PART 

HOME AND COMMUNITY

CHAPTER VII

WHAT IS A HOME?

by Lotte Moise

What types of homes do we envision in our communities for families with handicapped children or adults? Successful homes for developmentally disabled persons already exist, scattered across this country and throughout the world. They come in different sizes and for persons of different ages with varying degrees of handicap. Guidelines and evaluation tools are available.[1] Now we must begin to close the gap between dreams, scattered experiments, models, or plans—and real needs. If we will stimulate public awareness, generate public support, and demand public funds, we can have good community homes for all persons who need them.

Each community—be it a city, a county, a rural region—must prepare homes for a variety of people, based on a continuum of growth and development. If we see handicapped persons as developing human beings, then they clearly do not need a "lifetime residence." We don't expect our normal children to mark time in the same place. In fact they often hope, "Some day I'll get away from here to a place of my own," a hope which carries them through some rough spots. The disabled child has the same need to be assured that he will grow up—and away. His home must be a rung on a ladder leading to higher levels of achievement, self-esteem, and independence. For example, when I asked our daughter Barbara for her definition of a home, she said, "Home is a moving out."

The home must help young persons become as independent as possible. One of the first surprises of the Danish group home in which Barbara spent a month came on the first day. They handed her a key to the front door! A key is a symbol of adulthood. In the Danish hostel each severely retarded young adult is awarded a room key as soon as he can manipulate it.

[1] Some of these have been published by the Accreditation Council for Accreditation Council for Facilities for the Mentally Retarded in Chicago and the National Institute on Mental Retardation in Toronto.

Our next surprise was the fact that this group home in central Copenhagen was a three-story house, and the back stairs were steep and winding. In no time at all our fearful, awkward gal, raised in a groundlevel California house, learned to negotiate them—not one foot at a time, but with alternate feet, and even carrying something in her hand. Risk-taking does pay off. In contrast, when the family care home where she was staying in California was checked out for certification requirements, the official requested that horizontal shelves be placed in the glass panels on each side of the front door. These panels were about eight inches wide, and there was no way in which our husky 180-pound, 5 ft. 7 in. daughter could have fallen through them. Part of our overall public awareness energy needs to be directed at fire and licensing regulations on state and national levels.

SIZE OF HOMES

In addition to developing homes which allow for the growth and independence of residents, what are some of the other common and distinctive characteristics of good community homes? The first important factor is the size of the home. We are trying to integrate our handicapped friends and their homes into neighborhoods—yours and mine—so one of the base requirements for every kind of group home is *small size*. Experience has shown that the growth and development—the integration into the community and the acceptance by neighbors of the handicapped person—happen more successfully in a moderate-sized house than in a junior institution. In many cases, a normal house in a typical neighborhood can be adapted to its new role with minor changes.

The number of residents cannot be an absolute figure. It may mean two children to one family and six to another. The potential residents of the homes may have varying preferences regarding size also. Ann Shearer of Great Britain's Campaign for the Mentally Handicapped tells of the conference which was organized to consult mentally retarded young adults about homes. At the time the Government was planning for twenty in each residence. The conference participants overwhelmingly felt that this was too large a number and opted for six.

LOCATION

Location of the residence is the next important consideration. The home must be close to the mainstream of the community. I know a group of young people who live in a luxurious ranchstyle house overlooking the ocean—about ten miles from a small town. There is no public transportation, and the road is too dangerously curvy, narrow, and heavily traveled for safe walking. Their work consists of making gift items in the back of a little downtown store. The seven young men and women represent a wide variety of interests and abilities, but they can only get to and from town "in lock-step" via their large station-wagon. How much better for their individual growth if they could learn to navigate on their own—to church or to a movie or to shop. If they lived close to town they could learn to return home in time for meals or to find their way to new parts of town. This kind of risk-taking could pay off in increased independence.

In Denmark one hospital for severely retarded residents is located right along one of the main thoroughfares of Copenhagen. They are allowed to roam all over their 'campus' without restraints. There are no gates or locked buildings. "We haven't lost one yet," was the answer to my concerned inquiry about their amazing mobility. "Mealtime always seems to bring them back!" I am convinced that the only way in which a handicapped person can learn his neighborhood is by exploring it—just like everyone else. This does not mean that the handicapped person, any more than the normal person, can do what he likes without regard for safety. He too can be hit by a car or drown if he goes swimming. It does mean that we must help him develop the ability to make choices and then be ready to accept the risk of these choices.

ROOMS AND FURNITURE

For the handicapped infant and small child, the group home must be a *home*. There should be a crib for sleeping and a playpen to want out of, a highchair to be fed in and to throw food and spoons from when that time comes. There must be a sturdy children's record player and a beat-up old piano, and just ordinary furniture which can handle an occasional natural accident. There should be a nice safely enclosed yard with fascinating things in it like rubber tires and a sandbox

and perhaps a swing or a slide—a balancing bar and an obstacle or two.

The balance between sleeping rooms and living areas depends very much on the location of the home and the age and condition of the residents. A home in the country, in a moderate climate, can rely more on the outdoors than can a house in town. Little children tend to use their bedrooms mostly for sleeping and require more play space in the living area of the house. Therefore infants and children can share a smaller bedroom with two or three others, provided there is a large rumpus room with toys, physical therapy equipment, and a television. For the protection of adults and other children in the family, a quiet room should be reserved for reading or visiting. This arrangement shifts where the residents are adolescents or adults. Then the young person must have a choice in the number of roommates, and the bedroom will become a place in which to spend more time. The young adult may want to save allowance money or workshop earnings to buy a TV or stereo for his room.

The young person's bedroom (whether it is for one, two, or perhaps even three people) should be a retreat. Silence is a valuable commodity in any busy household. Privacy is everybody's right; and with adolescents and young adults, the rest of the household may need a closed door as protection from pop records. So each room must have a door and a lock, even if it's the kind that can be opened with a screwdriver from the outside.

The furniture need not differ from that of any other teenager's. If the bedroom is to be used as a sittingroom some of the time, a bed which converts into a couch is nice. Since she was young, Barbara has had to make her bed, change sheets (with help at first), fold and put away clothes into her own dresser. She has her own desk and used to have a children's phonograph in her room. To be able to take pride in their rooms the residents of a home should have a say in arranging their furniture. Individuality should be valued above conformity. Wall decorations may have a tendency to get a bit flashy during the pin-up and poster stage; but with a little guidance, sanity and good taste will prevail in the end. In Barbara's current residence the walls of the girls' bedrooms were recently painted, and the staff have ruled that nothing shall be placed on them. How easy it would be to mount a couple of large cork boards so that they could put up pictures of their families, postcards from friends, or other bright treasures.

Using a bathroom is one of the most basic self-help skills,

and this room will continue to be important as the adolescent learns to take pride in his appearance. The number of residents per bathroom certainly depends on circumstances and economics. In our own home the bathroom was off a central hallway; and when the children were small, we had just one for five of us. In Barbara's current residence, six girls in three bedrooms use one upstairs bathroom, but there is an additional toilet downstairs. This kind of sharing can provide training in patience and consideration. In fact, the personal interaction and character training of a busy bathroom in the early morning hours is invaluable. Unless the developmentally disabled resident has specific physically handicapping conditions, he or she does not need a private bathroom. Sometimes a partition around the toilet can allow another person to use the tub or shower at the same time. All bathrooms should have locks, and each resident must have a shelf or cubbyhole for his own potions and lotions and a rod for his washcloth and towel. I believe that it is part of training in responsible behavior to learn to handle simple first aid equipment and household remedies. A special shelf can contain bandaids, cough medicine, ear drops, kaopectate, milk of magnesia, and aspirin. Training in this aspect of responsible health care can be adjusted according to the age, maturity, and ability of the residents and will prepare them for adulthood when they may need to cope with more important medications.

The kitchen is probably the next most popular room in any house. Again there is no need for special institutional equipment although commercial mixers are fun to have in any home where there's lots of baking. Perhaps electric ranges are safer than gas, but rules can be made and enforced about who may strike matches, and when, and where. A broiler is a potentially dangerous piece of equipment, but parents and staff can establish the time for learning its use. Just as tiny toddlers and their mothers have to learn to avoid the back hinges of heavy refrigerator doors, so the person who is retarded can learn about burners and ovens.

Residents should have free access to the kitchen in spite of the high cost of food. Refrigerators are tempting treasure troves to most people, and padlocking them doesn't solve the overeating problem. Good nutrition, balanced meals and sensible snack habits are learned better when there is well-guided access to the refrigerator. Meals should be a fun time, and a large diningroom table can set a family of almost any size up to twelve. We started our family with good plastic tableware.

Later they learned to handle pottery and china with kid gloves—Barbara too.

THE RIGHT TO INDIVIDUAL LIFESTYLES

Furnishings for all of these homes will be as varied as the people who reside in them. Houseparents and residents come in all sizes, colors, styles, and textures; and homes can reflect styles and lifestyles from Danish Modern to Grand Rapids. Some residences in Denmark are models of elegance and good taste, and reflect their attitude that "nothing is too good for mentally retarded people," but even the Danes sometimes wondered how these beautiful new quarters might look a year later. Actually, the residents took such pride in their surroundings and possessions that they reached unexpected heights of care and responsibility. We talk of the retarded person's rights to education, rehabilitation, and treatment. Let's not forget their right to an individual lifestyle: neat or messy, chic or funky, straight or groovy, energetic or lazy—a little of all of these things, but not cut from the same piece of cloth, poured into one mold, all in a row! Homes must have rules and chores, of course, but all rules should allow for exceptions like sleeping late on weekends, not making your bed once in a while, or eating breakfast in your bathrobe.

It came as a surprise to me, sometime during Barbara's teens, that she did not always want to accompany me. Somehow I had no faith in her ability to stay at home alone, although she could answer and dial the phone and take simple messages. I worried about the woodstove; I worried about intruders. One day I was nagging her to come along when she exclaimed: "I wanna stay home, Mummy. I want my peace!" She had to tell me how comfortable it feels to be alone in one's house which is temporarily quiet and empty. Each home must recognize this need for privacy and the sort of "space" which has nothing to do with square footage, but rather with the right to be oneself. And this right also belongs to our more severely retarded fellow citizens and can and must be expressed in their homes. Even the most severely handicapped person should live close to the community where he can enjoy the stimulation, warmth, and companionship of family and friends.

Our local convalescent hospital recently accepted a profoundly retarded young lady of 20 whose mother requested her transfer from a large state hospital. Angela had spent all

of her life in a crib. At the Convalescent Hospital they lowered the crib bars and let her play on a pad on the floor. Soon she was crawling, then walking with help. The old folks kept track of her when she headed for the front door. Angela's mother came every day to help feed her the main meal. She learned to hold a spoon and feed herself; and after a while she slept in a regular bed, all night long, for the first time of her life. Even the maximum care which someone like Angela needs, can be given better in a less institutionalized setting.

Model programs of integrated apartments, for severely disabled persons exist in Sweden—with England, Canada, Germany, and Holland planning similar projects. A Swedish non-governmental organization, the Fokus Society,[1] provides specially designed apartments—modified slightly from surrounding apartments for 'normal' tenants. Most of the Fokus tenants are wheelchair bound. Seventy percent need help with dressing and going to the bathroom. Thirty percent have to be fed. Twenty-five percent have to be turned over in bed during the night. Most of them have other than physical handicaps. But in spite of the severity of their disability these people have been allowed to choose their lifestyle. The project provides special personnel and transportation, so that they can enjoy mobility and have access to work and social activities. Those who have ventured out of their protective nursing homes find dignity in being useful members of society. Return to the mainstream of life results in incredible developmental progress.

This return to the mainstream can only happen if we orient the home outward at all times. Residents must have the opportunity to venture forth and meet people on their own, not in a cluster or well-chaperoned group. For short-term intensive training, adolescent group homes may have boys or girls only. In that case friendships with members of the opposite sex must be encouraged and sex education provided. A sense of responsibility does not happen overnight on one's eighteenth birthday. The component skills of choosing, judging, planning, and deciding must be fostered over many years of sensitive, listening, non-judgmental houseparents.

Only a broad base of staff persons can make a system of residences work. Parents of disabled children will rest well only when they are assured of a continuing system of community residences, which, like our schools, come with a supply of motivated, well-trained, adequately paid, and sympathetic staff people.

[1] Brattgard, Sven-OIof, "Integrated Living for the Severely Disabled," in *Models of Service for the Multi-Handicapped Adult,* New York: United Cerebral Palsy of

For people are at the core of every home—people and their attitudes toward each other. Kahlil Gibran in "The Prophet" speaks straight to the residents of each community's homes for developmentally disabled persons. When he was asked to "Speak To Us of Houses," he said:

"Your house is your larger body,
In their fear your forefathers gathered you too near together,
And that fear shall endure a little longer. Your house shall not be an anchor but a mast. You shall not fold your wings that you may pass through
doors, nor band your heads that they strike not against a ceiling, not fear to breathe lest walls should crack and fall down You shall not swell in tombs made by the dead for the
living."