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ABSTRACT

This study examined the impact of deinstitutionalization of the mentally retarded on their communities, the extent of availability of support services, and the extent to which the Connecticut Department of Mental Retardation assures adequate quality of support services and day programs for people with mental retardation living in community residential facilities. Project components include: (1) a research literature review; (2) a description of the current system of planning, residential development and quality assurance; (3) case studies of six communities where people with mental retardation have been relocated from institutions; (4) content analysis of relevant media coverage; (5) a study of 12 individual placements into community-based residences in these six communities; and (6) a phone survey of 5 service providers in non-urban areas aimed at discovering problems experienced in accessing services for their residents. Results call for "fine tuning" of planning, placement, transitions, community entry/development, accessibility, quality assurance, and global issues. The appendixes include: the study design and interview guides; a literature review; and a description of the formal system. Includes 47 references. (PB)

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BECOMING A NEIGHBOR

AN EXAMINATION OF THE PLACEMENT OF PEOPLE WITH MENTAL RETARDATION IN CONNECTICUT COMMUNITIES

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ED 323137

BECOMING A NEIGHBOR

AN EXAMINATION OF THE PLACEMENT OF PEOPLE WITH MENTAL RETARDATION IN CONNECTICUT COMMUNITIES

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INTRODUCTION

Although community residences for people with mental retardation are a well established reality in Connecticut and around the country, major gaps exist in our understanding of the role that these settings play in the community. The systematic examination of group homes and similar settings has been largely limited to a few narrow topics. There are numerous clinical and observational studies of life within group homes. Yet, research on the interaction of group homes and communities has been limited to a few topics such as the effect of group homes on surrounding property values and the correlation of various methods of community entry with community resistance. Research that carefully examines the complex interactions of residential programs and their surrounding communities is essentially non-existent. The few efforts to examine the interplay of the person with a disability, the service setting, and the surrounding community are based on an applied approach and seek to determine those program characteristics that can enhance the community participation of the residents. Basic studies that can increase the understanding of people outside the field of developmental disabilities are almost non-existent.

Policymakers, parents of people with disabilities, and the public in general have numerous questions about what is happening in the field of mental retardation. Out of the corner of their eye they have caught sight of events that seem to contradict the negative images that they have associated with people who are mentally retarded. However, it is only when they are directly confronted with a group home opening on their street or a major shift in their state's policies that some of these contradictions become crystalized. In addition to confusion about the capabilities and characteristics of people who are mentally retarded, terms like "group home," "deinstitutionalization," and "community integration" are not part of the layperson's vocabulary.

Group Home? Numerous service providers and advocates throughout the country continually proclaim to anyone who will listen that community group homes are just that -- homes like any other. And indeed, the statutes of many states, including Connecticut, and at least one decision by the United States Supreme Court, proclaim that small group homes enjoy the same legal standing as the single family home. Yet legal fiat does not change the reality of perceptions by policymakers, community members, and parents that, all good intentions aside, a group home is not just a single family house.

Deinstitutionalization? To many segments of the general public, that tongue-torturing neo-logism, "deinstitutionalization," translates into the dumping of people from mental hospitals onto city streets. It means homeless people cursing on street corners. What has not attracted the glare of media attention, except in the comparatively rare case of major opposition to a group home, is the fact that in the field of mental retardation, deinstitutionalization is happening and is working well. Group homes, community living arrangements, community training homes, semi-independent and independent living apartments represent the successful side of deinstitutionalization. There will soon be states that have no institutions for people with mental retardation.

Community Integration? The achievement of the goal of deinstitutionalization is reflected in a subtle change in the literature in the field over the last few years. The term deinstitutionalization is seen less and less frequently. Now the recurring term, the dominant issue, is "community integration." The field is no longer concentrating on how to get people out of large segregated facilities -- that capability has been demonstrated. The focus of interest now is on assisting people with mental retardation to become full members of the communities in which they live. Throughout the country there are numerous service providers and researchers who are exploring what integration means for people with very severe disabilities.

Yet, with all this emphasis on community membership, the field has not done its homework. It has persisted in looking at this process solely from the perspective of the person with mental retardation and the service provider. It has failed to fully realize that the rules of the game have changed. Membership in the community means sharing information. It means opening channels of communication to perspective neighbors. At the minimum, being a neighbor involves answering some of the questions that lie at the heart of this study: How are community residences fitting into the life of our communities? Are they really meeting the needs of the people living in them?

Increasing accountability to neighbors is just one of the costs associated with community membership. Membership also brings with it, whether desired or not, a requirement for full participation in the life of the community. Unfortunately, many service providers, with a background in clinical practice, fail to see their necessary engagement with communities as part of the process of developing a base of support among neighbors. Rather they see themselves as the defenders of right against the force of prejudice and ignorance that they perceive to be rampant in the community. It is their duty to re-educate the community by forcing it to see the error of its ways. As we shall see, in this report, if people with mental retardation are to become fully integrated members of the community this confrontational stance must be dropped in favor of cooperation and consensus building.

In this report we have attempted to give a balanced presentation of the information that emerged from our interviews. In many cases, a balanced presentation simply means giving voice to the divergent perspective of the many actors in the system. At other times we are called on to synthesize information and offer analysis and recommendations based on the weight of evidence in our data and our knowledge of national trends in services to people with mental retardation. Undoubtedly individuals with divergent points of view will disagree with specific findings, conclusions, and recommendations in this report. This is to be expected. We trust that these disagreements will act as an impetus for open discussion surrounding the points that we raise.

Overview of Final Report

The balance of this introductory section includes a brief description of the methodologies employed to conduct this study including a summary of the relevant literature, and a synthesis of the formal service system which we developed to assist us in our data collection. The next section offers a review of the major actors who are shaping Connecticut's system of services for people with mental retardation. In the findings section of this report we review what we found with regard to community residences and issues of service planning, community entry, individual planning, service availability, and community impact. This section concludes with a discussion of a number of global systemic issues that transcend these other categories. The final section offers a series of recommendation for future policy and practice. The body of the report is followed by six case studies of community residences, a report on our survey of rural community residences, and an analysis of how the media covered issues related to community residences in the three regions which were the major focus of this study

Method

This study was conducted in response to a request for proposals (RFP) issued by the State of Connecticut, Office of Policy and Management, pursuant to Special Act 87-73 of the State Legislature. According to the RFP this study was to have three major foci:

- the impact of deinstitutionalization on the communities in which people with mental retardation reside and the factors which influence community acceptance of residential facilities or people with mental retardation in Connecticut;
- the extent to which the community support services and day programs for people with mental retardation are available and accessible in the communities in which they reside, and;
- how and to what extent the Department of Mental Retardation assures the quality of community support services and day programs for people with mental retardation who reside in community residential facilities.

In an effort to address these three priorities, six major activities were undertaken: 1) a comprehensive review of the extant research literature on the relationship between community residences and the communities in which they are located (described below and contained in Appendix 2); 2) a description of the formal system of planning, residential development and quality assurance (described briefly below and contained in Appendix 3); 3) case studies of six Connecticut communities where people with mental retardation have been relocated from institutions; 4) content analysis of media relating to deinstitutionalization and community development (i.e., relevant newspaper articles); 5) a retrospective study of 12 individual placements into community-

based residences in the six selected community residences; and 6) a phone survey of providers located in non-urban areas specifically to elicit any special problems they have in accessing services for their residents. This report represent a synthesis of all these activities.

Rather than describing the methodology in detail, we will briefly discuss our rationale in selecting a case study approach. A detailed description of the methodology including site visit and interview guides is contained in Appendix 1.

A review of the relevant literature on community residences revealed that a quantitative approach to the study of community residential development was not merited. Numerous rigorous studies have repeatedly shown that independent of the socio-economic status of the community, or regional area, the presence of community residences does not have an impact on property values or property turnover rates. Quantitative studies have also shown no impact on local crime rates or the overall character of the neighborhood. Therefore, replication of these findings was not deemed warranted.

Of greater interest is the *process* of community service development. It is common knowledge that some community residential services meet with substantial resistance from local residents. Their efforts to block a residence from opening can range from petitions, to challenging the residence on the basis of local zoning ordinances, to lawsuits and even violence. Concerns of local residents were in part the driving factor behind this project. An understanding of the nature of these concerns and the circumstances that stimulate them is crucial to those who plan for and provide services.

Given this perspective a multi-site community case study approach was selected. Case studies are the best method to use when examining "how" or "why" questions in the context of complex social phenomena. "This is because such questions deal with operational links needing to be traced over time, rather than mere frequencies or incidence" (Yin, 1987 p.18). As Schramm (1971) points out, the case study approach illuminates a decision or set of decisions, the reasons they were taken and the results that ensued. Case studies also offer the advantage of exploring variables that are already identified and the opportunity of discovering relevant factors that arise through the process of data collection itself.

The multi-site community case study also offers a fertile method of probing into the other foci of the project, namely the availability and accessibility of support services in the community, and the adequacy of quality assurance measures of these services. Information on these topics was gleaned through the interviews of the many parties that were conducted for the case study. Descriptions and perceptions of the adequacy of quality assurance mechanisms can be contrasted with how quality assurance is formally described in DMR documents. The adequacy and accessibility of community support was ascertained through the interviews conducted with the relevant parties including day service providers and local generic community service providers.

It was initially proposed that this study select six Connecticut communities that represent opposite extremes on the continuum of community acceptance. That is, three residences were selected that enjoyed positive community relations and support, and three that encountered community resistance. A master list of community residences representing cases of community acceptance issues was devised. This list was drawn from recommendations by the regional staff of the Department of Mental Retardation, the Corporation for Independent Living, private service providers, and other persons involved in the field of community services in Connecticut.

The following criteria were used to narrow the list of recommended sites. Although interested in geographic dispersion, project staff were reluctant to draw only one type or site (i.e. one with either positive or negative community reaction) from any one DMR region. Residences with both types of experiences were recommended from each region and to only select may be to unfairly suggest that there are meaningful regional variations in rates of community acceptance. The Regions to be studied were selected in consultation with the advisory committee, based on efforts to sample the range of socio-demographic characteristics found in the state.

Having selected the regions, site recommendations in each region were examined on the basis of demographics of the community, public or private auspices, type of facility, type of residents, length of operation, and nature of community opposition or acceptance. After narrowing the list to assure comparability in some areas, providers were contacted to obtain permission to study. In some cases permission was not granted because the community opposition was still quite fierce and/or the homes were just opening. It was feared that the study, involving discussions with neighbors and town officials, may well exacerbate an already difficult situation. In some instances, recommendations of sites that encountered very virulent opposition were not selected because the circumstances were so idiosyncratic that the study would not offer meaningful results. Final considerations of the homes were based on whether they together represented an array along the dimensions of local demographics, types of clients and auspices. After final recommendations from the advisory committee to this study, the six sites described in Table 1 were selected as the focus of our case studies.

The key to this approach is the use of multiple sources of information which represent the full spectrum of experiences and perspectives related to community residence development. Indeed a total of 177 interviews ranging in length from half an hour to 3 hours in duration were conducted for this study. Table 2 presents a break down of the range of people interviewed. This diverse range of information enables a process of triangulation to take place. The research team is able, by comparison across sites, to highlight a full range of issues, problems, and solutions at the individual, site, and system level. By sampling broadly and deeply from the range of experience surrounding service development, we are able to offer a study that transcends the characteristics of individual sites and becomes a case study of the State of Connecticut's involvement in the development of community-based service for people with mental retardation over the last several years.

TABLE 1
CHARACTERISTICS OF CASE STUDY SITES

CASE STUDY #	AREA OF THE STATE	COMMUNITY REACTION	TYPE OF PROVIDER	DATE OPENED	NUMBER OF RESIDENTS & SEX	AGE RANGE	COMMUNITY MEDIAN INCOME	COMMUNITY POPULATION
1	CENTRAL	POSITIVE	PRIVATE	SPRING '85	6 CO-ED	24-46	$14,032	136,393
2	CENTRAL	NEGATIVE	PRIVATE	SPRING '86	6 CO-ED	55-70	$26,628	18,608
3	WESTERN	MIXED	PRIVATE	FALL '85	6 CO-ED	30-46	$35,717	54,849
4	WESTERN	NEGATIVE	PRIVATE	FALL '84	6 CO-ED	25-45	$35,717	54,849
5	EASTERN	NEUTRAL	PRIVATE	SUMMER '88	3 MEN	47-64	$23,073	17,843
6	EASTERN	NEUTRAL	PUBLIC	FALL '87	2 WOMEN	34-69	$16,673	28,842

TABLE 2

PERSONS INTERVIEWED BY PROJECT STAFF

DMR CENTRAL OFFICE STAFF	14
DMR REGIONAL STAFF	14
CASE MANAGERS	13
PROFESSIONAL STAFF (Therapist, Consultants, etc.)	16
RESIDENTIAL STAFF:	
ADMINISTRATORS	16
DIRECT CARE	20
RESIDENTS	9
PARENTS & RELATIVES	10
ADVOCATES (Including Court Monitor staff)	10
ELECTED OFFICIALS	9
OTHER PUBLIC OFFICIALS (Police, Fire, etc.)	18
NEIGHBORS	20
OTHER COMMUNITY MEMBERS (Merchants, Realtors, etc.)	8
TOTAL NUMBER OF INTERVIEWS:	177

Summary of Literature Review

The literature review discusses findings of studies that pertain to the:

- impact of community-based homes for persons with developmental disabilities on surrounding property values and related concerns;
- impact of such homes on crime rates, municipal services, and the "character" of the neighborhood; and
- factors that contribute to initial community acceptance or resistance to the establishment of the residence.

Over eighteen studies were reviewed. The literature review in Appendix 2 provides summaries of six studies that dealt with impact on property values related to the presence of group homes specifically for persons with mental retardation or developmental disabilities. The remaining reports studied group homes for a variety of populations. The findings among all of these studies are startlingly consistent, that is that group homes have no impact on property values, selling time, or property turnover rates. This holds true despite the socio-economic status or population density of the neighborhood. Studies were conducted all across the country and in Canada. Consistent findings are also reported on the absence of any adverse effect of group homes on the "character" of the neighborhood or crime rate.

The literature review also served to identify variables that may be significant in community acceptance patterns. The literature reports on the influence of the demographics of the surrounding communities (e.g., commercial or transient zones, racial composition, housing patterns) and on the extent of communication between neighbors and service providers around the establishment of the home.

Summary of Formal System Description

This section provides a basic overview of the major components the service system for persons with mental retardation in Connecticut. This outline was based on state mandates regarding issues of residential program siting, individual planning and placement, and resource development. The formal system description was a crucial element in the total design of this project since it served as the reference point, a baseline, for the community case studies. The system "map" or formal system description is based on three sources of information: 1) document review; 2) review of the court order in CARC v. Thorne; and 3) key informant interviews.

This system map is found in its entirety in Appendix 3. The intention here is solely to give the reader an introduction to major elements of the regulatory structure in the state which are referenced in this report.

CARC v. Thorne. Throughout this report there are references to "class clients" and "Mansfield clients." These are people effected by the consent decree signed by the state and the plaintiffs in a case brought by the Connecticut Association for Retarded Citizens (CARC) which challenged the care received by residents at the Mansfield Training School. The consent decree requires the state to provide enhanced services for class clients and requires that they be given an opportunity to live in the community regardless of degree of disability. The *court monitors* are individual appointed by the court to oversee the implementation of the decree. In addition to these individuals -- who are all from outside the state, there is a staff based in Hartford to monitor day-to-day requirements. In addition to the Mansfield suit there is a second consent decree, *the Southbury consent decree*, which extends a similar array of special protections to people who were in residence at the Southbury Training School.

Zoning Ordinances. Connecticut has two pieces of statewide zoning legislation that bare directly on the development of community residences. The first of these (Ch. 124, Sec 8-3e) states that local zoning regulations cannot treat any community residence housing six or fewer persons as anything other than a single family residence. The other law (Ch. 124, Sec. 8-3f) requires that no community residence for persons with mental retardation be established within one thousand feet of any other such residence without approval from the local zoning board.

Community Resource Development and Site Selection. The system map in Appendix 3 describes the process by which DMR regional offices select and contract with the service providers on the development of a group home, selection of residents, and selection of the residential site. Planning efforts and community saturation are also discussed.

Case management. The case manager plays a central role in the processes of placement, planning, transition, and service coordination for people served by the Connecticut Department of Mental Retardation. The case manager is the individual client's principal spokesperson within the service system. As the Department of Mental Retardation defines it:

> Case management is a statewide process by which the department directs, coordinates, and monitors services to persons with mental retardation from the time the person enters the system to the time they are discharged. Case management assists persons who are mentally retarded to identify and secure services which meet their individual needs for growth, and to secure that their rights are protected. Case management ensures that the client's Overall Plan of Services (OPS) is being prepared,

> modified, and carried out by the interdisciplinary team (IDT), and that services are relevant to the client's current needs. (DMR, Policy 8, p. 2)

Interdisciplinary Team (IDT). The key actors throughout the individual planning process are the members of each client's Interdisciplinary Team (IDT). The makeup of this group should reflect the individual's needs and is made up of people who have direct knowledge of the client. So the composition of each IDT will vary from client to client and is subject to change over time. Except where federal or state licensing regulations impose other requirements, the IDT must minimally include the client; at least one parent, relative, guardian, or independent advocate; staff from both present and planned residential and day program; a member of the staff from the present or planned day program who instructs, teaches, or counsels the client; the case manager; and other specialists who are involved with the client, including but not limited to a psychologist, psychiatrist, social worker, nurse, physician, occupational/physical therapists, and speech/hearing/vision/ communication specialists.

Overall plan of services (OPS). The basic framework for all individual planning for each client served by DMR is the Overall Plan of Services (OPS). The initial placement meeting is the first in an ongoing series of OPS meetings which will continue as long as the person is in a residential or day program administered by DMR. The OPS is rewritten on an annual basis with a review every 4 months. Each team member submits written objective progress reports to be reviewed at the semi-annual meeting to assist in evaluating the effectiveness of the plan or to highlight deficiencies in the programs. However, if an emergency or a substantial change in the individual's life situation occurs, a full IDT meeting can be requested at any time by any team member to reassess the OPS.

Transition plan. As outlined within DMR's documents the process of client movement or "transition" is viewed typically as another aspect of the individual planning process:

> If the current placement is determined by IDT consensus to require change, the team shall specify the short (less then one year) and long range placement objectives, including statements of the client's residential, day and program support needs. (DMR, Policy 11, p. 11)

The effort to manage client movement in an orderly coordinated fashion is contained in the Individualized Transition Plan. A major intent of this plan is to assure that all of the members of the IDT are clear on their responsibilities to make the transition as smooth as possible. The Individual Transition Plan outlines specific activities to be accomplished before, during, and immediately after placement; and assigns tasks to specific team members to ensure the smooth and successful transition to the new program. To further ensure that no necessary aspect of the person's move becomes lost in the shuffle, DMR has developed a *Transition Planning Checklist* which lists 40 discrete tasks that must be attended to in order to facilitate a smooth move.

Appeal process. State policy and the consent decrees in the Mansfield and Southbury court cases outline a series of very specific processes for assuring the right of clients, parents, guardians, and advocates to appeal any programmatic, transfer, or other decision which is perceived as not being in the best interest of the client. The Programmatic Administrative Review is used in disagreements over program decisions arrived at by the team. This process is available to the client or his or her family or advocate. *Transfer hearings* are used in disputed transfers. State law requires notification of the client and family ten days prior to the scheduled move. A transfer hearing is a more formal hearing than the programmatic administrative review and happens external to DMR.

Program Review Committee. These committees, made up of contracted professionals such as psychiatrists, psychologists, special educators and agency executives, are in place in each region and training school. Their chief purpose is to review individual client programs that employ aversive procedures and/or behavior modifying medications. DMR policies require program reviews before aversive programs or medications are implemented.

Quality Assurance. The state has an interconnected system of quality assurance procedures in place to monitor the quality of services and assure that people with mental retardation are protected from abuse, exploitation, or neglect. These procedures include:

- *Licensing.* With a team of 22 inspectors, the Quality Assurance Division within DMR is responsible for licensing all relevant residential programs including group homes, community living arrangements, group residences, residential schools, habilitative nursing facilities, and community training homes. All residential programs are inspected before they open and annually thereafter.

- *Independent Professional Review/Utilization Review.* Professional and Utilization Reviews are required as part of the federal regulations governing care in ICF/MR certified residential programs.

- *Day Program Quality Review.* Every two years, a team comprised of a person with mental retardation, a family member of a person who has mental retardation (or other interested citizen), a staff person from one of the DMR training schools or regions, and a provider conduct program quality program reviews at all day program sites. A similar process for residential services is being field-tested in one region.

- *Medication Tracking.* DMR has established a system to track the medication usage of all clients in the system. A report on medication use is required every six months for any client in a supervised living arrangement who is receiving medication prescribed to modify his or her behavior.

- *Abuse and Neglect Monitoring.* Multiple agencies in the state are responsible for the investigation of suspected abuse and/or neglect with regard to persons with mental retardation.

- *Class Member Protections.* Several procedures are in place which are specifically targeted on assuring the quality of services to class members. These include: *Individual Reviews* which are conducted by case managers in each region and involve the use of a short-form "red flag" 25 item checklist; *and Long Term Care Monitoring* which is directed at class members living in long term care facilities and includes a review of medication regimens, day program, medical supports, restraints, and family involvement.

THE ACTORS:
ORGANIZING DIVERSITY

Basic to the understanding of any biological or social process is an appreciation of the various forces at work within the system. In this section we have attempted to give some organization to the process of community residence development by describing some of the major influences on that system as they emerged in this study. What should become evident from this discussion is that within the system of services for people with mental retardation there is a complex interplay of currents. While these actors all contend that they are seeking the best for people with mental retardation that does not mean they are all always pushing in the same direction. This situation only becomes more complicated when the system is embroiled in the political life of a community.

The Department Of Mental Retardation (DMR)

The Connecticut Department of Mental Retardation is a major actor throughout this study. To people in communities, DMR is the disembodied "state." To providers, DMR is simultaneously the funder concerned with cost containment and the regulator with hard and fast expectations who is constantly looking over their shoulder. To advocates, DMR is the "institution" that is the adversary and yet is also an ally in meeting the goals of the consent decrees and developing a system of community services. To parents DMR is the bureaucratic system that controls their children's lives. To legislators DMR represents an ever growing piece of the state budget that is confronting them with increasingly complex policy decisions.

DMR has a clear direction as articulated in its Mission Statement (see Appendix 3). Yet this ideal of a system that is truly responsive to the unique needs of individuals, families, and communities must be actualized in an organization where the roles of funder, regulator and service provider must be balanced. So while the values of the Mission Statement may provide a framework for much of what DMR does, day to day decision making is also likely to be guided by pragmatic considerations such as available funds, court imposed deadlines, and the day to day priorities of provider organizations.

The Advocate. The DMR mission statement is one that has a distinct advocacy orientation not found in many other states. Interviews reveal that most Department employees and administrators at all levels are comfortable with this new role. In fact, this role seems to connect many people in DMR, as well as many providers, with their initial motivation for entering the field of mental retardation: to prevent the bad old days of mental retardation services, with its endemic institutional and individual abuse, from ever recurring. This clear sense of mission is a major strength of the Department and of the providers who work with it.

Unfortunately, within a complex political environment where compromise is sometimes necessary a strong sense of mission can create problems. Particularly, when dealing with communities, this may create a tendency to see issues as black and white. When motivated by a strong sense of mission individual representatives of DMR and providers sometimes interpret legitimate community

concerns and misinformation, often resulting from lack of knowledge, as prejudice and opposition. Further, in discussions of funding priorities, community integration, and individual program planning, this sense of mission may create an attitude that comes across as a self-righteous stance which can foster confrontation rather than collaboration.

This problem is not only associated with representatives of DMR. As we mentioned above, this clear sense of mission dominates the field. However, when a person who is publicly perceived as representing "the State" projects a self righteous, "we're right, you're wrong" attitude, there is a potential for a strong negative reaction.

This clear sense of direction provides a strong set of criteria for making decisions and establishing priorities. In that regard it is the major strength of the DMR. In many others states, services operate without a clear value base. Decisions in these environments are "value-free," purely pragmatic, and shift with the each gust of the political wind. History has clearly demonstrated that such an environment does not serve the best interests of people with mental retardation. The key point here is a need to sensitize DMR employees, community developers, and providers to the way in which their strong proponence for community residences may be received by the lay public. Developing this awareness should enable them to be more sensitive in their interactions with communities.

The Funder and Regulator. The second major role filled by DMR is as funder and regulator of all services in the state. Needless to say this role presents a high potential for internal conflict with the advocacy role. In addition, this places the department in adversarial relationship with every provider in the state. The priorities established by the department, its regulations, its budget caps, its changing procedures, and so forth may be seen by providers as barriers to their real mission of meeting the needs of the real people they serve.

The Provider. Finally, DMR continues to fill a major role as a provider of a whole range of services in the state. These encompass day programs, institutional services, community residential services, case management, and family support services. With this role comes the further complication of the advocate for community acceptance, simultaneously providing services and acting as the watch dog over the service.

Private Providers

As this study progressed, it became apparent that all residential providers did not fit neatly under a single label. They all had a certain unity of interest in dealing with DMR to maximize their rate of reimbursement, simplify bureaucratic procedures, and obtain assistance in dealing with communities and accessing supportive services. But beyond this core of interests we found the provider community presented a very diverse picture.

Our interviews suggested that there is a four part typology of private providers. While the charter of all the provider organizations may sound the same, there is a great deal of variability among organizations which seem to fall into some rather specific patterns. The organization's attitude toward DMR, its approach to communities, its interaction with other agencies, its administrative structure, and even certain aspects of how its homes are run reflects where an organization falls in the typology we outline in this section.

Established community-based providers. In the course of the study we spoke with providers who had long and successful histories within their communities. These providers tend to have well respected members of the community on their boards including parents of disabled persons. Board members and provider staff tend to be very active in the community and are able to build enclaves of support within the community to endorse their endeavors. They are extremely conscious of public relations and wish to preserve the good will and trust they have built up within the community.

In conversations with such providers, we found they expressed that their mandate is to serve at least as many clients from the community as clients from institutions. Their perception is that there are persons who have lived in the community, usually with their families, for many years at no cost to the state. They believe that the needs of these persons for group home placements are often as pressing as those of persons in the institutions. This attitude is in conflict with the pressures placed on DMR as a result of the court action to deinstitutionalize. These providers are in the position to consciously decide not to expand the number of group homes they operate. They also tend to perceive that if they were to provide residential services to the very disabled clients still remaining in the institutions, they would not receive the monetary support from DMR to adequately serve these needy clients.

Highly professional organizations. For the most part organizations in this category trace their roots to experience gained outside the state. Some of these providers run settings in numerous states. In some cases they have been actively recruited by DMR to start services in Connecticut that many of the established providers in the state have been hesitant to undertake. This highlights an essential characteristic of these organizations -- their principal loyalty is to DMR and not to specific communities in Connecticut. As evidence of this point, some of the residential settings run by such agencies in the case studies were completely occupied by class clients who have lost contact with their families during their years of institutionalization.

Once a home is established this type of organization typically recruits an advisory panel of community members. However as a corporate entity their major officers are likely to be located outside of Connecticut.

These organizations project a highly competent professional image. This is often associated with a central office with a well developed infrastructure of

support staff and offices for the agency specialist (e.g., nurses, behaviorist, etc.). Several of the people we interviewed noted that in dealing with these organizations one often had the sense of encountering a mini-bureaucracy because of the administrative structure they had in place. Some of these same informants raised concerns about the amount of money which was allocated to overhead expense by these highly professional organizations. They saw the organization as housed in very nice offices, top heavy with administration, and with support staff who in some cases were paid more than direct care workers in the group homes. While no one questioned the competency of these organizations, these other concerns led some of our informants to wonder aloud where the organizations priorities lay..

Finally, the image which these groups project in their PR materials and in conversation is a "we have the skills and experience to deal with the very difficult client--we can do it!" In line with this image the homes run by professional organizations have all of their paper work up to date with all goals and objectives stated in the proper behavioral terms.

Well connected new agency. These agencies tend to have boards with varying composition. They often start on a shoe-string budget and have many financial struggles to overcome. They make good use of formal system resources such as site developers and management agencies. With their lack of financial resources, however, they often don't have the manpower it takes to thoroughly study potential clients to see if they would be appropriate additions to their group homes. They have not developed an adequate informal network within the system. Because of their lack of resources and experience, they sometimes end up in difficult situations with clients that result in disruptive and/or failed placements.

Small unconnected agency. Usually located outside of large urban areas, these agencies are confronted with many of the same problems as well connected new agencies, but also have been unable to gain access to the resources available within the formal system. They tend to be on precarious financial footing.

The Growing Infrastructure: Statewide Resources

As we noted at the outset, the system of community residences has become well established in Connecticut and throughout the country. With this establishment, the system has developed its own infrastructure of resources to support its activities. In our study two major components of this system emerged as significant. The first, the Corporation for Independent Living, in its role as a site developer, has a major influence on how a community residences are perceived and received in a community. The second, Residential Management Services, through its role in recruiting, training, and managing a large percentage of the residential staff around the state has a major impact on community residences and their surrounding communities.

The Experienced Developer: CIL. The Corporation for Independent Living (CIL) is a not-for-profit entity established about 10 years ago to assist residential agencies with the actual process of site identification, purchase, and development. This agency, has over the years, dealt with almost every conceivable situation related to site development and neighborhood entry. In talking with representatives of CIL, one is impressed with the degree to which the complex process of developing a community residence site can be routinized. The experience and expertise available in this organization is a valuable asset to any community agency in the state (See Appendix 5 for a copy of CIL's brochure). In addition to its specific expertise and fiscal resources, CIL is able to connect the new provider to other needed resources within the system such as management agencies.

CIL makes all of the sites which it develops accessible for people with physical disabilities. In addition CIL, based on its experience, identifies more renovations than an agency working on its own might undertake. This concern for detail is clearly borne of CIL's extensive experience and its clear focus on these sites being permanent homes for people with disabilities. While this lead to some additional cost and a longer development time, it does result in a growing stock of accessible housing in Connecticut.

When a property is identified and agreed to by a provider agency and DMR, CIL purchases the house using funds from its bond issue. Under the terms of the sale, CIL owns the property and remains responsible for upkeep of the major systems of the house. The property is leased to the provider for a period of 25 years. At the end of that time the principal and interest will be returned to CIL and the property is signed over to the provider agency.

It is worth mentioning here that CIL makes a conscious effort to use realtors, architect, and contractors in the community where the site is located. By sharing the business with the local community the financial benefits of the site are returned to the community, a sense of community involvement is created. As a result an ever widening circle of architects and contractors is educated about issues related to accessibility and the needs of people with disabilities.

In dealing with often overly rigorous oversight by town zoning commissions and fire marshalls, CIL's attitude is to be non-confrontational, even in cases where they know that the stipulations being required may be beyond the requirements of the law. They feel that the avoidance of the need for hearings and timely completion of projects far outweigh these often moderate increases in cost.

According to CIL officials, they try to be conservative in their interpretation of the relevant regulation, since at any time a municipality's inspector may change and after the fact hit the provider agency with a list of deficiencies. This is not to say that they are passive. CIL developers very actively point out to an inspector when they are stepping well beyond the bounds of what the law demands and of

course these retorts are backed up with a firm foundation of experience and a thorough knowledge of the relevant laws.

The Experienced Management Agency: RMS. The management agency responsibilities include staff hiring, training and general financial management of group homes. RMS has enabled inexperienced providers to realize their goals of successfully operating group homes.

One major issue that was raised in the study was in regard to staff training. There are two levels of training. The first level deals with issues related to meeting the demands for compliance with specific regulations. This entails addressing issues such as first-aid and safety, how to be a part of the individual planning process, psychotropic drugs, and how behavioral programs work. The second level of training needed in a community setting revolves around addressing some more intangible but nonetheless crucial issues. Here the focus should be on responding to the unique needs of particular clients, being responsive to the characteristic of the community, facilitating the real community integration of residents, and fulfilling the public relations role of the direct service worker. In regard to the second level of training which can be so crucial to the success of a residential setting at least one of our informants expressed concern about the thoroughness and creativity of RMS.

Court Monitors/Independent Advocates

The court monitor's office and the independent advocates have the unique advantage of having the most clear cut role in the system. By definition what they say they do is what they indeed spend most of their time doing. Their job is: 1) to assure that services to class members as a group and as individuals conform with the requirements of the consent decree, and 2) to represent the interests of people with mental retardation who do not have an independent spokesperson. In this formal role, they act as a major force influencing all other aspects of the service system in the state.

What is instructive is the informal use that is made of monitors and advocates by other actors in the service system. We heard on several occasions that a trump card in negotiations among services is the implication or the stated intention to call the advocate or the monitor if a matter is not resolved to the satisfaction of one of the parties. This underscores the ability of advocates to goad the system on formal and informal levels.

Parents

The very existence of community residences for people with mental retardation can be traced to the advocacy and service provision efforts of parents. Parents are the fundamental political base that DMR can count on to support it

before the legislature. So on one level, as a group of voters, parents of people with mental retardation are one of the most powerful components of the service system, but as individuals these parent may be the weakest.

Our interviews with parents, advocates, and representatives of DMR revealed that in Connecticut parents of people with mental retardation are simultaneously urging growth and counseling restraint in the development of community programs. This situation cannot be reduced to the simple pro-institution and pro-community. The reality is that all parents seek the best for their family member with retardation. But their definition of the best is often informed by different sets of experiences and expectations.

Integrationist Parents. Parents affiliated with the Connecticut Association for Retarded Citizens (CARC) were the driving force behind the litigation that is reconfiguring services in Connecticut. An abhorrence of the abuse in large segregated facilities and a belief that living in the midst of the community is simultaneously the best clinical intervention and the most effective quality assurance mechanism have served to unite an increasing group of parents in demanding community-based programs for all people with mental retardation. Increasingly this perspective is being reinforced by information from around the rest of the country and from a supportive administration at DMR.

Cautious Parents. As a counterpoint and a balance, other parents in Connecticut remain unconvinced that a totally community-based services system will be adequate to the needs of people with mental retardation. They promote a cautious go slow, wait and see attitude. Based on their experience they remain suspicious of radical change and are unprepared to trust to the good intentions of DMR. It should be made clear that these same parents are also supporters of the development of community residences as the appropriate service for most people with mental retardation, but they are just not prepared to abandon completely some components of the earlier model.

A number of factors seem to influence the thinking of these parents. Many of them have lived through a period when the only resource available was the institution and many of them know that institutionalizations, based on the best professional advice of the day, was best for the life of their family. Now the dominant professional opinion has changed. This leaves them wondering in what direction the next change of opinion will blow. Will families once again find themselves dealing with disability completely on their own?

Some of these same parents were very involved in the lives of the institutions where their children lived. They know that the reputation which some of the facilities in Connecticut had as the finest, best run facilities in America was well merited. They invested heavily in these facilities and saw that investment returned in good care for their child. They remain unconvinced that a variety of small settings scattered throughout the community will achieve that level of excellence particularly when it comes to services for the most severely disabled

individuals. They continually question who will be there to look over the shoulder of these underpaid direct care workers to guard against neglect and abuse.

Finally, this group of parents spent years lobbying and fund raising for specialized services to meet the needs of their family members. Now all the talk of community integration and generic services makes them nervous. Many of them have experienced the community as a cold closed place where there was nothing for their family members. They know from experience that "generic" services can easily become closed. They can further make their case by pointing to people with mental retardation living in the community who they see as receiving inadequate services and being cut off from a supportive social network--adrift in the mainstream.

Summary

Within the network of people concerned for the welfare of people with mental retardation there is universal agreement on the need to nurture the development of community living opportunities. Yet beyond that single unifying consideration there is a great deal of diversity. Literally every group of actors in this drama has its own perception of what the priorities are in this process. As these diverse actors interact with one another and with the communities of Connecticut, their experience offer some valuable lessons for them and their peers around the country. In the balance of this report we will point out what we observed by retrospectively watching this process unfold. We trust that this effort to synthesize this process will inform the policymakers who must oversee and fund the system and also aid the actors in better achieving their common goal of doing the best for the citizens of Connecticut who have mental retardation.

FINDINGS

Conducting this study was a gradual process of distillation. We began with wide ranging interviews with informants who represented the full range of interests concerned with the development of community residences for people with mental retardation. In the case studies presented later in this report these data were synthesized with a focus on the issues related to specific locations. The experience reported in the case studies, interviews with rural providers, information from the analysis of media coverage, and interviews with a focus which went beyond the concerns of a single site were analyzed in an effort to identify the major issues in developing community residences. It is these issues which are presented in this section of findings. An effort has been made in presenting these findings to integrate the diverse perspective which emerged from our multiple sources of information. What emerges is a discussion of a wide range of topics that might appropriately be read as "lessons learned" from Connecticut's experience of developing community residences. Further, where the points of view of our informants are so divergent as to preclude synthesis we have attempted to highlight what lies at the heart of the dispute. As a final note, it should be recalled that any methodology -- case study included -- has limitations. Though inferences have been drawn it should be remembered that only six sites were studied. This being said, the reader is cautioned to view these findings as more suggestive than conclusive.

PLANNING

When the earliest community residences for people with mental retardation were developed in Connecticut, planning was relatively simple. Homes were created when a parent based organization approached DMR with a proposal to develop a group home in their own community for their children. Regulations were minimal. DMR's response was likely to include negotiations over a budget and discussion of the few relevant laws and regulations. More than likely community acceptance would not be an issue since the parents could individually approach their neighbors about the need for this home for their children. Staffing would be an easy matter. After all, it only involved hiring one set of "house parents" and a few relief people. What is now the relatively complex task of finding, financing, and purchasing homes, was a relatively simply undertaking. Good will, good intentions, volunteer help, committed workers, and parent energy carried the day.

Today this straightforward process seems like ancient history. Yet, these good old days were barely a decade ago. Many of the people who are currently involved in the service system in Connecticut can trace their origins to an experience similar to that described above. Ten or fifteen years ago, the community residence was the exception to the rule. Today, community residential development has become "institutionalized" and community homes are increasingly the service of choice for people with mental retardation, and the standard against which other services are judged. Providers who once worried about where to go to get a couch donated to a group home are today confronted with complex issues of system, site, and transition planning. The following section examines the multiple levels of planning required to develop responsive residential services: system planning, site planning and individual planning.

System Planning

The last ten years have seen a multitude of new factors come into play in the planning process. The dominant focus of the field has shifted from the need to clean up and prevent the abuses associated with life in institutions to a concern with the rights of people with mental retardation to live in the community and to receive the support services they need. This shifting focus has been accompanied by growing state and federal regulation of community programs with an eye to preserving these very rights while simultaneously assuring that the abuse associated with the past does not reappear in the community. While the shifting focus of the field and increased regulation makes systemic planning difficult enough, this task is further complicated by the varied demands that advocates and family members place on the service system.

Balancing Priorities. Our interviews with parents and advocates and the review of the newspaper coverage of community development issues reveal that DMR and its providers are simultaneously being called on to address some very different sets of priorities. First, they must rectify some of the residual problems associated with earlier models of services. Second, they must respond to the very

different expectations of families and advocates who speak for people whose life experiences have been very different from those who were housed in institutions. Any efforts to plan the system of services must be informed by an awareness of these competing demands. Our interviews reveal that the diverse demands being placed on the system of services can be summarized under the three following categories.

1. **People who have lived or are currently residing in states schools and regional centers.** These are likely to be the last people with mental retardation in Connecticut to have a long term institutional history. The needs of many of these people as expressed in the court decree are currently driving the system. The fact that many of these people have, over the years, lost their connection to the community often complicates the process of community placement. Since many class clients have lost active family involvement over the years they are dependent on the legal expertise of the court monitor and appointed advocates to assert their right to services. Unfortunately, this dependence on professional representation reinforces the image of these people as outsiders to the community.

2. **Adults with mental retardation who are living at home** with aging parents. Some of these people may have had limited or no access to special education and day services. As a result, a number of these people may be invisible to the service system until a family crisis requires a request for assistance. The needs of these families focus on periodic respite and the desire for an orderly transition to some type of supportive living arrangement when they are no longer able to care for their family member. Because resources are not open-ended, the needs of this group have come into conflict with the demands that class clients have made on the system of services during the last several years. Parents who have kept their children at home see themselves as shut out from services. They see the energies of organizations that they have founded and nurtured diverted to serving class clients and away from their own children.

Up to this point the tension between these first two groups has characterized service planning in Connecticut. However, the very different demands of another group looms on the horizon.

3. **Children and young adults** who have had extensive special education services. This group potentially presents greater challenges to the service system than the demands of either of the other groups. Since they have much higher expectations from the service system. This group increasingly demands a full array of family supports, not just respite, and expects residential supports to be in place so that family members with mental retardation can move out of the home at the appropriate time. In addition there is a strong likelihood that this group will not find some of today's residential models acceptable; they will be looking for settings that are literally constructed around the specific needs of individuals. The fact that the needs of this group have largely been met by the education system has enabled the mental retardation service system to focus on the demands of other groups. Yet this third group is getting older, and any effort at long range

systems planning must take into account the fact that future needs present new challenges.

Caught in the middle of this tug-of-war is DMR and the state legislature which must balance these competing demands while keeping both the federal court and their constituents happy. Also thrown into this tenuous position are many of the newer providers who have either just gone into business o. have recently moved into .he state. Some of the criticism we encountered of these new providers seems to be related to a perception among some community parents that these agencies ignore community needs in favor of meeting the needs of class clients.

The divergent analysis presented here does not intend to ascribe motive or to make judgements about who is right and who is wrong. The community parents are not opposed to the needs of the class clients. Rather, the issue for them is services for their family members with disabilities. Presently, they see themselves getting little or nothing. One parent representing this perspective told us that in her region the only family support is a minimal amount of respite -- a service that is available solely because the regional director has manipulated the budget to assure some support to families. The issue is limited state dollars and limited services coupled with the perception that the very people who developed the community system now find themselves closed out of services. Individuals representative of this group are not opposing the needs of the class so much as they are asserting the needs of their family members.

This conflict over resource allocation is the major force at work in the Connecticut system of services for people with mental retardation. It overrides many of the issue that are nominally the major focus of this study. The resolution of this conflict will determine the future of services in Connecticut for some time to come. A study such as this cannot begin to address such a pervasive and important issue. It can only highlight the issues and facilitate discussion that can resolve these tensions over time. In the end, community parents, DMR, the court monitors, and the legislature must engage in a frank and open conversation that addresses these issues and resolves them in a manner responsive to the needs of all parties.

In the balance of this section we return to more circumscribed issues of system planning as they relate to some specific problems confronting the Connecticut mental retardation system as it moves to a largely community-based configuration.

Agency Development and Support. One major component on the DMR planning agenda should be the development of the infrastructure of the agencies that provide residential services. Some structures such as the Corporation for Independent Living (CIL) and Residential Management Services (RMS) are in place to assist in this effort, but it is not at all clear that such efforts are systematic. Clearly all agencies do not have the same level of expertise in areas such as community relations, staff development, resource development, and management. This lack of skills is particularly apparent in the case of the small

disconnected agency and the new agency. The study interviews reveal that some of the problems encountered in the process of residential development can be attributed more to lack of skill, flexibility, and innovative ideas than any other factor.

The mental retardation system has become relatively good at identifying specific skill development objectives at the individual level. It seems appropriate that DMR look for the same type of skill development on the part of the agencies with which it interacts. An individualized agency development plan should also be associated with general regional and statewide efforts in the area of information dissemination. There is a clear need to exchange information on issues such as community entry, community relations, innovative approaches to services, and staff development.

Developing and Nurturing Human Resources. Another key planning issue that DMR, provider agencies, the state legislature, and the state education system must address in a timely fashion is the development of the human resources needed to support the growth in community based human service programs. This is not just a problem in Connecticut -- it is a national issue. But it clearly has a major impact on the quality of services that a state is able to offer its citizens. There are two major considerations here: 1) the development of skilled professional resources; and 2) issues related to direct care staff.

Professional Development. It comes as no news that there is a major national shortage of skilled professionals in areas such as nursing, behavioral intervention, and physical, occupational, and speech therapy. Yet when there is a need for people trained to deal specifically with some of the special needs of people with severe disabilities, the field narrows substantially. If a further priority is placed on people with substantive experience in integrated community-based programs, most of the experts can be identified by their national reputations. This limited number of highly skilled people highlights the need for DMR to continue to use a range of consultants in some of its efforts at program development. However, consultants do not solve the long-term problem.

Throughout our study, providers pointed to a lack of professionals as a major day to day problem. The changing face of the job market is generally identified as the major reason for these massive shortages. But, again identifying the source of the problem does little to meet an immediate need. The fact is that the development of a new pool of professionals must be supported.

DMR, the University Affiliated Program, and the state university should explore the possibility of creating personnel development programs in the areas of behavior management, case management, and physical, occupational and speech therapy that are specifically targeted at the needs of the population served by DMR and its provider agencies. Connecticut is uniquely situated to provide national leadership in the development of professional training models that meet the special demands of a community based system of services. As an incentive for

retaining the graduates of these programs in the state, the possibility of tuition credits or student loans that would be forgiven after a specific period of service in the state should be examined. Seemingly, such incentives should draw qualified candidates from outside the state who would be attracted by a unique program and an affordable education.

Direct Care Staff. Our study in Connecticut and other efforts around the country have consistently revealed that the skill and sensitivity of one person can make a profound difference in the life of an individual and the success of a program. Yet the crisis in obtaining quality direct care workers is at least as serious as the shortages of professional staff. Commendably, Connecticut officials have attempted to address this issue by providing for an improved pay scale for community residential workers working in private settings. Interviews reveal that over the short term this has had some impact on extending staff tenure.

What is not addressed in the discussion of the staffing issue is the nature of the work force in this field, the expectations of the job, and future directions. These issues in themselves merit a report at least as extensive as the present undertaking. Some of the areas that should be examined are:

- *Work Force.* There is a strong possibility that the work force in this field is by its very nature unstable. Specifically, three groups seem to work in the area of residential services: 1) a transient personnel who are associated with the service industry and who change jobs frequently within the same sector of the economy; 2) young people who are attracted to residential work for a brief period of time then move on to graduate schools or to further careers in another field; and 3) people from either of these groups who come into the field, stay with it, and quickly move to management positions.

- *Job Expectations.* The wide range of demands placed on the direct care, essentially entry level worker, is not appreciated by the general public or some members of the professional community. Awareness of the wide range of demands is one source for the anxiety with which some knowledgeable individuals, usually parents, regard residential workers. They are asked to fulfill roles in self care, building maintenance, skill development, behavioral programming, and public relations in relatively low paid positions that are valued by only a small segment of the population.

- *Future Directions.* There is an increasing emphasis on a changing role or different roles in residential services which will concentrate the energies of the direct service worker in areas such as connecting people with the resources of the community and nurturing relationships with members of the community.

These factors should be taken into account in planning efforts related to direct care staff development. Certainly a decent salary remains a priority. Nonetheless, over the short term, training efforts and expectations should consider the transitory nature of the work force. From a bit broader perspective thought needs to be given to defining and nurturing the new roles and new "job categories" that will be needed to foster community integration.

Site Planning

Over and above the many specific issues related to the relationship between community residences and communities (to be addressed in a later section), there appears to be a well thought out, rational process of site selection and development at the DMR regional level. This process clearly reflects the experience of the region and that of CIL and other providers who do their own development. In some areas, the "sins of the past" -- including poor site location and "saturation" -- have been taken to heart and more responsive policies have been developed. DMR is particularly careful to avoid residential development in communities where there has been major opposition, intense development activity, or concern regarding possible saturation.

Saturation is a tricky issue. It is based on the premise that a community should have a "fair share" of the region's community residences. In a few communities in the state, some neighborhoods were "saturated" early on in the process of community development with people with mild to moderate handicaps who needed to be centrally located and have public transportation available. This was inevitable since there are only so many communities in Connecticut where public transportation is readily available. Part of the sensitivity about saturation is associated more with some of the negative experiences in mental health where there are stories of former mental patients being located en masse in communities. Over the long haul the question will be defused as communities are asked to provide for people who have always lived there. At this time, people returning from state schools who have not lived in a community for 10, 20, or 50 years are sometimes seen as outsiders. Planners must be very sensitive to the perception on the part of a community that it is being asked support a disproportionate number of community residences.

Early development in the some of the State's larger communities was governed by the conventional wisdom of the day that fewer problems of community opposition arise in transient urban areas. The effect of these two considerations, access to work and transportation and the "desirable" character of transient areas, did lead to concentrations of DMR clients in some areas. This has led, in due course, to the bad situations that critics of community programs cite most frequently.

The good news is that interviews clearly indicate that these lessons have been learned. Planning is not again likely to take the path of least resistance. Targeting new areas, however, has led some communities that were previously

exempt from development to respond negatively. In addition the perception remains in some community officials that if they present a desirable site for residential development they will be overwhelmed in the same way they have seen some other communities targeted in the past.

Unfortunately at times the DMR strategy of identifying some communities for development because of lower real estate costs or the present absence of any group homes can backfire. Recently, a community was up in arms because it became aware of three residences opening within a few months of one another. The perception was that the town was being overrun. In fact it had been targeted about a year earlier because it was an area of reasonably priced real estate which to that point had not had any residential settings established.

A major force on the side of DMR and the agencies doing community residence development is the protection provided by state zoning legislation. This law (Ch. 124, Sec. 8-3e) requires local zoning authorities to treat residences for 6 or fewer people with mental retardation and their support staff in the same manner as a single family residence. This makes it theoretically possible for community residences to be developed in any neighborhood in the state. We found that this protection enables developers to approach their task in a self confident fashion. They were not forced to be defensive about their activities. Occasionally, however, this assurance also led to a rather cavalier attitude regarding the opinions and concerns of neighbors and community leaders. For the most part, though, we found that developers avoided flaunting this legal protection in the face of community members in favor of a conciliatory approach.

DMR has attempted to be very careful about the 1000 foot rule, which restricts the distance between community-based residential programs. Such attempts require careful coordination with other human service agencies. To date coordination has often been done on a fairly informal basis, and the degree of cooperation seems to vary from region to region. There is a clear need for a more formal cooperative process among all agencies at the state and regional level. Computer technology seems to make the management of a basic information system using zip codes or street addresses a relatively easy matter. Once online such a system would be a relatively inexpensive yet valuable resource.

Over and above the basic need to keep track of where various agencies have located their programs, the increased focus on community-based programs in all sectors suggests a need for ongoing inter-agency collaboration. At the minimum, there is a need for periodic consultation about future development plans. Given the diverse experience of the various agencies in this area of community development it seems likely that such linkages could soon expand to include discussions of other substantive issues related to the relationships of services to their host communities.

A final word on the 1000 foot rule seems merited. The intention of this regulation is commendable and it should be retained. However in our study we

encountered at least one instance of what seemed to us to be overly inclusive enforcement. In one community a single man with mental retardation was going to be forced to leave the Community Training Home in which he lived because it was within a 1000 feet of a group home. In reality, a Community Training Home with a single resident has no more impact on the community than a home in which a member of the family has a disability and happens to live within a 1000 feet of a group home. It would seem reasonable that the rule should contain an exception for the case of foster homes and community training homes with only one and perhaps two clients.

The cost of property may continue as a major public relations problem for DMR and its service developers. A typical home owner who may have struggled to make a down payment for a home may find it hard to believe that the cost of real estate is one of the lower costs associated with running a community residence. Further since the general public is unfamiliar with the substantial costs associated with the maintenance of large public facilities, they may find it hard to believe that the cost of multiple properties in the community is no more than a congregate setting for the same number of people. Certainly DMR's current emphasis on small group settings (3 person) will help to control the cost of single settings. As one CIL representative pointed out, there is a relatively large stock of moderately priced housing available which will accommodate three people plus staff.

Over and above the efforts to purchase moderately priced housing the most efficient means of controlling real estate cost can be found in supportive living models of service. In these situations the residents lease or own the property (perhaps as part of a trust or inheritance) and the provider, usually DMR, provides staff only support in the home. The major challenge of this approach is developing flexible approaches to staffing that provide people with a sufficient level of assistance and direction to negotiate issues of daily living and relationships with the community.

Staff coverage in these situations is usually not 24 hours a day and that has also been a source of savings for service providers. In practice, this means that the supportive living approach has generally been used for people with mild to moderate retardation and no associated physical disabilities. It is worth noting that a number of states have recently begun using this model with more intensive staffing as a cost effective approach to serving people with severe mental retardation and/or physical disabilities. This often entails the staff being available 24 hours in a neighboring apartment and working in the client apartment full time when the people are home.

Supportive living, as it applies to renting, has received added impetus as increasing numbers of people with mental retardation move via supported work into competitive employment. While their salaries may not cover the full cost of rent, their contribution is substantial. The taxpayer sees a major saving because tax dollars are now called on only to supply a subsidy and not meet the full cost of the living arrangement.

Under a supportive living model, the property is really the home of the people living there so the 1000 foot rule does not apply. Nonetheless planners need to develop their own version of that guide for supportive living. Otherwise, the old issue of saturation may be re-emerging when the people being served by a supportive living program are directed towards a few apartment developments in a particular town. The efficiency of this approach involves using a limited clustering of clients. For example, support staff may live in one apartment in a large complex and serve people living in several apartments throughout the complex. Nonetheless, care should be taken to assure that these arrangements are distributed throughout the community so that a single development does not suddenly become an unlicensed group home.

Individualized Planning

The bulk of our discussion on this topic is contained in subsequent sections on individual planning and access to services. Here we would like to discuss briefly the issue of individualized planning as it pertains to planning at the system and site level. A major move in the field of mental retardation services is towards services that are client driven. Essentially this approach holds that highly focused individualized planning should be the major vehicle for all levels of planning from establishing training objectives to requesting funds from the state legislature.

The current direction in DMR in the area of eliminating the client levels classification system and the improving the individual planning process clearly demonstrates a sensitivity to individualized planning and indicates an effort to respond. However, in some other areas procedural requirements have unwittingly subverted efforts to truly structure a setting around the specific needs of individuals.

Interviews seem to indicate that some of the "problem placements" can be attributed to a failure to use individual centered planning or a failure to carry out an individual planning effort once begun. Sometimes these problems can be attributed to the limited expertise of new providers or new employees who may not be sufficiently attuned to the issue of individualized planning and so proceed as if services can be planned by "plugging anyone into the next available slot." In some of our sites, it was clear that many of the problems that providers encountered were the result of their limited resources during the establishment of a site. They did not have either the resources or the foresight to send staff people to Mansfield or another location and conduct an intensive pre-placement evaluation of potential residents.

The need for a thoughtful individualized approach is underscored when a specific characteristic of a person is offensive to neighbors. Two of our case studies contain complementary examples of this. In both instances we heard of a person who screamed persistently. In the first case, the provider became aware of this behavior on preliminary visits to Mansfield and thought about the proximity of the house in the neighborhood where the person was going to live. The provider

then approached DMR to "trade" residents and place the person who screamed in a home with a great deal of open property around it and place a much quieter but socially gregarious client in the original home. In the second study, a new provider agency did not have the foresight to anticipate the problem that a screaming resident would pose with nearby neighbors. Now this provider is faced with an awkward situation which has led many neighbors to be less than positively disposed toward the site.

At times it is clear that the pressure of placement time lines can undercut truly individualized planning. We heard several stories of sites that were very well conceived to match the specific needs of residents in wheelchairs but are not now occupied by anyone with physical limitations. The most telling case involved a home that CIL was developing based on the understanding that it needed to be completely accessible with fully adapted kitchen and bathroom and meet all fire codes related to people who could not evacuate be themselves. It is true that all CIL homes are accessible, but this level of full accessibility is only undertaken when it is necessary since the full range of adaptations is very expensive. Literally at the last minute the people slated to move into this fully accessible home were changed because of the need to place a certain number of class clients. The people who moved in have absolutely no need for a fully accessible site. When some of the people originally targeted for this site did get a placement it was in less than optimally accessible locations.

Some of the providers and site developers with whom we spoke clearly felt that it was necessary to slow things down a bit and refocus on the need to do all development on an individual-centered basis. A representative of CIL pointed out that he preferred to know who the actual people were who are going to live in a particular site. In that way he could plan for any specific adaptation that might be needed. He then went on to reflect that it would also be nice if people could have some input into selecting the decorations and furniture for a place that was going to be their home. This same perspective was shared by a case manager who felt that although providers do a fairly good job of identifying services it could be done better if some of the pressure of timelines eased off a bit. Specifically she felt that the individual focus could come to the fore. There would be less emphasis on obtaining services for the house and more on making the connection needed for individuals. The specific example focused on medical services. She felt that some physicians might not be prone to accept a group home with everyone on Medicaid into their caseload but might very well accept an single individual.

DMR, Providers, Parents, and Communities: Making the Partnership Work

As we pointed out above, the central issue in the State of Connecticut is an issue of system planning: How are the limited resources of the state to be equitably distributed over both the short and long term? The only resolution we see to this major issue is open communication and negotiation among all of the principal actors in the system. There clearly seems to be a need to re-establish a strong collaborative effort to seek the best for all of the State's citizens with

mental retardation. DMR's Five Year Plan and subsequent updates have established the parameters for system development. However, there is an ongoing need to negotiate the details of these future directions in a collaborative fashion. Without such collaborative planning, there is a risk that groups representing various interests will become more polarized and will lose sight of the full context in which they are operating. The best remedy for this is a planning forum in which all parties have a voice. After all, building community is fundamentally about people working together for a common goal.

In a similar vein, as will be seen in subsequent sections of this report, the process of community residential development demands that a collaborative partnership be fostered with neighbors and community leaders.

COMMUNITY ENTRY/COMMUNITY RELATIONS

A principal research question of this project was whether factors could be identified that contribute to community opposition and/or community support to the opening of group homes for persons with mental retardation. Community opposition to group homes is costly to both the community and to the service provider, and moreover, a negative community entry may have substantial repercussions on community-based social services altogether. Through the case study of six group homes -- that together present a continuum of degree of community acceptance -- some meaningful patterns of community interaction emerged.

It is important to remark at the outset of this discussion on the extent of the problem of community opposition. Anyone involved in the provision of services to persons with mental retardation in Connecticut can name instances of community opposition that were protracted and costly. We found however, that these instances were isolated and usually did not result in the withdrawal of the group home. More importantly, in nearly all cases, once the home was established, the organized opposition to the home dissipated and state personnel comment on "not having heard a word" about them. This underscores the fact that opposition is usually the result of fears of the unknown that are alleviated once the home is up and running. Nevertheless, opposition is a costly problem and efforts to eliminate its occurrence are warranted.

High-profile vs. Low-profile Community Acceptance

In the field of mental retardation the issue of community entry is usually addressed in terms of whether the service provider should take a high or low-profile entry to the home. The former refers to making direct and public contact regarding intentions to open a new home. This may involve for example, public meetings where the home and its residents are discussed, public announcements in the media regarding the home, presentations to town councils or planning boards, and/or individual notification and discussion with neighbors. The low-profile entry is based on the philosophy that as other new neighbors to a town do not have to announce or make public discussion of their intention to move into a home, likewise persons with mental retardation are not obligated to "ask permission" of their neighbors to move in. Consequently, the "low-profile" approach advocates that homes open up quietly, with as little notification and public eduction of neighbors as possible. This approach takes support in the belief that neighbors can best assess their feelings about a group home once there has been real exposure to the residents and their life-style and that moreover, public announcements and meetings tend to generate community opposition because of fears of the unknown, rather than quell it.

This study does not find that the dichotomy of low or high-profile entry is especially useful. There are cases where a high-profile approach was a factor in influencing both community acceptance and community resistance. Likewise a low

profile approach is associated with both acceptance and opposition. Therefore, alternative explanatory factors are required.

A third strategy of developing community acceptance is described by Weber (1978, full citation in Appendix 2 to this report). This strategy, discussed in detail in the literature review, is called by Weber "informing the select few." It emphasizes that certain neighbors and government officials, those in leadership positions or those who are most concerned with the home, should be informed and educated. The findings of this inquiry are most in keeping with this perspective on community development.

When Opposition Cannot be Helped

In the course of the research it became clear that in some cases community opposition cannot be prevented. Sometimes the confluence of events is so unique and of such a negative character that community opposition is inevitable. In the selection of the six sites for the case studies, it was found that some of the most strident cases of community opposition were of such an idiosyncratic character that they would not have served as useful demonstrations of community acceptance patterns. For example, there are incidents where the service providers were changed and the community was misinformed, or where blatantly poor planning resulted in over saturation of communities with persons who potentially posed a threat to neighbors.

In other cases it appears that neighbor opposition was so intractable that a struggle would be encountered no matter how well community entry was handled. This opposition usually revolves around concern for property value and fears about safety, and especially for children. Fueling *organized* community opposition (as opposed to simply a raft of community complaints) is often the presence of retired neighbors who literally have the time and inclination to do the organization and administration necessary for a pitched community battle. However, the presence of these unique circumstances is infrequent. More often community resistance can be ameliorated and legal battles can be prevented. The following is one crucial variable that often determines the quality of relations between neighbors and the group home.

Open, Responsive and Respectful Communication

More significant than high or low profile per se appears to be the quality and quantity of information made available to neighbors and to the larger town. Related to this is the style of communication. In two of the case studies where there was community opposition, neighbors interviewed reported their resentment at how they were made to feel, or how they were treated during interactions with provider agencies, especially during the initial phase of the home. For example, neighbors report that in expressing concerns, questions, and complaints to the provider agency they were made to feel as if they were "ungracious," "bothersome,"

"horrible," and "prejudiced." Moreover, neighbors complain that service provider agencies were evasive and not forthcoming about the range of behaviors and other disabilities that may have a palpable effect on the neighborhood. The limited information provided by agencies on property values to neighbors (although more is available) was often not successful in alleviating neighbors fears, especially those of neighbors living immediately adjacent to the home.

Inquiries regarding the opening of the home were reportedly met with "hard-nosed," "inflexible," and "self-righteous" responses about the state law and the rights of persons with mental retardation. Clearly the state law that mandates that group homes of six persons or less are treated as a single family home is a powerful and laudable weapon on the side of community service developers. Nonetheless when it is used as "sledgehammer" whereby neighbors are informed that "there is nothing they can do" about the home, it leaves some neighbors wondering about their own rights. Clearly, service providers need to strike a balance between the assertion of the rights of persons with mental retardation to live in the community and the treatment of community concerns with respect and patience.

Many times neighbor's concerns are not borne of bad intentions. A request for information on disability, types of behavior, level of supervision, property values and the like can be understandable, especially given the newness of community development. However, it seems that agencies and other persons may at times interpret these questions as a challenge, and may respond aggressively thereby planting doubt and suspicion in neighbors. An alternative approach would be a forthright discussion of the potential of inappropriate behaviors in the neighborhood, the number of visitors to the home, and so on. This coupled with ready assurances of agency response to any difficulties and the provision of concrete means of access to persons with the power to make immediate adjustments about any problems involving the home, should help reduce neighbor anxiety.

The solution to fears about the unknown seems to be a positive response that conveys both respect and understanding for the question and the questioner. To the extent that neighbors are made to feel powerless because of the state law, they can also be made to feel that have "a say" in ongoing plans through discussions about renovations and the like. An open attitude will produce good will among neighbors.

Perhaps of greater importance, is the clear need for *ongoing* ready avenues of information about the home and about persons with disabilities. This is very apparent in Case Study 2 where the absence of an identifiable source of information leaves neighbors wondering about whether there is abuse in the home, whether it is a home or a training facility, or just who has regulatory oversight of the facility. Neighbors would like to know who is on duty and who they should call with problems. There is also a need for a line of communication that is independent of the agency per se, so that questions and complaints about the agency itself, and/or about the larger administration of services can be responded

to. Case Study 2 demonstrates how the absence of such a line of communication allows community question's and suspicions (e.g., is there abuse going on at the home) to fester. This is most appropriately the province of the Regional DMR office and it is suggested that representatives there make themselves known to neighbors.

Another example of the importance of the ready availability of information to neighbors is provided in Case Study 5. Here we see rumors circulating about the excessive expenditure of public funds on renovations. However, through informal channels these rumors were directly addressed and thereby dissipated.

The case studies provide good evidence that a communication strategy that is marked by openness, respect, responsiveness, and follow-through will earn the good will of neighbors. This is clear again in Case Study 5. The environmental conditions for the opening of this home were not substantially different than for other homes and the potential for organized community opposition is evident. However, this home was opened by experienced developers and service providers. Here we find a director who met repeatedly with neighbors and went so far as to solicit their input on matters of renovation and local shopping. It is evident that she formed a personal relationship with these neighbors and by giving neighbors her number, she also gave them assurance of her personal response to any problems.

The matter of providing information is no less important regarding members of local town governance or planning commissions. Often these persons are the first to be contacted by irate neighbors. Some DMR regional administrators feel that the real test of whether opposition will solidify into organized resistance is whether town officials oppose or support the residence. For example, one planning board member in Case Study 2 expressed irritation about the lack of information he received on any planned homes, whereas a town selectman in Case Study 5, who was informed about the details of the home by the director, actively made connections between concerned neighbors and persons who could readily and adequately respond to their questions. Further, a selectman in Case Study 3 was in support of the development of the home.

The issue of open, responsive communication does not specifically address the question of when to inform neighbors about the plans for a group home, nor whether public announcements or public meetings should be used. There is substantial evidence that public meetings, especially when they become disruptive, can turn neighbors' ambivalence into confirmed opposition. Moreover, public meetings can provide the forum for organizing otherwise very disparate, unconnected neighbors. Although some suggest that the end result of this enhanced community awareness is beneficial, we would not like to see this develop at the expense of group homes. A more productive strategy seems to be repeated one-to-one contact with neighbors, especially with those who have concrete concerns.

Planning for Community Acceptance

Aside from the more general issue of communication, there are some specific environmental variables that influence community acceptance. Those discussed here are: transitional neighborhoods, choosing a site with care, size of facility, resident leased facilities and the "well connected" service provider.

Transitional neighborhoods. It is suggested in the literature that facilities established in lower income, urban, transient or commercial areas encounter less community opposition and our study bears this out. The two homes that had virtually no expressed community concerns about them (Case Studies 1 and 6) were both located in urban rental areas. The home in Case Study 3, although in an upper middle class suburban town, was also just around the corner from the major commercial district of the town. The lack of community opposition or the relatively small degree of opposition in these areas can be explained in several ways: 1) neighbors of group homes in transient areas may not have the long term investment, either financially or emotionally, to be bothered by the presence of a group home (this is reportedly not the case in blue collar but home owning neighborhoods); 2) urban residents are more inclined to feel that who lives next door is not any of their business and at the same time are often more tolerant of diversity; 3) commercial areas, with the continual change of faces, tend not to foster the same protectiveness over territory as does a residential area; and, 4) minorities may be more tolerant of and sensitive to the needs of the disadvantaged.

In contrast to the urban environment, the very rural site will also tend to encounter less community residence due to the sheer absence of neighbors. However, in Connecticut, even a "rural" area is fairly well populated and resistance has been encountered there as well. Nonetheless, the type of area that seems most prone to community resistance is the middle class suburbs. One does not find as much resistance in the upper or upper middle class areas probably because group homes are generally not located there. However, in the middle class suburb, there are many families who have managed to escape urban poverty in the past two generations, or whose resources are dependent on the strength of the economy. For these families their property value may be the single investment that protects their and their childrens' financial future.

Choosing a site with care. Residences can be established without relying exclusively on transitional and/or commercial areas. However, a residence planned for an exclusively residential area should trigger the need for greater care in selecting the site. As discussed in the prior section of this report some areas are identified by DMR regional staff as appropriate for community development. One can assume that the absence of any group homes does not necessarily make a neighborhood a good candidate for group homes. The home that encountered the stiffest community opposition in this study (Case Study 4) was the first group home to be opened in the town. One can therefore anticipate the first residence in any town is more likely to encounter resistance than will subsequent homes. On the other hand, scrupulous planning is needed to prevent the over-saturation of any neighborhood with residences from a variety of agencies. Such saturation will

understandably rile neighbors. Therefore, the need for regional interagency coordination is repeated.

Another consideration is that some neighborhoods may simply be more protective and willing and able to organize than others. Some kind of canvassing of a neighborhood to test the strength of opposition may be called for. (The literature review notes that neighbors are likely to report more tolerance for a group home than they actually feel so canvassing must be carefully constructed.) It may be wise to avoid those neighborhoods that seem ready to undergo an extensive struggle against the home. This would seem to go directly against the civil rights and interests of persons with mental retardation and it is acknowledged that once community opposition battles are won, neighborhoods do grow tolerant if not accepting of the group home on their block. Hence we see in Case Study 2 that neighbors report finding that "things seem to have worked out all right" with the group home or that they "don't even know (the home) is there." Moreover, the process of selecting homes that underwent community opposition for this study demonstrated that few homes continue to encounter significant resistance once they have opened. Nonetheless, the case studies show that an entrenched battle with the community leaves a residue of bad feelings and resentment. Such feelings can only undermine future goals of community integration together with the service provider.

At present the selection of sites for group homes seems largely in the hands of the provider or the developer. The amount of involvement of regional DMR staff in the selection varies from perfunctory approval to careful oversight. The need to carefully coordinate sites for group homes cannot be sufficiently underscored, and it would be most appropriately performed by the DMR regional office.

Small is beautiful. Another factor that can contribute to community acceptance is the size of the facility. Clearly this factor alone does not explain all cases. Positive community relations are reported in Case Study 3, a six-bed group home, and this study found anecdotal reports of virulent community resistance for two person apartment arrangements. Nonetheless, a home with more than two or three unmarried adults is a breach of norms in most communities, especially in residential areas of single family homes. These homes usually house a married couple with children, sometimes with a third generation present. The six person group home with numerous staff presents an altogether different social arrangement. Hence, residents are not only battling the stigma of the disadvantaged but also have to encounter the natural hostility that would meet any breach of social norms. To that extent, the smaller the facility, the more manageable the community residence will be because the home seems less odd.

Planning for smaller residences presents some problems and some advantages. Residences for one to three persons are more normative and are in keeping with "best practices" of residential development. Homes that house fewer persons are not perceived as "crowded," and the sheer number of persons do not complicate other important community variables such as amount of traffic and number of parked cars per home.

However, residences for only a few persons may be largely limited to apartments or condos. Most providers simply cannot afford to lease large suburban single family homes too less than six persons. Six person homes allow for some economies of scale (e.g. household supplies and staffing needs). Parents who are suburban residents prefer that their children reside in the kinds of homes that they grew up in. Moreover, development only in apartments and condos reduces the range of neighborhoods and towns that can be sites for community development. So the question of size of the facility presents a dilemma.

Resident-leased Facilities. Nearly all of the homes studied here are leased and operated by service provider organizations. In a kind of "institutional transference" neighbors come to associate the home with the provider and not with the residents themselves. This feeling is strengthened when there is turnover in the resident population. An alternative strategy, that is in keeping with "state-of-the-art" thinking about residential services is seen in Case Study 6. Here two women leased their apartment in their own names. They, successfully handled complaints to the landlord and to a much greater degree, neighbors associated the apartment with the residents and not with the service provider.

The "well-connected" service provider. Community residences that are planned and/or operated by a service agency with roots in the community will likely encounter less opposition. Many of the more successful community developments, as for example Case Study 3, were developed by providers who were well known in the community long before they sponsored a group home. The board of directors of these agencies are often comprised of town leaders. The membership also comes from town inhabitants. Members with disabilities and their families are usually visible at community events. The agency may have built a good reputation based on active involvement in community affairs, and/or successful operation of a sheltered workshop or recreational program. When these types of agencies open a home they can draw upon the support of neighbors and town leaders who are familiar with them and their members and who trust the agency's management capacity. Respected neighbors can informally and formally advocate for the residence and draw upon their personal reputation to provide assurances to neighbors.

The ability to enlist the support of neighbors and town leaders is not limited to the well-established provider. To the extent possible, any provider can and should make efforts to establish support for the group home in the community. When that is not possible other community entry strategies will also help.

Community Entry Strategies that Work

Other than environmental variables relevant to the planning of the home there are some specific strategies that tend to enhance community acceptance. Two are discussed here.

"Professional promotion". If an agency chooses to inform neighbors about the group home they will be well served by brochures or other material that sensitively addresses neighbors concerns while at the same attractively presents the lifestyles of persons with mental retardation. Good examples of such brochures are included in Appendix 4. Summaries of studies on property values should be easy to read and understandable to the lay persons. Newspaper clippings that portray group home life and/or studies or statements regarding property values and/or safety problems can be used as part of professional presentation. When these efforts are accompanied with a personal relationship with a person directly responsible for the home, neighbors' fears are more easily alleviated.

Positive structured contact with persons with disabilities and their families. Some respondents to this study advise that personal positive exposure to persons with disabilities can also help to assuage neighbors fears. It must be borne in mind that the typical adult citizen has had little or no contact with anyone with disabilities and so they may have notions that persons with mental retardation are prone to violence, anti-social behavior, or other undesirable attributes. A structured positive meeting with prospective residents may "ground" fears of the unknown. Because it may be a violation of residents rights to request that they meet with neighbors before moving in, this purpose can also be solved by having parents or family members of persons with disabilities speak of the capacities of their family member and of the meaning of community placements. These strategies can be especially effective in facilitating understanding or acceptance among neighbors.

Community Entry Mistakes

The aforementioned general prescription of good communication with neighbors and town leaders, and the other strategies discussed will enhance community acceptance. Similarly there are some activities that will inflame community opposition. This section reviews some "mistakes" that can be made when entering a community.

Renovations. Unfortunately, group homes generally require from a little to a massive amount of renovations. Renovations are made to conform to fire and health and safety regulations and to accommodate the special needs of prospective residents. CIL (who develops the majority of property for group homes) will renovate homes for accessibility even when accessible housing is not required by the prospective residents.

A massive amount of renovation will undoubtedly draw more negative attention to the home. Renovations were the chief problem in Case Study 5 where they caused neighborhood rumors and the complaints of the immediate neighbor because the new fence detracted from his newly planted bushes. Neighbors may not understand why, if the presence of six adults with mental retardation is reportedly no different than their own housekeeping arrangement, there needs to

be such extensive work. The presence of sprinklers, exit signs, and fire escapes that were visible from the window of one neighbor caused her to conclude that, contrary to the administrator's assertions, this was a commercial enterprise and not a home.

Therefore, one recommendation it to limit renovations if at all possible. If substantial renovations cannot be avoided it may be wise to advise and consult neighbors about them. This might have forestalled the problem over the fence encountered in Case Study 5 and it would add to neighbors' sense of involvement with and knowledge about the home.

On the other hand, many renovations are done at the request of local fire and safety departments. Sometimes these departments may request more renovation than is actually required by law. It seems (as in Case Studies 4 and 5) that appeasing local inspectors (even when their requests are more than is required) is a practice that enhances community relations.

Those renovations that are made, must also be done with an eye to keeping the home as conforming to the neighborhood norms as possible. Very large garages, conspicuous ramps, thoughtless destruction of the outside appearance will upset neighbors. Renovations that directly impact neighbors must be handled with special care (e.g. putting up fences, cutting trees, changing water runoff patterns).

A particular renovation that was the cause of the continuing sore spot for some neighbors is the conversion of garages into bedrooms or apartments. The conversion of a garage involves the loss of one or two parking spaces, contributing to the ongoing problem of parking for many group homes. It also adds to the conspicuousness of the home and it permits the addition of more persons into a housing situation that is overly crowded by community norms. Regional staff state that they now advise against any renovations of garages and it is suggested that this advise is adhered to.

Using the media. The media can be a powerful tool to communicate the values and purposes of deinstitutionalization. The media analysis in this report is filled with instances of articles that describe and commend community living. Likewise, the media can also exaggerate and inflate concerns. Even when newspapers are actively supportive of community development this interest may backfire causing increased resentment from neighbors who may feel like they are being painted with "the broad brush of bigotry." (Case Study 2 is instructive on this point.) In general, we find that newspapers are a double edged sword and the deliberate enlistment of their support may exacerbate community hostility.

Open public meetings. While this study clearly finds that open communication is needed, the conveyance of information through public meetings seems to be a particularly bad strategy. As mentioned, the open meeting can serve

to unite neighbors into an organized group when they had been previously oblivious to one another. Moreover the venting of fears and hostilities can serve to establish opposition where only uncertainty or ambivalence was previously present.

Once a home is opened however, community relations may not necessarily improve. Continued vigilance is required to keep or restore positive (or at least ambivalent) community feelings. Some factors that feed community resistance, even after a home is opened are discussed below.

Contributing Factors to On-Going Community Ill-Will

As stated most community opposition derives from fears of the unknown. However (as in Case Study 4), sometimes opposition to a home does not develop until the home is opened. This happens not because of fears of the unknown, but because of careless and/or deliberate actions of the service provider. The following problems are discussed: insensitivity to community norms, excess parking and traffic, and residents that create a disturbance.

Insensitivity to community norms. Every community has an established set of behaviors that are usually unspoken but nonetheless expected, shared and performed by the inhabitants. The breach of these expectations causes negative feelings from annoyance to strong hostility. The expectations of a community vary according to numerous factors (e.g., socio-economic status, urban/rural location, ethnicity of inhabitants). The goal of community development is to be "as close as possible" to the norms of the community and therefore it stands to reason that group homes should be sensitive and adaptive to community norms in order to both be in accord with their philosophy and to generate the least amount of community complaints. Unfortunately, homes that undergo continued community opposition sometimes show a lack of sensitivity to community norms.

This is demonstrated in Case Study 2. Here we find that in the first year of the residence, a home located in a middle class suburb, left a bright spotlight on all night in the driveway. During shift changes late at night persons would come by to pick up staff members and would loudly blow the horn. Loud conversations and even fights broke out between staff members. Loud music was heard from the backyard and staff members parked on the front lawn. The use of large commercial suppliers by two homes was also not in keeping with community norms. It especially irked one neighbor (in Case Study 3) who shares a driveway with the home because the trucks occasionally caused some damage to his landscaping.

An important community norm for most suburban living is the upkeep of property. In Case Study 2, during the first year of operation the property was poorly kept. Leaves were left unraked, flowering trees were cut down, lawns were unkempt, and there was occasional litter. These breaches of community norms

resulted in continued complaints to agency and town governance representatives. It took about a year for the agency to get most of problems rectified and neighbors still complain about the front lawn.

The community norms described above are fairly obvious and might strike most people as just "good sense." There are other norms that require attention as well. In Case Study 3 there were particular expectations about the kind of window Christmas decorations that were used. Neighbors may expect the exchange of cookies at Christmas time, or flowers and tomatoes during the summer. To the extent that a home discovers and performs these expected behaviors they will indeed by regarded as good neighbors and as ordinary neighbors. When residents are not able to perform these actions independently it is incumbent upon staff to see that they are done.

The importance of staff training and supervizory oversight to prevent and eliminate this kinds of insensitivity to community norms cannot be overemphasized. Some of the homes that enjoy good community acceptance employ "a good neighbor policy" (included in the Appendix). These statements reflect the active attempt of an agency to sensitize staff (and residents) to the importance of adhering to neighborhood norms.

Excess parking and traffic. One particular community expectation has to do with the number of parked cars around a home and the amount of traffic on the street that the home generates. In several case studies, the presence of the home on the block was strikingly obvious by the number or parked cars lining the street. The number of cars pertains to the number of residents, and therefore the number of staff, that are present in the home. As mentioned, most single family homes, usually have a maximum of two or three cars. A group home, with as many as six residents, live-in house parents, and numerous other staff may have as many as 12 cars on the street. This problem is greatly exacerbated when interdisciplinary planning meetings are held at the home.

Regional staff report that present policy is to hold meetings at DMR or other offices and this policy is commendable. However, it seems that many homes are either unaware of the policy or choose to ignore it. One agency representative said that holding meetings in the homes was consistent with normalization philosophy. It has also been reported that agencies are encouraged to park in the rear and not convert garages. Again, this is an important consideration in community life.

Residents that create a disturbance. Ongoing community upset about a home can often be attributed to a single resident with deviant behavior. The resident who screamed in Case Study 2 or the resident who cursed in front of adolescent girls reported in the rural case study are both examples where the behaviors of residents can foment community anger. Like the above examples, these are not instances that indicate community intolerance or prejudice, they are instances of breaches of community norms, and the reaction they provoked from neighbors is understandable.

The numerous efforts needed to address behavioral challenges are discussed elsewhere in this report. In brief, adequate individualized planning, supervision, behavioral consultation and training are needed to ensure that residents with challenging behaviors do not jeopardize the goodwill of a community toward the home or to deinstitutionalization at large.

How Community Support is Maintained

Keep the neighborhood knowledgeable. An aspect of the process of open communication described earlier includes continued rapport and communication with the community once the home is opened. A good illustration of this is Case Study 5 where the invisibility of the residents to neighbors led to unwholesome speculation about their activities and whereabouts. Through happenstance, this was communicated to agency staff, who proceeded to take the residents on walks in the neighborhood and to involve the residents in yardwork outside. Similarly in Case Study 1, inquiring neighbors were given a tour of the facility and met with staff and residents.

Other devices that are used to help acquaint neighbors and residents and to make the home and its activities visible are open house gatherings, invitations to cook-outs, block parties and the like. Once the home is opened these are useful strategies that neighbors reported being appreciated as attempts at being "neighborly." When the neighborhood is sponsoring its own gatherings it is also important that some residents and staff attend and make themselves known to the community at large.

Contribute to the community. Group homes can make substantial contributions to the community and this fact can play a role in neighborhood acceptance. In Case Study 5 for example, the home was purchased from someone who had previously rented the home to other persons who were not very careful with the property. Neighbors saw the establishment of the group home as a positive step toward neighborhood enhancement. Similarly, in Case Study 1, the home presented a stabilizing and enhancing effect to a transient community concerned about urban blight. In Case Study 2 neighbors were appreciative when the home improved the neighborhood through landscaping and planting.

Many neighbors and members of the larger town appreciate and value the residents of group homes who are able to contribute to community volunteer events. Fire marshalls and directors of senior citizen centers remember the volunteer efforts of residents with Christmas drives and "meals on wheels" programs. One administrator attributed the acceptance of his home by the community because they opened the pool in their backyard to the use of neighborhood children.

General participation in community life will also enhance the warm feeling of neighbors toward the group home. In Case Study 4, residents attended a senior

citizen dance and one resident with his dancing partner was photographed in the local paper. Many neighbors called the residence and brought the photo over, enjoying the recognition of their neighbor. Participation in church and religious activities can be especially meaningful for both residents and their neighbors. Often the church will play an active role in encouraging tolerance and understanding of their different parishioners.

Respond to complaints/problems. The last strategy discussed here, but perhaps one of the most important in fostering and maintaining community good will is the direct and rapid response to problems or complaints. The measure of goodwill found in Case Study 4 is largely due to the fact that the home did rectify neighbor complaints over noise, property upkeep, lights and so on, although perhaps not as quickly as they should have. Even when problems cannot be immediately resolved, neighbors should be informed about the steps being taken to resolve a problem. An important corollary of this, is to keep any promises that are made. The case studies contain several examples where statements are made and then not followed up by agency staff. This is understandably irksome to neighbors. Part of the problem here, of course, is the difficulty of communication between the layers of any organization, but again, because group homes are situated among families and not among other organizations, the potential of lost communication must be attended to.

CONCLUSIONS

In pulling all of these findings together, the data tends to support the third strategy of community development, i.e., informing the select few. The provider agency should provide ready information to the key individuals involved with or most concerned about the home. Of interest, many of the findings described here are also listed in Weber's (1978) "suggestions" around community entry (e.g., prepare an organized neighborhood education plan and materials, be clear and straightforward when educating neighbors, avoid large group meetings with neighbors, develop a "good neighbor plan", stress with neighbors the steps that will be taken in the event that problems arise in the home, and anticipate that community support will grow with time). They are also echoed in Normann, M. & Stern, R. (1988 – full citation in Appendix 2).

The consistency of findings, contributes to firmer conclusions about community acceptance patterns based on research.

INDIVIDUAL PLANNING

As presented in the DMR manual on the Overall Plan of Service (OPS) and reflected in the regulations on individualized planning, Connecticut has a formal system for individual planning that is consistent with the state-of-the-art nationally. In fact, the process could serve as a model for many other states since the Connecticut OPS process stands in marked contrast with standard practice in many other places.

In most states the mandated individual planning process can be complied with by the meeting of a interdisciplinary team which essentially fills out a form in the appropriate behavioral language. The standard practice in such states often appears to be more concerned with completed paper work and documentation of staff time than with identifying goals and services that are truly in line with the real needs of an individual. Review of individual plans in such settings often reveals that everyone in the same community residence has essentially the same goals. One is left with the impression that this type of process serves the interest of the planning team rather than the interest of the person receiving the services.

The intent of the Connecticut OPS process is clearly to guard against such a pro forma exercises. It is constructed around a framework called "Personal Futures Planning" that is generally regarded as the most well articulated model of person-centered planning currently available. This process calls for the full active involvement of everyone concerned with the welfare of the person with a disability, including the person, family members, friends, and advocates. It takes an "ecological" perspective of the person's needs. That is to say it looks at the person strengths and weaknesses within the context of the actual demands of daily life. This perspective on the interaction of person and environment lends itself to the identification of long and short service/support needs as well as the source for this support.

The integration of the OPS process with the required approach to transition planning results in a structure that if fully utilized, seems to ensure that even the most idiosyncractic needs will be met. It provides for a complete paper trail, necessary interagency connections, and the identification of needed services when a person actually needs them.

Such is the intent of the formal system of individual planning and transition. But how is this formal ideal realized in the day to day lives of the homes and people we studied? It depends. There is a wide degree of variability. In our study we examined situations which seemed to cover the whole spectrum. At one extreme, we observed a new provider who attempted to implement every possible formal structure, including extensive preliminary visits of direct care staff to the institution. On the other extreme was an older setting in which much of the transition process was informal (and predated much of the formal system that is now in place). In all cases there were some problems, but the problems did not seem to lie with the OPS/transition process. Rather, the difficulties we observed

seemed rooted in the planning related problems which are discussed below. In fact, if the formal process is implemented as outlined and if the process is conducted with sensitivity to the problem discussed here it should be as effective as any human process in meeting the needs of an individual.

Short Circuiting the System

In a substantial number of instances the planning process really has not been given a fair trial because it has been short circuited. The term "short circuited" is chosen because it is not that the process has been consciously subverted. In some cases the planning process was short circuited very early on in the establishment of a residential setting. A prime example of this is the example given earlier in which DMR (because of the pressure to meet Consent Decree time lines) arbitrarily changed the people slated to go into a home that had undergone substantial renovations for persons who were non-ambulatory. As the representative of CIL pointed out this is not a very efficient use of resources.

Another short circuit occurs when an emergency placement is necessitated which may result in displacing someone for whom a site has been developed. The system has only a very limited number of spaces for these emergencies, so when they do arise it is necessary to bump someone else from a pre-planned placement. This may be unavoidable. The realities of planning are that while it must be based on rules, it must also retain a little flexibility to respond to crisis events. It is also worth noting that in DMR's guides to individual planning the potential for a crisis placement is highlighted. A clearly articulated process is setup to insure that all the "i's" are dotted and the "t's" crossed, at least retrospectively. It seems unrealistic to expect more than this.

A related issue in regard to implementation of the individual planning process is spotlighted in one of our case studies. In this case a gentleman moving into a community residence had very little transition planning and yet has services that are seen as being as good or better than many of his housemates. The key to this situation was that the man was moving into a setting in his own community. He was able to maintain the entire network of relationships and services that had been negotiated by his family over his life span. He had no problem getting a doctor since he continued to go to "his doctor." This is instructive because it points to the ideal of what community residence transition should be like: a smooth movement that is part of the regular transition which every person makes during his or her life. It addresses community integration because this man was not seen by the neighborhood as a DMR client. He is Raphael, Anna's son. He remains a member of the community and the community recognizes its responsibility to him, even though his "contribution" to the community may be minimal because of his disability. Finally, Raphael's transition, although it observed few of the formal requirements, is a classic example of truly individualized planning; his services were uniquely attuned to his needs not those of a group. If DMR's planning documents and mission statement are read carefully, Raphael's case -- with his orderly transition and the maintenance of his own constellation of supports -- should stand as an archetype for how the system is intended to work.

There is another consideration in Raphael's story that merits some consideration in a discussion of planning "short-circuits." In his case we see one approach to developing a truly individualized placement that has now been undercut by the formal system and the centralized administration of DMR. At the time of Raphael's move into the community residence, the providers, with their roots in the community, had substantial input into the identification of residents for their sites. So in his case the provider was able to lobby for his selection for placement in the group home even thought he was essentially unknown to the DMR system. At the present time this degree of local control has been lost. DMR has complete control over who ultimately is placed in the community. As we mentioned above, this is a direct result of the demands of the consent decree. This loss of input has complicated the service environment and contributed to the withdrawal of some of the older providers from the provision of new or expanded services.

The most frequent cause for occasional failures of the individual planning process was and is the withdrawal of one or more of the contracted providers from their agreement. In the case studies and interviews a variety of factors were cited for this occurrence. However, one factor seemed to stand out: in almost every case the provider who contracted to serve a group withdrew when he or she met the individuals.

This pattern of withdrawals appears to indicate that the actual arrangement for services was not individualized. In most cases the contract was arranged as part of the paper work necessary to have a new site licensed and no real effort was expended in discussing individual characteristics and needs with the potential provider. We consistently see generic community service providers, physicians, dentists, Y's, pharmacies, and so forth who are used to serving individuals and families being asked to contract to serve a group. Is it any wonder that residential providers are consistently being referred to clinics and special programs to obtain services? The norms of the community are that these generic services are for individuals; groups go to clinics and special programs.

Clearly the current press for significant community residence development makes the full individualization of the process very difficult if not impossible. However, the lesson seems clear. In an effort to realize the goals of community integration, individualized services, and being a good neighbor, providers must, after homes become established, begin to eliminate group contracted services and move toward developing individual client to provider relationships for their residents.

Lack of Experience/Lack of Skill

Some of the difficulties encountered in the placement process can be attributed to the lack of experience or lack of skill of either provider agencies or individual participants in the planning process. In general, we feel it is appropriate to lump lack of skill and lack of experience together. We saw no

evidence of incompetence that continued over a long period of time. It seemed that providers and other participants in the process are learning from their mistakes.

The first area where a lack of experience is evident is in the actual OPS/transition process. In some cases, the person-centered OPS process seems to be implemented as though it were little different from the traditional planning meeting. In other words the focus on the individual seems somewhat subordinate to the demands of managing a group care facility. A key to the future success of this process appears to be efforts to assure the full participation of all concerned parties and improving the skills of the case manager as a group facilitator. As one case manager explained, continued participation in the planning process has sensitized her to the need to have a frank open discussion in which all of the issues are put on the table. As she saw it, some of her earlier efforts were too instrumental and focused on filling out the form. A more opened-ended meeting, even though it might require a follow-up, is what is needed. In that way ideas can be generated, problems identified and, hopefully, resolved.

Lack of experience in the area of individual planning was also reflected in the failure of some providers to take full advantage of the opportunities available to them. Specifically some of the sites had little pre-placement contact with Mansfield or other locations. They lost an important opportunity to learn more about a prospective resident and allow their staff to interact with the person. In cases where the pre-placement visit did occur the residential staff was alerted to potential problems and were attuned to the characteristics of the people with whom they were going to be working.

In some cases failure to have pre-placement contact or to fully address individual planning may reflect a lack of resources to pay staff to perform these important functions. DMR and provider agencies need to keep this in mind when they plan for the start up costs associated with a new site or with the transition of a new resident.

Lack of Resources

A consistent complaint of residential providers is that they do not have sufficient resources to provide a fully individualized environment for their residents. In most cases, this translates into not having enough staff to be able to respond adequately to the complete range of needs in one of their settings. This seems to be less of an issue in smaller homes where the presence of two staff enables a regular, personalized interaction with three residents. This is very different in a setting where these same two staff might be involved with six residents.

This problem clearly strikes at a central issue in community integration. The philosophy suggests that there should be fewer demands on paid staff as people develop relationships with community members who will provide "informal"

support to them as they go to dinner, to a doctor's appointment, to a movie, a dance, or work. Advocates of this position point to examples of this occurring in various places around the country. However, it is important to note that these success stories often do not happen spontaneously. People involved in some sort of a service provider role often help "facilitate" these relationships. In some of the settings visited, this level of integration was starting to happen, but it usually involved a former employee, family member of an employee, or the continued direct involvement of the staff person in the relationship. So this ideal of integration can happen, but staff and management must view this kind of activity as a worthwhile expenditure of staff resources. This implies that DMR needs to clearly communicate to its provider agencies that this kind of activity is valued. The issue then becomes one of establishing a clear set of priorities for staff, so that they can judge how to most effectively use their time.

If fostering community involvement is a clear priority for residential providers there is a need to make sure that direct care staff have an adequate supply of two other important resources, ideas and connections. In our interviews a lack of resources in these areas was especially evident in the whole issue of recreational services. The individual planning process needs to be informed by people who have creative and practical ideas and also have a connection with the resources needed to bring these ideas to fruitions. This need for creativity and community connections is crucial in all aspects of individualized service provision, but becomes even more important when community integration is a clear priority.

Lack of Flexibility

A major ingredient in a successful individualized approach to services is flexibility to respond to the unique circumstances of each person. In the case studies, this is highlighted by the interaction between a residential and a day program over the need for a resident to be out of the home during specific hours every day because there was no staff available. The day provider had established its program to be completely community-based. However, the structure of the group home staffing was based on a very traditional sheltered workshop hour (9:00 AM to 2:30 PM). The residential provider was therefore not prepared to respond to the exigencies of irregular work hours, second or third shift employment, or the need to use normative community sanctions for inappropriate behavior.

This situation highlights two problems in planning: 1) a failure of one program to communicate clearly with another (noted earlier); and 2) the lack of the structural flexibility found in some models of staffing and funding services. While this example is clear, these two problems may also explain frequently missed medical appointments or the lack of recreational opportunities. In addition, the use of group provider contracts to obtain individualized services may also reflect a lack of flexibility on the part of provider agencies or the system as a whole.

An increased emphasis on community membership and complete individualization only serves to underscore the need for flexibility. It does not take much imagination to see a day when all the residents of a community residence are on very different daily schedules. Will DMR and its providers be able to respond or will they find it necessary to constrain this process because of their organizational limitations?

Case Management

Case management is included in this discussion not because it is a problem, but because it is the linchpin on which the success of the individual planning process hinges. The case manager is the facilitator for the interdisciplinary team meeting which develops the OPS and the Transition Plan. It is the ongoing role of the case manager to mediate turf and other disputes which interfere with agencies effectively meeting client need. Ideally the case manager is the eyes and ears overseeing the services in an effort to assure that the best interests of the person with a disability are being addressed.

The recent re-structuring of the role of DMR social workers into case management is intimately connected with the development of the OPS and transition process. In the study sites where there was a consistently involved case manager we found a positive effect on the lives of people in the system. Unfortunately the case management system has not fully stabilized and we also noted substantial turnover in some instances.

Several informants mentioned that within DMR there continues to be resistance to the case management role by some individuals who prefer the title "social worker" and its more circumscribed role. One case manager supervisor said that unfortunately the system was just going to have to "wait these people out" and work around them in the meantime. She felt that many workers and certainly all new workers were committed to the case management role and its promise for the clients' quality of life.

There is a perception on the part of some parents that the case management work force is as unstable as the direct care work force. Parents tell stories of numerous case managers in a relatively short periods of time. Such frequent changes do not seem to be conducive to the role as described by DMR. It appears that in some cases the case manager job serves the same role as the direct care job -- it provides people an entry to the system and they very quickly move onward and upward or out to pursue other employment. Supervisory personnel indicated that there were efforts to rectify this situation and stabilize the work force. One contribution to this perception of transience among case manager is the practice of changing case loads. Again, supervisors admitted awareness of this problem and stated, at least, the intention to address it.

The reason for the flux in case management may be the issue of job expectations and case loads. On paper the responsibilities of the case managers are substantial. In reality they may be overwhelming. If a case manager has a case load of 30 to 40 people who are relatively stable, it may be a reasonable ratio. In fact several case manager interviewed had numerous clients who were involved in some sort of transition. It was all some of these workers could do to keep their heads above water by meeting some of the minimal requirements related to paper work and the requirements of the court decree. Once again a major contributor to this pressure is the fact that these workers are caught in the middle of system in a state of transition. Nonetheless the best interests of the community clients could be served if some mechanism could be established for weighting case loads based on the current status of the actual clients rather than the need for equal distribution of numbers among all case managers.

Summary: The Proof is in the Placements

The value of any process of planning lies in the results, the services obtained, the individual gains made, and the satisfaction of the consumers and their family members. Although the process of individual planning has some problems it works pretty well. The procedures outlined by DMR should only lead to improvements with time as this approach becomes internalized by workers in the system.

This study did not entail a massive examination of client outcome as the result of community placement. However, most of the stories we heard and the situations we observed supported the contention that for the most part people are getting what they need in the way of services and leading good lives in their homes. In other words, at the individual level a sound planning process is in place and as for the most part working well. There clearly is a need to enhance some of these services and increase the full degree of individualization in the planning process, but in general people involved in the process are sensitive to these issues.

Parents and providers by and large reported that people have responded well to their new living situations. Many of the relatives of class members admitted that, after initial ambivalence about their family member moving into the community, they have been very favorably impressed by what they see. Some noted that their family member previously got nothing and now has a better life than they could have imagined possible. Almost every home has a story about someone moving out of a large facility who started demonstrating skills which no one knew they had or who immediately stopped some problematic behavior. In several cases we heard about people who re-established contacts with family members which were essentially severed during most of their institutional stay. Finally, a consistent story is the drop in the use of psychotropic medication. Admittedly, this is influenced in part by consent decree requirements but it is clear that the more individualized attention of the smaller community settings has contributed to this decrease.

There are individual situations that reflect poor planning and the lack of services. However, based on our study, they are exceptions. Yet, failure is highly visible in the community. A living arrangement for a person with some very significant behavior problems which collapses in front of the neighbors is likely to gain media attention. A person who screams all day long is going to elicit inquiries from next door. People who are very critical of the ability of the service system to adequately support people in the community will be sure to highlight these failures to help make their case. And, if the advocates of community integration are true to their rhetoric, they should welcome this exposure. Throughout the literature on the need to deinstitutionalize people with mental retardation there is reference to enhanced quality assurance in the community because of increased exposure. The thesis, confirmed, by the media analysis and case studies, is that the inadequate services of the past will not recur in the community because neighbors will be there looking over the shoulders of the provider, or more likely, over the backfence.

ACCESS TO SERVICES

Day Programs

For all case study homes, day programs are in place. Access to some form of day program or the ability to maintain the placement is not an issue. However, in selecting cases there are issues around adequacy of some programs, how placements for residents are planned and how services are coordinated.

In a few cases, there is concern that the day program may not be adequate. In one home for elderly residents, the initial day program was provided in the home. There was a great deal of concern that this program was not providing sufficient stimulation and variation for the residents. Subsequently, a new facility was built and the residents now go out of the home during the day. Similarly, day programs for some clients with severe disabilities are sometimes seen as not providing sufficient therapeutic services. There is concern that these residents may often simply be warehoused during the day. This is considered to be a generic problem. Some interviewees reported that there is a lack of knowledge by some day program providers regarding how best to provide a therapeutic environment for residents with severe disabilities.

More commonly, day placements are viewed as inappropriate rather than inadequate. Advocates and parents indicated that they feel the programs are not sufficiently geared to the individual, particularly in vocational situations. There are many stories of residents who fail in a particular job placement not because of a lack of skills but because of poor planning and a lack of proper supports. For example, one parent told how her son who was very capable but very slow was placed in a fast food restaurant and subsequently failed in this job. In another case, resident was not performing well in a sheltered workshop where she assembled pens. After years in this placement, it was discovered that she hated the job and hoped to work with animals. She had never been asked before. There is a concern that day placements are not being carefully planned -- not taking the individual's strengths and weaknesses into account and more importantly not including the resident in the process.

Individualized planning requires that day programs possess the diversity and variation necessary to meet the unique needs of residents. There is concern that this is not the case. Interviewees commented on the preponderance of fast food service jobs when clearly this is not an appropriate setting for all residents. One respondent indicated that some day programs are not acting creatively or aggressively in seeking new employment opportunities for residents. The respondent feels many employment resources in the community remain untapped.

Adequate day placements that attend to individual residents' needs also require clear communication and coordination between the day program and the residential staff. In one case, a resident was seeking competitive employment but needed more support in the process. Who was responsible for providing this

support varied depending upon who was being asked. Often the hours of the day program are used as a time when residential staffing can be very low. However, the more individualized and unique placements for residents become, particularly with competitive employment, the more likely they will entail varying hours, different transportation needs, etc. This places greater demands on residential staff and thus on providers' resources. If day placements are to truly address and meet the unique needs and preferences of individuals, providers and day programs need to clearly delineate responsibilities. It must be a mutual, concerted effort.

Medical Services

Hospitals. Residents use local hospitals. This service is typically seen as adequate. The one issue raised had to do with hospital requirements, in some instances, of one to one staffing of patients and the placement of some adult clients on pediatric units.

Another issue raised that pertained to hospitals had more to do with the back-up service available after hospital care. A resident in Case Study 2 underwent serious medical treatment in a hospital and afterward required skilled nursing care during recovery. His group home is unable to provide this. At the same time, an extensive stay in a skilled nursing facility will jeopardize his group home placement, because his daily rate can only pay for once place at a time. In another case, a resident was hospitalized in order to begin a program of psychotropic medication. The resident's advocate felt this was an unnecessary hospitalization and that the group home should have been able to support the resident's medical care needs on outpatient basis.

Physicians. Providing adequate, quality medical care is a problem, to varying degrees, for each home reviewed. While each home contracted with health care providers upon opening, the quality of these providers and their tenure has varied enormously. While many homes have good medical services in place, it has been a difficult and time consuming task to secure such access. The following discussion addresses issues in obtaining primary care physicians but these issues can be seen as broadly applicable to all medical personnel.

Barriers/Obstacles. The most often cited reason for a physician to refuse care for group home residents is inadequate Title XIX payments. Many physicians will not even discuss providing care. This fact severely limits the choices providers have in finding a physician. One home reported making 50 phone calls before a physician could be located. Other providers find that it is not simply the money that discourages physicians. Payments are received so belatedly and the documentation involved is so excessive that many physicians who would otherwise serve the clients despite the low payment are ultimately dissuaded. Another provider suggested that the bureaucracy makes physicians feel that they are being "second guessed" in their work.

Another issue that is frequently cited is physicians' unwillingness to treat the developmentally disabled population in general. This issue has a number of facets. In one region, physicians who had been employed by DMR had fostered a belief among other doctors that it took a particular expertise to treat persons with disabilities. As a result, according to some interviewees, these other clinicians were discouraged from treating residents. While some unique expertise may be necessary in some specialties (i.e., psychiatry, neurology), this is not necessarily the case for primary care physicians. While many providers feel a frustration with the lack of clinicians who are responsive to the group home population, most say their experiences argue against the need for a particular expertise.

Additionally, there are the typical prejudices that constrain access, like one physician who feels a certain resident's mannerisms will be too distressing for other patients. Some physicians have agreed to serve residents without a great deal of understanding about the residents' characteristics. In one case, a physician terminated his services to a resident with a severe disability because he thought the person would be like "someone in the Special Olympics."

In one case, an accommodating physician had become known as receptive to the clients and had subsequently been inundated with requests. This led the physician to discontinue serving all residents. In this reversal, a physician's receptiveness to the population ultimately worked against the residents.

Some providers studied have sought coverage through a local HMO and some have been successful. However, the results are often discouraging. One provider was told that the HMO rates are based on an estimated utilization rate of between two to four visits a year per person. The provider was told that the average person with developmental disabilities sees a physician sixteen times per year. While this statistic seems high, if mandated quarterly visits or taking blood levels to monitor medication are considered, it may be accurate. If this is the case, how many residents can a private provider be expected to serve, especially at a reduced rate? Are residents being taken to physicians more often than is really necessary? This information poses questions that warrant consideration.

Quality. These barriers greatly affect the issue of quality. Most providers interviewed feel that the difficulty in accessing medical services negates their ability to be selective. It is often so difficult to find a physician that changing a physician to achieve quality is a moot point. Seeking new services may mean being without services for long periods of time. The greater the medical needs of the residents, the less likely choices based on quality can be made -- being without services is too threatening to the health of the client. There is concern that "you get what you pay for" and so Title XIX reimbursements relegate residents to less effective physicians. Many providers studied must utilize medical personnel who are not located conveniently because it is their only choice. It is often not a question of *who* can best serve the residents but who *will* serve the residents.

Coping with barriers. A number of methods are used in order to recruit and retain the services of a physician. Providers who are able to hire consultant physicians to oversee multiple homes seem to have the easiest time in obtaining medical services. In some instances it may be possible to hire a full time staff person. In other cases, the provider pays the physician additional consulting fees to meet with residential staff or perform in-service trainings, in essence supplementing Title XIX payments. These arrangements also give the provider a greater sense of control over the quality of the services received. However, this solution is not feasible for some smaller providers.

In some communities, providers have been able to access clinicians who have an institutional background. In these cases, the whole set of barriers having to do with a lack of understanding for the residents is avoided. In one region, as part of a new plan for medical services, DMR is contracting with an out of state provider to supply medical services to the regional center. In addition, this provider will perform education and out reach activities with local physicians to encourage services for community clients.

Other providers use a personal relationship, often with the house manager, as a means of encouraging the physician to stay. Sometimes residential staff may already have ties with physicians that they can use. In other examples, physicians are literally wined and dined. Many program managers indicated that they thought the physician would leave if they were no longer associated with the house.

In other cases, providers indicated that they bend over backwards to accommodate the physician, far more so than a "regular" patient would do. This method includes being scrupulous about keeping appointments and accepting appointments that may not be convenient for the residents or the provider. It is typically perceived by group home providers that there are few a "nice" people out there who are willing to help them, like an act of charity.

Issues. These methods of coping raise questions about the group home resident as consumer. By way of example, one group home resident had previously lived with his family in the same community for many years. His family had a long standing relationship with a family doctor and associated specialists. The family continued to take the resident to this doctor and felt that the care was excellent and probably better than that provided to the other residents of the home. This example illustrates a number of issues. It debunks the myth that expertise is essential for caring for the residents. It also establishes a more typical consumer/provider relationship with a physician, rather than one based on an "act of kindness."

This example also raises questions about the tendency for providers to seek doctors for group homes rather than a doctor for an individual resident. It was observed that homes with six residents often have more difficulty in obtaining services than homes with three residents. While from an administrative point of

view the use of one physician for several residents or for several homes makes sense, it undermines the normative relationship of patient/doctor. It also raises the issue of what is reasonable for one physician to handle. Low payments from Title XIX become more onerous for the medical provider who serves multiple group home residents.

In addition to considering balancing this patient/doctor relationship, there remains a concern about securing access to any physician. Many providers suggested that they needed assistance not only in finding clinicians but in helping clinicians to realistically understand the needs of this population, including the fact that there may not be any special needs. Similar to the way neighborhoods may be educated about their new neighbors, there may be a need to educate the medical community about their new patients. Ignorance, not a lack of expertise, may be the problem. Recently, DMR has instated regional health services coordinators. This may prove to be an important and worthwhile step toward addressing this issue.

Other Physicians. The considerations and issues discussed thus far appear to hold true for a variety of medical personnel. The following discussion highlights or emphasizes issues as they pertain to a specific discipline or related field.

Specialists. The issues discussed above are exacerbated when considering the services of specialists like neurologists. For one thing, there are usually fewer physicians in a given specialty. The inadequacy of Title XIX payments is magnified in the case of specialists. Further, there may need to be more understanding among specialists of the needs of people with mental retardation. For example, developing an eye prescription for a non verbal patient presents special challenges.

Psychiatrists. Next to dentists, psychiatrists and psychologists are reported to be the hardest medical personnel to locate. As with every other type of physician, Title XIX fees and red tape are cited as the greatest obstacles. However, in this case, the particular needs of the residents also play a role, especially in regard to the quality of care. Some respondents reported that the psychiatrist does not take enough care and time with residents. Other respondents feel that psychiatrists are more likely to prescribe medication and less likely to attempt counseling. It was perceived that clinicians sometimes lack knowledge on behavioral interventions that might be useful. In this area, it may be argued that some expertise in developmental disabilities would be helpful. Again, however, the options are so limited that coverage not quality is the issue.

Dentists. Some homes are without dental care and all have found dentists to be extremely hard to obtain. Reimbursement levels and the special needs of the residents combine to make it nearly impossible to obtain or retain a dentist. The greatest success is reported with homes that have been able to find a dentist who has had some experience in an institutional setting.

Nursing. There is a national shortage of nurses, both RNs and LPNs. Many homes did not have the full complement of nursing staff that they wanted. Some providers use a consultant nurse, but might have been better served by a full time staff nurse. Most providers reported that they "made do." Rarely is pay or the disability of the residents mentioned as an issue. There simply are not enough trained personnel.

Specialized Therapies. Like nursing staff, there is a critical shortage of physical therapists, speech therapists, and occupational therapists. While Title XIX payments and a lack of understanding of people with developmental disabilities were sometimes cited as contributing problems, it was generally agreed that the national shortage of allied health professionals was the major problem. Residents are often not receiving or waiting months for the appropriate therapies. In most cases, a therapist pays monthly or biweekly visits to a home and trains the residential staff to carry out a therapeutic plan. There were concerns voiced about the adequacy and thoroughness of this training. These concerns were also voiced when the shortage required providers to utilize DMR therapists.

Providers who maintain enough homes to support staff therapists usually had better luck in hiring someone. In these cases the stability and quality of these services was improved. And yet, if the staff person left, it could take weeks or months to find a replacement.

Residential Staff

The labor market in Connecticut is very tight and the recruitment of residential staff is not simple. However, providers expressed more concern about retaining residential staff than recruiting them. Situations varied from homes with very high turnover to homes with a stable, dedicated staff that had to work second jobs in order to support themselves. Money was consistently cited as the single most important cause of turnover. It is difficult to maintain quality staff if comparable state positions receive higher wages and better benefits. Many respondents said that recent legislative changes in salary structure had greatly improved their situation.

In addition to simple turnover, there is some concern about the nature of the community residential workforce. Unlike institutional staff who often turned their positions into careers, community residential jobs are seen as attracting transient entry level workers or workers who use the job as a means to another end (i.e, house manager, administrator, etc.). As a result, there is concern about the group home staff being able to provide sufficient stability and continuity for the residents.

On the other hand, DMR workers do staff a number of group homes around the state and do not experience these same problems. This work force is perceived as relatively stable and highly skilled. However, it should be noted that one

respondent was concerned about DMR staff making the transition from an "institutional" to an "independent/community" value system. The respondent finds the DMR residential staff dependable and supportive but perhaps too supportive. For example, the staff was more likely to take a resident to the store than teach the resident to get to the store on his or her own. A similar concern was expressed about community staff who had prior experience in nursing homes. These workers often seemed inattentive to community norms around residential living.

Behavioral Challenges and Resources

Residents who are behaviorally involved can present the greatest challenge and often show the most marked improvement with placement in a group home. This issue is addressed separately because a broad range of services, both traditional and untraditional, is implicated.

DMR does have a system called Positive Futures Planning for residents with behavioral challenges who are experiencing difficulty in the community. When a resident is identified as having trouble, a meeting of all the significant people in that person's life -- providers, physicians, parents, relatives -- is convened. Often the resident is included as well. The planning group tries to identify the resident's patterns of success and failure over the years and to create a future plan and placement that address these patterns. In order to implement this plan efficiently and effectively, there is another part of this program called the Line Action Network. This network allows the futures planning group to have access to key state bureaucratic personnel so that the plan can be implemented fully and without delay. This is an important and well thought out process for handling difficult placements. However, respondents did articulate other issues in regard to residents with behavioral challenges which are outlined below.

Residents with behavioral challenges often encounter the most neighborhood opposition. For example, one home encountered no overt opposition from the community until a resident, in anger, went out into the street and was cursing, by chance, in front of a family's adolescent daughters. This episode incited the community and fueled fears that had been unarticulated until that point. It is this need to manage behavioral problems that lies at the heart of the successful placement of these residents, good relationships with neighbors and true integration into the community. It is the need to manage these behaviors that creates a need for access to a multitude of interacting resources.

It is important that the behavior be carefully matched to the character of the community and to the other residents. In Case Study 2, a resident who frequently screamed was placed in a home in a densely populated area. Needless to say, this situation created tension in the neighborhood. Likewise, some providers expressed a desire for more careful consideration in grouping residents together. One resident's behavior may pose a threat to another resident's development. Many rural providers feel that the seclusion, open spaces and lack of urban problems in rural communities is very therapeutic for residents with behavioral challenges.

Being able to exercise more choice and planning options in the placement of behaviorally involved residents is seen as desirable.

Many homes utilize a behavioral specialist who establishes behavioral programs and trains residential staff in behavioral interventions. Additionally, homes may employ a psychiatrist who is responsible for overseeing the administration of psychotropic medication. Ideally, these clinicians work in concert with residential staff to provide a comprehensive program. As with other specialized therapists and physicians, trained professionals are at a premium. As a result many providers feel they have inadequate support in this area and there is concern about the quality of the care that they do have.

There are many concerns about the use of psychotropic medication. Some family members and advocates are concerned about the high levels of medication received by residents. In some cases, this is seen as a result of inadequate resources -- residential staff, mental health clinicians -- for dealing with the behaviors. In other cases, it is seen as the result of inadequate training and understanding. There is concern that the need to control behavior is taking precedence over actively treating the behavior. There is concern that a diagnosis of mental illness allows the administration of medication without sufficient checks and balances. On the other hand, there is substantial evidence in the case studies of the reduction or elimination of medication for some residents. This success is attributed to the placement of these residents in a group home environment and to the attention that provider agencies pay to this matter.

Ultimately, the successful management of behavioral challenges falls to the residential staff. Most providers feel that their staff does a good job in handling residents and that when outside assistance is sought (i.e, the police) by staff members, it is an appropriate decision. However, the shortage of behavioral specialists may affect the level of training for staff which in turn may result in inappropriate responses to problems. Others argue that using the police is a normatively appropriate reaction given the need to impress on residents the consequences of their actions.

The police are a commonly used community resource for managing residents' behavior. In every case and particularly in rural areas, the police are described as being extraordinarily helpful and sensitive. In turn, police departments did not indicate that they felt over used or called unnecessarily. Often traditional authority figures such as a policeman have worked to contain residents' behavior. In one example, a patrolman explained to an aggressive resident that assault was a criminal offense and the resident could be taken to the station and charged in court. The provider reported that aggressive behavior by the client was greatly reduced after this incident. Another provider felt that the police and the threat of legal sanctions in general should be used more often to address behavior issues. This provider felt that some residents who are conscious of their actions feel protected from the law.

The behaviorally involved resident presents a great challenge to the community residential system, a challenge that has an impact on neighbors, community services, residential staff and professionals. As such it requires an integrated approach that uses and accounts for each of these components. It is an approach that starts with the planning of the home and requires access to a multitude of disparate services along the way that must be woven together to present a coherent yet individualized response.

Recreation

Many residents utilize the local YMCA, adult education classes, gyms, bowling allies, movies, and so forth for recreation. In some communities, however, these local recreation programs have been reluctant to include people with disabilities. There are stories of difficulties in obtaining YMCA memberships. In another case, a resident was asked to discontinue an aerobics class, apparently because her mere presence made the other members of the class uncomfortable. In a few cases, the resources were not accessible to wheelchairs. Homes that have the greatest success in accessing these resources seem to have sufficient residential personnel to take residents individually to desired activities.

It is noted, with some concern, that many homes are looking for or maintaining "specialized" programs. For example, one home rents a gym just for the residents rather than using a local facility. Other homes have residents participate in social or recreational events sponsored by a local agency for persons with disabilities. In one case, social events involved two or more group homes getting together. In other words, segregated activities are sought out and used rather than integrating the residents into existing community resources. In certain instances this can be explained by community resistance but in other cases it is active choice on the part of the provider.

Recreational activities often involve all house members. Such group activities present certain problems. If five members of one home take the same class that only has only eight participants, by definition it can become a "specialized" program. Approaching community resources as a group can place a strain on the resources themselves. In another example, residents belonged to a community group for senior citizens and participated in all the activities. However, the community group, while initially welcoming the residents, began to feel that they were being "dumped" there. For some residents, to benefit from community recreation activities -- to become more than a change of scenery -- requires individualized support.

The issues raised here are directly related to residential staffing. Integrating residents into existing community activities and assuring that they get the most out of them requires individualized attention and support. In many cases, there is not enough residential staff to achieve this goal. Some homes have made excellent use of volunteers to fill in this gap.

The adequacy of recreational activities for severely impaired residents was raised as a separate issue by a few providers. These providers felt that integration into existing community activities was simply not appropriate or helpful for the residents. There was a desire for assistance from the state in designing programs that would be recreational and therapeutic. These providers did not feel that they had sufficient resources to meet the recreational needs of these residents.

Transportation

A lack of public transportation is considered endemic in Connecticut. Homes with access to public transportation often found it inadequate and given how little public transportation exists, there is a limit to how many homes could be sited in close proximity to transportation networks. In response, nearly all homes have a van or car that is associated with the house. Again, the availability of residential staff to serve as drivers sets the limits of this solution.

Urban homes had an advantage since some services are often within walking distance. Local merchants are familiar with the residents because they can frequent the stores more often. As a result, these residents seem to have better contact with their community as opposed to homes that must use a vehicle to reach town, limiting shopping trips to once or twice a week.

It is interesting to note that rural homes having no access to public transportation did not see transportation as a problem. The van and driver was seen as adequate to meet the residents' needs. However, in one rural home residents had reached a degree of independence such that the provider felt that they would be better served in an urban environment where they would be free to go to the store on their own. This situation points to an important constraint in rural homes. There are not any opportunities for residents to learn personal transportation skills. They are always dependent on staff members. There is an inherent limit to their independence.

IMPACT OF GROUP HOMES ON THE COMMUNITY

Regarding the development of community facilities for persons with mental retardation, one commonly raised concern, and a focus of this study, is whether community group homes have an adverse impact on municipal services or other aspects of community life. For each of the six case studies, representatives of local fire, police and health departments were interviewed regarding any impact on their services because of the home in question, or because of the presence of community-based group homes in general. In addition, local and state government representatives, real estate agents, neighbors, and local merchants were asked for their perceptions regarding the impact of the home on the community. Strikingly, virtually every respondent affirmed that there was no adverse impact on community services or on the community as a whole. The details of this finding are discussed below.

Police and Criminal Activity

Police in every site reported that their services were not overly taxed because of the presence of the group home. As discussed in the section on access to services, police are at times relied on by some residences because of resident behavior. The case studies also discuss several occasions when police were called to the residence by neighbors. However, none of the occasions involved any kind of serious crime; at worst they involved some disturbance of the peace or incidents in the residence itself that some would argue should have been handled by residential staff. These minor incidents notwithstanding, the police, though aware of the group homes, do not find that their ability to provide their services to the community is any way affected by the home.

Fire

Like the police, fire departments report no undue use of their service by group homes. The only palpable effect on the fire department was reported by one fire marshall who noted that, because yearly fire inspections are required for any home of more than three persons, his inspection roster has considerably increased. He was also concerned that the one or two person apartments that do not undergo yearly inspections may pose an increased risk of fire hazard. Like the police, fire personnel are aware of the group homes and would approach any rescue efforts there with special considerations, however, no fire marshall found an unusual number of calls from a group home.

Real Estate

In Case Study 2, two homes in the immediate vicinity of the group home were rapidly sold during the time of the renovation of the property, and many persons attribute this "panic selling" to knowledge of the group home. However, other communities did not undergo any noticeable increase in property turnover rate.

The vacant homes near the group home in question were sold again without difficulty. Anecdotal reports from real estate agents and neighbors suggest that there has been no noticeable impact on surrounding property values. Neighbors that immediately abut the homes remain doubtful however, that they will be able to get the full market value for their home. Real estate agents report that selling a home near a group home presents a "unique circumstance" but they are unable to confirm that there is an impact on property value or length of time to sell. Sometimes the presence of a group home will actually enhance the stability of the property values of a community. This was seen in Case Studies 1 and 5.

Health, Water, Sanitation, Transportation or other Municipal Services

None of the group homes underwent any unusual health crises, and aside from yearly inspections, the presence of the homes have made no impact on health departments. Representatives from other services were not queried, however, reports from local officials and neighbors do not suggest that any of these services are burdened because of the group home. The only remark to this effect concerned sanitation since one home seemed to produce copious amounts of trash, and it is safe to say that any home housing six adults plus staff compared to a single family will produce more trash. As discussed earlier, one planning commissioner was irritated at the lack of information that was given his board about the homes or intentions to open any new homes.

One local official noted that the elderly residents of one group home had less impact on the public transportation system than do other elderly residents in town because the group home residents relied on their van and staff for transportation. Apart from this, there is no reason to think that a home would adversely affect water, sewage or other services. Moreover, it appears that community residences contribute significantly to local businesses.

As far as the "character" of the neighborhood, most homes once opened continue unnoticed and they are for the most part inconspicuous to any passersby. The only significant exception to this is parking and traffic which is discussed below. One local government administrator noted that the intense struggle over the opening of the group home in Case Study 4 resulted in some lasting bad feelings between neighbors who supported and those who opposed the group home. Other than the specific problems encountered by agency insensitivity to community norms (e.g. poor property upkeep, noise discussed in the community entry section) most residents are found to be "good neighbors."

Parking and Traffic

As discussed in the section on community entry, the single enduring and seemingly prevalent adverse impact that community group homes have on the surrounding area is parking and traffic. To repeat, homes of six persons with staff, that hold frequent team meetings involving many persons at the home, will

undoubtedly generate substantial numbers of parked cars and increased traffic. One immediate solution to this problem is holding meetings elsewhere and other attempts can be made to reduce the number of parked cars (e.g., ask official visitors to park at some distance to the home, making parking possible at the rear of the home, ask staff to carpool).

QUALITY ASSURANCE

Introduction

Prior to the conduct of the case studies, one hypothesis regarding the phenomenon of community acceptance was that the adequacy of quality assurance procedures could conceivably affect the success or failure of community residential development. The material gained from the six cases plus the rural site analysis does yield some information about the efficacy of quality assurance but it is a very particularistic picture and does not provide a full understanding of the sweep of quality assurance activities in the state. This is in large measure because qualitative research techniques (which rely on observation and interviews) are particularly sensitive to the expressed concerns of informants who tend to focus on their immediate environment and not the larger context within which the service is provided.

With this caveat, the following discussion is organized according to five categories: individualized planning, program monitoring, medication monitoring, case management, and training.

Individual Planning

The individuals included in the case studies had been placed in their homes over a period of time ranging from five years to a little over six months previous to the study. From the state of their records, it is clear that those who made the transition recently enjoyed a more intensive and comprehensive planning process. Specifically, recent movers, such as the individuals in Case Studies 5 and 6, had the benefit of the transition check list and the improved Overall Plan of Service. Some of these individuals had also experienced the "positive futures" process in the course of the preparation of their individual plans.

Though these intensive planning procedures cannot be expected to anticipate all subsequent events (e.g., the problems in securing appropriate day programs for the gentlemen in Case Study 5), they clearly outline service needs and implementation requirements.

The only two problems in individual plans uncovered in the site reviews had to do with over regimentation and service availability. Specifically, in a few of the cases, there did not appear to be any attempt to identify individual providers for the residents. Rather, one provider was identified for everyone in the house and in some instances a contract was let to serve all of those in the home. Though the reason for such "group" purchasing may have been the shortage of certain services (such as medical and dental), it appeared that more care could have been taken to identify professional and other services more tailored to the individual.

The second problem, which occurred in Case Studies 4 and 6, was that some of the services identified in the plan and checklist were not in fact available once the individual moved into the residence. This issue arose in large measure because of changes in service availability that took place after the plan was completed. Given the vagaries of securing medical, dental and specialized therapies described elsewhere, this disjuncture between the original plan and the presence of services once the home is opened may be inevitable in some cases.

Program Monitoring

Licensing and Certification. By and large, staff interviewed at the sites were not aware of licensing activities and could not identify a particular experience with licensing reviews. Further, the new program quality reviews in residential programs had not yet begun except at a few trial sites not included in this project

With respect to the one state-run home explored in Case Study 6, the current certification process (since the state cannot "license" its own facilities) seemed somewhat cursory and focussed primarily on the structural elements of the women's apartment. Though it clearly turned up some potentially dangerous problems (lack of railings leading to the basement and on the back porch), it does not appear to have had much to do with more programmatic elements in the home (e.g, extent of integration, participation in community activities, etc.). As noted in the description of the DMR Quality Assurance system, however, the present certification procedure for state-run homes is under revision and will, according to DMR officials, move closer to procedures that pertain to privately-run homes.

Case Study 6 also raises some interesting issues regarding program monitoring given the fact that the apartment ostensibly belongs to the two residents since they signed the lease. Thus whether the home is state run or private, the focus of quality assurance in this instance is more appropriately on the capabilities of staff and their contribution to increasing the women's community presence.

Paperwork. With respect to reporting issues generally, many of the house and agency staff interviewed complained about the onerous paperwork requirements associated with a range of quality assurance procedures. Though it was not clear in every instance what specific provisions were causing problems, it did appear that staff felt overwhelmed by documentation detail that they did not feel was entirely relevant to their jobs.

Medication Monitoring

The issue of the appropriate use of medications came up in at least twice in the study -- once in Case Study 6 and once in the review of rural sites. In Case Study 6, the Court Monitor's office raised questions about both the level and need

for p notropic medications for the two women in the home. The concerns were ultimately communicated to a program review committee where psychiatric diagnoses were confirmed and dosages approved. In this instance, had a psychiatric diagnosis not been advanced, a behavior plan would be required in order to justify the use of such medication. According to Court Monitor staff, they are concerned that such diagnoses may be too easily secured and that the program review process is therefore not completely satisfactory.

In the second instance, which occurred in one of the rural sites, the problem was not the procedures per se but an ignorance of their application. The specific event involved the implementation of a psychotropic drug regimen with one client without clearing the move through the program review process.

Advocates

Many of the individual clients identified as part of this project are class members and have been assigned an advocate. These advocates perform a distinct quality assurance function and their presence is a goad to the system to respond to the individual needs and capacities of their clients. In one instance, in Case Study 5, the advocate provided much needed continuity for clients in the home at a time when case managers were changing and day program issues were up in the air. In other instances, the advocate has monitored medication issues and pushed for increased community integration.

Case Management

Where the case management system has been fully implemented, the system is working very well. In some instances, however, systems are still in transition. In Case Studies 5 and 6, for instance, a great deal of turnover in case management was noted. Additionally, some regional officials interviewed noted that there are still diverging conceptions among so-called case management staff regarding the appropriate roles and responsibilities. Some individuals, according to those interviewed, still practice a form of social work associated with the social services function in institutions. Others, however, have adopted the system brokering, planning, and resource mobilization role more consistent with state-of-the-art case management.

Training

Some of the case studies illuminated the need for additional training in particular areas. Specifically, in Case Study 4, some of those interviewed noted the need for improved staff capabilities in the areas of medication management, medical conditions, and behavior management. While DMR regulations mandate training of staff commensurate with the needs of people, there still appears to be a perception among some of those interviewed that more training is needed. In Case

Study 6, staff interviewed noted that they would welcome additional training in areas such as the financial entitlements of the residents. Others interviewed with respect to this case noted that the staff could benefit from training in community integration, the identification of community recreational activities and means of facilitating more independent functioning in the two residents. The need for such training may be particularly important in state-run homes where some of the staff have spent several years in institutional settings.

Divergent Expectations

The more general issue with respect to quality assurance has to do with program expectations. An issue which ran through a number of our interviews was the presence of two divergent perspectives on the appropriate criteria to use in evaluating community-based programs. The first set of expectations is in line with the point-of-view expressed in the DMR mission statement. The second set of expectations largely reflects efforts to assure the quality of services in specialized service settings.

The first set of expectations places a priority on community integration. The primary criteria involve access to generic services, use of residential and work opportunities that blend into the community, development of informal supports (supports provided by neighbors and friends rather than by paid service providers), use of specialized professional skills primarily to support community based activity (e.g., speech communication work which focuses on developing functional communication within actual community environments), and the consultative role of the professional.

The second set of criteria emphasizes the specialized needs of people with mental retardation. From this point of view, services are evaluated based on the extent to which they assure that residents have peers on the same level with whom they can relate, use specially adapted and constructed settings which are often distinctive, have support provided by direct care staff, use traditional clinical approaches to therapies, and have direct services provided by professionals.

This cursory overview of these two perspectives should make it clear that the efforts to apply conflicting criteria to the same settings reflects the current state of transition in services for people with mental retardation. One perspective appeals to the ideals of community integration, while the other set reflects the priorities of the generation of professionals who sought to reform institutional services. The direction of the field as mirrored in this report seems clearly toward community integration. Nevertheless, the system of services in Connecticut needs to have clear standards that simultaneously promote community integration while reassuring parents and others that the specialized needs of people with mental retardation will be addressed regardless of where they live.

Conclusion

The quality assurance system in Connecticut is perhaps one of the most comprehensive and multi-faceted in the country. For those who are concerned with maintaining it as a dynamic set of tools for system improvement, the role of quality assurance in assuring community integration should be explored. Current concerns are directed primarily at programmatic issues and structural issues particular to the residential "facility." This study suggests that an equally important concern is the extent to which the "home" blends in with the neighborhood. Therefore, there may be a need to examine more non-traditional quality standards such as the extent to which the agency maintains the landscaping at the home, the way in which the agency controls noise during shift changes, and the steps they have taken to cut down on traffic such as scheduling meetings off-site.

Further, given a growing concern about community presence. integration and client choice-making, it will be important to develop means for assessing the level of skills among community staff persons in facilitating these objectives.

Another area to be examined is the way in which quality assurance systems should respond to the concerns of neighbors. Clearly neighbors should be made aware of the ways in which they can report any problems at the home and channels of communication between agency leadership and neighbors should be kept open. Since some would assert that living in a neighborhood as opposed to an institution is in itself a quality assurance protection, outlets should be provided for community concerns. Neighbors do notice things and their observations can, if handled in a sensitive fashion, provide a first line of defense against abuse and mismanagement.

Finally, these case studies underscore the importance of the independent program quality review being contemplated by DMR. The review, which will include advocates, family members, and people with disabilities, can provide a level of oversight not currently available. It may also, where warranted, provide a vehicle for assessing neighborhood concerns and responding to questions and suggestions.

GLOBAL ISSUES

There are a number of provocative aspects of this type of research. It involves continuing interaction with a wide variety of interesting and amazingly cooperative and helpful people. The process itself keeps the field worker constantly engaged in trying to make sense of widely divergent perceptions of the same series of events. Simultaneously the researcher must attempt to understand the point of view of the individual subject sitting across the room. Through the entire process, there is the intellectual excitement associated with the sense of exploring new territory. Finally, the exploratory nature of this work means that some of the findings which result from this process may not fall into the neat categories the funder or the researchers had in mind when the project was conceptualized.

This study contains its fair share of findings that are important yet clearly fall outside the parameters of the initial RFP. In the section on system planning we have outlined some of the issues related to the apparent competition for allocation of resources that we found to be a pervasive background to this entire study. This finding is perhaps the major area of "discovery," and, as noted earlier, appears to be central to the resolution of many other issues in the field. There were a number of other "global issues" that emerged from the interviews. We feel these merit scrutiny in any discussion of community residence development. These findings cover the following topics: public perception of community residences, the limits to a community's acceptance, and achieving community membership.

Public Perception of Community Residences

As we talked to community members, it became increasingly clear that they thought about community residences in a manner completely different from DMR, providers, and advocates. Many of those in the official system have made the jump from talking about group homes as "homelike settings" and defending their legal status as single family dwellings to actually believing that service settings are really the same as single family homes. Those in the field need to recognize as they deal with neighbors that the rhetoric of community residences does not always match the reality. The failure to fully appreciate this fact may lie at the heart of the confrontational attitude with which many providers and advocates approach communities.

The essence of these divergent perceptions of community residences may lie in the inherent tension between the community residence as "home" and the residence as a "facility" administered by an agency. The neighbors have no delusions that a group setting is someone's home. Many of them can harken to the experience of living in a college dorm or a military barracks. No matter how pleasant these places were they always were temporary places of residence; home was always where the family was.

Some of the reaction that a group home elicits from community members is really an honest effort to understand this phenomena. In essence the concern is "How do I relate to this thing you call a home?" On the other hand when communities have mounted substantial opposition there are two other possibilities at work: 1) some community members are reacting solely in terms of misinformation and perhaps deep seated prejudices against people with mental retardation; or 2) many are reacting not to the people but to having a group care "facility" open up in the neighborhood. Some advocates, we interviewed, contended that this resistance to a facility was actually an effort to mask the socially unacceptable display of prejudice against people with disabilities. This analysis is not necessarily accurate. The more we listened to neighbors, the more they tended to highlight the facility-like aspect of the group home. In some cases this critique came from people who were supporters of the home and involved with the people living there.

Some of the neighbors and other community members were quite articulate in outlining the contradiction between the rhetoric of home and the reality of a facility. A number of people commented on the crowded "frat house" nature of many of the larger homes. In several locations we heard comments about the fact that the group home did not use community stores but had most of their food and other supplies provided by large commercial suppliers. This was accompanied by the disconcerting image of a shared drive or a residential street that was blocked while a 12 wheel semi-trailer unloaded at the neighbors' "home." Other neighbors mentioned the large exit signs, sprinkler systems and other safety accoutrements that may have been mandated by the town fire marshall. Also highlighted is the tendency of homes to have all kinds of schedules and clip boards scattered around the house or to have a business office on the premises. Finally almost everyone commented on the constant meetings, people coming and going at all hours, and the incredible number of cars these places seem to attract.

To summarize, the neighbors heard what they were being told about these places being homes just like any other home, but they have eyes to see for themselves. What they saw left them convinced that they were living with a facility on the street and not just another family home. As we have noted most communities and neighbors have adjusted well to this reality but they remain very clear on the difference.

The Limits of Acceptance?

In several of our interviews, community members raised the question of how much tolerance can legitimately be asked of communities and neighbors. In some cases this question revolved around the flexibility of the community to accept a whole group of people who looked and behaved in a manner significantly different from the normative standards of the community. In at least one other case this concern focused on individual tolerance for people who often did not observe all of the typical social conventions.

Several neighbors, who had initially been active in opposing a community residence and had now adopted an attitude of passive resistance, mentioned that they found the presence of people with significant differences to be profoundly disturbing. They spoke of the need to modify their lifestyle in order to avoid exposure to their new neighbors. A number of providers recounted stories of neighbors who felt that exposure to the residents of a group home might have a long term deleterious effect on the psychological development of their children. In another case, involving a home for older people with very significant handicaps, concern was expressed about family members being exposed to ambulances and the death of some of the residents.

On the level of the individual, a community member told us of what she felt were the extraordinary demands for acceptance placed on members of a church congregation where a number of group home residents participated. In essence this discussion revolved around failure to observe some social graces and expectation regarding group membership. Specifically, these formerly institutionalized people interrupted conversations and seemed to make major demands on members of the congregation who responded to them. In addition, they failed to contribute to congregation events in which they participated.

We raise these concerns because they emerged in our interviews. Clearly some of the concerns should alert service providers to factors they need to take into account in planning for sites and individuals. Some of the points made by these informants can be resolved by training efforts, some physical renovations to homes and property, or by use of smaller settings for people with a more severe level of disability. However, a major factor here seems to be the prejudices to which providers are so sensitive. Much of this is no doubt borne of a lack of knowledge and lack of exposure. This suggests a need for a greater degree of work in the area of education and public relations. Perhaps, the best hope for confronting this issue is the expectation, expressed above, that the next generation will have a very different point of view regarding individual differences.

Achieving Community Membership

Just as there are real differences between group homes and family homes there remains a substantial difference between being in the community and being part of the community. In our discussions with service providers we were not always sure that they saw this difference. It seemed that many of the people with whom we spoke felt that the community should welcome the people in the group home with open arms. There seemed to be an expectation that the neighborhood should shower them with all of the regard and concern that was, for instance, granted to the 85 year old woman living at the corner, who had lived here for 60 years and raised five children one of whom was now first selectman.

These unrealistic expectations clearly demonstrate a failure to appreciate the ways communities work. As anyone who has ever moved into an established neighborhood can attest, it often takes a very long time to shed the label of the

"new comers." Any level of involvement or membership, other than the laissez faire attitude which dominates many American residential communities, often has to be earned through a contribution to the community. Often a neighbor who has standing is one who added something to the life of the community by playing a special role or taking leadership in some common effort.

Because of some unique barriers to full or spontaneous acceptance, group home providers need to pay special attention to their efforts at earning full community membership for their residents. As we have pointed out, the group home structure itself, with a clear identity as a facility will remain a barrier. All talk of prejudice aside, the fact of the residents' disabilities will remain somewhat of a barrier that neighbors may need assistance in overcoming. In addition, two other important considerations were raised as a result of our interview and site visits: first, the public perception of the group home as a "strange household" and second the role of children in community formation.

In several of our interviews it became clear that over and above the obvious perception of the group home as a facility, there was a subtle discomfort with it as an alternative lifestyle arrangement. The curiosity about what really went on in a group home was linked to a perception of it as something akin to the commune of the late 1960s. The discomfort that neighbors had about living next to a commune seemed to be tinged with a question about the nature of the relationships in a house where a number of unmarried men and women lived together or a group of people of the same gender co-habitated.

Another totally unanticipated finding in our study involved the role of children in the whole process. The central role which children play in the formation and structure of our residential communities is captured by the community concern which always accompanies and often precedes concern for property values, "Will our children be safe?"

What struck us as we interviewed neighbors was the normative role that children play in building a sense of community. In the typical community children often are instrumental in the development of relationships between neighbors and in developing a sense of involvement with the larger community. It is the interaction between children and common needs for baby-sitters and concern for issues like local traffic that often lead adult neighbors to become involved with each other. Even in the case where an older household has no children at home, an interest in the younger children of their neighbors leads to interaction. On the level of the larger community, one of the most frequent reasons for participation in the political life of the community is concern for issues like education, child care, and community resources, such as playgrounds.

The important consideration for residential providers is an awareness that their residences do not have the natural resource of children to act as a catalyst to community membership. As we have seen, there are characteristics of the group

home household structure that make the uninformed public seriously question whether children should interact with the residents.

This entire issue of the crucial role of children in building community was further underscored by the frequent stories we heard about children bridging the gap between the residents and other members of the community. Often we were told it was the children in the neighborhood who had the first personal interaction with residents. Sometimes this led to problems because of misunderstandings on the part of the adult neighbor, but likely as not these interactions had positive outcomes. In at least two instance we were told how the interactions around children led former opponents of the community residence to become allies. In one instance some of the residents now "look after" the playing children of one neighbor, and the neighbor baby-sits for the group home manager.

The findings of this project portend a positive perspective on the long term outcome of the development of community residences. Many of the adults who raised concerns about group homes had never interacted with a person with a disability. The experience of their children will be very different. They are growing up with classmates and neighbors who have disabilities. As adults, their level of understanding and acceptance will far exceed the abilities of even the most enlightened members of their parent's generation.

The basic message about the potential for achieving real community membership and actual community integration, is that it is a very gradual process. The reality is that it has just begun. Many of the concerns raised about this process reflect the evolving history of the process. Becoming a neighbor takes time.

RECOMMENDATIONS AND CONCLUSIONS

CONCLUSIONS AND RECOMMENDATIONS

The findings of this study reflect a residential system in transition from one based on segregated custodial facilities to one based in normal neighborhoods around the state. Such a transition -- especially if it is hastened by litigation and court oversight -- is complex and tends to sharpen disagreements about the most appropriate mode of service delivery. Further, the implementation of change, even when it is informed by experience and sophistication, often seems to proceed more by trial and error than by systematic design. This seeming discontinuity, however, is a reflection of the mid course corrections required when new directions are being charted and is to be expected. The test is whether the corrections are made in a timely and systematic fashion. The system in Connecticut appears to have made these adjustments and continues to strive toward a more integrated and meaningful life for people with mental retardation.

Our study shows that a firm programmatic foundation has been laid in the community and that the basic needs of people are being met. Nonetheless, there are still areas where additional attention is required. Such "fine tuning" is an integral part of any evolving system reconception and it is hoped that the implementation of the recommendations listed below will bring the reality of services to people with mental retardation closer to the ideal as reflected in the Mission Statement of the Department of Mental Retardation.

PLANNING

System Planning

- The Department of Mental Retardation (DMR) has carried out a Five Year planning process and has subsequently updated these efforts. However, there remains a need for a truly collaborative planning process that includes DMR, in concert with provider agencies and parent groups, to arrive at a consensus regarding the future vision of the system. Such a plan should be based on an accurate assessment of the future demands that will be placed on the service system. The development of this plan should provide a forum for balancing the interests of groups that presently see themselves in competition for limited public resources and, thereby, nurturing a common vision of the future among all parties concerned with the services for people with mental retardation in Connecticut.

- DMR should carefully examine the overall administrative performance of the residential system and should develop an infrastructure of resources that will provide long-term support to residential provider agencies. The beginnings of this support system exist in Corporation for Independent Living (CIL) and Residential Management Services (RMS), but there is a

need to look at specific areas of assistance such as site development, management practices, and staff development and training.

- The Developmental Disabilities Council should establish a forum for all community providers to exchange information on issues such as community entry, community relations, innovations in services, and staffing.

- DMR should develop individualized agency development plans with clear goals and objectives delineated for the growth and skill enhancement of each of its provider agencies.

- The University Affiliated Program in Connecticut should take responsibility for coordinating the efforts of all relevant actors (DMR, universities, the state education department, etc.) in the state in the development of a long-term plan for increasing the number of professionals (nurses, behavioral specialist, case managers, physical, occupational, and speech therapist, etc.) available to work with persons with mental retardation in community settings.

- DMR should conduct an intensive examination of issues related to direct care staff in the community based system. This examination and planning effort should concentrate on the nature of the work force, job expectations, future directions, and training in an effort to develop an approach to this issue that aggressively addresses the future needs of the field.

Site Planning

- The Office of Policy and Management should develop a formalized (and perhaps computerized) system for statewide and regional interagency coordination regarding site selection for all human services. Such steps are needed to ensure that no area becomes "saturated" or overwhelmed with social service centers and/or community-based programs (e.g., shelters, nursing homes, group homes). This coordination should include state departments for corrections, youth services, drug and alcohol abuse, etc. Different measures for different social services should be used to determine saturation levels (e.g. an area may be able to support more group homes than it can semi-secure settings for juvenile offenders). (Presently group homes for persons with mental retardation cannot be spaced less than 1000 feet from each other).

  * Care should be taken, by coordinating the development efforts of various providers, to assure that numbers of sites are not suddenly developed in a single community where none had heretofore been established.

- DMR should examine the current application of the 1000 foot rule to assure that it does not adversely affects the development of 1 and 2 person community training homes, foster homes, and individualized supported living arrangements.

- DMR should continue to explore alternative models of residential services (e.g., supported living, consumer-owned or leased residences) that assist community integration of the people living in them, decrease the cost of purchasing property, and minimize the impact on the neighborhood of heavily staffed alternatives.

Individualized Planning

- DMR should strengthen Overall Plan of Service (OPS) guidelines to assist Interdisciplinary Team (IDT) members to better match residents with neighborhoods. Any residents with known or potential behaviors that would be disruptive to the community (e.g., screaming) require highly individualized residential planning that keeps the interests of neighbors at the foreground. Such planning will aid the long range goals of community acceptance and integration.

- DMR training for the creation of the OPS and for residential staff should include increased attention to aspects of individualized planning and resource development that may not receive enough deliberation (e.g., recreation, transportation, and medical care) in the IDT and among direct care staff.

- DMR guidelines should stipulate that when planning a new site, staff in the new setting should have an opportunity to observe the resident in the current setting and discuss the characteristics of the individual with staff who are currently involved with the person.

INDIVIDUAL PLACEMENT, PLANNING, AND TRANSITION

- DMR guidelines on the Overall Plan of Services (OPS), transition, and case management provide a model for effective planning that meets the needs of DMR clients. However, these values do not always filter down to the direct care providers both in residential and day programs. Training currently available for IDT members and case managers should be enriched and expanded to include persons providing direct services. This will help to assure that services are delivered in a manner consistent with the individualized spirit of the OPS guidelines and over routinization and standardization can be prevented.

- All participants in the individual planning process need to be guided by the same set of criteria in establishing the priorities in a person's life and in planning the nature of their own involvement with the client. These criteria are contained by implication in DMR's mission statement. DMR and provider training of all professionals and direct care workers needs to underscore how these principles should be articulated in the lives of people with mental retardation.

- DMR should ensure that all members of individualized planning teams should receive training that will help sensitize them to the person-centered nature of their planning efforts. This training must emphasize the need for participating agencies (e.g., day programs and residential programs) to openly discuss their differences regarding appropriate services for an individual, even if it slows down the development of the plan.

- Individualized planning and the development of sites which are responsive to unique needs of individuals require budgetary flexibility at a level very close to the person so that resources can be altered and refined to respond to sudden changes in individual circumstances. DMR should explore individualized funding models being implemented in other states including Colorado and Nebraska.

- The unique role of the case manager as the key to the success of the individual planning process must be recognized. This central role must continually be underscored by DMR through training, policy statements, and other forms of formal recognition that emphasize the important status of case managers. DMR should examine case load sizes and composition to assure that they are reflect the varying needs of individual clients and are based solely on numeric quotas.

COMMUNITY ENTRY/DEVELOPMENT

- Regional DMR staff should have greater involvement in the community entry process. Specifically:

  * Providers should submit a description of their process of community entry in their residential services plan to the regional office.

  * Regional staff should review the process description to see that it includes substantial one to one contact with neighbors, especially abutting neighbors, prior to and after the opening of the residence.

* Regional staff should offer technical assistance to providers in planning community entry, perhaps including the preparation of professional presentation materials about community acceptance issues. DMR central office may be in the best position to prepare some materials (e.g., about property values) that could be used statewide.

* As standard practice, a regional staff person should personally introduce themselves to immediate neighbors and other neighbors who seem especially concerned about the residence. They should explain the oversight role of DMR with private residences and provide neighbors with their phone number and means of access to information independent of the provider agency.

* Regional staff and provider staff should advise relevant town and local government officials about the plans for a group home at the same time that they are advising neighbors. As much information as is necessary should be made available and any potential problems should be forthrightly discussed.

* Regional staff should be responsive to any emerging problems reported by the neighbors by working closely with the provider to solve any problems.

* Regional staff should require that all inter-disciplinary meetings be held off the site of the residence to reduce parking and traffic problems.

- In planning a residential site the following factors should be carefully considered by regional staff:

  * The fewer the number of persons living in a residence the more the residence will approximate the norms of single family living.

  * To the extent that the residents themselves are perceived by neighbors to have "a stake" in the residence or the neighborhood (i.e., they themselves or their family own or lease the property or staff members are also residents on the block) neighbors will be more assured of the positive contribution that the residence will make to the neighborhood.

  * Careful attention should be paid to maintaining the exterior of residences in a manner that is consistent with the norms of the neighborhood. Several steps can be taken including reducing the number of visibly parked cars around the home, extending the

driveway to parking behind the house, requesting that visitors other than family or friends of the residents park at some distance from the home, and asking staff to car pool.

* All renovations must be made so that the home remains as inconspicuous from the surrounding property as possible. Avoid potential points of conflict such as shared driveways.

* Reasonable requests from neighbors about site planning should be given consideration.

- Residential providers should be especially sensitive to practices that reinforce a public perception of group homes as facilities and should make every effort to avoid these practices in favor of activities that are normative for the communities in which the homes are located. To accomplish this providers should:

  * Prepare "good neighbor" policies that are sensitive to the norms, expectations and conventions of the surrounding environments.

  * Conduct staff training sessions that focus on how to assess and respond to neighborhood expectations.

  * Pay attention to maintaining the home in keeping with the norms of the neighborhood (e.g., keeping the property clean and neat).

  * Give neighbors a ready means by which they can communicate problems and concerns both before and after the opening of the residence and during its ongoing operation.

  * Create opportunities for residents to contribute to community and neighborly life.

ACCESS TO SERVICES

Day Programs

- Planning placements in day programs and work sites should pay greater attention to residents' strengths, weaknesses and preferences. In order to

facilitate this individual planning, DMR should assist day program and residential providers to develop a wider variety of community employment opportunities (i.e., recruiting new private employers to enter into partnerships with providers).

Medical Services

- The Department of Income Maintenance should conduct a systematic study to determine the relationship between the accessibility and availability of medical and dental services to persons with mental retardation on the one hand, and the level of Title XIX payments and the complexity of reimbursement related paperwork on the other. According to several interviewees, securing such services is severely constrained by the low level of present reimbursement rates and the extent of documentation required for payment.

- A concerted effort by the state needs to be made to educate community medical personnel about the needs of group home residents. Outreach to local clinicians could include realistic information about persons with developmental disabilities and the kinds of services they need.

- Regional DMR staff should consider ways in which a one resident/one doctor relationship can be implemented. If an individual resident can approach an individual doctor as a consumer, many of the existing problems in accessing medical services might be minimized.

- The University Affiliated Program (UAP) should determine the level of additional state support that could be made available to train more professionals in nursing and specialized therapies such as physical and speech therapies (e.g., establish tuition for service, exchange programs). In the meantime, DMR in conjunction with the UAP should help providers to identify creative methods for securing access to these services. One possible solution would be to use scarce specialists as consultants rather than staff. In this role, the professional would evaluate the resident and train residential staff to carry out a therapeutic program in the context of the residents' daily living activities.

Recreation

- Recreational activities too often center around specialized, segregated programs. Staff availability and training must be augmented to facilitate the integration of residents into existing community activities.

- Providers need assistance in developing appropriate recreational activities for residents with severe disabilities. The special needs of these residents make access to these traditional recreational activities very difficult and providers do not have the resources to create the kinds of activities that they feel they need.

Behavioral Interventions

- Though the advent of the Line Action Network and the positive futures planning has enhanced the responsiveness of the system to the needs of people with challenging behaviors, providers could benefit from increased support and funds for staff training (e.g., in "gentle teaching techniques," means of accessing technical assistance, and crisis intervention mechanisms) to meet the needs of such persons. They would also benefit from greater control in grouping and placing residents with behavioral challenges in homes. Appropriate settings and mixes of residents are crucial to the success of community placement for these residents.

Transportation

- The one van, one home tradition places clear limits on integration, but may be the only means of transportation in suburban and rural areas. However, this problem should not restrict residential development to areas where public transportation is available. Instead the challenge is left to providers to maximize community integration and independent skill enhancement despite such limitations.

QUALITY ASSURANCE

Individual Planning

- The use of the "positive futures" process and other related individualized planning techniques should be retained and expanded.

- Participants in the Overall Plan of Service should be encouraged to seek professional and other specialized supports tailored to the individual client's needs and preferences rather than purchasing professional and medical supports on a group basis.

Program Monitoring

- DMR should carefully evaluate the new certification process for state-run homes to ensure that it addresses the same types of issues that comprise licensing of private residential programs.

- DMR should review its current licensing procedures to determine their applicability to apartments and other similar dwellings which owned or leased by clients themselves.

- DMR standards should be reviewed to ensure that a balance exists between requirements for specialized and professional supports and those mandates aimed at issues such as integration, community presence, and choice-making.

- Current paperwork, reporting and documentation requirements should be reviewed to determine relevance to quality assurance goals.

Medication Monitoring

- Staff working in residential and day settings should be kept aware of policies aimed at the regulation of psychotropic medication and other behavioral interventions including the role of the program review committee.

Advocates

- The use of advocates to represent the interests of individuals with mental retardation who are not class members should be explored.

Case Management

- Case managers play a key role in the transition of individuals into community residential programs. It is therefore important to develop mechanisms that ensure the continuity of case managers in the lives of persons with mental retardation.

- Continued training of case managers in areas such as system brokering, planning and resource mobilization is necessary to ensure a unified approach to case management around the state.

Training

- DMR should request additional funds to increase training of residence staff in meeting the needs of dual diagnosis clients, care of persons with medical problems, medication oversight, financial entitlements, and community integration and recreational activities.

GLOBAL ISSUES

- Through training and other efforts, DMR staff, site developers, provider staff, and advocates must be made aware of the discrepancy between the rhetoric of group homes as "homes" and the perception of these settings as "facilities" by the general public. This awareness should be reflected in their dealings with members of the community.

- Residential providers and particularly direct care workers should be made aware of the complexity involved in assisting the residents of group homes to achieve community membership. This awareness must include knowledge of the barriers to acceptance that are inherent in the structure of residential services, a sensitivity to the kinds of activities that are needed to overcome these barriers, and an understanding of the often slow rate at which neighborhoods and communities open their doors to newcomers. For example providers and other service professionals should be aware that:

  * to the extent that children are involved with the residence (e.g., live-in or with staff members who live nearby) integration into the fabric of community life will be enhanced; and

  * as long as several unrelated adults are living together in the same house, community resistance to this non-typical social arrangement should be anticipated.

- DMR and other relevant state and local authorities need to be aware that a segment of the general public continues to relate to people with mental retardation on the basis of misinformation and prejudices. A long term effort in the area of public information and education needs to be designed to eliminate this problem.

CASE STUDY 1

CASE STUDY 1

History and Context

This case study examines a private, non-profit, urban, group home for six hispanic clients. The developer of this home, who is also hispanic, was motivated to open the residence because no other homes existed in the state that served the needs of hispanic persons with mental retardation. The goal of the developer was to open a residence located in the hispanic community, staffed by bi-lingual, bi-cultural individuals who would be sensitive to the cultural needs of the clients, including their traditional food, religious activities, festivals and so forth. The leaders of the hispanic community encouraged the developer to pursue the goal, since they believed there was a legitimate need in the community that such a group home could meet.

La Plaza (not the real name) was incorporated in 1981. A board of directors was established in 1983. A proposal for the residence was submitted in 1982 but it was turned down by the Department of Mental Retardation. According to regional staff, DMR believed that La Plaza was not established enough in the community to be able to put in place all the necessary components for the operationalization of a group home and that the plans were not specific enough regarding such issues as staffing ratios. DMR wanted proof of community support and required La Plaza to seek liaison with day providers, site developers and a management service for the residence.

The developer was able to forge the relationships with day program and other providers by 1983 to the satisfaction of the Department of Mental Retardation. In addition, members of the hispanic community and La Plaza board members wrote letters in support of the new agency. In 1984, La Plaza got approval of a second RFP. There is a belief on the part of the developer that her agency came under more intense scrutiny than other providers because of the hispanic orientation. She perceives that she somehow had to "prove" that there was a hispanic disabled population.

The urban area in which the home is located has been the site of numerous homes for a range of needy people including former inmates, people with mental illness, and troubled youths. No homes for persons with mental retardation, however, have been sited in this area. The saturation problem had at one point become a political issue but did not affect the development of this highly specialized program.

Site Development and Neighborhood Entry

This case study focuses on a building located on a side street in a hispanic neighborhood in a major urban area. The street is on the fringe of an economically depressed area, and has mixed residential and commercial zoning.

The home is one block from a major street which considered "dangerous". There are several lawyers' and accountants' offices located in rehabilitated brownstones down the street from the community residence. The structure is the middle of three connected walk-up apartment buildings. It was converted from a multi-family dwelling to a single family dwelling, while the two surrounding structures remain multi-family dwellings. The building has three floors and was purchased by the site developer after a fire had damaged the property. The Windfall Profits Tax Act allowed private investors to purchase and preserve the historic 100 year old structure.

The site developer, the Corporation for Independent Living (CIL), found the property, purchased it and contracted the renovation work. CIL also attempted to purchase the adjacent units for Section 8 and moderate income housing, but was not successful. Construction delays were responsible for the home opening in 1985 rather than in 1984. La Plaza leased the property from CIL and will own it after 25 years. The management of the residence was turned over to an independent management company. This arrangement for contracted management was required by DMR because of La Plaza's inexperience in running a group home. The management relationship was also encouraged by CIL. La Plaza ended it's relationship with the firm in 1987 at the point that the La Plaza staff felt they had become sufficiently sophisticated to run the home independently.

The block in which La Plaza is located has a great number of rental apartments owned by absentee landlords. One block down, however, there are renovated lawyers' and accountants' offices. Thus, the character of the neighborhood is mixed. La Plaza's entry into the neighborhood was fairly quiet, with the exception of some response from one member of the block association who lived down the block, and one other neighbor two doors from La Plaza. The nature of their concern was mainly that of property values, especially since the neighborhood had many problems with crime, and the church down the street ran a shelter for the homeless. Both neighbors were unfamiliar with the concept of a group home. The president of the block association at that time happened to be in the human services field, and was able to quell the fears of the neighbors. When the neighbors saw the improvements made to the building, they believed that the group home would bring more stability to the area and there were no more complaints. The director's philosophy about neighborhood entry was that persons with disabilities have just as much of a right to move into a neighborhood as other people, and therefore do not need to make a formal announcement.

There was some concern on the part of the management agency regarding La Plaza's location in a high crime area. They were worried that some of the role models for the residents would be the drug users who frequented the alley behind the residence. They saw the female residents as being especially vulnerable because of a lack of safety skills. Some of the people interviewed for staff positions were concerned about the neighborhood and the security of their cars. Some refused to work in the area. There has not been enough parking for staff, so arrangements were made so that staff could have evening parking in a lot behind the house. It is the norm for cars to line both sides of the street since it is an urban area with few garages or driveways and a relatively high

population density. The management agency, however, ultimately recognized the strengths of the area -- a fairly close-knit hispanic neighborhood which was on a bus line and very close to stores, banks, and churches. Many of the merchants of the area, like the residents, were from Puerto Rico and spoke Spanish. The management agency believed, along with the director of La Plaza, that this was an area where it would be easy to maintain and strengthen the residents' cultural identities.

Several neighbors stopped by La Plaza after it opened. They were curious about who lived there. Neighbors visited with the residents who would sit on the front porch, and the house manager would often give tours of the home and would answer questions about the residence. The perception of the home by neighbors (mainly hispanic neighbors) was that it was some kind of school. Staff attempted to explain that while they teach the residents skills, it is a home and not a school. Neighbors felt comfortable about the home because of the openness of the staff and the residents and that the inhabitants spoke Spanish. Residents gradually became known to the neighborhood merchants and to other people living in the area. The residents all became active in the church down the block, which further aided in community integration.

The management service was responsible for hiring staff, staff training and the financial management of the home. They found it difficult to obtain enough seed money to hire staff and pay for the other necessary activities required for opening the home. They deferred management fees so that La Plaza could pay for staff and other necessities. This is in contrast to how funding through DMR now works, which is to hold to a negotiated budget with 12 monthly payments, despite whether the census is at capacity. This insures that there is enough money to pay staff salaries and other fixed costs.

La Plaza went through the normal licensing procedures. There were no issues around adaptive environmental changes since the clients had no or minor mobility problems. The bedrooms are on the second and third floor with steep stairwells and the residence could not easily accommodate persons with serious mobility problems.

All clients are in day programs. On weekday mornings there are often no staff in the home. During weekday afternoons and evenings there are usually 2-3 staff, with one overnight staff every evening. There are usually two staff persons on during the weekends.

Transition Planning

Identification and Selection of Clients. Four men and two women live at La Plaza. Like other community residences, some residents came from the community and s from institutions. At the time La Plaza opened, the provider approacl institutions and community agencies about placement of clients in the new home. According to the management service, it was difficult to locate enough hispanic referrals to fill the home before the home was

supposed to open. There was the sense that hispanic families are more open than other families to keeping their family member with a disability at home both because of a more accepting attitude toward disability and because of a distrust of the "system." Interviewees also mentioned that coordination problems among La Plaza, the management company, and referring community agencies may have contributed to the delays in achieving census. In addition, it was perceived by some interviewees that it was difficult to get referrals from DMR case managers, possibly because they generally don't speak Spanish and as a result it is more difficult to deal with the families.

Once the individuals were identified as potential residents, there seemed to be enough information communicated in order for evaluation and transition to take place. The house manager at that time had previously worked at a day program and advocated for some of the clients she knew in the day program to move to La Plaza. Because she was hispanic and bi-lingual, it was easy to communicate with families, but difficult in some cases to convince them that community living would be a positive step toward independence and adult functioning. Some of the clients were from the immediate or nearby neighborhoods, which helped some families to allow their family member to move to the home.

Raphael (not his name), a 26 year old resident, moved into La Plaza in May of 1985. Raphael had been living at home and was attending a local day program working in the sheltered workshop. Anna, Raphael's mother, was working and finding it difficult to coordinate their schedules. There was often nobody to be at home with Raphael at the end of his day and in the evening. Anna also felt that he didn't have enough contact with his peers and she could not spend much time with him because of her long work hours. Raphael's siblings were all married and living in their own homes.

The social worker at the day program was aware of Anna's desire to have Raphael move to a community residence long before La Plaza opened. Raphael had been on a waiting list for a community residence for several years. The social worker knew of openings at La Plaza and filled out an application for a level of care assignment from the Regional Eligibility Team (RET) and a referral to the management company. Raphael was assigned a functional level 3, which was compatible with the level of structure within La Plaza. La Plaza's house manager knew Raphael from the day program and could advocate for his admission to the home. Although the Regional Eligibility Team assigned a level of care to Raphael, he was essentially a client unknown to DMR, according to his current DMR social worker. The placement and transition process for this resident was therefore much more informal than the processes other clients were involved in. This type of informal process no longer exists because DMR now identifies all potential clients for movement into community residences.

The decision to have Raphael actually move out of his own home was a very stressful decision for the family. When Anna was told about La Plaza, she visited the residence several times with members of her family. Anna was glad that Raphael would be learning bus routes and other independent living skills.

She was comforted by the fact that the staff were primarily bi-lingual and bi-cultural, and that the location was in walking distance of her home. Anna felt her son would be accepted at La Plaza. Raphael visited the home and stayed there overnight. La Plaza staff, management agency staff and the day program social worker decided that Raphael would be an appropriate resident at La Plaza and he was accepted for admission. Raphael and Anna were invited to attend the OPS meeting. At this meeting, Raphael's service needs and goals were discussed with direct involvement from Raphael and his mother. Arrangements were made for Raphael to continue to see the same neurologist for his seizure disorder, to see the dentist down the street from La Plaza, and to continue in the same day program. Raphael has frequent family contact and his mother is warmly received by the other residents when she visits.

Amelia, a 39 year old resident who moved into La Plaza in February of 1986, is a class member. Amelia had lived at Mansfield from 1971 to 1982. Her family had not been able to cope with her behavior problems. After leaving Mansfield in 1982, Amelia lived in two other group homes. Home A, the group home Amelia was living in prior to moving to La Plaza was closing, and she needed a new placement. In addition, Amelia's mother was unhappy with her placement at Home A, as was Amelia's DMR social worker. They both felt that it was an inappropriate placement for Amelia, as the other residents were aggressive, the home served too many clients, and there didn't seem to be enough supervision. They felt her appearance and hygiene were not being adequately managed at Home A.

Amelia was considered a priority client by DMR, because of her class membership and because her current living situation was ending. Amelia was identified as a client appropriate for La Plaza by DMR. Her social worker believed that Amelia had the potential to function in a supervised apartment setting, but no apartments were available. The next best alternative was to see how she would progress in a six bed placement.

Amelia's mother and other relatives visited La Plaza and had the opportunity to meet with staff members. Amelia spent a weekend at the home. She was pleased to be with other hispanic persons and be able to eat Puerto Rican foods and speak Spanish with the other residents. Amelia's family was pleased that Amelia would be living much closer to their homes and that she would be with other hispanic people. They agreed to her placement at La Plaza and along with Amelia, attended an OPS meeting where services and goals were discussed. Amelia made the transition to La Plaza's medical and dental providers, and stayed at her current day program. According to those familiar with the process, the paperwork between DMR and Home A was coordinated well, and the administrative transition was smooth.

Staff from court monitor's office came to interview Amelia and La Plaza staff approximately 1-2 months after Amelia's placement. The plan had been to place Amelia on a supported work crew at her day program, but this move was held up until it was felt she had adjusted to her new placement at La Plaza. The court monitor urged that Amelia be placed on the work crew and stressed that this should occur when Amelia had adjusted to her new home.

Amelia's move to the work crew from the workshop was made successfully one month after her move to La Plaza. Amelia has family contact, although it is less frequent since her mother passed away.

Process and Events. Raphael and Amelia moved to La Plaza in the days before the existence of the transition checklist. Raphael's placement and transition were done rather informally, with most of the communication occurring among the day program, his mother who requested placement, and La Plaza. It is unclear exactly what role DMR played in Raphael's placement. In terms of transition documents, Raphael's file contains the day program's application for community placement to DMR, the RET assignment sheet, medical information from the time of the transition, and an OPS dated one month after Raphael moved to La Plaza. This OPS meeting was attended by La Plaza staff, management agency staff, a consulting psychologist, Raphael and his mother. There are also records from the day provider documenting Raphael's abilities and areas of needed improvement and goals, as well as the psychologist's report and medical information.

Amelia's process of transition was more formalized that Raphael's, perhaps due to her class status. She was identified by DMR as appropriate for placement at La Plaza, and her DMR social worker was involved in the transition process from the previous placement. Amelia's file indicates that the ID team met in November of 1985 with Amelia and her mother to discuss a change in her placement from Home A to another community placement, possibly La Plaza. The ID Team conference gave approval for placement in January of 1986 and assigned a placement date in February, 1986. There are copies of letters to Amelia and her mother from DMR dated February, 1986 regarding Amelia's move to La Plaza. In addition, there are records documenting Amelia's visit to La Plaza before moving in. The discharge summary from Home A by the DMR social worker in January, 1986 documents the reasons for the move and recommendations for services. The court monitor's records contain a letter dated January 1986 agreeing to Amelia's placement; but stressing the importance of a supported work placement, a letter dated February, 1986 from the case manager saying that she recognized the need for a supported work placement but also the need for time for Amelia to adapt the residence; and a letter dated March, 1986 from the court monitor commending Amelia's placement on a supported work janitorial crew.

Availability of Services. Both Raphael and Amelia were to remain with their pre-placement day providers, though Amelia moved from the workshop to a supported work placement. Both Amelia and Raphael participate in religious services and other activities at their local church. Both residents participate in group recreational activities with the other residents at La Plaza, and in activities sponsored by the day programs. Residents have travelled on group trips to Puerto Rico and other cities. The home maintains a photo album documenting these activities. They are both able to use the bus and travel independently, as well as shop at local markets, and so forth. Both see a dentist whose office is within walking distance of the group home and they are seen at the local hospital's outpatient clinic for medical services. Raphael is seen by a neurologist with whom he has maintained a relationship for many years.

The availability of mental health services to the Spanish speaking people who are disabled is widely recognized as being insufficient. Amelia has had need for special counseling regarding sexual issues, and finding this help has been difficult. Raphael needs speech therapy services which are also difficult to find for Spanish speaking persons. It should be noted that both Amelia and Raphael speak English, but prefer to speak Spanish. La Plaza has attempted to meet these needs with the help of DMR and the day programs, but Spanish speaking professionals needed in these specialized areas are generally unavailable. The La Plaze administrator believes that as her network grows wider, it is easier to find allied professionals, although she believes that there is a serious shortage. La Plaza contracts consulting services from the only licensed spanish speaking Ph.D. level psychologist in the area. Her time is in great demand and she cannot provide ongoing counseling.

Impact on Community Services

There doesn't seem to be any evidence of significant impact on community services. Local merchants and neighbors are aware of the La Plaza residents and watch out for them. This has been important in a neighborhood beset with crime. There have been incidents where residence staff have called the police to come over and speak with some residents regarding the consequences of stealing. There were occasions when a resident stole from staff members. There was one incident where the fire department was called because of a pan left on the stove and this resulted in some smoke. These incidents, comparatively speaking, are minute in comparison to what the police and fire departments have to cope with as routine matters in this neighborhood. The residence has been broken into two times, but the break-ins seem to have been stopped by the closing off of the back porch to the alley behind the home. There is no indication of any impact on sanitation or public health services.

Current Status

Service Availability. As noted above, the main problems in service availability are in those specialized areas where there is an inadequate supply of Spanish speaking professionals. The area of mental health services is an area of critical need because not only are there few psychiatrists and psychologists who speak Spanish, there are even fewer who speak Spanish and also have expertise in the area of mental retardation. There is also a shortage of professionals in other specialized areas such as speech therapy and sexuality counseling. The availability of general medical and dental services has not been a problem for the residents of La Plaza. Amelia has independently used the emergency room at the nearby hospital or one occassion when she was feeling unwell.

The day providers have generally been able to provide appropriate programming for La Plaza residents. Amelia was placed in a competitive employment situation for awhile, although this placement did not work out for a number of reasons. Raphael continues in the workshop, and this is seen as an appropriate placement due to his cognitive limitations. Both Amelia and

Raphael seem pleased with their current work and living situations. Relatives interviewed have stressed that La Plaza has truly become Amelia's and Raphael's home, and they regard the staff and other residents as extended family members. Amelia hopes someday to have her own apartment, and La Plaza staff encourage her growth in achieving this goal.

Relations with immediate neighborhood. As stated above, many neighbors and local merchants know who the La Plaza residents are, and look out for them. Some neighbors may not know, however, that La Plaza exists. La Plaza staff have concerns about the level of crime in the neighborhood, but see the positive aspects of living in a hispanic neighborhood as outweighing these concerns. The director would like to see fewer absentee landlords and more owner occupied housing in order to ensure more stability in the neighborhood.

CASE STUDY 2

CASE STUDY 2

History and Context

This home is located in a mid-size town that is immediately adjacent to a major city in central Connecticut. It is operated by a private non-profit church related agency. This agency (referred to as RA in this report in order to protect anonymity) supports numerous group homes for persons with a range of disabilities in Connecticut and another wing of the organization provides services for the elderly. RA also manages group homes for other sponsoring agencies. The study home was opened in May 1986. Although the agency headquarters are out of state, the executive office of the agency is in state.

The town is the site of at least five group homes for persons with mental retardation and it supports other residential programs for other individuals as well. There has been no history of organized neighborhood resistance to group homes in this community.

Description of home and residents. This home is the residence of six elderly persons with moderate to profound mental retardation. Two persons are non-ambulatory and together the residents have a range of health needs such as Alzheimer's disease, diabetes and restricted diets. Many residents had previously lived in nursing homes and the court order spurred the opening of this group home which serves only class clients.

The single level home is on a fairly densely settled street in a residential section of town. The home is part way down a block and is surrounded by other homes. Retired neighbors and families with children reside on the block. The neighborhood can be characterized as middle income, with many families working in the public sector. The street is not far from the center of town where there are numerous shopping centers. A short walk brings one to a bus line and the major hospitals of the nearby city are a short drive away.

The home is quite attractive and is in keeping with the other homes on the block. A ramp adjacent to the front door is rather inconspicuous. A "driveby" would not cause one to notice anything unusual about the home except for the following features: a large plain van that can clearly seat many people is often parked in the front; there are bedrooms where one might ordinarily expect a garage; and on each occasion that this researcher visited the home, there were as many as ten cars filling the driveway and lining the street. No other home on the block sports so many cars and the home can be clearly identified by their presence.

The inside of the home has been substantially modified to accommodate the residents in wheelchairs. Doorways are widened, there are grab bars, and shower stalls that permit a wheelchair to roll in. As mentioned, the garage was converted into bedrooms. Extra exits were built, and the backyard is partially paved and has a ramp to provide accessibility. There is a small office in the

front of the home that contains a desk, records, and a copy machine. Until about a year ago, the basement was used as an office for the day program. The home is tastefully furnished and decorated and appears well-kept.

Site Development/Neighborhood Entry

According to RA administrators, they were approached by the regional DMR office to open a facility for elderly persons with mental retardation because of their previous experience working with geriatric homes. Most of the class geriatric clients had been institutionalized for a long time and so had no real "nexus" in that particular town. However, the home in this town was chosen because of its affordable price, its proximity to commercial areas and health services and because the home could be easily renovated to support non-ambulatory residents. Administrators also appreciated the spacious backyard, the floor plan, and the quiet street where residents might be able to take walks.

There was no notification to neighbors about their intention to buy the home. Upon purchase, however, RA administrators visited neighbors, described who would be living at the house and invited neighbors to a meeting about the home. Although some of the neighbors' concerns were allayed at the meeting, others describe the forum as a generally negative experience. Administrators report that they follow a policy of not "apologizing to neighbors" for moving in and of not "asking neighbors permission" but rather of observing a "good neighbor policy" which is accommodating to neighbors' requests and complaints.

Neighbors, however, describe the administrators as "having a hard nosed attitude" and "no flexibility." At the meeting, the administrators described the rights of the residents to live in the community and the state statute which protected the opening of homes. According to neighbors, the residence was presented as a "fait accompli" and the neighbors felt frustrated that they had no recourse about any of the plans for the home. Moreover, neighbors resented being made to feel that they were "ungracious" for posing their questions.

Subsequent to the meeting, one family contacted the town council and state legislators. Elected officials confirmed that the state statute prevented any reversal of the plans for the home. Feeling defeated, the neighbors most anxious about the home did not pursue any organized resistance. During the months of renovation, a town council meeting was held to discuss whether this town was being unfairly targeted for community development. Regional DMR administrators attended this meeting and noted that only two families from Oak St. (name changed to protect anonymity) showed up at the meeting, and they did not vocalize any opposition.

Ensuing problems. The actual opening of the home in May 1986 proceeded without incident. The real problems with the home came during the first year or so of operation. As one neighbor described it, they were not anticipating any problems, the problems themselves emerged. One of the first

was the ramp that was built. By all accounts this ramp was large, ugly and terribly conspicuous. As one member of the service system described it, "the ramp could dock the QE II." Neighbors began to file complaints with town selectmen and state officials. As it turned out, the ramp violated some town zoning ordinances. In fairly short order the ramp was removed and the present attractive ramp was built.

Over the following year a series of neighborhood complaints arose over what can be best described as a breach of community norms and common courtesy. Many of the complaints centered around actions from the staff of the home. For example, neighbors describe that the shift change at 11 PM would be accompanied by blaring of horns from cars of persons who came by to pick up leaving staff. Loud conversations and the shining of headlights would disturb neighbors. A bright spotlight would be left shining on the driveway throughout the night. During waking hours the staff would on occasion play loud music from the backyard. Neighbors report that were these the actions of bothersome teenagers they would be inclined to call the police, but the nature of the home made them reluctant to do so. On one occasion a neighbor reported that a staff member engaged in a loud and angry argument with another person in front of the home. This time, neighbors did call the police. Neighbors describe staff as treating the home "like a workplace" and not like their own home.

It is not insignificant that nearly all, if not all, of the direct care staff and the house manager are people of color, whereas all of the residents are white as are most of the surrounding neighbors. One agency supervisor wonders whether the lack of communication about problems between neighbors and staff can be attributed to this fact. It may also be significant that many of the staff members appear to be former employees of nursing home facilities which could no doubt generate a different set of expectations about the work place.

However, the problems with this home were not limited to staff inconsideration. According to neighbors, in at least the first year of operation the grounds of the home were kept poorly. Lawns were allowed to overgrow, leaves remained unraked, and there was occasional litter. Attractive flowering shrubs were cut down and the staff did not seem to be knowledgeable about shrub and tree care. According to neighbors, a work crew of persons with mental retardation was used to keep up the property, but their services were unreliable. A cement post that was placed in the backyard and then not utilized was never pulled out. To one neighbor this demonstrated the lack of caring that the agency has for its property.

Problems around parking also surfaced. Immediately evident was the extraordinary number of parked cars and visitors to the home. Particularly disturbing, was the initial practice of parking cars on the front lawn. Neighbors report that some staff persons still park facing in the wrong direction.

The most disturbing aspect of the home, however, is the presence of one resident who habitually screams. The screaming is described by neighbors as being at the top of the lungs and going on for hours at a time, throughout the day, and sometimes in the middle of the night. The screaming is loud enough to be heard by neighbors across the street and it disturbs outdoor recreation.

Response to problems. This series of problems spurred numerous complaints by neighbors to the agency, to the DMR regional office, and occasionally to town and state government officials. As mentioned, the problem with the ramp was fairly quickly resolved by its replacement with the present attractive ramp. The problem with staff inattentiveness to community norms required greater attention. As one RA supervisor noted, an "education process" was necessary to train staff about making noise and other considerations involving neighbors. He said that it takes about a year to get a residence "under control" with all problems worked out. A top administrator acknowledged that in the beginning there were some "management problems" which have since been solved by more careful screening of direct care staff. Care is now taken not to disturb neighbors during shift changes. The bright spotlight on the drive was removed and driveway lights are not left on all night. There have been no further incidents involving staff arguments. Staff are now instructed not to park on the lawn.

Neighbors report that property upkeep has improved although occasionally the lawn goes unattended for awhile. The supervisor reports making a concerted effort to keep the property in good condition.

The problem of the screaming resident is more intractable. Neighbors report have gone to the home and inquiring whether this resident could receive medication that would ameliorate the problem. According to them, the staff responded by saying that the state did not permit them to administer such medication. The neighbors made numerous complaints, wishing to be able to disturb administrators in the middle of the night as they had been disturbed. The agency did respond by moving the bedroom of the offending resident to the other side of the house. To reduce noise during the summer, when open windows exacerbate the problem, an air conditioner was installed. In addition, RA staff instituted behavioral programming, which according to them substantially reduced the yelling.

The agency also responded to neighbors concerns by trying to open avenues of communication. A supervisor, hired after the opening of the home, has made direct contact with neighbors, encouraging them to call with problems. He gave them his card with his beeper number so that he could be contacted at any time. Administrators report installing a "good neighbor policy" designed to establish friendly relations with neighbors by being sensitive and responsive to needs.

Transition Planning

Identification and Selection of Clients. It was the Mansfield litigation that spurred the development of this home. Under pressure to establish community residences for class members residing in nursing homes the region sought RFPs for the establishment of a six person group home. RA had an established reputation and was selected as the provider. The site of the home was approved by DMR. According to regional staff, they are currently more active in the selection of the site of homes than they were when this home was developed. The foremost consideration in approving a site is whether the town will be unduly saturated by social service facilities. Reportedly this determination is made informally by consulting with the Department of Mental Health on the numbers of homes opened or planned for in the target area. Secondly, sites are checked to determine whether they comply with the "1,000 foot rule." Last but not least the home is evaluated to ascertain whether the needs of the residents will be met including access to services, ease of renovation to support client needs, and other considerations such as proximity to family.

At the time of the opening of this home, DMR regional staff had a list of those class mer bers in their region who required community placements. Case management staff were familiar with the clients who were in nursing homes. They knew that the home would be renovated to support two residents who were non-ambulatory. According to administers at RA, DMR prepared a list of about ten names of persons recommended for placement. RA staff selected the six residents according to age, appropriate distribution of functional abilities, the desire of the person to live in a group home, and discussions with guardians and transitional team members.

One of the nursing home residents who was proposed for placement and later accepted by RA was Harry (a disguised name). Harry had expressed an active desire to move into a community facility. Specifically, he wanted to have his own room and possessions, perhaps a pet, and the opportunity to do some gardening. At team meetings held in the nursing home, Harry agreed to move into a community placement and his OPS registered this as a goal.

Harry had been a resident in an institution since 1939. In 1969 he resided in a boarding home for ten years until he was transferred to the nursing home. There he was identified as an appropriate person for the new geriatric group home. According to his records, at the time of his transition, Harry was obese, was on psychotropic medication, and had a chronic skin disorder. Harry has good verbal skills and a number of community skills. Harry grew quite anxious after he moved, frequently expressing his concern that he would be moved from the group home. His behavior resulted in an increase in medication. Presently, Harry is hospitalized with a serious illness. This will be discussed later.

The second resident studied here is Janet. Like Harry she had spent decades in an institution and was later in a nursing home when DMR staff selected her as an appropriate person for the new home. Janet is non-ambulatory, with almost no verbal skills. She requires extensive assistance in

self care activities. She is nonetheless alert and attentive and able to make some of her wishes known through gestures.

Process and events. Harry's transition begins when he was first approached about moving to a group home while living in the nursing home. This was documented in an OPS. At first reticent about moving, Harry grew accustomed to and then enthusiastic about the idea. At the time that Harry and Janet made their transition, little documentation was required from the court monitor's office. The office does have a record of "transitional meeting minutes" which were then required by the region. The minutes identify members of the transitional team, Harry's strengths and needs, and activities required for the transition. According to his then case manager, Harry visited the home on several occasions prior to his move. His record contains evaluations that were necessary and level of care determinations. Regarding access to health services, at the time of the transition team meetings it was simply stated that the group home provider would secure these services prior to the move.

Subsequent to the move there was some correspondence with the court monitor about reducing Harry's medication level which was finally accomplished. Letters from the court monitor also addressed the ongoing presence of an office in the basement of the home that was used by the day program staff, and concern that this office was not accessible to residents. For the first year of the home's operation, day programming was done by another agency on-site at the home. It took about a year for the day program to open its own facility. Presently all residents are transported by the group home van to the "Opportunity for Older Adults" program which is designed to serve elderly persons with mental retardation.

The OPS subsequent to Harry's move describes his successful adjustment to the home and a letter from the court monitor commends the RA facility for providing "model transitional planning." His former case manager feels that the numerous visits were especially helpful in preparing Harry for the transition and his present case manager feels that Harry has benefitted substantially from his move. He has taken enjoyment from his own possessions and has made frequent use of community church and recreational opportunities.

The process surrounding Janet's move to the residence did not differ substantially from Harry's. She was identified in an OPS prior to the move as being appropriate for a community based facility. Her DMR nurse/case manager was familiar with Janet and suggested her as a good candidate for the home. Just prior to her move Janet received a "notice to resident of transfer" which describes her rights in the process. A transition meeting is described in the nursing records. Janet was visited by the RA agency staff and was accepted for placement.

Janet's advocate describes the transition process as going "reasonably well." The advocate was adequately informed of events. Subsequent to Janet's

move, an OPS describes Janet's successful adaptation to the home. Her advocate and case manger (like Harry, Janet has no significant family involvement) feel that Janet has benefitted greatly from the move. The advocate describes "a whole new world opening up for her." She now has her own clothes and personal possessions that she takes great enjoyment in. A recent cataract operation restored her very impaired vision. Her case manager spoke of Janet's obvious enjoyment of a Christmas party, where after kicking to the music, she seemed like she was just about "to get off her wheelchair and start dancing."

Janet's advocate was also satisfied with her transition to more age appropriate activities. Janet had been in the habit of always carrying with her a particular doll. After her move, staff slowly encouraged her to relinquish her doll in exchange for carrying a pocketbook. After some months of living with many personal possessions, especially her own jewelry, Janet was able to let go of the doll. Although Janet's advocate thought this transition was handled well, Janet's case manager expressed some reservations about the change, explaining how the doll had a lot of personal significance for Janet.

Service availability. Although all group homes are required to demonstrate access to services in order to be licensed by DMR and subsequently opened, this home was opened when some services were not yet stable. Nursing services, in particular proved to be a problem in the first year or so of the home's operation. DMR nurses and visiting nurses were used until RA was finally able to secure their own nursing contract. Even then, there was significant turnover in nursing staff until RA raised nursing salaries.

In the first weeks of the residence, accessibility to other medical services was also a problem. Staff members report going through the yellow pages and making numerous calls until some general practitioners and specialists agreed to take on the residents.

As mentioned, the court monitor was involved in making sure that reductions in psychotropic medications were made. The court monitor was also involved in overseeing that an adapted wheel chair was secured for Janet. Her advocate finally submitted a "programmatic administrative review" after some months had lapsed ar] an adapted wheelchair was still not obtained.

Although a day program was immediately available to the residents upon transition, it consisted of programming within the residence. As mentioned, this continued for about a year until the day program opened their own facility. Again, the court monitor's office was involved regarding the inappropriate office space in the basement used for the day program.

Another problem that beset the residence upon opening was direct care staff. Although, there was adequate staff, there was considerable staff turnover until recent parity legislation increased direct care salary. Another initial problem was that direct care staff was not trained in transferring clients (e.g.,

from wheelchair to bed, etc.). That has since been resolved. All told, it took some time before the residence had established a full complement of appropriate services.

Impact on Community

Fire. On the whole community service providers report no adverse impact of the group home. The town fire marshall is aware of the home but has received no calls or complaints about it. He does a yearly inspection of the facility. Other group homes in town have occasionally pulled a false alarm but that has not happened with this home. The fire marshall reports that fireman take special precautions when they know they are dealing with a residence of persons with disabilities.

Police. A computer search of police calls in the past year involving the home shows "a pretty clean report." There were five incidents in total involving: two medical related calls, one car lockout, one "suspicious circumstances", and one fire alarm. This is described by police as having minimal impact on their service. The police captain did not recall any incidents involving staff.

Health. The town health inspector makes yearly visits to the home. Aside from the parking problem she finds that the home makes no adverse impact on municipal services. In fact, she describes the senior citizens in the home as having proportionately less impact on services than do other senior citizens in town. Other senior citizens require special public transportation arrangements whereas the seniors in this home rely on the house van. Regarding parking, she suggested that meetings are held elsewhere and/or visits should be staggered.

Real estate. Since the opening of the home, two properties (one adjoining and one opposite) went quickly on sale. Both neighbors and the house manager attribute this "panic selling" to the presence of the group home. However, there are conflicting reports as to who sold because of the home and who sold for other unrelated reasons. The properties were sold without any undue delay and apparently at no significant drop in property value. The home that was sold next door to the group home was bought by a young couple with two children. They were unaware of who the residents were next door at the time of the sale.

One real estate agent in town reports that he is unaware of adverse impacts on property values because of group homes, however he treats sales involving group homes as "unique circumstances." In one instance where he was selling a property one lot away from a group home under construction, he found that he was asked by prospective buyers to explain the unusually large and seemingly commercial residence that was being built. (A multi-car garage was being built in the rear.) He shared the little that he knew about the home and he felt that the information may have dissuaded some buyers. Eventually

the home sold without incident but perhaps at somewhat less than the full market value. This agent felt that it was important not to renovate homes so that they are conspicuous on a drive-by. He suggested that tensions with neighbors would be eased if group home officials "reached out" to neighbors so that neighbors felt like they "had a say in the matter" and were well informed.

Zoning and planning. A member of the zoning board who was contacted for this study had "received a lot of complaints" about the RA home. He received calls about the ramp and about noise during shift changes late at night. He attributed problems to "low-cost help." Unable to do much from his position, the official "tried to make concerns known to state people." This zoning board member expressed irritation at having no leverage over the state statute. He felt that DMR and private agency staff should make a greater effort to contact and inform town officials about plans regarding group homes. "A spirit of cooperation (with the town) would be greatly appreciated," he said.

Commercial and recreational services. Regarding commercial services, this home had at first been using commercial suppliers of food and household goods. They found this to be unworkable and they now use local supermarkets. They also frequent other local businesses such as the hardware store and tailors.

The residents also make frequent use of the town generic senior citizen center. They have attended dances, bingo and other events. Residents have also done some volunteer work at the center and other members with disabilities from group homes have helped with the "meals on wheels" program. The program director of the center is well aware of the residents and feels that they have made no negative impact on the center services and she has had to make no special accommodations for them. "They come like everybody else." The other seniors at the center seem to accept the residents and she has received no complaints about them. Her only concern is that sometimes it seems that residence staff "deposit" the residents for a few hours, when they have nothing else to do, for activities that they are not appropriate for. She describes one instance where a job fair was being held at the center and businesses were interviewing interested seniors. The residents were brought there even though she felt they had no real interest in employment.

Current Status

Access to services

Health services. After some time, the difficulties in securing health services were largely resolved. RA now has nursing consultants on board and the supervisor feels that schedule flexibility and autonomy has helped keep this position stable. With some trouble they have found a local general practitioner. Some residents have Medicare parts A&B which helps to pay for his service. A neurologist with a good reputation that accepts Medicaid was found at the University of Connecticut. Other health specialists have been secured and the

staff have relied on the hospitals of the nearby city. There have been no problems with emergency medical services.

There was however, a very substantial problem obtaining dental services. For over a year they could not find a dentist who would both accept Medicaid and the residents. The agency supervisor reports that through his personal connections, they were finally able to find a dentist in a town about 10-15 minutes away. To keep the dentist, the supervisor is scrupulous about keeping and being on time for appointments. He has also invited the dentist to dinner and to do inservices at the home on dental hygiene for additional fees. Nonetheless, the supervisor feels that when he himself leaves the agency the dentist will stop serving the residents.

Another substantial problem was obtaining psychiatric and psychological help. Here the specific issue is insufficient reimbursement from Medicaid. Again, both services are now in place but agency staff attribute that to their own personal resources prior to employment at RA. They don't think that the psychiatrist would take on any new clients and special care is taken to make sure that those services are retained. Moreover, the supervisory staff feel that when they leave RA the mental health professionals will also stop serving the residents.

Physical and other specialized therapies continue to be difficult to get. Presently, they receive physical therapy from a DMR regional employee. This person, however, does not do hands-on work. DMR also provides some behavior consultation. Two residents have behavior programs for occasional aggressive behavior. Their program also retains on contract a nationally known psychiatrist specializing in dual-diagnoses clients.

Staffing. Presently, during peak activity hours the staff to client ratio is one to two and one to three. The home also supports two awake overnight staff positions. The house manager is present at the house during daytime hours. The staff ratio is adequate with the exception of one resident who has Alzheimer's disease and needs constant attention. It took some time and a great deal of effort before RA was able to secure funding from DMR for one to one staffing. Turnover of staff was acknowledged to be a problem in the first year of the program. Since then however, parity wages with institutional staff were established and staff turnover has stabilized. As mentioned nearly all of the staff are people of color and many come with prior experience in nursing homes.

Social/recreational activities. The residents of this home frequently attend events at the local generic senior citizen centers. They also often go to local restaurants, movie houses, and shop at local malls. One neighbor commented that the residents could often be seen carrying their lunch bags onto the van for some sort of trip. The agency, they commented, "keeps them on the go."

Harry in particular has attended the theater in Hartford and professional sporting events. He attended a senior citizen dance at the local high school where a photo was taken of him that was published in the newspaper. Harry and another resident also went to the church sponsored camp during the summer. Church is an important part of Harry's life. An old friend takes Harry every Sunday to church service.

All members of the home attend the "Opportunity for Older Adults" program which is designed to be a day program for retired adults. This program also involves the residents in community outings and social events. As mentioned for some time the day program was held in the residence. Presently the day program is "five minutes away" from the residence. A daily log keeps program staff "in touch," and the day program submits evaluations to and attends the yearly planning teams. The current program director reports seeing a lot of progress in the residents over the time they have attended the program.

Guardianship/family status. Neither Harry nor Janet have active family members. Attempts have been made by case managers to involve family members. Both have an advocate. Although family members have been used as limited guardians for the medical purposes they are reluctant to sign up for full guardianship because they fear that they may become financially responsible.

Although there has been some turnover in Harry's advocate, Janet's advocate has been involved with her for many years and takes a very active role in overseeing program services. Although Janet's advocate is on the whole satisfied with service provision, she speaks of the difference between community presence and community participation. Whereas the group home has succeeded in the former, the latter would involve the participation of Janet in community organizations and events that are taken for granted by other neighborhood citizens. Janet is fond of children and the advocate would like to see her volunteer in a day care center. The advocate also notes that Janet has some trouble with one of the other residents. Whereas most other persons have choice over who their roommates are, Janet does not, "she can't move out."

The advocate was also instrumental in seeing that the adapted wheelchair was finally provided. She recalls that the DMR regional office reportedly never received her first programmatic administrative review (described in Appendix 3 of this report) for the chair and a second request was necessary with continued follow-up. The advocate would like to see Janet receive more physical therapy but understands that it is very difficult to get these professionals. She noted that although the residents attend programs through the Parks Department, often these programs are segregated. The advocate supports continued deinstitutionalization but feels that greater expertise is necessary because persons with greater complications will be coming out. On the whole she thinks there needs to be increased orientation of staff to normalization principles and client rights. Although the group home is a vast improvement over the nursing home, this advocate does not feel that the nursing home is an

appropriate yardstick for measuring services. Rather one should ask, "Would I be comfortable here, is this a program I would like to live in?"

A very significant problem has arisen over Harry's well being. He was recently hospitalized and diagnosed with a serious condition. After treatment he will require skilled nursing care. Admission to a skilled nursing facility is especially unfortunate for Harry as he had expressed increased anxiety prior to his illness that he may be transferred from his group home. Although the group home wants Harry to return, they would be placed at financial risk if Harry resides in a skilled nursing facility for more than a few weeks. The home has been successful in obtaining a respite client during Harry's absence so that his placement at the home is not placed in jeopardy.

Relations with surrounding neighborhood. From the outside it appears that relations with the surrounding community have stabilized. The agency, regional DMR office, and the state representative have not received a formal complaint in the past year. Many of the earlier problems were rectified. The two homes that went up for sale were sold without incident. The home sponsored a cook-out for the neighborhood this past summer and several neighbors attended and relations were finally. Neighbors often see the residents going down the street, especially in the summer, and they find the residents friendly and will return waves. A family with two children have moved in next door to the home. For the most part they report no problems with the home, and the children will occasionally go over and interact with the residents.

Despite this seeming acceptance of the home, closer query of relations reveals persistent concerns and some bad feelings among neighbors. The most significant enduring problem is the screaming resident. Even with the change in bedrooms, air conditioner and increased staffing, this resident remains audible to neighbors, even to those living diagonally across the street. This is especially the case in the summertime. One neighbor who is retired can hear the screams throughout the day. Another finds that her time to relax at home or in her garden is disturbed by the screams. A different neighbor, who had moved in subsequent to the opening of the home, could not understand why anyone would be screaming so much and supposed that there must be some abuse going on in the household. He wondered whether screaming could be typical of persons with mental retardation and he also noted that he had heard staff members yelling back at the resident. The amount of screaming leads two neighboring families to ask why these homes are not placed in areas with more land surrounding them. The homes on this block are only a driveway apart. Not opposed to community living per se, neighbors feel that increased acreage would eliminate disturbing neighbors with noise. Although neighbors have ceased making active complaints about this problem, they feel that the problem has not been adequately resolved.

Another enduring problem is the amount of cars parked at the home. During each visit to the home by this researcher, this home could be readily picked out by the number of cars that lined its driveway and street. This problem is exacerbated by the conversion of the garage to bedrooms, the large

van, numerous staff, and most especially by the practice of holding meetings at the home. As one neighbor noted, "the tons of cars parked all along the street makes it look like there is something special going on there." She wondered whether the home is actually used as a teaching/training center.

There are remaining concerns about property upkeep. Although much improved, the leaves may still be left unraked for some time resulting in blown leaves onto other neighbors lawns. Several neighbors also noted the copious amounts of trash that the home produces and one person said he found an open bag of trash cast way out onto the far backyard of the group home. In it was evidence that the trash came from the home, and in it also was an empty bottle of liquor. This led this neighbor to question the quality of the staff employed at the home and reinforced his concern that staff were abusing residents.

This neighbor also expressed annoyance about another property related concern. One of the renovations included changing the pitch of the land. Consequently, there is some runoff of rainwater from the group home property onto the neighbor's lot and both properties can become very muddy in heavy rains. This neighbor was approached by the house supervisor regarding the construction of a trench for the runoff and the neighbor gave permission to cut down a few trees to accomplish this. Since that time he has heard nothing form the group home. Desiring the trench to be built, he wonders when and whether the group home will ever go through with these plans.

A less concrete problem is the impact of the home on at least one neighboring family's sensibility and lifestyle. This neighbor finds that the sheer presence of the residents "is very distressing and disturbing." In the summer, when members of both households are out in the backyard, the "incessant muttering," occasional screaming, and overall deformity of the residents significantly affects one neighbor. Because she "feels for these people" she finds their disabilities to be very "upsetting." As a result she says that she often cannot take her relaxation from her usual gardening hobby. Moreover, the neighbors are now reluctant to bring any houseguests out to their backyard when the residents are out.

A similar problem is the enduring resentment of the home for placing the neighbors into the position of "feeling ungracious" because of their concerns about the home. They don't like having to call and make complaints. They resented being thought of as "burdensome" and unneighborly persons because of their complaints. Although well informed of the rights of the residents to live in the community, they wondered why it seemed that they as neighbors had no rights in the matter of community development. As neighbors who immediately abut a group home, they feel they receive the brunt of any problems encountered. They remain unconvinced that as immediate neighbors their property value won't be adversely affected.

Neighbors also expressed puzzlement over the amount of state money being spent on the residents. They wondered whether institutional care wasn't less expensive than the care received in the group home. Given the cost

of one to one staffing, the numbers of people who seemed to be involved in the home, they wondered whether tax dollars wouldn't be more appropriately spent on education than on persons who seemed little aware of their surroundings. One neighbor "didn't see the point" of teaching a resident how to make a sandwich when there were so many other urgent social needs.

Although not specifically named, a need for information and communication was evident. As mentioned, one neighbor wondered about typical behaviors and harbored concerns that residents were being abused without seeming to know how or whether to verify these issues. Other neighbors were not sure whether there is any state supervision over the church related facility. They also wanted to know whether it is true that, as had been told to them by a staff member, the state does not permit the use of psychotropic drugs. Another neighbor wondered whether this wasn't indeed a training facility and what was the purpose of all the cars at the home. There also were concerns about cost of care and property value. During interviews, this researcher, in some way seemingly connected to the state, was specifically asked for information about these issues. Although one neighbor had the number of the home's supervisor, it was clear that this neighbor wanted information from a source outside of the agency. They hoped that this report may be an instrument by which some of their concerns are heard and addressed.

On balance neighbors acknowledge that the agency has "made an effort" and many initial problems are rectified. They feel that the agency (not the residents themselves who are incapable of much social interaction) is trying "to be good neighbors." Some neighbors do support community development and support the rights of persons with mental retardation to live in communities. But the ongoing problems with the screaming resident, number of cars parked, and property upkeep continue to keep community relations ambivalent among the closest neighbors.

CASE STUDY 3

CASE STUDY 3

History and Context

This case study examines a private, non-profit, suburban, six person group home in a medium sized community in a suburban town, adjacent to a mid-size city in southeastern Connecticut. Piedmont House, (not the real name), is located next to the business district of the town center, and abuts the library, but is on a street consisting almost exclusively of large, stately, well-maintained private residences. Piedmont House is itself one of these large residences.

The developer of Piedmont House, AB (not the real name) is a long standing, well known agency in the area. AB operates a large network of day program services as well as other residential facilities. AB purchased the property where the home is now located in 1984. The town had originally purchased the property in 1983 for the purpose of expanding town center parking. The town's plan was to demolish the structure and turn the property into a parking lot. The property was located within the historic district and the historic district commission objected to the destruction of the structure and replacing it with a parking lot. Some members of the local neighborhood association also objected to such a use of the property. The historic commission was successful in blocking the plan to create a parking lot, but this left the problem of what to do with the property.

Site Development and Neighborhood Entry

The first selectperson, who was on the board of AB, suggested that a good use of the structure would be as a group home for individuals with mental retardation. The town then offered the property to AB and to another agency which also developed group homes for persons with disabilities. Only AB was interested since the other agency was involved in developing another property at that time. The idea of selling the property for a group home was objectionable to some town officials, neighbors, and other town citizens. The concerns they voiced were mainly about property values, parking for the residence and the continued unmet need for town parking.

AB and the first selectperson met with the neighborhood association. A presentation was given explaining what a group home was, including a description of what persons with mental retardation were like, and a discussion regarding property values. AB asked for the support of the neighbors in pursuing the development of the property. The neighborhood association decided to support the development of a group home, though the neighbor directly next to the property who shared a driveway remained quite concerned about the project. It should be noted that among those in the neighborhood association was a couple with a child with mental retardation. This couple enthusiastically supported the development of the group home, and were involved in suggesting such a use for the property.

Before the property was sold to AB, the proposed sale of the property for a group home was a prominent issue in the town meeting over a period of several months. The issues had a high profile in the local media. The debate centered around property values, concern about the selling price and attempts to somehow use the property for parking. Some people also mentioned safety issues. AB, along with the first selectperson and a group of dedicated parents of AB clients organized to gain support in the community for the group home. They launched a phone campaign to make the community aware of the issue and to gain support for the sale of the property to AB. A brochure was developed by a public relations specialist which highlighted the desire for group homes to be good neighbors, and provided information about persons with developmental disabilities. Parents came to town meetings and spoke of the importance of having such homes, and voiced their concerns regarding what would happen to their children with disabilities once the parents were elderly or had passed away. Finally a compromise was struck involving parking. AB was willing to give a portion of the backyard, which abutted the town library, to the town for the purposes of building a parking lot. The town meeting eventually approved this plan, and the sale of the property to AB went through in the fall of 1984. The home was then named after a family who had been particularly active in both AB and specifically in the efforts to support the home.

Major renovations were done to the property. The historic commission required that the mandatory second story fire escape be completely enclosed so as to blend architecturally with the structure. Civic organizations supported the home by covering the cost of various aspects of the renovations. Shrubs, landscaping and a sprinkler system were donated amongst other items. When renovations were complete, the home offered four bedrooms and two bathrooms on the second floor, and a kitchen, living room, dining room and staff area including a nurses office on the first floor. Laundry facilities are in the basement. The home is tastefully decorated and the upkeep of the property is scrupulous. There are plaques on the walls of the home indicating information such as who donated landscaping resources. Although this is understandable given the significant generosity of civic groups, it is outside the norm for home wall decor. When the researcher visited the home, there were cars parked on both sides of the street in front of the home. Because of the proximity of the library, business district and doctor's office, it wasn't possible to attribute the number of cars to the presence of the group home. In fact, the presence of two hour parking signs indicated that overflow parking was expected in this area.

By the time the residence opened, the staff was on board and the staffing ratio was two to four staff per six clients with one awake staff for overnight.

In November of 1985, after the residents had moved into Piedmont House, neighbors and others in the community were invited to an open house hosted by the residents, staff, and AB.

Transition Planning

Two women and four men ranging in age between 30 and 45 reside at Piedmont House. All are considered to have mild to moderate disabilities, and one resident is also deaf. At the time that AB was planning for the residence, the transition checklist did not exist. AB dealt directly with DMR case managers at the regional center and with case managers at other state institutions. As noted in Case Study 1, DMR now identifies all clients for community placement through a regional office. AB was very concerned about the composition of the residents of Piedmont House. They hired someone whose specific task it would be to find out the skills and habits of the residents coming from Southbury Training School, and to develop a questionnaire designed to assess the residents' and family's goals, preferences, dislikes and concerns. This task was to be slated for the house manager, but she had an accident before this process was to occur and never returned to the position.

Jane (not her real name), a 36 year old resident, moved to Piedmont House from Southbury Training School. She had lived at Southbury from age 5 to age 33. Jane's family remained in contact with her through the years. Jane's admission and transfer process to Piedmont House began when her case manager at Southbury put her name on the placement coordinator's list. She lived in a cottage with 25 - 30 other women. Jane was quiet and her case manager felt she needed a smaller setting where she could get more individual attention. AB had notified Southbury of an opening for a woman at Piedmont House. A referral was sent to AB and the Regional Eligibility Team was sent an application to assign a level of care. An AB staff member was on the RET and he became aware of Jane. Jane was assigned a level 2, consistent with the structure to be offered by Piedmont House. The Southbury case manager sent AB an information packet on Jane. One concern that Jane's Southbury case manager had was that Jane's family lived out of the region. She was worried that there would not be enough opportunities for family contact. At the time, clients could be placed outside their home region, but this is no longer true.

Prior to selection for admission to Piedmont House, the Southbury case manager brought Jane and her mother to visit another AB residence and the workshop at the day program. Jane's mother was very concerned about Jane's adjustment to a community residence because Jane had lived almost her entire life at Southbury. But Jane's mother was becoming unhappy about the cottage Jane lived in, especially because of safety issues. She believed that there was little respect for her daughter's possessions, and that upset her. After Jane's mother saw the community residence and the workshop, she became more enthusiastic about the idea of Jane moving out of Southbury. Jane and her mother were interviewed along with the Southbury case manager to provide information to the AB admission team. AB staff made additional trips to Southbury to observe Jane and speak with the staff there about Jane. Jane had a pre-admission physical and was accepted for admission to Piedmont House in September of 1985 and she moved in at the end of October, 1985. Jane's mother was unable to attend the introductory meeting of clients and their families held at the town library in September. Piedmont House was not opened as of September due to construction

delays, and AB held the parent/client meeting at the library, directly adjacent to the home.

Karen, a 30 year old resident, moved to Piedmont House from her family's home. Karen had always lived with her family in a nearby community. Karen's mother was concerned about her daughter's recent withdrawn and unhappy behavior, and was having trouble coping with Karen's resistance to her authority. Karen's mother's health was deteriorating and she was worried about what would happen to Karen if she could no longer care for her. Karen's mother consulted AB staff, where Karen had been attending the workshop day program for many years. AB staff suggested that the family and Karen see a psychologist to help understand what was happening. The family followed through with this suggestion, and after two years they decided that Karen might be happier living in a group home with peers. Karen had been in respite care on weekends from time to time at another parent agency residence. It was clear to her mother that Karen enjoyed spending time with her peers and being more independent.

Karen's mother had mentioned her desire to place her daughter to Karen's DMR case manager. The DMR case manager met with Karen to talk about moving to a group home. In her annual evaluation, the case manager recommended the move. The case manager met with Karen's mother and AB staff. The case manager assisted Karen's mother in applying for the move to a community residence. The case manager submitted an application to the Regional Eligibility Team for an assignment of a level of care. Karen was assigned a level 3, consistent with the structure to be offered at Piedmont House. An application was then submitted by the case manager to the Residential Planning Committee at the Ella Grasso Center, and Karen was placed on a list which went out to residential providers, including AB. AB staff worked with the case manager and the family psychologist to advocate for Karen's placement on the list of clients in urgent need of placement. Karen received urgent status, primarily due to her mother's ill health.

Karen's application was reviewed by AB admission team. Karen and her mother were interviewed and a questionnaire was completed regarding habits, preferences and dislikes. Unlike Jane, AB was very familiar with Karen and her mother. Karen had been a client of the workshop since she was a teenager, and her mother had been active at AB over the years. AB's main concern regarding Karen was how she would get along with her new roommate, Jane. Karen and her mother were both sent letters of congratulation on admission to Piedmont House in September, 1985. Karen and her mother attended a meeting at the town library later in September to meet the other residents and their families. Karen moved into Piedmont House at the end of October, 1985.

Process and Events. As stated above, the transitions of Jane and Karen into Piedmont House occurred before the existence of such documents as the transition checklist. The first step of Jane's transition out of Southbury was her case manager's decision to place Jane on a list to be considered for community placement. Jane's file at Piedmont House contains the DMR referral summary

indicating a Specific Service Request, dated 5/8/85, for a community residence and workshop placement. Reasons given for the request were: Southbury's ability to offer Jane only maintenance programming vs. skill enhancement, and that her family was unable to care for her at home. This report also contained client history, information on the family, current client functioning and results of testing in hearing and language, scholastic achievement, vocational functioning and a medical report.

The record contains several other documents, including: (1) Application to Determine Eligibility for Funding of an Individual in a Private Community Residence, which contained the reasons for transition, a skills rating and financial data, (2) Regional Eligibility Team summary for determining a level of care (level 2), (3) resident in-take questionnaire from AB asking about habits and preferences, minutes of the intake interview at AB, (4) Social Service Evaluation from the Southbury case manager which explores such issues as Jane's mother's reaction to visiting an AB Community residence and indicates that Jane was admitted to Piedmont House with a move-in date in October, 1985, (5) residence application to AB completed by the Southbury case manager, (6) copies of congratulations letters regarding admission sent to Jane and her mother, and (7) OPC dated December, 1985. The file appears to indicate a significant degree of planning for the transition of this client. Jane's mother is very pleased with Jane's placement at Piedmont and believes that her daughter is also very pleased with her living situation. Jane's mother is unable to have frequent visits with her daughter because of distance and the responsibility of caring for Jane's disabled father. She is concerned about staff turnover, she has never questioned the quality of care at Piedmont House. She believes the staff tries hard to resolve problems that arise.

The first step in Karen's transition was when her mother alerted AB and the DMR case manager to the problems she was having with Karen at home. Karen's file at Piedmont House contains the following documents: (1) Residence Application dated March, 1985 to AB. This includes a hand written letter from Karen's mother explaining the problems at home and her concerns about the future, (2) Summary Interview from AB evaluating Karen's skills, family desires, and so forth, (3) Questionnaire regarding applicant suitability for admission to a community residence completed by AB vocational staff, dated June, 1985, (4) letter from the RET chairperson to AB indicating an assigned level of care, (5) Referral Summary recommending group placement, dated August, 1985, (6) Resident Intake Questionnaire asking about habits, preferences, and so forth, (7) report of a consulting psychologist on test results, dated July, 1985, (8) report from the CST meeting from the regional center indicating Karen's placement on the urgent waiting list and documenting reasons for group placement, dated August, 1985, (9) copies of letters of congratulation on admission sent to Karen and her mother, also indicating a move-in date and an invitation to a gathering to meet the other residents and their families, dated September, 1985, and (10) OPC dated December, 1985. This file also indicates a significant degree of planning for transition. Karen's mother is very pleased with Karen's placement at Piedmont, and has seen her become much happier. Karen feels more independent and more her own person. Karen's mother has been active at AB and values the relationships she has made through the organization. She believes there is good

communication between the parents and the residence staff, and that staff is responsive to her concerns. Karen's mother attends parents' meetings at the home. The most recent being to enable parents to meet with the new house manager.

Availability of Services. Both Karen and Jane attend AB's sheltered workshop day program. Karen has continued to do well at the workshop. Jane has had a somewhat stormy adjustment to the workshop, though it must be considered that she was institutionalized for many years. Jane's mother has reservations about the fit of the workshops placement. Jane is very interested in animals and her mother would like to see her work in some setting with animals. Piedmont House residents are able to attend religious programs developed especially for them as well as special classes at the local high school. For recreation and socialization, they primarily attend group activities with the other residents of Piedmont House. These activities may include residents from other parent agency group homes. Karen participates in special Olympics swimming and practices at the local YMCA. At the time of data collection, AB was in the process of securing memberships at the Y for Piedmont House residents. Residents of Piedmont House are able to make use of the town center commercial area which is in the immediate vicinity. They receive most of their medical care at a nearby HMO, though gynecological and dental services are provided through a hospital in a nearby town. At the hospital, there are clinicians experienced with and willing to care for developmentally disabled patients. Piedmont House staff escort all clients to dental and medical appointments. Piedmont House has a nurse who is on site several hours per week, and a consulting nutritionist to assist staff with menu planning and coping with Karen's and others' special dietary needs.

There has been a concern voiced by Piedmont House staff regarding the availability of dentists who are willing to care for the residents both from a clinical and a financial point of view. There seems to be a lack of interest in serving these clients because of their anxiety levels and resulting behaviors, and because of the inadequacy of Title XIX reimbursement.

Impact on Community Services

There is little evidence that the presence of the group home has had an impact on community services in any significant way. The police have not been summoned by either complaining neighbors nor by the group home. The fire department's only official contact has been in the inspection process. The fire chief was pleased that a particular type of sprinkler system he advocated was installed. Some members of the fire department have been involved with the group home through civic organizations. There have been no contacts other than inspection by health and sanitation personnel.

Current Status

Access to Services. As stated above, there is some concern regarding access to dental care. Some persons interviewed indicated that they would like to see increased opportunities for integrated socialization and recreation in the community, though the residents are using a fair number of resources at this time. These resources appear to be mainly segregated, limited to the disabled community. A deaf resident is involved with a member of the community who is also deaf. Piedmont House staff hope to see this client become even more involved with the deaf community. Karen's mother indicated that she would like to see a swimming program available all year for Karen, though this was being addressed in securing YMCA memberships for the residents.

Relations with immediate neighborhood. Piedmont House appears to have positive neighborhood relations. The adjacent library had no complaints at all about the home. A neighbor across the street who has a daughter with a disability regularly invites the residents to his home to visit, and the group home invites his daughter to some of its activities. The residents enjoy the local shops and restaurants.

The relationship Piedmont House has with the private residence with whom it shares a driveway is somewhat more complex. While this neighbor feels very positively about the staff and the clients, he is upset about the shared driveway situation. This neighbor believes that the commercial vehicle drivers who make deliveries and pick up garbage from the group home have little respect for his landscaping, and that commercial vehicles take away from the residential atmosphere of the block. He also believed that the driveway and parking area for the group home would be larger than the actual resulting space. He states that he was told by AB that there would only be two staff cars parked in the driveway at one time. There are often three cars parked there. It should be noted that there is an area off the drive and adjacent to the neighbors' garage where there are parking spaces for the staff. This area does not block the driveway, but limits the space around the neighbors' garage. AB pays for a plowing service, thus relieving the neighbor of this expense. This neighbor favored the building of a driveway on the other side of the house for the group home, though this did not occur. The neighbor feels somewhat deceived by the assurances of AB regarding the space available in the driveway and the number of cars that are parked there. The concerns of the neighbor, however, did not keep him from inviting the residents of Piedmont House over for a picnic.

CASE STUDY 4

CASE STUDY 4

History and Context

This home, opened in November 1984, was the first group home for persons with mental retardation opened in this suburban town, adjacent to a mid-size city in the Southeast corner of Connecticut. It is operated by a private non-profit agency. Presently, there is one other group home operating in town and a third is scheduled to open. There is currently a controversy surrounding the planned opening of a home for AIDs patients in the town and a shelter for the homeless has also opened with some community concerns.

Description of home and residents. The home is located in a two story building on a fairly densely settled street. It is on the corner of a circular drive, with a neighboring home to the right and neighboring homes opposite. The home on the left is facing in another direction and is separated by an incline and some shrubs, so that it seems as if the group home is on its own corner of land. There is a sizeable backyard and a driveway. The garage is converted into separate living quarters for a live-in staff person. There is an enclosed stairway leading down from the second story at the side of the house.

The surrounding area is strictly a residential setting, zoned for single family homes. The nearest shops are many blocks away and a drive is necessary to reach any major shopping centers. There is no public transportation immediately available to the home. The neighborhood can be characterized as white collar, middle to upper middle income, with many professional residents.

Upon a first drive-by, the home is in no way recognizable as distinct from other homes on the street. There are no signs erected or other conspicuous features. At closer inspection, the front yard is relatively more cluttered with leaves and branches than are other homes on the street. One will also notice the second entranceway where the garage doors might be expected.

This group home is the residence for six young adults, three men and three women, with mild to moderate mental retardation. None of the present residents are "class" clients. Rather they are "community" residents, many of whom grew up with their families in the same town of the group home. There have been some changes in the composition of residents since the home's opening. Most of the residents attend a sheltered workshop in the town during the day, one has a supported work placement, and another has a competitive job. Residents are transported to work by a van provided by the sheltered workshop and/or by staff cars.

Although none of the residents present overly serious medical challenges, there are numerous medical concerns. One resident is suffering from an ulcer and from sleep apnea (a potentially dangerous condition where an individual stops breathing for long periods of time). Another has a serious foot problem;

he requires weekly medical attention, and is presently on crutches. Residents have a variety of other conditions that require periodic generic and specialist health care along with daily medical regimens. At least one resident is taking psychotropic medication.

The residence supports 24 hour staff coverage, including an awake overnight position. During peak activity hours the staff to resident ratio is 1:3, at other times it is 1:6. The live-in staff person works week-day mornings and week-ends and part-time staff complement the house manager position and other full time staff.

Site Development and Neighborhood Entry

The non-profit agency that operates this home (referred to as OA in this report to protect anonymity) leases the home from a private investor group. Several members of the board of directors of OA are also members of the investor group. OA was fully responsible for the site selection and development of the residence. This home was the second home that OA opened (the first was opened in a nearby town) and the agency now operates several others.

The history of this home actually begins with the attempt to purchase and lease another home in the same town. OA had already received funding and approval from the Department of Mental Retardation to open a home for six persons and several of the prospective residents were already identified for the move. In November of 1983, OA began negotiations with the owner of one property and had secured a verbal commitment to sell. Prior to the formal purchase, OA announced their intention to buy the property and had a meeting with local neighbors. Subsequently, community opposition to the purchase mounted and over 70 neighbors formed an organization to prevent the purchase. Local town officials were involved and the owner reported that he received numerous calls from neighbors pressuring him not to sell the home to OA. According to a report at the time, at the height of the controversy, another potential buyer of the property materialized, reportedly unaware of the controversy, and offered to buy the home for more money. The owner of the property suddenly and unexpectedly sold the home to the new buyer leaving OA scrambling to find another property for the prospective residents.

During this time the neighborhood organization initiated legislation through the town governing body to require that the Board of Selectman be consulted and informed of any plans of the state to open group homes in the town. The neighbors had complained about a lack of communication from OA and of not being sufficiently informed about ongoing plans. Later, this motion was overwhelmingly defeated by the Town Council.

According to OA administrators, these events led to two decisions; one, to specifically avoid informing the public about their intentions to buy another property until the purchase had gone through; and two, to hold a public forum about their plans after the purchase went through.

OA searched for a home in the town since several of the residents selected for the home came from homes in the same town. The home they selected "perfectly" met their needs. It was affordable and in the kind of neighborhood that was in keeping with the lifestyle of the parents of the prospective residents. The neighborhood seemed "cozy" and there was adequate room for the residents. Although not in immediate proximity to a commercial area or transportation routes, the home was close enough to shopping and to a nearby sheltered workshop. Adequate health services were available in the town and within a short drive in the adjacent city.

OA plans proceeded as anticipated and the property of the home under study was purchased without incident. OA administrators indicated that they spoke to neighbors on a one to one basis and invited them in person and by flyer to a public meeting to be held at the home. Mixed reactions from neighbors prepared OA for a possible struggle with the community. In hindsight, neighbors could not remember exactly how they were informed about the house, but most referred to learning about the new home through a newspaper article that announced the sale and the time of the public meeting. It is clear, however, that neighbors met privately before the public meeting. At the meeting, most residents present voiced their fears and opposition to the home.

By all accounts the subsequent public meeting went badly. In a crowded room with over 60 persons attending, tempers flared on both sides and one informant referred to a "shouting match" taking place. Whereas words such as "angry, horrible, and obnoxious" are used by agency staff and others to describe the neighbors, the OA administrators are charged by neighbors with being evasive, self-righteous, dishonest and equally hostile. Moreover, tension mounted between neighbors who were supportive and neighbors who opposed the residence. The concerns of the neighbors at the time were that:

- a decline in property values would result;
- six adult men (an all male residence was initially planned) with retardation and unknown and unspecified emotional disturbance, behavior problems or other disabilities pose a threat to the numerous young children who played in the area;
- the activities of the residents would not be adequately supervised, that the staff were not sufficiently qualified or compensated, and that no contingency plans were made in the event of unanticipated staff shortage;
- the home had been purchased without informing the neighbors, that neighbors were "hoodwinked";

- o six unrelated adults, whether "nuns or fraternity students" do not belong living in a single family residential area; and that the presence of a "boarding house" would change the character of the neighborhood;

- o OA staff had not satisfactorily addressed neighbors concerns and are not forthcoming about some of the problems that will be encountered;

- o an increase in traffic will result, jeopardizing toddlers who ordinarily play in the very quiet street;

- o the state has no right to pass statutes that supercede local zoning ordinances and allow group homes to be opened "by fiat"; and,

- o despite the guise of a humanitarian purpose, the investors in the property stood to gain substantial financial returns.

In the ensuing months, as renovations proceeded on the house, neighbors continued to meet and began to explore legal avenues for preventing the home from opening. The rift between opposing and supporting neighbors widened. According to OA representatives, they continued to meet individually with neighbors but the opposition was firm. Finally, about twenty families each contributed money to retaining a lawyer with an established reputation in zoning law. Correspondence ensued between the attorneys of OA and of the neighbors, in which OA responded in detail to questions about the residents and staffing arrangements. At this time, a state representative also arranged a meeting between neighbors and Department of Mental Retardation officials. However, this too was unsuccessful in addressing neighbors' concerns, and the residents and their attorney prepared to legally fight the opening of the home.

OA approached an opening date in early July of 1984 and requested and secured an issuance of certificate of zoning compliance by the town zoning administrator. Initiated by opposing neighbors, a public hearing was held on the issuance of the certificate. There the neighbors' attorney argued that OA had not met the letter of the state zoning exemption which refers to "housing" two staff when only one live-in staff was planned for, and by having only a "provisional" license from DMR rather than an actual licence. Lawyers for OA argued that two live-in staff and an operating license was not the intent of the state statute. The zoning board unanimously agreed to deny the request to reverse or modify the decision to issue the certificate.

Subsequently, this decision of the zoning board was appealed, delaying the start of the home. However, insufficient votes were acquired to overturn the original issuance of the certificate. At this time, residents were ready to move in, but the neighbors requested a superior court judge to issue a temporary injunction to stop the home's opening, and OA was ordered not to open the home, until other appeals were heard by the court. A restraining order was granted until a hearing on the injunction was held in October 1984. The legal

grounds for an injunction, however, require that neighbors be "adversely affected and aggrieved" because of the operation of the home. At the hearing, evidence was produced on whether property values would be affected by the home. After the hearing, the judge visited the home and on November 8th, he denied the request for an injunction on the opening.

Once the injunction failed the residents immediately moved in (November 14th, 1984) and subsequently the neighbors decided not to pursue any further costly legal challenges to the home. All told, there was a delay in the start up of the home of up to six months which was costly to: 1) the residents who were anxiously waiting to move in, 2) OA who paid for attorney fees, 3) the investors in OA who lost several months of rent, and 4) the neighbors who fruitlessly paid for expensive legal fees.

Renovations to the property. According to staff, OA had to meet excessive fire and safety regulations that are reputedly unnecessary by DMR standards in order to obtain licensure. Sprinklers, smoke alarms, exit signs, and an enclosed staircase from the second story had to be in installed. The town fire marshall explained that these were necessary fire regulations that pertain to group homes. Other renovations included the conversion of the garage into separate living quarters with an additional entrance on the front of the building.

Role of the media. Newspaper coverage played a rather high profile role in the development of this home. All of the events are well documented in local papers. In the regular news stories of the various events, on the whole a balanced presentation is made of the concerns and contentions of both OA and of the neighbors. There are however, sprinkled throughout the months of coverage, a number of editorials, letters to the editors, and feature stories that clearly exhort readers to understand and accept the needs and qualities of persons with mental retardation and of their rightful place in community residences. Other articles directly addressed the problem of when to communicate plans to open a group home suggesting that it is a dilemma that experts are unable to resolve. Family members of persons with mental retardation wrote asking for understanding and others described their embarrassment at having their neighbors mount a protracted battle against the home. Neighbors are still resentful of the way they were portrayed in the newspapers, feeling they were unjustly criticized by reporters who had made no direct contact with them. Some neighbors felt that OA had established a relationship with the press prior to their decision to purchase the home on their street specifically for the purpose of swaying public opinion. As mentioned, several neighbors recall first hearing about the home through a newspaper article and felt that they were being criticized in the papers before their opposition to the home had even solidified. They in fact directly attribute some of their opposition to how the story was handled by the press and to OA for contacting the newspapers before they themselves were contacted. One neighbor disparaged OA's claims of being "good neighbors" when they had deliberately enlisted media support.

To what degree OA had deliberately enlisted media support is unclear. They did announce how the first home had been bought "out from under them." From that time on, the media clearly pursued an active interest in ensuing developments including the purchase of the second property. Moreover, the portrayals of OA's need to find a second property were quite sympathetic. However, OA may not have specifically influenced or encouraged this coverage.

Transition Planning

Identification and selection of clients. Following procedures of the time, OA submitted a proposal to the DMR regional office to open a six bed group home. The region provided a list of persons appropriate for the level of care proposed for that home. Subsequently, the then executive director of OA and other staff reviewed and selected the residents for the home. Decisions were made according to the urgency of need for a home, and the appropriateness or "fit" between the proposed person and the other residents of the home.

Of the six original residents selected, several have since relocated. Behavioral challenges and other difficulties principally explain their departures. One woman who was selected at the opening of the home and who still resides there is Linda. Linda in now in her early 30's. She attends a nearby sheltered workshop. Linda has fairly good communication, self-help and community living skills. However, she is prone to "emotional outbursts" where she will shout. Described as moody and easily frustrated, Linda is on psychotropic medication to control mood swings. Linda grew up with her family in a nearby town and attended public school. Later she resided in several residential schools and as a young adult was placed in a long term care convalescent home. Her parents were quite unhappy with her placement there. She was substantially medicated and spent nine years in what her father calls a "psychiatric backward." Her mother describes Linda as taking on the mannerisms of a "tottering old lady" like the other residents who surrounded her. Her parents began to actively seek an alternative residence for her after nearly nine years of living in the convalescent home. They heard about OA and the home that was proposed, and established contact with them around selecting Linda for the home. The wait for moving in, after the months of delay, was described as frustrating for Linda.

The second resident that will be reviewed here is Billy. He is a young man in his early thirties with mild to moderate retardation and good self help and community living skills. Billy is currently in a supported work placement in a cafeteria. Billy moved into the home in 1986. He had resided with his family until his early twenties, when after his siblings moved away and he appeared depressed, his parents were advised to place him in a group home. He was placed in a home at some distance from his town of origin and after some time his mother began to seek an alternative placement closer to home. As a parent active in disability affairs she was informed of an opening at the OA home. She got in touch with the provider and Billy was accepted for placement there.

Transition process and events. When Linda's parents arranged for her transition they met considerable resistance from the staff of the convalescent home. Staff expressed their assessment that Linda would not "make it" in a group home and their psychological staff advised against the move. Linda's parents sought an evaluation from another psychologist who supported the move. Moreover, staff of the convalescent home warned Linda's parents that once she was taken from the home, she would not be able to return to it. Linda's mother attributes some of the resistance to the fact that Linda was a "favorite" of the staff often assisting them with their duties. Despite these objections, Linda's parents pursued the move. According to them the staff of the convalescent home did not participate in transitional planning. The extent of their cooperation was handing over some records at the time of the move. Linda's parents picked her up at the home and brought her to the new group home.

Being a community client who made a transition several years ago, there were few procedural requirements and there was little documentation of the actual move. In fact, except for some nursing records, there are no other notes or yearly treatment plans from the convalescent home. From the time of her admission to the group home, however, there are consistent progress notes and yearly service plans. The transition is referred to in the Overall Plan of Service following her admission to the OA home and the transition team leader is mentioned. There are no other indications of specific plans made for the transition and there is no specific reference to the transition team. Nonetheless, Linda's mother expressed satisfaction with the move and feels that Linda has made a splendid transition to her new home.

Billy's transition record shows somewhat more documentation perhaps because of the later date or because he was transferred from another group home. Like Linda's parent, it is Billy's mother who appears to be the most significant player in the transition, making the contact, and a lot of the arrangements including providing the actual move to the new home. A social summary from the previous group home mentions the parent's request to move Billy closer to his home town. The then case manager prepared a "discharge/transfer" report and a letter from the state was sent to Billy informing him about his rights regarding the impending move. A subsequent Overall Plan of Service written from the OA home refers to Billy's successful transition to the new residence. There are no other evident references to details, plans, or transition teams surrounding his move.

Nonetheless, Billy's mother expresses satisfaction with the move. She had met with the house manager of the home prior to Billy's move. Billy also had an opportunity to visit and to spend a weekend at the home before he moved. He quickly made a friend upon moving and Billy's mother felt he adjusted rapidly and well to his new home. Billy now lives so close to home that he is able to make frequent visits and he has even walked back by himself from visiting with his family to the group home.

Service accessibility. In order for a home to obtain DMR licensure and open the home, they must list by name the providers of the various health and

habilitative services that they will be using and OA reportedly followed these procedures. Specifically, both Billy and Linda had a vocational placement ready for them when they transitioned into the residence. According to their parents, other health services were also in place.

Impact on Community

Contacts with the fire, police and health departments of the town gave no evidence on any adverse impact on municipal services because of the presence of this group home. The fire marshall referred to making yearly inspections of the home and had no recall of fires or hazardous situations. The local police captain, although aware of the home reported no unusual activities that involved undue use of the police. Although some neighbors reported increased patrol of the streets at the time of the home's opening, the captain did not recall this. Neighbors reported two other times the police were involved: once, when a resident together with the child of a neighbor called at the window of another child in the very early morning to come out to play and the mother called the police. In another incident, a resident was reportedly being taught how to drive by a volunteer and while driving had gone over the sidewalk, crashed into bushes and went lurching down the street. The neighbor, frightened for playing children, called the police then as well. The house manager reports calling the police about once every two years. However, as stated the police themselves had no perception of their services being overly used.

A planning and zoning board official, who took the post subsequent to the opening of the home, saw no involvement of the zoning board with group homes. They have received no complaints recently and the issuance of building permits seems to be a routine matter. Town selectman and state legislators, both currently and at the time of the opening, report no significant impact on the community. One noted that the tension between supporting and opposing neighbors still persist. Otherwise, they too have received no on-going complaints.

Regarding impact on property values, neighbors report no unusual turnover of property. They, however, remain unconvinced that the presence of the home will not adversely effect the selling price of their home when it comes time to sell, although they can site no specific instances where it had. Immediately abutting neighbors to the home feel that they are most likely to experience a drop in property values. OA administrators however, point out that just after the home opened a nearby house was sold at $10,000 over the market value.

Current Status

Access to services

Health services. Agency administrators report that all health and habilitative services are secured for the residents. Residents use a variety of local doctors and specialists and will use the hospital services of the nearby city. The have had no trouble with their occasional use of emergency services. OA now has a nurse on contract to service the nursing needs of all of their homes. Some difficulties in obtaining family doctors were expressed because of the inadequate Medicaid reimbursement rate, and some services (e.g. specialized neurology) are secured by travelling a fair distance.

Although a full complement of health service seems to be in place, at least one parent expressed concerns about the quality of health services that are secured by group home staff. One parent finds that doctors in town are not willing to take all six residents of the group home and those that do are of lower quality. Therefore, individual doctors are necessary but difficult for group home staff to identify and maintain. She herself, over the years of raising her child, has established valued relationships with medical specialists in town and nearby. She is very active in supervising the health care needs of her child and relies exclusively on those doctors that she trusts. She feels that without this parental scrutiny other residents suffer less than excellent medical attention.

Group home staff acknowledge that specialized therapies (i.e, speech, physical and occupational) are harder to obtain. OA is too small to contract their own staff so they rely on DMR resources. Consequently, at least one person has been on a waiting list for a year for speech therapy. Psychiatric and psychological services have also been harder to obtain. This is attributed to professional reluctance to take Medicaid clients. A psychiatrist is now available to the home and he supervises the psychotropic medication regimen.

Challenging behaviors. The house manager reports that they rely on behavioral support provided by DMR (i.e. behavioral consultation). However this service apparently was not sufficient to prevent the return of at least one resident because of aggressive and inappropriate behaviors. They report no need of a crisis intervention team and have rarely used the police.

Staffing. Agency staff seem satisfied with their staffing ratio, and turnover and recruitment does not seem to be a pressing problem. Neighbors also report a fairly stable staff composition. Parents, however, expressed a good deal of concern over the quality of staff training. Of particular concern was the staff's capacity to handle medical emergencies and to be attentive to changing symptoms and other requirements for medical attention. There are reportedly several occasions of mix-ups in medication administration. Parents are also concerned about the overall inadequate amount of training given on basic job skills such as habilitative training and handling behavioral challenges. Although there is reported to be plentiful training opportunities in Hartford,

other parts of the state do not have such access. Consequently, a parent group attached to OA has concentrated on sponsoring in-service training sessions and bringing in guest speakers. Bolstering staff training remains a top priority of some parents.

For the most part, neighbors feel that there is adequate supervision of residents. However, they recall occasional instances when residents were walking about unsupervised. Some incidents involved: a resident wandering over to another person's property; a resident walking up the street greatly agitated, cursing and gesticulating; a resident throwing pebbles at the window of a neighborhood toddler in the very early A.M.; and the apparent lack of judgement in trying to teach one of the residents how to drive. Neighbors have occasionally been bothered by visitors to the residence. In one instance a strange person wandered into the home of a neighbor while the neighbor had briefly stepped away.

Day/vocational services. Parents are generally satisfied with the service received at the local sheltered workshop. Residents have been able to move up to levels of increasing skill capacity. Two concerns were expressed. One was that the workshop serves persons with a variety of disabling conditions including mental illness, and one parent thought that this may have an adverse impact on some members with mental retardation. Secondly, one parent reported that her child had been placed inappropriately in a supported work site which was not in keeping with his specific strengths and weaknesses. Consequently, the placement failed, hurting her child's self-esteem. She subsequently refused another supported work site that posed the same problem. The resident has finally been placed in yet another site where his abilities match the needs of the industry and where he is enjoying much success.

Recreation. The residents use a variety of generic recreational facilities. The local health club is too expensive, but they have been able to attend classes at the local adult education facility. They often use nearby restaurants and movie theaters and have gone horseback riding. Staff have been commended by parents for taking residents, sometimes on their own time, to adult education classes. They have also been commended for being responsive to parental requests for involvement in specific programs. Some consternation is expressed over taking the residents "en masse" to dances and social events sponsored by local disability groups.

Parental involvement. Parents are for the most part very satisfied with the services that their child is receiving, and many are quite active in their child's life. The residence at OA represents to some parents the best placement the child has ever been in and an immeasurable improvement over nursing homes or institutions. Staff are described as being dedicated and one parent said "[the house manager] treats residents like they were her own family." Parents are also grateful for the support they receive from state and local government officials.

Parents seem satisfied with their involvement in the child's planning process although some describe the OPS as being only a paper process largely irrelevant to actual ongoing events.

The parents of OA have formed an active parent group that seems to have a lot of meaning and benefit for the participating parents. Through the group, they have been able to learn "the ropes of the system." More importantly the group has given parents confidence in communicating with residence staff and making demands if necessary. Prior to the support group, parents reported being afraid to ask too many questions fearing that doing would "upset the apple cart" and could even jeopardize the placement or the treatment of their child. They were simply glad to have their child in a community facility. They now understand that they have rights and that despite frequent absence of communication between staff and parents, both are desirous and open to contact. Parents report going over to the group home on weekend mornings and together helping with repairs and modifications. As one father said, "they (the group home) can't do it alone." Parents acknowledge that not every resident has the benefit of such active involvement and they are therefore attempting to reach out to estranged or distant family members as well as to provide more oversight to the welfare of these residents. One parent mentioned that some other parents, especially the older ones, have only "the vaguest notion of the daily life of their child." They have therefore encouraged parents to go into the home and talk to staff and observe activities. One mother mentioned the recent training offered for parental monitoring of facilities which she attended. Although she signed up to conduct the monitoring she has not been contacted about it since the training.

As for improvements, aside from the concerns about staff training and competence mentioned earlier, parents think there needs to be greater effort to inform parents about their rights and about the ongoing support groups available to them. They are also concerned about the diminishing number of community placements and the emphasis on class clients. A concern was expressed that the residents at OA were actually too crowded. Bedrooms are shared and closets are small.

Relations with surrounding neighbors. Over the years, tension with community neighbors have eased. As noted there are no ongoing complaints by neighbors to town or other governmental officials and municipal services report no unusual activity. The rift between supporting and opposing neighbors has been ameliorated. Supportive neighbors have maintained an active relationship with the home, with frequent visits. One family had two young adult daughters employed at the home. Families with children with disabilities have also found companionship with residents.

At least one neighbor, originally listed as one of the plaintiffs opposing the home is now a very active supporter of the home. This neighbor has two young daughters who formed a relationship with the toddler of the house manager. Subsequently a babysitting arrangement emerged between the two mothers. The neighbor is now a frequent visitor to the home. She knows all of the residents by name and is fully supportive of their right to live in that

household. She even mentioned that the residents will sometimes look out for and walk her two children home.

Other neighbors (members of the original plaintiff group) report that they "don't even know the home is there" or that "things seem to have worked out alright." The home sponsored an open house which was attended by friendly neighbors. This past year the residents attended the annual block party. Although some neighbors ignored the residents, others were friendly.

However, this friendliness is not shared by all neighbors. One ongoing problem identified by several neighbors is parking. With the garage converted there is no room for other cars. Between live-in staff, working staff, parents visiting and persons attending meetings there can be numerous cars lined up the block. There is no doubt that there is a related increase in the amount of traffic as well. Although parking on the street is legal, the home is quite unusual in the number of cars it supports. Meetings at the home are reportedly discouraged by DMR regional staff, yet this is apparently still practiced.

In addition, the composition of the household is decidedly different from the rest of the neighborhood. Despite a legal ruling otherwise, the home, supporting six unrelated adults and staff members is quite different from the two adult and some or no children household that is the norm for most of the other homes of the house. One neighbor describes the oddness of seeing the six residents seated in a small patch of sunlight on their front lawn. Apparently, a staff member thought a little sunshine would be good for the residents of the usually shaded home.

One neighbor reported feeling that despite claims to the contrary, she experiences the group home as being nothing other than a commercial enterprise. She points out that she is able to see a large exit sign in the home through her kitchen window, and that the additional fire escape, and converted garage are indicators of an unusual use of the property. She is also skeptical about the financial arrangements of the home, wondering whether investors were not going to make a handsome profit off the property. Another neighbor noted that the presence of so many cars leads one to wonder "what is going on there" though she surmised that the cars are from visiting parents. The home does receive deliveries from large commercial suppliers adding to the "commercial" feel of the home.

Aside from specific problems, at least two families harbor abiding resentment at the home's presence. Part of the resentment is attributed to the whole conflagration that surrounded the opening of the home. As discussed, one neighbor felt that the newspapers were deliberately used by the group home to paint a picture of "horrible" neighbors and she wonders how the group could consider themselves to be "good neighbors" when they contacted the newspapers. Neighbors relate the occasional incidents when police were called or residents were unsupervised as evidence of the inappropriateness of the group home in a single family neighborhood. There is continued resentment that state laws give neighbors no leverage over the opening of a home in their

neighborhood. Abutting neighbors are convinced that their property value (if not any other nearby property) will be adversely effected.

In hindsight some neighbors feel that they were not given a straight story by OA, that it would have been much better for OA to acknowledge that there were some legitimate concerns (i.e. traffic, parking, supervision, property values). Neighbors feel that they would have benefitted from an accurate description of the disabilities of the future residents and the behavioral concerns, if any, there were.

One neighbor thinks that less opposition would have been encountered if the home moved in quietly with no public meeting or newspaper coverage. This neighbor is especially angry at the self-righteousness that permeated discussions with OA. She says neighbors were made to feel like they were obnoxious bigots rather than as having legitimate concerns. A neighbor felt that another service provider with well established roots in the community, would have handled community entry much better and would have encountered less resistance.

This neighbor still complains of a lack of information about the home. She does not know who the staff are or who she should call with a problem or complaint. She does not know who the residents are and she is aware that there have been several changes in staff and resident composition. She feels that a local newsletter describing ongoing activities or changes in the home could be one worthy way of giving neighbors access to information about the home.

On the whole, as the present Executive Director of OA put it, the home "is tolerated" by the community. At least a few neighbors are still sufficiently upset that they feel that they cannot reciprocate ordinary neighborly activities (e.g. a return wave, or allowed use of their phone); whereas others are indifferent or are actively involved with the home.

CASE STUDY 5

CASE STUDY 5

The subject of this case study is a home for three men ranging in age from 47 to 64 located in the eastern part of Connecticut. The home is a ranch style house with an attached two car garage located on a horseshoe shaped residential street in a prosperous middle class suburban community. The home is located just about half way around the horseshoe as it turns uphill to rejoin the main thoroughfare. Its fits in well with the other two dozen or so homes on the street, which are all of approximately the same age but reflect a variety of architectural styles. The only characteristics which differentiate this home from others on the street is the entrance ramp, which integrates nicely with the appearance of the house and its attached deck, and an air conditioner which seems rather oddly positioned in a wall immediately adjacent to the front door

The men in this home all have fairly significant disabilities. They were initially described to us in this manner: "Well all of the men are 'level 5s' with some behavior problems. Only one speaks and another one is blind." The men are all ambulatory. They are also all members of the Mansfield Class. They have very extensive institutional histories. The two men whose case histories were reviewed for this study, Morton and Sam, spent 49 and 53 years in the Mansfield Training School.

History and Context

This community residence is one of the first efforts by a new provider in Connecticut. The organization has been operating homes in other New England states for approximately 11 years. Their director in Connecticut indicates that they have an established track record of developing homes for people with severe disabilities and behavior problems. Based on this experience they were recruited to go into business in Connecticut. Presently they are operating homes in two regions and are in the process of developing several sites.

It is worth mentioning here that the level of disability, the extensive institutional history, and label of "behavior problems" associated with the gentlemen living in this house is directly related to the need for DMR to recruit and foster the growth of new residential providers. The pressure to meet the deadlines and quotas of the Mansfield consent decree are seemingly more than the existing system of in-state providers could handle. In our interviews reference was specifically made to two major considerations. First a number of the established providers either had reached the limits of their growth or were at least temporarily overwhelmed by a recent spate of development. The second reason given for the need to look to new providers was the unwillingness of some older providers to accept residents with more severe levels of disability and especially not those individuals identified as having behavior problems. These factors presented DMR with a bit of a problem since most of the people still in residence

at Mansfield and the other state schools have more severe disabilities and/or problem behaviors.

With these considerations in mind, the DMR region issued an RFP for residential providers in early 1987 which identified a need for the development of approximately 3-4 person community living arrangements. The RFP identified the range of characteristics associated with individuals at the Mansfield Training School who were candidates for community placement during the next fiscal year. For the most part the men in the house we are concentrating on are representative of the descriptions in the RFP with the obvious exception that some of the people in the RFP were women. The RFP further suggested possible groupings. Relevant to this site was the description of three visually impaired people (two men and one women) as one possibly homogeneous group that might provide a basis for a proposal and subsequent site development.

While based on the identified needs of specific persons for community living, the initial proposals solicited in this process asked the potential provider to present a broad agenda for development which identified the organization's long range goals, stated its organizational philosophy, described its general approach to development, outlined its anticipated timelines, discussed anticipated expenditures, and concluded with a review of previous experience. These proposals were reviewed and the organization interviewed by a broad range of actors concerned with community residence development including relevant representatives of the regional staff, parents of people with disabilities, and currently active private community providers.

Based on this process and a check of references, this organization was asked to develop a specific community residence plan which identified actual individuals from the region at Mansfield (at that time 50-60) who they intended to serve. In the case of the site being examined here, the initial proposal was for a three person site which would serve the individuals with visual impairments identified in the regional RFP.

Site Development and Neighborhood Entry

Once the provider had a firm agreement with DMR to develop three homes in the region, it turned to the Corporation for Independent Living (CIL) to handle the actual process of site identification, purchase, and development. This was undoubtedly a wise decision for an organization which was just beginning operation in Connecticut. In this way they immediately gained access to almost a decade of experience in developing community residences in the state.

While the decision to use CIL had many benefits for the provider agency it did slow the actual development of this site. The extensive amount of work that CIL had during this period and its policy of making all sites accessible extended the process of site development by as much as six months. The entire process at this

site took a little over a year, while a typical CIL project takes eight to nine months. The extended timeframe here reflects the fact that this project sat at CIL with no action being taken on it for approximately 3 months. This delay should not be attributed to incompetence or bad management. Rather the fluctuating intensity of community residence development means that at some periods CIL, with its limited pool of experienced developers, will be confronted with more work than it can handle in a timely fashion.

Purchase. Once CIL began working on this project it took about a month to locate the present site. The person responsible for this project addressed the seven following questions in his efforts to identify potential properties for this agency.

1. Was the property outside of certain community in the region that DMR staff indicated were over utilized for community residences?
2. Was the property within the typical range of price for houses in that area?
3. Were the basic systems of the house (heat, water, electric, sewage, foundation, etc.) in good shape?
4. How easily could the property be adapted to be accessible and meet the special requirements of the three individuals with visual impairments who were initially identified as the residents?
5. Given the visual impairment of the targeted residents, was the property reasonably level and on a low traffic street?
6. Were hospitals, stores, and recreation opportunities within a reasonably short driving distance?
7. Was the site near the likely day program for the three identified residents (if any of the potential residents were able to travel independently this question would have been is the site in reasonable proximity to public transportation)?

Working through a local realtor who they had used in the past, CIL identified the present site of the home as a prime target for this agency's development. Before proceeding it was necessary for the representatives of the provider agency and representatives from the DMR region to tour the home. Both of these groups had to agree to the purchase. During the tour, all of the strengths and weakness of the property were pointed out and the CIL representative presented a preliminary sketch of the needed renovations. Based on these approvals, CIL put an offer on the home. About a month elapsed between purchase offer and closing, which occurred in mid-October 1987.

This particular site was the property of an employee of DMR who was preparing to move south because of her spouse's medical condition. This chance occurrence has created the mistaken suspicion in the mind of at least one neighbor

that there was some sort of collusion and an inflation in price associated with the sale of this property

Renovations. While the sale was pending a local architect was contacted to develop preliminary plans for renovations of the property based on the needs identified by CIL and the provider. These plans went through several revisions to assure that the provider was fully aware of what was being done and had complete input. Immediately after the closing bids are solicited for the work and a contractor is identified, the architect, the CIL representative, the contractor, and representatives of the provider walk through the home with detailed plans to assure that there is no confusion over what is to be done before the work is undertaken.

At this site the initial plans for renovations entailed putting in a large, fully accessible bathroom, opening up the kitchen, enclosing the laundry area, re-doing one bedroom as a result of the bathroom work, installation of new doors on the bedrooms, a ramp to the front door, a deck overlooking the back yard, and a fence to assure residents would not be endangered by a drop off behind the property. The CIL representative felt this was a relatively uncomplicated renovation job and may have involved a little less than the average amount of work. As a result of inspection by the fire marshall a sprinkler system was also slated to be installed.

A community residence for three people is essentially subject to the same level of regulatory control from building inspectors, sanitary engineers, and fire marshalls as any single family house. However, it has been CIL's experience (confirmed by the information collected for this study) that as soon as local authorities are aware that a home will be a residence for a group of people with retardation they subject all plans to a heightened degree of scrutiny. This means that approvals which are routinely obtained in two or three days for a typical home may take up to a month to be processed. This heightened oversight is often accompanied by modification in the plans being required. CIL sees the local authorities taking a "we'd rather be safe than sorry attitude" toward approval of all sites.

In the case of this site when the fire marshal "suggested" the installation of sprinkler system CIL felt that, although it was technically not required, it was a reasonable recommendation given the characteristics of the likely residents. Further a fully finished lower level, with sliding doors that open onto the yard is unusable because the ceiling is approximately 1 inch too low for use under the relevant licensing regulations. This did not create a problem for the developer or the provider since they were aware of the potential problem from the beginning and expected that use of the basement would be dis-allowed. Since the original intent was to find a single level house this restriction did not cause them a real problem. All this aside, the presence of a full floor of very pleasant rooms which are in essence as big as the main floor of the dwelling and yet completely unused elicits at least a quizzical response from visitors and neighbors.

During the renovations process the representative of CIL was on the site on about a weekly basis to insure that work was on schedule and that everything was up to specifications. In addition, the director of the provider agency visited at least monthly. She seems to be very attuned to some of the subtle concerns that can influence community acceptance. In this regard the agency makes an effort to sensitize its staff to some of these concerns by having a rather detailed "Good Neighbor Policy" (See Appendix 4). She used her visits to meet with neighbors and talk about plans for the house and the residents who would be living there and to identify herself as the person to be called if there were any concerns about the property or events in the house once it opened. This interaction with neighbors is quite conscious on her part even down to talking to male neighbors about the renovations being done and discussing the local stores with the women in the area. She also made a point of asking the contractors to avoid destroying the lawn, to keep the work site cleaned up, and to let neighbors know they could have ready access to the discarded materials from the site. It is reported that a couple of neighbors took advantage of this last offer.

Renovations to this site began in November of 1987. All work was completed and the site licensed during the first half of May 1988. The residents moved in during the last two weeks of June 1988.

Community Concerns. Very shortly after the sale of the house became known, a number of neighbors began to make inquiries about the nature of what was going on at this location. Two individuals called the selectman for the town. This gentleman is very positively disposed toward community residences and has a particularly good relationship with the regional director. Further because of this community's proximity to the regional center, he feels that in general the local community is very supportive of the activities of DMR and really does regard the Department and its private providers as good neighbors.

He responded to the inquiries by assuring the neighbors that they had nothing to be concerned about. He explained in general what was going on and the relevant laws which applied. He finished by assuring the neighbors that someone who could answer their specific questions would give them a call back. He then called the regional director, explained the neighbor's concerns, and asked that she give the people a call. The regional director then called the neighbors and explained the situation to them. In these cases this response seems to have been sufficient since there is no further indication of concern about the site from these individuals. The selectman is very clear in his opinion that if you have open lines of communication and responsive people who give honest answers to questions there should generally be little or no difficulty associated with the establishment of a community residence.

Word of these inquiries from the neighborhood were forwarded to the agency administrator who immediately called the selectman. In their conversation, he reaffirmed his support for DMR and its community efforts. He then asked her for some specific information about the home such as the number of residents and the staffing pattern. After answering his questions, she explained that since the

agency was new in the community she would really like his advice on how to approach the neighbors and deal with concerns. He affirmed that he thought she was taking the right approach by being open and responsive and ended the conversation by reassuring her that he was confident that there would be no difficulties. She was clearly left with the impression that he had become a major ally.

After the home opened the agency director found that a number of the families in the area were very positively predisposed toward the community residence because they saw it as having a stabilizing effect on the property. It seems that the previous owner had only lived there for a few years and before that the site had been a rental property for quite some time. During that period there had been numerous renters who did not always maintain the property. The expectation was that the agency was there for the long haul and would probably maintain it better than it had been in the past.

One of the next door neighbors contends that he never received a satisfactory response to his inquiries concerning the community residence. At the time he found out about the sale the went to the town hall and spoke to someone in the zoning department. As he recalls it the response he got was "They're protected by a state law. They can move in if they want. There's nothing that you can do about it." He says that in fact he had no intention of doing anything about it; he was merely looking for information. This interaction at the outset seems to have predisposed this neighbor for what he sees as a very negative interaction with CIL over one of the planned renovations.

The one really negative outcome associated with the development of this site may have been unavoidable for any agency working on this location. However, CIL's vast experience may have made it less than fully sensitive to the concerns of this neighbor. Basically, because his concern over the fence that was planned for the property was a minor point when measured against some of the other issues CIL has confronted it may not have received the attention that it merited. Unfortunately from the perspective of the neighbor the fence was a very major matter.

The neighbor in question had moved into the area in 1985 and at the time he became aware of the plans for the development of the community residence next door had just about completed some major work on his property including landscaping. One aspect of the landscaping included planting Arbor Vitae bushes along the property line. After his initial unsatisfactory inquiry at the own hall he kept close track on the work next door. As a result of his interactions with the workers he made contact with the representative of CIL who was managing the site development. They had several conversations about various aspects of the renovations which usually entailed CIL explaining why a particular thing was being done.

Toward the end of the renovation the neighbor became aware of the plans to put up a fence right next to his new Arbor Vitae. Initially he objected to any fence at all, but then agreed that given the characteristic of the people who would be living in the house a fence made sense. When the fence was delivered for installation he objected to the style of the fence and the way it was to run the full length of the property line. CIL agreed that it was not necessary for the fence to go beyond the line of the house, so they eliminated a couple of sections originally slated to continue across the front lawn. As it turns out the neighbor really feels that the style of the fence and its height is objectionable and detracts from the appearance of his house. At one point he accosted the architect when he was visiting the property and suggested a way to cut the fence down and make it less obtrusive. He recalls the architect as saying "Hey that's not a bad idea. That might work. I'll talk to the people at CIL and someone will get back to you." Unfortunately no one got back to him. In another conversation with the CIL representative he suggested that they get a new fence and let him have some say on its design. The CIL representative's response was: "I have to control cost on this project and that fence is already paid for. So, if you want a new fence, fine. We'll do it. Just one thing -- you'll have to pay for it." Needless to say, from the perspective of this neighbor, this issue was not satisfactorily resolved.

The net result is one neighbor who has been left with a very negative image of DMR, CIL, and the provider agency. Fortunately this bad experience has not generalized to the people who live and work in the site. He is particularly pleased about the way the staff and residence planted flowers and the way the property is maintained. In his view of the community residence development process is another case of a large detached bureaucracy running roughshod over the concerns of neighbors and communities.

The power of rumors to have a potentially adverse on community perception of a site is also underscored here. Some time after work had begun at the site a number of neighbors began sharing the information that the property and its renovations were costing something over $500,000.00. This was attributed to an employee of the contractor who said the property cost $225,000.00 and the renovations would minimally cost $250,000.00 and probably more. The actual cost of the property was closer $250,000.00 and the final bill for all renovations came to approximately $135,000.00.

Added to this underground concern about seeming excessive expenditure of public funds, some of the same neighbors were initially concerned because they so rarely saw the men. They thought they were spending all of their time in the home. As it turned out this was because the home had an attached garage. The men and the staff got in the car in the garage and then drove off to the store or some recreational activity. In addition, there was perception that something was being hidden because the open house which had been promised before the home opened had not yet materialized.

These concerns were resolved through a complex informal system. The case manager became aware of these concerns from a colleague who was a friend of a

neighbor. She then attempted to defuse these rumors by sending word back through the informal channels that the cost information was way off base and that the men were in fact almost constantly on the go in the house car. In addition, she sent word to the house manager about the lack of presence the men had in the community and the need to remember the open house. The house manager reminded the staff to take the men for individual walks in the community and shortly the staff and residence also began doing some yard work planting flowers and generally being a bit more visible to the neighbors. The open house was scheduled for the fall.

Although none of the neighbors mentioned it, the home was readily identifiable from the corner because of all the cars parked around it. The agency tries to observe a policy of having large group meetings at sites provided by the region to avoid a massive parking problems. However one of our visits was during a regular weekly staff meeting and there were seven cars in front of the home, not counting the house vehicle which was out of sight in the garage. Even when visiting late one afternoon the presence of three cars was clearly not in line with the neighborhood norm of no visible automobiles.

Transition Planning

This site is noteworthy for the degree to which the formal procedures regarding transition planning and process were observed. Our review of case records and interviews reveal that literally every required document is on file and every procedure suggested to ease the transition process was implemented. Undoubtedly this degree of compliance reflects the fact that this setting is barely half a year old and was one of the first efforts of an organization just beginning operation in Connecticut and therefore anxious to impress DMR with its efficiency. As we shall see this adherence to formal procedures is no guarantee that everything will go smoothly. On the other hand it should be underscored that our review of this site revealed a basically well thought out process which for the most part has the desired outcome of assuring that all the needs of people moving into the community are addressed.

Identification and Selection of Clients. As noted above, the original RFP identified three visually impaired people from Mansfield as a potential group for a community residence. This site was initially developed with that group in mind. Later in the Winter of 1988 the agency director and the house managers began going up to Mansfield to connect with the staff there and begin specific planning for opening this home and the others being developed by this agency.

As a result of these early visits it became apparent that the original grouping was not appropriate for this setting. The one individual who seemed to be central in this regard was a man who spent a great deal of the day screaming. The agency staff felt that the house in this neighborhood were too close together for this kind of behavior and that he should be placed at another site being developed by this agency which had 3.5 acres of land around it. DMR concurred in this opinion.

Based on their visits to Mansfield, review of client records, and discussions with direct care workers at the institution the provider agency suggested an alternative grouping for this site. This group included one of the individuals originally targeted for this site and two other men. The two new men were Morton and Sam, the two men whose case records we reviewed for this study. In both these cases their records reflect a concern for a variety of problem behaviors during their years of institutionalization.

Sam was particularly defensive of his personal space and used spitting to tell people to get away from him or to communicate refusal to engage in a task. In addition, he was regarded as very resistant to any changes in routines or environment and so was seen as a particular challenge for the transition process.

Morton on the other hand displayed behaviors which clearly reflected his long stay in an institution. He is extremely gregarious: always approaching new people, introducing himself, and continually shaking hands. He was also reported to be very careless about making sure he was fully clothed after using the bathroom. There is also some mention that Morton is resistant to preforming some activities and very possessive of certain possessions such as his radio.

While these men were seen as presenting some major challenges to the community agencies, their ages, level of disability, and "life style" were seen as very compatible with one another and with the third man in the home. The agency suggested this grouping to DMR in early April of 1988. DMR approved this arrangement and also pointed out the need to get the men into the site before the end of the fiscal year on June 30. There was a real concern that if this time frame was not met the entire project could be put on hold indefinitely.

Process and Events. This time frame was completely compatible with the speed of work on the property and the progress the organization was making in recruiting and training staff. It merely had the effect of giving a clear target date, whereas if the agency had progressed at its own pace the home would have opened in a bit later.

By May 1st the residential agency had hired all of the staff for the new residence and completed most of the training. The full complement of staff for this home came to 10 people: the manager, five full time staff, and four part time people. The home was to be staffed on a shift pattern which allowed for three staff in the home during major program periods of the week and an all night awake person. During the middle of each weekday from approximately 11:00 AM to 2:00 PM no direct care staff are scheduled. The house manager is the only person scheduled to work and her duties frequently involve meetings or other obligations which take her out of the house. This of course means that under this arrangement supplemental staffing must be arranged if one of the residents is not in a day program.

As soon as the staff's preliminary training was completed they started spending the bulk of their work week at Mansfield State School observing and interacting with the men and getting information from direct care people there. Rather than just watching the men the agency gave the staff some instruments such as the *Vineland Adaptive Behavior Scale* as a framework to structure their observations. In addition they reviewed each man's entire case record. Most of the staff spent well over 100 hours at Mansfield during the 45 days before the first man moved into the home. All of the staff who were involved in this process report that it was extremely valuable. The general training which the staff had just completed was immediately applied to addressing the specific needs of the men with whom they were going to work. This made the new information that they had gained much more valuable to them than just being bits of disconnected information. Another outcome of this developing relationship was that the agency was able to identify the staff person who would be the principal staff person for each of the men before they even moved into the home. The ease with which the men actually made the move into the home seems to confirm value of this process.

During the first week in June the formal transition meeting was held for each of the three men. This meeting was chaired by the DMR case manager who is responsible for coordinating transitions from Mansfield. These meetings generated very specific transition plans for each of the men. These plans point out concerns, identify special service needs, and suggest some ideas to help ease the transition. At the same time the DMR transition checklist was completed indicating that all services were in place and that all of the necessary procedures had been completed or were in process for completion before the men moved.

During the first two weeks of June each of the men made a preliminary day long visit to the house where they were met by the staff people who they knew from the visits to Mansfield. On these day trips they were accompanied by staff people from Mansfield who came to make suggestions and to be available in case of problems.

The staff from Mansfield and the community residence staff had the greatest concern about Sam's ability to handle the transition. It was felt that he would certainly resist the move and everyone expected an increase in his spitting behavior as he asserted territorial domain over his new home. With these concerns in mind he was slated for several preliminary visits of varied length. The staff also decided that he should be the first man to move in the home and that he should be there at least a week before the next man joined him.

Sam's initial visit was a revelation to everyone involved. He arrived with seven support staff from Mansfield, all of whom were convinced that the visit would be relatively short and that there might be a need for all of these people to get him safely back to the institution. Sam walked in the door, strolled through the house, and was shown his room. He then went to the bathroom on his own with no assistance, came out, and sat down in the living room to watch television. A bit later he prepared his own lunch and ate it in the dining room. As the house manager tells it the staff from Mansfield were flabbergasted. Here he was doing

things that they had never seem him do and he did not spit once all day. They left convinced that he should move in at once.

Our interviews contain unclear information about whether the time lines or other plans for the transition were changed because of this very positive experience. In any case Sam moved in on June 21st, He was followed a week later by Morton. The third man moved in on July 2nd. All of the moves took place without incident. Staff people recount how they were very anxious and on their toes just because of the reputation these men had and the picture that had emerged from reading their institutional case records. Yet, after the move took place it was as if they had lived in the house for ages. There was a very satisfying let down.

By the end of July all of the men had their initial 30 day OPS meeting. This was again chaired by the transition coordinator, apparently because the case manager who had been hired for these clients quit before he ever started working. By this time some of the initial glow of the men's move had begun to wear off as some of the plans encountered difficulties.

Availability of Services. At the transition meeting it was indicated that all necessary services were in place. In reality it took some doing to achieve this feat. Many services were obtained through professionals hired by the agency's central office (nurse, nutritionist, behaviorist). Several others were obtained by group contracts which the agency negotiated with a provider for all of the homes they were opening during this time period (speech, dentist). Recreation entailed identifying the range of local resources (this was done by a directory prepared by the agency). Others had to be obtained for each home independently (drug store, medical). Finally, day services were arranged in coordination with DMR on an individual basis based on evaluation at Mansfield and availability of local providers.

The services based in the parent agency office have presented no problem other than recruiting people in an environment where skilled professionals in these fields are at a premium. In general, the people from the DMR region and the court monitor's office are very satisfied by the quality of work from the people hired by this agency.

The contract services have not worked out anywhere near as well. Within a month after the home opened the agency under contract to supply speech and communication services produced a preliminary assessment and offered a program design. No one in our interviews discussed the specifics of what followed but apparently there was a major dispute between the residential agency and the speech clinic about the appropriateness of the reports and recommendations. The result of this dispute was that the speech clinic withdrew from the contract. Initially, the residential agency attempted to provide for the men's communication needs on their own. This efforts received a negative evaluation from both the

DMR region and the court monitor. So under pressure from those two powerful entities a new speech therapist was recently contracted.

At the present time it appears that the home is going to have trouble with its dental provider. This particular dentist's decision to stop seeing group home clients will have extensive ramifications since he is presently under contract with at least six homes. One case manager feels that the real issue may be that this one provider has been overwhelmed with DMR clients just because he was willing to take them. This may be true. He told the agency administrator, "I've had it with the state! Payment is slow, people miss all kinds of appointments, there's no pre-notification of people with Hep-B. I won't renew my contract."

In the area of recreation the direct care staff attempts to make major use of the public facilities in the area during the weekends. The men all use the restaurants and stores in the area. But as the staff started to look for groups and activities geared for these men they found very few things. When they approached the local YMCA about recreation for the residents they were told "We don't have any programs for the retarded and we are not going to start any." The underlying issue here may be that they are looking for and requesting specialized activities instead of fitting into what already exist in the community. Even within these limitations the case manager reports, "These guys seem to be on the go all the time."

The pharmacy is one local generic resource which was obtained easily and has turned out to be very supportive. It seems that this local merchant was very happy to get the business. When staff and residents come in they are greeted as valued customers. If they have to wait for an order they are invited behind the counter to wait in the employee lounge area.

The home has arranged for medical care at a clinic about 20 miles away. This reflects the fact that all community resident programs in this region are having a very difficult time finding doctors who will treat their residents. While obtaining medical providers who will accept Medicaid reimbursement is a problem throughout the state, it is particularly pronounced in this region. The house manager and her staff had to contact over 50 physicians before they found this clinic. In most cases, their inquiries about care for the men was met with a "no" before the request was fully out of their mouths. At the present time this care is adequate but inconvenient and in some circumstances, such as hospitalization, would be a major strain on the home's staff resources.

While the day programs for all three men were identified in the transition plan and appeared to be a relatively straight forward matter, in practice the realization of these plans for two of the men (Sam and Morton) was much more involved. The resulting conflict between the residential and the day program over this issue would make a fascinating study of the politics of organizations. As interesting as that may be, here we will confine ourselves to a description of the issues as they relate to services for the two men.

Central here are divergent perceptions of the planning process and the special issue which confronts a system of services that is attempting to be completely community-based but may not have all of the resources in place to support such as system.

The transition plans for both Sam and Morton are both very clear in stating the issues related to movement into day programs. In Morton's case, it is suggested that he begin full time as soon as possible since he does not handle sitting around the house very well -- particularly because he also enjoys being with a variety of people. Further it is suggested that since he had experience on a job crew at Mansfield, such a placement would be appropriate for him in the community. In Sam's case, the emphasis was on the need for a gradual transition and low pressure situation which would not create the tension apparently associated with his spitting behavior.

Based on preliminary observations the day program provider felt that both men would need transition time. The implication here was that the men would have to spend more time in the home initially since the day agency is completely community based. As the director put it :

> We don't have a nice quiet sheltered workshop that someone can go back to and nod off if they don't feel like working....And that also means if someone's behavior is such that they only can make it for a hour at a community site--so be it. Part of what we are doing is placing the normative demands and normative sanctions of the community on these people as they work in the community residence....If someone starts spitting or forgets to pull their pants up, they've got to leave the site and try again tomorrow."

The day program director feels that these concerns were clearly communicated to the residential agency. Unfortunately this communication seems to have been solely informal and not reflected in the transition plan. At any rate, the residential agency made no arrangements for extra staff to be available during the initial phase of the men's day program. The demands for extra coverage which resulted from the need for the men to be at the home quickly ate up the crisis budget which was allocated for the house.

While the day agency had to agreed to accept Sam, the residential director feels that they just did not have a program ready for him and so were stalling with talk about gradual transition. On the other hand, the day program director seems to be very serious about structuring a program around the needs of the individual and being particularly sensitive to handling behavior normatively which would present a problem in a completely community-based program. In Sam's case the day agency initially started by sending someone into the home to work with him.

When this issue escalated in association with concerns about changes in Morton's program, it was necessary for the advocate for both men to call a meeting of all concerned parties and iron out these difficulties. As result Sam began to

attend the new Opportunities for Older Adults (OOA) program for which he was initially slated. This community-based program entails exposure to a variety of activities of both a vocational and recreational nature including participation in some community elder activity centers. The remaining constraint here is that if Sam has a behavior problem he must return home with the resultant demands on the residential program resources. Fortunately Sam's behavior is markedly improved since he moved into the community, so he has not often been sent home.

Morton was initially assigned to a job crew in a local restaurant. It soon became apparent that a job crew at Mansfield was not the same thing as a community based crew. Morton's excessive friendliness and lack of certain self care skills led him to be dropped from the program. This again placed unanticipated demands on the residential program. The day program's response was to enroll Morton in the same OOA program as Sam. The case manager reports that within this program the agency seems to be making a strong effort to offer an approach which is truly responsive to this man's particular range of interests.

Impact on Community Services

This home has had no more impact on the services in this community than any other household of the same size. They have made no extraordinary use of any town services. Over and above the inspections which were needed before the home opened the only use of any town department that anyone can recall was the need to have the town sanitary engineer come out when they needed to have the septic system redone early in the fall.

Current Status

Access to services. At this point all of the issues related to access to services have been resolved. The residents have a physician who they visit regularly although it requires a bit of a car ride. As noted above the issue of dental care is presently up in the air.

The three men are all involved in a day program on a full-time basis, although there continues to a divergence of opinion between the administrator of the two agencies about how well things are working. It is clear that at the administrative level the problems encountered during the transition process will color all interactions for a long time.

At the level of the direct care workers there seems to be somewhat better communication between the two programs. However, the residential workers are not at all clear about the nature of the community-based elder experience program which serves two of the men. The residential staff's expectation for them, even thought they are in their sixties, seems to be in the direction of some type of supported work program. The day/vocational staff seems to be oriented towards

expanding the men's range of experience and fostering behaviors that are appropriate in integrated community settings with less emphasis on the work aspect of the activity. They feel this type of program is more appropriate given the deprived experience these men have had because of a half century of institutionalization.

In the area of recreation the residential staff continues to grapple with what they see as limited opportunities. There seems to be extensive use of special programs (i.e., dances etc. specially run for group home residents). Residents regularly go shopping and out to meals at restaurants on a one to one basis with members of the staff. And as a result of moving into the community a slight degree of family contact has been established for two of the men.

The staff in the residence has been relatively stable over the nine months since they were recruited. Two people have left: one very early on and a second in December. These people have been replaced with others who were already involved in the home on a part time basis. So all of the full time direct care workers have worked at the house since it opened. The original house manager has just recently been made regional coordinator, so she will have much less involvement in the home.

Relationship with Surrounding Neighborhood

The home has quickly become part of the neighborhood. Once the initial rumors were scotched and the neighbors saw flowers being planted and the residents and staff walking on the street, most concerns were satisfied. Any lingering doubts about the home seem to have been resolved by the open house held just before Thanksgiving. Everyone on the street was invited and, although the weather was miserable, about half the neighbors showed up. Everyone involved, including the neighbor who had the unfortunate experience regarding the fence, indicate it was a pleasant occasion. The staff mention that most of the neighbors wave and say hello to the men. A few people drop over occasionally. Sam attends synagogue on a regular basis with a staff person because of the suggestion of neighbor that he really should go and he certainly would be welcome. Another neighbor and her brother, who is disabled, go out bowling and for pizza with Morton and a staff person on a regular basis. It's worth mentioning that in neither case has the behavior of these two men, which was such a concern at the beginning, caused any difficult during these community activities.

The original manager for this home played a pivotal role in the largely successful establishment of this site. Her sensitivity to community concerns, even when they reached her through informal channels, seems to have been instrumental in defusing any neighborhood concerns. Her personal commitment to making the agency "Good Neighbor Policy" more than a pleasant sounding series of principle helped to teach her staff what it means to be a good neighbor. Further, her ability to communicate to her staff the need for the residents to be actively involved in the community, even when their history of "behavior

problems" might have counsel a more conservative tact, has gone along way toward establishing the men as real member of the community. Finally, in the convoluted interaction around obtaining and coordinating services, she was crucial in maintaining open channels of communication, identifying resources, and generally seeking the best interests of the residents over the issue of organizational turf.

After less than a year, this home and the men in it are clearly accepted in this neighborhood. To put this in context, one neighbor said "This area is pretty much empty all day, with everyone working, at night and on weekends people come home and keep pretty much to themselves." In other words the status quo for relations between neighbors in this community, like in so many other could be characterized as "benign neglect" or "laissez faire." So if anything these men and their home may have a more extensive network in the local neighborhood than is typical for their neighbors.

CASE STUDY 6

CASE STUDY 6

History and Context

The home described this case study is the only state run residence of the six homes examined. It is located in an urban area in the eastern edge of Connecticut. State residential development in the region where this study home is located began 18 years ago with the creation of the first group home. The home, which provided residence for 14 individuals, was purchased by a local civic organization and turned over to the state. The next major initiative was the development of surplus state property into an apartment complex for 37 people (there are now 23 people at the site in addition to state offices and further reduction is planned). According to state regional staff, as individuals living in the community became more independent, they were moved into individual apartments where they received either "drop-in" or minimum supervision.

Over time, it became clear that some individuals needed more supervision, so state regional personnel developed "clusters" of three two bed apartments with 8 hour, on duty supervision. They state now has two buildings with 16 individuals living there. The two apartment buildings are about two to three blocks from one another. About two years ago, state staff opened the metropolitan community living arrangements (CLAs) (not the real name) which now include a total of 50 to 60 apartments.

There has been concern in the community of this study about saturation. The issue came to a head when the state Department of Mental Health wanted to develop a group home in the city. According to regional staff, the possibility of a mental health home in the community aroused opposition because of negative associations with the nearby state hospital. At the time that the concern was voiced, there were 71 individuals living in the city including people in community training homes (CTHs).

The city has been used extensively for community development because it has relatively low rents; accessibility to community resources, such as recreation and churches; and availability of medical care. As a result of meetings with state representatives from the area, the state agreed to limit development to people with ties to the town.

Community acceptance in the area has also been affected by events in other parts of the region. For instance, about two and a half years ago, there was a plan to move individuals with a history of "sex offenses" into a cluster program in an upper income community. The information about the move leaked out and concerns were voiced regarding the ability of these individuals to succeed in the community without 24 hour supervision. The story made the local papers which in turn resulted in a petition to the city council and the expressed concern of state legislators. The placement was subsequently

terminated. Due to the efforts of one staff member at the proposed home, the neighbors were eventually persuaded that persons with mental retardation could live in their neighborhood and four women moved into the site.

Finally, according to regional staff, another failed placement also generated some community opposition. An individual from Mansfield was placed in an upper middle class community. The person exhibited some eccentric behaviors and neighbors became upset. The individual was eventually moved to a special program at the developmental center. As a result, according to staff, some neighbors have become anxious about "people from Mansfield" but seem more tolerant of persons from the nearby regional center. It was explained that the community around the regional center has always felt somewhat involved with the facility and its residents.

Site Development and Neighborhood Entry

The study residence is a two bedroom apartment that houses two women. The residence is run by the state, but the two women hold the lease on the apartment.

As noted above, several CLAs had been developed in this part of the region. The major CLA complex, which is located in a blue collar area of the city, included six renovated accessible units. According to region staff, these are probably the only accessible apartments in the area. The apartments had been deemed appropriate for non-ambulatory individuals living at the regional center who were also fairly high functioning.

In addition to these CLAs, regional staff were also contemplating renting a home in the city where the study home is located. The deal, however, fell through even though staff had been trained and were ready to greet three residents -- all men. It was at this point that a landlord approached the regional staff and told them that he had a newly-renovated apartment available to rent. He himself had some experience with people with disabilities as a lifeguard at a camp for people with disabilities and had a family member who was a special education teacher. According to regional staff, such a contact was not an isolated event. Other property owners have approached the state offering apartments for rent. Staff explained that the predictability of payment and the longevity attendant upon a lease with the state was a substantial draw.

Regional staff decided to use the site as a CLA and the home became part of the administrative unit that includes the supervised apartments mentioned above. This home, however, is not in a lower income area but rather is located on a major street in the city that also includes individual residences as well as large homes that have been turned into professional offices for doctors and lawyers. There is a major regional hospital two blocks away and single family dwellings on either side. The house is attractive and is comprised of two apartments, one upstairs and one downstairs. The CLA is downstairs and the landlord's sister lives upstairs. There is a convenience store across the street,

and it is close to public transportation. There is nothing conspicuous about the structure except an occasional state car parked at the curb or in the driveway.

Because the CLA is state run, it did not go through formal licensing inspection. Inspectors employed by DMR central office did, however, come through to assess the home. According to staff at the apartment, state inspectors recommended that railings be put on the cellar stairs to ensure that the residents did not fall. The state subsequently put in the railing. When the home opened in late 1987, the staff that had been scheduled to work at the home that never opened (noted above) were shifted to the new CLA. Many of them had previously worked in other state CLAs in the area.

In terms of neighborhood entry, there was no special strategy employed. The two women residents signed the lease and the apartment was legally theirs. The character of the neighborhood -- urban and located on a busy street -- did not suggest the need for a direct campaign prior to the opening of the home. The other tenant of the building was related to the landlord so she was fully apprised of the move. Basically, the women signed the lease and moved in.

Transition Planning

Identification and Selection of Clients. Two women live in the CLA. They are both class members -- one because she was at one time a resident at Mansfield and the second because she was "at risk" of institutionalization. When the home was on the drawing boards, the first woman, Maria, was living in another state CLA. Maria, who is about 69 (no one seems to be entirely sure whether Maria is 69, 70, or perhaps older), had spent many years in institutions. According to regional staff, her first experience with the public system was when she was 19 years old and was committed to a mental health facility. When Maria was in her 30s, the facility psychologists gave her an intelligence test and determined that she was "mentally retarded." She was then sent to Mansfield. From her records, it appears that Maria's first community placement was in 1970 in a boarding home. In 1985, the state began efforts to move Maria to a community training home. After trial visits and several changes of mind, Maria decided in December of 1985 that she wanted to go to the community training home. In January of 1986, the Monitor approved the placement and Maria moved to the CTH. At that time she also went to work in a semi-supported work setting working in a bakery.

In the Fall of 1986, Maria's advocate requested a formal program review to ascertain the appropriateness of the level of psychotropic medication that Maria was taking. Two weeks later, the advocate was notified that Maria's problems (associated with "schizophrenia") had subsided and that medication levels would be altered.

In mid 1987, the CTH provider notified the state that she wanted to retire and move out of state. Maria was placed, on a "respite" basis, in one of the

accessible CLAs previously designated for non-ambulatory, high functioning regional center residents. Her roommate at the apartment was a young woman with a physical disability who, according to region staff, got along well with Maria but had hoped for a younger roommate. At a meeting of the ID team in June of 1987, Maria was recommended for placement in a CLA given her needs for 24 hour supervision. Following the ID team meeting, Maria's advocate indicated concern that Maria might not be considered for placement in her current CLA, but transferred to another residence. She was particularly concerned about Maria's ability to adjust to yet another move and noted her successful adjustment to her current home.

The subsequent ID team meeting in July did not recommend that Maria remain in her current placement, but rather suggested that another CLA be developed. They also suggested that Sally would be an appropriate roommate. Following the meeting, the regional director contacted the Monitor's office to assure them that care would be taken to ensure that Maria would not undergo any undo stress and that the placement would be carefully designed.

The second person in the home, Sally, has never been institutionalized. She is 34 and spent most of her life living with her parents who are also her guardians. According to Sally, she contracted "hydroencephalitis" when she was 14 years old. It is not clear from the record whether this was the beginning of her problems. Sally's record begins in 1985 when she was sent to a group home for respite services. According, to regional staff, Sally's mother and father were finding it increasingly difficult to deal with Sally's emotional and behavior problems. The respite placement was repeated in 1986 at which time Sally had a "psychotic break." She was sent to a local inpatient facility. At this point, her family acknowledged that they could no longer care for her and a placement in the group home where she had gone for respite was arranged. Sally continued to work in a sheltered workshop where she had worked for several years prior to her placement.

According to regional staff, the day program placement was inappropriate. This became even more apparent when Sally became the subject of a "positive futures" planning process. During the course of the activity, Sally acknowledged that she hated her repetitive work at the sheltered workshop and that she was wanted a more challenging job. Regional staff stated that it was at this stage that the staff of the group home became solid advocates of Sally's placement in a smaller, more homelike setting and in a job that would truly challenge her abilities.

Perhaps because of the advocacy of the staff at the group home, Sally was chosen to be the second resident of the apartment.

Process and Events. The process of transition for Maria began with the development of the transition plan in November of 1987. The file includes the transition checklist as well as an OPS. The services on the OPS that were noted to be in place were medical, psychiatric, dental, recreation, transportation, physical therapy, and occupational therapy. Sally's transitional

planning meeting was also held in November of 1987. Her mother and father were both present at the meeting. The OPS suggests that all necessary services were in place for the transition.

In order to introduce the two women, regional staff arranged several visits between the two at each other's place of residence. The two decided that they liked the apartment and wanted to live together. Prior to moving in early 1988, Sally and Maria visited the apartment and helped to clean and set up the residence. According to one of the women, they did not have much say over how the apartment would be decorated. Both women had known the staff that would be working at the apartment in other settings.

In early 1988, the transition checklists and other relevant planning material were forwarded to the Monitor for review and approval. Following a community placement review, the Monitor staff notified the regional office in March of 1988 that they were "unable to conclude that placements are consistent with relevant requirements of the Consent Decree and accordingly cannot and do not support them." The specific issues raised by the Monitor had to do with the lack of a dentist for Sally and the fact that both women were taking psychotropic medications (Maria: Thorazine; Sally: Prolyxin and Eskalith) without the presence of a behavior plan.

The regional office responded to the Monitor in May noting that a dentist had indeed been found for Sally and that both women had documented psychiatric diagnoses that supported the need for the types of medications being received. No further correspondence is included in the file.

Availability of services. Both Sally and Maria have doctors and dentists. There is a large regional hospital only two blocks away. According to regional staff, the hospital is fairly cooperative although they still require one-to-one staffing while an individual is in the facility and may put them in a bed on the pediatric ward. Both women receive services from a publicly supported HMO. Maria also sees an internist who's office is across the street. She also sees a psychologist affiliated with Seaside every three months. Transportation is provided for the women by state staff. They do not use public transportation. Maria also has an appointed advocate.

Since moving into the house, Sally has left her sheltered workshop and is working in an enclave at the local Caldor's. The record indicates that an individual transition plan was filled out at the time that the job shift was made. She seems to be happy with her new job. Sally does complain about her roommate who smokes and gets up early in the morning. She has expressed a desire for a younger roommate. Maria seems very pleased with her home.

Sally enjoys bowling and also does cross-stitching. According to staff, recreational aides are available through the regional center and they prepare a monthly calendar of events in the area that are free or can be enjoyed at little cost. There is not recreational "plan" per se. Sally's mother expressed concern

that her daughter does not have many social activities compared to the recreational program at the group home.

Impact on the Community

There is no indication that this home has had much if any direct impact on community services. In responding to a question about whether the police, fire, or ambulance services had ever been summoned, mention was made of one incident in which a night shift staff member called the police in frustration over the lack of heat in the apartment. Both staff and residents had been complaining for some time that the heat was turned down early in the evening below 60 degrees but the landlord had not corrected the problem. Following the presence of the police, the heat was increased at least temporarily.

With respect to the impact of residences in general on city services, the fire marshall indicated that to date he did not feel that the services of the fire department had been affected. He noted that his services (fire inspections) had been somewhat taxed lately given the numerous requests for annual inspections that had just crossed his desk. He also expressed some concern about the future given the number of three person homes that are being developed. In these small homes -- if the residents are self preserving -- there are few fire safety requirements. He said his apartment would be taxed if a triple-decker with apartments of three persons each caught on fire and they had to evacuate the residents. He would like to see these homes filled with sprinkler systems to insure resident safety.

With respect to the police, there do not appear to be any unusual demands on their services. There have been calls for assault and theft by residents of other CLAs and according to one respondent the police have been extremely sensitive and competent.

Current Status

Service Availability.

As noted above, both women appear to be receiving the services that they require. The only significant issue appears to be a lack of integrated recreational programs.

Relations with immediate neighborhood. The women in the house appear to have very little contact with individuals in the immediate area. They do accompany staff to do shopping but do not appear to have any independent contact with local merchants.

The only problems they have encountered appear to be with the heating in the building. At one point, after repeated attempts to raise the temperature, Sally wrote a note to the landlord directly asking for his intervention. He sent back a very respectful and responsive letter and the problem appears to have been ameliorated somewhat. The landlord's sister who lives upstairs has had contact with the women and has invited them to a picnic. The residents complain, however, of the noise on the second floor from heavy footfalls -- from the woman and her family as well as the children in the home day care program she runs. These complaints, however, seem to the normal problems encountered by tenants in dealing with landlords.

SPECIAL CASE STUDY
ACCESS IN RURAL AREAS

SPECIAL CASE STUDY

ACCESS IN RURAL AREAS

To assess whether or not there are issues related specifically to the development of community residences in rural sites, phone interviews were conducted with five such residences -- two in Region 1, two in Region 5 and one in Region 3. Providers with rural homes were identified through DMR regional offices. These providers were contacted and asked to select a home which they felt, was situated in the most rural location. For each home, the executive director, house manager and DMR case manager were contacted. In some cases, as available and as information warranted, an advocate, court monitor or relative of a resident was interviewed as well. The interviews themselves ranged from 15 minutes to one hour long. The primary focus of the interview was to assess the availability of services in rural areas. Additional questions were posed about residents' past and present relationships with neighbors and the degree to which residents were involved with the community.

It is important to note that most of these sites might more accurately be described as "rural suburban." None of these homes are more than 25 minutes by car from a sizable city and some are much closer. Most are located in housing subdivisions and situated on one or two acres of land. Only one home had additional acreage and a barn, more befitting the classic image of a rural location. Nonetheless, in all cases, both the DMR regional contact and the provider considered these homes to be rural relative to the location of other community residences.

Most of the homes are modern ranch or cape style with three or four bedrooms. The homes have two to six residents, the average home has three residents. The residents' level of disability ranges from non verbal and non ambulatory to mild mental retardation with some behavioral involvement. In each case, residents sharing a home also have similar levels of impairment. Two homes house residents with more severe impairments, profound mental retardation and medical involvement, one home serves residents with moderate to mild mental retardation and severe behavioral problems, the remaining two homes serve residents with mild mental retardation and behavioral challenges. The homes have been open anywhere from four years to nine months and most have been open for about one year. Some of the residents in the homes are class members, most have come to the homes from an institutional setting.

Most providers reported that when selecting a rural location for a home, the overriding consideration was the proximity of an existing day program. The availability of other types of services, while investigated, was not a primary concern in planning for the home. In three of the homes, residents were placed in a rural site either by the residents' choice or as a therapeutic decision. Residents with behavioral problems, in particular, are seen as benefitting from an environment that offers more space and fewer problem situations than an urban environment. In one case, residents with severe behavioral challenges have progressed to the point where they all hold jobs in a downtown store run by the provider. It is perceived by the provider and the DMR case manager that the rural site has benefitted the residents but now

they would be better served by living in the city, nearer their work and in an area where they would have more autonomy, being less dependent on staff for transportation. The provider has petitioned to move the home downtown and the case manager wholeheartedly supports this proposal. This is the only case where the rural site is now seen playing a transitional role but it is also the site which has been open for the longest time.

The telephone interviews primarily addressed the issue of accessibility/availability of services in rural communities. While there are many similarities in responses which will be outlined below, only two homes cited the rural location as a negative factor in obtaining services but neither of the contacts at these homes feels location is the determining factor in the service shortfall. Interestingly, both of these homes, unlike the other three, are serving residents with severe impairments. For providers serving residents with profound mental retardation and medical involvement, comments like "resource poor area" and "the availability of services is ridiculous, there aren't any" abound. Providers serving less severely impaired residents in rural areas find similar problems but the issues are not as severe nor as compromising to the quality of care. It would seem that not only is it harder to find quality services for residents with more severe impairments but the difficulty in providing services is more threatening in these cases. To paraphrase one respondent, this is a medically fragile population and to be without services is frightening.

Residential Staff. The residential staff for each home ranges from six to ten people. Finding capable staff is a problem for each home. None of the homes find it to be an intractable situation. Most felt that they had problems when they first opened but now have established a more stable group. The rural location and related lack of transportation for staff was only cited by one home as a reason for staffing difficulties. This is also one of the homes that is closest to an urban area. The primary issue around recruiting and retaining residential staff was reported to be money. Providers indicated that, the fact that DMR positions pay higher wages and have better benefits made it difficult to retain staff. Recent changes in staff funding (parity legislation) have made it easier for providers. Three contacts cited this change as improving their staffing situation.

Medical Services

Nursing. Most providers have a staff nurse and some providers require the house manager to be a trained nurse. All respondents agree that there is a chronic shortage of nurses that is a national problem and has little to do with the rural location or Connecticut.

General practitioner. Obtaining the services of a general practitioner is not typically seen as a problem. Most homes utilize a local provider or a consultant physician employed by the provider for multiple homes. However, a few homes have needed to change their physician in the first year and this is especially true of the homes serving residents with more severe disabilities.

These latter homes find it difficult to locate physicians who have experience in dealing with a disabled population. On opening, one home signed a contract with a doctor. When a resident became ill, the doctor reneged on the contract. He said that he thought the clients would be more like the children he sees in the Special Olympics. He felt these clients would be disturbing to his other patients. For all homes, it has taken work to find a good physician but most are now satisfied. But providers serving residents with severe disabilities have really needed to "shop around."

Specialists. Most homes find it extremely difficult to obtain the services of a specialist. Again, providers serving residents with severe impairments report having the most trouble. The only home which had no difficulties is being referred to specialists through their general practitioner. It is often necessary for specialists -- eye doctors, neurologists -- to have a particular understanding of working with persons with disabilities. One neurologist is quoted as saying, "you expect me to do something with this?" "This" referred to a resident who is non verbal. All homes expressed a willingness to drive across the state for these services so that again the rural location is not at issue. The problem is perceived by respondents as a lack of qualified physicians who are willing to work with the residents.

Psychiatrists/psychologists. An even more severe shortage of psychiatrists and to a lesser extent psychologists was reported. Nearly all of the homes have had trouble finding a psychiatrist and/or are not particularly satisfied with the one they have. It is so difficult to obtain services that there is little or no room to exercise any choice regarding quality. Most respondents feel that the rural location gives them fewer choices of clinicians but again this is not reported as the primary cause of the problem.

Dentists. Dentists are very difficult for providers to find. Dentists who are contracted for services rarely stay very long. Again, respondents indicated that the issue is not that they are not out there but their willingness to treat the population.

Hospitals. All the homes use the nearest local hospital. No problems or concerns regarding this service were reported.

Issues in Obtaining Medical Services

The difficulty in finding medical services in the community was consistently attributed by all respondents to the method and level of Title XIX reimbursements. Medical personnel find the reimbursement for their services inadequate. This is particularly true for specialists and psychiatrists for whom the special needs of the residents pose extra work while reimbursement levels are below their usual fee. General practitioners who might typically only perform a yearly physical are reported to be easier to find and retain. Additionally, physicians who are willing to accept a lower payment often find the delay in payment and the concurrent paperwork to be too much. Many o'

the respondents feel that physicians would be willing to serve the residents if it were not for this combination of red tape and low wages. It is generally perceived that the rural community has the medical personnel to serve the residents but is unwilling to do so because of the Title XIX bureaucracy.

A lack of expertise in working with persons with mental retardation is also frequently cited as a contributing problem. Again, this is a larger issue with respondents serving residents who are more seriously impaired. Physicians who are initially contracted for the home often leave because of ignorance about what it means to treat the residents. There is a need for specialists who are able to make diagnoses with non verbal clients. There is a need for psychiatrists who have a greater understanding of the medication and counseling needs of persons with mental retardation. DMR referrals for physicians are reported not to be particularly helpful. The homes serving residents with more severe disabilities voiced a desire for greater support from DMR in accessing and training clinicians to meet the needs of this population. Respondents feel that medical personnel could learn to work with the residents but that there was not much incentive for them to do so. Homes that are situated near state schools found it easier to gain access to resources primarily because medical personnel are more likely to have a familiarity with persons with disabilities.

It should be noted that the majority of these homes have medical services in place and feel that they are adequate. However, the greater the residents' need for these services the less likely this is true. Additionally, most staff feel that they have less control over the quality of their services -- particularly psychiatric services. They feel that they either stay with the practitioner that they have or risk spending weeks without care while they look for a new practitioner.

In rural locations, there are fewer medical personnel from which to choose. However, all providers said that they are able and willing to take the residents anywhere in the state for the appropriate care. Some providers who are near the state borders are seeking permission to use medical providers in other states. Twice, Rhode Island was mentioned as having medical resources that are not available in Connecticut.

A number of different tactics for coping with this situation were described. One provider has little or no trouble recruiting or retaining a consulting physician and psychiatrist. The provider pays the physicians out of a consulting budget to spend some time each month in consultation with the residential staff. With this method, the provider is able to essentially supplement the Title XIX payments and develop a system which provides greater quality control. Other providers have developed close personal ties with physicians or providers and go out of their way to cater to physicians' schedules and needs in order to achieve a level of stability.

Specialized Therapies. All respondents reported a shortage of physical therapists, occupational therapists, speech therapists and behavioral

specialists. Some of the homes have little or no need for these services, while the other providers have specialized therapies in place but have found them difficult to obtain. In all cases, a consulting or staff therapist trains the residential staff to implement whatever therapeutic program is deemed appropriate. Most providers indicated that they would probably use more specialized therapies if they were more readily available. In at least one case, some specialized therapy is received at the residents' day program.

Respondents considered the absence of these specialists to be a statewide, if not national, problem and not specific to the rural location. Simply put, there are not enough trained personnel in these areas, especially in physical and speech therapy. Low Title XIX reimbursement levels were mentioned as part of the problem in obtaining these services, but it was cited far less often than it was for medical personnel. One respondent mentioned that the physical therapists in the area are accustomed to dealing with accident victims and are neither interested in nor adept at working with persons with mental retardation.

Day Programs. Nearly all the residents are in some type of day program ranging from supported employment to a simple activities program. As mentioned earlier, the accessibility of a day program was a crucial consideration in siting the home. None of the respondents indicated that maintaining or finding a day program is difficult. On average, residents travel about fifteen minutes by car to reach their program.

In at least two cases, the quality or adequacy of the day program was questioned. One respondent feels that a structured program serving the residents did not have enough carefully planned and therapeutic activities resulting in too much time is spent in front of television. In another case, the respondent feels that the supported employment program lags far behind the goal of community integration. Not enough is being done by the program to tap community employment resources. This respondent sees the rural location as contributing to this problem, reducing the number of employment opportunities. Despite these concerns, the day programs are seen as improving and making a conscious effort to do so.

Transportation. Each site has a van or car which belongs to the home. None of the respondents indicated that transportation is a problem.

Recreation. Differences in response to this question have more to do with the level of disability of the resident than with the rural location. Residents who are not severely impaired used the local YMCA, aerobics classes, movie theaters, gyms, and so forth. In these cases, the availability of facilities is considered adequate.

Homes that serve residents with more severe disabilities, residents who were more likely to use wheelchairs and to be non verbal, found themselves at a loss when it came to recreational activities. Providers feel that the typical

activi[illegible]like bowling or movies are clearly inappropriate. They feel a need for suppo[illegible]to provide recreational activities for these residents. Two respondents expressed a need for state sponsored programs in this area.

Any other restriction regarding recreational activities is related to having a sufficient number of residential staff members. One home found that they rarely have enough staff members to take the residents on group outings since the residents need so much attention. In another case, where residents are more self sufficient, an outing might be cancelled if one resident decided not to go. There are not enough staff members to cover both the home and the outing.

Police and Fire Departments. In all cases, providers reported that relationships with these community services are good. Of the homes that have needed to call the police, patrolmen or state troopers were found to be exceptionally helpful and understanding. The same holds true for the fire department. In at least two cases, the provider feels that the relationship with the police would not be as good in an urban environment. Both of these respondents feel that the police in a rural setting are more willing and able to be sensitive to the residents.

Neighbors. Most of these homes have encountered some opposition to their presence. Typically, the opposition was minor and has been resolved. Nonetheless, the word most often used to characterize the neighbors' attitude toward the home is that it is "tolerated." This tolerance ranges from repressed hostility to relative indifference. In these six homes, there are few if any on ongoing relationships between the residents and the neighbors. As one respondent stated, "they don't invite us over for coffee."

Community. Most homes feel that the residents use and have access to the resources of the surrounding community. The larger goal of actual integration into the community has yet to be reached. Interestingly, true community acceptance is an issue regardless of the residents' level of impairment. One respondent who cared for residents with severe disabilities said that the staff is sometimes reluctant to take them out into the community for fear of subjecting residents' to unnecessary scorn or humiliation. In another case, a resident was asked to discontinue an aerobics class unless a doctor's note was obtained. The respondent feels that the resident simply made the other members of the class uncomfortable. In both cases, house staff feel highly protective of the residents and saddened by the community's lack of understanding.

Somewhat better relationships were reported by residences that are located near a town that has DMR facilities. In these cases, the community has more experience in dealing with persons with disabilities and is more understanding.

One respondent discussed the fact that a relationship with the residents takes a commitment of time that most members of the community are either unable or unwilling to give. Two providers feel that they need support in gaining community acceptance. One respondent would like to see DMR assist the provider in preparing the community for a group home. When a home is being established, the provider rarely has the extra resources to adequately reach out to the community and could use assistance from the state. It was also suggested that the state take a more active stance in educating the public about persons with mental retardation.

Conclusion

It seems that the question is not whether the rural community is able to meet the residents' needs but rather whether the community will meet their needs. Location appears to play a secondary role in the inability to obtain services. Services are lacking because of the burdens Title XIX imposes -- bureaucratic as well as financial -- and the inexperience of community service providers in working with persons with disabilities. These two factors serve to reduce the pool of possible service providers, a pool that starts small because of the rural setting. This problem is exacerbated and reaches more serious proportions when residents have severe disabilities and are medically fragile.

Despite the difficulties, providers typically portrayed themselves as obtaining necessary services and coping. Respondents stressed the beneficial effect the rural environment has for residents. However, they also expressed a desire for more support from the state around certain issues. They wanted assistance in educating the community and educating community service providers about persons with mental retardation. They wanted help in accessing quality medical personnel and recreational activities for persons with severe disabilities. In general, providers felt that the residents are happier in the community and the community is capable of supporting them. However, there is room for improvement between this fact and the present reality.

MEDIA ANALYSIS
REGIONS 2, 4, AND 6

CONTENT ANALYSIS REGION 2 MEDIA

In DMR Region 2 we reviewed the newspaper coverage of issues related to services for people with mental retardation during the period from September 1987 to September 1988. A total of 27 articles drawn from local papers were reviewed for this analysis. The articles fell into three categories: articles having to do with DMR policy, budget plans, the budget shortfall, and other specific issues surrounding the implementation of DMR programs; human interest pieces on disabled clients usually focusing on their positive adaptations to community living along with family testimonials to the positive growth that community living has brought; and stories on neighborhood opposition to group homes. Table 2 provides a summary of the themes discussed in the balance of this section.

DMR Plans, Problems and General Information

DMR Plans. Several articles refer to the five year plan DMR developed in 1987 to move 900 clients from institutions to the community, and the $40 million required to accomplish the movement goals. These articles generally described the types of programs contemplated for community placement (three and six person homes) along with associated costs.

Problems. Subsequent to the announcement of this budget, the media reported on the $6 million budget error that prevented DMR from achieving its placement goals in year one of the plan, the legislative response to the budget crisis including greater scrutiny of DMR, problems in compliance with the 1985 court order to move institutionalized clients into the community, and consternation among the advocates, clients, and their families

TABLE 2:
SUMMARY OF MEDIA COVERAGE IN REGION 2

MAJOR THEMES	SUB-CATEGORIES	NUMBER OF ARTICLES
DMR		
	Planning	2
	Problems	4
	General Information	2
Human Interest		10
Neighborhood Opposition		10
TOTAL		**27**

over delays in placing clients in the community. One particularly striking article documents the high costs of caring for very difficult clients in the community, DMR's defense regarding these expenditures, and the concern of public officials, some of whom are reluctant to speak out publicly on the issue because of its sensitive nature. Other problems documented by the media have to do with the failure of various facilities to meet licensing standards, problems in finding appropriate placements for clients, quality of care issues, and in one case, problems with provider reimbursement.

General information. One article describes a study done in Westchester, New York on property values which includes participation by a state realtors' association. This study states that property values are not affected by the presence, in this case, of group homes for the mentally ill. Another article describes a family support pilot project which gives monthly stipends to families who keep their severely disabled children at home. The purpose of the money is to cover expenses incurred by families to meet the challenges of caring for such children in the home.

Human Interest Stories

This category includes stories about clients living in the community in various group homes. There were descriptions of a group home developed by a former state institution employee that enabled clients to care for pets and horses in addition to their regular day programs, and the freedom the provider felt in caring for these clients in this setting versus the rigidity of the state institution. There was an article about a mother of a disabled woman who founded an organization out of concern over the lack of activities available for her daughter during the summer, and how the mother went on to develop a

group home for four autistic women. There were several articles describing the adjustment of clients in the community. These situations were presented in a positive manner, clearly reflecting media support for the independence achieved by clients in the community compared to the conditions of institutional living.

There is some overlap between the human interest stories and DMR plans, problems and information categories. There are articles documenting problems with the lack of placements or problems with placements in which family members and clients express their personal concern. The delineation of the problem is usually followed by a DMR official explaining why the problems exist, usually attributing the problems to budget shortfalls and the high cost of care as the culprits in these situations.

Neighborhood Opposition Stories

Most of these articles focused on the opposition of neighbors to group homes opening in Canton, South Windsor and Wallingford. The concerns of neighbors were similar in each community and centered on: property values, the consequences of the property being sold to some other kind of organization after the group home moved out, (specifically if it became a halfway house for drug addicts), disturbing noise emanating from the homes , a lack of information about the planning of the homes and details regarding to the daily management of the homes, parking and increased traffic, and the "safety" of neighborhood children.

In Canton, the neighbors were attempting to get the license of the home revoked, and in South Windsor, most of the effort was directing at trying to prevent the opening of proposed group homes. The articles suggest that in most cases, the Corporation for Independent Living, (CIL), the site developer, was viewed with suspicion by neighbors. It was reported that neighbors believed that the developer was out to make a quick profit and felt that CIL often withheld information. CIL was quoted as vigorously defending the rights of disabled citizens to be in the community and defending their operational practices. DMR, in these stories, supported CIL and often appeared with CIL at meetings in the communities.

Summary and Conclusions

In summary, it appears that the media's portrayal is quite supportive of community living and the deinstitutionalization of persons with developmental disabilities. There are many accounts of positive adaptation to community life by DMR clients. The media also gives voice to those who are concerned with the way DMR has spent its funds. Though not accusing DMR for misuse of funds, the media does tend to bring to the attention of the public the high cost of supporting persons in the community. It is important to note, however, that stories on the high cost of community living are almost always cast in a favorable light compared to the even higher cost of maintaining clients in

institutions. The media generally appears to be sympathetic to neighbors who want to be apprised of plans for the development of group homes, but has little sympathy for complaints regarding persons with disabilities.

CONTENT ANALYSIS REGION 4 MEDIA

Since there was extensive newspaper coverage of the two homes described in Case Studies 3 and 4, the content analysis for this region is largely limited to a review of the documents surrounding these events (from the time period of December '83 to November '86). There is scattered representation of media coverage in subsequent years. The articles fall roughly into five groups. The first is news coverage of the events related to or spurred on by the opening of these homes. The second are editorials and letters that are mostly supportive of community living. Third, there are a few articles that positively portray community living as a human interest feature. There is also reportage on DMR plans and problems. Lastly, are three articles that provide in-depth analyses of substantive issues in community development.

TABLE 3:
SUMMARY OF MEDIA COVERAGE IN REGION 4

MAJOR THEMES	NUMBER OF ARTICLES
Community Residence Development	39
Editorials and Letters	12
Human Interest Stories	4
DMR Plans and Budget	9
General Analyses of Development Issues	3
TOTAL	**67**

News accounts of community residence development. The bulk of the articles gave detailed accounts of the events surrounding the opening of the two case study homes. They include reports of community attempts to change local legal practices aimed at group home development. The articles on the whole portrayed, in a balanced fashion, neighborhood concerns and agency perspectives on community development. Occasional references were somewhat disparaging of neighbors. For example one news article lead with the statement that neighbors are suffering from "it's OK if its not in my backyard syndrome." The article closed by reporting how one neighbor said that it is the neighbors and the not the agency that will ruin the neighborhood. The article then suggested that this was probably true given one neighbor who was quoted as saying "there goes the neighborhood."

Perhaps the most interesting thing about this set of articles is the extent of the coverage itself. As mentioned in the Case Study 4, coverage began with the opposition surrounding the unsuccessful attempt to purchase the first home, and then closely followed virtually every subsequent development. This coverage came from several area papers. Although this was the first group home in this town, this "high -profile" coverage is nonetheless surprising.

There were several articles detailing the events and debate surrounding the home in Case Study 3. These focused primarily on the activities occurring in the town meeting. There were many parties involved in this as the property belonged to the town and commercial areas were potentially affected by the result of the size of the parking lot to be developed behind the group home.

Supportive editorials and letters to the editor. Significantly, there were several editorials that had prominent page position and headlines that clearly exhorted neighbors to "have a heart" and to support "these less fortunate, more innocent human beings." This same editorial also defended the state zoning statute. Also receiving prominent display were several letters to the editor, some from families with a member with disabilities, which again asked for understanding and for neighbors to give community residences "a chance." Some of these letters and editorials predate the formation of community opposition to the home in Case Study 4. A few letters were also printed from opposing neighbors which explained their position.

Human interest stories. A few feature stories were plainly in support of community development for persons with mental retardation. Several articles profiled residents in their home, the gains they made in the group home and the ordinariness of their lifestyle. Other features sympathetically addressed the plight of families who were waiting for community placements for their family members.

DMR plans and Budget. Several articles discussed more general statewide matters regarding DMR policies and activities. These included discussion of deinstitutionalization and the court consent decrees. There was some coverage of the DMR budget shortfall and the related adverse effects. Of special interest is a series of recent articles that revolved around the concerns of some parent groups over the current direction of DMR as expressed in the current DMR state plan. Failed placements, poor supervision, and inappropriate behavioral incidents were described to support parents concerns over DMR's emphasis on deinstitutionalization, which comes at the expense of community-based clients who would benefit from the same community resources. This series included interviews with the former and present commissioner of DMR and highlighted their contrasting philosophies. On the whole the articles were sympathetic to these parent concerns and somewhat damning of recent DMR initiatives, while neglecting to mention that the consent decrees were the result of activities of other parents.

General analyses of community development issues. The final category of articles report on larger developments of community living in

Connecticut. They presented an depth analysis of substantive issues in community development, namely: the precedents in zoning law vis a vis community group homes, a discussion of the controversy in the field regarding when and whether to tell neighbors of an intention to open a group home, and the fears that typically beset future neighbors of group homes for persons with mental retardation and other populations. These features involved some research and reported on "expert analysis" of the issues. On the whole, the tenor of the articles was sympathetic to community development.

CONTENT ANALYSIS REGION 6 MEDIA

In DMR Region 6, we reviewed the newspaper coverage of issues related to services for people with mental retardation during the period immediately before and after the opening of the sites we selected for study. This period of time covers most of the 1988 calendar year. A request for articles from the fall of 1987 did not uncover anything relevant, although the project staff is confident that there was some media coverage of community residence issues during that period.

A total of 30 relevant articles were reviewed. The content of these articles fell into four major categories and a number of sub-categories. The basic content of each of these categories will be reviewed in the subsequent sections of this analysis. Table 4 provides a summary of the themes found running through the coverage in Region 6.

Community Residences

The largest single group of articles we reviewed recounted the controversy surrounding various efforts to develop several community residences. An article and several letters to the editor deal with various neighbors' concerns about the fact that property can be purchased for community residences with no input from members of neighborhood. One of the letters is especially concerned with what the writers see as the excessive cost associated with the homes purchased for community residences. Another series of articles follows

TABLE 4:
SUMMARY OF MEDIA COVERAGE IN REGION 6

MAJOR THEMES	SUB-CATEGORIES	NUMBER OF ARTICLES
Community Residences		
	Resistance, hearings, etc.	7
	General	4
	Unionization	2
	Human interest	1
Seaside Regional Center		
	Abuse	5
	Reorganization	2
	Renovations	2
DMR budget		
	Effect on community development	3
	New plan for medical services	1
A threatening individual in the community		4
TOTAL		**30**

the progress of a law suit brought by the State Attorney General over a restrictive covenant that prohibited sale of property for use as a group home. A final article discusses a local zoning board's refusal to allow an exception to the 1000 foot rule so one man with mental retardation man could remain in his Community Training Home.

Four of the articles we reviewed dealt with group homes in general terms. Two of these articles discuss how these homes, which may be new to some neighborhoods, are a well established reality throughout Connecticut. One of these articles then points out how the process of group home development will decrease the census at Seaside regional center which might in turn result in closure. Another article discusses how a small parent-run agency developed several group homes and now has a resident and one of the staff people making presentations to foster community support. A final article describes a study done by the University of Connecticut that indicated that most people do not want group homes in their neighborhood.

Two articles discuss the dispute between a group home provider and staff over the issue of unionization. According to the report, the provider refused to recognize the union that was selected in a vote by the staff. The first article reports that the staff picketed the agency and the DMR central office to demand recognition of the union. The other article recounts that the agency's

appeal to the National Labor Relations Board was rejected and that the agency would have to start negotiations with the union.

A final article in this group is a human interest story about life in a Community Training Home. It concentrates on the full participation in community life available to the people living in the home and the high quality of their relationship with the provider.

Seaside Regional Center

Early in the year a group of articles report on the release of a report that documents the degree of abuse found on certain units at Seaside the previous year. The articles variously focus on the content of the report, the charges against and disciplining of staff members, the threat by advocates to request a federal investigation, and the institution's plans for reorganizing in response to the report.

Several months later, there are two articles reporting on the actual implementation of the reorganization plan. The lead of one article recounts how one resident looks forward to moving into a new private room. The reporter then discusses the gradual decrease in the number of residents in the facility and highlights some of the specifics of the reorganization. Another article on the same topic begins by recounting the physical renovations and staff redistribution. It then points out that the reorganization has met with opposition from staff and parents. Central to the opposition seems to be the transfer of clients with behavior problems from the units where the abuse of the previous year had occurred. These clients are to be mixed in with the rest of institutional population rather than placed in special units. The reorganization articles do not make reference to the earlier abuse situation which stimulated the changes.

A final article on Seaside reports that no contractors entered bids for safety renovation originally scheduled to take place during the summer 1988.

DMR Budget

During the annual discussion of the state budget, an apparent short fall in the allocation to DMR became apparent. Apparently this short fall was the result of an error in the preparation of budget requests and specifically threatened funding for private community residences. Each of the three articles which specifically address this issue has a different focus. The first makes two points: first, the short fall reflects a failure to budget for the increased costs of staffing in privately run community residences; and second, if this results in deferring development it will set back deinstitutionalization at Mansfield. The lead of the second article is a family human interest story emphasizing how lack of funds means that families with adult children at home will need to wait even longer for group home spaces. The final article, which

reports the ultimate resolution of the budget crisis, highlights the fact that a number of legislators feel that the state may be providing inentally retarded people in the community with "a Cadillac as opposed to a Chevrolet level of services."

The final article in this category picks up on the theme of the possible excessive cost of community services provided by DMR. This article is an editorial which questions whether the DMR regional plan for a new and more expensive plan for medical services is acceptable. This is framed in a general discussion of the high per client cost of DMR services and a call for more fiscal accountability by the Department.

A Threatening Individual

These articles, which appeared in September and October, are unusual because they focus on the specific problems associated with the efforts to maintain one individual in the community. The progression of articles presents an escalating series of events that eventually resulted in the man being removed from the community residence--in this case an apartment where he was supported by DMR staff. This high degree of public exposure is rooted in the fact that on three occasions the man in question was charged by the police.

The earliest article appeared as a result of his arrest on disorderly conduct charges for yelling obscenities at passing motorists. However the bulk of the article recounts some of the neighbors' concerns about his behavior which for the most part entailed stopping and talking to people and following them onto their property. This is accompanied by a response from DMR staff that attempts to explain that he is no threat to anyone. Under the headline "State says neighbors fears of retarded man are unwarranted," a DMR official explains that his unusual behavior is the result of his failure to develop typical social skills because of all the time he spent in an institution.

Unfortunately, subsequent events only reinforced the neighbor's perception that the man was a physical threat. On two additional occasions he was arrested based on complaints from staff members in his residence. In the first instance, the police were called because of the suspicion he had stolen money from a staff person. As a result of this incident he was charged with threatening, disorderly conduct, resisting arrest, and third degree larceny. About two weeks later the paper recounts that he was again arrested, this time for chasing a staff person with a pipe and for slightly injuring a policeman who responded to the call.

An article that appeared between the two stories of his arrests reports on a town meeting in which the regional director attempted to respond to the community's concerns. The article reports that the DMR official agreed to place the man in a new location but that it might take some time to arrange the transfer. Two other major points are made in the article. First, the degree to which members of the community said they did not trust DMR is underscored.

Second, in the conclusion of the article the regional director is quoted as saying that although DMR would consult with neighbors about any new placement in this site, neighbors would have no legal recourse if they objected.

Summary

During the period in which the homes we studied in Region 6 were being developed, the public was getting a variety of mixed messages about people with mental retardation and the development of community residences. In the media they saw that group homes, in general, were controversial and possibly expensive. Further, the stories about some specific individuals confirm that, all protestation to the contrary, there are people with retardation living in the community who present a threat to community members. On the other hand, the newspapers report that community residences in their various configurations are a well established part of many communities and they provide benefits to the people living in them. In addition, the media is fairly clear in documenting many of the problems associated with institutional services. Yet, a recurring question in much of the media coverage seems to be "while it is true that people with mental retardation merit public support, are they getting more than their fair share?"

APPENDIX 1:
STUDY DESIGN

STUDY DESIGN

This paper presents a summary of the study design used in this project. As we pointed out in the body of the report this project involved four major activities: 1) case studies of six Connecticut communities where people with mental retardation have been relocated from institutions; 2) content analysis of media relating to deinstitutionalization (i.e., relevant newspaper articles); 3) a retrospective study of twelve individual placements into community-based residences in the six selected communities, and 4) a survey of 5 group homes located in rural areas with a specific focus on the accessibility of services in theses locations. The process and strategy of each major activity is discussed separately here.

MULTI-SITE COMMUNITY CASE STUDIES

Once the sites to be studied were selected, as described in the introduction to this report, the following components went in to the case studies : 1) identification and selection of key informants, 2) development of interview guides, 3) data collection and data analysis. Each of these are discussed below.

Identification and Selection of Key Informants

In order to develop a comprehensive understanding of the impact and history of each site numerous key informants were identified and interviewed at each site. To the extent that they are knowledgeable, they were queried about the major foci of the study -- issues of impact of deinstitutionalization, community acceptance, availability of community supports, and quality assurance mechanisms. The following groups of key informants were interviewed:

- *Provider staff:* The director of each provider agency of the selected site, other executive staff that are knowledgeable about the residence and the house manager or equivalent position. Wherever possible the original directors and staff who were directly involved with the opening of the site were identified and contacted.

- *Case manager staff:* Case managers that are or were expressly involved in the placement of the individual selected for the retrospective study of the placement process, and case managers of both the current and previous residential provider.

- *Residents and family members:* Residents selected for the retrospective study (see Retrospective Study of Individual Placement Process) on the individual placement study and their family members.

- *DMR regional staff:* Persons involved with community siting and individual placement including persons from the regional eligibility team.

- *Developers:* Relevant developers of the property involved with community siting or individual placement.

- *Neighbors:* Neighbors on either side of the residence and opposite to it. These individuals were in turn requested to identify other neighbors or previous residents who were active or involved with the establishment of the home.

- *Town or municipal service providers:* Local fire chiefs or inspectors, police chiefs, transportation officials, and providers of generic services such as recreational centers.

- *Day program providers:* Executive and programmatic staff who serve residents from the targeted homes.

- *Local Realtors*: Persons knowledgeable about the effects of deinstitutionalization on property.

- *Town/municipal administrators and government representatives:* Town selectman, mayors, administrators, state representatives who were involved in or are knowledgeable about the home. They were also asked to identify members of the community who were involved with or concerned about the opening of the targeted residences.

- *Other identified persons:* Each person interviewed was asked to name other persons who may be relevant to the study goals. These included for example: attorneys, local news reporters, or advocates.

Provider staff were asked first to identify the individuals on the above list. Where possible they were requested to offer introductions on behalf of the project staff. Where was not possible, project staff made contacts with the individuals directly and requested permission for an interview by explaining the purpose of the project. Interview times were arranged in advance and at the convenience of the interviewee. Where provider staff were unable to identify the relevant individuals, other means were used such as referring to town directories and asking neighbors.

Interview guides

The use of an interview protocol is crucial in a case-study process because it helps to ensure comparability of data across sites.

This study used three interview guides (see Attached) which reflect the three distinct perspective present within this study: the community, the client, and the service system. The Community Members Interview Guide was used with neighbors, generic community service providers (i.e., local recreation programs, hospitals, social service agencies, etc), merchants, public officials, local health and safety officials, and local Realtors. The second guide was used when interviewing residents, their parents, guardians, or independent advocates. The final interview guides was used with all informants who are associated with the formal system of services for people with mental retardation including case mangers and other members of individual Interdisciplinary Teams (IDT), residential direct care and managerial staff, DMR regional staff, day program direct care and supervisory staff (this includes education, vocation, and day activity programs), and residential property developer (primarily representatives of Corporation for Independent Living CIL).

The first and third guide are made up of two parts. In each case the first part presents a basic core of topics to be discussed with all respondents who fall in that particular group. The second part of the guide is made up of list of topics to be explored with individuals who fall into a particular sub-group of respondents. In addition, the third guide contains numerous question which focus more on the individual placement planning process than on the development of the residential site.

Interviewees who are knowledgeable about more than one aspect of the study were queried on the relevant topics at the same interview. For example, family members of the residents were able to answer questions on the adequacy of support services as well as on the quality assurance mechanisms.

All interviews were prefaced with an explanation of this study. It was made clear to all of the respondents that our primary concern is on understanding what actually occurred during the development of the particular residence under study. Nevertheless, comments and anecdotes related to issues of community residence development were collected when they are offered. Decisions about the applicability of material was left for the analysis phase of the project.

The need to be open to the information people offer is based on the premise that anything which a respondent chooses to recount within the framework of our inquiry obviously has some relevance to the way that person thinks about the issues. It was especially important for the interviewer to remain open to what neighbors and other community representative have to say. The kinds of stories people revealed how they perceived the community residence. For example, an initial perception might be that people were opposed to the opening of a group

home because they did not want people with retardation living next store. However, by listening to people it may become apparent that the crucial issue might be renovations to the property, fear of a governmental entity moving into the neighborhood, or concern over property being removed from the tax rolls and in fact have little or nothing to do with the people with retardation who are living there.

A final note, ***these guides were intended only as an aid to the interviewer to assure that all relevant topic are discussed; they are not questionnaires to be filled in during each interview.*** These guides attempted to be relatively comprehensive in there identification of issues to be explored in each interview. However, the wording here is in no way indicative of how the information was obtained; that was left to the individual interviewer. In this approach to research the primary instrument is the person of the researcher. Its success depends on his or her ability to elicit meaningful responses from the informant and then explore those responses until their significance is clear. In this regard, most of the topics listed on these guides will emerged in the natural flow of conversation. Hence the interviewer did not resort to a labored question and answer format but elicited a free flowing in-depth discussion of how the process of residential development effected the respondent. This serves to underscore the major strength of this approach to inquiry: it is not constrained by the preconceived notion of the researchers as to what are the major issues to be explored.

Although the interview guides contain the majority of topics explored, some information was acquired without interviews. Of interest is whether the house is clearly distinguishable from the surrounding properties or noticeably unusual. Also of interest is whether the house is located on a busy or quiet street (it has been suggested that residences on quiet streets encounter more opposition), in the middle or on the corner of the block, and whether the property is kept up in keeping with the environs. These factors were ascertained by observation.

Data collection and data analysis

Having identified the key informants at each site, project staff conducted the interviews. A single project staff member was assigned to each of the sites. This will help to ensure that a cohesive understanding of the circumstances was acquired and communicated to other project staff.

Project staff used the prepared interview guides so that comparable data is collected at each site. However, as new relevant themes surface, they were noted and included in the analysis. At the conclusion of interviews project staff will transcribed interview notes and enter them onto a computerized text processing program. This will afford retrieval of specific quotes and themes across sites.

Based on the interview notes and the media analysis (discussed in the next section) a profile of each site was developed. The profiles present data from across the sites organized by topic area. This organization of the diverse information collected during the case studies enabled us to highlight consistent patterns, unique situations, and dominant issues in the areas of residential service development, support services, and quality assurance mechanisms. Using the profiles, comparisons were made in the effort to find patterns of consistency and/or difference. Each case study was used as a point of contrast and comparison so that universal explanatory relationships could be developed.

CONTENT ANALYSIS OF PRINTED MEDIA

A major barometer of a community's reaction to the development of a community residence for people with disabilities is found in local press coverage. An examination of this coverage provided the project with a ready catalog of the main actors, key issues, and pivotal events in the development of each of the targeted residences. A media analysis also was able to draw attention to any problems associated with the availability of community support services and with quality assurance measures. In addition, to providing some basic information which was valuable to the project, a review of print media gauged pre-existing community attitudes toward community residential development and provided a sense of what contributed to those attitudes. This information supplemented the data collected in the community case studies.

The standard approach for systematically examining media coverage of an event falls under the broad rubric of content analysis. Content analysis is the process of making inferences from symbolic materials such as texts. While content analysis methods are not codified, the unifying factor is a systematic approach. Inferences are not drawn out of the researcher's pre-conception of the material. Rather, all conclusions are firmly grounded and supported by reference to the material which provides the raw data for this approach. In this study the content analysis will concentrate on determining what the "community" was reading about community residences and people with disabilities during the period in which the targeted residences were being developed.

As soon as the list of targeted residences was approved the individuals who were directly involved in the development of each residence and those currently involved in their day-to-day operations were contacted. They were asked to identify the major periodicals that cover the community in which the residence is located. It has been our experience that community residential agencies or regional offices often keep very complete records of all media reporting (favorable and otherwise) that deals with their programs. Administrators of the agencies were asked about the possible existence of such files and requested to share them with this project. Some of the providers and regional administrators provided us with these media files even before we began data collection. Public officials were also be asked for their recollection and impression of media coverage of residential development.

All articles dealing specifically with one of the targeted residences were first be skimmed for

1) the names of major actors,
2) central issues, and
3) key events in the history of the setting.

After this initial reading all of the articles were carefully and systematically re-read in an effort to identify recurring themes or any underlying tenor in the articles. Themes identified by the on-going discussion of particular issues, such as possibility of hepatitis infection or traffic conditions. Tenor of the articles was determined by the nature of the anecdotes recounted in the coverage, percentage of space allocated to proponents and opponents of the residence, and statements of opinion (editorials, etc).

Typically, the unit of analysis in a content analysis is the word or phrase. Some common forms of content analysis include "frequency counts, key-word-in-context listing, concordances, classification of words into content categories, content category counts, and retrieval from text based on content categories and co-occurrences" (Weber, p. 127). However, there is ample precedent for a more holistic approach to content analysis in which an entire article or story is the unit of analysis. This approach has been used extensively to examine media portrayals of people with disabilities (cf. Bogdan & Knoll, 1988). The written materials which are examined using this approach are usually classified or coded using thematic categories which are found running through the entire body of work. The codes used often start out as rather broad statements regarding the content of texts. As the process of analysis proceeds, these statements are gradually clarified. The net results is that at the conclusion of the analysis each category can be summarized in a clear concise statement of those elements which unify all of the texts which are identified as being representative of a particular theme. Since most themes are not mutually exclusive, this approach is able to deal with the ambiguity which is often found in written material.

In this study, each of the articles reviewed was catalogued in a manner which summarized the content of the article. The entry for each article will include the following:

1) Basic identifying information including title, author, date, periodical, length, presence of pictures, and location in publication

2) Community and residences covered by this publication

3) Type of article (e.g., local news, national or regional news, feature, or human interest)

4) Connection to other coverage (e.g., Does this article follow-up on or refer to another article?)

5) Content (e.g., reports on public hearing, fire, zoning, personal development, etc.)

6) Number and types of anecdotes used in story (e.g., stories of personal growth or neighbors dealing with non-responsive bureaucracy, etc.)

7) Tenor (i.e., does the article present a positive, negative, or fully balanced perspective on community residence development)

The conclusion of this process provided a concise summary of the nature of the press coverage of each of the targeted residences and a sense of the atmosphere at the time of the residential program development. Comparisons based on dominant anecdotes, editorial tone, general tenor of articles, amount of coverage, and major themes were drawn between all of the sites under study. This will allows the project to distinguish any aspects of press coverage which differentiate a particular residence or group of residences.

RETROSPECTIVE STUDY OF INDIVIDUAL PLACEMENT PROCESS

A review of DMR regulations, manuals, and policy statements (the formal system) provides an overview of how the process of individual planning is supposed to happen. However, a real understanding of how decisions are made regarding community placement can only emerge from examining how the process has actually worked in the lives of specific individuals. A major strength of a case study approach, used in this studies, lies in this ability to highlight the difference between how something is ideally supposed to happen and how it actually occurs. The distinction between the ideal and the reality of individual placement may be particularly important for understanding the difference between a residence which has encountered few problems and one that has had massive difficulties. The placement process review is also sensitive to whether sufficient community support services were planned for and are being received. Further, it is able to draw attention to the efficacy of quality assurance measures.

Identify 2 individuals in each targeted setting

To accomplish this task two individuals residing in each of the 6 targeted community residences were selected by random drawing. Achieving an objective of understanding the placement process requires the examination of confidential records and interviews with friends and relatives of the residents. Therefore, the informed consent of the identified residents and/or their legal guardians was obtained. Within the two weeks after the approval of this design the residents whose placement records are to be examined was identified. The purpose of this study, the uses which will be made of the information obtained, and reassurances that no individual will be able to be identified from project notes or reports was explained to the responsible parties. They were asked to sign an informed consent form (see Attached) giving this project free access to all relevant records and authorizing state and agency employees to discuss the individual in question with

project staff. This permission was obtained for all of the individuals identified in the initial drawing.

Review case records

The case record for each of the identified individuals was reviewed for all records relating to the decision to place the person in the residence under examination. Specifically the selected files were reviewed for

1) The Overall Plan of Service in which the person was identified as a candidate for a community residence
2) The Overall Plan of Service which actually planned for the person's move
3) The Transition Plan formulated for the move
4) The Transition Checklist for the move
5) Revised Overall Plans of Service which reflect the person's adjustment to the new residence or problems with the new placement
6) Case notes, meeting notes, and correspondence that bear directly on preparation for, implementation of, and follow-up on the person's move to the site.
7) A list of all the people who were involved as members of the Interdisciplinary Team or otherwise involved in planning for the person's move.
8) Indications that basic quality assurance procedures have been implemented, including: client's being informed of their rights; utilization and follow through on appeal procedures; reviews of medication and behavioral interventions; and, in the case of class members, individual case reviews

From this information, a profile was developed for each individual of all the considerations that went into the placement decision. This profile focused on such factors as the special needs of the individual and the capacity of the residence and the surrounding community to meet those needs.

Interview key actors involved in the individual placement process

All of the people identified in the previous activity as major actors in planning for the person's move were interviewed. This included parents, other relatives, DMR regional staff, residential agency administrators, case manager, residential service workers, staff from the individual's previous place of residence, day program representatives, and others IDT team members. In all interviews it was be made very clear that the primary concern is on the placement process and on the individual whose case is being examined. These interviews focused directly on the respondent's recollection of the decision to place the individual under consideration. In particular, they were asked to outline the major factors which contributed to this placement decision (an individual placement interview guide is

attached). Any new information gained during these interviews was used to supplement the placement process profiles developed from the review of files.

Key actors were also be asked to describe and evaluate the community support services available to residents. They also addressed the adequacy quality assurance mechanisms. The interview guide lists the questions that were asked of key informants.

Interviewees were also asked to identify all others who were involved in the placement decision. This acted as a check to assure that the list of people identified using the case records is complete. Individuals not mentioned in the case records but mentioned in the interviews were also contacted for an interview.

Synthesize information on individual placement

A profile of the placement process was developed based on each source of information (i.e. administrator interviews, procedures manuals, case record reviews, interviews with parents, relatives, and non-professional staff). These profiles outlined all of processes and considerations that went into the decision to place an individual in a particular residence. They were organized chronologically according to the sequence in which events actually occurred and/or were "supposed" to occur. These profiles were then compared several ways to see if any pattern of differences emerges.

SURVEY OF RURAL SETTINGS

In response to the concern of the project advisory committee that the six case studies would not address the special problems of community residence located in more rural regions of the state a component was added to the original study. To assess whether or not there are issues related specifically to the development of community residences in rural sites, phone interviews were conducted with five such residences -- two in Region 1, two in Region 5 and one in Region 3. Providers with rural homes were identified through DMR regional offices. These providers were contacted and asked to select a home which they felt, was situated in the most rural location. An interview guide (see attached), drawn from the already designed guides for the case studies, was formulated to guide this process. For each home, the executive director, house manager and DMR case manager were contacted. In some cases, as available and as information warranted, an advocate, court monitor or relative of a resident was interviewed as well. The interviews themselves ranged from 15 minutes to one hour long. The primary focus of the interview was to assess the availability of services in rural areas. Additional questions were posed about the residents' past and present relationship with neighbors and the degree to which residents were involved with the community. The analysis of this information was included with the case studies as one of the major sources of data for the conclusions of this project.

INTERVIEW GUIDES

COMMUNITY MEMBER INTERVIEW GUIDE

Topics to be discussed with all *community* respondents

What do you know about the residence at ..... ?

To the best of your knowledge who lives there?

How did you first come to hear about the plans for a group home to be developed there?

The opening of the home:

- The previous owner/tenant
- Notification of the neighbors
- Changes to the property
- The residents moving in

Initial community reaction:

- How did neighbors react
- Did any neighbors do anything to actively hamper the opening of the home
- Did any neighbors do anything to assist the opening of the home
- How did public officials react

Personal reaction:

- How did you feel about the plans for the opening of the house? Why?
- What was the greatest cause for concern?
- Has that changed over time? Why?

What events relative to this home made the greatest impression on you?

In general, what has the impact of community residence development been on your community?

How would you characterize the situation around the home now?

Based on your experience how could the process of selecting and developing sites for this type of supported living situation be improved?

Who else should we talk to who is knowledgeable about the issues related to the development of this community residence?

Topics to be discussed with neighbors
(In field notes indicate location of home relative to the community residence)

How long have you lived here?

How has the presence of the community residence effected your neighborhood? *(Probe for concerns regarding safety, "character of the neighborhood, traffic, behavioral incidents, appearance of the building*

Has the presence of the community residence i any way effected your life style (i.e., Do they do anything differently because of the presence of the home)

Do you often see the people who live in the community residence in the neighborhood, around the community? In what context?

Do you know any of the people who live/work in the community residence *(Probe to get a sense of how well they know people--do they recognize people on the street, do they know them by name, have they ever been in the community residence)*

Topics to be discussed with generic service providers and community merchants (including transportation)

Do the people living/working in the residence make use of your services?

If yes, what has kind of an impact have they have on your service.

If no, why not?

Have you had to make any special adaptation/modification to your services because of the community residence?

Has the presence of the residents or their demand for services presented your agency with any particular problems.

Topics to be discussed with public officials (selectman, commissioners, mayors, legislators, etc.)

Based on your knowledge and your experience with your community, why do you think this residence (encountered opposition) or (was well accepted).

What has been the nature of your involvement with the community residence?

What do you feel should be the proper level of involvement for some one in your position?

What was the result of your involvement

How and why did this involvement come about?

Do you think there are adequate means in place to ensure quality services in the home?

Do you feel that sufficient effort goes into assuring that the residents of the home have accesses to the resources of your community?

Topics to be discussed with local fire, water, health, & police officials

Has the residence had any impact on you services? Describe.

Does your agency do anything special because of the residence?

Did you or members of your agency have any involvement in the planning or development of the residence?

Should you have more/less involvement? Why?

Did you have any complaints about the residence during the first 6 months it was opened?

What was the nature of the those complaints?

How has that changed over time?

Do you think residents receive enough services/supports to ensure a safe and healthy environment for them and their neighbors?

Topics to be discussed with local Realtors

Have you ever been involved as agent for the seller or the buyer in a transaction in which an agency is developing a community residence?

If so please describe that experience

From your experience as a Realtor what works well and what needs improvement in the process of community residence development?

Has the presence of community residence had any impact on the value of real estate in the immediate vicinity

Do you deal with the presence of a community residence in the vicinity when you are show a house? If so, how?

Do you give any special advise to people selling a house near a community residence?

GUIDE FOR INTERVIEWS OF RESIDENTS, PARENTS, GUARDIANS & ADVOCATES

Topics to be discussed with residents and their parents/guardians

When did you first become aware of the plans for (you/focal person) to move into the house at ..... ?

Tell us the history of how ..... came to live in this home:

Who was responsible for bringing it about?

Tell us about the IDT planning process

Were services (day, health, transportation, recreation, etc.) adequately prepared before transition?

Are they adequate now?

What resources in the community does ..... use?

Are there any services/resources in the community which ..... would like to use or has tried to use that were not open to him/her

Are there any services/resources in the community which ..... would use but are not available in this community?

What was the greatest problem encountered?

What worked best in the process?

What was the best result of the move?

Do you feel that ..... is part of the community in which he/she lives? Why?

Do you feel that there is adequate oversight (quality assurance) in the residence where ..... lives?

Do you think residents receive enough services/supports to ensure a safe and healthy environment for them and their neighbors?

Do you feel there are adequate resources available in the home where ..... lives (e.g., staff, supervisors, consultants, housekeeping, dietary, training, etc.)

Based on your experience how could the process of selecting and developing sites for this type of supported living situation be improved?

Based on your experience how could the process of individualized planning as it relates to residential placement and transition be improved

Do you feel that you have sufficient control over decisions effecting (yourself) (your family members) (the person for whom you advocate)?

Who else should we talk to who is knowledgeable about the issues related to .....'s placement in this residence?

GUIDE FOR INTERVIEWS OF SERVICE PROVIDERS

Topics to be discussed with all respondents who are involved with the system of formal service provision

Recount your recollection of the chronology of events leading up to the opening of the residence at .....

How was community entry handled?

What was your level of involvement?

How do you account for the level of community acceptance/resistance encountered at this site?

Do you have enough input into the individual planning processes?

Who best represents the client's interest in the planning process?

Based on your experience how could the process of selecting and developing sites for this type of supported living situation be improved?

Based on your experience how could the process of individualized planning as it relates to residential placement and transition be improved

Who else should we talk to who is knowledgeable about the issues related to ..... placement in this residence?

Who else should we talk to who is knowledgeable about the issues related to the development of this community residence?

Topics to be discussed with case mangers and other IDT team members

Tell us the history of how ..... came to live in this home:

Who was responsible for bringing it about?

Tell us about the IDT planning process

Were services (day, health, transportation, recreation, etc.) adequately prepared before transition?

Are they adequate now?

What resources in the community does ..... use?

Are there any services/resources in the community which ..... would like to use or has tried to use that were not open to him/her

Are there any services/resources in the community which ..... would use but are not available in this community?

What was the greatest problem encountered?

What worked best in the process?

What was the best result of the move?

Do you feel that ..... is part of the community in which he/she lives? Why?

Do you feel that there is adequate oversight (quality assurance) in the residence where ..... lives?

Do you think residents receive enough services/supports to ensure a safe and healthy environment for them and their neighbors?

Do you feel there are adequate resources available in the home where ..... lives (e.g., staff, supervisors, consultants, housekeeping, dietary, training, etc.)

Topics to be discussed with residential staff

What type of people live in this home? (focus on behavioral and health related issues)

How much do they interact with the neighbors

What is the staffing pattern?

Are there any problems with parking or traffic?

How does the house relate to the neighbors?

Has up-keep of the property been a problem?

Has the house had any incident involving health, police, or fire authorities?

Has the agency made any changes to the property?

Have there been any behavioral or other incidents in the neighborhood which have caught the attention of the neighbors?

Do you feel there are adequate services available for the residents in the community?

What types of audits and other quality assurance activities regularly take place in this residents?

Topics to be discussed with DMR regional staff

How much planning actually went into the selection of this particular location as an appropriate site for a community residence?

How much consideration was given to the specific needs of individuals in planning for the opening of this residence?

In the case of (A specific resident) how much consideration of his/her unique needs went into the decision that he/she should live at this location?

How much did you coordinate with other agencies in selecting this site?

To what extent were you involved in the opening of this site?

How did the regional office assist the provider in dealing with the resistance which was encountered?

Topics to be discussed with day program providers

When did you become aware that a new residence was being developed that would provide you with new clients or When did you become aware that a new client *(with reference to the specific case of the focal person)* for your service was moving into your service area?

Were you satisfied with that amount of notification?

What was your degree of involvement in planning for the transition of ..... into your agency?

Are you satisfied with that level of involvement?

From your perspective how can the individual planning process, especially as it relates to transition and the need to develop day services, be improved?

Did the opening of this (or any other) residence have an impact on the quality of life of other people with mental retardation in your community?

In your service to what extent do you utilize generic community services? Please give some specific examples as they related to ..(the focal person)..

Topics to be discussed with residential property developers
(In some cases this may be representative of the agency that runs the residence)

Why was the site at ..... selected for development as a community residence?

Was this home built or were renovations made?

What other factors went into this decision?
(Probe for consideration of
1. *Accessibility of generic community services*
2. *Availability of specialized services*
3. *Unique needs of people targeted to live in the setting.*
4. *Saturation issues*
5. *Renovation issues*
6. *Availability of affordable real estate in the area)*

Please describe the full chronology of events leading up to the opening of the residence at ..... ?

What were the major problems encountered in this development?

Were any of these problems unique to this site?

During this process of development who or what were your greatest assets/aids in the community, in the agency, in DMR?
Why?

During this process of development who or what were your greatest barriers in the community, in the agency, in DMR?
Why?

Did the people who were selected as the original residents of the site play any role in the process?

CONNECTICUT CASE STUDY GUIDE

CONNECTICUT STUDY GUIDE FACE SHEET/EYEBALL SURVEY

Residence name & address

Number of clients, sex, age range, day placements

Client functioning levels, physical/medical disabilities, types of behavioral challenges

Staffing pattern: # of staff on duty per shift, live-in or live nearby or other, staff interaction with neighbors?

EYEBALL SURVEY

Is the home in the middle or corner of the block; quiet or trafficked street

Is home conspicuous? (signs, alarms, ramps, odd architecture in relation to surroundings, other)

How does upkeep of property compare with environs?

How is parking handled?

KEY INFORMANTS INTERVIEWED:

COMMUNITY MEMBERS:

NEIGHBORS: _____

_____

_____

_____

_____

REALTOR _____

MERCHANTS _____

_____

PUBLIC OFFICIALS:

ELECTED: _____

_____

_____

POLICE _____

FIRE _____

SANITATION _____

HEALTH _____

ZONING _____

PLANNING _____

GENERIC COMMUNITY RESOURCES
(Identified as used by residents OR located in proximity to the residence.
FOR EXAMPLE: YMCA, COMMUNITY HEALTH CLINICS)

_____

_____

_____

_____

_____

_____

SPECIALIZED PROGRAM PROVIDERS

SPECIAL EDUCATION _____

_____

VOCATIONAL _____

_____

OTHER (RECREATION ETC.)

_____

_____

RESIDENTIAL PROVIDER STAFF

AGENCY ADMINIS. _____

ORIGINAL MANAGER _____

PRESENT MANAGER _____

DIRECT CARE STAFF _____

_____

_____

DMR STAFF

REGIONAL DIRECTOR _____

ASST. DIR FOR RES SERVICE _____

PLANNER _____

ASST. DIR FOR
VOC SERVICE _____

LIAISON WITH
SCHOOLS _____

SITE DEVELOPERS:

AGENCY
ADMINISTRATOR _____

PERSON RESPONSIBLE
FOR SITE _____

PERSONS INTERVIEWED RE INDIVIDUAL PLANNING PROCESS
(2 FOCUS PERSONS PER SITE)

FOCUS PERSON: _____

NON PROFESSIONALS

FOCUS PERSON _____

PARENTS, ADVOCATES or GUARDIAN _____

_____

_____

PROFESSIONAL IPT TEAM MEMBERS (AS IDENTIFIED IN FILE)

CASE MANGER _____

_____

POSITION:_____

_____

POSITION:_____

_____

POSITION:_____

_____

POSITION:_____

_____

POSITION:_____

_____

POSITION:_____

_____

ALL INDIVIDUAL FILES SHOULD BE REVIEWED FOR THE FOLLOWING ITEMS:

1) The Overall Plan of Service in which the person was identified as a candidate for a community residence

2) The Overall Plan of Service which actually planned for the person's move

3) The Transition Plan formulated for the move

4) The Transition Checklist for the move

5) Revised Overall Plans of Service which reflect the person's adjustment to the new residence or problem with the new placement

6) Case notes, meeting notes, and correspondence that bear directly on preparation for, implementation of, and follow-up on the person's move to the site.

7) A list of all the people who were involved as members of the Interdisciplinary Team or otherwise involved in planning for the person's move.

8) Indications that basic quality assurance procedures have been implemented, including: client's being informed of their rights; utilization and follow through on appeal procedures; reviews of medication and behavioral interventions; and, in the case of class members, individual case reviews

RURAL SITE INTERVIEW GUIDE

CONNECTICUT INTERVIEW GUIDELINES FOR RURAL SITES

GUIDELINES FOR TELEPHONE INTERVIEWS WITH EXECUTIVE DIRECTOR, HOUSE MANAGER, ADVOCATE, DMR CASE MANAGER.

Provider Agency:

Residence Name and Address:

Date of opening:

Description of location, acreage, nearest neighbor:

Nearest town, size

Number of clients, sex, age, day placements:

Residents' functioning level, physical/medical disabilities, type of behavioral challenges, clients on psychotropic medication:

Relationships with neighbors:

Accessibility of nearest town, access to stores, recreational facilities, etc.:

Transportation used:

Fire and Police Depts, aware of home, ever called, relationship?

How is medical care, eye care, dental care provided? Hospital used? (distance from home, home visits, able to handle client's disability, difficulty in obtaining services, etc)

How are occupational, physical and other therapies provided?

Are psychological, psychiatric, specialized behavioral consults provided?

Are there other specialized therapies provided? Are there are others which you wish were available?

Are there any persistent difficulties in obtaining health and habilitative services?

How many residential staff members work at the home? Difficult to recruit?

Are residents in a day program? Location, nature, hours?

Was the availability of services considered when the location of the home was chosen?

Are the quality and quantity of services available to adequately meet clients' needs? What is needed?

What resources in the community do the clients use?

Are there any services/resources in the community that you would like residents to use that are not available in this community?

What quality assurance mechanisms are in place for the home?

Do you have any comments, suggestions, problems about the availability of services for the clients in this home? Any other concerns about having a home in a rural area?

INFORMED CONSENT FORM

PERMISSION TO CONDUCT INTERVIEWS, REVIEW CASE FILES, AND DISCUSS CASE HISTORIES

The Connecticut Office of Policy and Management has contracted with Human Services Research Institute (HSRI) to conduct a study requested by the State Legislature. This study is intended to provide an evaluation of the impact of the deinstitutionalization of people with mental retardation on 1) Communities, 2) Services available in the communities, and 3) The quality of such services.

As one method for conducting this study HSRI is examining the processes used when a person is placed in a supported living arrangement such as a group home. To do this it is necessary to review how the process of placement occurred in the lives of specific individuals.

We are asking for your cooperation and assistance in this part of the study. We would like to review the placement process as it was implemented in (your life) (the life of your child) (the life of the person for whom you are the guardian). Specifically this means that by signing this form you are giving the staff of this project permission to:

- o Review all case record relevant to the placement of the person named below in his/her current place of residence;
- o Discuss this placement process with all parties involved in planning and implementing it including the individual placed (if appropriate), parents and guardians, members of the Interdisciplinary Planning Team, residential staff, and day program staff; and
- o Discuss the success of this placement and current services needs of the named person with staff currently working in his/her residence and day program

****

I give permission for the Staff of Human Services Research Institute to conduct a review

of the placement of _____

in the residence at _____

administered by _____

I give this permission with the understanding that:

1. This study is examining the placement process and is not studying the people effected by this process

2. This study will be conducted as outlined above;

3. All information collected for this study will be kept confidential: All information collected under this part of the project will be compiled and reported in a form that will make it impossible for any reader to identify the source of information or the person being discussed;

4. Any participant can refuse to answer any of the questions we are asked;

5. Any participant can ask the project director or any other project staff questions related to this project at any time; and

6. Results of this project eventually will be prepared as a report to the Connecticut State Legislature and disseminated throughout the State.

_____ _____

Signature Date

Relationship to person named above:_____

If the person giving this permission is a client of the Connecticut Department of Mental Retardation, the undersigned witness testifies that this process was adequately explained to the individual and they are satisfied that the person understood the nature of this permission.

_____ _____

Signature of Witness Relationship to person named

_____ _____

Signature of HSRI Representative Date

_____ _____

Signature of Project Director Date

Please feel free to call Valerie Bradley, James Knoll, or Marsha Ellison at HSRI (617-876-0426) or Susan Omilian at the State Office of Policy and Management (203-566-4478) if you have any questions or concerns about this study.

APPENDIX 2:
LITERATURE REVIEW

Introduction

This literature review was the first product of this project. Its purpose is twofold: 1) to document the literature on the impact of group homes on property values and related concerns, and 2) to ascertain the variables reported in the literature that bear on community acceptance patterns. Because the impact on property values has been extensively studied by other researchers, and does not warrant replication, the presentation of the findings of the literature obviated the need for this project to conduct another complex and costly study on property values. The second goal of the literature review is to identify factors pertaining to community acceptance. This in turn aided the community case studies of this project.

The literature review is organized into the following sections:

- o impact of community-based homes for persons with developmental disabilities on surrounding property values and related concerns;
- o impact of such homes on crime rates, municipal services, and the "character" of the neighborhood; and
- o factors that contribute to initial community acceptance or resistance to the establishment of the residence.

Impact of community-based homes for persons with developmental disabilities on surrounding property values and related concerns

Despite generally positive public attitudes toward persons with developmental disabilities and the values that prompt deinstitutionalization efforts (President's Commission on Mental Retardation, 1975; Kastner, Ruppucci, & Pezzoli, 1977; Roth & Smith, 1983), adamant community resistance sometimes surrounds the establishment of particular homes.

Attitude surveys prior to the establishment of a given residence do not test how residents will respond to an actual home. Persons may respond to attitude surveys according to perceived social desirability rather than by genuine feelings. This is illustrated by Zultowsky and Farina (1988). They asked a sample of Connecticut residents how they feel about the integration of children with mental retardation into their homes and schools. Then respondents were asked how they expected their neighbors to respond to the same issues of integration. There was a statistically significant difference between the more liberal attitudes espoused by the respondents themselves and how respondents expected their neighbors to feel. This suggests that the "social desirability" effect was operating and that despite surveys that report positive effects,

planners can expect to encounter substantial community opposition to deinstitutionalization.

It has been suggested that as much as one-third to one-half of residential facilities have encountered such opposition and that an unknown number of other facilities were effectively stopped by the host community, (Scott & Scott, 1980; Sigelman, Spanhel, & Lorenzen, 1979; Berdiansky & Parker, 1977; Sandler & Robinson, 1981). Numerous strategies are employed by host communities to prevent the opening of new residential services. Among the most effective is use of restrictive zoning laws to block the residence. (These practices have been tested in numerous court cases, see Schonfeld [1985] for a comprehensive summary). Other efforts include stringent oversight by fire and other regulatory agencies, involvement of local government, media attention, and outright sabotage. Often substantial public resources are spent by state and contracted agencies to counter these activities. Community resistance to residential services revolves around a core set of fears and uncertainties by local residents. For example, neighbors fear health and safety risks to their families, demands on local community resources, increased crime rates, and an impact on the overall character of the community (Sigelman, Spanhel, & Lorenzen, 1979; Lubin, Schwartz, Zigman & Janicki, 1982; Berdiansky & Parker, 1977).

Foremost among these concerns is property values. Local residents often fear that the proximity of the group home will adversely affect property rates, will increase property turnover and the length of time required to sell property. A great deal of research has focused narrowly on this concern and the evidence is unequivocal that the presence of group home has no effect on community property values, or turnover rates. Research has been done in many areas across the U.S. and Canada and in communities reflecting a range of socio-economic status. Despite different research designs and methods of measurement, the findings consistently show no adverse effects. Moreover, some studies have employed real estate boards and other independent parties to lend further credibility to findings (Mambort, Thomas, & Few, 1981; Edwin Michaelian Institute, 1988).

Eighteen studies on the impact of property values were reviewed for this report. Of these six dealt specifically with group homes for persons with mental retardation or developmental disabilities. A capsule description of each of these six studies follows.

Dolan, L. & Wolpert, J. (1982) *Long term neighborhood property impacts of group homes for mentally retarded people.* Princeton, NJ: Princeton University, Woodrow Wilson School of Public Affairs.

This study updates a previous study done by the authors in 1978. It analyzes market process and turnover rates for properties neighboring thirty-two group homes in eight New York state communities. The updated study allowed an investigation of property sales in five years subsequent to the citing of the sampled homes. Using multiple regression

techniques, the study analyzed property transactions before and after establishment of the group homes and compared these to a set of matched control sites. The analysis indicated that proximity of neighboring properties to a group home does not affect their market values in the short or long term and that establishment of the group homes was not associated with higher property turnover rates in the short or long term.

Edwin G. Michaelian Institute for Sub/Urban Governance of Pace University. (1988). ***Group homes for mentally disabled people: Impact of property values in Westchester County, New York.*** **White Plains, NY: CRISP.**

This study replicates the methodology described above (Dolan & Wolpert, 1982) but focused on a sample of 17 group homes all within Westchester County, a largely upper middle class to wealthy community. The study was conducted in collaboration with the Westchester County Board of Realtors. The study shows that group homes have no adverse impact on the property of neighboring homes within 600 yards of the group home. Moreover, property turnover rates were low in areas surrounding the group homes.

Wiener, D. Anderson, R. & Nietupski J.. (1982). Impact of Community-based Residential Facilities for Mentally Retarded Adults on Surrounding Property Values Using Realtor Analysis Methods. ***Education and Training of the Mentally Retarded,*** **17, 278-282.**

In two medium sized Iowa communities, this study compared the selling prices of eight homes within a one-block radius of a group home, with the selling price of matched homes of comparable value (as determined through realtor analysis methods) sold in the same time period but not situated in the proximity of a group home. All homes were sold within 3.5% of the average selling price of the matched homes, except for two homes which were sold above the range of selling prices of the matched homes.

Minnesota Developmental Disabilities Program. (1982). ***Analysis of Minnesota Property Values of Community Intermediate Care Facilities for the Mentally Retarded.*** **St. Paul, MN: Dep't. of Planning Energy and Development**

This study compared the assessed property values of neighborhoods with a group home for the year proceeding and the year following the establishment of the home. Changes in these values were compared to changes in similar neighborhoods without group homes. Overall, neighborhoods group homes had a mean percent property value increase of 25.9% and those without homes increased value by 26.7%. These differences were not statistically significantly different. Moreover, the number of properties sold in the differing neighborhoods were virtually the same suggesting that group homes do not cause an undue rise in property turnover.

Lindauer, M., Tung P., & O'Donnell F. (1980) *The effect of community residences for the mentally retarded on real-estate values in the neighborhoods in which they are located.* Brockport, NY: State University of New York.

This study examined neighborhoods around seven group homes in New York opened between 1967 and 1980 and two control neighborhoods. It found: the presence of group homes had no effect on selling prices; some "panic" selling of homes occurred just before group homes opened; no decline in selling prices; no difficulty selling homes; and no decline in property values on increase in turnover after homes opened.

Lauber, D. (1986). *Impacts on the surrounding neighborhood of group homes for persons with developmental disabilities.* Chicago, IL: Governor's Planning Council on Developmental Disabilities.

This study examined the impact of 14 group homes in municipalities with differing population density. The average sale price of all residential ownership sales within a five block radius was compared for two years prior to and subsequent to the homes opening. Change in sale prices were also compared with changes in a "control" neighborhood. Data strongly indicated that group homes did not effect surrounding property values and the mean sale price after group homes were opened was unrelated to opening the group homes. The study also found that group homes do not engender an increase in property turnover rates.

As mentioned, all of the above studies focused entirely on residences for persons with developmental disabilities. It is important to note that numerous studies have replicated these findings for other populations as well (City of Lansing Planning Department, 1976; Linowes, 1983; Wagner & Mitchell, 1980; Breslow, 1976; Dear & Taylor, 1982; Knowles & Baba, 1973). These latter studies reviewed the impact of community homes for populations including juvenile delinquents, the mentally ill, and former prisoners and found no effect on property values for any of these types of facilities. The Mental Health Law Project (1988) maintains an annotated bibliography on the effect of group homes on neighboring properties for all populations. Another compilation of studies on property values and related concerns about group home development is available from CRISP (1986). Nearly every study reports no impact on property values, turnover rates, or the length of days on the market. Given these consistent findings, concerns about adverse effects on property can be confidently dismissed.

Impact of Homes on Crime Rates, Municipal Services, and the "Character" of the Neighborhood

The resistance to community-based facilities is most often voiced in terms of property values. However, other fears are often voiced by concerned

neighbors including: neighborhood safety and impact on neighborhood "lifestyle" or character usually because of increased traffic, noise, use of municipal services, and/or unkempt appearance of the property. All of these issues have received less extensive examination than the issue of property values, but there is persuasive evidence that these fears are ungrounded as well. The following studies address these concerns:

Dolan & Wolpert (1982) *Long term neighborhood property impacts of group homes for mentally retarded people.* Princeton, NJ: Princeton University, Woodrow Wilson School of Public Affairs.

This study compared 32 homes in New York State to its neighbors on the same block for conspicuous building structure, modifications, condition of the house and yard, visibility of residents and/or staff and the number of parked cars. The study found that few homes are conspicuous along these measures, and moreover that the homes are generally well-maintained, the condition of the homes are consistent with adjacent dwellings, and there was no relationship between conspicuousness of the group homes and property value or turn-over rates.

Lauber, D. (1986). *Impacts on the surrounding neighborhood of group homes for persons with developmental disabilities.* Chicago, IL: Governor's Planning Council on Developmental Disabilities.

This study conducted an assessment of whether persons with developmental disabilities who live in the community pose any threat to neighborhood safety. They researched the number of times group home residents were accused of and were convicted of crimes. This was expressed in a rate of number of crimes per 1,000 persons and was then compared to the crime rate per 1,000 persons of the general Illinois population. The crime rate of persons with developmental disabilities living in group homes was substantially lower than the crime rate for the general population. Criminal behavior among persons with developmental disabilities who live in group residences generally involves minor crimes against property, disturbing the peace or disorderly conduct.

Mambort, T.; Thomas, E. & Few R. (1981). *Community Acceptance: A realistic approach.* Dayton OH: Montgomery County Board of MR & DD.

In this study a professional appraiser was hired to study the impact of seven group homes located in Montgomery County, Ohio. The appraiser found that the homes were consistent with and compatible to neighboring properties, the group homes were better maintained than the surrounding properties, residents of the home were generally not visible or noticeable from the street and the nature of the home's purpose is not conspicuous from the street.

The results of studies based on other populations concur with these findings. A San Francisco study of group homes found that noise levels, traffic

volume and parking demand did not seem unusual for a residential neighborhood (cited in Lauber & Bangs, 1971). Moreover, crime rates do not rise in communities surrounding group homes for other populations (Empey, Newland, & Lubeck cited in Lauber & Bangs, 1974; Sigelman, 1979; Teplin, 1985).

Despite limited empirical research on these issues, other evidence suggests that these concerns are "non-issues." Several studies have noted that despite resistance to community-based residences, once a residence is opened community opposition withers and disappears (Lubin, Schwartz, Zigman, & Janicki, 1982; O'Connor 1976, Conroy & Bradley 1985, Sigelman, 1979). These studies suggest that acceptance grows as neighbors have actual contact with persons with developmental disabilities. Fortified with this understanding, advocates of community-based services have wrestled with how to best secure community support and deflect opposition based on unsubstantiated fears. The next section of this review examines these efforts.

Factors that Contribute to Initial Community Acceptance or Resistance to the Establishment of the Residence.

While the data consistently indicates that group homes pose no threat to property values or the safety and well-being of neighbors, the opening of new homes nonetheless continues to meet strong opposition in some communities. As a result, planners wrestle with how community development can best proceed in a way that minimizes neighborhood resistance. The literature provides some guidelines.

An early investigation was conducted by the Association for Developmentally Disabled in Ohio (1982). Based on surveys of operators of the home and neighbors nine factors were described that affect community acceptance. The factors are:

- The number of similar homes already in place in a neighborhood (neighborhood saturation);
- Transiency of the host neighborhood (transient neighborhoods are less likely to present opposition);
- Amount of local traffic (homes sited on streets with moderate traffic experience less opposition);
- Previous use of the homes (those homes previously occupied by nuclear families are more likely to be opposed);

- o Age of neighbors (younger neighbors are less likely to oppose the group home);
- o Single income neighbors (neighbors of single income households are more likely to oppose the residence);
- o On-street parking (facilities that use on-street parking as opposed to parking lots on the property are less likely to be opposed);
- o Male residents (homes of male rather than female residents are more likely to be opposed);
- o Amount of staffing (there is a moderately positive correlation with the number of staff employed and the degree of community acceptance).

Another issue that has received some attention is the size of the facility. Holmes (1979) concludes that community reaction is more positive toward apartment clusters than toward group home development. In a survey of attitudes and policies of local planning and zoning officials, most respondents indicated that limiting the size of the group home was the most important local consideration (Jaffe & Smith, 1986). This report seconded the importance of adequate dispersion of group homes in a given community.

Another study by Sigelman (1976) provides a different set of factors. Based on a survey of 655 adults of sentiments toward persons with developmental disabilities, a profile of demographic variables related to likely acceptance to group homes was generated. There was a strong inverse relationship between age of the respondent and willingness to accept group homes. Blacks were more positive than either Anglos or Mexican-Americans. Frequent churchgoers, persons who rented homes, and persons who label themselves as liberals were all also more accepting to community-based residences. Berdiansky & Parker (1977) echo this interpretation when they suggest that "less concern over community relations could be given to heterogeneous neighborhoods in the inner city and transitional zones. Residents in such areas often live with a great diversity of 'deviance' or possess little community pride or loyalty" (p.10). Finally, Seltzer (1984) provides evidence that community opposition was higher in neighborhoods that consisted primarily of homeowners and when the property value of the residence was higher.

However, the implications of these findings are disturbing, since tney suggest that community residences should be cited in black or ethnically mixed neighborhoods, comprised of mainly young adults who rent rather than own homes and who coexist with substantial "deviance." Certainly this limits the number of communities a planner might search in and moreover, it defeats some of the main principles of normalization.

Weber (1978) offers another set of characteristics that influence community development:

- o Neighborhood variables;
  - * cohesion and family orientation of community
  - * history of neighborhood organization
  - * leadership in the area
- o Sponsoring agency variables; and
  - * Auspices
  - * Agency credibility
  - * Agency experience in the field
- o Legal variables (i.e., how solid is the legal basis of the home)

Weber offers the following suggestions in promoting community acceptance:

- o have a thorough knowledge of the neighborhood;
- o have a sound legal basis;
- o organize a neighborhood educational plan and materials well in advance of entry;
- o in educating neighbors be clear and straightforward;
- o avoid large group meetings with neighbors;
- o assign the group home parents to the job of educating neighbors;
- o don't promise there will be "no problems" from clients;
- o educate important persons in advance;
- o don't expect complete support at once;
- o execute a "good neighbor" plan;
- o be respectful of neighbors.

Rather than trying to figure out which type of community or type or residence will engender the least opposition, another approach is suggested in the literature. This is whether opening facilities should make a "low" or "high

profile" entry into the neighborhood. Seltzer (1984) offers this description of the two approaches:

> In the high profile strategy, community members are notified about the intention to establish a community residence well in advance. They are often provided with educational material about mental retardation, deinstitutionalization, normalization, etc. and may be invited to participate in the development of the facility. In the low-profile approach, the community residence is established as inconspicuously as possible. Community members have the opportunity to become acquainted gradually with clients and staff members. (p. 2)

Proponents of the high-profile approach recognize that there is no actual basis for most of the fears of local residents, and that community acceptance grows with actual contact and understanding of persons with developmental disabilities. For example, Kastner, Repucci & Pezzoli (1979) demonstrate that persons with more favorable attitudes toward others with mental retardation either desired contact with persons with mental retardation or who had otherwise had some contact with persons with disabilities or had been exposed to information on mental retardation. Planners have concluded that community opposition can be deflected by offering contact with persons with developmental disabilities and by public education on the matters that concern local residents prior to opening homes. For example, two Florida agencies have recently conducted a campaign entitled, "Group Homes: It's a Family Matter" that is to be targeted to persons who influence local policy making and to likely neighbors of future group homes. The campaign includes videotapes, fact sheets and other media presentation. The purpose of the campaign is in part to foster support for liberalizing a state zoning law.

In a handbook on community development (Normann & Stern, 1988) agencies are advised to: schedule a Neighborhood Information Meeting, initiate a "door-to-door" canvass of the neighborhood, prepare a press release and information packet, and notify key local government officials.

In addition, some supporters of the high profile approach feel that the community has a right to know in advance about any planned facilities and that community opposition is fostered by a surreptitious approach (Berdiansky & Parker, 1977). For example, Kastner, Repucci, and Pezzoli conclude their report of a survey on community attitudes by saying:

> ... the next goal in the field should be to encourage public education and facilitate community integration to move actual sentiments more in line with survey responses. Based on the present findings, the best approach to this goal would be to promote as much public exposure as possible, both through information modes such as public campaigns and literature and through increased contact among mentally retarded people and their neighbors in the community. (p. 143)

The authors are careful to point out earlier in the study that contacts actually need to be structured to insure positive interaction between neighbors with and without disabilities.

Advocates for the low-profile approach, on the contrary, argue that prior public education and exposure may be more apt to rouse community opposition rather than to quell it and that communities will grow accepting of the home once they have actual exposure to it. Moreover, they argue that persons with developmental disabilities have no more obligation to inform neighbors of their intention to reside in their locale than does any other group of persons.

One of the earliest arguments for the low-profile approach is described by Berdiansky and Parker (1977):

> One popular way to establish a group home is to use the Machiavellian approach: the developer makes secret arrangements for the project and then presents the group home to the community as a *fait accompli*. When neighbors see the home in existence, they may realize that the residents are basically harmless and that any resistance would be fruitless. Advocates of this approach see extensive preliminary public relations and neighborhood canvassing as counter-productive and encouraging open discussion of controversial and organized resistance. (p.10)

For example, Baker, Seltzer, and Seltzer (1974) report that group homes that attempted to prepare and educate the community prior to opening were also more likely to report community opposition. In a subsequent study by Seltzer (1984) community residences that conducted public education were statistically more likely to encounter opposition than did a matched group of facilities that did not encounter opposition. Moreover, there was no difference in the likelihood of encountering opposition if the residence employed a site-selection committee which included local neighbors, including local residents on the board of directors of the residence, or by having staff members specifically designated to public relations. Moreover, opposition was least likely to be encountered when the community became aware of the existence of the residence after it had already been in operation and most likely when the community learned about the planned residence during the six month period before it opened. The author concludes that public education efforts may have unintended negative consequences and may provoke rather than minimize opposition. Berdiansky and Parker (1977) likewise conclude that community objections to group homes were not allayed despite frequent and lengthy meetings with neighbors.

One way to understand how public education may foster community opposition is by recognizing that neighborhood meetings can provide a forum for the ventilation of fears that would otherwise be kept private. Ambivalent parties can be swayed by outspoken neighbors who are opponents. A public meeting itself can provide a means for organizing opposition. Sigelman (1976) reports that despite the favorable attitude possessed by the majority of

neighbors prior to opening a home, one intense critic was subsequently effective in swaying opinions and rousing community opposition.

An alternative to the low or high profile debate is offered by Weber (1978). Based on his experience of developing 30 group homes for children he describes a third strategy of community entry called "informing the select few". In this approach "certain local residents are informed and educated, as well as agency and government officials." Weber emphasizes educating those persons who are most concerned, and setting up channels of information that respond quickly to any expressed concerns.

Conclusions

Based on substantial evidence, it can be confidently concluded that community-based residential services for persons with developmental disabilities pose no threat to local property values, turnover rates, or the time required to sell property. The existing research also suggests that group homes likewise pose no threat to community safety or to community "character."

The literature gives less direction in determining those factors that contribute to community opposition. Although it appears that opposition is less likely to occur among neighborhoods of lower income, lower property value, with greater transiency, of mixed racial composition, and with a younger population, this would hardly justify the siting of group homes exclusively in neighborhoods of these characteristics.

Other variables contributing to community acceptance that are highlighted in the literature are: size of the facility, relative neighborhood saturation, amount of traffic and types of parking used by the facility. However, more studies would have to be done to substantiate the importance of these variables.

The literature on community attitudes is equivocal, stating that although positive attitudes may be voiced, the actual response of neighbors to a group home can be very resistive. Public education and contact with persons with disabilities, although the logical response to this dilemma, may actually provide a greater forum for the organization and fomentation of community resistance. The low profile approach is also bolstered by the notion that people with disabilities should not be required to "ask permission" before they move into a neighborhood.

This literature review served to highlight those factors that needed to be investigated in the case studies of the impact of deinstitutionalization on communities in Connecticut. While the issue of property values can be laid to rest, the community case studies investigated impact in terms of character of the neighborhood, group home appearance, and the use of municipal services.

The third section of this review also suggested that the following aspects be investigated in the case studies: size of facility, neighborhood saturation, amount of traffic and parking usage, staffing patterns, demographics of the surrounding community, and whether community developers adopted a "low-profile" or "high-profile" approach to community entry.

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APPENDIX 3:

DESCRIPTION OF THE FORMALLY MANDATED SYSTEM OF COMMUNITY SERVICE DEVELOPMENT AND CLIENT PLACEMENT IN CONNECTICUT

DESCRIPTION OF THE FORMALLY MANDATED SYSTEM

This document presents one of the initial components of the legislatively mandated study of the development of community services for people served by the Connecticut Department of Mental Retardation. What is presented here is a "map" of the service system for persons with mental retardation in Connecticut. This system outline was constructed based on what is known in the state about siting, placement and resource development.

The formal system description was a crucial element in the total design of this project since it essentially served as the reference point, a baseline, for the community case studies. The purpose of the case studies was to determine what actually took place prior to the development of residential resources. In other words, the case study material provides factual information on what happened which can be contrasted with the formal description of what the process ought to be.

This formal system description also provided a basis for formulating the key informant interview guides which were employed during the community case studies. Elements from this formal description provided the categories that were the focus of the questions which were asked of all those interviewed during the subsequent phase of this project

The system "map" or formal system description is based on three sources of information: 1) document review; 2) review of court order; and 3) key informant interviews.

1. **Document Review.** During the initial phase of the project, staff identified all statutory, regulatory and planning documents that specify the state's procedures for the siting and development of residential arrangements in the community as well as for the placement of individuals with mental retardation in such homes. Such documents include the state laws regarding the conduct of the mental retardation system, the departmental regulations that specify the responsibilities of the various key actors in the resource development process, and policy memos that describe particular aspects of the site development and placement enterprise.

2. **Review of Court Order.** Because significant portions of the state's deinstitutionalization activities are governed by the court order in the CARC v. Thorne and Southbury cases, staff also reviewed court-mandated procedures including preliminary assessments required, content of the individual client plan, timelines for placement, nature of the residential arrangement and monitoring requirements.

3. **Key Informants Interviews.** In order to gain a more detailed understanding of the community development and placement process, relevant state officials and representatives of some of the major private agencies were interviewed including the commissioner of mental retardation, the deputy commissioner for programs, the deputy commissioner for administration, the six regional directors, the director of the division of quality assurance, DMR director of strategic planning, regional residential services staff in 3 regions, DMR consent decree coordinator, court monitor staff, representatives of the Corporation for Independent Living (CIL), representatives of Connecticut Association of Rehabilitation Facilities (CONNARF), representatives of Connecticut Association of Residential Facilities (CARF), representative of the Connecticut Association for Retarded Citizen (CARC), a state legislator, a representative of the Governor's office, and representatives of 10 community providers.

This report is intended to be descriptive in nature, therefore no critical analysis of the processes described is attempted. A substantive analysis is contained in the final report of this project where it can be informed by an understanding of how these processes are actually implemented in the field. This report is divided into three sections, reflecting the major aspects of the community development process: 1) Resource Development; 2) Individual Placement Process; and 3) Quality Assurance.

RESOURCE DEVELOPMENT

This section reviews: 1) how individual eligibility for DMR services is determined, 2) the steps involved in securing a contract to open residential services, and 3) how residential sites are developed. The presentation is based on DMR practices that are current at the time of this report. Although some of the case study homes opened while other policies were in effect, these prior polices have little bearing on the findings of this report and consequently are not discussed. The material presented is drawn from Department of Mental Retardation regulations and manuals, information supplied by members of the Department, other key informant interviews and other documents.

Client eligibility determination

Potential consumers of Department of Mental Retardation services are referred to the Case Management Division of each of the six Department regional offices. Referrals are made by private service provider organizations with the permission of the individual, other legal representatives, or responsible state agencies. Referred persons must meet the statutory definition of mental retardation and must require residential services because of one or more of the following factors: 1) a need to deinstitutionalize, 2) a need to prevent institutionalization, 3) a need for age-appropriate or other specific types of residential services, 4) the urgent need of that person for placement to prevent functional deterioration, and 5) because of a financial need for assistance in securing residential services.

The Department's first responsibility is to provide community residential services for members of the CARC v. Thorne consent decree. The Department is already behind in meeting these obligations. The Department must also attend to the needs of persons who require emergency placement because of the breakdown of their existing residential situation, other persons in the community who are in need of residential services, and special education students who are transitioning into adult activities.

Each year, the Commissioner's Office of DMR issues a statewide notice of the availability of funds for day and residential services. The notice includes the number of persons to be served on a regional basis. This notice (based in part on legislative authorization of monies to the department) will determine whether any region can support an expansion of services.

In order to juggle the various competing interests (e.g., persons still institutionalized, persons who require emergency services and other needs), each regional office develops a list of persons who get priority for any expansion of services. Subsequently, the process for selecting the provider(s) to serve these persons is begun. A substantial percentage of residential and day services are provided by private, non-profit corporations. However, the Department of Mental Retardation has developed, and still maintains, more than 50 group homes under its own auspices and the public sector continues to develop residential services.

Steps involved in receiving a contract for the provision of services with the Department of Mental Retardation

On a regional basis, formal and informal discussions are begun with service providers to determine their interest and capacity to develop residential services for the persons designated to receive them. Interested providers then submit a "letter of intent." The letter specifies the details of the organization, organizational goals, and the proposed process and timeframe to meet the residential needs of the region. A review team in each region evaluates these organizations according to the guidelines established by the Department (e.g., whether the provider's stated purpose and direction are in line with the DMR Mission Statement -- the Mission Statement is described in greater detail under the "Individual Planning" section). Through this process, providers are selected to develop services and are submitted for approval to the regional director.

The regional office subsequently drafts a "letter of agreement" that is signed by the regional office and the approved service provider. This letter outlines the responsibilities of both the regional office and the provider, and the time frame for the development of the service. The letter also details the provider's responsibility to obtain a full understanding of the individual clients (through meetings with the client, the case manager, and the interdisciplinary team); to make the sites selected for the residence available to the region for review and approval; and to develop a residential services plan. The region agrees to make all necessary information available and to provide coordination and technical assistance.

As mentioned above, the provider develops a "residential services plan." The plan specifies how services are to be developed which are client specific, meet the needs of the region, and are in keeping with the DMR mission statement. The plan specifies the identity and the number of residents in each site, the staffing pattern and compensation levels, from whom professional/medical services will be obtained, the costs of program components, and a description of the operation of the whole program including daily routines and back-up systems for special programming.

Once the residential services plan is agreed upon, the regional office signs a "letter of commitment" that outlines the specifics of the service to be developed. This triggers the process of rate setting. The provider submits a request to the Department of Income Maintenance. They in turn establish an interim daily rate per client for "room and board." The interim rate remains in effect until a regular room and board rate is established based on actual operating expenses (e.g. rent, insurance). A separate rate is established for service purposes (i.e., direct care and habilitative services). This rate is based on: staff salaries, administrative costs, staff training costs, and related expenses. The provider may also request specific start-up funds and/or loans prior to the opening of the residence.

Once the rates have been established the DMR contract administration writes the contract for the provider. Before admitting clients the home must undergo licensing review. In order to be licensed the program must present

signed certificates from the local fire marshall, the attending physician for the home, and the attending dentist along with assurances regarding availability of day program and other professional services.

Development of the residential site

Regional staff work together with providers on the selection of the residential site. A regional office may have a specific town or community in mind at the time of negotiations with the provider organization because of the home community of the selected residents or other reasons. Regional offices are required to approve the selection of a given site. The actual amount of involvement with the selection of the residential sites varies by DMR region.

Most often providers will propose a site to the regional office. A range of factors usually come into consideration when selecting a site. The optimal location is generally based on the family relationships and habilitative service needs of the potential residents. Another consideration is access to public transportation and other local medical and consumer services. A significant factor is the cost of the housing and the cost of any necessary renovations to the site. Providers may also consider the historical receptivity of the town to community development.

Within the geographic framework negotiated with the region, the provider or its agent works with local realtors to locate appropriate sites. Any rehabilitation or renovations necessary to bring the property in line with the needs of the potential residents or into compliance with licensing, building and fire safety codes are the responsibility of the provider. Compliance with building, fire, and safety codes is determined by local inspectors.

The time frame for the entire process of site development from selection to renovation to moving-in varies. It has reportedly been accomplished in as little as 90 days. However, the average development time is closer to six months with some sites taking closer to 18 months depending on ensuing complications.

The matter of notification of neighbors is left largely to the discretion and philosophy of the service provider agency. Some providers engage in extensive notification of neighbors while others feel it is not necessary. A number of people interviewed echoed the sentiment that persons with mental retardation should not have to notify neighbors that they are moving into a residence any more than should any other individual. In practice, agencies can be found doing everything from personally notifying every household in the area, to moving in unannounced.

While some private providers undertake all aspects of resource development, the majority of private providers sub-contract this work to an

agency which specializes in resource development, and then assume the programmatic operation of the residence as it nears opening.

Corporation for Independent Living (CIL)

CIL is the major developer of specialized housing in Connecticut. It is a private, non-profit organization with several non-profit subsidiaries. CIL works under sub-contract with private service providers to provide any or all of the following functions: real estate development, site selection, planning, inspection and evaluation, financial feasibility analysis of alternative project sites, construction and rehabilitation of the site, leasing of the property to the contractor, management of properties including rent collection, insurance management orientation and training to lessee agencies, loans for furniture and other start-up costs, a lease service for furniture and equipment, and consultation to other groups involved with community housing project.

Presently CIL leases over 200 properties to non-profit agencies operating residential services (these include individuals from departments other then mental retardation). Over 1,000 individuals are served through CIL in 91 towns. CIL is involved in the "lion share" of resource development in Connecticut. In fact, some providers who do attempt resource development on their own do so with consultation from CIL.

CIL has a policy of making almost every site they are involved with fully accessible for persons in wheelchairs irrespective of whether the clients selected to move in require accessible housing. CIL sees this policy as increasing the available stock of accessible housing in Connecticut. This policy is worth noting because some interviewees suggested that it unnecessarily increases the time needed to develop a site.

Zoning Ordinances

Connecticut's statewide zoning law affords a great deal of protection to its citizens with mental retardation. The law (Ch. 124, Sec 8-3e) states that local zoning regulations cannot treat any community residence housing six or fewer persons as anything other than a single family residence. This effectively permits community residences to be developed in neighborhoods of any type of zoning.

Given this powerful zoning override and the anticipation of the potential of oversaturation of neighborhoods with community residences that the statute may incur, another section of Connecticut's zoning law was passed. The so-called "1,000 foot rule" (Ch. 124, Sec. 8-3f) requires that no community residence for persons with mental retardation shall be established within one thousand feet of any other such residence without approval from the local zoning board. While the law is effective for homes for persons with retardation, it does not address homes for other populations. Some

communities feel they face a preponderance of state-sponsored services. At present there is an agreement between the Departments of Mental Health and Mental Retardation to collaborate on minimizing issues of neighborhood saturation during residential services planning. However, this agreement does not include other agencies such as corrections and youth services. CIL administrators and other service providers state that they canvass potential sites to see if there are residential or other service centers for *any population* within 1,000 feet of the proposed site, and will not develop that site if there is.

INDIVIDUAL PLANNING PROCESS

This description of the formally mandated process for individual planning and placement in a community setting is based on the series of interviews and the review of the relevant state documents outlined at the beginning of this report. The following documents were particularly useful in preparation of this section:

- DMR's ***Family Members' Handbook***,
- DMR's ***Overall Service Planning: Guidelines for Team Process and Documentation of Team Meeting Outcomes*** (July 1, 1982), and
- DMR, **Policy Bulletins**
  - -- #8 "Case Management" (May 1, 1986)
  - -- #9 "Eligibility for DMR Services" (May 1, 1986)
  - -- #10 "Program Placement" (May 1, 1986)
  - -- #11 "Overall Plan of Services" (May 1, 1986)
  - -- #12 "Discharge" (May 1, 1986)
  - -- #13 "Advocates" (May 1, 1986)
  - -- #15 "Nexus" (December 1, 1987)

The individual planning process seems to have eight major components which will merit consideration as part of this study: The organizational context of planning, Case management, Placement process, Overall plan of services, Transition plan, Nexus, and Appeal process. The relevant characteristic of each of these elements will be discussed in the sections that follow. In line with the intent of this formal system map, these outlines are drawn, wherever possible, directly from DMR's description of the process.

The organizational context of planning

What emerged from the documents and interviews is a seemingly thorough process--or more appropriately series of interrelated processes--of planning

which attempts to be driven by the needs of the individual. Direction is given to this planning process by continual reference to DMR's Mission Statement as the compass which should guide service development in Connecticut. As is appropriate for such a global document, it reflects a broad statement of values:

> The mission of the Department of Mental Retardation is to join with others to create the conditions under which all persons with mental retardation experience:
>
> - Presence and participation in Connecticut town life
> - Opportunities to develop and exercise competence
> - Opportunities to make choices in pursuit of a personal future
> - Good relationships with family member and friends
> - Respect and dignity.

As a guide for translating these goals into plans for specific individuals the department outlines seven principles of service planning. These include:

- All people can learn and grow;
- People who have mental retardation share the same general needs with all other people;
- The planning process should focus on the whole person, not just his or her deficits or problems;
- Services must be individual and relevant
- An understanding of the person's needs and competencies is key to supporting the person
- Purpose and process are more important than forms
- A good planning process should move from general to specific. (See DMR, 1987, ***Overall Service Planning***, pp.6-9)

The continuing key actors present throughout the individual planning process are the members of each client's Interdisciplinary Team (IDT). The makeup of this group should reflect the individuals needs and is made up of people who have direct knowledge of the client. So the composition of each IDT will vary from client to client and is subject to change over time. Except where federal or state licensing regulations impose other requirements the IDT must minimally include

The client;

At least one parent, relative, guardian, or independent advocate;

Staff from both present and planned residential and day program;

A member of the staff from the present or planned day program who instructs, teaches, or counsels the client

The case manager; and

Other specialist who are involved with the client, including but not limited to psychologist, psychiatrist, social worker, nurse, physician, occupational/physical therapists, and speech/hearing/vision/ communication specialists.

Case management

The case manager plays a central role in the processes of placement, planning, transition, and service coordination for people served by the Connecticut Department of Mental Retardation. In this regard this role constitutes the individual client's principle spokesperson within the service system. By definition the person of the individual case manager is central to the processes we are examining here. As the Department defines it

> Case management is a statewide process by which the department directs, coordinates, and monitors services to persons with mental retardation from the time the person enters the system to the time they are discharged. Case management assists persons who are mentally retarded to identify and secure services which meet their individual needs for growth, and to secure that their rights are protected. Case management ensures that the client's Overall Plan of Services (OPS) is being prepared, modified, and carried out by the interdisciplinary team (IDT), and that services are relevant to the client's current needs. (DMR, Policy 8, p. 2)

The case management function has three major components 1) intake and referral, 2) client program management, and 3) record keeping. While functions such as intake and record keeping are important, in fact they are ancillary to the central case management role as client program manager. In that regard the components of this aspect of the case manager role, as described in DMR Policy 8 "Case Management", are a central focus of study.

Specifically the case manager has responsibility for:

1. Convening and chairing the Interdisciplinary Team (IDT) which develops or modifies the client's Overall Plan of Services (OPS).

2. Working with clients and families to identify client needs, refer clients to appropriate services provider(s) with timely follow-up, and to assist client's and families in securing services.

3. Providing client support which includes

   - Informing clients, family members, guardians, and advocates of their legal rights
   - Monitoring client progress in meeting the goals and objectives established in his or her OPS
   - Visiting the client in his or her service setting on a regular basis
   - Coordinating provision of emergency services as may be needed
   - Contacting families at least quarterly to report client progress
   - Assisting clients/families to resolve placement adjustment problems as needed.

4. Ensuring review of client behavior programs

5. Ensuring coordination of all services in OPS

6. Meeting with providers of services to give feedback on programs and offer assistance

7. Reporting to regional administration when services are not being provided as specified in OPS.

8. Securing approval of purchase requests

9. Tracking progress of resource development efforts

10. Referring the client's needs to the individuals responsible for regional resource development when resources are not presently available.

Placement process

The individualized planning process begins from the moment that a person is defined as eligible for services from DMR:

> A case manager shall be assigned, shall ensure that all team members are assigned, and shall schedule the first IDT team meeting within thirty (30) days after the clients enters the system. (DMR, Policy 11, p. 9)

From the outset the person-centered focus of this process is underscored:

> All placement planning for clients of the department shall be based on the needs, strengths, and preferences of the individual person regardless of the availability of current resources. (DMR, Policy 10, p. 2)

This process is to be informed by comprehensive professional evaluation:

> Clients considered for placement shall be evaluated by appropriate psychological, medical, and social services personnel to determine their placement goals and to ensure that the services selected will meet the specific needs of the client. (DMR, Policy 10, p. 2)

Another major consideration in the initial stage of planning is the maintenance of the new client's network of relationships:

> The department shall attempt to provide placement in a region based upon the presence of individuals significant to the client, including parents, siblings, other relatives or close friends. (DMR, Policy 10, p. 2)

Within the IDT process this information is synthesized and updated:

> Recommendations for initial placement are based upon the Interdisciplinary Team's consensus regarding placement requirements to meet the client's specific needs. The IDT shall review all preplacement evaluations, update them as needed , and shall identify the client's programmatic needs and service options focusing on the least restrictive setting possible for the client. (DMR, Policy 10, p. 5)

Based on this review of the individual evaluation and their knowledge of the system of services,

> The IDT shall make an initial determination of resource availability.

- If resources are available, the casemanager shall arrange for visitation of potential residential and day program sites by the client, family, guardian and/or advocate.

- If initial review of resources available reveals no suitable current programs or if the placement visit(s) do not result in agreement as to the specific residential and day program, information on the clients needs shall be referred to regional staff who are responsible for resource development. (DMR, Policy 10, p. 6)

Even with this well developed planning process DMR remains aware of the fact that difficulties can arise with any placement. Therefore, guidelines are presented for procedures to follow in dealing with placement problem:

In the event that problems with the placement occur, the case manager and the client's Interdisciplinary Team may:

- Seek professional consultation and assistance from other professional staff employed at the client's residence or day program.

- Review the individual's OPS for possible modification of the program or placement component.

- Seek consultation or assistance from outside the agency, including the referring region or facility.

- Provide short-term supplemental assistance at the placement as long as the emergency exists.

- Explore other alternatives such as respite for the clients and/or his or her caretaker, or short-term backup placement of the client outside of the facility.

- Compile data regarding unmet needs for use in planning for future development. (DMR, Policy 10, p. .7)

Overall plan of services

The basic framework for all individual planning for each client served by DMR is the development of the Overall Plan of Services (OPS). The initial placement meeting is the first in an ongoing series of OPS meetings which will continue as long as the person is in a residential or day program administered by DMR. The OPS is rewritten on an annual basis with a review every 4 months. Each team member submits written objective progress reports to be

reviewed at the semi-annual meeting to assist in evaluating the effectiveness of the plan or to highlight deficiencies in the programs. However, if an emergency or a substantial change in the individual life situation is occurring a full IDT meeting can be requested at any time by any team member to reassess the OPS.

DMR's attempt to give clear direction to it programs is reiterated in the policy detailing the OPS requirement:

> The purpose of the Overall Plan of Services is to ensure that the services provided to clients use culturally valued means to help clients achieve culturally valued lives.

This document then goes on to outline in a more specific fashion how this goal is to be reflected in the OPS:

> The Overall Plan of Services process shall encourage integration of the client into normalized settings and shall strive continuously for placements into the least restrictive program alternatives. The process shall be developed in keeping with accepted principles in the field of mental retardation and shall enhance the client's environment. The Overall Plan of Services Process shall focus upon:
>
> 1. DEVELOPMENTAL GROWTH. All clients , regardless of age or level of disability, continue to learn and develop throughout their lives given positive expectations and a proper environment
>
> 2. INDIVIDUALIZATION. Planning and programming to meet the unique needs, strengths, and interests of each client.
>
> 3. INTEGRATION. The opportunity for people with and without handicaps to form good relationships where they live, work, and learn.
>
> 4. USE OF GENERIC SERVICES. Access by persons with mental retardation to existing services within the community in which they live (e.g., recreation, transportation, medical care).
>
> 5. SUPPORT OF NATURAL SETTINGS. Strengthening and maintenance of family involvement and the home residence
>
> 6. FULL CITIZENSHIP STATUS. Acknowledgement of the same rights for a person with mental retardation as are constitutionally afforded all citizens. (DMR, Policy 1, p. 6)

The OPS process results in the production of a written plan that describes the services the client will receive and the manner in which they will be delivered. The principle components of this written plan include:

1. A list of the person's strengths, needs, and preferences.

2. A list of prioritized goals;

3. Each goal is operationalized by behavioral objectives that are stated in terms that are positive and objectively measurable.

4. Each objective is accompanied by a specific service plan which describes what program staff will do to assist the client to achieve the objective.

5. An evaluation procedure is described that will be used to determine whether the teaching strategy are actually helping the client master the objective.

6. These basic elements may be supplemented with

   a. An Individualized Transition Plan which focuses on the support needed to achieve a successful move,

   b. An Individualized Spending Plan which focuses on developing the clients money management skills. or

   c. An Adaptive Equipment Plan which describes the special equipment the client needs to achieve the greatest degree of physical independence.

It should be noted that DMR has devoted considerable effort to assuring the person-centered focus of the OPS by carefully outlining the process entailed in the development of this document in ***Overall Service Planning*** guidelines (DMR, 1987). Given the scope of this study three diagrams which schematize the planning process are particularly useful. These are reproduced on the following pages. Figure 1 presents a flow chart which synthesizes the planning/implementation process. Figure 2 outlines the major factors that must be considered in looking at an individual's service needs. These considerations are clustered according to the three major elements in the service system residential, vocational/education, and personal supports. Finally Figure 3 lists specific questions which should be asked about the specific individual and his or her participation in 6 major domains of daily life. The answers to these question are intended to inform the process of service review outline in Figure 2.

FIGURE 1

THE PROCESS OF OVERALL PLANNING

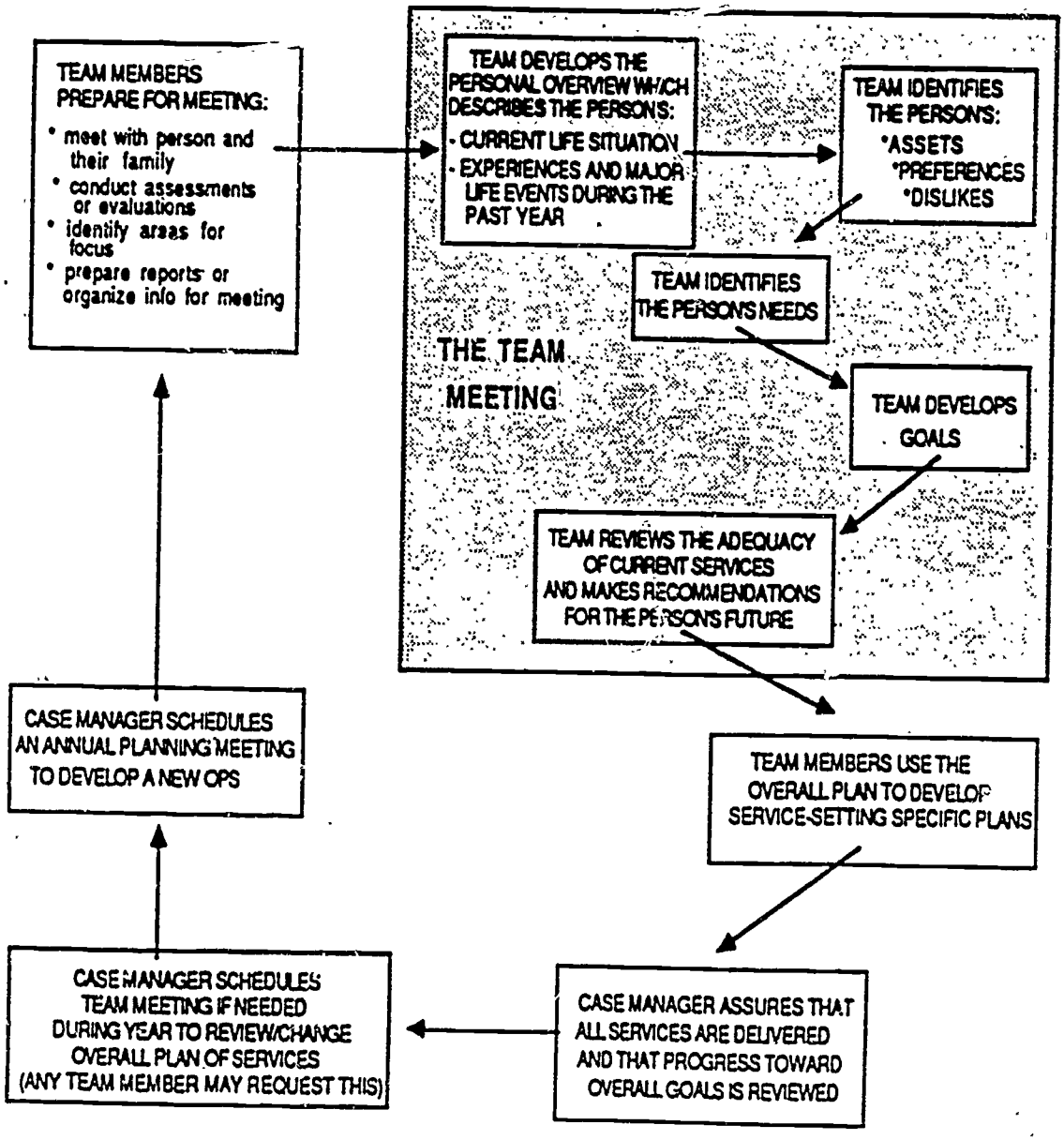


FIGURE 2

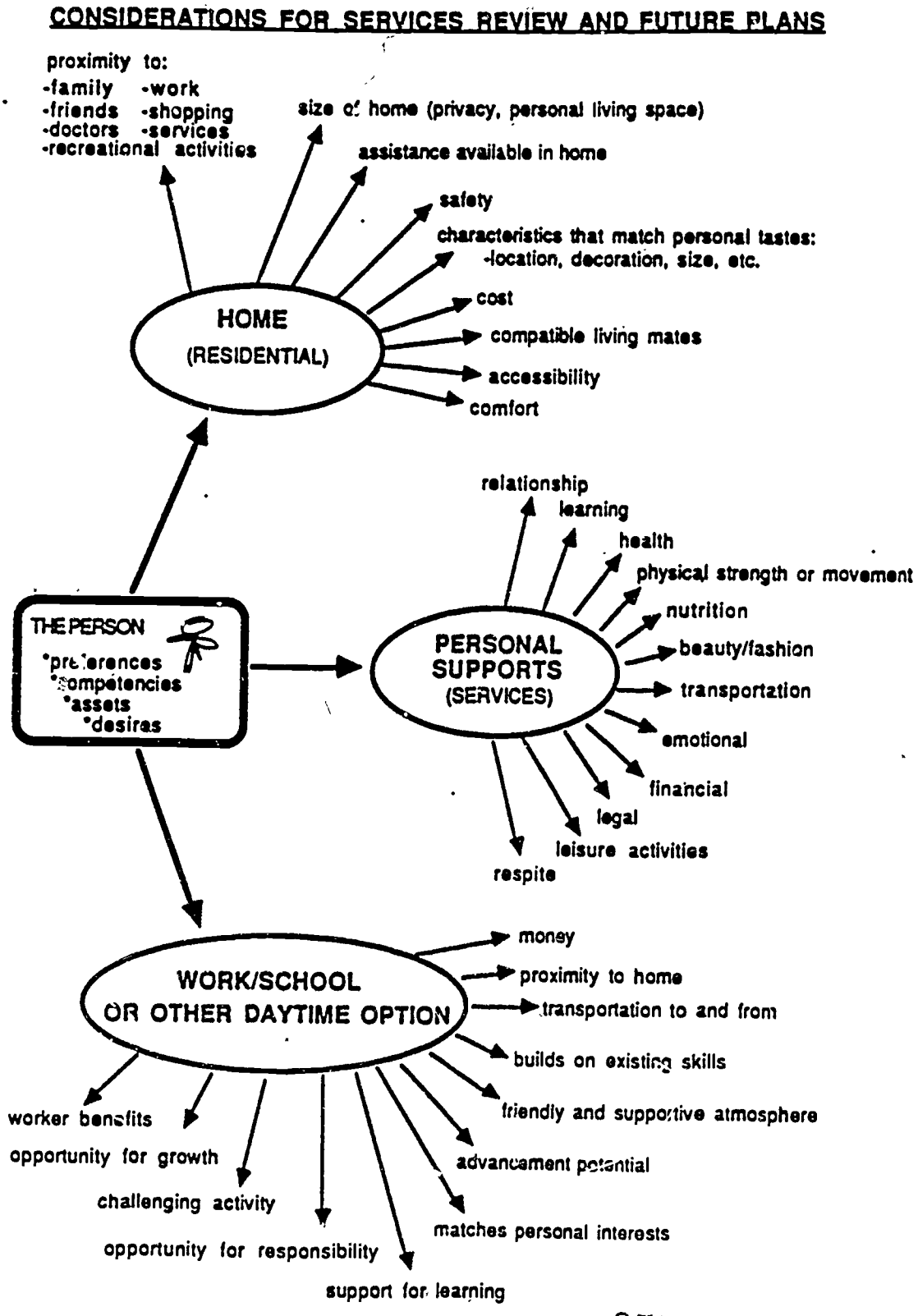
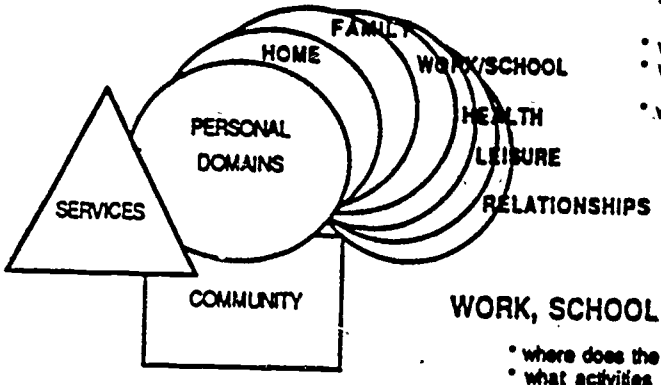

CONSIDERATIONS FOR SERVICES REVIEW AND FUTURE PLANS
proximity to:
-family -work
-friends -shopping
-doctors -services
-recreational activities
size of home (privacy, personal living space)
assistance available in home
safety
characteristics that match personal tastes:
-location, decoration, size, etc.
cost
compatible living mates
accessibility
comfort
HOME
(RESIDENTIAL)
THE PERSON
•preferences
•competencies
•assets
•desires
relationship
learning
health
physical strength or movement
nutrition
beauty/fashion
transportation
emotional
financial
legal
leisure activities
respite
PERSONAL
SUPPORTS
(SERVICES)
money
proximity to home
transportation to and from
builds on existing skills
friendly and supportive atmosphere
advancement potential
matches personal interests
support for learning
opportunity for responsibility
challenging activity
opportunity for growth
worker benefits
WORK/SCHOOL
OR OTHER DAYTIME OPTION

FIGURE 3

QUESTIONS TO GUIDE THE DEVELOPMENT OF A PERSONAL OVERVIEW



FAMILY

- who are the person's family members?
- how often does the person visit with his or her family?
- where do the person's family members live?
- what support do family member's provide to the person?
- what support does the person provide to his or her family?

WORK, SCHOOL OR OTHER DAYTIME OPTION

- where does the person spend his or her day?
- what activities is the person involved in?
- how far does the person travel each day?
- what are the hours the person is away from home?
- how does the person get to where he or she spends the day?
- does the person get paid for work?
- what is the person learning?
- what support does the person get during the day?
- who does the person spend his or her day with? co-workers? schoolmates? staff?
- does the person like what he or she does during the day?
- what are the person's personal goals?

HOME

- where does the person live?
- who does he or she live with?
- does the person have a private room?
- who are the staff who spend the most time with the person?
- what support does the person need at home?
- what opportunities and activities does the person have available ?
- how long has the person lived in this place?
- does the person get along with his or her housemates?
- does the person like where he or she is living? why or why not ?
- is the home close to things the person likes to do?
- do you see the person remaining in this home? why or why not?

HEALTH

- how would you describe the person's general health?
- does the person have any specific difficulties?
- what medication does the person take? why?
- when was the last time the person saw a doctor?
- does the person see any health specialists?
- can the person monitor his or her own health?
- does the person use any supportive corrective or assistive devices?
- does the person have any allergies?
- how is the person's nutritional status?
- does the person sleep well?
- has the person had any injuries or health problems in the past?
- does the person receive any regular therapy or treatment?

RELATIONSHIPS

- who are the person's friends?
- does the person have an advocate?
- how much time does the person spend with people other than staff?
- where does the person spend time with others? at home? at work? other places?
- what restrictions does the person have on his or her relationships?
- what opportunities does the person have to meet people?

LEISURE

- how does the person spend his or her free time?
- what does he or she like to do?
- what activities are available for the person to choose from?
- does the person have people to spend free time with?
- how often does the person participate?
- how often are activities offered?
- what supports are available to help the person participate in activities? (transportation, staff, materials, etc.)
- how does the person access community activities?

Transition plan

As outlined within DMR's documents the process of client movement or "transition" is viewed typically as another aspect of the individual planning process.

> If the current placement is determined by IDT consensus to require change, the team shall specify the short (less then one year) and long range placement objectives, including statements of the client's residential, day and program support needs. (DMR, Policy 11, p. 11)

> Transfer of clients from one department facility to another shall be:
>
> - Based upon the needs of the client as determined by the IDT
> - Conducted in an orderly manner with the least amount of disruption possible
> - Require notification to all parties involved at least ten days prior to the transfer
> - Require a Transition Plan as a component of the OPS.(DMR, Policy 10, p. 2)

The effort to manage client movement in an orderly coordinated fashion is contained in the Individualized Transition Plan:

> For each client being transferred from one residential or day program to another, an Individual Transition Plan shall be developed by the IDT in accordance with procedures outlined in DMR 11, "Overall Plan of Services." The IDT shall include a representative from the prospective provider(s) of the new service as well as provider(s) of the present service. (DMR, Policy 10, p. 6)

A major intent of this plan is to assure that all of the members of the IDT are clear on their responsibilities in making the transition as smooth as possible (a copy of the forms used for this purpose is found in Appendix A):

> The Individual Transition Plan should outline specific activities to be accomplished before, during, and immediately after placement; and assign tasks to specific team members to ensure the smooth and successful transition to the new program (DMR, Policy 10, p. 6)

To further ensure that no necessary aspect of the person's move becomes lost in the shuffle, DMR has developed a **Transition Planning Checklist** which lists 40 discrete tasks that must be attended to in order to facilitate a smooth move (See Appendix A).

As this transitional planning process is discussed in ***Overall Service Planning***, it is recognized that a number of client moves will occur as the result of some sort of crisis. Although this type of situation precludes the careful preliminary planning outlined above, standard practice is to work through the entire transition planning process as soon as possible after the move. The intent here is to restore order to the person's life as soon as possible and ensure that all service providers take full responsibility for their involvement in the individual's life.

Nexus

Nexus refers to the DMR policy which specifies that

> Clients of the Department of Mental Retardation will be provided services in the region in which they or people significant in their lives reside. (DMR, Policy 15, p. 2)

This policy is based on the premise that people are best served in the locale where they have existing significant relationships which are independent of the formal service delivery system. The need for such a policy reflects the fact that in the past people with mental retardation were often placed in service or moved based solely on the availability of a programmatic slot that was deemed appropriate for that individual with little or no thought given to their network of personal relationships. As a result many of people with retardation effectively lost contact with family members or have been unable to develop or maintain enduring relationships with other members of the community.

Based on this policy the issue of Nexus can be a major consideration in DMR's planning for an individual:

> If a client's interdisciplinary team determines that there is a significant family member or friend in another region and that it is in the client's best interest to be in closer proximity to that person, the two regions shall plan jointly to transfer the client. In making that determination the interdisciplinary team shall consider the following:
>
> A. Family and friendship ties that are relevant to the individual's needs.
>
> B. Current community participation and its importance to the individual's needs and desires such as:
> - residential programs
> - day programs
> - recreation and leisure activities
> - civic and church involvement.

C. Reasons a move to another region is in the individual's best interest, with particular attention to how family or other relationships support the person's presence and participation in the community.

D. The adequacy of the current region's efforts to support and sustain the relationship without relocation. (DMR, Policy 15, p. 6)

Appeal process

State policy and the consent decrees in the Mansfield and Southbury court cases outline a series of very specific processes for assuring the right of clients, parents, guardians, and advocates to appeal any programmatic, transfer, or other decision which is perceived as not being in the best interest of the client. Rather then providing a narrative of how these processes are setup we have included on the next three pages the more than adequate schematics which DMR provides in its ***Family Members' Handbook*** to illustrate these procedures. Figure 4 illustrates the procedures for review of decisions related to the OPS, Figure 5 outline the process for appeal of a transfer decision, and Figure 6 illustrates the additional the special hearing process established for Mansfield class and Southbury clients.

The programmatic administrative review is used in disagreements over program decisions as decided by the team. This process is available to the client or his or her family or advocate. Transfer hearings are used in disputed transfers. State law requires notification of the client and family ten days prior to the scheduled move. A transfer hearing is a more formal hearing than the programmatic administrative review and happens external to DMR.

Program Review Committee

These committees, made up of contracted professionals such as psychiatrists, psychologists, special educators and agency executives, are in place in each region and training school. Their chief purpose is to review individual client programs that employ aversive procedures and/or behavior modifying medications. DMR policies require program reviews before aversive programs or medications are implemented.

FIGURE 4

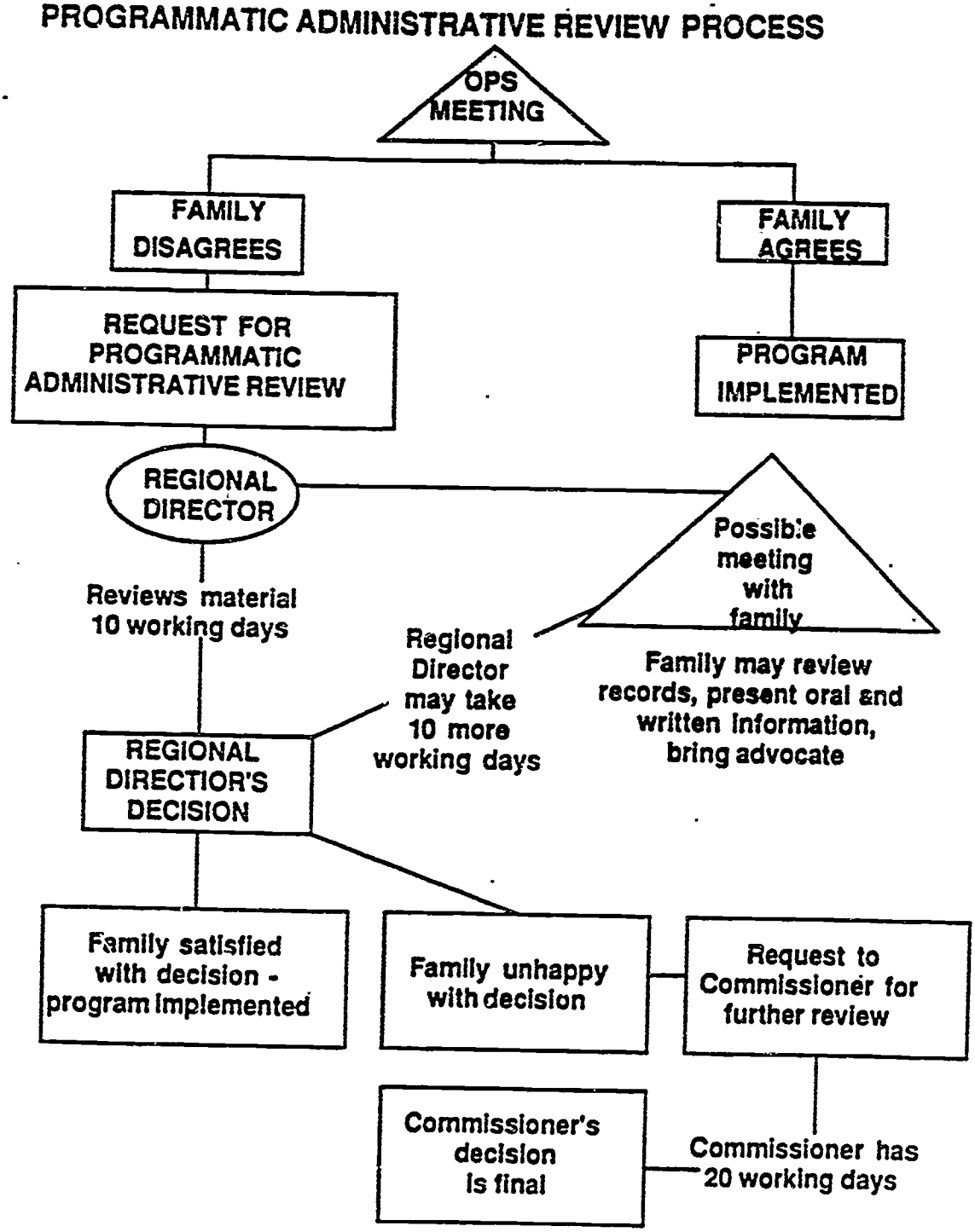

PROGRAMMATIC ADMINISTRATIVE REVIEW PROCESS
OPS MEETING
FAMILY DISAGREES
FAMILY AGREES
REQUEST FOR PROGRAMMATIC ADMINISTRATIVE REVIEW
PROGRAM IMPLEMENTED
REGIONAL DIRECTOR
Possible meeting with family
Reviews material 10 working days
Regional Director may take 10 more working days
Family may review records, present oral and written information, bring advocate
REGIONAL DIRECTOR'S DECISION
Family satisfied with decision - program implemented
Family unhappy with decision
Request to Commissioner for further review
Commissioner's decision is final
Commissioner has 20 working days

FIGURE 5

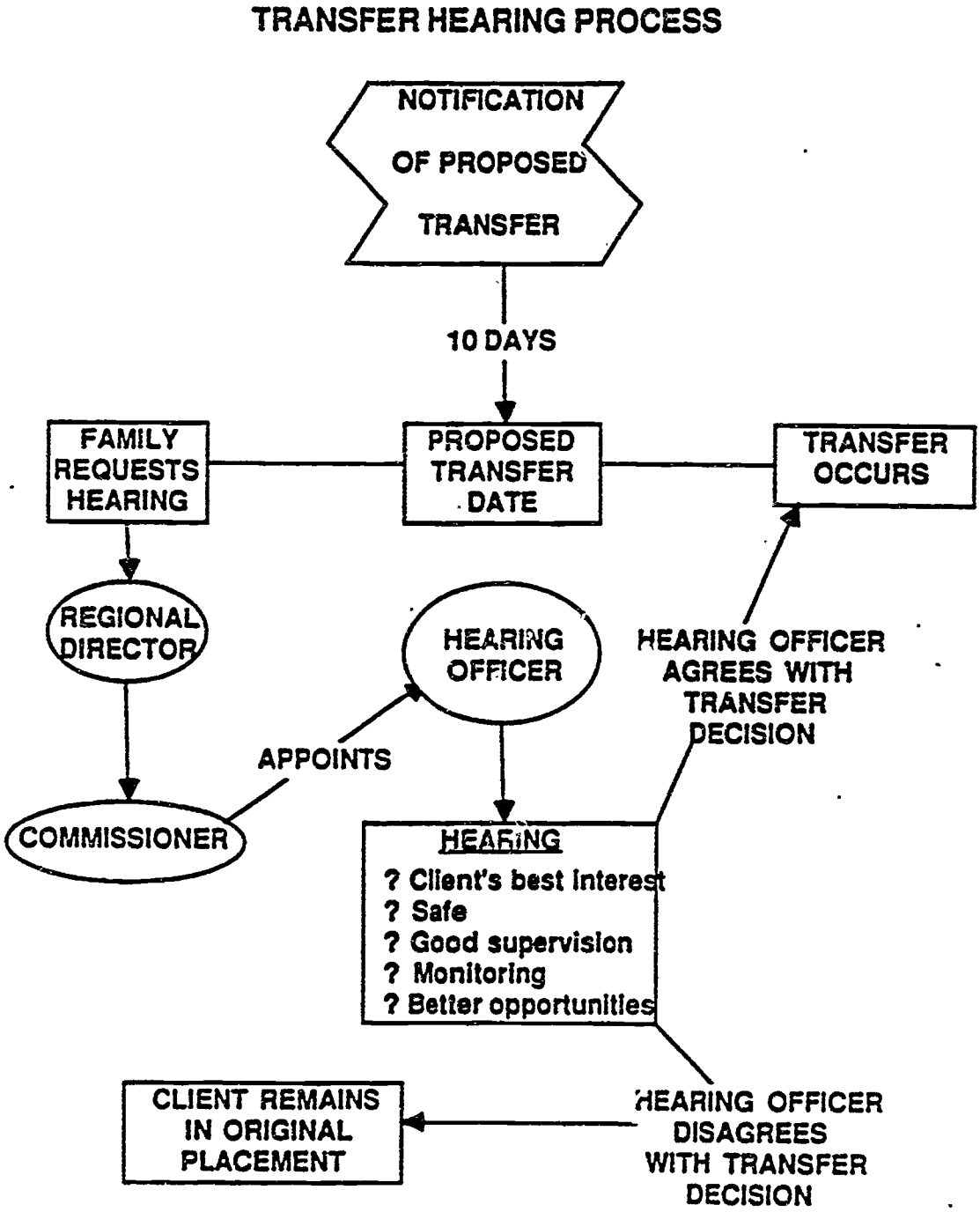
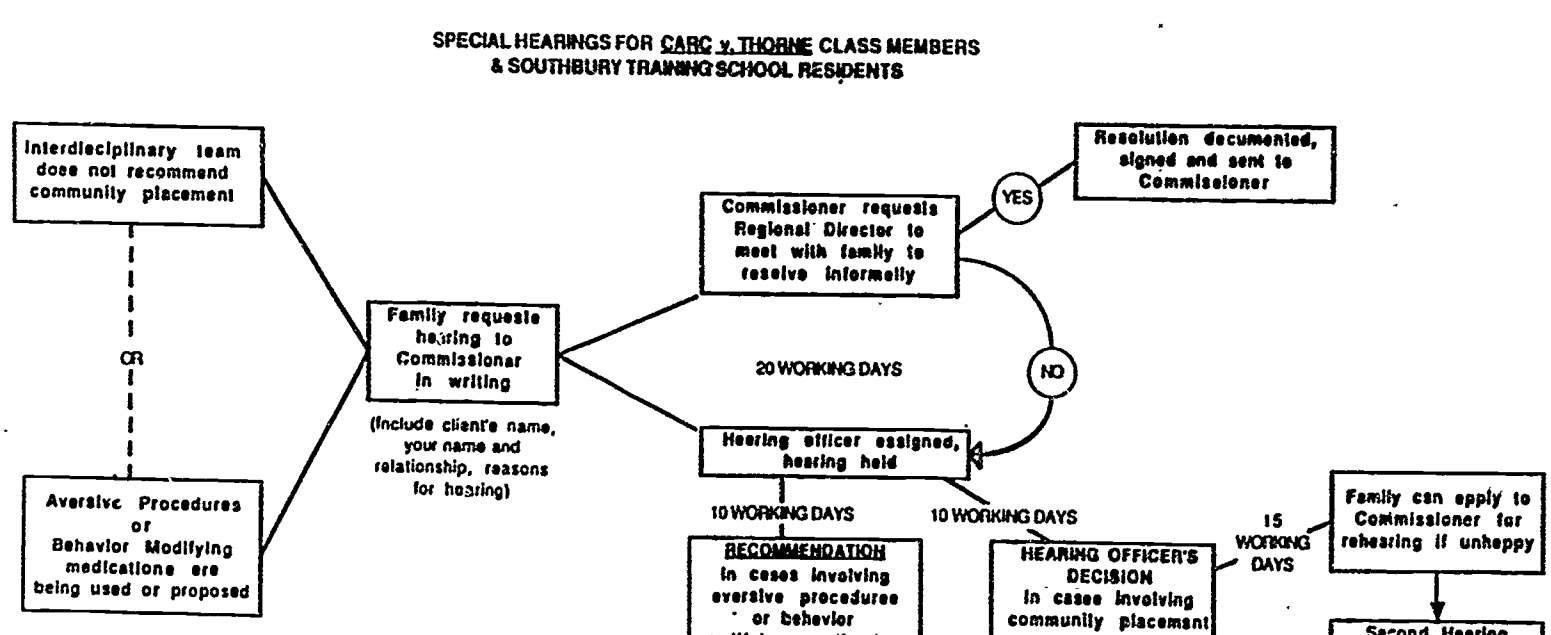

TRANSFER HEARING PROCESS
NOTIFICATION OF PROPOSED TRANSFER
10 DAYS
FAMILY REQUESTS HEARING
PROPOSED TRANSFER DATE
TRANSFER OCCURS
REGIONAL DIRECTOR
HEARING OFFICER
HEARING OFFICER AGREES WITH TRANSFER DECISION
APPOINTS
COMMISSIONER
HEARING
? Client's best interest
? Safe
? Good supervision
? Monitoring
? Better opportunities
CLIENT REMAINS IN ORIGINAL PLACEMENT
HEARING OFFICER DISAGREES WITH TRANSFER DECISION

FIGURE 6


SPECIAL HEARINGS FOR CARC v. THORNE CLASS MEMBERS
& SOUTHBURY TRAINING SCHOOL RESIDENTS
Interdisciplinary team does not recommend community placement
OR
Aversive Procedures or Behavior Modifying medications are being used or proposed
Family requests hearing to Commissioner in writing
(include client's name, your name and relationship, reasons for hearing)
Commissioner requests Regional Director to meet with family to resolve informally
YES
Resolution documented, signed and sent to Commissioner
20 WORKING DAYS
NO
Hearing officer assigned, hearing held
10 WORKING DAYS
RECOMMENDATION
In cases involving aversive procedures or behavior modifying medications Commissioner's decision is final
10 WORKING DAYS
HEARING OFFICER'S DECISION
In cases involving community placement
15 WORKING DAYS
Family can apply to Commissioner for rehearing if unhappy
Second Hearing Officer's decision is final

QUALITY ASSURANCE

The following section describes the key elements in Connecticut's formal quality assurance system aimed at services for persons with mental retardation. The quality assurance system in the state has been greatly influenced by the CARC v. Thorne consent decree and subsequent related court activity. Many of the elements in the system are relatively new and some are still in the planning stages. Further, some procedures pertain to all individuals receiving services within the state while others are limited to class members.

CARC V. THORNE

The consent decree requires the state to develop a quality assurance system that includes six basic functions:

1. To ensure that class members live, work, learn, and recreate in a humane physical and psychological environment which affords each the opportunity to interact with and participate in the community;

2. To ensure that class members are protected from harm;

3. To review and monitor individual habilitation plans to ensure that such plans are developed and are in fact implemented;

4. To ensure that case managers and providers have such training as is necessary to effectively and professionally discharge their responsibilities under this order;

5. To determine through an analysis of individual program data whether class members are progressing or regressing in programs and services developed through this order;

6. To periodically publish a report which shall be distributed to the Public Health Committee of the Connecticut Legislature and State Office of Protection and Advocacy for Handicapped Individuals which shall be available to the public which discusses and analyzes the data collected under subparagraphs 1 through 5 above.

ORGANIZATION OF THE ANALYSIS

The description of the state's quality assurance system is divided into three parts: 1) program and environmental monitoring; 2) individual/client-based monitoring; 3) protection of rights and client well-being. In addition, the

first two sub-sections are divided into two parts -- procedures applicable to all individuals and procedures aimed solely at class members.

In preparing this analysis, several documents were useful:

- DMR, ***Transitional Planning Checklist*** (Rev. 8/88);
- DMR, ***A Guide to Program Quality Review of Day Programs*** (October 1986);
- DMR, ***Statewide Quality Assurance Methods*** (8/31/88);
- DMR ***Progress of Quality Assurance Efforts*** (10/26/88)
- DMR, ***Policy Bulletins***:

  #1 "Clients Rights" (May 1, 1986)

  #2 "Abuse and Neglect" (May 1, 1986)

  #5 "Program Review Committee" (May 1, 1986)

  #6 "Human Rights Committees" (May 1, 1986)

  #20 "Policy on Safety" (May 1, 1988)

  #30 "Mortality Review" (July 1, 1988)

- CARC v. Thorne, ***Defendants' Answer to Motion for Contempt*** (July 15, 1988);
- CARC v. Thorne, ***Consent Decree*** (April 1984)
- Connecticut Applied Research Project, ***Reports 1-7***;
- DMR, ***Licensure of Private Dwellings as Community Training Homes for Mentally Retarded and Autistic Persons***, (April 17, 1984);

- DMR, ***Licensure of Private Facilities as Group Homes, Community Living Arrangements, Group Residences, Residential Schools, and Habilitative Nursing Facilities for Mentally Retarded and Autistic Persons.***

REVIEW OF PROGRAM, AND ENVIRONMENTAL QUALITY

General Procedures

Licensing. With a team of 22 inspectors, the Quality Assurance Division within DMR is responsible for licensing all relevant residential programs including group homes, community living arrangements, group residences, residential schools, habilitative nursing facilities, and community training homes. All residential programs are inspected before they open and annually thereafter. Within 10 days of the inspection, licensing inspectors must provide the facility with written report listing any deficiencies. The provider in turn provides the Division with a "plan of correction."

The licensing inspections are based on standards developed in 1984. Within the next few months, however, DMR plans to issue new licensing regulations that are "designed to more fully reflect the mission of DMR . . ." The revised standards are the product of a comprehensive analysis begun in the summer of 1987.

Further in November 1988, DMR implemented an annual inspection and review procedure for community-based, state-operated residences. Though, the state cannot license its own facilities, DMR maintains that the procedure is as rigorous as that applied to private residences. Sanctions will be made through performance appraisals of state regional staff.

Independent Professional Review/Utilization Review. Professional and Utilization Reviews are required as part of the federal regulations governing care in ICF/MR certified residential programs. These reviews, according to DMR, "have the dual purpose of determining if the individual is receiving 'active treatment' as required under federal regulations, and assessing overall program compliance with regulations." DMR revised its IPR/UR survey instruments two years ago, making it more "client centered." DMR also maintains that the new procedures enhance the ability of reviewers to provide technical assistance.

Day Program Quality Review. Every two years, a team comprised of a person with mental retardation, a family member of a person who has mental retardation (or other interested citizen), a staff person from one of the DMR training schools or regions, and a provider conduct program quality program reviews at all day program sites. The reports that are submitted by the review teams after visiting a program are used by the provider and the department collaboratively to produce "quality improvement plans." These enhancement

plans document program improvements to be initiated by the provider. In addition, all community sheltered workshops must be accredited a national accrediting body. All 42 workshops are currently accredited by the Council on Accreditation of Rehabilitation Facilities (CARF).

Residential Program Quality Review. DMR is currently working on a residential program quality review activity modeled on the day program assessment described above. The procedure was field tested was field tested in Region 4 in November 1988.

Supported Employment Tracking and Reporting. DMR has instituted a tracking system for clients in supported work programs that yields information on programs performance with regard to integration and economic outcomes. A Supported Employment Graphic Summary is periodically issued which depicts the trends for class members, and other clients in support work programs.

Procedures for Class Members

Longitudinal Study. As part of the Longitudinal Study conducted by Conroy and Feinstein Associates, a periodic review of program characteristics is conducted which includes an assessment of "regimentation" or individualization, and physical quality. Each program site that serves a class member is assessed once a year as part of the general data collection activity. This analysis is in addition to the individual client progress assessment noted below.

INDIVIDUAL/CLIENT-BASED MONITORING

General Procedures

Transition Planning Checklist. The Transition Planning Checklist (Appendix A) is completed for all individuals "experiencing a major life change such as a change in residence or day setting." The checklist is completed by a case manager and is intended to be "a final check to ensure that actions that will contribute to a successful transition for individual have been taken." The checklist is divided into the following areas:

- Inclusion and Preparation -- preliminary activities including the inclusion of the individual and his or her family in the planning process and the completion of various financial arrangements.

- Visits -- assurances directed at the maintenance of social relationships and attendance of the client at proposed residential and day service sites.

- Service Arrangements -- activities associated with the individual's involvement in roommate selection and the respect of individual preferences as well as the preparation of staff of the program. This are is further broken down into additional items related to specific service readiness including health supports, transportation, day services, etc.

- Family and Advocate Involvement -- assurances that client has access to an advocate and the family or guardian has been involved in the transition plan.

- Personal Arrangements -- activities surrounding the individual's personal possessions, funds, and moving day procedures.

- Transition Planning -- assurance that all staff responsible for the care and supervision of the individual have been involved and that key service providers have received a copy of the plan.

According to those interviewed, the Transition Checklist is currently the only individual monitoring activity required for all clients in the system.

Procedures for Class Members

Individual Reviews. The individual review process is now divided into three parts -- quarterly, annual, and biennial -- each conducted by different reviewers. The first component is designed to identify clients at risk of failing in a placement or who are otherwise in jeopardy. The review is conducted by case managers in each region and involves the use of a short-form "red flag" 25 item checklist. Such reviews are conducted three times a year beginning three months after the Overall Plan of Services is developed. The regional or training school director is notified immediately of any red flag and an assistant director is designated to monitor the situation. The Q.A. Division is also notified. The regional or facility director has 30 to resolve the problem. If 30 days pass without resolution, the director of the Q.A. Division requests a status report.

The second part of the individual review is an external individual review conducted by Conroy and Feinstein Associates. The review includes an annual assessment of progress in adaptive behavior, maladaptive behavior and vocational efforts. It also includes an assessment of the extent of social integration of the individual as well as his or her participation in choice-making. The process of assessment also identifies "red flags" when individuals have regressed or when other data suggest that the client may be in jeopardy.

The third part of the individual review process coincides with the biennial program quality review. As noted earlier, these reviews are conducted by a

group external to DMR. A draft instrument for this process was field tested in late 1988.

Long Term Care Monitoring. This procedure is directed at class members living in long term care facilities and includes a review of medication regimens, day program, medical supports, restraints, and family involvement. The coordinator of the long-term care monitoring is a member of the Medicaid certification team at the department of income maintenance and assists in evaluating compliance with federal regulations as well as with DMR policies and procedures.

PROTECTION OF CLIENT RIGHTS AND WELL-BEING

Medication Tracking. DMR has established a system to track the medication usage of all clients in the system. A report on medication use is required every six months for any client in a supervised living arrangement who is receiving medication prescribed to modify his or her behavior. The reports are screened by regional and training school staff for possible problems. The system is capable of detecting compliance with the DMR medication policy which "emphasizes reduction and elimination of unnecessary medication." According to DMR, it also makes it possible to mount "direct remediation efforts toward those programs and physicians who appear unable or unwilling to comply with DMR policy.

Mortality Review. DMR, within the past year and a half, has initiated a mortality review procedure with the following mandate:

> All deaths of clients for whom the department bears direct or oversight responsibility for medical care shall be subject to mortality review as a means of monitoring and evaluating the quality of health care provided to the deceased client and to improve ongoing health care delivery for clients.

The new policy established a statewide Medical Quality Assurance Board to assure that client deaths are reviewed and to examine the quality and appropriateness of medical and other services provided to the deceased client. Members of the Board include the state medical examiner, the director of quality assurance, a private physician, a parent, the medical directors of the two training schools, the DMR director of community medical services, and a representative of the Department of Health Services. Ex officio members include the court monitor's staff, the Office of Protection and Advocacy, DMR's consent decree coordinator, and the long-term care coordinator.

Abuse and Neglect Monitoring. Multiple agencies in the state are responsible for the investigation of suspected abuse and/or neglect with regard to persons with mental retardation. According to Policy Bullletin #2, "Abuse and Neglect," the current procedure is as follows:

Employees who have witnessed or have knowledge of suspected acts of abuse and/or neglect shall immediately make a verbal report regarding the matter to the supervisor of the department, program, or agency to which they are assigned. In addition, the appropriate agency shall be notified:

* Office of Protection and Advocacy if the client is between 18-59 years of age,

* Department of Children and Youth services if the client is under 18 years of age, or

* Department of Aging if the client is over 60 years of age, and

* Department of Human Services if the incident occurred in an ICF/MR facility

* State police, in cases involving assault or sexual abuse in a department-run facility

* Local police, in cases involving assault or sexual abuse in a privately-run facility.

The policy also requires the provision of training to every new DMR employee regarding the identification and reporting of potential abuse and/or neglect situations.

Policies on abuse and neglect, however, are being revised to reflect more standardized procedures and refinements in the definitions of abuse, neglect and unusual incidents. The process is also being modified to ensure the involvement of the QA Division at every juncture. Further the entire reporting format is being put on DMR's mainframe and sample reports are being generated. It is anticipated that such reports will be made to the Commissioner on a monthly basis. Data will also be shared with regional directors who will be required to take corrective action.

Clients, staff, family members or other interested persons may also report suspected incidents or other client rights issues to the regional human rights committees. The committee in turn recommends possible interventions to the Regional Director or Training School Director. Additional responsibilities of the human rights committees include:

- Detecting patterns and trends in the use of behavior modifying medication and restraints through the review of all incident and investigative reports in the region;

- Submitting quarterly reports summarizing aversive procedures and abuse/neglect reports to the Commissioner's office;

- Reviewing overall service plans that call for aversive programming;

- Requesting investigation of suspected abuse and/or neglect by appropriate state agencies.

Finally the Office of Protection and Advocacy also plays a role in monitoring abuse and neglect. Based on recent negotiations the Protection and Advocacy Office now sends weekly reports of allegations and determinations to DMR. Allegations must be investigated by the appropriate facility within seven days. If allegations are substantiated a protective service plan may be required. The protective service plan must in turn be reviewed quarterly by the individual's interdisciplinary team.

Programmatic Administrative Review

As described in the previous section, when a client or his or her representative feels that there has been an incorrect or inappropriate placement or there is some other disagreement over program content or quality, the administrative review process can be initiated.

APPENDIX 4:
RELATED MATERIAL

GOOD NEIGHBOR POLICY

POINTS TO REMEMBER:

Point 1: Most people are less than thrilled that their neighborhood has been selected for the site of one of our group homes.

Point 2: The two most common fears expressed by neighbors are: drop in property value and attack by one of our residents.

The best way to address and defuse the tension underlying the sentiments outlined above is to be a GOOD NEIGHBOR.

A GOOD NEIGHBOR: (Residents AND Staff are to consider themselves to be in this category)

1) TAKES PRIDE IN THE APPEARANCE OF THE HOUSE AND ITS SURROUNDINGS;

* keep the lawn cut
* plant flowers & pull weeds
* sweep sidewalks
* use only patio furniture for outside functions
* no cigarettes thrown on ground
* garbage properly stored before and after pick up
* no cars parked on the lawn (park on driveway surface or along curb in front of house)
* trim hedges and shrubs
* rake leaves
* shovel snow
* car parked in the garage and the door kept closed
* pick up litter on and around the property
* outside lights turned off after guests or staff arrive or residents come home
* curtains and shades should be properly hung and drawn (should look attractive to passerby)

2) TAKES TIME TO GET TO KNOW (AND HELP) HIS/HER NEIGHBORS;

* introduce the residents and yourself
* take a daily walk around the neighborhood (start with trips to mailbox, around the block, etc.)
* ask neighbors about events, customs, stores (trash pickup, libraries, block watches, etc.)
* smile and wave at the neighbors you see
* stop and chat about the weather, flowers, road conditions, improvements to their homes
* offer to help an older person with groceries, shovel snow, rake leaves

* invite neighbors in for a get acquainted tea, send over fresh baked cookies, have a holiday party
* participate in paper drive, buy Girl Scout cookies, join in on house decoration contests

ALWAYS REMEMBER TO INCLUDE A RESIDENT WHEN YOU MEET A NEIGHBOR (IF NO ONE IS AROUND MENTION THEM BY NAME).

3) PROJECTS A POSITIVE IMAGE:

* speak positively about the residents, your work, the agency, other neighbors
* speaks courteously to and about others (no yelling, cursing, defiance)
* be respectful of others privacy (no loud music, horns honking, doors slamming, early morning lawn mowing)
* conform to neighborhood norms (obey speed limits, noise curfews, house decorations)
* make sure our residents always leave the house dressed appropriately
* dress in appropriate work clothes (leave the short shorts and mini skirts home, no ripped or torn clothes)

ALTHOUGH THIS IS THE HOME OF OUR RESIDENTS, IT IS YOUR PLACE OF EMPLOYMENT. ACT ACCORDINGLY!

4) HELP HIS/HER NEIGHBORS TO UNDERSTAND AND APPRECIATE THE RESIDENTS WHO LIVE NEXT TO THEM.

* don't take offence at neighbors questions. Look at it as an opportunity to educate them
* interpret our residents' communication signs and teach a few signs to the neighbors who are interested
* explain in a calm and professional manner the reasons for our residents' unusual appearance, demeanor, and behavior
* be able to explain the difference between mental retardation and mental illness
* tactfully remove a resident who is acting in an inappropriate manner

OCCASIONS WILL ARISE IN WHICH NEIGHBORS MAY NEED TO BE ASSURED THAT EVERYONE AND EVERYTHING IS UNDER CONTROL. DO SO IN A CALM, PROFESSIONAL MANNER. DON'T ELABORATE ON THE SITUATION. ALWAYS THANK THEM FOR THEIR CONCERN.

How will the group home affect your neighborhood?

The group home will look like most homes in the area and will not be distinguishable from other houses. The character of the neighborhood won't be changed either. Property values aren't affected. A study by Princeton University and a Michigan research project undertaken by a professional appraiser found that a group home over an extended period of time had no affect on neighboring property values.

Group homes may even enhance the neighborhood. Parents and Friends ensures the community homes they operate are well maintained, painted on a regular basis, with attractive landscaping.

What is Parents and Friends of Retarded Citizens?

We have been serving retarded persons for more than 30 years. The organization was started in 1951 by Mrs. Evelyn Kennedy, the mother of a retarded son, who wanted more for her son than a life in an institution. She brought together a group of other parents from this area and with the help of some friends forged an agency that has been a pioneer in Connecticut and in the nation. First to establish community residences in Connecticut, the agency is the largest private, non-profit organization in the state serving the retarded. Parents and Friends, is supported by the United Way and many, many corporations, business firms, and individuals, parents and friends. It is nationally accredited for the outstanding services it provides to retarded people.

There are many variables in selecting a group home, convenience to transportation, shopping and other community facilities. A group home is meant to be just that; a home, and the people who will live there need the support and neighborliness of you and others in your neighborhood.

You can be a good neighbor and visit a group home and even offer to help out. Volunteer support is welcomed by the residents and their supervisors.

Parents and Friends of Retarded Citizens
184 Garden St., Bridgeport, CT 06605
Phone (203) 576-0211

Meet your new neighbors

They will live here, work here, play here.

They are all retarded.

Many people who are retarded are moving into group homes in communities like yours.

They'll be able to get to know you, and you can get to know them.

You can be a good neighbor And so can they.

ERIC

What does community living mean?

Many people who are retarded are moving into neighborhoods like yours. They will live in group homes, with staff supervision. These homes will offer them the chance for more independence and opportunities.

The people in group homes may have lived at home before, or may have been in state operated facilities. Now they are being given a chance to live a more independent life, with a home of their own.

The community residence provides them with a home and a "family".

None of us knows just how much we are capable of doing and the same is true of the retarded. Living in a group home may allow them to learn new skills, find a good job, become a more self reliant person, and feel good about themselves.

What are retarded people like?

People who are retarded learn more slowly than others and often take longer than most people to adjust to new situations and ways of doing things. They have different kinds of personalities, just like any group of people, and some may have physical disabilities.

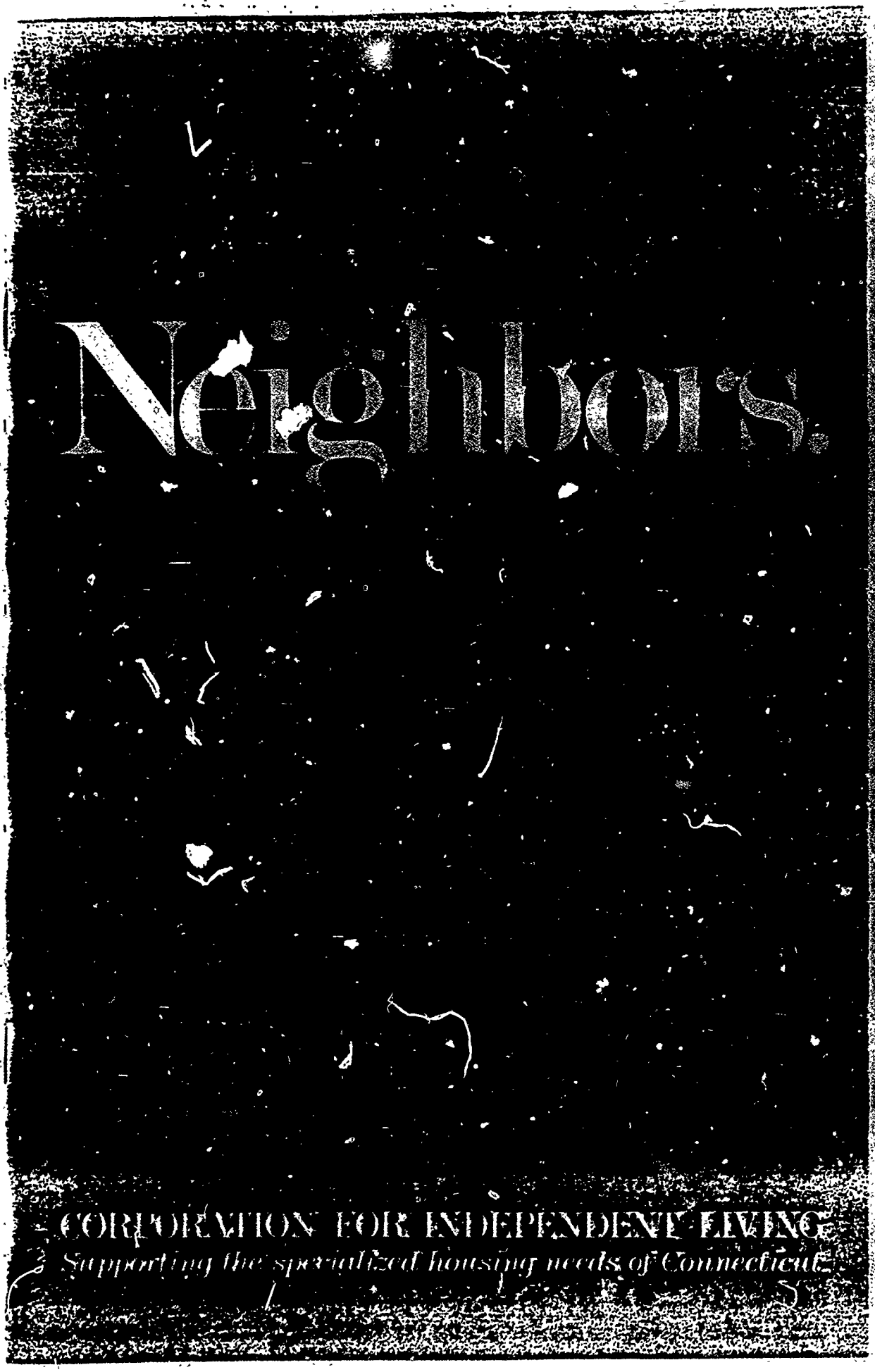
They need the opportunities and special services that are provided through Parents and Friends of Retarded Citizens, that will allow them to reach their greatest potential.

What will the people in the group homes do?

The residents of a group home will go to a job or a special training program at the Kennedy Center each day during the week. On weekends they will do the chores around the house, or go shopping, or just relax. The residential supervisors give the residents guidance and help them to take responsibility.

People who are retarded, just like anyone else, have their own favorite activities and living in a group home gives them the freedom to pursue their interests. Sometimes the group will take trips together, or some will go home to visit their families. They may be involved in community activities too. Parents and Friends provides weekend recreation programs for those who wish to participate.

ERIC


Neighbors.
CORPORATION FOR INDEPENDENT LIVING
Supporting the specialized housing needs of Connecticut

Neighborhood.

Everyone wants the same things. A job. Friends. Food. A place to call home. Neighbors. People with retardation, mental illness, physical handicaps are no different than anyone else in this respect. But their housing needs can't always be satisfied by ordinary means in the ordinary world.

The agencies that support these individuals have neither the time nor the specialized expertise required to operate successfully in the world of buying, selling and leasing real estate. Or customizing it to meet the needs of their clients.

Both have come to rely on the unique capabilities of an organization which deftly straddles two worlds. The ordinary world of "real estate development." And the world of human services.

Corporation for Independent Living

CIL is a private, non-profit organization dedicated to the purpose of developing small homes which allow people with handicaps, developmental disabilities, or who are in need of structured residential programs, to know the *joys*—and the responsibilities—of being on their own.

CIL was founded in 1979 as a coalition of non-profit agencies which were frustrated with their lack of success in creating community living opportunities for people with disabilities. CIL has become a major force in the development of small, community-based residences for people with all types of specialized housing needs.

CIL has been instrumental in developing a substantial amount of housing which is operated by other non-profit agencies around the state. Today, hundreds of people live in residential neighborhoods throughout Connecticut.

CIL receives generous support from the State of Connecticut as well as the Federal Government. But, also uses innovative techniques to obtain private financing for its projects. CIL has consulted with non-profit agencies to secure unconventional financing, allowing for the development of affordable housing for people who are victims of domestic abuse, have histories of mental illness, or require the use of a wheelchair.

CIL has been successful in using private syndication financing. It has been the general partner in limited partnerships which own 150 properties housing close to 750 people. It has maneuvered the revenue bond market to finance sole ownership of its real estate.

Neighborly.

In practice, CIL is a holding company with several subsidiary corporations which were organized in 1985 by functional area of responsibility to assist CIL in carrying out its mission. The subsidiaries are also non-profit, and operate under the control of CIL, whose primary function is to coordinate their activities and to engage in public education and awareness activities.

CIL Realty Inc. This subsidiary acts as a real estate ownership entity and as the general partner in limited partnerships controlled by CIL. All of the properties are leased to other, non-profit CIL member agencies which operate residential programs for people learning to live more independently CIL Realty Inc. contracts with CIL Management Inc. for management of all its properties.

CIL Development Inc. Operating under contracts with CIL Realty Inc., this subsidiary provides a full range of real estate development services. This includes site selection construction and rehabilitation, as well as resident coordination and placement. The subsidiary also assists CIL lessee agencies in meeting various funding, licensing and regulatory requirements.

CIL Consulting Inc. provides a number of services to member agencies which are not using CIL Realty Inc. to help them develop community housing projects. Services provided on a consult basis are offered to a wide variety of groups and can encompass all stages of project development. From conceptual program design to construction, occupancy and management. CIL Consulting works with HUD, the State Department of Housing, the CHFA, Connecticut municipalities, private corporations and conventional banks. The special expertise of this division is "creative financing," that is, combining public and private sector resources to create affordable housing for tenants who need support services and have limited incomes. In addition, CIL Consulting is an active advocate for the development of housing support systems for CIL's various client groups.

CIL Management Inc. provides management services to CIL Realty Inc. properties, including rent collection, insurance management, facility inspection and other aspects of lease administration. CIL has the ability to expand its activities to all CIL member agencies. In addition, CIL Management provides orientation and in-service training to CIL lessee agencies.

CIL Financial Inc. administers two major loan programs for CIL. Under a guarantee provided by CIGNA, loans for "Furniture & Equipment and Start-Up" costs are made available to CIL lessees to assist in the development of community residences. Using funds provided by the State Department of Housing, the "Loans for Accessibility Program" makes loans to private homeowners to make their dwellings accessible to and useable by household members with physical disabilities.

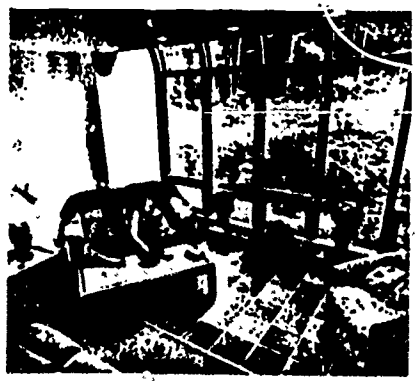
CIL Leasing Inc. provides a lease service for furniture and equipment for community residences.

ERIC

Neighborliness.

CIL provides member agencies with technical assistance needed to help them develop small, community-based housing for their clients. A wide variety of services are available

Planning and Site Evaluation. CIL will perform a housing needs analysis and assist in developing an overall project plan including type of housing, location, support services, resources, licensing requirements, etc.



In addition, CIL will inspect and evaluate alternative project sites, taking into account such considerations as local zoning regulations, fire and safety code regulations, condition of major systems, appraised property values and other requirements. CIL will also provide financial feasibility analyses of alternative project sites, based on evaluation results.

Project Development. CIL provides a full range of assistance in this area including site control, developing construction requirements, selecting project architects, obtaining cost estimates from general contractors, negotiating construction contracts and securing the services of surveyors, engineers and other professionals needed to complete the design phase of a project.

Financial Packaging. CIL financial services include preparation of requests for capital financing and coordination of funding agency processing of requests to secure commitments for long-term financing, obtaining cost reimbursement rates or other rental subsidies to support the capital and operating costs of the project.

Construction and Occupancy: CIL assists in monitoring construction or rehabilitation of projects, as well as obtaining the services of supervisory architects if necessary. CIL also advises operating agencies regarding need for licenses or other requirements for operating community residences. The corporation assists in the staffing and occupancy of the project once it is complete, and helps establish sound project operation and management procedures.

Loans For Accessibility: CIL makes available low-interest, long-term loans, funded by the State Department of Housing. Loans are intended to help low/moderate income individuals and families modify their homes to accommodate residents and family members with physical disabilities. CIL also assists in evaluating accessibility needs and the design of appropriate modifications.

Special thanks to Patty Ed Vincent Patty and Chris for allowing us to photograph them in their home

END

U.S. Dept. of Education

Office of Education
Research and
Improvement (OERI)

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March 21,1991

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