase (or decrease) in market prices as in matched control areas” and that “immediately adjacent properties did not experience property value decline.”

North Carolina experts agree that property values are not affected by group homes. “This fear has been shown to be baseless,” says Turnbull, the Institute of Government attorney.

Turnbull has also written extensively on the crime issue. “There is substantial evidence that mentally retarded people are not more prone to criminal activity than non-handicapped people and that, with proper supervision (such as provided in group homes and in community-based employment, treatment, and education), they are less likely to become involved in the criminal justice process than non-handicapped people.”

The situation for mentally ill people is more complex. But a recent report of the President’s Committee on Employment of the Handicapped, after a three-year study of a halfway house for people with mental health problems, found no evidence of criminal-type offenses. “Recent data indicates that the

incidence of violent or felonious acts apparently has no significant relationship to mental illness,” writes Turnbull.

And the evidence goes beyond the purview of experts. In 1976, the American Association on Mental Deficiency released a national study of attitudes towards homes for developmentally disabled people. It showed that community opposition decreased **after the homes opened** in 87 percent of the cases. “Neighbors just don’t give themselves a chance to become acquainted with people who are mentally different,” says Toni James, western regional advocate for the Governor’s Advocacy Council for Persons with Disabilities. “Community education is essential, but handicapped people cannot wait until that long process is finished. There ought to be a law to help get the ball rolling.”

State law does not specifically forbid the use of restrictive covenants or local zoning ordinances to block the establishment of group homes in residential neighborhoods. During the Asheville debate, the City Council imposed a moratorium on zoning and building permits for such homes until regulations could be agreed upon and made into law. After weeks of debate, the City Council granted a permit for the new home, ruling that the Kenilworth applications had been made before the moratorium was imposed and that zoning restrictions could only affect future group homes. While the new Kenilworth home appears to be proceeding as planned, the fate of future homes — in Asheville at least — rests on a clarification of state law.

Community-Based Service

Requirements of North Carolina Law

1. A judge who presides over an involuntary commitment hearing must determine whether commitment to a program less restrictive than a state psychiatric hospital is appropriate and available.
2. Before admitting a child to a state psychiatric hospital, a judge must first determine that a placement less restrictive than a psychiatric hospital is insufficient to meet the child’s needs.
3. Local social service agencies must provide protective services to abused, neglected, or exploited mentally handicapped adults and children.
4. Guardians of adults adjudicated incompetent must prefer community-based treatment and residential services over institutional services.
5. State and local governments may not discriminate in housing against mentally handicapped adults and children.
6. Area mental health authorities must have plans for using state, regional, and local facilities and resources to provide mental health services to the citizens in that area.

Excerpted with permission from “Group Homes for the Mentally Handicapped,” by H. Rutherford Turnbull (Institute of Government, University of North Carolina at Chapel Hill, 1980)



Photo by Paul Cooper

The ritual of meals, perhaps better than any other ritual, illustrates the influence of environment. In these contrasting settings, note the difference between "everyday" grooming and closely cropped haircuts and institutional dress.

Residents of Raleigh home sponsored by Community Group Homes, Inc. Doris Jones is sitting at the end of the table.

Mealtime at a mental retardation center.

Photo Courtesy of Training Institute for Human Service Planning, Leadership, and Change Agency, Syracuse University, Syracuse, New York.

The state has a vital interest in the fate of group homes: it currently licenses group homes; it funds area mental health authorities, which may use some of these funds to help establish group homes; it operates four psychiatric hospitals and four mental retardation centers, where the cost per person is higher than community-based residential placement; and it funds community-based treatment and educational programs. But in 1975 and again in 1979, legislation designed to clarify the group home statute was defeated in the General Assembly. These bills required local governments to grant permits to group homes on the same bases as they do for similar dwellings. The bills, based on model statutes developed by a number of groups including the American Bar Association and the Ohio State University Law Reform Project, included a statement of policy, a definition of a group home, a definition of the types of handicapped people eligible to live in a group home, and a provision that state licensing would override local zoning and building codes and restrictive covenants.

In the 1975 law which did pass, however, the General Assembly seemed to support a policy of de-institutionalization for the state. But this policy has too often been thwarted, usually by neighborhood opposition to group homes, and probably will continue to be without a strengthening of the sort proposed in 1975 or 1979. A coalition of disabled people, parents, advocates, and human service



providers will again ask the General Assembly to clarify the current law in 1981.

If the Legislature responds, more people like Richard Cohen and Doris Jones will find a place to live other than a restrictive home or an institution. "I'm a little independent at Handi-Skills but not all the way," says Cohen. "I would like an outside job. My counselor thinks I'm going to be ready before too much longer. Living in the group home was the first step. I'm just taking it one step at a time." ■

Protective Legislation

In the last decade, a number of laws have passed Congress and the North Carolina General Assembly aimed at reversing historical patterns which have segregated disabled people in institutions or isolated them in their homes. Most are based on the constitutional principle of the least restrictive alternative: when a government significantly intrudes in a person's life, it must do so in a way that is least restrictive of the person's freedom. The normalization principle — using means which enable disabled persons to live as normally as possible — has been the other underlying basis for most of the legislative developments. The major ones are listed below:

Education

1. Equal Education Opportunities Act, 1974, 1975, General Assembly). Primarily policy statements and procedures for due process hearings to resolve disputes.

2. Chapter 927 (1977 General Assembly). Known as the Creech bill, it establishes the state policy of providing a free and appropriate public education to children with special needs. An "appropriate" education is one provided in the least restrictive setting, i.e., as integrated as possible with non-handicapped children, and one that also meets the particular needs of each child according to an individualized education plan developed jointly by parents and educators.

3. Public Law 94-142 (1975, Congress). Similar to, but more comprehensive than, the state law discussed above (Chapter 927). Binding on all school systems which receive any federal money.

Non-Discrimination

1. Section 504, Vocational Rehabilitation Act (1973, Congress). Prohibits discrimination against handicapped persons wherever federal funds are used. Implementing regulations refer specifically to public schools, colleges and universities, health and welfare agencies, and federal grantees in areas of employment and architectural accessibility.

2. Section 503, Rehabilitation Act (1973, Congress). Requires affirmative action (more than non-discrimination) to employ handicapped persons by companies with federal contracts over \$2,500.

3. Architectural Barriers Act (1968, Congress). Intended to assure the physically handicapped ready access to and use of buildings that are constructed, financed or leased by or on behalf of the United States.

Protective Services

Protection of the Abused, Neglected or Exploited Disabled Adult Act (1975, General Assembly). Provides that a court order can be obtained to protect disabled adults who are neglected, abused, exploited or denied essential services by their caretakers or for whom there is no one to give legally adequate consent for essential services.

Financial Assistance and Benefit Programs

Social Security Disability Insurance, Supplemental Income (SSI), Aid to Families With Dependent Children (AFDC), and state/county Special Assistance all provide financial assistance which can help to make community living financially possible for disabled people who are eligible. Medicare and Medicaid pay the costs of health services in the community, although they have also been used to pay for institutionalization. The federally funded and state administered Vocational Rehabilitation (VR) Program provides rehabilitative services to disabled people with "employment potential." North Carolina also administers the federally funded Title XX Program which makes possible Adult Day Activity Programs (ADAPs) and other social services.

Community Mental Health

Community Mental Health Centers Act (1963, Congress). Makes funds available to community mental health centers that have comprehensive mental health programs for people in a defined geographical area. In North Carolina, 41 locally governed "area programs" administer mental health, alcohol, and drug abuse services as well as mental retardation services. Because of a lack of funding, the community services are not at all comprehensive.

Developmental Disabilities

Mental Retardation Facilities Act (1963, as amended, Congress). Known as the DD Act, it requires statewide planning to improve services and eliminate unnecessary institutionalization.

Developmentally Disabled Assistance and Bill of Rights Act (1975, Congress). This amendment to the DD Act requires the states to assure, in exchange for federal money, quality services, individualized planning, a near-prohibition on the use of physical restraints, a prohibition on excessive drugging, and placement in the least restrictive setting for persons who become severely disabled before the age of 22. One federal appeals court has interpreted this law to mean that practically everyone presently in a Pennsylvania institution should be in community settings instead. This law's requirements as discussed here have had little impact in North Carolina.

Involuntary Commitment

Involuntary Commitment Statute (1973, 1977, and 1979, Congress). Provides that a person with mental health problems may not be committed to a mental health facility without his consent unless he is dangerous to himself or others. A person with mental retardation may only be committed if he has an accompanying behavior disorder that makes him dangerous to others. The commitment decision must be made by a judge and the respondent has the right to an attorney (paid for by the state if necessary). This process may be used to commit a person to an outpatient facility as well as an institution. Commitment must be to the least restrictive setting available.

Advocacy

Governors Advocacy Council for Persons with Disabilities (1979, General Assembly). Consolidated two existing advocacy agencies. Council staff members provide information to legislators, work with parent and consumer groups and are advocates for individual disabled people who face discrimination.

Possible Future Developments

1. enforcement of existing laws to promote de-institutionalization;
2. a more explicit statutory commitment to de-institutionalization;
3. a reordering of state financial commitment to favor community services instead of institutions;
4. the abolition of the commitment to institutions of people who are labeled dangerous to themselves merely because they cannot care for themselves;
5. the expansion of the non-discrimination obligation (Vocational Rehabilitation Act, Section 504) beyond only federal grantees;
6. a state law prohibiting the use of zoning or restrictive covenants to obstruct the establishment of small, scattered supervised community residences for disabled persons.