

Developing Services to the Mentally Retarded/Developmentally Disabled*

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What have we learned? A great deal. When we began, I for one knew little or nothing about serving mentally retarded, in fact was a little in awe of them, somewhat frightened by their behavior and limitations, but I felt strongly that we had to serve them.

IN June, 1981, state funding was made available to private as well as public agencies by the Maryland Division for Mental Retardation and Other Developmental Disabilities (MRDD) for an "Alternate Living Unit" program to serve higher functioning mentally retarded persons then housed in two state institutions. The Jewish Family and Children's Service of Baltimore responded positively to the proposal.

The agency had not ever before served the long-term needs of the mentally retarded, because we saw such service as the responsibility of the state, and because long-term care requires enormous sums of money. The principle of normalization, however, states that mentally retarded (MR) persons should be served in the "least restrictive environment." Aiding in deinstitutionalization and closing of unneeded institutions thus became part of a growing responsibility of community based agencies such as ours.

After some staff on-site visits to ALU programs—for orientation to the problem and determination of feasibility of service—consultations with State officials, and thorough consideration by the Board and Associated Jewish Charities, it was agreed that the agency proceed with the proviso that legal responsibility would remain with the State and as long

as State funds were available. The agency was also charged to do a needs assessment of the mentally retarded in the community.

This account omits the details of the struggle and effort that went into this early process. We dealt with the issues (to mention a few) of being partners with the State with all of its ups and downs in funding, the regulations, the mixed messages, the sectarian nature of the agency and whether we would be willing to serve a non-Jew under prevailing Federation policy, and the adequacy of the budget. There were differences among members of our and the Associated Jewish Charities Boards as to the degree of our responsibility. There were many times during these months that the staff of JFCS involved in this process thought that the death knell had been rung on our proposal.

A study by our planning committee; which included canvassing opinions of 91 community leaders, professionals and families, showed that the MR community felt 1) an acute need for more supervised housing and a thorough investigation of group homes or other living arrangements, 2) that an information and referral system should be established and concomitant with that, there should be more outreach to the MR community, and 3) that the Jewish community should increase the number of social, leisure and vocational activities available to the handicapped.

We were most fortunate to hire a

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graduate student in special education to fill the half-time coordinator position that was created. He had had many years experience in working with the retarded as the coordinator of a similar program in New York City.

In consultation with the chief of the state MRDD, we had established criteria for screening potential residents. He or she had to be ambulatory, have manageable medical problems (i.e., drug controlled), have self-help and communication skills, attend a day program, be potentially able to learn cooking and cleaning chores, and to be able to function without awake night supervision. We did not use an IQ range because we thought it was not a reliable measure of functioning since all of the potential residents had been institutionalized for so long and tested long ago.

With these guides to selection, we accepted three women as our first charges. The resident staff we employed, all, had had some education and/or experience with this or a similar population. We also rented a three-bedroom apartment that would accept a Federal "Section 8" subsidy and be approved by the State agency.

We took possession of the apartment on July 1 (1982). Technically, we could not approve the three residents until they had an overnight visit. We could not have an overnight visit until we had an apartment. We could not have an apartment until the residents signed the lease. We dealt with these "catch 22s", and had our overnight visit which went very well. The Admissions Committee, required by the program guidelines and comprised of professional and community people, met and approved the three residents. The required two-week notice was given for release of the residents. The home was set up for observance of the Kashruth. Candles are lit and blessings over washing of hands, wine and bread are observed on Friday

nights. Our consulting Rabbi affixed the *mezuzah* at the apartment with the residents present. Synagogue services on Friday evening or Saturday morning are attended by one resident faithfully.

Though the State early raised questions about our offering a sectarian service, our lawyers researched the state law governing discrimination in provision of services. Race and national origin are mentioned, but not religion. Technically, we are within the law.

When we evaluated the first six months, we saw positives and negatives, and what areas of concern could be changed and what could not. First and most importantly, the residents all seemed to have made some improvement. Barbara, 38, had been almost non-verbal when she came and now talked a great deal more. Alice, 27, had been very stubborn and obstreperous and had used loud, obscene language. Though this behavior had not been extinguished, it had improved somewhat, making it easier to deal with her. There had been no serious acting out and the residents seemed to get along with each other rather well. There had even been some evidence of concern for one another. With supervision, the residents had learned to help prepare dinner, set the table, do their laundry and clean the apartment. It had been a hard six months, but there had been progress.

There were several areas of concern that we had experienced in this program. We found that the residents needed constant supervision and that the funding schedule originally worked out was "bare bones" and did not account for medical appointments, or any contingency. We succeeded in getting an increase in state funds. Though our house staff gives adequate supervision and does show a modicum of caring, there is a certain lack of commitment to the program and to the people. Consequently, we find that there is no real

sense of home and no head of the household to set an emotional tone of warmth and unity.

Unlike larger providers, our program is one unit, rather than one among many, creating yet more isolation. For example, we do not have the ability to "juggle" residents and staff when holidays or emergencies make coverage difficult. Providing social outlets has been a continuous effort. Though our residents attend a weekly meeting for mentally slow individuals at the Jewish Community-Center, there is little else besides movies, bowling and some visiting. A more sensitive issue is that of sexual outlets. While institutionalized, these women all had boyfriends and had sexual freedom. How we handle this has been discussed with other providers and among ourselves. We have no clear answer yet. If the residents were more independent, perhaps they could have their lovers when away from the apartment.

Part of the six months' assessment was to evaluate the possibility of opening another ALU or two. In the meantime, the state shifted its method of funding and extended the Request for Proposal process to human services, supposedly a consumer-oriented process, that has proven to be almost impossible to deal with. The procedure involves a Request for Proposal and the state personnel preparing a list of residents in the institutions with a little information on them, and holding a "bidder's" conference in which one reviews the information on the clients and submits a proposal based on the needs of these individuals. Then the bidder waits to see if they have been awarded the contract. The sectarian issue remained a somewhat difficult one. We did not feel completely comfortable in saying outright that we would prefer to serve only Jewish residents, so, instead, in reviewing the list we searched for Jewish

names, tried to find the religious designation in the record which was not always there and generally felt surreptitious in our search. The expansion of the program became more of the state's prerogative than ours; a reverse situation.

An expansion of the ALU program looks promising. The State legislature had passed a bill allocating funds for supervised housing for MR individuals residing in the community who are deemed in danger of institutionalization. What this latter phrase means is unclear, but it is the State's responsibility to compile a list of appropriate individuals. Last winter we went through an extended process of reviewing a RFP list, made selections, had them approved, talked to the families etc. only to be told in May we would *not* be funded and would need to go through the RFP process again. Needless to say, we were angry and devastated at the process we had begun with the families and now had to interrupt.

Given the indications from the community assessment of needs pointing to non-resident services as well, we have employed a half-time specialist in special education to coordinate four undertakings that we had proposed in order to receive a funding grant:

- 1) To develop a specialized baby-sitter service
- 2) To develop an information and referral service for families of the retarded
- 3) To develop support groups for families of the retarded
- 4) To develop specialized training programs for our casework staff who are or will be working with these families.

As of this writing the baby-sitting service training and the support group for families are under way. Our coordinator came on board the end of November of 1983. Before she began, plans were

made to run an eight-week JFLE group for parents of mentally retarded children. In order not to duplicate service, the JFLE coordinator and the new project coordinator developed a package combining the JFLE support group with the sitting service. First, the new project coordinator began an all-out campaign of recruitment of people interested in the "sitting" training by approaching local colleges, schools, synagogues, and Jewish organizations. A large mailing and advertisement in local Jewish and neighborhood papers were additional means of recruitment.

An intensive two-day, five-hour (each day) workshop for training sitters was developed to include participation by outside specialists and to include even a woman with two retarded children who came to talk of her hands-on experience. Over 120 calls were received requesting this training and we invited 60 to attend. Out of this total, 21 came to both sessions and became "certified". Then the service was offered to the parents who were planning to come to the JFLE group. Thus, two purposes were served. First, parents attending the group had somewhere to leave their children, and second, the sitters had some more experience with mentally retarded children while under the supervision of the coordinator. The group ended the first week in May, with plans being discussed for developing a continuing support group.

Out of this process there was developed also a list of sitters that was sent out to those families that had responded to the advertising of this service in the media. We dubbed this the "Special Needs Sitter-Service" so as to not stigmatize or label it and to allow for possible expansion to other needs in the community, e.g. parents of disabled or the elderly. This list was sent out April 1 and an evaluation form was sent to potential users. A later meeting with the

sitters was scheduled to glean information about their experiences. Twenty-eight Jewish families have been involved.

The information and referral service and the special training for the staff also have begun. We have centralized all requests for mental retardation services to the coordinator, and a questionnaire was sent to the staff inquiring of their interests in training and their level of knowledge and/or experience.

Results are positive. That segment of the Jewish population that has, or has family members with, mental retardation has responded favorably to our interest in their problems. The anger and frustration they felt before at our not addressing their needs are being replaced by hope and more positive feelings.

Where do we go from here? Our staff feels strongly that we should continue to use whatever resources are available to offer services even if this means working with the unpredictable state process. We would be willing to do it by educating the families we are working with to these problems.

What have we learned? A great deal. When we began, I for one knew little or nothing about serving mentally retarded, in fact, was a little in awe of them, somewhat frightened by their behavior and limitations, but I felt strongly that we had to serve them. We first thought that a trained social worker was needed for the coordinator position. We know now that hiring special education people was most appropriate. They have given us the missing piece we do not have, and we in turn have given them a further clinical understanding of families and community they may not have. We have mutual respect for each other and our expertise. Our coordinator of the ALU is not Jewish, but he has put much into understanding and providing the necessary Jewish compo-

ment. The projects have been exciting and rewarding for staff, client and board. Everyone has invested time and a great deal of energy into development of services to the mental retardation population which are dynamic and growing.

Bibliography

Annual and Five-Year Plan for Comprehensive Mental Retardation Services for the City of Baltimore, FY 1981-1985, Baltimore City Health Department, 1981.

Annual Plan for Comprehensive Mental

Retardation and Other Developmental Disabilities Services for the City of Baltimore, FY 1983, Baltimore City Health Department, 1983.

Final Report of the Joint Oversight Committee on Reinstitutionalization. December, 1981. Md. State Senate Committee Report.

Flynn, R. J. and K. F. Nitsch, *Normalization, Social Integration & Community Services*, Baltimore: University Park Press, 1980.

Novak, A. R. and L. W. Heal, *Integration of Developmentally Disabled Individuals into the Community*. Baltimore: Paul H. Brookes, 1980.

25 Years Ago

Within the family—this laboratory and testing-ground of human values—one acquired first, the idea of a group of brothers and sisters, and, eventually, of a world of brothers and sisters, all children of one loving Father. "Do not oppress your fellow-man—for he is your brother."

The Jewish family has changed. But this idea lives on in us unbroken, though in different forms and guises, and impels our community to vigorous social and charitable thought, planning, and deeds. In this, the noblest attribute of the Jewish family of old, we may recognize the contribution our group is prepared to make in the radically new era into which we are moving.

There are, to be sure, various ways out of the dilemma of modern man who refuses to become a machine; there is friendship, creativity in literature and the arts, dedication to great causes, the regenerating power of deep religious faith.

But if we don't misread the signs of the times—we are confronted by a

strangely paradoxical development: more and more people will expect help to neutral approach: our public institutions and various organized bodies.

This is already apparent. For example, today's student expects the University to give him not only learning, but personal esteem and affirmation. He does not come merely as a potential scholar but as a human being seeking help in establishing his identity; often a teacher feels that the student's whole existence is at stake. The same is true in our hospitals, and more strongly still, in our synagogues and social agencies.

No research, no statistics, no social criticism will prevent the ever more comfortable, externally secure American family (including the Jewish) from becoming progressively more functional, more mechanical, more fragmented.

Nahum N. Glatzer
this *Journal*, Spring, 1960