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THE EFFECTIVENESS OF STATEWIDE MENTAL RETARDATION SYSTEMS PLANNING IN IOWA

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THE EFFECTIVENESS OF STATEWIDE
MENTAL RETARDATION SYSTEMS
PLANNING IN IOWA

Masters Research Project

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PREFACE

The planning process described in this paper was developed and facilitated by a consulting firm, the Environmental Design Group, Inc., 14 Arrow Street, Cambridge, Massachusetts 02138.

The initial two-week planning process took place in May 1975 before I was employed by EDG. Using the PAK process (as described in the text) the initial policy directions were established. In October 1975, EDG's contract was expanded to a more comprehensive planning process. The four major parts of the planning and the staffing was as follows:

<u>Planning</u>	<u>Number of Staff</u>
Statewide policy	2
SHS architectural	5
Districts	2
Licensing and certification	1

As part of this team of consultants, my primary role was that of District Planner in Dubuque. My responsibilities included:

- Development of the planning process and schedule for a model community service delivery system for the mentally retarded. This included needs assessment, functional and administrative models, cost analysis, seven-year master plan, and implementation strategies.

- Facilitation of the planning groups' participation. This involved conducting public hearings and running planning meetings involving service providers, elected officials, government administrators, and consumers.
- Supervision of a staff of seven MR specialists.
- Staff training in planning techniques.
- Documentation of the planning process and development of a transfer document of the planning tools used so that other areas could conduct similar planning activities.

The work which I was doing was integrally related to all other aspects of the statewide planning. In addition to regular staff meetings during which the entire staff shared ideas and related their component's progress, I frequently was able to assist in the statewide policy planning although it was not my major responsibility. Afterward, I also have responsibility for editing all documents (with the exception of the architectural report) for the firm.

Therefore, I had a rather unique opportunity to observe the activities of most of the planning participants. To supplement these observations, I questioned various participants about the planning activities and results six months after completion of the process. The six-month period which had elapsed gave them time to develop somewhat more objective opinions about the process and the results. Most of their comments were substantiated by other participants.

I. INTRODUCTION

Things are changing in Dubuque, Iowa. Dubuque, a typical midwestern town, and its surrounding communities have just completed plans for providing services to their mentally retarded citizens. The success of this effort can only be measured in terms of its effect on the mentally retarded person. For example, rather than travel hundreds of miles to state diagnostic facilities--a venture that is costly both in terms of the money and the time involved--a mentally retarded person will soon receive a diagnosis and evaluation in his or her own community. Instead of just being told what type of treatment and services are needed, parents will actually be included on a team of local professionals who will assess their child's needs. At the same time, a case manager will be appointed who is responsible for seeing that the services provided are appropriate to the person's ever-changing needs and that the person is regularly re-evaluated to maintain the relevancy of the received services to these needs. Case management or the coordination of services will also prevent the usual "falling through the cracks," or lack of continuity of care which typically occurs when a person moves among the myriad of services available. Also, all the services received will

be provided in the community and will meet recognized quality standards.

This scenario is not a pipe-dream. It is very close to becoming a reality. It has the active support of hundreds of the area's residents who are presently conducting a wide-spread public education effort to make more citizens aware of the rights and needs of the mentally retarded and the community's plans to resolve them. County funds have been allocated to employ a staff to begin local diagnostic and evaluation services and the district office of the Iowa Department of Social Services (DSS) has designated staff to assist with the plan's implementation.

These plans and actions do not reflect a drastic change in attitude or philosophy. Rather, they indicate a redirection of efforts into channels which are well-organized and productive. They were made possible through an extensive and participatory planning effort in the state of Iowa which began with the desire to improve services for the mentally retarded and to bring more money into the mental retardation service system through the federal Title XIX program, a program for funding residential services both institutional and in the community. Since the Title XIX program represented a major source of new funds for program development, the state of Iowa decided that the need to plan for quality MR services extended beyond the purview of institutional development. The state

thus conducted an integrated comprehensive planning process which involved hundreds of citizens, service providers, county officials, and state agencies. The product of their effort was a plan for a system of care which is supported by all the groups involved and which, when implemented, will substantially alter the quality of life for Iowa's mentally retarded citizens by providing comprehensive community services and by diminishing the role of large residential institutions in a system of community care.

This paper describes Iowa's unique experiences and accomplishments in comprehensive planning for services for the mentally retarded. It is important first to understand the historical context and development of services prior to this planning process. Therefore, this paper will first describe the traditional function of institutions, the more recent emphasis on community services, and the importance of federal legislation such as Title XIX. Iowa is no exception to this history. To this point, the paper describes their system of institutional care, its supporting political milieu, and the difficulties encountered in developing community services. Finally, it will detail Iowa's attempt to restructure a major social service delivery system. The planning process was all-encompassing. It began with a top-down approach and evolved to include widespread participatory planning which gave legitimacy to and encouraged local decision-making about the development of a

responsive service delivery system. Prompted by the attraction of Title XIX funds, many divergent interests came together to promote the development of a total system. It was a process in which the participants had many hesitations and fears about the outcomes. Institutions saw the territorial encroachment of outsiders which threatened their very existence. Yet they participated--they had too much to lose by ignoring the process and they also saw a potential for coopting the planning and at the same time making substantial financial gains for their effort. Simultaneously, the community service proponents were for the first time given an opportunity to actualize their ideas. However, the community feared that the institutions would increase their power through the planning process.

The planning process began in the spring of 1975 when the state hired a consulting firm, the Environmental Design Group, Inc., to conduct a two-week policy planning session. In November of that year, comprehensive planning began and consisted of state policy development, institutional architectural planning, model district community planning, and the development of licensure and certification procedures. By July 1976, the major portion of the formalized planning was completed. Five major reports were generated by the consultants to document the process:

- Iowa Title XIX Statewide Policy Planning
- Campus Masterplans for the State of Iowa
- Model District Planning: Community Planning for the Mentally Retarded and Developmentally Disabled

- Iowa Title XIX ICF/MR Provider Participation Packet
- Iowa Title XIX Report on the Proceedings of the Committee on Joint ICF/MR Licensure and Certification

II. THE MENTAL RETARDATION SERVICE

DELIVERY CONTEXT

A. Historical perspective

The National Association for Retarded Citizens has estimated that a little over three percent of the total population is mentally retarded. These people are a small minority in our population, unable to exert a major influence on the society; yet they require a disproportionate amount of care and services. The care of these people has traditionally been oriented toward isolation and removal from the mainstream of social interaction. For centuries, those whom families were unable to keep them at home were relegated to poor-houses, prisons, county farms, private boarding houses, or, when affordable, private sanitariums. Those who were kept at home received little or no special care and were more often than not an embarrassment or stigma to their household.

During the nineteenth century, a social reform movement began in reaction to the poor community conditions and lack of treatment which existed for the mentally retarded. Large government-run schools were instituted to provide education and training services which the local communities were incapable of providing. By the end of the

nineteenth century, these large institutions were increasing in size and number. Due to the inability to properly screen for appropriate admissions and inability of families to provide care, the institutions became a home for many who did not belong there in the first place. However, these facilities were not well-funded and the residents received little or no treatment. Residency soon became a sheltering function rather than one of treatment.

This continued until after World War II, when the discovery of psychotropic drugs and behavioral therapy which alleviated some individuals' bizarre behavior stimulated a new movement to treat people with mental health disorders within the community. As community treatment gained credibility, a parents' group movement began to advocate for community mental retardation services as well. At the same time, institutions which had continued to increase in size were becoming difficult to administer. A move to decentralize the larger hospitals began. Patients were placed in units based on their residential origins. Along with this was a trend to decentralize decision-making within each patient unit. As a result of the community's increased responsibility, the communities began to become more aware of their area's institutionalized citizens' service needs.

Although the current trend is increasingly moving toward satisfying the service needs of the mentally retarded

population in the community, the progress in developing these services has been slow. Although it is estimated that only four percent of the mentally retarded population reside in institutions, nationally, a disproportionate amount of dollar resources is allocated to this type of care: approximately \$300,000,000 for treatment and maintenance; another \$100,000,000 for institutional construction. Only \$150,000,000 is spent on community services.¹ The persistence of large institutions can be attributed to a number of factors:

- There is often community and family resistance to deinstitutionalization.
- Institutions can be a legitimate source of treatment for certain patients (those with long-term chronic maladies or with low-incidence problems).
- They often provide politicians with a patronage resource: both in regard to employment opportunities as well as patient placements.
- Institutions are still often the only alternative for treatment since there are insufficient community services.

The emphasis on institutional services has resulted in treatment which generally follows the medical model by treating mental retardation as an illness and which stresses long-term individual treatment. The traditional "distance" (both logistically and philosophically) from the communities they serve has fostered a highly specialized residential service which has developed in a void without coordinating with other needed services such as education, health care,

and rehabilitation. Additionally, the inequitable division of resources and emphasis on direct patient services has resulted in states being unable to find community services for the needs of the mentally retarded citizens who remain in the communities.

This disparity has been more and more frequently emphasized as the movement in support of service provision in the community has flourished in the 1960s. This trend is characterized by a move away from medical model treatment in an institutional setting. The stress has been on increasing supportive services as well as less restrictive therapeutic care. The trend has emphasized the need for a comprehensive array of services; in other words, a community system of care which provides a full spectrum of services to meet a mentally retarded person's life-time of needs.

The shift in emphasis has required and will continue to require changes in public policy and planning. The traditional process of allocating fiscal resources for institutional mental retardation services has increasingly come under fire from advocates of community services. These advocates have adopted a public education orientation to familiarize citizens with service needs, program costs, and service delivery alternatives. Consequently, citizens have become more supportive in the implementation of community programs. Their participation has been laid over an increasingly comprehensive and rational planning process

which allows for program development based on assessments of the community's service needs, resource analysis, development of funding strategies and priorities, and quality assurance mechanisms, and which is then juxtaposed against the institution's funding requests. The importance of planning for a community system of care has resulted in a reorganization and redirection of states' planning efforts. Federal policies and funding have fostered this shift.

B. Federal involvement in community services

In 1962, President Kennedy's Panel on Mental Retardation stated:

The challenge to state institutions is how to accelerate the change from isolated facilities to smaller units close to the home of the patients and to the health, education, and social resources of the community; and the challenge to both state and private residential facilities is how to replace the old concept of custodial care, wherever it still exists, with modern programs of therapy, education, and research.²

A Presidential address on the "critical health problems" of mental health and mental retardation in 1963 stressed the need for federal support for prevention, skilled manpower, and program and facility improvement. It called for the use of federal resources to stimulate state, local, and private activity in community service development. Specifically, President Kennedy stated:

The key to the development of this comprehensive new approach toward services for the mentally retarded is twofold. First, there must be public understanding and community planning to meet all

problems. Second, there must be made available a continuum of services covering the entire range of needs. States and communities need to appraise their needs and resources, review current programs, and undertake preliminary actions leading to comprehensive state and community approaches to these objectives. To stimulate public awareness and the development of comprehensive plans, I recommend legislation to establish a program of special project grants to the states for financing state reviews of needs and programs in the field of mental retardation.³

Spurred by the lack of state money to provide more diverse, appropriate care to the mentally retarded, the federal government had the opportunity to stimulate program development by becoming an innovative fiscal resource.

One result of this momentum was the enactment of Public Law 88-164, the Mental Retardation and Community Mental Health Centers Construction Act of 1963. This was basically a pragmatic step which had the short-term goal of expanding services in a flexible manner to meet the varying needs of different areas. In addition to funding community services through a grant-in-aid program, the law also called for a single state agency to be designated as having planning and implementation responsibility.

Programs such as this have had piecemeal impact on MR service development. However, the vast amount of funds needed to develop an adequate, comprehensive care system is still lacking. Deinstitutionalization which has occurred to date is the result of a conglomerate of social and welfare programs which affect segments of targeted populations such as the poor, the elderly, or

children. No unified national strategy or management mechanism has been developed to implement and coordinate deinstitutionalization. A more recent example of this is the revised Title XIX of the Social Security Act (Medicaid legislation) which establishes standards for the development of Intermediate Care Facilities for Mentally Retarded persons (ICF/MR).⁴ This legislation provides a fifty percent reimbursement for providing residential services to clients who are in facilities which either meet federal standards or have submitted plans for meeting the standards within two years. It also requires that people be placed in appropriate support programs according to an individually tailored treatment plan developed by qualified MR professionals.

The potential for providing community services under Title XIX exists since persons of all ages and who meet eligibility requirements can live in residential programs which can be either institution- or community-based. However, Title XIX and its regulations are a complex foundation for mental retardation services. First of all, its interpretation and implementation are still unclear. Different states have implemented the law in varying ways. Some develop residential services which follow the traditional medical model while others may have a developmental orientation. When the medical model approach is followed, the residential staffing is largely medical personnel

(physicians and nurses) and all care is generally provided in-house since staffing costs are high and the person's disability is viewed as chronic "illness" which can be treated with medicine and long-term care. This philosophical approach is conducive to locating ICF/MRs on the campuses of already existing institutions or else it fosters the development of "mini-institutions" in the community. On the other hand, a developmental model which emphasizes non-medical services such as social and rehabilitative training can be followed by contracting with other community vendors outside the residential facility as the clients' major program component. This approach is not so prevalent since the medical influence is strong and very difficult to reconcile with a developmental approach to service provision.

Although Title XIX does provide an incentive for developing better services for the mentally retarded (whichever philosophical approach is chosen), the development and administration of such a program can be a costly, difficult process for a state. First of all, the federal requirements for participation must be coordinated with any state requirements for program licensure and certification. If such regulations don't exist, states must develop them; if regulations do exist, then they most likely would have to be modified. The coordination of state requirements with federal requirements is a very awkward, awesome task

and typically does not work smoothly or effectively. It is also quite time-consuming since the red tape encountered when dealing with so many agencies as are necessary on both levels can hinder development.

Once the Title XIX program is underway in a state, the manner in which the state implements the program causes a number of other problems which typically result in a period of up to two years for a facility to be developed. Although many of these procedures and requirements were instituted for quality assurance or as community input mechanisms, they in effect become hurdles which often deter programs or increase the cost of development.

At the federal level, there are very specific requirements which have to be met before a program can be certified. Over 1200 items must be checked. A tendency exists to look at the 1200 items separately and rigidly rather than how each might be part of a total program. The survey process for conformance is the same regardless of program size, which presents an administrative burden to small programs. Also, as is usual with federal programs, an avalanche of paper documentation is required in order to "prove" that someone is someplace or that something has been done.

Another difficulty frequently encountered is the maze of state reviews necessary for certification and licensure. First of all, anyone planning to receive Title XIX

funds must go through the state's process for determination of need for capital expenditures or substantial change in program under Section 1122 of the Social Security Act, amended in 1972. The 1122 process involves up to four groups for approval. Questions asked include: "Is the capital expenditure worthwhile?"; "Is the program capable of getting financing?"; "Will it operate efficiently?"; "What will the impact be on the rest of the system?"; "Will people be taken out of one place and beds emptied as a result?".

Another state review procedure is that which is required for program licensure. This involves an initial and thereafter annual inspection to assure compliance with the provisions of the rules. In many states, the ability of individuals residing in the program to act in "self-preservation" determines whether or not a categorization of institutional or residential occupancy is applied for licensing. This determination affects the type of facility needed, staffing, programming--and ultimately costs. Other necessary reviews are conducted by the State Fire Marshall for the program's compliance with the Life Safety Code. Finally, a program must be able to pass a local community inspection and review for compliance with the Uniform Building Code. Interspersed with these reviews, persons developing residential programs must meet with various community boards or groups which determine that area's

particular need for the program; the costs to the community support systems such as schools, workshops, etc; and conformance to local zoning codes. Often, the lack of community support can bring an end to program development.

Finally, many states now establish program reimbursement rates. The purpose of these regulations is to promote economy, efficiency, and cost-conscious program management. Theoretically, they also consider the program elements and thus have different reimbursement rates for different types and levels of services. However, it is frequently the case that these rates are an over-simplification of program costs, are rigidly applied, don't reflect changes in the area's cost of living, and in highly specialized, costly programs such as Title XIX residences, are usually inadequate.

Thus the bureaucratic system which consists of all these regulations and procedures effectively makes it difficult and costly to develop community ICF/MRs under Title XIX. However, Title XIX is attractive to states because of its fifty percent reimbursement rate. The dilemma is posed to the states as to how to implement the program in a way which is easy for vendors to get through the administrative maze quickly and at minimal expense while also developing quality community programming. This was the question which the state of Iowa asked initially and which led to a comprehensive mental retardation service planning process.

III. IOWA'S MENTAL RETARDATION SERVICE DELIVERY SYSTEM

As with most states' MR (mental retardation) service systems, Iowa's has two major sectors--the publicly provided services and the privately provided services. The state government directly provides services at two state hospital school (SHS) complexes with a total population of 1500 MR people. The private sector is also partially dependent upon public funds to finance services. This financing has traditionally been tied to categorical federal programs such as Title XX, Developmental Disabilities, and educational funding. Although these funds are channeled through state agencies, there is little coordination of their distribution which in turn contributes to the variability and fragmentation of services in the community. In addition, although the state has responsibilities in both the private and public sectors, the two are not coordinated. For example, the services provided at the SHSs are not coordinated with those in the community even though the community often has to rely on their services, which include a diagnosis and evaluation program. The Iowa State Department of Social Services (DSS) Division of Community Services is responsible for planning and administering both community

and institutional MR programs under Chapter 222 of the state's laws.

The major portion of funds in the state are allocated to the two SHSs which gives these institutions an inordinate amount of power over the MR service system. These facilities, Glenwood and Woodward, each serve half the state. Even within these two facilities, there are very basic differences in orientation. The administration in Woodward has emphasized the need to assist the communities in the deinstitutionalization process. Technical assistance to community programs is one of its major policies. This is done primarily through parent and staff training programs and increased direct services to the community. In addition, Woodward has actively pursued community placements for its residents by establishing a short-term care unit to handle acute care situations. Glenwood's rate of community placement is not as high as Woodward's due to the administration's emphasis on careful monitoring of and high standards for community care. Therefore, programs which fail to equal the standards of programming at the Glenwood SHS have difficulty in getting patients out of the institution.

"Any 'institution' (in the sociological sense) that has much momentum but no viable rationale is likely to strive for self-perpetuation on the basis of its previous rationales and practices."⁵ Although the major trend is

toward deinstitutionalization in Iowa, a very powerful safeguard exists to maintain the existing institutional system. The main arguments for maintaining these facilities is that there are inadequate and poor quality community programs. The peer relationships and support that exist for residents in the institution also provides a strong rationale for their continuance. Additionally, there is the view that institutions are the best protection of those who are unable to care for themselves. This reasoning is particularly appealing to parents who want assurances that their children will always be cared for.

However benevolent these arguments may be, there is another more self-serving reality which both Iowa SHSs face --the politics of running an institutional system. A major facet of the political arena which governs the development of MR services is the bureaucracy established to administer and direct the state-sponsored MR facilities. This bureaucracy and its supporters have successfully garnered control over the budgeting process for mental retardation services. In responding to the SHSs' annual budget requests, the state legislature is usually quite cooperative--aware of the potential political support available through the hundreds of staff at the SHSs and the families of the residents.

This is not to say that the budgeting process is unaffected by other participants and political pressures.

However, the only "experts" available to sort out the pros and cons of policy decisions are the employees of the public bureaucracy. Therefore it is inevitable that the tradeoffs in the political realm are often viewed in terms of jobs and bricks and mortar rather than in terms of human care. The rational planning process of program budgeting and the accompanying weighing of program alternatives in terms of effectiveness and priority development are often viewed as a threat to the existing employment arrangements.

This political realm within which the institutions function has a direct bearing on the type of services provided there. The attitudes and interests of the direct care staff are often fashioned by the structures within which they operate. Few attendants, nurses, or cafeteria staff develop strong sympathies for patients because their settings are not conducive to it. Patients are considered behaviorally bizarre--a condition which is often exacerbated in the institutional environment where incentives for different behavior are more often than not lacking. The prevailing image of patient care is that it is to occur in the proper setting, according to well-spelled out treatment methodologies and rules, and monitored by registered professionals--in other words--following the traditional medical model. Bureaucratically, this model of rigidly defined structure, enables the administration to manage large and often understaffed programs. Thus the patient's

care mainly consists of daily medication and routinized schedules for daily life activities.

The other side of Iowa's service delivery system is the community programs. While the DSS is responsible for running the SHSs, it also has a decentralized administrative structure; essentially creating a philosophical split in the administration. There are sixteen district offices run by District Administrators who are responsible for community program development and monitoring. As part of the DSS hierarchy, information and recommendations about community program needs and administration are fed up to the central office level where the management feeds back selected changes through the system. However, there has been an increasing disgruntlement with this system as the local communities began to realize that the messages they were sending were having little or no impact on the policies being developed. The most recent example was the Title XX planning process which had just occurred in Iowa. An active citizen participation vehicle was established with the promise of increased community services. Needs were measured and program priorities set. However, the bureaucracy proved to be unresponsive to this input when Title XX funding levels were cut and the administration decided to maintain previously existing programs.

This action reinforced the reality of communities as the least powerful agents in the mental retardation

service arena. With many diverse interests and usually as many different spokes-groups, the organization and direction which would better enable the community to impact upon the system have been lacking. Lack of information and understanding of how the bureaucracy functions and is managed has made it difficult to know which questions to ask, who to ask them of, and how to actually get a response. Because of this, communities initiatives have often been destined to failure.

In recent years, however, the community interest in mental retardation services has become increasingly focused against the traditional institution-dominated service delivery system. The changing emphasis has been on developing community care alternatives. Not only has the emphasis been on increasing services, but also the quality of the treatment. In response, state and federal government have begun to regulate the development of community services by developing licensing and certification procedures and regulations to safeguard the public expenditures which reimburse patient care in community facilities. The Joint Commission on Accreditation of Hospitals has also developed standards for MR program certification. While these mechanisms are intended to ensure quality care, they effectively hinder community program development by creating a plethora of red tape and by increasing development costs, as previously described. The result has been that there are few community

MR services. The few which do exist depend largely on public monies for fees charged for client services. Unlike some states, Iowa DSS has few contracted programs.

IV. IOWA'S TOTAL SYSTEMS PLANNING

Within this schizophrenic bureaucratic framework, Iowa decided in 1975 to investigate the possibilities of participating in the revised federal Title XIX program which establishes standards for the development of Intermediate Care Facilities for Mentally Retarded persons (ICF/MR). At the same time, the state decided to pursue a major policy planning effort as an integral part of their Title XIX qualification since it provided a timely opportunity to assess the existing MR service delivery system and had the potential to give shape to a more desirable system. Also, it was realized that the qualification requirements would impel the state to make immediate capital investments which would have far-reaching implications on the future orientation of MR services. Issues which were raised included whether or not Iowa should invest in the existing institutions or in new community services, whether to renovate or build anew, whether the planning and construction should be for changing uses, and how to create a normalized environment which also meets client's specialized needs.

It was considered imperative that the implementation of Title XIX improve the quality of MR care in Iowa. Thus

certification of the State's institutions would have real implications for the services provided in the community and for DSS's administrative responsibilities. It was finally decided that a State Policy Planning Group be established to conduct Title XIX planning within the context of these broader issues. As a result of these recommendations, the Iowa Legislature mandated that the Department of Social Services (DSS) qualify its MR services under the Title XIX legislation.

In order to test the issues raised and then devise a strategy for qualification, the DSS contracted with a consulting firm to use participatory techniques to facilitate a two-week intensive planning session. The State Policy Planning Group was established, composed of twenty-six individuals representing all of the major interests in MR care. Thus within DSS, the superintendents of the SHSs and some of their staff were in the group as well as central office staff and community service oriented District Administrators and MR specialists. Other state agencies were also included in the group since their participation was essential for both licensing concerns and for need to create an integrated service delivery system. To this point, the Department of Health, Governor's Office of Planning and Programming, and the Department of Public Instruction had representatives in the group. Local government was represented by members of Area Education

Agencies and the Iowa State Association of Counties. The MR consumer interests were represented by members of the Iowa Association for Retarded Citizens and the Developmental Disabilities Council. Finally, vendor interests were handled by private providers from the Iowa Nursing Home Association and other local programs. The group's goal was to make policy recommendations to the DSS on the entire MR care system in Iowa, to ensure that the planning for Title XIX certification at the State institutions would be within the context of those policies, and to assure the development of a coordinated state-wide system.

Although these individuals were all very much concerned about the service needs of MR people, it is important to note that the group's composition reflected very diverse and often opposing philosophies and attitudes about how to provide the necessary services. With this problem in mind, a special effort was made to involve SHS representation in this group. Eleven of the twenty-six were SHS employees, including the two superintendents. This initial planning session was the first time all of these people had come together to actually work toward a unified approach to MR service delivery. The planning process used enabled them to discuss, understand, and work out many of these differences. The accomplishments of this group established the philosophy behind the rest of the State's MR planning.

Three major areas of concern were pursued. The group first agreed upon the principles and philosophy to guide the development of an MR service delivery system in the State. Secondly, the group proposed a model system which they felt best responded to the MR person's needs. Finally, they developed the initial policy directions to be followed in order to implement and support the system.

The policy directions which came out of the process clearly emphasized that the MR service delivery system should be responsive to the "normalization principle"; that is, the MR person should be able to reach a level of existence as close as possible to that which is normal for the mainstream of society. Normalization was specifically related to programs by saying that it translated into client movement toward the least restrictive environment possible. In order to accomplish this, the group stressed that programming needed to be highly individualized--the person in need should be the focal point of the service delivery system. Thus they saw the need to develop mechanisms for assessing, selecting, and developing the resources which would be most responsive to the individual's needs.

Another major concern was the availability and accessibility of care. There needed to be a sufficient array of services to comprehensively meet known needs and to enable the client to choose among services. Also, they

saw that operating procedures should minimize administrative, cultural, social, financial, and geographic barriers to receiving services.

Finally, they agreed that the service should meet quality standards. The programs and the service delivery system should have built-in mechanisms for monitoring the quality and effectiveness of outcomes in relation to client goals. The group also stressed the need for service to be responsive to expressed and unexpressed needs, the need to maintain reliable records, and the need to ensure the client's right to choose among different types of services.⁷

The group also set initial guidelines for service and facility development in order to promote quality care at the local level. The mechanism which the group saw as most essential to successful community development was local support. It was felt that, under the normalization concept, services should be provided as close to the home as possible. The initiative for such program development needs to come from the community and be in response to that community's particular identified needs. The group also stated that other assurances of successful community development are to have all programs meet a consistent set of standards and to coordinate Federal, State, and local financial resources. In addition, there is also a need for more MR professionals in Iowa. Technical assistance on needs assessments, financial planning, program design,

site and building planning, and standards interpretation are also needed on the community side.

A final and most important recommendation was that concerning the future role of the State Hospital Schools in the MR service delivery system. The group recommended that the institutions should become resource centers to complement the services being developed and provided in the community. Thus the services they would provide would be those which the community was incapable of developing, because of cost or insufficient demand. This would include staff training, technical advice on programming, and highly specialized services. It was considered essential that these services be connected to the statewide system of services and its consumers.⁸

How to achieve a system which followed these directions was the planning group's next task: They defined four major areas of concern--the development of statewide mechanisms and policy direction to assist in implementation; the need for community plans for service development which would be supported by the area's residents; the immediate and long-term need for SHS facility renovation; and the need for technical assistance for the development of residential facilities in the community.

A uniform state policy direction was considered essential since many of the changes needed could only be achieved through the establishment of statewide mechanisms.

For example, a major problem was the need to develop financial resources for community development through the coordination of Federal, State, and Local funds. At the same time, there had to be a strategy for effectively organizing the State's role in coordinating and monitoring local service development, the State Hospital Schools' role, and the relationship between the two. The mechanisms for doing this included rewriting laws, establishing regulations, providing incentives and technical assistance for service and facility development, and program monitoring and accounting. To this point, the major portion of State planning needed to center on the State's administrative structure, funding mechanisms, and a statewide placement policy to assure appropriate client care.

At the same time, it was essential to develop State Hospital School architectural and physical design guidelines. The first need was to develop the technical plans of correction which would enable the state to qualify for Title XIX funds. These plans had to be in accord with the new policies of normalization and deinstitutionalization. Since the capital expenditure for qualification was anticipated to be large, the group felt it was necessary to scale it down to the extent possible in light of a policy reflecting phased development and a new emphasis on community program development. Master plans needed to be developed for each campus to guide its development for the following ten years.

In conjunction with the master plans, it was realized that architectural schematics which followed the normalization concept would be useful guidance to the campus architects.

Within this policy framework and essential to successful deinstitutionalization and the development of normalized, quality community services was the need for public acceptance and support. Additionally, there had to be a plan for the logical development and financing of a system of services which reflect the community's needs and wants. Hence the group urged that each district conduct its own community planning process.

Finally, technical assistance for the development of residential facilities in the community was seen as essential in order to facilitate the development of community services. It was realized that it would be helpful to develop licensing and certification standards which would integrate the procedures of the various state agencies which regulate such development. While doing this, the objective would be to create an understandable procedure for developers to follow.

The group felt that the resolution of these problems was essential to the quality implementation of Title XIX in Iowa. The need for further planning which would integrate the approaches taken with the direction of the group was evident. The group and the Department also realized the benefit of pursuing a participatory planning approach.

Thus the Task Force requested that DSS sponsor a comprehensive planning process for MR services which would concentrate on these four components.⁹

The initial two-week planning process was conducted using a planning process called PAK, the Planning Aid Kit.¹⁰ Its development was supported by the National Institute of Mental Health for the purpose of enabling citizens to participate effectively in mental health policy-making areas. The process is responsive to user needs by directly involving them in the process. By providing specific ways to collect and relate accurate information and to document the process, planners are able to achieve efficient and effective participation. Its design of a highly structured sequence of meetings ensured the participants' consideration and resolution of planning issues. This process, using large wall posters, first recorded all participants' concerns, clustered the concerns into similar categories, developed programs for resolving the concerns, and then reached a group consensus about the best program and the next steps to be taken. Most importantly, the PAK process provided a way for this group of people with diverse backgrounds and interests to consider policy issues and come to agreement about ways to resolve them.

The consulting firm also had considerable success in using another participatory planning process called "Ecologue." This process had been developed to allow

users to become aware of their environment, how it affects their lives, and how to best modify it. This was accomplished by providing users with the tools and techniques for analyzing, understanding, and discussing their environments and the issues related to them. During the sequence of meetings, the participants develop alternatives, establish policies to guide the changes, and then review the impact of the alternatives. Finally, the participants generate possible solutions and, after discussions, develop the type of environment which is best suited to their needs.¹¹

The Department of Social Services felt that by using these participatory planning techniques, a planning process could be developed which would respond to the four major issue areas raised by the State Policy Planning Group, and respond to the different motivations of the major actors. It is important to consider the motivations of the participants in the planning process. The current power holders, primarily the institutional representatives, first of all, saw a challenge to their power base and their operating philosophical convictions. Not wanting to passively relinquish the status quo, they had to participate. Secondly, not only was their own survival as powerful institutions at stake, but, presuming that they overcame this challenge to their autonomy, Title XIX funds could be directed toward them, thereby increasing the quality of facilities and care, which would thus reinforce their power

bases. Rather than fight against the planning process, they joined it, hoping to manipulate and coopt the movement. At worst, their participation would ensure some control over the resolution of the challenge in which they would get some part of the Title XIX funding.

On the other hand, the community's dissatisfaction with the existing situation made them enthusiastic participants in the hope of obtaining something better--money for community program development and the concurrent diminishing of the SHS's power. The Title XIX planning process gave them, for the first time, a chance to be involved in the early critical stages of the process and the development of a clear image of the service delivery system desired, rather than the traditional reactionary "review and comment" level of citizens' planning participation. It also enabled them to be actively involved in the politics of program development, a knowledge which would be essential to their future success--an exercise in the practicalities of political horse-trading.

The planning sessions therefore consisted of a sharing of opinions about the existing care system and policy negotiation among the relevant actors in the system. It is important to note that not all participants acted in their "own interest" or in the way others would have expected--having unequivocal viewpoints. They dealt with a complex set of issues and concerns. The resulting

articulation of interests and the ensuing debates and negotiations permitted the original ideas to evolve into more sophisticated concepts. However, these concepts needed to be developed into more definite plans of action. Therefore, in October 1975, with funds from the Developmental Disabilities Council, the DSS rehired EDG, the consulting firm, to develop, conduct, and document a more extensive planning process.

There were four major aspects to the continued planning. The first was policy planning. The report of the Task Force had recommended that the group continue to advise the DSS. After some modification of its membership, it was decided that the State Policy Planning Group should continue to make recommendations about the development of statewide mechanisms for the implementation and coordination of Title XIX planning and to more completely develop their previous recommendations. The process had two major elements. The first was the creation of a DSS central office staff task force to provide staff support to the State Policy Planning Group. The second was the continued meetings of the State Policy Planning Group.

Campus and architectural design was the second major part of the planning. The Ecologue process was to be used at the State Hospital Schools to involve residents, their parents, local providers, and campus administration and staff in the design of the campus and its buildings.

The resulting plans were then to be coordinated with the expansion and capital improvement plans of the administration. The results were to be reviewed by the State Policy Planning Group as they affected the issues of the campus role and size, construction, and renovation, the residential mix, and programming.

At the same time, a prototype for district service delivery system planning would be developed. The state chose to select two districts as models to do systems planning, and later to transfer the process to the remaining 14 districts. The process was again to be participatory, relying heavily on community organization and the PAK process. The major objective of this process was to develop a plan which would be responsive to the community's MR service needs and which would receive community acceptance and support. At the same time, there was to be a policy testing process in which the State Policy Planning Group and the district groups shared ideas with each other for consideration and constructive comment.

Critical to the development of community facilities and placements was the need for the facilities to meet quality standards through state licensure and certification procedures. Thus this was the final portion of the planning. Traditionally, the maze of disjointed procedures that a developer had to go through (Department of Health, Department of Social Services, the Fire Marshall, 1122 review, etc.)

frequently had the effect of discouraging developers from building community facilities. Following the State Policy Planning Group's recommendation, the Commissioners of the Department of Health and the Department of Social Services appointed a committee to develop goals, guidelines, and action plans for joint licensure and certification of MR residential facilities. The planning group consisted of representatives from the relevant state departments, county government, providers, and consumers. The PAK process was to be used for eight meetings during which the group would develop guidelines and recommendations for licensing and certification procedures which are integrated, assure points of control for clarity and accountability, call for compliance with district plans, investigate a sound financial basis for ICF/MR rates, and establish a determination of need procedure. The resulting recommendations were to be written up by a joint task force.

Thus, the federal Title XIX program became the impetus for the state of Iowa to conduct a total reevaluation of its total MR service delivery system in order to plan for the allocation of resources which potentially would impact every aspect of the system. This planning process took place within the framework of a state government which was following the national trends toward cost-accounting and program budgeting procedures--trends which utilize rational planning procedures to determine the value

of one program as opposed to another and develop priorities for the expenditure of scarce resources. Every effort was made to actively involve representatives of all sectors of the population which would be affected by the decision-making process. The openness of the process was largely in response to the community's clamor for change in the system and to the need to carefully study the implications of any possible changes on the established system.

V. PLANNING RESULTS

A. Statewide policy planning

After the conclusion of the initial effort, it was considered imperative that the State Policy Planning Group continue to make recommendations about the development of statewide mechanisms for the implementation and coordination of Title XIX planning and to more completely develop their previous recommendations. In order to accomplish these goals, a DSS central office task force was created to provide staff support to the State Policy Planning Group. The meetings of the State Policy Planning Group were again facilitated by the consultants through the use of the PAK process. The process again proved to be quite effective in coming to consensus on some very unique problems. At this time the group no longer concentrated on idealistic planning. In many instances, the political realities and the need for difficult decisions were obvious. However, the group derived authority for their actions from an agreement with the Department's Commissioner who stated that he would be guided by the consensus of the group. The Commissioner agreed to act on the policy recommendations arrived at by unanimous consensus as long as such action did not require him to act illegally or beyond the areas

of his responsibility. Thus the group had the incentive to work through these difficult situations.

A major recommendation from the group was that it be their responsibility to review all policy and planning issues and that they also have an advisory role in the implementation of Title XIX and the development of the MR service delivery system. Thus, they would be responsible for continuously coordinating and monitoring development as it relates to the previously established statewide policies of normalization and deinstitutionalization. In order to assist them in this role, the central office task force, and a subcommittee of the group developed a two-year planning schedule which detailed the critical decision points and activities for all portions of the system.¹² To further assure the implementation of the service delivery system, the State Policy Planning Group recommended that a separate administrative unit be established within the DSS to take action on approved policy recommendations, to raise pertinent policy issues when appropriate, and to provide staff support to the group's activities.¹³

Another major result of the State Policy Planning Group's efforts was the development of the initial steps toward the establishment of a statewide residential placement policy. It was felt that this policy was instrumental to the creation of an appropriate balance between the utilization of the SHS's and community-based services and to

assure client placement in normalized, least-restrictive environments. The decision-making surrounding a client's admission, readmission, transfer, and discharge for residential services is critical to community placements and the deinstitutionalization process. The group's efforts concentrated on three areas of concern: the need for placement based on the client's evaluation and individual plan for treatment, the need for rate determination, and the need to assure quality programs through program and space availability guidelines.

Therefore, they recommended that a client's placement was to be based on the individual's needs as evaluated and interpreted by a locally-based qualified MR professional. This evaluation should be responsive to the philosophies of the development model, normalization, and service location in the community. In addition, the client's needs should be regularly re-assessed and his/her program modified as a result.¹⁴

In order to further ensure the availability of quality placements, the programs in which a client is placed must be programmatically and fiscally responsible. Therefore, it was recommended that regular audits be conducted, rates be consistent, and that a ceiling be placed on the rates. It is also essential that state financing of services follow the client from the SHS to a community placement.

Finally, the group considered it imperative that services be considered a right for the MR person and that Chapter 222 of the Iowa Code be rewritten accordingly. Also, before a program could qualify for DSS reimbursement, it should be licensed, meet all certification and determination of need requirements, and be in compliance with the district's MR service plan. No placement should be made without an individual needs evaluation or without the guarantee of client follow-along (case management) and advocacy.

The final major area which the State Policy Planning Group viewed as being extremely important to the nurturance of a community service delivery system was the funding mechanism to support it. The community side had been plagued by financial problems such as the lack of start-up funds and unpredictable budget cuts. The residents at the SHSs, on the other hand, received their support from State appropriations which were actually composed of a combination of Federal and County funds, of which eighty percent comes from the counties. Within this structure there was no means for transferring the client-support funds from the SHSs to the community as deinstitutionalization occurred. At the group's initiative, the DSS conducted a cost study to determine more precisely the extent of county expenditures for MR services. It was realized that it was possible, using existing state laws, to alter the present way of allocating

money in order to allow the funds to follow the client from the SHSs to a community placement. Thus the group began the necessary steps to channel money into community development, and after more research, these policies were to be implemented.¹⁵

Thus the State Policy Planning Group was able to develop and agree to a number of concrete administrative steps which would help operationalize the policies they established earlier. During this longer planning process, however, the group encountered a number of difficulties which threatened their existence as a group.

The group had initially made the recommendation that the SHS architectural development be balanced with the development of community residential programs. Their primary concern was that the state might perpetuate, through bricks and mortar, a more established role for the institutions that would, in effect, hinder the development of community programs. Furthermore, they also wanted to ensure that SHS development was responsive to the principles which they had agreed upon--responsiveness, individuation, accountability, and normalization. They were therefore in the difficult position of simultaneously attempting to upgrade the quality of care in the SHSs while also trying to dismantle certain portions of the institutions. To this end, they developed a five-year technical plan of correction for the SHS to qualify for Title XIX payments. The plan

called for an institutional population reduction from 1500 to 975 in five years. However, Regional HEW did not accept the time frame for the plans. Thus the group had to reconsider and modify their expectations around the rate of community program development. The result was an acceptable two-year technical plan which called for an SHS population decrease to a population of 1287.

In addition to the HEW difficulties, the planning also faced difficulties closer to home. Midway through the process, both the DSS Commissioner and the Governor's office considered delaying the planning effort due to the increasingly obvious financial burden the resulting plans would have on the state. First of all, the technical plans of correction called for a \$9,000,000 appropriation for SHS renovations and new construction. There was also increasing uncertainty about the fiscal implications of the community residence program. Unfounded projections of the cost for the community programs were being rumored in the state legislature, creating an unhospitable attitude toward the planning. The group dealt with these difficulties by emphasizing a policy of responsible deinstitutionalization and promoting quality community programs. Ultimately, they compromised with the legislature and decided to proceed with the SHS program with a first year appropriation of \$4,500,000. In order to respond to the concerns about the community program costs, it was clear that they needed to predict

the characteristics of the population to be deinstitutionalized in order to plan more precisely for that population's community needs. The group thus developed the placement policy as well as refining their role in regular monitoring of SHS development.

Thus the group was forced to evolve from "pie-in-the-sky" long-range planning to more sophisticated realistic decision-making. These decisions became operational within the fiscal constraints of the state. Although the group's overwhelming consensus was that the community desperately needed program funds, in order to qualify for Title XIX, they had made a trade-off which resulted in the institutions receiving the total appropriation for the next fiscal year. They also realized the need not only to develop policies but also to assume responsibility for promoting their policies and developing strategies for their implementation.

B. State hospital school architectural and physical design guidelines

The initial two-week state policy planning session defined the role of the SHSs and their contextual relationships to the entire MR service delivery system. In so doing, the group stressed that it was difficult for institutions to provide a normalized setting for their clients and that to the extent possible, deinstitutionalization could occur. SHS residents would still include those needing long-term care and those low incidence problems needing highly

specialized and complex treatment. They also specified that the SHSs should serve as resource centers to community facilities by providing services such as personnel training and technical advice to community programs.

Although the rate of decrease in institutional population is largely dependent upon the development of community placements, the State Policy Planning Group requested a technical plan of correction which would coordinate deinstitutionalization and facility renovation over a five-year period. After the development of interim standards, plans were developed which called for a decrease of the institutional population from 1500 to 975. As previously described, when presented to the HEW Regional Office for acceptance, the plans were not approved since a two-year plan for facility conformance was required. At that point, the State adjusted the plans to reach compliance in two years and to reflect a decreased population level of 1287 within that time.

Within the technical plans of correction, provisions were made for a decision-making process to occur in which the State could evaluate the progress being made in deinstitutionalization and the subsequent need for further SHS facility renovation. This was done by creating two waves of construction. After completion of the first wave, a review of the status of community facility development and placement rates would determine whether or not to continue,

increase, or reduce the rate of SHS facility construction. Thus a policy decision would be made at a critical point which would determine the future of the campuses.

The second major architectural product of the planning process was the campus master plans. As previously described, during the Egologue process, it was the participants' objective to create a normalized environment for those residents who would not be the beneficiaries of deinstitutionalization. The process at the State Hospital Schools involved residents, their parents, local providers, and campus administration and staff in the design of the campus and its buildings. The resulting plans were then coordinated with the expansion and capital improvement plans of the SHS administration and finally reviewed by the State Policy Planning Group as they affected the issues of the campus role and size, construction, and renovation, the residential mix, and programming.

The key to the type of environment planned was the type of client to be served; that is, the "normalized" physical design of the campuses varied according to dependent/independent client mix. Since this future mix was basically an unknown, two assumptions were made. The first was that no matter what the rate of deinstitutionalization, there would be an identifiable number of clients with certain characteristics who would always need SHS services, and their specific environmental needs could

be defined. This was reflected as the major portion of those improvements being made in the first phase of campus development. The second assumption made in the development of campus master plans was that the same residential mix (but decreased total population) would exist on the campuses. This was considered to be middle ground which would make it easier later to adapt the plans to reflect a more/less dependent population mix.¹⁶

The plans tried to achieve a more normalized environment by designating major activity zones for administration, programs, residential facilities, and services. They also stressed the importance of pedestrian accessibility to campus facilities in addition to the need for vehicular circulation and parking zones. Also, there were provisions for outdoor recreation and program space. There was also an emphasis on "deinstitutionalizing" the buildings and the re-use of old residential space for program uses.

Another product of the SHS master planning was the architectural schematics for residential facilities using the input of the Ecologue participants. These examples of facilities were based on the normalization principle and were designed to be supportive of an individual's growth and development. The designs incorporate the need for an individual to have privacy and to have a developmentally challenging environment. They also stressed that the resident's environment should be flexible enough to adapt

to the individual's changing needs as s/he develops and grows.¹⁷

C. Community service delivery system planning

The ultimate purpose of the community planning process was to provide the districts with an opportunity to plan for their own service delivery system, which would be responsive to their area's specific needs. It was also intended that the plans would provide the specific context necessary for successful implementation of Title XIX ICF/MR programs in the communities. The districts were given virtually a free hand to create the systems which were needed and supported by the communities. The districts were given ready access to the tools necessary to accomplish this task: planning expertise (the consultants) and MR expertise (a staff task force).

The first task which had to be accomplished in the districts was community organization. The participation and involvement of citizens was considered essential in order to give the plan beginning directions and mandates as to local wants and needs. It would also assure acceptance of the planning results and the participants would eventually assist in the implementation of the plan. Secondly, a major goal of the planning was the development of a needs assessment which evaluates the available data as well as the present supply and demand for services. It also was to devise a strategy for obtaining and using

information and data in the future.

The citizen participation and data gathering then laid the groundwork for developing a service delivery system plan which would describe the services to be provided and which would fit within the socioeconomic context and capabilities of the area. A seven-year master plan was then developed which detailed the implementation schedule, estimated the cost of providing the services, and developed a plan of action for implementation. This included recommendations for administrative structures, located responsibility for services, and identified potential funding sources. Also, as noted earlier, the community planning process and the state policy planning formed a feedback cycle in which both groups shared ideas with each other for consideration and constructive comment. Issues which were particularly suitable for this included: administrative structures, financial and interagency coordination agreements, and funding issues.

Finally, the planning process provided a learning-through-experience process for those who did the staff work --DSS's Mental Retardation (MR) Supervisors. By assigning these personnel to work nearly full-time under the supervision of the consultants during the four-month planning process, they in turn were prepared to implement similar planning in Iowa's other districts. Also, the consultants developed a document to help transfer the planning

methodologies developed from the model district planning process to other Iowa districts.

The community planning was tied to the basid DSS administrative units--the sixteen service districts. In order to give the planning process credible statewide acceptability, it was decided that two districts would be chosen as models with special attention given to important socio-political, economic, and demographic factors within the state. The districts selected were Dubuque and Sioux City.

The Dubuque district consists of five counties with a total population of 204,600 and a median family income of \$10,300. Two major population centers--the towns of Dubuque and Clinton--account for 47 percent of the population. The remainder of the population live in the surrounding rural areas.

The Dubuque area has a somewhat higher concentration of MR services than most other areas of Iowa. The services available range from highly specialized residential care for non-ambulatory children to nearly comprehensive services located within one facility. It is important to note, however, that these services tend to be located in the more populous areas of the district, leaving the rural areas with a minimum of care services and with accessibility problems to those that do exist.

The Sioux City district, which also has five counties, has a total population of 170,000. The median family income is \$8,300. Sioux City is the only urban area in the district, with 37 percent of the population living there. The nearby communities in South Dakota and Nebraska combine with Sioux City in an area known as Siouxland and interrelate closely in spite of state boundaries. However, the MR planning area included just the Iowa portion of Siouxland.

With relatively few providers of MR services, the Sioux City district had very little prior coordination of efforts in the development of services. The services available include sheltered workshops, educational programs, and some residential programs.

In order to accomplish the goals of the planning process, in both model districts three planning groups parallel to those established at the state level, were established: a Staff Task force of seven MR professionals who gave staff support to the other planning groups; a Core Planning Group composed of key public and private MR personnel and consumers from the district, county, and local levels; and an Extended Planning Group composed of public officials, public and private providers, and the general public.

The Extended Planning Group met three times at open hearings to provide direct input to the planners. At the

first hearing, they gave beginning directions, at the second they reviewed and commented on the draft plan, and at the third they approved the final plan and began implementation steps. The Core Planning Group met weekly for four months and actually developed the plan using the input of the Extended Planning Group.¹⁸

The results were plans which consisted of a needs assessment, ideal model delivery system, cost analysis, and seven-year master plan for implementation. Almost all MR services defined as being needed were designated to be developed in the local communities. This implied a major change, for example, in the diagnosis and evaluation process for clients which was at that time occurring at only a few State facilities. Another major thrust of the recommendation was for the development of a central point of entry where a client would receive an individual needs assessment, have developed for him or her an individualized treatment plan, and have a case-manager assigned to follow-along with the client as s/he receives services in order to assure their appropriateness.¹⁹

It is important to note that this process involved hundreds of community people as active participants. It received initial direction from the community and the final products were reviewed by them for acceptability and compliance with their directions. Once it was determined that the plans were acceptable to the public, efforts were made

to maintain public involvement in the implementation of the plans. To this end, county planning groups were formed to assist in public education and support of the plans. Since then, they have made presentations to County Boards of Supervisors as they began the county budget preparations for the coming fiscal year. District DSS offices have begun to reallocate staff and designate funds for the initial steps of the plans and the planning groups have well-defined on-going functions which they are presently performing. However, it is important to note that successful implementation of these plans is not totally dependent upon local action but also upon the State's actions. Recommendations to the State from the districts have included: establishment of a funding mechanism to support the local plans, development of State placement policies, the need for a State data collection and retrieval system, the promotion of a legislative mandate to define a mentally retarded person's right to services, and the need for inter-agency agreements.

It is clear that the original goals of the planning process were substantially achieved. The groups were composed to reflect all relevant interest groups. Attempts were made throughout the process of encourage the members to be active participants. The core planning group participation, the most demanding as far as time commitments, was very successful in spite of a few minor problems. One difficulty was that consumer input from parents and relatives

of the MR population was difficult to achieve. Midway through the process, more parents and relatives were recruited to participate. However, it proved to be difficult for them to acclimate themselves into a process which was already underway. Another difficulty occurred around the attendance of some core group members. For example, in Dubuque, the Vocational Rehabilitation representatives did not actively participate; in Sioux City a similar situation existed with the County Board of Supervisors.

In spite of these difficulties, an important effect of this process was the creation of a high degree of enthusiasm and activity about the plan and its implementation. This spirit was a direct result of the vested interests and commitments which the participants had in the plan. It also, for the first time, enabled the disparate interest groups to unite and politicize what had previously been an ad hoc, disjointed effort to develop community services. These efforts now had developed a wider support base in the community and the planning process legitimized many of their efforts.

D. Licensure and certification

Parallel to the community planning effort is the need for the facilities to meet quality standards through state licensure and certification procedures. Following the State Policy Planning Group's recommendation, the

Commissioners of the Department of Health and the Department of Social Services appointed a committee to develop goals, guidelines, and action plans for joint licensure and certification of MR residential facilities. The planning group consisted of representatives from the relevant State departments, county government, providers, and consumers. The PAK process was used for eight meetings during which the group clearly defined a unified approach to the licensing and certification of MR residential facilities which also specifies points of control to assure clarity and accountability.

The group's recommendations also required that the development of residential facilities be in accordance with the district's plans and that responsibility for this assurance remain at the district level. In addition, it was recommended that a timely and responsive technical assistance process be established. This process would enable potential developers to become acquainted with and understand the steps to be followed at the State, County, and local levels. This includes information about funding availability, an area's identified needs, program requirements and standards, local fire and building codes, and zoning regulations. Besides receiving this assistance from the concerned agencies, a handbook would be developed. Guidelines for the cost/effectiveness of the services were also developed.

VI. CONCLUSION

Although a large portion of the planning for MR services has been completed there is still more to be done. For example, the State's other fourteen DSS districts still have to develop plans for their communities. In addition, the Iowa Code is being revised to clarify responsibility for the mentally retarded person. The DSS also has to improve linkages between itself and other state agencies to attain more effective cooperation.

At the same time, implementation of the plans has just begun. For example, the architectural design work is already underway for the first phase of SHS development. In the model districts, the plans are currently being publicized and presentations are being made to County Boards of Supervisors for inclusion in their budgets. The district DSS office and ongoing planning groups have also begun the steps necessary for the establishment of a central-point-of-entry to the system. Already, some districts have begun to take the initial steps necessary in order for all to be completed in time to make requests for a legislative appropriation next year. The State Policy Planning Group's recommendations for a funding mechanism and placement policy are currently being finalized for approval.

The participatory processes used in the Title XIX planning enabled people with diverse interests to get together and come to a consensus on what they wanted and what to do about it. The process and techniques used provided an organized forum for the thorough discussion, understanding, and resolution of ideas which at times were conflicting and at other times complementary. Hundreds of Iowa citizens were involved in an activity which was clearly fruitful. Their planning efforts clearly defined the direction toward which the state system of MR care was to be developed. More critically, they specified the actions to be taken to attain the envisioned system. This included a strategy for effectively organizing the State's role in coordinating and monitoring local service development, the State Hospital School's role, and the relationship between the two. In addition, they developed logical plans for development for a system of services which reflect the community's needs and wants.

In the time which has passed since these activities, a number of concrete achievements can be documented:

- The State qualified for Title XIX funding in a relatively short period of time.
- Construction of ten residential units at the two institutions has been completed.
- The federal funds have not been diverted to the general fund as they have in most states. Rather, Title XIX funds are funneled directly into MR services.

- At the state level, coordination of the planning headed off much of the potential political in-fighting by creating a formal arena for decision-making.
- Program vendors were able to impact the facility licensing and certification procedures and make them more responsive to their needs.
- Institutions were directly able to hear the community's issues and problems with the existing system of care.
- Communities were directly able to become more politicized and systematic in making known their demands about deinstitutionalization.

A number of problems were also evident as a result of the planning. Primarily, all of the first round of funding went to the institutions in order to meet the federal requirements for Title XIX eligibility. The community vendors received only partial satisfaction from the process. However, they now have a promise of being able to capitalize on Title XIX funding--but to date there has been no direct pipeline. Another problem was that the state DSS bureaucracy itself became splintered between supporting the institutions against the community development interest groups.

However, the critical issue upon which the value of the entire process and the fate of thousands of mentally retarded people rests is the rate of community service development and deinstitutionalization. It is obvious that large institutions don't just dissolve of their own volition. Nor, on the other hand, can communities simply

develop services through sheer will power. What is needed is some type of thrust to accomplish these goals; and in this case, it appears that the impetus must be financial.

It can be observed that money invested in SHS campus development will be reinforcing an institution which is already strong. Rather than becoming a part of the MR service delivery system, it will become the service delivery system and community services will be incidental. However, the second phase of campus development and the resultant increase in funds to the SHSs can only be deterred if the community placements can be made. This can only occur if the community has the money and the technical assistance to give them the capability necessary. The licensing and certification procedures, as recommended, will provide the technical assistance necessary. However, the funding for facility development is the major difficulty. There are two major avenues for the state to pursue in order to achieve this goal: a funding mechanism and an additional state appropriation.

By conducting the cost study, the state is beginning to detail the present flow of dollars through the system: the first step in developing a funding mechanism. The data obtained will show to what extent communities are now paying for services. It is likely that this will show a considerable investment already being made by communities. It is therefore important that the current dollar-flow system be

restructured to permit and encourage the communities to pay for locally-provided services.

Yet, even if a mechanism is developed which pays for services in the communities, it will not matter if there are no services immediately available. A major problem for the private sector is the lack of start-up funds for development. There is also a need for money to support local coordination, monitoring, and planning. To this end, it is important that a lobbying effort take place to educate the legislators and general public about the need for community services.

In spite of the fact that the planning and implementation are still ongoing, two observations can be extrapolated from the process. First of all, it was clear that the consultants had a viable and much needed role in the planning. Their participatory methods as well as their determination of the time frame for the decision-making were definite advantages in the process. They provided the structure necessary to organize many-faceted comprehensive systems planning. Secondly, the process emphasized the necessity of having top-down support for the policy decisions as well as the need for grassroots community support. Without the support of the DSS commissioner, however motivated, and ultimately the Governor, the communities would not have been able to confront the large institutions. This multi-layered process enabled the

state to troubleshoot political problems at the highest level and at the same time to be responsive to community input.

NOTES

¹Gunnar Dybwad, Challenges in Mental Retardation, p. 117.

²President's Panel on Mental Retardation, A Proposed Program for National Action to Combat Mental Retardation, p. 134.

³John F. Kennedy, Message from the President of the United States Relative to Mental Illness and Mental Retardation, p. 11.

⁴Public Law 92-223, Medical Assistance Program: Intermediate Care Facility Services.

⁵W. Wolfensberger, Changing Patterns in Residential Services for the Mentally Retarded, p. 131.

⁶EDG, Iowa Title XIX ICF/MR Statewide Policy Planning Report, pp. 1-2.

⁷Ibid., pp. 7-41.

⁸Ibid., p. 15.

⁹Ibid., p. 42.

¹⁰Richard Krauss and Curt Lamb, Planning Aid Kit: Introduction to PAK, pp. 1-8.

¹¹Stephen Carr, Ecologue, pp. 1-5.

¹²EDG, Statewide Policy Planning Report, p. 58.

¹³Ibid., p. 62.

¹⁴Ibid., pp. 63-66.

¹⁵Ibid., pp. 51-55.

¹⁶EDG, Campus Masterplans, pp. 35-36.

¹⁷Ibid., pp. 144-68.

¹⁸EDG, Model District Planning, pp. 7-8.

¹⁹ Ibid., pp. 17-19.

²⁰ EDG, Report on the Proceedings of the Committee
on Joint ICF/MR Licensure and Certification, pp. 20-21.

BIBLIOGRAPHY

- Carr, Stephen. Ecologue. Cambridge, Massachusetts: MIT Urban Studies Program, 1974.
- Dybwad, Gunnar. Challenges in Mental Retardation. New York: Columbia University Press, 1964.
- Environmental Design Group. Campus Masterplans for the State of Iowa. Cambridge, Massachusetts, 1976.
- _____ . Iowa Title XIX ICF/MR Provider Participation Packet. Cambridge, Massachusetts, 1976.
- _____ . Iowa Title XIX Report on the Proceedings of the Committee on Joint ICF/MR Licensure and Certification. Cambridge, Massachusetts, 1976.
- _____ . Iowa Title XIX Statewide Policy Planning. Cambridge, Massachusetts, 1976.
- _____ . Model District Planning. Cambridge, Massachusetts, 1976.
- Kennedy, John F. Message from the President of the United States Relative to Mental Illness and Mental Retardation. Washington, D.C.: U.S. Government Printing Office, February 1963.
- Krauss, Richard, and Lamb, Curt. Planning Aid Kit. Washington, D.C.: National Institute of Mental Health, 1976.
- Lamb, Curt. Planning for Community Control of Community Mental Health. Cambridge, Massachusetts: Environmental Design Group, 1974.
- President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. Washington, D.C.: U.S. Government Printing Office, October 1962.
- Public Law 92-223. Medical Assistance Program: Intermediate Care Facility Services. Washington, D.C.: U.S. Department of Health, Education, and Welfare, 1973.
- Wolfensberger, W. Changing Patterns in Residential Services for the Mentally Retarded. Washington, D.C.: U.S. Government Printing Office, 1969.