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# COMMUNITY RESIDENCES FOR MENTALLY RETARDED PERSONS

A summary of a study of seven community residences

by Kurt Wehbring and Ciele Ogren

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#### **FOREWORD**

The publication of this report marks a major event in the redirection of the NARC Research Program and reflects a major product of that redirection toward research which has practical implications for the day-to-day lives of mentally retarded citizens.

The new thrust in finding alternatives to large multipurpose facilities, such as more home-like, community based facilities, has had far reaching impact. One of the priorities for NARC Research was consequently the study of diverse patterns of living arrangements for mentally retarded children and adults. The present publication represents the fruition of that redirection in the residential models areas.

This monograph is a summary of a more complete and extensive report on case studies of seven community residential facilities for mentally retarded persons. The opinions and conclusions presented herein represent the views of the authors, and do not necessarily reflect the policies and positions of the National Association for Retarded Citizens. The summary report gives a brief overview of each of the seven facilities, described in greater detail in the final study report, and summarizes the characteristics of the successful models. The detailed final report, entitled <a href="Case Studies of Community Residences for Mentally Retarded Persons">Case Studies of Community Residences for Mentally Retarded Persons</a>, may be purchased directly from the Literature Sales Clerk, NARC, 2709 Avenue "E" East, Arlington, Texas 76011.

John K. Sterrett, Ph.D., Chairman NARC Research Advisory Committee

#### **PREFACE**

Both the increased availability of community-based services for retarded persons and heightened efforts to reduce the number of people living in institutions have prompted a dramatic increase in community residences for retarded people. Throughout the country, groups of parents, concerned professionals and others are establishing small residential facilities for retarded people in their home communities. These pioneering groups have usually had to work out the concepts and practicalities of establishing a community residence on their own. There has been little information on the experiences of group homes — their successes and their problems.

To help provide parents, community home operators and professionals with information on the experiences of community residences, the National Association for Retarded Citizens commissioned this study of seven facilities. The seven represented a diversity of sponsorship, size, organization, philosophy and program. These experiences can be instructive to others considering starting a home or who presently are involved in an ongoing home.

#### Selection of Facilities

The criteria for selection of homes in this study included a) severity of retardation; b) administrative structure; c) geographical distribution; and d) funding pattern. In consultation with a nationally recognized authority in community residences, six facilities were initially identified and contacted regarding their willingness to participate. All facilities agreed to take part in the study. A seventh facility was included at the recommendation of the NARC Research Advisory Committee and subsequently agreement to participate was obtained from this residence.

In carrying out this study, we visited all the homes to make on-site observations of their operations. We interviewed residents, houseparents, social workers, parents, organizers and others who participated in the lives of the homes. Additional information was obtained from documents and records. Afterwards, the case studies were reviewed with representatives of each of the homes to assure accuracy of facts, although the interpretations are those of the study team.

We were both surprised and pleased by the openness and warm reception we received from all the community residences. We found the sponsors, staff and residents to be proud of their homes and willing to talk candidly with us. To them, and particularly to the residents who are delighted and challenged by the responsibilities of living in the community, we offer our thanks.

Kurt Wehbring Ciele Ogren

#### HIGHLIGHTS OF THE COMMUNITY RESIDENCES

## Lori Knapp Home

Many community residences are working well for mildly and moderately retarded persons able to gain skills necessary for living in the community, but few have met the challenge of severely retarded persons. The Lori Knapp Home is showing that it is possible for a community home to meet the needs of severely retarded individuals. Eight severely and moderately retarded children, most having physical handicaps, are blossoming from the effects of their home in Prairie du Chien, a rural town of southwestern Wisconsin.

Lori Knapp Home was founded in 1972 by Donald Knapp, father of one of the residents. His dream — to bring his daughter home from the institution to her own community — came to fruition through the support of the State Bureau of Mental Retardation, Wisconsin's agency for community living systems. The Central Wisconsin Colony, a large state-supported residential facility, supervises the home and provides training for the staff, a major ingredient in the success and quality of the home.

The general atmosphere of the home is that of a caring and cooperative family. As in all large families, the older children help with the younger children, only here helping often means lifting a "brother" if he cannot walk, or feeding a "sister" if she cannot feed herself. The house staff (two houseparents, a relief houseparent, and a part-time aide and cook) have been selected

for their abilities to be warm and loving parent substitutes. They give nurturance, guidance, supervision and discipline with a firm but loving hand.

The house itself also enhances the quality of living in the home. Special features of the house, including wide hallways and doors (a must for speeding wheelchairs), an electric chair lift between levels, and two bathrooms with specially designed toilets, tubs and showers, make it almost ideal in meeting the children's needs.

Daytime activities include public school classes for six of the children; the other two attend the Personal Development Center. After school and during weekends, summers and holidays, a high value is placed on physical recreation activities. Picnics, walks, swimming at the adult home pool (an indoor heated pool used year round by several community groups), parties, barbecues, Special Olympics and Badger Camp (a summer camp) are among their favorites.

Lori Knapp Home is not without its problems and limitations. Sometimes the composition and size of the home pose management problems: eight is a large number of children, especially since four of them are non-ambulatory and two require extensive care. It is difficult to incorporate the physical and occupational therapies the children need daily into a normal home setting with a very busy schedule, so this requires constant attention. And the home needs a busvan equipped with a power lift and storage places for wheelchairs and crutches. Without such transport, it is difficult to make excursions in the community. However, greater problems have been overcome: obtaining community acceptance of the home; integrating the children into the mainstream of life and the community; and circumventing attitudes and treatment of the children that would limit their leading normal lives.

While the Wisconsin state plan utilizes non-profit homes as a primary model for community living, a very few of Wisconsin's group homes are proprietary, such as Lori Knapp. Advantages of the latter model for the state are that the homes are relatively easy to start, since the proprietor assumes primary responsibility for the operation and style of the home. A disadvantage is that it is more difficult to improve the quality of homes when called for because administrative lines of authority are not clearly spelled out and overlap in some instances. In order to maintain quality, the plan calls for the state institution to play an active role in providing community consultation, staff training and supervison.

#### **Lupine House**

Lupine House was founded by a group of parents in the San Francisco Bay Area who felt their teenage daughters would soon need a more independent life of their own. Although the founding group had no previous experience, within a year they were able to raise funds from a local foundation, locate a home, obtain a license and find a house counselor. They were almost blocked by neighbors, who claimed the home violated zoning regulations. However, by mobilizing community support, they were able to persuade the Planning Commission to permit the home. The home is a large, comfortable, private house in a woodsy, suburban neighborhood.

The program for the six, young, mildly retarded women emphasizes independence, responsibility and improved self image. Within the home, these goals are put into practice by having the women do the cooking, cleaning, menu planning and shopping. The house mother acts as a teacher but seeks to provide the women many opportunities to learn on their own. Outside the home, all the women have a daytime activity. Two commute by bus to San Francisco to competitive, low-skill level jobs; two are in vocational training programs; and two work at a sheltered workshop. Finding interesting work has been difficult. Even the two competitively employed women find their jobs somewhat boring, though they enjoy the pay and the freedom of having their own income. Four of the women also attend evening courses in basic math and reading at the local junior college.

The home is governed by a 15 member operating board. In order to provide broader perspective and limit any tendency to be overly protective, only four of the fifteen positions are held by parents. The other members are professionals and interested citizens. Dayto-day decisions are made by the housemother and the administrator. At first, the administrator was a volunteer parent. However, since a second home was opened, the administrator has been paid. Having an administrator outside the home has provided continuity and allowed the houseparent to concentrate on program rather than administrative matters.

Lupine House shows how a group of parents can establish a group home and overcome technical problems as well as community opposition. They have created a social environment that gives opportunities for growth and independence, while balancing the parents' concerns for the safety and well-being of their daughters.

#### The Hearth

The Hearth in Erie, Pennsylvania, is the first residence established in the United States as part of a network of communities for retarded individuals called L'Arche (the ark) founded by Jean Vanier. Its philosophy is distinctively different from other community residences.

What makes the philosophy of the Hearth different is its religious orientation. Stated values include simplicity and poverty (in the sense of detachment from cultural riches), the importance of caring and loving between people, and the acceptance of retarded people simply because they are fellow men and women. Retarded people are seen as capable of experiencing deep spirituality. Distinctions between staff and residents are minimized. At the Hearth, the staff live with the handicapped persons rather than work for them.

The Hearth provides a residence for up to eight mildly and moderately retarded men and women. Its style is that of a large family: everyone helps with the housework and meals. Celebration is an integral part of the life of the home: celebrations of birth-days, religious holidays, the arrival of a friend, a resident's departure.

Founders of the Hearth, a Catholic Priest and a Sister who taught at a local college, have intentionally worked to develop a community, not just a home. The community includes not only the residents of the Hearth, but also neighbors and friends from the surrounding community. Frequently friends will drop in for a visit or join in the Sunday afternoon worship services at the home. The Hearth community extends also to other L'Arche communities: residents frequently visit L'Arche homes in Canada. In April, 1974, the members of the Hearth flew to England for a pilgrimage with other L'Arche members to Cantebury. For several residents, it was the first time on an airplane.

The Hearth is interesting because it suggests a unique way of relating to handicapped people.

#### **Manchester Group Home**

Frequently there is a polarization between those who favor a community-based approach and those who favor institutions. Connecticut's Mansfield State Training School has demonstrated that such a polarization is unnecessary. This state institution has spurred the development of community residences while at the same time improving conditions at the institution.

Mansfield opened its first community residence in 1964. Since then, nine more homes have been developed and in 1973 the institution was appropriated \$1.6 million to open another 25 community residences.

The Manchester Group Home, one of the training school's original 10 homes, is a residence for 10 mildly and moderately retarded men. Six of the men have spent long periods in institutions — from 6 to 36 years; the other four came directly to the home from their natural or foster parents. The home provides a sheltered environment so that the men are able to live and work in the community.

Seven of the men are competitively employed, two work at a sheltered workshop and one attends school. Those who earn wages pay room and board based on a sliding scale. The Manchester Association for the Help of Retarded Citizens provides the services of the Manchester Sheltered Workshop for the male residents of the group home. In addition, the Association sponsors parties and social events for the residents.

The two houseparents, a couple in their fifties, live in the home and technically are "on duty" from 3:00 p.m. to 11:00 p.m., although in fact they are available whenever needed. They prepare the evening meal which the men eat together, order the food, manage the funds of the residents, help them find jobs, buy clothes and settle disputes.

The Manchester Board of Education also plays a key support role in providing adult basic education programs at the home and in sponsoring a new Regional Occupational Training Center which offers services to residents under age 21.

Mansfield State Training School leases the home, hires the houseparents and provides a social worker who visits weekly to counsel the residents and helps thehouseparents resolve problems. For economy, groceries are ordered from the Mansfield commis-

sary. Mansfield also has arranged recreational programs in the community for residents and provides transportation. In order to provide a day program for group home residents who did not have the skills to participate in sheltered workshops, Mansfield organized the Hartford Project, a social skills and workshop program.

Some of the advantages of having an institution develop community residences are as follows:

- 1. practical experience in the administration of residential services for mentally retarded persons;
- 2. an already-established funding stream via the state agency administering the institution;
- accountability for quality of services resting with a single organization; and
- availability of support services through the institution in cluding diagnosis and evaluation, counseling, and transpor tation.

There are, of course, potential disadvantages in that the homes may simply replicate institution-style dormitories off-campus or develop into "mini-institutions." Through a conscious effort, including a separate administrative unit, Mansfield appears to have avoided this problem.

## **Cheyenne Village**

Cheyenne Village has developed an innovative program which begins with highly structured living and training and leads to independent living in a series of steps. The first step is closely supervised living at McLaughlin Family Lodge, a 27 unit motel near Colorado Springs, Colorado. Forty residents in the supervised living program on the grounds of McLaughlin Family Lodge reside in newly constructed facilities, ten persons to a living unit. These facilities were constructed under guidelines of the Department of Vocational Rehabilitation and meet the needs of persons with multiple handicaps. The motel work — cleaning rooms and maintaining the grounds — provides legitimate vocational experience as well as an opportunity to observe and meet other people.

When residents have shown sufficient ability to work at a job and take responsibility for their own lives, hey move to the staffed Training Apartments in Colorado Springs. These are two duplex apartments where 14 men and women are trained in community living skills such as cooking, shopping and using community recreation programs. The next step is Counseling Apartments where the residents live on their own in an apartment with a roommate. These apartments are scattered throughout the community. The staff of the county's central placement, referral, and follow-along unit have the responsibility for support services in this program. These counselors visit on both a scheduled and unscheduled basis to work on problems as they arise and to reinforce progress made by the clients. In the final step — independent living — counselors no longer visit residents; however, Cheyenne Village's commitment continues, and staff are available whenever a former resident needs help. In the first three years of operation, 14 residents have proaressed to Counseling Apartments, and five to independent living.

To help residents become self supporting, Cheyenne Village has an extensive occupational program. Training is focused on job habits and attitudes rather than specific skills, since it has been found that absenteeism, disputes with employers and similar problems are the main cause of job loss by the residents. Counselors assist residents in finding jobs and working out on-the-job problems which may arise later.

A cornerstone of the program is the Individual Program Plan which is developed in concert with the client, staff, parents or guardians, and participating agency representatives. Through the Individual Program Plan which incorporates into it the rights and

responsibilities of each client on an individual basis as well as the program components, the client can be held fully responsible for his actions. Whenever possible, specialized consultation is held with parents to assist them in recognizing the individual rights and responsibilities of their adult son or daughter.

A feature of the program is the weekly meeting of the Interdisciplinary Teams at the living unit level. These meetings are a combination of staff/resident in-service training and individual reviews of client programs. For a client to progress from the initial high level of supervision to a less supervised status, a major developmental milestone must be achieved. A resident himself is a full participating and voting member in this process.

Through a program of living skills and work training, Cheyenne Village offers some 65 people increasingly independent levels of residential care and long-term support for those who have reached independence.

## **Community Living Program**

While many planners and staff of community residences agree that independent living is an implicit goal of normalization for retarded people, they do not always agree upon the means to achieve this end. Staff of the Community Living Program in San Diego, California, emphasize two ingredients they feel are crucial to independence: accepting personal responsibility and making judgments. Accordingly, residents in training learn to experience the consequences of their actions and to face choices and alternatives requiring them to make decisions. This freedom to learn by mistakes is balanced by a supportive atmosphere providing built-in success opportunities and readily available counseling.

The Community Living Program is an urban apartment community where 26 moderately and mildly retarded young adults live in their own apartments in a large two-story apartment complex. It was developed in 1972 by a group of professionals with the leadership of a Salvation Army social worker. While practicing at managing their own lives, residents attend evening classes two or three times a week where they get one-to-one training in cooking, household management and budgeting. In these sessions residential counselors use teaching aids such as tape-recorded recipes and budgeting envelopes labeled with pictures. Residents get additional training in larger group meetings that include the entire apartment community. Social expression, legal rights, health and interpersonal relationships are among the topics and skills covered. These sessions are followed by small group discussions. Here, too, innovative techniques are used to make the learning more effective. For example, to learn about fire safety, the residents practiced using a fire extinguisher to put out a fire set in an alley by a safety officer. In learning about decision-making, tenants role-played scenes with door-to-door salesmen and with neighbors who frequently borrow things.

The program staff (one resident counselor, three living skills counselors, a full-time social worker and a half-time follow-up social worker) strive to maintain a tenuous balance between freedom and support. A basic trust in the abilities of the tenants to succeed is evidenced in the freedoms permitted. For example, tenants manage their lives and apartments with a minimal number of rules imposed by the program. Since tenants are responsible for the payment of bills, the staff allow utilities to be disconnected when bills go unpaid. Further, throughout the training, tenants are given alternatives and choices to permit them to exercise their decision-making ability. To balance these freedoms, support is

given. Counselors tailor training so that successes are built in — some tasks are purposefully made easy to accomplish.

In addition to its unique program, the Community Living Program also has a unique structure. The apartment building is a leased-housing facility for eligible, low-income persons used by special permit from the Public Housing Authority. Tenants apply for their own apartments and pay rent that is affordable within their small budgets. When their training is complete, they can move to another leased-housing facility. This arrangement is advantageous for the program sponsor because no capital outlay was required for the building.

Administration and operation of the program is shared by the Salvation Army's Bureau of Social Services and an Advisory Committee. As the sponsoring agency, the Salvation Army plays a major role in determining whether the program ideas are financially and operationally feasible and in obtaining funding for the programs. The Advisory Committee is composed of Salvation Army staff and volunteers, project staff, parents and staff members of a dozen community agencies.

After one and a half to two years of training, graduates — there have been 20 to date — move to other apartments in San Diego and manage their lives independently with support from the program's follow-up social worker. Most of the graduates have been unable to move to low income housing and are paying rents that are substantially higher than they paid while in the program. The graduates are doing quite well and all have some amount in savings. Staff visit with graduates once or twice a week to help with problems and graduates return to the program frequently to visit friends. In addition, a group of volunteers works with the graduates to increase their contact with the community and thereby increase the chances of successful independent living. Graduates, volunteers and staff are pleased with the success of living independently in the community.

#### Hamilton Street Residence for Children

With the increasing acceptance of the concept of normalization as one of the most important principles in developing services for mentally retarded people, a forward-looking parent group in Omaha, Nebraska (GOARC — Greater Omaha Association for Retarded Children) put the principle into action. In 1970, after much searching for a suitable house, they located a brick duplex in a transitional residential neighborhood, remodeled it and opened a community residence for six moderately and severely retarded children in need of intensive training for behavior problems. The effort was courageous since the prognosis was supposedly poor that several of the children would benefit.

Not long after GOARC opened the home, day-to-day operation of it was assumed by the Eastern Nebraska Community Office of Retardation (ENCOR), a comprehensive multi-county system serving more than 1,000 mentally retarded persons. This cohesive network includes residential, vocational, developmental, recreation, counseling, evaluation and transportation services. Themes of the services are: <a href="integration">integration</a> into services for non-retarded individuals; <a href="dispersal">dispersal</a> of service <a href="clusters">clusters</a> throughout the community; <a href="movement">movement</a> through continuous services; <a href="spin-off">spin-off</a> of services (ENCOR only fills service gaps); <a href="flexibility">flexibility</a> and <a href="change; evaluation">change</a>; <a href="evaluation">evaluation</a>, internally and externally. All the services are permeated with the philosophy of normalization.

At the Hamilton Street Residence, the staff attempt to maintain as home-like an atmosphere as possible, particularly at mealtimes and bedtime. They attend to details such as ensuring that belongings are appropriate to the children's ages and avoiding demeaning labels in referring to behaviors or physical conditions of the children. Maintaining the family atmosphere has to be juggled with meeting the special needs of the children. To do this, staff view the children first as individuals in need of freedom, and secondly as children with special needs — an approach that is not always easy since some of the children have problems including tantrums, rocking and head-banging which are difficult to handle.

The special needs of the children are met with a fairly intense behavior modification program, monitored with Precision Teaching charts and tools. The program is approached in a humanistic way, using positive substitutes for inappropriate behaviors. The staff also accentuate the strengths of the children, ignoring difficult behavior and reinforcing more desired behavior. Though "programs" are used for a good part of the time the children are

home, they also are given free time to explore and play by themselves. During the day, the children attend public school classes or Personal Development Centers, where attempts are made to coordinate behavior modification methods and programs with the home.

Hamilton Street Residence is administered by the Residential Services Division of ENCOR. This division has five area coordinators who are responsible for the overall supervision of community residences. Hamilton Street Residence is supervised by the area coordinator for the district in which it is located.

The home is staffed by a young houseparent couple, an assistant houseparent and two residential assistants who work a total of 200 hours a week. The large staff is necessary both to meet the special needs of the children and to meet the obligations of working within a large system. Besides managing the home, the staff assess the training and physical needs of the children, attend meetings of teachers and of ENCOR staff and keep behavior modification records.

An evolving role and challenge of the staff is supervising and coordinating Alternative Living Units — satellite homes in the community where several of the children have recently moved. The Alternative Living Unit concept did not come into being merely for the sake of change, but developed out of pressing needs. For example: a) it was necessary to find a way to meet service needs more quickly as the acquisition of additional group homes was becoming unrealistic (e.g., to contain costs and ameliorate neighborhood resistance); b) developmental progress of children was being hampered by the grouping together of six children with severely maladaptive behaviors; and c) the need to adjust the fashion which residential services were delivered in order to provide more normalized services. Responsibility for progress and movement to the least restrictive living environment rests with the staff rather than the clients. Instead of saying to a client, "You must do this and this before you can move to more normalized environments (e.g., the concept of "exit criteria"), the question is now being asked. "What kind of support structure must we provide for this individual to allow him or her to move to a less restrictive living situation?"

This home demonstrates that severely and moderately retarded children with complex behavior problems can grow and mature beyond expectations of parents, professionals, and staff in a community-based residence. The home also demonstrates the role of a comprehensive service system in the operation of a community residence. The advantages of such a system are several:

- 1. procuring funding that might not ordinarily be available to a smaller organization;
- 2. providing cost beneficial administrative services spread over a number of homes;
- 3. effective coordinating program plans for individuals among services within one system; and
- 4. providing increasingly independent living opportunities, thereby ensuring movement for the resident who needs it.

A notable ingredient in the success of this system is its commitment to change. This openness and availability to new programs and ideas gives hope that the system will sustain and continuously renew itself.

#### **COMPARATIVE ANALYSIS**

#### Initiation of the Residence

A tradition in the mental retardation movement is the strong role parents have played in developing services for their retarded children. It was not surprising, therefore, that the genesis of the community residences in this study was mainly with groups of parents. Of the seven homes, four were started by groups of parents having no suitable living alternatives for their children. However, these parent groups did not work alone. In each case they were able to enlist the support and cooperation of professionals in working through the necessary details and moving their ideas from concepts to reality. The parents carried out many valuable functions: generating enthusiasm and support for the residence, raising funds, seeking out staff, working out the legal arrangements, finding a suitable facility, frequently locating prospective residents, helping to establish the philosophy and approach of the home and maneuvering politically when community opposition or zoning issues emerged. The professionals, working in partnership with the parents, provided assistance in technical areas such as obtaining funding, meeting licensing and code requirements, and guiding and facilitating the meeting of administrative requirements. Professionals also were influential in helping to shape the ideology and program of the homes.

The three homes not initiated by parents were equally instructive. The home in Connecticut (Mansfield) was started by a state residential institution which has developed a community residence program. The new administrator of the institution was aware that many of its residents could function in the community. The administrator also recognized that community living could be substantially less expensive than institutional living. San Diego's Community Living Program was initiated by a group of professionals with the leadership provided by a Salvation Army social worker. The committee of agency representatives recognized the lack of community residences and training programs to prepare retarded people for community living. The Hearth, on the other hand, was started by three individuals who had little previous experience working with the retarded men and women. They were motivated by the example provided by the L'Arche movement and by hearing Jean Vanier, its founder, describe his experiences.

A comparison among the homes with respect to sponsors, governing boards, number of residents and unique features is given in Table 1.

# Table 1 COMPARISON OF COMMUNITY RESIDENCES

NAME 1.	SPONSOR	GOVERNING BOARD	NUMBER OF RESIDENTS	UNIQUE FEATURES
Lori Knapp Home	Parent originated	None	8 moderately & severely retarded boys & girls; 4 non-ambulatory	Warm, family atmosphere, ex- tended family includes adult home; in-home program for severely retarded children; organized by a parent; super- vised by state institution.
2. Lupine House	Parents/Associations for Retarded Citizens	Parents & professionals	6 mildly & moderately retarded women	Warm, home-like atmosphere; housework and skills training; parent involvement; outside administrator; housemother as counselor
3. The Hearth	Small group of com- mitted religious individuals	Interested citizens and professionals	6 mildly & moderately retarded men & women	Residents and staff live to- gether; strong sense of com- munity; religious orientation; Hearth philosophy
4. Manchester Home	Mansfield State Training School	Institutional Board only	10 mildly & moderately retarded men	Started by an institution; back- up program by institution; leisure time program;employ- ment assistance by house- parents.
5. Cheyenne Village	Group of parents formed non-profit corporation	Interested citizens and parents	73 mildly & moderately retarded men and women	A development and training program leading to independent living; reality approach stressing self responsibility; support of interested citizens.
Community Living     Program	Salvation Army	Mainly professional	26 moderately & mildly retarded men & women	Training of residents by coun- selors; emphasis on making decisions; community feeling; a transitional arrangement to independent living; collabora- tive inter-agency effort.Public Housing Authority facility.
7. Hamilton Residence	Eastern Nebraska Community Office of Retardation	ENCOR Board only	6 moderately & severely retarded boys & girls	Part of a system of services; use of behavior modification program; normalization philosophy carried out in detail.

The development of community residences is relatively new in the United States and all of the founders of homes had little information about the process when they started. (The one exception is in Connecticut where the Mansfield Training School had been developing homes for several years and thus had accumulated experience.) In their efforts to educate themselves, the forming committees frequently visited other community residences. The Hearth founders spent time at L'Arche homes in France and Canada, and the original staff of the Community Living Program had visited homes in Scandinavia. Cheyenne Village founders visited a number of homes in other states and hired a consultant to do an economic feasibility study of their concept.

Because of the lack of available information and experience, the planning period took an average of 12 to 18 months. In the case of Cheyenne Village, over three years from the original commitment to the program initiation was required. No doubt, the planning period could be shortened and the process made less difficult if future founders of homes could be provided with information and technical assistance in forming the home.

It is impressive that the founders were able to establish the homes with so little guidance and precedent. Four of the homes (Lupine, Hearth, Cheyenne Village and Lori Knapp) were started without supporting organizations to guide and manage them. In three cases (Manchester, Community Living Program and Hamilton), there were existing organizations which provided a base onto which the home was added. However, whether a pre-existing or a newly formed organization was used to launch the homes did not appreciably alter the sequence of events bringing the homes into being. With the exception of Mansfield, all the homes followed a similar course of development.

Initially, one to three individuals became concerned about the need for a community residence and enlisted the support of others. A period of discussion and sometimes study would ensue where the need was further defined and possible steps outlined. At some point, the initiators made a decision to go forward —a house was obtained, funds were solicited or some other specific step was taken which moved the process from discussion to action. Although their problems were only beginning, the founders were able to make the commitment to action and begin developing the facility.

## **Development of the Residence**

Finding a suitable building in a convenient location soon became a primary focus in the development process once the decision to go forward had been reached. All but one of the residences studied used existing buildings. The exception was Lori Knapp Home, which was developed as a standard single family home with modifications such as ramps for wheelchair access, wider doors and adaptations in the bathrooms.

The variety of arrangements that were devised for obtaining a facility reflects the ingenuity and persistence of the organizers. Two of the residences were in large private homes that were leased from private owners (Lupine and Manchester). Two others were in single family dwellings that were purchased by the sponsoring organization (Hearth and Hamilton). Cheyenne Village was a combination of facilities: an operating motel that was purchased by Cheyenne Village, part of which was used as a residence while the rest continued as a motel; three homes in the community which were leased and used as halfway houses; and a number of apartment units scattered throughout the community used by residents in the final stage of the program. The Community Living Program was able to obtain the use of an apartment facility through the leased-housing program of the local housing authority.

fn seeking a home, a *number of factors were shared in common:* a pleasant neighborhood where the residents would be safe, available public transportation, proximity to likely places of employment and special programs. Inevitably there was the need to consider the trade-off among these. Large, older houses which were within suitable price ranges were frequently in older, less desirable neighborhoods. On the other hand, an older neighborhood often had a diverse mixture of people, making others who appeared somewhat "different" more easily tolerated.

Most of the homes needed some minor alterations or additions to make them suitable for group living. Typically some safety features such as smoke detectors or alarm systems were required by fire codes. Although these fire and safety code requirements were not difficult problems in the homes studied, in other cases such requirements have put a heavy financial burden on small group home operators. For example, when the sponsors of the Community Living Program were initially searching for a facility, they learned that a home with more than six persons fell into a category of facility with stricter fire and safety requirements than a small "family care" facility (in California, less than six persons), and could not afford to meet the stricter code requirements.

Licensing requirements were able to be met by the homes without too great difficulty. However, a few incidents illustrate the type of problems that can develop if licensing requirements are too inflexibly administered. In Lupine House, residents could not return home early because licensing regulations required supervision at all times, and the house counselor did not come on duty until the late afternoon. In another situation, the residents were required to obtain a physician's prescription in order to take skimmed milk in their diet.

Zoning laws created some difficulties in three of the seven homes. The account of the Lupine House difficulties is typical of a number of cases around the country. Lupine House organizers overcame community opposition through persistent efforts at explaining the project and rallying supporters who were able to persuade the Planning Commission to permit the homes. In the case of the Hearth, a request for rezoning to permit a larger number of persons in the home was accepted only after more than a year of deliberation.

Once established, the homes and residents have tended to have good, if somewhat distant, relationships with neighbors and the community. Indeed there have been occasions when those who opposed the location of the home have subsequently turned into friends and supporters of the home. The Hearth provides an interesting example of interaction with people in the neighborhood and community. The Hearth organizers worked at establishing a sense of community at several levels: within the house, with neighbors and friends in the community and with other L'Arche communities.

## Operation of the Residence

The way the homes work from day to day is a product of a number of ingredients: philosophy and goals underlying the development of the home; staff capabilities; characteristics of the residents; program structure; available community resources; program results; and cost and funding sources. Therefore, it is not surprising that though similarities exist among operational ingredients, no two residences look and work the same.

**Philosophy and goals.** Whether implicit or explicit, philosophy and goals were of great significance in shaping the operations of the seven homes. Most of the homes claimed they were following the normalization principle, but what this meant in the practice of

each home was quite different. In applying the normalization principle, most of the homes gave attention to things readily observed as "normal." Examples included: creating a home-like atmosphere where decor was warm and comfortable; maintaining age-appropriateness of possessions and dress of the residents; referring to residents in a non-demeaning manner. The actual goals of the homes were developed from local needs, perceptions and experiences, and the specific goals were quite varied.

That independence was a specific goal for most homes was seen in their provisions for residential "steps" permitting residents to experience increasingly more autonomy and in their attention to training skills necessary for independent living. Two residences emphasized self-responsibility in a specific way: Chevenne Village, in its use of "reality therapy" (allowing residents to experience the consequences of their actions), and Community Living Program in creating alternatives requiring residents to make decisions and develop good judgment. Implied in nearly all of the programs as well was concern with self-worth and self-image. The Lupine House policy manual specifically indicated "improved self-image" as a program goal. Community Living Program was careful to provide for success experiences to help residents maintain their self-values during training. Most of the homes also saw decreased aberrant behaviors, increased integration with the community and job success as means by which residents could increase self-esteem.

Children and adult homes alike shared the tenuous task of balancing and juggling freedom and support. Staffs of the Community Living Program and Hamilton Street Residence commented specifically on the difficulty of allowing residents sufficient freedom to explore and experience their own rights and autonomy as individuals, while at the same time providing adequate support for continued growth and special needs.

Staff. Next to program philosophy, staff were the most critical factor in the operation of a community residence. When asked what qualities made a good staff person, administrators mentioned: good health and vitality, patience, endurance, innovation, ability to be organized, confidence and a basic belief in the capabilities of mentally retarded people to grow. This last was perhaps the most frequently endorsed characteristic. Previous experience in working with retarded children or adults did not seem to be as critical as was possession of the foregoing qualities, although nearly half of the staffs had such prior experience.

Initially, staff selection was largely a hit and miss affair, since most of the home administrators had no prior experience in operating homes. They did not know what qualities to look for in potential staff. Most residences placed ads in local newspapers describing the positions to be filled as "houseparents" or as "counseling or teaching jobs" and were consequently deluged with applications from seekers of people-oriented jobs. Initial selections were based almost entirely upon the intuition of administrators.

Several administrators concluded that persons who took jobs because they wanted to feel needed by other persons were not good choices. These administrators came to believe that to be effective in a community residential setting, staff persons must place high value on their own independence in order to tolerate and foster freedom for the residents. One home soon discovered that their first housemother gave up her own personal life for her "girls," but was not able to promote the autonomy needs of the women residents.

Typically, staff in the homes studied were single people or young married couples in their twenties. Most had one or more years of college education. Exceptions included Manchester (a couple in their fifties), Hearth (a priest and nun in their thirties) and Cheyenne Village (started by a couple in their thirties who employed mainly single, young adults).

Experience also taught home administrators that because of the heavy demands for attention upon the staff, the lack of privacy, low salaries and other changes in life circumstances, even young, energetic employees would typically remain only one or two years. Some administrators labeled this as the "burn-out" syndrome and viewed counseling and houseparent jobs as short-term ones. While new staff can add energy and novel ideas to a program, it is sometimes very difficult for residents to adjust to frequent staff turnover, particularly since some are for the first time in their lives enjoying a primary relationship with consistently available, caring adults.

Personnel turnover and "burn-out" are realities of community residences. Regular hours, more adequate salaries and adequate vacations could possibly help alleviate some of the pressures on staff.

Characteristics of the residents. Of the seven community residences studied, five served primarily mildly and moderately retarded adults, while two homes provided community care for severely retarded children. Many of the residents at Cheyenne Village, while only moderately or mildly retarded, also had be havior problems and had been in trouble at established institutions. (See Table 2.)

**Program structure.** Since most of the residents of the homes were similar, the intensity and style of the training approach were out-of-home activities which focused primarily on training to live in the community. In-home programs consisted of teaching practical and social skills, while out-of-home programs included academic, vocational or sheltered work experiences or competitive jobs.

While the content areas given attention in in-house programs were similar, the intensity and style of the training approach was greatly varied. Lupine House used household chores as means for teaching household management; thus, the women residents did all the household work with guidance provided by the houseparent. The Community Living Program residents were responsible for maintaining their own apartments and cooking their own meals. Counselors met residents in their own apartments for one-to-one training sessions in cooking, household management and budgeting. Even more structured training occurred at Cheyenne Village where training had three specific parts (living skills, vocational adjustment and social adjustment) with concrete steps of progression leading to independent living. Themes common to all the in-home training programs were self-discipline and responsibility to one another.

The two homes for children in the study had, in addition to the usual living skills training, special training programs dealing with handicaps or behavior problems. Lori Knapp Home used firm but loving discipline in teaching living and behavior skills. Physical therapy and occupational therapy (primarily motor feeding skills) were available for the children with physical problems. Hamilton Street Residence used behavioral procedures to teach both living and behavior skills for children with rocking, headbanging and tantrum behaviors.

**Community resources.** In all of the homes, residents went to outof-home programs during the day. Adults went to school, sheltered workshops, vocational training programs or competitive jobs. In the smaller homes, houseparents helped residents find

	Community	Res	dents Age		Level of	Other	Prior	
	Facility	Male	Female	Range	Retardation	Disabilities	Residences	
1.	Lori Knapp Home	4 boys	4 girls	10-17	moderate — severe	non-embulatory	state institution	
2.	Lupine House	an last service	6 women	17-32	mild moderate	speech problems	parents' homes	
3.	The Hearth	3 men	3 women	17-40	mild — moderate	none	state institutions	
4.	Manchester	10 men		19-52	mild — moderate	blindness epilepsy	parents' homes and state institution	
5.	Cheyenne Village	35 men	38 women	17-40	mild — moderate	behavior problems	parents' homes and state institutions	
6.	Community Living Program	16 men	10 women	18-44	mild — moderate	muscular dystrophy, cystic fibrosis, epilepsy, diabetes	parents' homes, state institution, and local community	
7.	Hamilton St. Residence	4 boys	2 girls	10-12	moderate~ severe	hydrocephalus spina-bifida cerebral palsy	parents' or foster homes and state institutions	

suitable jobs. In the larger, more comprehensive programs (Hamilton Street Residence and Cheyenne Village), there were vocational training programs where residents began working at jobs closely supervised by program staff, but later progressed toward jobs in industry or contract jobs held by the program. These programs had job stations in firms, permitting program supervisors to go on location with the residents. Experience soon revealed that the social aspects of the work environment rather than prerequisite technical skills, were the most difficult for residents to grasp, but the most important in holding a job: e.g., being punctual, showing up regularly for work, being responsible to see the job through to finish and getting along with fellow workers.

Approximately one-third of the residents in the homes were competitively employed. While the residents liked their jobs for the money and the independence they gave, residents often said their jobs were dull and repetitious. The consistency with which this was reported emphasized the problem retarded people have in finding satisfying jobs in a high-skills-oriented job market.

Children attended classes in the public schools or centers which concentrated on the development of perceptual and motor skills. In both homes with children, attempts were made to coordinate in-home and school teaching. Community residences may look forward to working even more directly with public schools in future years, given new legislation mandating public school responsibility for the education of every child of school age.

**Costs.** The per person costs ranged from a low of \$2,075 to a high of \$6,278 per year as shown in Table 3. Comparisons between homes are somewhat misleading for several reasons. First, there was no common accounting practice so that the figures are not always comparable 1. Second, many of the homes received services from volunteers which often were not accounted. Third, many of the budgets provided were for the early years of operation, before the program and costs had stabilized. Finally, present-day costs will undoubtedly be considerably higher than during the reporting period because of inflation.

The Rehabilitation Research and Training Center in Mental Retardation at the University of Oregon has recently developed an accounting system for group homes for developmentally disabled persons. The Accounting Handbook represents a distinct, useful product from a research project funded by the Social and Rehabilitation Services of the federal government. The manual consists of three sections, including the Accounting Handbook, a Practice Set illustrating use of the manual and a Reporting Manual containing the forms useful in accounting for group home operations.

The Handbook can be ordered from Materials Distribution, Rehabilitation Research and Training Center in Mental Retardation, University of Oregon, 2nd Floor Clinical Services Building, Eugene, Oregon 97403.

Table 3 COMPARISON OF COSTS OF RESIDENTIAL FACILITIES

	Item	Lori Knapp Home	Lupine House	The Hearth	Manchester Home	Cheyenne Village	Community Living Program	Hamilton Street (ENCOR)
1	Housing	310,706	\$ 6,740	\$14,622	\$ 8,934	\$ 46,640	\$1 2,900	\$10,008
2	Food	6,600	4,500	3,672	5,007	27,500	_ **	7,300
3	Personnel	11,220	18,121	10,225	16,487*	216,000	39,290	16,460
4	Miscellaneous (licensing, accounting, office expenses, education)	780	1,778	350	400	6,800	870	2,700
5	Transportation	300	850	880	na	na	900	1,200
6	TOTAL COSTS	\$29,606	\$31,989	\$29,749	\$30,828	\$296,940	\$53,960	\$37,668
7	Number of residents	8	6	6	10	73	26	6
8	Cost per resident per year	\$ 3,701	\$ 5,332	\$ 4,958	\$ 3,083	\$ 4,068	. \$ 2,075	\$ 6,278
9	Budget year	73	74	74-75	73-74	74-75	73-74	74-75

<sup>&#</sup>x27;Includes \$3,000 for social worker's time \*\*Food purchases are made by residents from their own resources.

Sources: Cost figures submitted by facilities

na Indicates not separately accounted.

In all of the homes, personnel costs took up the greatest part of the budget, an average of 56 percent. Staff costs ranged from a low of 34 percent to a high of 73 percent. Homes with more severely handicapped people required relatively larger staffs and consequently per-resident costs were higher.

While advocates may claim community residences are less expensive than institutional care, a comparison of cost figures reported here or elsewhere to institutional costs may not be in order. Institutional costs frequently include a number of programs (such as behavior training, educational and recreational programs and medical care) whose comparable costs do not show up on the balance sheet for community residences. Quality care, whether it is in the community or in an institution, will not be cheap.

**Funding sources.** Locating funds to support residential homes has constituted a challenging task, one that has been responded to with great drive and imagination. Typically, the organizers raised funds from friends and local foundations to get the project off the ground. Once started, a number of different sources — federal, state and local — have been found to pay for operating expenses.

Cheyenne Village's approach is illustrative of the way different sources of funds can be brought together to pay for different pieces of a total program. Room and board costs at the motel are paid through federal Supplemental Security- Income (SSI) payments. When residents move to the counseling apartments, they pay their own room and board from wages they earn. The federal government pays three-fourths and the local government one-fourth of the costs of the personal and social growth programs. Vocational Training funds pay for the salaries of the job counselors, while separate state funding pays for job placement and follow up.

The Community Living Program was able to pool together funds from general revenue sharing, the regional H.E.W, center, the state Developmental Disabilities Program and local foundations and agencies.

#### **Observations**

**Need for diversity.** These seven exemplary homes are strikingly diverse in their styles, philosophies, sizes, sponsorships and characteristics of residents.

This diversity is healthy because the community-based approach to care for retarded people is in its early, formative years. Furthermore, retarded people differ widely in their abilities and preferences. Diversity provides them choices in where they live.

Importance of program philosophy. The program philosophy is like a hidden hand which influences even the smallest details in the home. Who prepares meals? Can residents be home alone? Should there be group or individual activities? The decisions on these and hundreds of other programmatic questions are influenced by the program philosophy which guides the home. Frequently the philosophy is only implicit. However, it appears well worth the time and effort it takes to shape and continuously reshape the philosophy.

The concept of the retarded person and the goals of the program appear to have the greatest influence on the program philosophy. If the retarded person is perceived as being able to learn and grow, then the program philosophy leans toward independence and self responsibility.

There were a variety of goals in the homes. Most had more than one goal. They included:

- 1. providing a permanent residence;
- 2. training residents so they can live on their own;
- 3. fostering a sense of community;
- 4. influencing society by providing a model of human community;
- 5. providing a long-term protected environment to alleviate concerns of parents about the care of the children when they cannot care for them:
- 6. reducing public costs of caring for retarded people;
- 7. decreasing the population in state institutions;
- 8. altering adverse social behavior so that retarded people can live in less structured environments; and
- 9. providing an atmosphere for human growth and development.

Each home found its own balance between providing support and encouraging individual freedom. Institutional living may prevent learning by removing risk and uncertainty. One resident was not allowed to drive when he lived at home. Now that he has progressed through the Cheyenne Village training program and lives on his own, he drives his own car. In the group homes studied, personal growth and development was greatest where residents were allowed ample freedom to learn and develop.

Necessity of community programs and services. For a community residence to be successful, community programs and services must be available: employment, education, recreation, transportation, and counseling. The programs of all the homes in this study depended on community daytime activities. The implication is that in developing a community residence consideration must be given to the availability of a wide variety of community services.

Public transportation was of particular concern in all the homes since only in a few cases were residents able to drive and own cars. Most of the homes owned their own vehicles or had arrangements for special transportation. Residents were also trained to use public transportation but often such service was infrequent or inadequate.

**Sense of community.** In all of the programs studied, the sense of community was very evident. This was true for the large programs (Cheyenne Village and Community Living Program) as well as the small homes.

In the interest of meeting the "normalization principle," the goal of community residences frequently is "independent living," meaning living on one's own with ties to the community residence eventually severed. However, such a goal may overlook the need to develop a social support network. Would it not be more useful to encourage former residents to maintain their social ties with the group home?

Learning about one's community may be one of the significant lessons of the community residence experience. The community can also benefit, by learning that people who happen to be retarded are a part of the human condition and have something genuinely worthwhile to contribute.

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