Planning for the Mentally Retarded in an Intermediate Jewish Community: The Experience in Dallas

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Planning occurs in a social context, and, therefore, it should emphasize the social process of group problem-solving and plan implementation. Planning services and programs for the mentally retarded is a relatively new phenomonon in the Jewish community.

Introduction

The movement to remove the mentally retarded from institutions in this country began in earnest in the 1960's under President Kennedy. It still remains to be seen whether the commitment to provide alternatives to institutionalization will be truly realized. Many communities have been ill-prepared, either psychologically or economically, to accept the mentally retarded in their midst. In a period of inflation and federal cutbacks in funding human services, the challenge rests with each community to firmly establish its own commitment to the mentally retarded and assure them there will be quality alternatives to institutionalization.

The Jewish Federation of Greater Dallas and its constituent agencies had been discussing the issue of services to mentally retarded Jews for some time. One agency, in fact, had initiated a work-training program; however, it never was implemented in the way envisioned. As a stimulus to these positive undercurrents, one family deeply interested in mental retardation donated a significant sum of money to the Federation's endowment program to help the Jewish community establish, within five years, a small group

home for mentally retarded adults. The use of this gift would determine the extent of Federation involvement and it could commit the Jewish community to a long-term program. The idea of a feasibility study was therefore formulated as a means for determining what was involved in establishing a small group home. The donor agreed to using accrued interest from the gift to support such a study.

The feasibility study is viewed, conceptually, as part of the problem definition phase of the planning process. In this planning phase the function "is to suggest what activities may be necessary to overcome obstacles, or indeed, even to indicate whether or not a plan should be initiated." This paper reviews the recommendations of the feasibility study as presented to the Social Planning Committee and Board of the Federation. It also describes the decision-making process which was adopted for conducting the study. The paper concludes with the importance of process in any social planning endeavor.

¹ Edmund M. Burke, A Participatory Approach to Urban Planning. New York: Human Sciences Press, 1979, p. 154.

The Participants and the Process

Selecting a Consultant and Advisory Committee

A subcommittee of the Social Planning Committee of the Federation was formed in the Fall of 1980 to choose a Consultant to conduct the feasibility study. Several individuals were interviewed. The selection of the individual finally accepted was based on: (1) his knowledge of the Jewish community; (2) his flexible style; (3) his desire for an advisory committee to bridge the possible gap between his academic background and university workplace with the Dallas Jewish community; and (4) the sense of the Selection Subcommittee that this candidate would conduct a study closely tailored to the Dallas Jewish community rather than come with a prepackaged set of conclusions.

The Consultant requested an advisory committee which would meet on a regular basis. Representing the Dallas Jewish community, the committee would provide input into the study's direction, serve as a resource, and, if the study determined it as feasible, be an advocate for the planning and implementing of a group home. Five categories for membership on the Advisory Committee were agreed upon by both the Consultant and Federation professional. They included:

- 1. People who have a vested interest in the establishment of the project, i.e., relatives of the retarded.
- 2. Liaisons to the Federation establishment, i.e., members of the Social Planning Committee and Federation Board.
- 3. Representatives of the constituent service agencies within the Federation system, i.e., executives or representatives of the Jewish Community Center, Jewish Vocational Counseling Service, Jewish Family Service, and Home for Jewish Aged.
- 4. Knowledgeable people outside the Federation system who could be used as resources, i.e., people with expertise in

mental retardation, zoning, real estate or the Jewish component.

5. A chairperson who had the time, commitment, and ability to be a spokesperson for the project.

The ideal membership criteria was agreed upon by the chairperson of the Social Planning Committee and, after she was selected, by the chairperson of the Advisory Committee. All of the prospective committee members were located. All agreed to serve on the Advisory Committee except for a rabbi. Even after an extensive search, no rabbinical representative was found willing to serve on the Committee. The Consultant anticipated the evolution of a core group out of this Advisory Committee which eventually would be responsible for the planning and implementation.

The role played by the Advisory Committee was significantly different from the role usually played by lay leadership in the Jewish community. For example, the Committee was neither a task force nor a subcommittee able to make recommendations to a committee or board on some major work completed. In a reversal of roles, the Advisory Committee had been formulated to advise the Consultant. He determined their legitimacy and existence; however, the Committee did desire independently to provide input into the final report.

Several questions emerge, highlighting dilemmas pertaining to the relations among the various participants in the process: Was the Advisory Committee structured so that its conclusion regarding the feasibility of the project would be foregone? Was it appropriate to establish an Advisory Committee with the idea that it might be an advocate for the project? Were there any decisions that the Advisory Committee would be allowed to make, in addition to either supporting or not supporting the final recommendations of the study?

Dynamics of the Advisory Committee

The committee meetings were structured to be informative, providing as much exchange of ideas as was possible between the Consultant and the Advisory Committee. Before each meeting Committee members received anywhere between five and ten pages of reading material that would be discussed at the meeting. In addition, several members were asked to make presentations based upon either their own experiences or upon research into a topic relevant to the feasibility study. This emphasis on early preparation and involvement stimulated dialogue rather than report-giving. The Advisory Committee's comments were usually insightful and acknowledged by the Consultant. Some members, however, indicated a distrustful attitude toward the Consultant when he did not immediately adhere to the Committee's collective insights. Many members had or developed a vested interest in the project; the Consultant's job was to be objective. The Consultant spent much time establishing himself as the one person entirely responsible for the content of the final report. The Committee could advise him and submit a separate report if they so wished. Because of the Consultant's personal behavior in accepting the Committee's points-of-view, coupled with his final conclusion that a group home was feasible, the sometimes tense interpersonal relations among the participants were resolved. The Committee voted unanimously to support the feasibility study and its recommendations.

The overall plan of action called for six Advisory Committee meetings, with one being an optional field visit. The idea of a field visit was to allow members of the Committee to observe directly a viable group home serving mentally retarded adults within the Dallas community. Additionally, arrangements were made for parts of the Committee to view "Best Boy," a film on retardation. Committee members were

so enthusiastic that all of them decided to participate in both options. Attendance throughout the process was consistently high; over 80 percent attended each of the six meetings.

The Consultant mailed a draft of the feasibility study to all Advisory Committee members. At the last Committee meeting, each section of the report was reviewed. Several suggestions were made which were incorporated into the final report.

The Chairperson of the Advisory Committee contributed to the presentation of the report to the Social Planning Committee and Federation Board. While the report was clearly the Consultant's, the Social Planning Committee was given a definite indication that a group of interested people, the Advisory Committee, had agreed to its contents. Many Committee members attended the Social Planning Committee meeting for the presentation. The Social Planning Committee voted to support the report and forward it to the Federation Board where the final decision about planning and implementing a group home would be made.

Roles, Responsibilities, and Contexts

The professional Federation planner who was assigned to staff the feasibility study project had to deal with three levels of accountability: (1) the Consultant; (2) the Advisory Committee; and (3) the Federation establishment. Functioning primarily in the planning roles of organizer and enabler, the Federation professional operated in two different settings: formulation of the agenda and during the meetings.²

Prior to each Advisory Committee meeting, he met with the Chairperson of the Advisory Committee and Consultant to structure the agenda of the meeting so that the appropriate items would be discussed constructively. He wanted to ensure that the Committee had a sense of accom-

² Ibid., pp. 270-272.

plishment after each meeting. These meetings served to clarify issues, to simplify the presentation of agenda items, and to determine the most efficient and effective ways of addressing them. This was especially important in light of the academic background of the Consultant.

The role played by the Federation planner at the Advisory Committee meetings involved performing the usual staff role of recorder and arrangements coordinator. In addition, he gave support to the Consultant as distrust of him was shown by several Committee members. Members who expressed distrust did so only before the Consultant reached his conclusions.

The Federation planner helped the Committee and the Consultant maintain objectivity in assessing the feasibility of establishing a group home. On many occasions he had to reinforce the purpose of the feasibility study, especially the objective analysis of the implications of the project. Since a large as well as long-term financial commitment by the Federation for the project was a possibility, such objectivity was imperative.

The planner was the Federation spokesman. He was frequently called upon by both the Advisory Committee and Consultant to discuss the resource capability and decision-making process of the Federation as they applied to conducting the feasibility study and the possible future establishment of a group home. Throughout the study, he was a resource for the Chairperson, Advisory Committee and Consultant for those items having to do with the formal structure of the Jewish community and the relationship of the project to the overall goals of the Federation. Most members of the Advisory Committee had never been involved in a Federation committee up to this time and knew little about the organization or its functions. Consequently, such seemingly simple steps of presenting the study first to the Social Planning Committee and then to the Federation Board were troubling to the task-oriented Committee members involved in the planning process.

The Feasibility Study

Scope and Methodology

The feasibility study analyzed the capability and practicability of the Dallas Jewish community to establish a group home for mentally retarded Jewish adults. It included: (1) different types of group homes, their characteristics, and costs; (2) supportive services needed by the mentally retarded, their availability in Jewish and non-Jewish communities; and (3) zoning requirements. This analysis was coupled with an examination of the specifically identified and potential population of Jewish mentally retarded in Dallas. Together they supported the study's recommendations to the Federation's Social Planning Committee.

The recommendations were guided by the principle of normalization, i.e., "utilization of means which are as culturally normative as possible, in order to establish and/or maintain interpretations, personal behaviors and characteristics which are as culturally normative as possible."3 The literature suggests that four sub-goals are necessary in achieving normalization in residential services and facilities for retarded persons: (1) Recognition of the right of self determination; (2) Recognition of the dignity of risk and failure; (3) Normality in all life components: work, education, home and social environments and activities; and (4) Integration of services and facilities with the community: physical, social and cultural.4

³ Wolf Wolfensberger, "The Principle of Normalization in Human Services. Toronto: National Institute on Mental Retardation, 1972, p. 28.

⁴ Community Living Alternatives for Persons With Developmental Disabilities, Volume 1: The Model, Springfield, Illinois: Governor's Planning Council on Developmental Disabilities, 1977, p. 3.

The data analyzed in the study included baseline information on the target population, small group homes serving mentally retarded adults, support services and programs, and legal requirements. Valuable material was provided by the Association for Retarded Citizens (ARC) at the national level, ARC of Fort Worth, Jewish ARC of Southfield, Michigan, Dallas County Mental Health Mental Retardation Authority, planning departments of Dallas and neighboring suburban communities and the Dallas Federation's constituent agencies. Also reviewed was an earlier study of the needs of the mentally retarded and their families in the Dallas Jewish community.

A major limitation was the inability to determine more precisely the number of mentally retarded Jewish adults residing in Dallas. Cost, time, and a specific mandate of the Social Planning Committee not to undertake any additional needs assessment made this type of in-depth study prohibitive.

Target Population

Mental retardation refers to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period.5 A three percent prevalence figure is frequently cited in estimating the number of mentally retarded in the U.S.; however, several factors challenge the underlying assumptions of this figure and provide a strong rationale for its reduction to the more conservative, but probably more accurate, one percent figure. Table 1 adapts a study of a prototype community of 100,000 and applies the one percent prevalence figure against a population of 25,000, our best estimate of the Dallas Jewish community.6 According to the table, retarded adults 20 and over total 61 for a population of 25,000.

Table 1

1% Prevalence Figures for Mental Retardation in a Community of 25,000

Age (in years) 0 - 56-19 20-24 25+ Total 10 0 - 192 5 1 5 13 9 5 19 20-49 17 50 50+ 6 150 6 25 187 12 49 250 Total 17 172

Recommendations

The fundamental question asked of the Dallas Jewish community is whether it should establish a small group home for mentally retarded Jewish adults. The study encourages such a direction. Where the leadership will come from and how one proceeds are the focus of the following recommendations. ⁷

A. Recommendation No. 1 — Type of Group Home: Six to eight residents is the standard for small group homes; however,

⁵ Herbert Grossman, (Ed.), Manual on Terminology and Classification in Mental Retardation (revised). Washington: American Association on Mental Deficiency, 1977.

⁶ George Tarjan, et. al., "Natural History of Mental Retardation: Some Aspects of Epidemiology," *American Journal of Mental Deficiency*, Vol. 77 (Jan. 1973), pp. 369-379.

⁷ A Group Home for Mentally Retarded Jewish Adults in Dallas, Texas: A Feasibility Study. Jewish Federation of Greater Dallas, May 1981.

no standard exists for the mix of residents. Residents' functional level does influence operating costs of a home. While segregation by sex may mean greater success in starting a home, using this and other residents' characteristics should be weighed against the principle of normalization.

In Dallas, it was recommended that a group home be established capable of accomodating six to eight Jewish men and women. It should be able to serve individuals who function at a moderate degree of mental retardation or higher and who do not posssess secondary disabilities requiring major environmental or staffing changes. Each resident should be capable of either sheltered or competitive employment. Exceptions, however, should be made for individuals functioning below a moderate level if they demonstrate potential for growth and can benefit from living in a small group environment; adaptive behavior is critical to such determination.

B. Recommendation No. 2 — Staffing: The hiring of an executive director or project director should commence at the earliest possible date upon approval to plan a group home. Site selection, screening applicants, formation of a board of directors, obtaining funds, selecting and training staff, and public relations are major responsibilities demanding immediate attention.

C. Recommendation No. 3 — Site Selection: Trade-offs exist in selecting an appropriate site. At the head of the list may very well be sacrificing the "best" choice in terms of normalization. Possible negative attitudes generated in a neighborhood may be viewed as more costly than actual dollars needed to start and operate a home. Obtaining specific use permits can be lengthy and expensive, and they subject the sponsor(s) to community opposition.

It was recommended that the site chosen have the least possibility of being denied and that it be the most accessible to the major Jewish agencies. In the case of the Jewish ARC in Southfield, Michigan, their first group home, located in Detroit, was eventually sold and new suburban housing obtained that was better integrated into the Jewish community.

D. Recommendation No. 4 — Case Management System: A formal procedure is recommended for managing each resident of a group home. At present there are gaps in the availability of services in Dallas to meet the needs of mentally retarded adults. A full range of services needed by this population should include: family support, residential placement, income maintenance, advocacy and protective services, transportation, health and mental health services, education, leisure time and recreation services, vocational counseling and employment.

Jewish Family Service was deemed the most appropriate agency to serve as case manager based upon its experience in resettling soviet Jews. Similarities in the two programs exist in serving individuals needing a comprehensive and integrated service system. Dallas Home for Jewish Aged (Golden Acres), with its many years of experience in providing long-term care, is an important complementary resource. Implicit in the design of the case management system should be a precise determination of the responsibilities of each Jewish agency to the residents of a group home and other mentally retarded Jews in Dallas. Interorganizational relations should also be determined with other agencies and organizations serving mentally regarded.8

E. Recommendation No. 5 — Funding: The quality of care, long-term planning, monitoring, freedom of residents, security of the program's future, and administration are all influenced by the primary source of

⁸ Lesa Andreasan, Carolyn Cherington, and Jeffrey Schwamm, Existing Procedures and Recommended Policies for a Case Management System for Developmentally Disabled Individuals in the Westfield DMH/MR Area. Watertown, MA: Social Planning Services, Inc., 1978.

funds. The major source of financing should provide least restrictiveness in the kind of program considered in the best interests of the target population. Those involved in the planning of a group home should generate financial support from the Jewish community and look to public funding where appropriate. A resident's ability to pay may serve as one factor to eligibility in a home, but every effort must be made to insure that family income is not a criterion for exclusion.

F. Recommendation No. 6 — Transportation: Transportation should be incorporated into planning a group home. As a service, it has implications for all Dallas Jewish residents, e.g., elderly, who find themselves handicapped by lack of accessibility to needed Jewish and other community resources. Such a vital service may suggest another forum for action than one primarily concerned with mentally retarded.

G. Recommendation No. 7 — Group Home Task Force: A formal body should be established to undertake the planning of a home. As a partnership effort among parents of mentally retarded Jews, future residents, Jewish Family Service, Jewish Vocational Counseling Service, Jewish Community Center, Dallas Home for Jewish Aged, and Federation, the activities of this body should be jointly coordinated by Federation staff and lay representatives of the Social Planning Committee.

The participation of the Federation should not at this time be necessarily interpreted as a financial commitment to the management and operation of the home. The Task Force should become the sponsor of the home. The Federation may undertake responsibility to convene meetings and coordinate planning. Formal leadership for continuing success of the home will hopefully emerge from this Task Force, possibly with the nucleus of a board of directors and acceptance by one of the agencies for overall management and operation of the home.

Discussion

Planning occurs in a social context, and, therefore, it should emphasize the social process of group problem-solving and plan implementation. Planning services and programs for the mentally retarded is a relatively new phenomenon in the Jewish community. It is a complex field which usually assumes a long-term financial commitment, especially with respect to housing. The actual plan to provide these services and programs should evolve from a decision-making process that asks from the very outset, "How feasible is the idea?" The answer, in the case presented here, suggests a systematic and gradual approach to planning that involves an active lay group in problem-solving on feasibility, and hopefully, plan development and implementation. An in-depth and unbiased answer to the feasibility of undertaking the establishment of a group home for mentally retarded Jewish adults in Dallas was initiated with the hiring of an independent consultant. Despite some interpersonal tensions, the employment of an Advisory Committee greatly facilitated and legitimized the technical work conducted by the consultant.

Several roles have been identified which may be played by the Federation planner in working with consultants. It is both desirable and assumed that Federation professionals will give their expertise to a lay group involved in the planning process. Initiating a meeting of Consultant, Chairperson of the Advisory Committee and Federation planner prior to beginning the feasibility study was one illustration of the agency professional effectively drawing together the interests of the organization (Federation), the technical expert and the lay group. The actual completion of a technical report such as a feasibility study is made that much easier when attention is devoted to these three forces early on in the social planning process.

In September of 1981, the Federation Board met to take action on the recommendations of the Consultant as accepted by the Advisory and the Social Planning Committees. Board members voted unanimously to endorse all recommendations and give sanction to the formation of a

Task Force that is responsible for developing a plan. Once a plan is accepted by the Federation, the actual occupancy of a group home can take place. It remains to be seen what problems will be encountered in the ensuing phases of plan development and implementation.