DISCUSSION PAPER #2

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THE BIG STICK: PLACING PERSONS WITH MENTAL RETARDATION IN COMMUNITIES

Gina Vega, Director The Office of Community Studies

The Office of Community Studies

Department of Urban Studies

Queens College/CUNY Flushing, New York 11367

I. <u>BACKGROUND</u>

The deinstitutionalization of the mentally retarded and developmentally disabled in New York State has had a profound effect on community behavior over the last ten years. Prior to the passage of Mental Hygiene Law, Chapter 468 of the New York Laws of 1978, most of the mentally retarded and developmentally disabled population lived in large institutions, amid conditions of varying degrees of degradation. No one saw them; no one thought about them. Once the scandal at Willowbrook State School in Staten Island was made public through the efforts of Geraldo Rivera, who televised the horrors at the institution in 1972, the parents of mentally retarded children and adults "went public" with their stories and entered a class action on behalf of their children for appropriate and humane care of the developmentally disabled and mentally retarded. The result was the "Willowbrook Consent Decree," mandating the deinstitutionalization of Willowbrook residents.

The Decree led to additional legislation meant to ease the establishment of group residences within local communities. The Site Selection Law, commonly known as the Padavan Law, defined a reversal in public policy towards the mentally disabled, and supported the establishment of small, community-based living environments which would promote the "normalization" of the

has been the subject of numerous court cases due, in part, to the vagueness of its descriptive language.

The Padavan Law mandates the following steps:

1) The sponsoring agency notifies the municipality of its intent to establish a residence at a specific location within the municipality.

2) Within 40 days of notification, the municipality must do one of the following:

(a) approve the site

(b) suggest one or more alternative suitable sites within the municipality for such a facility

(c) fail to respond

(d) object to the establishment of a community residence on the grounds that such a residence would result in a concentration of such facilities in the area that the nature and character of the community would be substantially altered.

approves the site, the agency may proceed to establish the residence. If an alternate site is suggested, the agency must determine its suitability for a residence. If the municipality objects on the grounds of alteration of the nature of the area or if the agency and the municipality cannot agree on a site, either party may request a hearing before the State Commissioner. The burden of proof at such a hearing lies with the municipality. If

by small, vocal minorities, and that these minority views are not representative of the community as a whole. Opposition can succeed, however, when this minority obtains political backing and is vociferous in its opposition, and when the neutral majority offers little active support for the proposed home.

In their book The Willowbrook Wars, Rothman and Rothman detail the successful opposition to a group home when the minority has strong political and religious backing. The Greek Orthodox community in Astoria, supported by the local priests and politicians, generated so much fear and demonstrated so effectively that the state gave up its attempt to locate a group home there. In Riverdale, site of the most protracted group home battle in New York State history, OMRDD was forced to drop its plans to establish a residence on Valle Avenue after 25 months of negotiation with the community and the ultimate intervention of the Borough President who claimed, in 1979, that Riverdale would never have a community residence.

Although we have now seen many instances of successful group homes for the retarded in New York State, these results were uncertain when the first homes were established and the Padavan Law instituted. There was no reason for communities to feel confident about their future in the beginning of the deinstitutionalization process. Given this uncertainty, opposition was not surprising. Opposition became habitual, the

II. THE STUDY

During the summer of 1986, I conducted a study of community reaction to the siting of group homes for the mentally retarded in Queens and Westchester counties. The purpose of the study was to isolate the common themes of opposition to community residences and to formulate an approach to group home establishment which would obviate some of this opposition.

The study entailed the examination and analysis of the unsolicited statements made and questions asked at public hearings for group home siting approvals during the 30 months from January, 1984 to June, 1986 in the two counties. A total of 13 hearings were held and studied. Four hundred forty-two individual statements or questions were extracted and organized into four major categories:

- 1. ECONOMIC FACTORS;
- 2. BELIEFS ABOUT THE MENTALLY RETARDED AND CONCERN ABOUT THE LEVEL OF SUPERVISION OF GROUP HOMES;
- 3. QUALITY OF LIFE ISSUES;
- 4. RESENTMENT OF STATE SUPREMACY.

ECONOMIC FACTORS included such issues as the amount the State pays for a particular property, the tax burden on the

III. FINDINGS

It is no surprise that opposition seemed to appear more frequently for group homes run by voluntary agencies than it did for group homes run by the State, since almost three times as many homes are run by voluntary agencies as by the State.

What is surprising is that the emphasis in the opposition to the establishment of group homes has shifted from the generally accepted category of fear and prejudice to anger about the powerlessness of the average citizen and the apparent omnipotence of the State. Upon examining the categories listed above, we note that 11.1% of stated concerns were economic in nature (N=49); 17.9% of concerns had to do with misunderstandings about mental retardation and the quality of supervision offered by the staff (N=79); 26% pertained to quality of life issues (N=115); and 45% of concerns indicated frustration, anger, and a feeling of helplessness at the power of the State (N=199). [See Figure #2]

These figures show a sharp change in expressed causes for opposition to community residences from economic and quality of life issues, to the more basic issue of individual rights. The result has directed responsibility to the State, making it accountable for the success or failure of communities in

As with most partisan statements, the truth lies somewhere between these two extremes. Fear and misunderstanding about the mentally retarded has diminished over the years, as has concern over property values. We must combine the quality of life concerns with the misunderstandings about retardation and worries about sufficient quality supervision in group homes, to even approximate the percentage of complaints about state supremacy. [See Fig. #3]

However, the accusations of paternalism and imperialism may be well-founded. As of 1985, 34 states and the District of Columbia had passed state zoning laws to facilitate the integration of the mentally retarded and developmentally disabled into the mainstream. These laws supersede, in a variety of ways, municipalities' rights to determine zoning, to define education and rehabilitation, to determine the nature of a community, to describe a family, to enforce non-discriminatory practices, and to impose restrictive covenants on its members. 2 These rights to self-determinism have not been surrendered willingly: the literature shows extensive and time-consuming lobbying and redrafting of proposed legislation since the adoption of deinstitutionalization policy in the Willowbrook Consent Decree of 1975. One result of this legislation has been to confuse local town councils and community boards as to the role they play in the siting procedure.

In an attempt to encourage an equitable distribution of group homes throughout Westchester County, CRISP (Community Residences Information Services Program) has developed recommended dispersal criteria based on population, land area, dependent populations, residential facilities and tax exempt properties in the county. The goal of these criteria is to provide the necessary guidance, both to the agencies and to municipalities, to evaluate local involvement in the establishment of group homes in comparison with other communities within the county. Despite the limitations of its program, including the difficulty of factoring in availability of housing stock and cost effectiveness, the CRISP program is lauded throughout the State. Acceptance of group homes in one's community becomes much more palatable when it is obvious that the State is really trying to avoid "dumping" on any community.

Twenty-nine states have addressed the issue of dispersal in their zoning laws. Distance between facilities may vary from 300 feet in Minnesota to one mile in Utah. Limitations based on population density also vary to the same extremes: from 1 percent of the municipality's total population in Wisconsin to .005 percent of a city's population in Nevada. These states do not appear to have experienced legal challenges on the grounds of saturation. That loop-hole was closed to the apparent satisfaction of all parties. The complexity of the problem,

Notification

An additional area of contention with regard to State behavior pertains to the notification procedure outlined in the Padavan Law, and consequent doubt that the procedure truly was followed. At hearing after hearing the communities complained that they were not notified; not notified early enough; must labor under a constraining time frame and are kept from getting sufficient information. One suspects that this concern about time frames and advance notice has more to do with rallying the community against the proposed home than it does with obtaining information about a specific site, but there is no empirical evidence to support this theory. Therefore, this objection is considered at its face value. Fifteen percent (N=30) of the state supremacy statements revolved around this issue. Upon examination of the actual procedures surrounding notification of the local community, we discover that, if we are to believe the community boards and agencies, notification has been full, wider than necessary, and timely. The community boards notify by mailing fliers to hundreds of local organizations, legislators and community leaders, as well as by announcements in the local newspapers, and personal visits to the neighborhood. The agencies also often make personal visits to the residents of the blocks surrounding the proposed site and attend meetings of local When the hearing is scheduled, notification often occurs no sooner than the week prior to the hearing due to these factors. When the community board notifies local residents via fliers left in doorways, these fliers may be discarded unread by the residents because of their resemblance to "junk mail" and advertising circulars. The residents then claim lack of notification, rightly or wrongly. Perhaps this low-profile method of advisement is an inadequate attempt to notify but, short of calling every resident in a neighborhood on the telephone, it is probably the most efficient way to communicate, remembering that local block associations and civic associations are usually invited to participate in the original committee meeting.

The Public Hearing

The occasion of the hearing, itself, incorrectly seen as a State function by the public, is also under the gun. We hear accusations of personal interest on the part of members of the community board; public hearings being "loaded" with professionals and parents of retarded children; prior secret negotiations; and unfair procedures by the boards themselves. This identification of the community board as the "enemy" takes

introduced into the community by the State (and/or the agency, acting as the agent of the State). The communities simply do not believe that the mentally retarded and developmentally disabled are the only population which will be admitted to a particular site. Even though the law makes it clear that the population may not be changed automatically (Chapter 785 of the Laws of 1982 requiring a group home which is no longer needed to be placed on the open market), the communities refuse to accept this explanation. Based on what they consider previous "sneaky" State behavior, they lose all faith in the sincerity of the State's commitment to protect all populations, their own included. They begin to suspect that the State will purchase adjacent houses to enlarge the facility and, since they have limited recourse, that they will be at the mercy of the policy-makers.

This fear is not unfounded. We have seen instances of low-profile siting and legislation which is heavily lobbied by forces more organized than local communities. We have read articles by planners advocating this approach. As C.K. Sigelman states:

"If attitudes are considered at all, the planner should contemplate not attitudes per se but the likelihood that various types of citizens will act on negative attitudes...(there) is ample room for the realistic planner to operate, selecting a site which will optimize program success without fretting over intricacies of attitude".

IV. CONCLUSIONS

Where do we go from here? Is it satisfactory for the State to adopt a policy with considerable social ramifications and simultaneously limit the opportunity for real participation in the implementation of this policy by the community? We have documented a history of dissatisfaction with the present method of policy implementation, and will now address the implications of alternate methods of pursuing normalization.

Normalization has been described as a two-part equation: changing the behavior of the retarded and changing our perception of the retarded. Both are essential for optimal results. I suggest that a third element must be included in this model: inclusion of the community in policy implementation. The State has the right and the power to exclude the community; conversely, it has the power and responsibility to include it. Our current Site Selection Law does not address this issue satisfactorily.

Fair Hearings

The implicit threat of eminent domain appears to have a negative effect on the willingness of the community to accept the mentally retarded. We are not suggesting that the State be

realistic definition of "concentration which would substantially alter the nature and character of the community". This "intelligible principle" cannot long stand without clarification of language.

Education

We have seen that attempts to educate the community often have backfired. The educational effort should not be discarded: however, it should be re-evaluated. Most people receive their first and only formal exposure to information about retardation and normalization at a time at which receptivity is at its nadir, that is, at a public hearing for site selection. At that time, communities are only interested in protesting, shouting, and venting their frustration. They are not in a frame of mind to assimilate information which is alien to their accepted beliefs. It is possible that, at such a time, any effort to educate will be wasted and may increase the dissonance with which the community is struggling. In 1987, it seems to be the idea of being forced to house the mentally retarded in the neighborhood, rather than the misunderstanding of retardation itself, that has become the issue. We cannot hope to dispel misconceptions at one emotion-laden meeting such as a public hearing. A more comprehensive educational program is in order.

be made available to every school as part of the standard curriculum.

These programs should allow for an extended question and answer period, as well as an open discussion of fears and misunderstandings. This process would offer an invaluable opportunity for sensitizing the community to the needs of the mentally retarded and the ways in which they can assist in normalization if they do live near a group home.

<u>Integration</u>

Recent research has shown that group homes are not being integrated into the community even when they are accepted by the neighbors. 10 The residents are frequently ignored by the other families on the block, rather than being encouraged to participate in local community affairs. This so-called "acceptance" does not fulfill the precepts of normalization; the residents are as isolated during their expeditions to the ice-cream parlor, supermarket, church or bowling alley as if they were being bused in from an institution. They have not become part of the local scene. In order for deinstitutionalization to really work, this must change. The NAC's should be encouraged to take a more active role in this process; it will not happen without their help.

subsidizing the production of additional attempts, and use its clout to have them broadcast on more widely viewed channels.

Newspapers can also be enlisted in the education effort. In recent years, there has been an increase in the number of positive articles about normalization. However, we still see evidence of confusion on the part of reporters about the difference between mental retardation and mental illness. 11 This distinction, and clarification of other pertinent facts, must be made and reinforced periodically by the State, either through its information office or a public relations office directly under the control of OMRDD where, one assumes, accurate information will be available. Frequent press releases must be issued to generate the amount of coverage necessary. This office must keep the public aware of changes in legislation, and should encourage participation by the public in making such changes. With sufficient positive information, public attitudes will begin to

This method of sensitizing the community is a long-term approach. Paybacks will not be evident in the near future. However, since retardation is not a temporary condition and will always be with us, our approach need not be uni-dimensional or oriented only to immediacy.

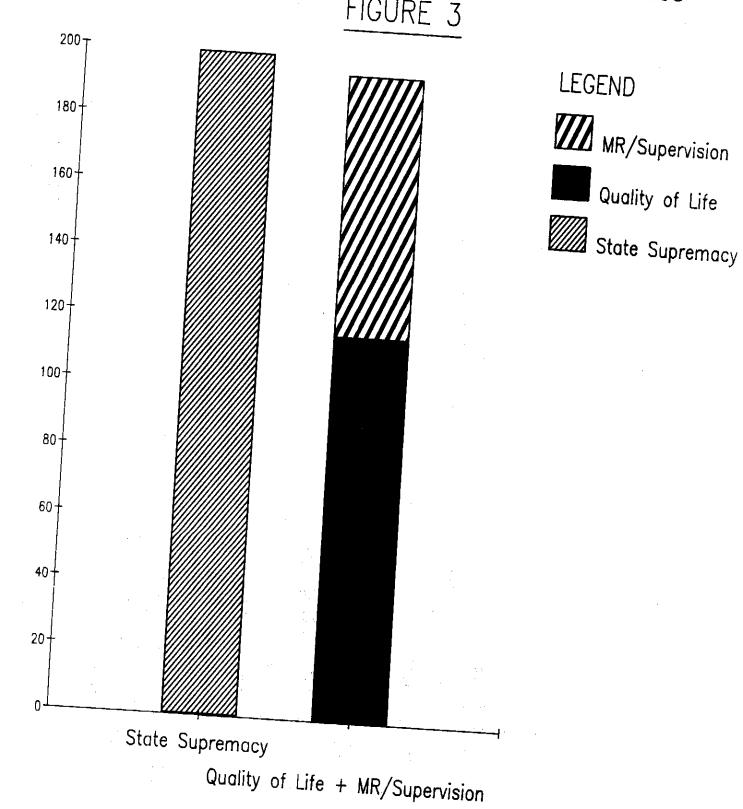
The Padavan Law is a start. At the present time, its greatest success has been in redirecting community opposition

TABLE #1

SAMPLE STATEMENTS AS CODED IN CATEGORIES

STATEMENT AS CODED IN CATEO	GORIES
How many people here would buy a home next to a	CATEGORY
Very expensive report :	Economic
Very expensive renovations would have to be made	:. H
where they live.	
How can four or five staff members take care of	MR/Super- vision
The yours at the	n
The young children in the community may tease the retarded and provoke them into violence.	11
day at a group home.	Quality as
The area is delicately balanced and this group	Life Of
home will affect the area negatively.	**
This location is unsuitable because of safety	
My frustration is	ti .
My frustration is a sense of being taken for granted that I resent.	5+a+.
If the community	State Supremacy
could we have done?	ti .
If the association is so concerned about the welfare of the retarded clients, then how can home when the people of the neighborhand	**
so opposed to it? the neighborhood are	
Why is it that the State, who has mandated the law, will now oversee the law, which will administer the law, now becomes a participant operating within this law?	"
What is a community? I don't know what a community is anymore.	tt
The community is being railroaded.	
rallroaded.	11

STATE SUPREMACY Issues = MR/SUPERVISION + QUALITY OF LIFE Issues FIGURE 3



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