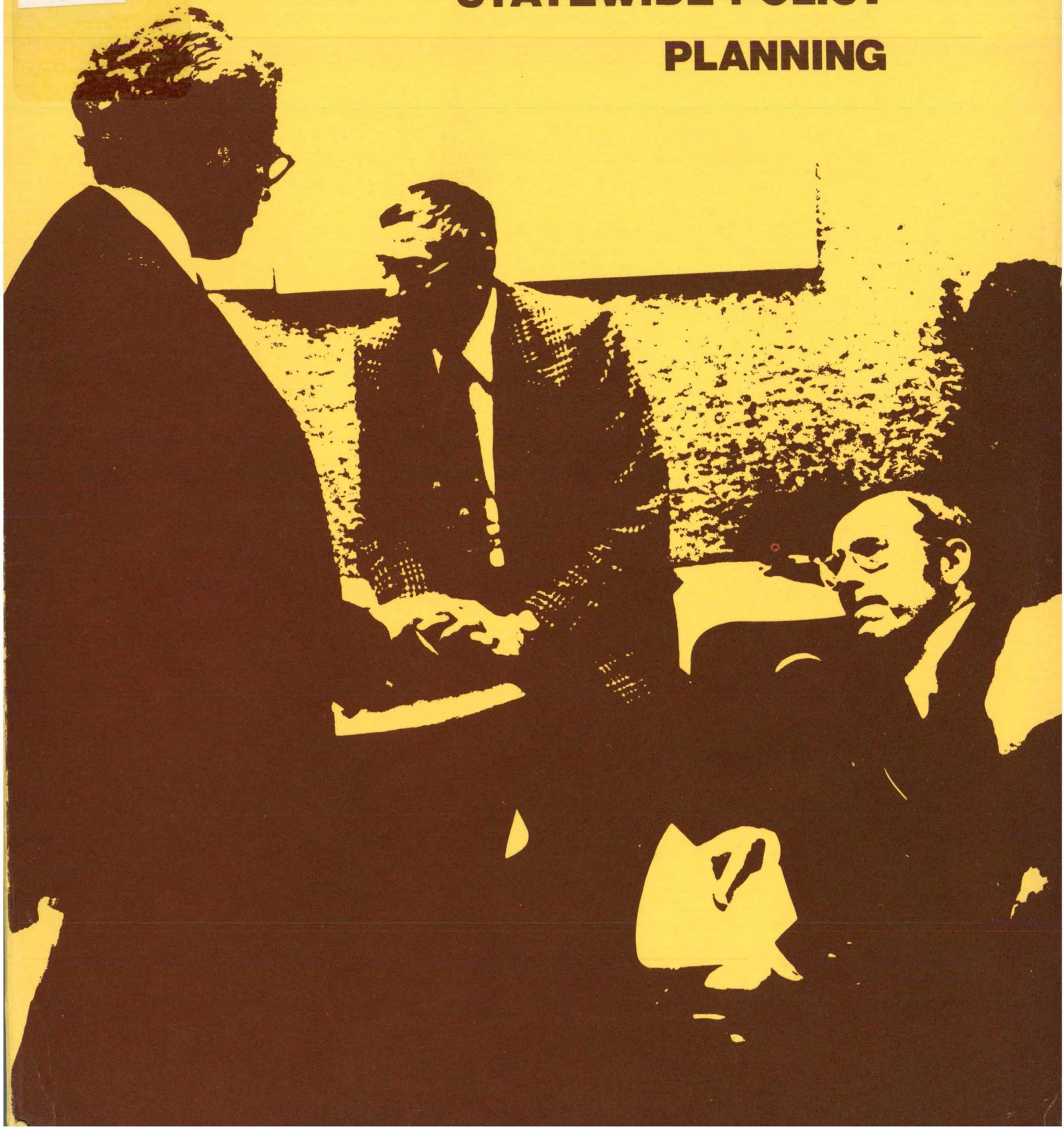
IOWA TITLE XIX STATEWIDE POLICY PLANNING



IOWA TITLE XIX
ICF/MR STATEWIDE POLICY PLANNING REPORT

STATE POLICY PLANNING GROUP

Sponsored by:
IOWA DEPARTMENT OF SOCIAL SERVICES

Consultants:
ENVIRONMENTAL DESIGN GROUP, INC.
CAMBRIDGE, MASSACHUSETTS

MARCH 31, 1976

Environmental Design Group Inc.

14 Arrow Street, Cambridge, Massachusetts 02138 · 617-868-6850

March 31, 1976

Kevin J. Burns, Commissioner
Iowa Department of Social Services
Lucas State Office Building
Des Moines, Iowa 50300

Dear Commissioner Burns:

This report is submitted as a final documentation of the group facilitation services that EDG has performed, for the Title XIX Policy Planning Group, under article 4.0 and section A3.0, of the initial and amended Iowa State Medical Assistance Program Contract.

The report is divided into two main sections and appendices. The first section details the two week policy planning process which was conducted under the initial contract. The second section describes the various issues and activities which occurred during the set of policy group meetings conducted under the amended contract. In addition the appendices contain the lists of participants, a summary schedule of the two week process, and the placement policy guides which were produced by the reorganized group.

Stephen Knapp and William Karg of our staff were instrumental in the preparation of this report. I would also like to acknowledge the cooperative attitudes and the uncounted hours of effort by the participants without whom this report would not be possible.

Finally we would like to acknowledge the splendid cooperation and assistance we have received from the Central Office ICF/MR task force, Co-Chaired by Mr. Nicholas Grunzweig and Ms. Linda Cooper, and the support we have received from your office in completing this work.

Sincerely,

ENVIRONMENTAL DESIGN GROUP INC.

Gerald W. Robinson

Gerald W. Robinson
Project Director

GWR/jw

TABLE OF CONTENTS

PREFACE

TWO WEEK PLANNING PROCESS

- Introduction 1
- Group I Report 4
- Group II Report 21
- Group III Report 30

SIX MONTH PLANNING PROCESS

- Introduction 42
- Contract Monitoring 42
- Funding Mechanism 51
- Structure and Function of the State Policy Planning Group 56
- Placement Policies 63
- Analysis of Six Month Planning Process 66
- Summary of Next Steps 68

APPENDICIES 70

- List of Participants
- Session Schedule
- Placement Policies

PREFACE

Since April of 1975, the Department of Social Services (DSS) has been working on a mandate from the State Legislature to qualify its services for the mentally retarded for Federal reimbursement under Title XIX (Medicaid). This program would bring a large amount of funds to Iowa and necessitate quite significant changes in order to qualify its residential institutions (particularly Glenwood SHS and Woodward SHS). Hence, the DSS decided to examine the whole future of the system of services in planning its strategy for qualifying for the funds and developing ways to expand them. To assist in this task, DSS appointed a Title XIX policy planning group in July of 1975 and reorganized it in October 1975.

This report documents the two more significant phases of their activities and recommendations to date. The first section reports in great detail the two week policy planning process in which they participated and the policy recommendations which resulted from their deliberations. The second section documents the subsequent set of meetings in which a reorganized policy group participated and the policy recommendations they made as well as the activities they became involved in to assist the enaction of the initial set of policy recommendations.

The Appendices include lists of participants for both groups, a summarized session schedule for the 2 week policy sessions, and the policy recommendations made in the second set of meetings regarding placement policy.

At this writing, the reorganized Title XIX Policy Planning Group is still actively involved in advising and assisting DSS in the development and implementation of the policy for the states service delivery system for its MR/DD citizens.

TWO WEEK PLANNING PROCESS

INTRODUCTION

The mandate for the inital planning group meetings was to suggest needed policy recommendations to the DSS on the over-all State M.R care system to insure that planning for qualifying T-19 funds would be within the context and complement the further development of the statewide system.

The group was composed of 26 individuals representing the various divisions of the DSS and other participating or potential participating state agencies in programs for the developmentally disabled including representatives from the Glenwood and Woodward State Hospital Schools for the mentally retarded. In addition , representatives from private M.R. service providers, the Iowa Association for Retarded Children, and the Iowa State Association of Counties were invited to participate in the planning session. (See the list of policy planning session participants in Appendix 1).

The planning group met for 35 hours over two weeks from July 29 to August 8, 1975. (A summarized meeting schedule is included in Appendix 2.) The process was prepared and facilitated by the Environmental Design Group (EDG), a Cambridge,Massachusetts architectural and planning firm in conjunction with a T-19 Task Force from DSS. EDG based the two-week session on the Planning Aid Kit (PAK), a particpatory planning process it developed under a grant from the National Institute for Mental Health as a planning tool for community mental health and mental retardation planning. EDG had used the process extensively for mental health Catchment area planning and for T-19 ICF/MR planning under a contract with the State of Massachusetts.

In the first session participants were given orientation materials and presentations covering issues including their mandate; T-19 general information; planning issues involving the State Hospital Schools, the community, and T-19 technical plans of correction. The participants were also presented with summaries of the available M.R. socio-demographic data. These presentations were highly interactive, and the participants generated eight wall posters of concerns related to the information they received.

The second session was designed to elicit all the concerns participants had about the present M.R. service system and how it might be improved. The majority of participants were administrators who had much experience with both past and present M.R. planning and programming in Iowa and were therefore able to generate 16 more wall posters of issues and concerns they had about M.R. services. In all, the group cited over 250 "concerns."

The DSS central office task force and the EDG consultants summarized the concerns posters into 30 broad problem clusters and divided them into three major categories:

- Statewide Care System
- Service and Facility Development
- State Structure and Administration.

The large planning group was then divided into three small groups according to best judgments about the match between the three problem cluster groupings and the individual professional interest, background, and experience that each participant brought to these concerns.

Both the problem cluster groupings and group assignments were presented to the group and were adopted with slight modifications. There was clearly some overlap with issues and also participant interests, but the small groups minimized duplication as much as possible.

The small groups then began to work on their assigned problem areas with a clear division of purpose and principle emerging.

Group I. Statewide care system -

purpose - "What it should be"
principle - Services to be delivered through a structure which is client centered.

Group II. Service and Facility Development

purpose - "Getting it there"
principle - Services to be brought close to home.

Group III. State structure and administration

purpose - "Keeping it going"
principle - Government to be more responsive; make decisions closer to those served.

A fuller description of how each group worked through their issues and the recommendations they produced are contained in the following sections of this report.

On August 8, 1975 the group presented its findings and recommendations to Commissioner Kevin Burns and the DSS. This report documents the material presented and hence cannot represent department policy. Commissioner Burns has pledged to give the suggestions herein full consideration. It is expected that as planning for T-19 funds continues, further work will have to be done on the issues raised.

GROUP I: STATEWIDE CARE SYSTEM

What It Should Be

Group I had the difficult problem of deciding what M.R. services should be available in the State of Iowa for all of its developmentally disabled citizens. In the first day of planning, 113 concerns were generated by the larger planning group relating to this problem. The DSS T-19 task force and EDG consultants had grouped these into 11 problem clusters which then became the focus for Group I's work on a Statewide Care System. (See Appendix A & B).

The group discussed these problem clusters and refined them into a working agenda of issues for which they could suggest solutions.

The participants and EDG facilitators then agreed that the best way to invent solutions for these issues was to build ideal models from which policy recommendations could be derived. (Group I's models follows in this section.)

In building the models, the group generated a list of all the principles they felt an M.R. service delivery system should follow and then a list of all of the M.R. programs and services it should contain.

In order to save time and build on the work of others who had previously undertaken similar tasks, the group then looked at several fully developed lists of M.R. service principles and programs from other sources and selected one which closely matched its own for adoption.

After completing these initial work steps the group then concentrated on developing a model service delivery system and a set of recommendations for its report back to the large group on the last day of the planning process. Group I's working agenda, models and findings are contained in the following pages.

GROUP I: WORK AGENDA

Lifelong Array of Services

- Put all needed services (M.R. and non-M.R.) into a continuum of care model.
- Determine scope and size of geographic service areas.

Roles of Service Providers

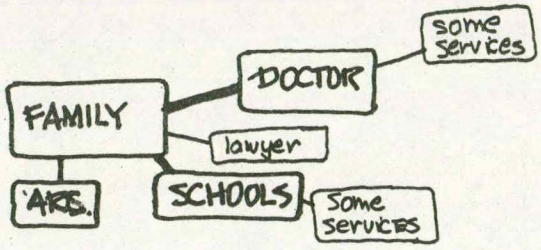
- Determine potential service providers for each needed service and recommend most favorable.
- Determine ideal relationship between institutional services and community service system.

Discuss policy needs for the above.

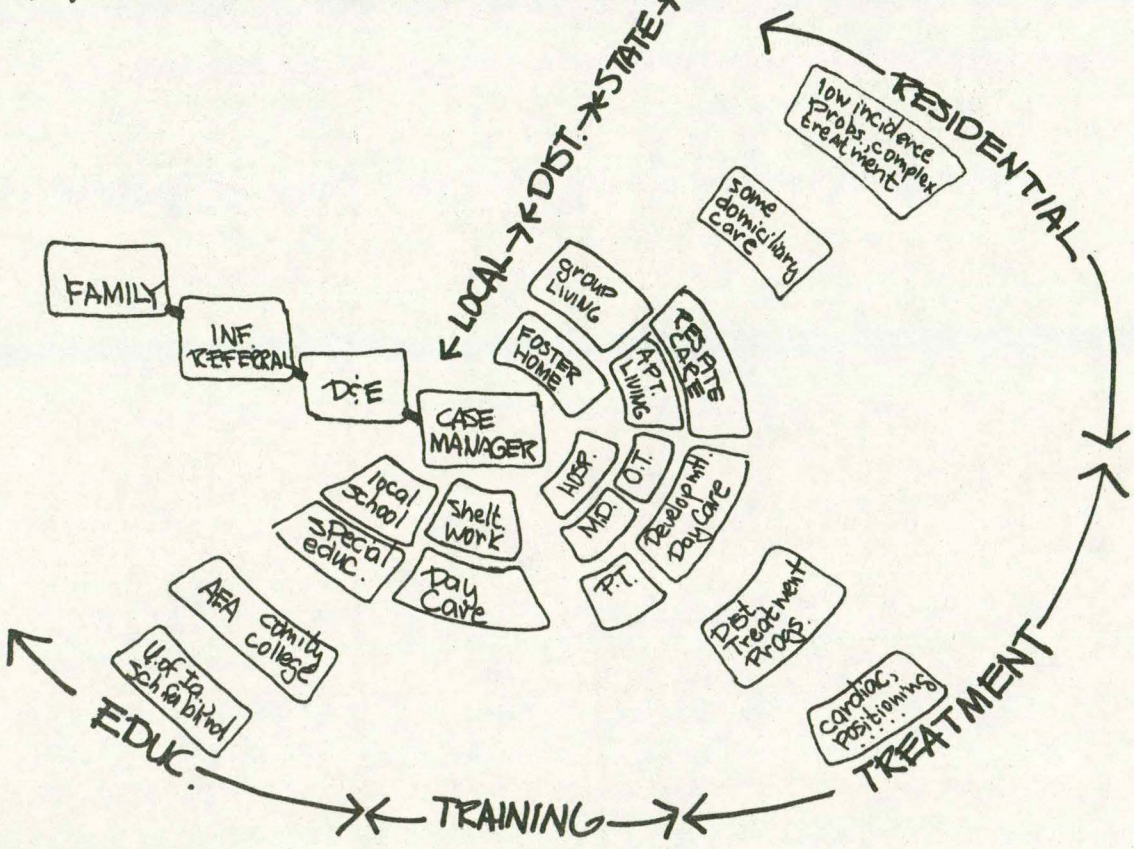
Develop report of recommendations for large planning group.

MODELS of SERVICE DELIVERY

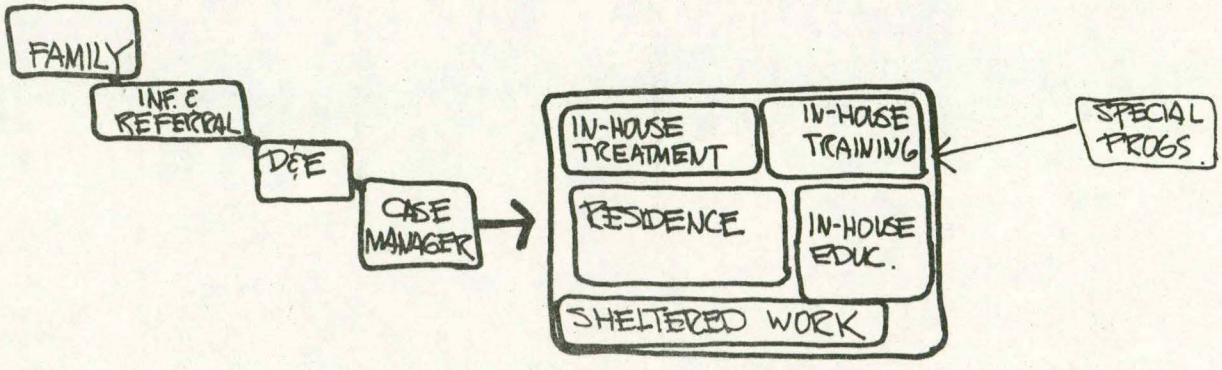
A. TRADITIONAL PRIVATE MODEL



B. LOCAL, GENERIC SERVICE DELIVERY MODEL



C. RESIDENTIAL CARE MODEL



GROUP I: RECOMMENDATIONS

General Recommendations

- That the State of Iowa develop a Lifelong Comprehensive Array of M.R. Services sufficient to serve all of its MR and developmentally disabled citizens.*

  * Throughout this report when the term mental retardation is used it implies all other developmental disabilities.

- That such services shall be no less comprehensive than those defined in the service delivery recommendations of the group.

- That such services be delivered following the principles of responsiveness, availability, accessibility, records, quality control, accountability, normalization, and voluntary choices. (A full definition of these principles and their sources are cited at the end of this section beginning on page 16.

Service Delivery Recommendations:

- The following services shall be provided as generally defined[1] to all M.R. clients to protect their human rights and insure access to appropriate services which meet quality standards of care.

  - INFORMATION AND REFERRAL Provision of an up-to-date listing of all appropriate resources, which can be made available and quickly accessible to professional persons serving the developmentally disabled individual and his family so that they can refer them to the needed, appropriate, and most readily available resources. It also can support public information activities concerning the problems of the developmentally disabled.[1]

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[1] All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

- FOLLOW-ALONG Establishment and maintenance of a counseling relationship on a life-long basis with developmentally disabled individuals and their families, as they desire, for the purpose of assuring that anticipated changes in needs and for needs arising from crises are recognized and appropriately met.

- PROTECTIVE Provision of a system of social, legal and other appropriate services which assist individuals who are unable to manage their own resources or to protect themselves from neglect, exploitation or hazardous situations without assistance from others, and to help them exercise their rights as citizens.

Where: These services shall be provided at the local-county level with full coordination by the District Administrator or his/her designee.

Who: These services shall be provided by or through the DSS.

Prior to the initial provision of services or placement in residential care, each client shall receive a comprehensive Diagnosis and Evaluation by an appropriate interdisciplinary team of qualified professionals. Such examination shall minimally cover the following service definitions:

- DIAGNOSTIC Provision of coordinated services, including but not limited to psychological services, social services, medical and other services necessary to determine the presence of a disability and its cause and complications.

- EVALUATION Systematic appraisal of pertinent physical, psychological, vocational, educational, cultural, social, economic, legal, environmental and other factors of the developmentally disabled individual and his family (a) to

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(1) All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

determine extent to which disability limits daily living and work activities, (b) to determine if disabling condition can be corrected or minimized by services, (c) to determine nature and scope of services to be provided, (d) to select service objectives, (e) to devise a program of action.

Where: Diagnostic and Evaluation services shall be delivered at the local-county level whenever practical, but shall at least be available in each of the 16 DSS service districts.

Who: These services shall be provided or arranged for by the District Administrator or his/her designee.

Members of the Diagnostic and Evaluation teams shall include but not be limited to qualified M.R. professionals as defined by the T-19 ICF/MR regulations.

The State Resource Centers shall provide training, support, and monitoring to maintain the quality of the Diagnostic and Evaluation services.

The State of Iowa shall, through its appropriate agencies and the development of Federal and other funding sources, provide or arrange for the following array of M.R. services as defined, sufficient to meet the needs of its M.R. citizens.

- TREATMENT Provision of interventions (physical therapy, speech therapy, behavioral modification, medical treatments, etc.) which halt, control, or reverse processes which cause, aggravate, or complicate developmental disabilities.

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(1) All services definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

- DAYCARE Comprehensive and coordinated sets of activities providing personal care and other services to pre-school, school-age and adult developmentally disabled individuals outside of their home during a portion of a 24-hour day. Service should provide at least personal care, training, counseling and recreation services carried out under careful supervision. May be developmental services for children or activity programs for adults.

- TRAINING Instruction designed to (a) develop skills in performing activities of daily living, (b) enhance emotional, personal, and social development, (c) provide experiences conducive to the acquisition of a positive self-concept and desire to learn, (d) provide experiences for gaining useful occupational and pre-vocational skills.

  (1) Personal-Social Adjustment
  (2) Pre-vocational
  (3) Vocational

- EDUCATION Provision of structured learning experiences based on appropriate evaluations through the use of a varied curriculum of practical academic subjects primarily designed to develop ability to learn and acquire useful knowledge and basic skills, and to improve the ability to apply them to everyday living. (a) Pre-school, (b) Primary, (c) Intermediate, (d) Advanced.

- SHELTERED EMPLOYMENT Provision of structured programs of activities involving work evaluation, work adjustment, occupational skill training and paid, part-time or full-time employment for those who cannot be readily absorbed into the labor market because of severe disability(ies).

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(1) All services definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

(a) Long-term -- Continuing service for those who have adjusted to the learning and practice of work but are unable to sustain the demands of competitive employment.

(b) Transitional -- Goal is eventual placement in competitive employment. Primary features are work and personal adjustment.

(c) Sheltered Placement -- Provides a full or part-time position in a facility, other than as a trainee. For individuals unable to sustain competitive employment.

(d) Homebound Work -- Work which can be done in an individual's home. Evaluation is necessary to locate those who develop the ability to leave their homes for sheltered or competitive employment.

- COMPETITIVE EMPLOYMENT Provision of placement and support services necessary to allow persons with limited disabilities the opportunity for gainful and competitive employment.

- PERSONAL CARE Daily supportive service to maintain health and well-being of person to prevent regression and other complications. Should be 24-hour supervision and must be provided in conjunction with one or more other appropriate services. Includes such things as food, bodily care, clothing and stimulation.

- COUNSELING Giving of professional guidance on the basis of knowledge of human behavior and the use of special interviewing skills to achieve specified goals mutually accepted by counselor and client. Includes family planning, genetic, premarital, etc.

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(1) All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

- RECREATION Provide for planned and supervised activities designed to (1) help meet specific individual therapeutic needs in self-expression, social inter-action, and entertainment, (2) develop skills and interest leading to enjoyable and constructive use of leisure time, (3) improve well-being.

- TRANSPORTATION Provision of necessary travel and related costs in connection with transporting developmentally disabled individuals, and where necessary, members of their families, to and from places in which they are receiving other services. May also include taking services to the homebound as well as delivery of raw materials and pick up of the finished product from homebound industries, where indicated.

- RESIDENTIAL SERVICES

  -- NATURAL HOME

  -- SPECIAL LIVING ARRANGEMENTS Provision of living quarters for persons who need some degree of supervision. Special leisure time activities. Services are for developmentally disabled persons who can leave the place of residence for work, recreation, or other reasons.

  (a) Hostels - Standard homes which have been modified, if necessary, to accommodate small groups. Primarily for adults.

  (b) Boarding Homes - (1) Temporary placement of child who has a home which continues to function as the primary and legal residence. A five-day boarding facility. (2) Placement of adult into a family setting, where he receives board and room but requires little supervision.

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(1) All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

(c) Foster Placement - Placement of a child into a foster home when needing more personal care and supervision than they would have in a boarding home.

(d) Apartments - For individuals requiring only a minimum of supervision with supervisors living nearby, but not with them, and providing services as needed.

-- DOMICILIARY CARE Provision of out-of-home living quarters, supervision and personal care to developmentally disabled persons needing 24-hour supervision. Differs from Special Living Arrangements by the degree of supervision and the amount of personal care provided.

-- RESPITE CARE Temporary residential care for short-term placement because of family crises or other necessary interruptions to the client's residence of most meaningful tie.

Where: All components of the above array of M.R. services are best provided at the local-county level; however, service may be more practically provided at the district or State levels when:

(a) The incidence of the problem is too infrequent to warrant provision at the local-county level.
(b) The treatment of the problem is too specialized, complex, or multifaceted for quality care at the local-county level.
(c) The family and client desire by choice, available services outside of the local-county level.

Who: DSS and other appropriate agencies shall be responsible for the provision

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(1) All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

of or arrangements for these services including generating new funding sources when necessary.

DSS District Offices shall be responsible for developing these services through:

(a) Direct service

(b) Purchase of services

-- Public (county
(city
(other public agencies

-- Private (profit vendors
(nonprofit vendors
(other community organizations.

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(1) All service definitions are direct excerpts or modified excerpts of the Federal Guidelines for Services to the Developmentally Disabled.

Recommendation on Role of State Hospital Schools

In the comprehensive array of M.R. services the present state hospital schools shall function as specialized resource centers providing:

- Direct Services
  - (a) for low incidence M.R. problems
  - (b) for complex, or multifaceted treatment needs
  - (c) for short-term or transitional care for those who by choice or necessity cannot received adequate services elsewhere.

- Indirect Services
  - (a) Education and training of M.R. professionals and other M.R. service personnel including follow-up and support.
  - (b) Program consultation and technical assistance to M.R. service providers.
  - (c) Research
  - (d) Demonstration projects
  - (e) Support and monitoring of D&E services to the District and local-county level.

Note: Minority Report - SHS's shall monitor services when other agencies cannot provide adequate monitoring.

PRINCIPLES OF THE SERVICE DELIVERY SYSTEM

The service delivery system mediates between the client and his cultural environment to mitigate and compensate for the abnormalizing effects of disability. It does so essentially in two ways; by improving the client's capabilities to provide for himself, and by modifying environmental conditions to bridge remaining gaps between personal resources and the normal fulfillment of need.

Because living is a complex process of interactions, the delivery of assistive, supportive, and protective services requires a complex, interactive system. To the extent that service elements remain separate and uncoordinated, they lose effectiveness and tend to fragmentize the person. Systems of service delivery will doubtless always fall short of ideal coherence, but, to the degree that they are directed toward normalization, they exhibit certain indispensable characteristics, which are reflected in the operation of an individual agency. The most essential characteristics concern responsiveness, balance, and the cross-disciplinary approach; accessibility; individuation, which includes acceptability and participtation; records; quality control; and accountability.

RESPONSIVENESS

The service delivery system must focus on the needs of the unique community area that it serves. Once the target population is identified, the parameters of need relating to this population must be determined. Demographic analysis should include a full account of not only the target population itself, but also of the resources of the community relevant to these conditions of disability. The service delivery system must be designed in the light of this knowledge.

The needs of clients change with the advancement of knowledge, the evolution of social life, and the changing aspirations of people. The service delivery system must be responsive to these changes; otherwise it will fall back into sterile habits of institutional self-perpetuation that serve no one but the agencies themselves.

Responsiveness must be expressed through responses to the specific developmental needs of clients. Throughout an effective service delivery system, every component agency must be able to respond to any individual appeal, either by initiating direct service itself, or by referring to an appropriate source and systematically following up to see that the problem is solved. In addition, the service delivery system, as a whole and in all its parts, must reach out to expressed or unexpressed needs.

AVAILABILITY

In order to serve the target population for which it exists, a service delivery system should have a sufficient array of components, actually present

to meet the array of needs known to exist. The ultimate goal of the system should be to make available within the community all of the necessary instrumentalities to meet the needs of the disabled population. Obviously, such a goal will be difficult to attain and will require a process of evolution. The process, however, should be one in which carefully defined, time-limited objectives are progressively translated into concrete operations.

Availability applies also to the comprehensiveness of services. While service systems may differ greatly in number and elaboration of component elements, and in their level of sophistication, there is a minimum constellation of such components that must be available if the needs of a disabled population are to be served realistically. The state of the art and the problems of semantics make the formulation of such a minimum constellation somewhat tentative, but the following are suggested as a basis for defining comprehensiveness; provision for an overall indivdual support system; individual assessment; attention to health needs; attention to developmental needs in the areas of sensorimeter, communicative, social, affective, and cognitive development; services to support employment and work; access to specialized religious nurturance; recreation and leisure; family related services; and attention to needs for mobility.

The availability of such a set of services reflects the array of essential human needs that are affected by disabilities in varying degrees and patterns. A service delivery system, therefore, should have this degree of comprehensiveness if the varied patterns of need in the population are to be met, and if the specific objectives of an individual agency are to be achieved. The system, moreover, should seek to have sufficient services available to provide options and alternatives, both to enable consumers to have the opportunity to choose from among alternative services, and to simulate agencies providing similar services to continually seek to improve their programs.

The economics, as well as the normalcy, of the service delivery system dictates that all resources of the community should be available to and utilized by the disabled. These resources should include generic services available to all citizens. Agencies deliverying specialized services must coordinate their programs with the resources of the general community, in order that the needs of their clients may be served in a manner that is consistent with normal community experience. The principles should be followed rigorously that no special service is provided to meet needs already appropriately served by generic agencies. Specialized services should be developed only when generic agencies are unable to accommodate special needs.

Another dimension of the availability is the completeness with which the service system can meet adequately the needs of all persons. The system must make the needed services available to persons of all ages, at all degrees and patterns of disability, of all socioeconomic and ethnic subcultures, and of both sexes, and it must make services available in the forms appropriate to these differences. This does not mean that every agency should provide direct services to everyone, but every agency must be an integral part of a system that does.

ACCESSIBILITY

Though services are available in the community, unless those who need them have access to them, services cannot be rendered. Access may be limited by many factors: lack of information, bureaucratic red tape, immobility, household responsibilities, fear, geographic or social isolation, lack of transportation, language or other cultural barriers, cost, or the agency's lack of responsiveness and follow through.

Each service delivery system should have an affirmative action policy to facilitate access by all who have need. This policy should be refelected in operating procedures that minimize the effect of all potential barriers, including those listed above, that might impede access.

INDIVIDUATION

The focal point of the service delivery system must be the person in need. Too often in the past, society's response to atypical people has taken the form of programming by category. Once the person was indentified as belonging to a particular deviant group, certain program packages were presumed to be applicable, such as assignment to a special class, institution, or government agency. Such an assignment was often accompanied by denial of other concurrent program options. Labels led to the application of standardized remedies rather than to individual program planning with effective provision for client program coordination.

Disabled persons, like other citizens, should have access to a variety of options in order to secure the most effective and acceptable means of reducing disabilities. Such access requires the conditions of availability and accessibility described in the preceding sections; but it also requires the development of mechanisms for selecting and assessing the particular array of resources most suited to each person, according to his needs.

This concept is consistent with the principle of normalization, inasmuch as it is normal for citizens to exercise initiative and choice in accepting or rejecting various components of the health, education, and social service systems according to their perceptions of need.

Inherent in the concept of individuation are a number of principles that should permeate all service delivery systems. One such principle is <u>acceptability</u>. The way in which services are organized and delivered must be congruent with the social and cultural values of the recipients, as well as of the providers of service. For example, the names of agencies, the labels applied to their clients, and the way these clients are interpreted to the public must be appropriate to their purposes and programs, must support the dignity of the person and must safeguard his personal and legal rights.

RECORDS

Adequate record keeping and information transmittal are indispensable to the continuity of individual program planning. This is an especially sensitive aspect of service delivery, and it must be handled with great care. Records must be adequate to ensure continuing understanding and effective assistance by the staff, but without reducing the person to abstract entries in a filing system. Records must furnish documentary evidence of the client's progress and of his response to programmed services, but the dangers of rigid interpretation, over-prediction, and self-fulfilling prophecies must be avoided. Records must provide a reliable source of information and a means of communicating among all persons and agencies contributing to the client's program, and the service delivery system should provide for the movement of records between agencies with ease and dispatch, but the rights of the clients to privacy and confidentiality of information must be safeguarded. In using records as data for a research and education, the anonymity of the client must always be preserved.

QUALITY CONTROL

The purpose of a statement of standards for the evaluation and accreditation of a community agency is to ensure that the agency provides services of quality to those whom it serves. Quality is not something that just happens to an agency's program; quality must be promoted, developed, protected, and controlled. The community agency and the service delivery system of which it is a part must have built-in mechanisms for monitoring the quality of its operations, and for bringing about the necessary reforms promptly and efficiently. While quality may be determined in part by conformity to formal standards relating to structure, organization, operating policies, staffing, physical plant, equipment, and the like, conformity with such standards alone must not be taken as the measure of quality.

Quality can be measured only by comparing outcomes with goals, and the goals of an agency serving the disabled are attained only as it helps disabled persons to achieve specified objectives in their lives. To meet the standards for quality services, an agency must demonstrate that it has effective methods of program evaluation for comparing outcomes with goals, and that ongoing program evaluation is coordinated with a built-in mechanism for the consequent review and modification of agency operations.

ACCOUNTABILITY

The accreditation process is one means by which the agency may demonstrate accountability. By first conducting a self-survey to assess its operations against the nationally accepted standards and then participating voluntarily in an evaluation conducted by the recognized accrediting body, the agency can demonstrate accountability to the persons who support it, and whom it serves.[1]

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[1] Standards for Community Agencies Serving Persons with Mental Retardation and other Developmental Disabilities, 1973, Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals; 875 North Michigan Avenue, Suite 2201, Chicago, Illinois 60611.

NORMALIZATION PRINCIPLE

The normalization principle has received wide-spread acclaim among professional and volunteer ranks as an appropriate approach to the management of mentally retarded individuals. This principle is expressed in the formula, "To let the mentally retarded person obtain an existence as close to the normal as possible. Thus the normalization principle means making available to mentally retarded (persons) patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."[2]

Normalization as it relates to training programs and residential services implies movement from:

1. More to less structured living
2. Larger to smaller facilities
3. Larger living units to smaller living units
4. Group to individual residence
5. Dependent to independent living[3]
6. Segregated to integrated living

The relationships and interaction between Glenwood and Woodward State Hospital Schools and services and facilities located in other Iowa communities should be guided by "Principles of the Service Delivery System" and the components, including movement, implied by the "normalization Principle."

VOLUNTARY CHOICE PRINCIPLE

While the service delivery system should guarantee every developmentally disabled citizen's right to treatment necessary to achieve his fullest potential habilitation it also should protect his rights to choose; therefore no program should mandate a client's participation against his will or the will of those entrusted with his care unless such choice is proven to be against his best interests through proper and legal due process. Implementation of this principle requires that real program alternatives be available.

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[2] Bengt Nirje; Swedish Association for Retarded Children: The Normalization Principle and Its Human Management Implications in the Changing Patterns in Residential Services for the Mentally Retarded: President's Committee on Mental Retardation; Washington, D.C. 20201; January 10, 1969

[3] Standards for Residential Facilities for the Mentally Retarded, 1971, Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals; 875 North Michigan Avenue, Suite 2201, Chicago, Illinois 60611

GROUP II: SERVICE AND FACILITY DEVELOPMENT PROGRAM

Getting It There

With the growing conviction that services should be provided as close to the home as possible, the State must establish the mechanisms which will promote quality care at the local level. How to get needed community programs started was the charge for Group II.

The large planning group had set the context for Group II's efforts by raising a range of concerns related to the process of developing new services and facilities in the community, for example:

- increasing private and community programs does not guarantee quality.
- Community operators do not have the resources. Department of Social Services or Title 19 resources should be made available.
- Technical assistance is needed. We need direction, management training and planning.
- To increase counties' willingness to improve, raise our own expectations.
- Need professional and para-professional manpower.

Group II began its work by talking about the process of developing programs and the important agencies or groups involved. Though the array of programs available and disarray of groups with some control over the development process prohibited a detailed dissection of particular problems, in the time available the group identified a series of major gaps in the current system. It focused on issues stymying all kinds of development (county facilities, private for profit, non-profit). These issues, and the recommendations cluster into five categories:

Community Organization

The initiative should come from the community and be based on identifiable individuals' needs. The group focused primarily on improving the needs assessment process.

Manpower Needs

To develop, operate and monitor programs, the State must attract and train many professionals and paraprofessionals.

Technical Assistance

To get programs up and running, community groups and providers need a full array of technical assistance. The major issues are the lack of clear responsibility for providing technical assistance, the lack of coordination, and the inadequate resources to do the needed work.

Program Standards

Standards must be integrated and cover all programs consistently. The group discussed the need for more emphasis on program standards as well as facility or hardward standards. Another major issue covered by the group is standards enforcement.

Funding

Without funding the rest is naught. Major issues include the coordination of Federal, State and local resources and the design of financial incentives for appropriate care.

The group prepared policy recommendations in each of these categories. However, because the realization of these suggestions depends upon a continuing effort involving the DSS and other organization, the group set as a precondition and its initial recommendation that this Planning Group have a continuing role in reviewing what comes out of this process.

A MODEL OF THE ISSUES IN SERVICE AND FACILITY DEVELOPMENT

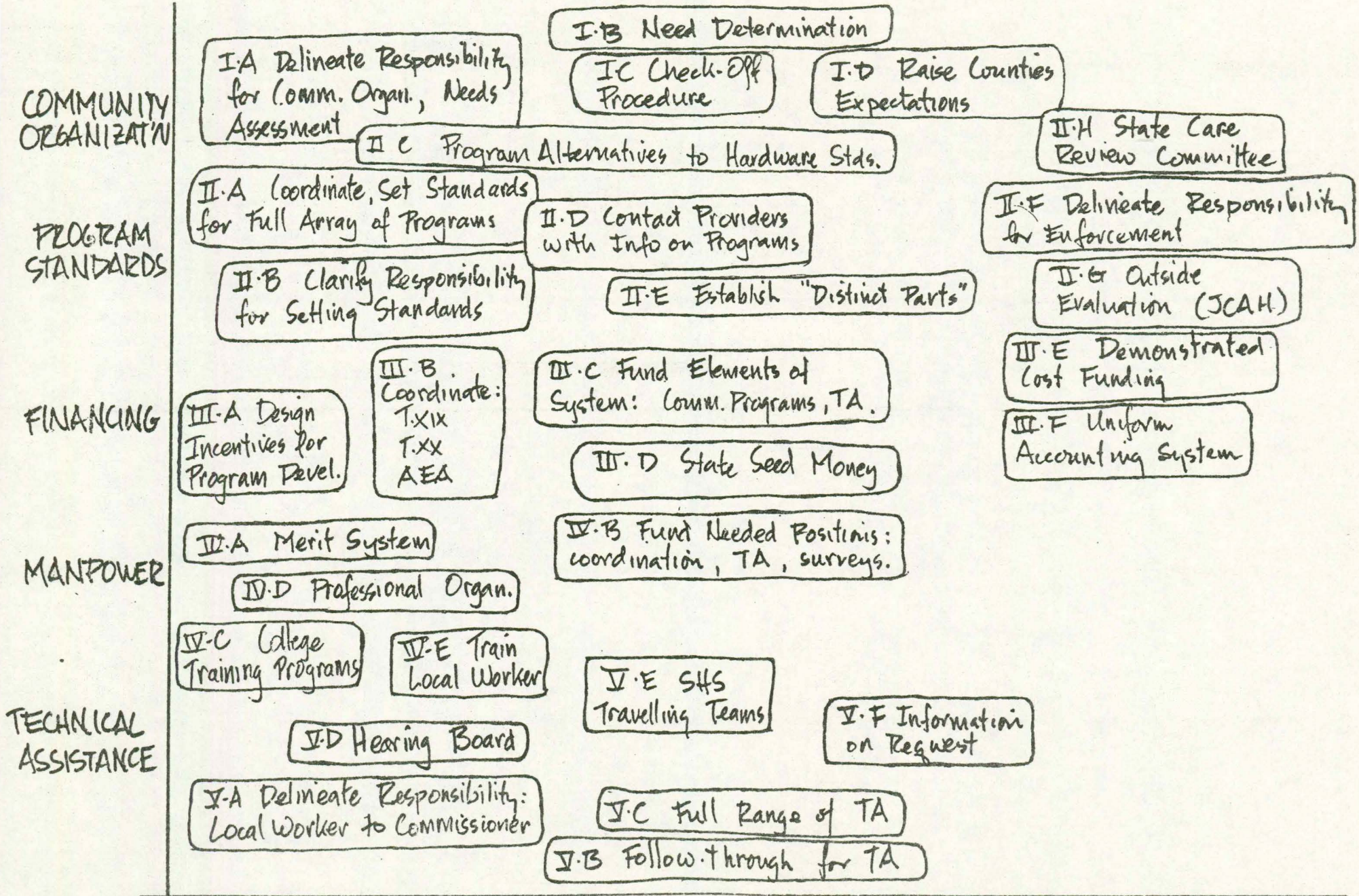
To illustrate the work which must be done to facilitate the development of ICF/MR's and other programs in the community, the five categories of issues can be shown in relationship to three phases of program development:

(1) Establish Statewide Mechanisms
(2) Service and Facility Development Process
(3) Program Operation

These three phases distinguish the work which must be done to establish a system (writing regulations, changing laws) from the sequence of steps a developer must follow and from the monitoring and accounting functions which are necessary to ensure the quality of programs in operations.

The model below illustrates what issues in each of the five categories must be resolved for each of the phases. The committee's recommendations in each of the issues follows. (The numbering of the issues in the model is keyed to the listing of the recommendations.)

MODEL of the ISSUES in PROGRAM DEVELOPMENT



POLICY RECOMMENDATIONS

I. Community Organization

The group felt that it was important that the initiative for program development should come from within the community. Though a wide range of issues arise in laying the groundwork for program development, the group concentrated on the needs assessment process where they saw major inadequacies.

A. Delineate responsibility for leading and coordinating community organization, particularly needs assessment. District Office should have primary responsibility.

B. Before establishing a program the sponsor must identify individuals who (1) need the service, (2) who have indicated they will use the service. This is necessary to avoid the proliferation of programs based upon imprecise, overlapping estimates of need.

C. Establish a "Check-Off Procedure" in which appropriate community (and State) organizations must approve a proposal before a program can be developed.

D. Raise counties' expectations for the quality of care to be provided in county care facilities and private community facilities.

II. Program Standards

Program operators are currently faced with an assortment of standards with conflicting definitions and requirements, inconsistently administered.

A. Coordinate and integrate standards for all programs for the developmentally disabled. All such programs should meet a consistent set of standards, such as Title 19 ICF/MR or JCAH.

- Standardize definitions for vocational, educational,

training, and other key terms.

- State and local codes should use standards, terms and definitions consistent with Federal standards.

B. Clarify responsibility for setting and administering standards. DSS should be responsible for program standards. These should be coordinated with Health licensing procedures.

C. Emphasize program, rather than facility standards. Program alternatives to the hardware standards of the Life Safety Code should be developed. For instance, the term "ambulatory" should be changed to "mobile", and interpreted to include persons who are mobile because staff are available to assist them in evacuation.

D. Disseminate information about the ICF/MR standards to interested organizations, especially to all program operators so they can prepare for compliance.

E. Require that all developmentally disabled persons in residential facilities (including county care facilities, MHI's, nursing homes, and penal institutions) reside in a "Distinct Part" as defined in the ICF/MR. (This recommendation should be balanced against the principle of normalicy.

F. Clarify responsibility for enforcement. Enforcement is essential if the standards are to achieve quality care.

G. Require periodic outside professional evaluation, such as JCAH. It is not possible for a department to monitor itself or other departments.

H. Establish a "State Care Review Committee" to oversee the writing and administration of standards. The group should be widely representative.

III. Financing

Policies are needed to get the most out of Federal, State and local resources.

A. Design incentives for appropriate program development. The group suggested that State money be made available to match the Federal share in private community facilities, and that county money provide the match for State institutions and county care facilities. As such incentives can have far-reaching implications, considerable care is necessary in setting policies. The DSS should look further into how the "least restrictive environments" and best programs can be created, and it should determine the effect of these incentives on existing and developing programs, including the county care facilities and the MHI's. There should be discussions with county representatives to plan the role of the counties in financing, the counties having been able to work most effectively as a "fiscal conscience." *

B. Coordinate Federal resources. With the assistance of staff from the Kansas City HEW Office, the State must determine how Title 19, Title 20, and AEA money can most effectively cover the full range of services. With approaching deadlines and changing programs, the State must watch over impending transistions to ensure that clients are not left without services or providers without resources. One particularly sensitive question to resolve is how educational programs for persons in ICF/MR's(in the community and at State institutions) will be covered.

C. Provide resources necessary to develop community-based ICF/MR's. Not only direct program operation budgets need to be created. Technical assistance programs operating out of District Offices or State Hospital Schools must be funded. Staff must be hired in all the State agencies responsible for surveying programs and enforcing standards.

* Minority Report: Ideally, all funds should come from the same source. There should be an emphasis on the quality of service, rather than the structure of the program. Incentives should be maintained for counties to develop appropriate care programs.

D. Create a State seed money fund to initiate new programs and remodel existing programs. DSS should administer the fund programmatically, possibly in a manner similar to the Day Care seed money program. The fund could be used to set up demonstration projects, particularly for innovative county programs.

E. To regulate program expenditures in community ICF/MR's establish a "demonstrated cost funding" rather than rate setting procedure. This is necessary to accommodate the range of program costs associated with individual plans of care.

F. Establish a Uniform Accounting System for Title 19 ICF/MR's, as simple and as much like the current system as possible, but the billing system must be more efficient and timely than under Title 20. Reduce the paperwork; the audit trails are there. Operators should be given assistance in setting up the accounting forms early, before the program gets into operation.

IV. Manpower Needs

There are not enough professionals and para-professionals available in the State to staff the range of programs implied in current plans. Steps must be taken to increase the supply and to reduce turnover. In another related issue, the State must increase the number of positions in State agencies to enable the planning, technical assistance, standards enforcement, and program operation.

A. Modify the merit system to create categories of needed professionals.
   - Adjust pay scales to attract and hold staff.

B. Fund the needed positions in planning, technical assistance, standards enforcement, and program operation.

C. Direct and provide incentives to the State college and university system to train new people.

D. Encourage the formation of organizations for developmental disabilities professionals, possibly a division of IWA.

E. Train the local workers in county and district offices to utilize the range of resources available. Prepare and maintain manuals.

V. Technical Assistance

Insufficient technical assistance to potential sponsors of new programs is a major road block. Responsibility for providing assistance is fragmented and resources are scarce.

A. Delineate a line of responsibility for providing technical assistance that runs from the local worker to the Commissioner. As it is now, the local worker can be stymied by unresponsive authorities in the first attempts to initiate a program.

B. The District Administrator should have the responsibility of acquiring and coordinating the needed technical assistance. The DA should have the responsibility of following a proposal through all steps of program development.

C. The full range of technical assistance (including community organization, needs assessment, financial planning, program design, site and building planning, standards interpretation, staff hiring, and diagnosis and evaluation) should be available and funded.

D. Empower a Hearing Board to act as an ombudsman to local workers, sponsors and others whose efforts to develop programs are stymied by the system.

E. The State Hospital School's should operate as Resource Centers. They should operate traveling teams which can provide specialized technical assistance to developing community programs.

F. Make operational and effective a central clearing house for information on request.

GROUP III : STATE STRUCTURE AND ADMINISTRATION

Keeping It Going

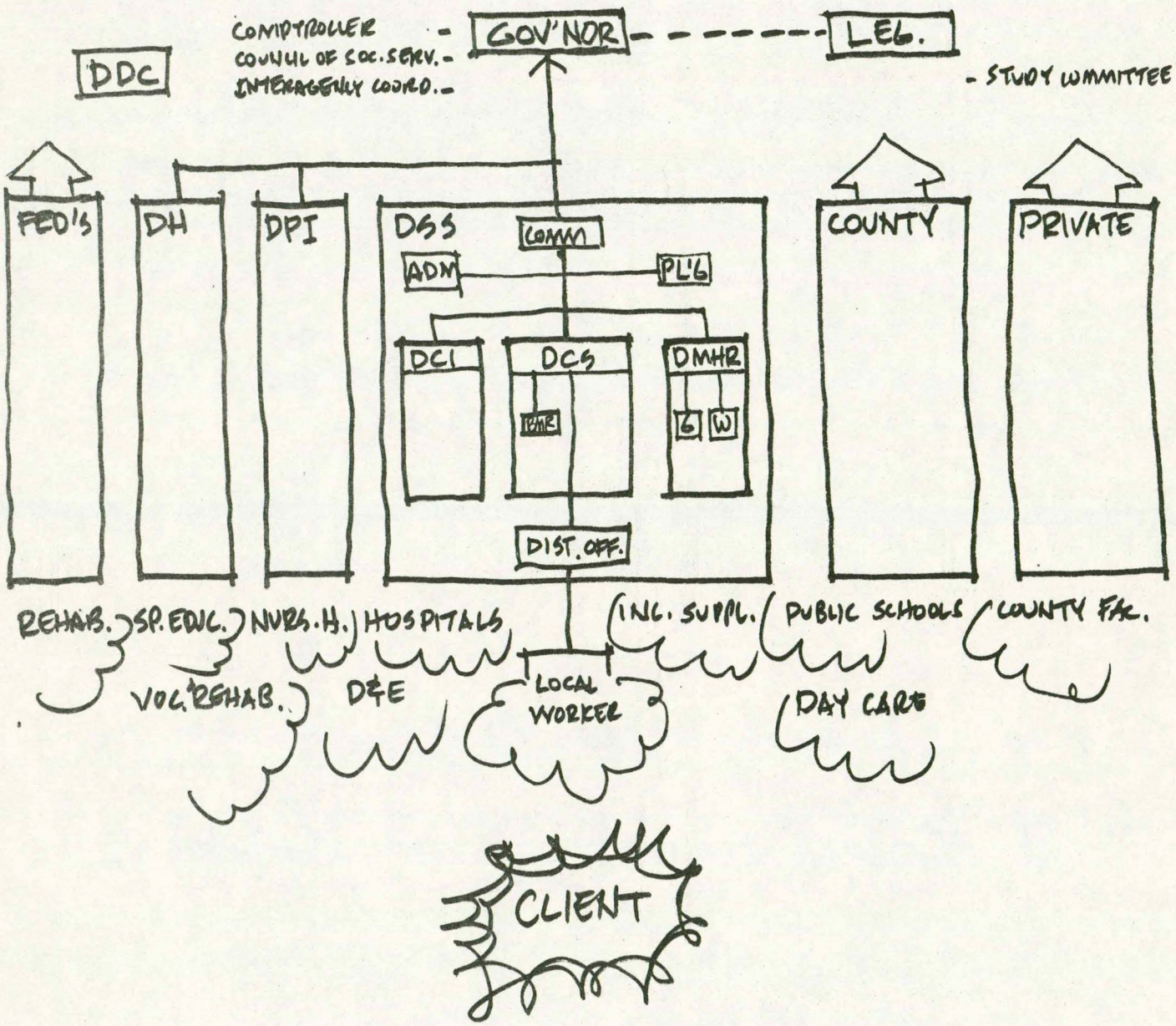
Charge and Procedure

Five of the eleven pages of concerns were listings of problems that the planning group saw with the State structure for administrating services for mentally retarded people. (This was perhaps due to the fact that most of the group members were administrators and that a focus for the planning was to see if the presently institutionally focused services might become more community based.) To tackle these problems, Group 3 decided to map out the State structure and suggest ways to improve it. The procedure was to identify the elements of service delivery; (2) chart its administrative structure; (3) outline the links of communication, authority, responsibility, money plans and service delivery; (4) identify the gaps, conflicts, unclarities within the system; and (5) recommend changes or additions to the structure. Also included were specific charges to determine the future role for the planning group and suggestions for improving the data used by the system (this last charge the group did not have time to take on).

Consequently, Group 3 created "the monster", the product of clumping together the available tables of organization. An attempt was made to show all the service elements (outlined as clouds) that touched the client (shown as impacted by clouds), and then how they linked. The result, "the monster", was a mass of confusion (roughly 12' long x 5' high) that the group members felt caricatured fairly their image of the system. They decided only to look for those gaps that seemed important to improve service delivery for the mentally retarded; in effect, to treat M.R. services as a program and to administrate such a program through better coordination of its service delivery elements. This was done by identifying gaps that emerged from discussions of problems and then simplifying "the monster" so that it could illustrate the administrative gaps and suggestions for repairing them. (See Group III model.)

MODEL of the STATE STRUCTURE & ADMINISTRATION

("The Monster" - simplified version)



Some Underlying Assumptions

Towards the conclusion of its discussion, Group 3 attempted to summarize what, in retrospect, seemed to be guiding principles for its recommendations. They shared a general notion of the large group which seemed to be to make services fit a more normalized pattern be more community controlled and based. There was a strong agreement that the present administrative structure (albeit conflicted and master-like) needed only minor modifications to accomplish this, and that a key element for progress was to support and improve the year-old district offices. They felt this could be accomplished by better central coordination of M.R. services, by treating them as a single program run by several agencies, rather than creating a separate new one.

A second assumption that seemed to guide the direction the recommendations took was to make the system more client centered. As the simplified "monster" diagram illustrates, the administrative structure functions to develop and coordinate the cloud of services so that they are adequate and available to the client. A key element in linking them to the client was seen as the local worker, operating from the local offices of each district.

The direction the suggestions took was to bring the decision-making about clients closer to them and their advocates (e.g. the local worker). Some notions on how to accomplish this were:

- To coordinate service personnel at lower levels of administration. this might be done by having more decisions happen at local levels, by-passing time consuming, perhaps less responsive, higher level decision-making.

- To stimulate the development of more decentralized, local service elements, particularly by improving incentives and settling jurisdictional conflicts such as between counties and local offices of DSS or between the State Hospital Schools and the District offices.

- To have an "open government", getting related agencies and more consumers (such as counties, parents groups) involved in dialogues

about services, in effect bottom-up participation in the management of them.

Recommendations

After sketching the administrative structure, the group decided to make recommendations about four issues: (1) the problems of local workers; (2) agency relationships; (3) the role of the State Hospital Schools, and the future role of the planning group.

LOCAL WORKERS' PROBLEMS -- "Between a rock and a hard place"

A key to the success of a client centered system was seen to be the ability of a local worker to serve as a good contact and entry point to the system. At present, he was seen as caught between the demands or responsiveness of the DSS (his employer) and the county (his work context). To alleviate his difficulties it was suggested that he become more helpful to both -- to have more authority from the State and to be able to aid the development of the county system. Two issues were singled out as key--having clearer authority for the clients and better access to services.

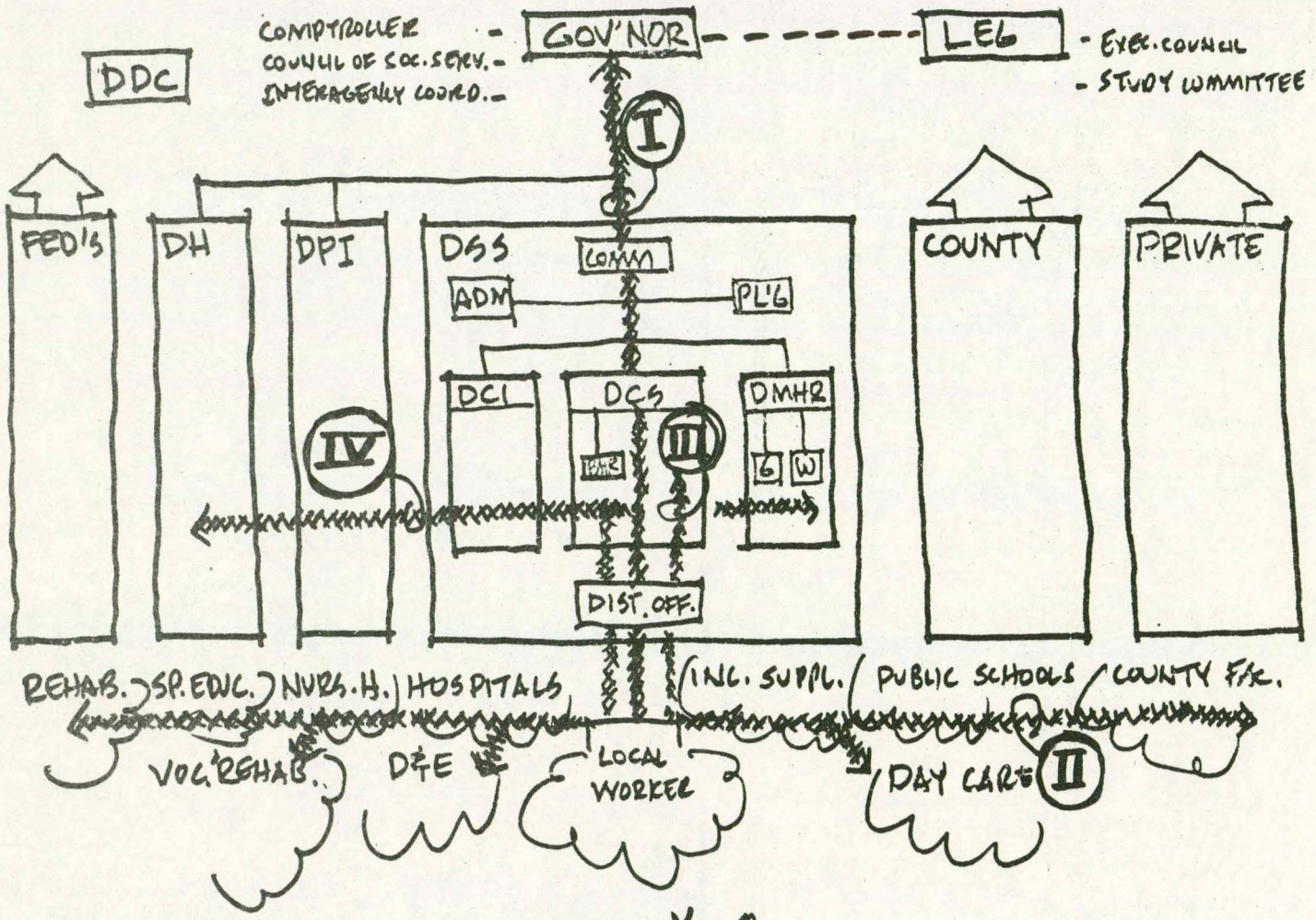
CLARIFY RESPONSIBILITY FOR THE CLIENT -- Recommendations (See Link I)

At present, the responsibility for clients can be held by other elements of the care system than the office of the Commissioner of the DSS. Particularly, the State Hospital Schools can be held responsible for their clients, even after they leave the schools, particularly by being out on convalescent leave rather than discharged.

- o REVIEW AND REVISE CH.222 While the group was not clear on the particulars of who should have the ultimate responsibility, it was recommended to revise Ch. 222 and all related sections of the Iowa Code in in order that the allocation of such responsibilities could help clarify the respective authorities of the State Hospital Schools, counties, and the DSS. Any resolution of this issue was seen as complex, involving many legal and political issues. However, it was strongly recommended that if the responsibility for the clients were to be the Commissioner of the DSS, and a line of authority traced clearly to the local worker (through the

MODEL of the STATE STRUCTURE & ADMINISTRATION

("The Monster" - simplified version)



FOR THE LOCAL WORKER

RECOMMEND

LINKS I, II, III, IV

DSS and District Office), the role of the local worker could be strengthened.

- o SETTLE COUNTY-DISTRICT DISPUTES. The local worker is now caught between identifying with the problems of where he works (the county) and the needs of his employer (the DSS). This split becomes more critical as the need to develop local services grows--the amount of dollars spent locally grows and the conflicts between the different providers can become more acute--private vendors, county facilities, State institutions. So long as the policy concerning the relative responsibilities is an open question, the conflicts between these can hinder the local workers' efforts to help the development and provision of services. The hope expressed was that as the DSS puts more funds into the local system (e.g. from Federal programs), uses incentives for development and improves monitoring, the local workers' strength will increase.

IMPROVE ACCESS TO SERVICES -- Recommendations (See Links II, III, IV)

A primary function of the local worker is to be able to interface his client to the needed services. A client's needs have to be mapped against service availability and client eligibility. At present, the local workers have to understand a confusing array of services to be accessed through complex procedures. Four areas for improvement were suggested--the first being to train more local workers, and the other three being to connect them better to the system--giving them more control over local services, accessing higher levels of the DSS, and improving procedures for linking to other agencies.

- o TRAIN MORE LOCAL WORKERS. The quality and availability of local workers varies from district to district. Generally, however, it was realized that the district system was only one year old. Hence, more training is needed to make the worker familiar with M.R. problems and especially, the strings to pull to manipulate the system. It was also felt that more people were needed to be local workers.

- o CONTROL OVER LOCAL SERVICES. (See Link II). The local delivery elements--school systems, county facilities, hospitals, social work

agencies--are under different authorities, and hence coordination at local levels or responses to individual client needs are uncertain. It was felt that upper level coordination is called for; hence specific recommendations are found in the section below on improving agency relationships. For access to the system, a placement committee involving local, State, county, and professional authorities was recommended.

- o BETTER ACCESS UPWARDS IN THE DEPARTMENT. (See Link III). The links to authority are presently through the District Administrator through the Division of Community Services. Again the newness of the structure and the pull of local, county needs tended to make this connection not very powerful. It was felt that this might improve, both over time and as the responsibility for services increased in the DSS.

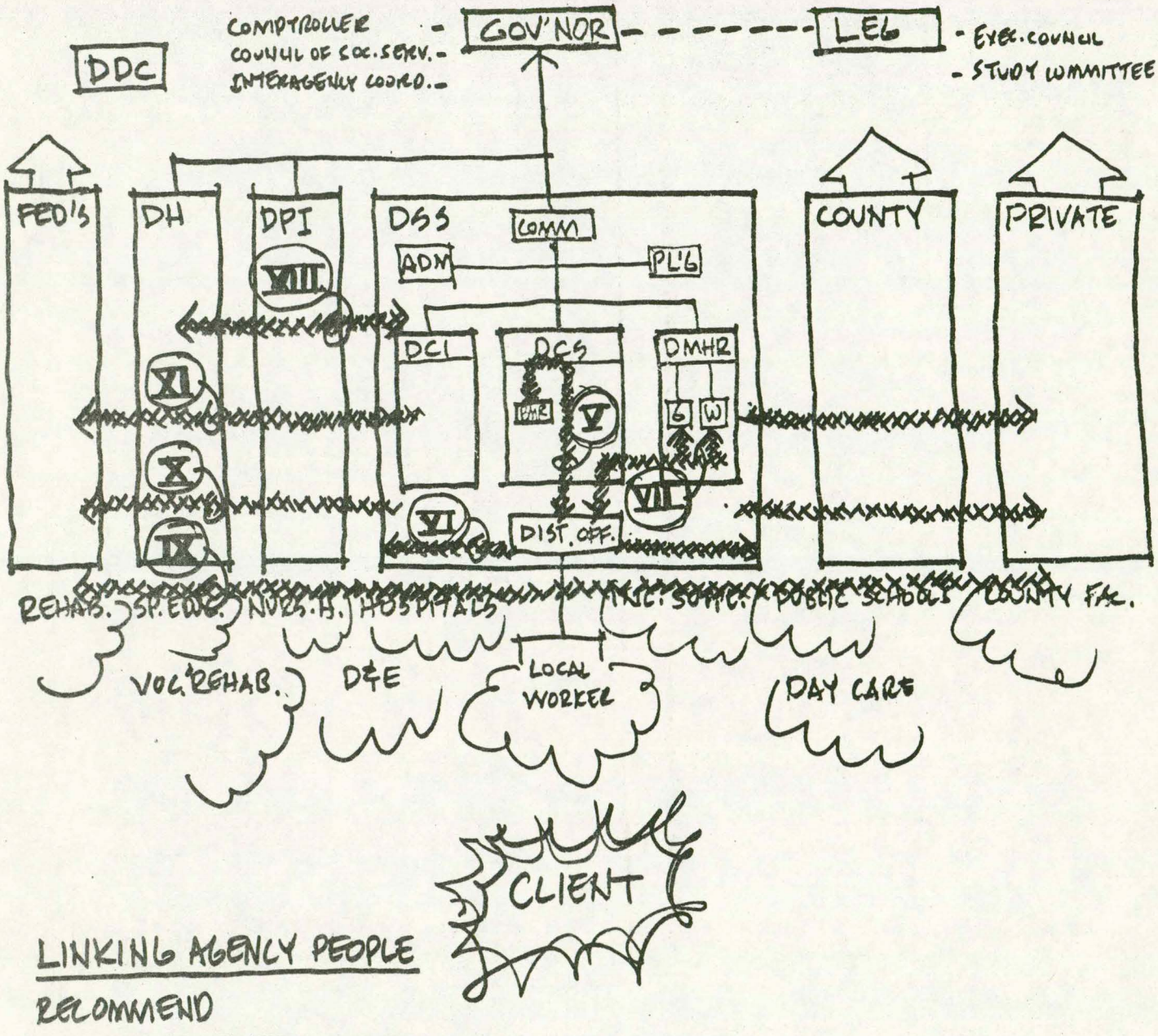
- o IMPROVE PROCEDURES FOR LINKING TO OTHER AGENCIES. (See Link IV). A major tool of the local worker is a seven volume set of notebooks of procedures for accessing services. At present, the system is cumbersome and the problem really becomes one of fitting a client to where it is easiest to find services rather than where he might best be served. The key to solving the problem also lies in improving relationships between agencies in order to make more simple, clear, and effective the procedures for accessing services.

AGENCY RELATIONSHIPS -- "Tame the Monster"

Particularly when there is a need to develop a more decentralized service system, it is necessary to have a lot of effective interaction between all the elements of the system. A general principle mentioned above, is to get communications, planning and authority to program levels of the administration in order to be able to settle problems more locally (the "bureaucratic by-pass"). This means forming more committees at lower levels, composed of an array of program administrators and service deliverers. Though there is a cost involved in having more committees and meetings, the gain may be a more coordinated, locally responsive system. The recommendations below are divided into two categories--to make communication better among State agencies and then between the State and other elements of the service system.

MODEL of the STATE STRUCTURE & ADMINISTRATION

("The Monster" - simplified version)



LINKING AGENCY PEOPLE

RECOMMEND

LINKS V, VI, VII, VIII, IX, X, XI

ESTABLISH BETTER LINKS ALONG STATE AGENCIES -- Recommendations (See Links V, VI, VII, VIII)

The links seen as needed in the State are both within the DSS and then between the DSS and other State agencies. Four key links were cited, the first three being within the DSS.

- o IMPROVE LINK BETWEEN CENTRAL OFFICE AND THE DISTRICTS. (See Link V). Presently the districts report directly to the director of the Division of Community Services, and the link to other M.S. programs is indirect. For example, there is no direct link between M.S. specialists in the districts and the Bureau of Mental Retardation (and sometimes conflict between the Bureau and the district administrators). This issue will especially need clarification if the State responsibility for clients grows.

- o HAVE M.R. SPECIALISTS MEET STATEWIDE. (See Link VI). If districts are to develop and share M.R. services, cross-district communications should be improved. It was recommended that M.R. specialists meet and elect chair people who could represent the problems that occur at the level of service delivery and have authority over programs and to coordinate planning.

- o LINK THE STATE HOSPITAL SCHOOLS TO THE DIVISION OF COMMUNITY SERVICES. (See Link VII). In order to coordinate the development of Glenwood and Woodward with that of the districts they serve, links through the DSS must be made. It was suggested that the district administrators and or M.R. specialists from the regions served meet and elect chair-people who may be involved in the planning procedures. It was also suggested that counties be encouraged to do the same.

- o RELATE DSS PROGRAM STAFF TO COUNTERPARTS IN OTHER AGENCIES ON A PROGRAM BASIS (See Link VIII). Many programs require the cooperation of various state agencies. For example, Title 19 and Title 20 will require the cooperation of the DSS, the Fire Marshall, the Department of Health, and the Department of Public Instruction. The problems that

occur are not just policy questions such as might be handled by the commissioners, but rather detailed operational problems that constantly occur as programs are developed and operated. It was suggested that DSS staff who work on specific programs form committees to work with their counterparts in the other agencies for each program. An example is a T-19 coordinating committee that will be detailed below. Such groups can coordinate the programs by establishing procedures such as local workers now use.

o RELATE STATE AGENCIES TO OTHER M.R. SERVICE DELIVERY ELEMENTS -- Recommendations (See Links IX, X, XI). Many authorities are responsible for delivery services. The group recommended that these need coordination at the county, district and State levels, that committees be set up at each of these levels, and that the primary responsibilities of each level be clarified. It was felt that M.R. agencies need not become a separate bureaucracy but should stay spread throughout the other mainstream service agencies. Rather, committees should be formed to mold M.R. services and be coordinated like a single program. An initial suggestion was as follows:

County Committee (See Link IX)

Prime function - to deliver services

Members from - County Board of Supervisors
public schools
DSS (county director, services supervisor, M.R. specialist)
DPI
ARC

District Committee (See Link X)

Prime function - to plan services, monitor services

Members from - DSS (M.R. specialist, District Administrator)
Special Education (AEA Director)
Vocational Rehabilitation
Area D.D. Council
State Hospital School

State Committee (See Link XI)

Prime function - To coordinate services, set standards, procure funds, do some development and planning

Members from - (See the Committee suggested below for T-19)

ROLE OF THE STATE HOSPITAL SCHOOL

Group 3 essentially agreed with the suggestions of Group 1 about the role of the State Hospital Schools, particularly that they serve as resource centers to meet the needs that local institutions cannot such as indirect services of training personnel, giving advice to communities, and developing programs. The group felt residential services should be at the SHS primarily for specialized problems such as mentally retarded people with mental illness or behavior disorders (long-term care) or with severe physical handicaps (short-term care).

The major focus of attention was to link their services and the planningof them to the larger system and its consumers. A range of possibilities was discussed (e.g. strengthening parents groups, using outside judgments by professionals such as JCAH accreditation, having a Board of Directors composed of County Supervisors, selling services on a contract basis like other vendors). Any resolution was seen as having complex, highly political consequences. Since the State Hospital Schools are presently part of the DSS, it was recommended that the DSS designate the future of the schools and that this be done as part of the consideration involved with planning for T-19. This planning is to help link the development of the SHS to the communities and to establish mechanisms for continuing to relate them to the communities they serve. (It was suggested that representatives from the committees formed to link to the SHS above--See Link VII--be used for this purpose and to be represented on the committee mentioned below).

FUTURE ROLE OF THE PLANNING GROUP

Because it was difficult to resolve the many issues raised by the group in considering how the DSS should handle the potential impact of T-19 funds, it was recommended that the work of the group be continued. It was recommended that the DSS MANDATE A T-19 IFC/MR COORDINATING COMMITTEE, as follows:

Suggested membership to be composed of representatives from:

Dept. of S.S. - Div. of M.H.R. - Director)
- Glenwood)
- Woodward)
)
Div. of Comm. Services - Director) to be the
- M.R.) D.S.S. working group
- Medical Services)
)
Districts - Chairman of Glenwood region)
- Chairman of Woodward region)
- M.R. Specialists/supervisors)

Other agencies - Fire Marshall
- Health Planning Council
- Dept. of Health
- Dept. of Public Instruction
- Developmental Disabilities Council

Outside the State agencies - ISAC
- IARC
- Private Vendors
- County groups

Functions and structure are to include:

- o A chairperson who is nearly full time, a core group from the D.S.S. working group who participate almost as much.
- o Staff or other help taken from existing D.S.S. personnel, temporary new help, or through contracting with EDG or other groups.
- o The working group in D.S.S. is to meet frequently, and its operations are to account to the whole group.
- o The ultimate accountability of the group is to the commissioner of D.S.S., and its role is to advise and suggest to him.

SIX MONTH PLANNING PROCESS

INTRODUCTION

On November 10, 1975 a second set of State Policy Planning Group meetings began. The purpose of those meetings was to track the Environmental Design Group planning work (Campus Master Planning, Model District Planning, and the Vendor Demonstration Project) and to develop a funding mechanism for implementing the ICF/MR program in the community; however, this agenda began to change after the first meeting. It was clear that, unlike the two week planning session in the summer, events were occuring within and without the Department of Social Services which would impact and alter the agenda of the Group. Although the original purposes were ultimately accomplished, the Group broadened its agenda to include other significant issues which were critical to the survival and quality of the ICF/MR program in the State of Iowa.

The following section of this report describes the revised activities of the State Policy Planning Group in terms of the history of the issues, the process for resolving the issues, the Group's resolution of the issues, and the next specified steps, if any, which were (or are) required. The Six Month Schedule (See Appendix 2) shows the issues and the schedule over which the issues were processed by the Group.

CONTRACT MONITORING

STATE HOSPITAL SCHOOL MASTER PLANNING (See Master Planning Report)

History: In the spring of 1975, the State of Iowa, through legislation, expressed its desire to qualify the State Hospital Schools for certification under the Title XIX ICF/MR program. In order to be certified it was necessary to bring the facilities and programs at the State Hospital Schools into

Federal compliance. This process required the development of technical plans of correction and a Master Plan for each campus. Additionally, in its two week planning session, the State Policy Planning Group made recommendations affecting the State Campuses including a balancing of the architectural programs with community residential programs. The Planning Group was concerned that the State might perpetuate, through bricks and mortar, a role for the institutions which would make the development of community programs difficult. They were further concerned that the campus facilities reflect the principles of quality which the State Group had previously set forth--namely, responsiveness, individuation, accountability, and normalization.

The first agenda change occurred in November when the Regional Office of HEW rejected the State's five year technical plan of correction which would have reduced the institutional population from 1500 at that time to 975 in five years. Instead the Regional Office required a two year technical plan at a population level of 1287. This change was reviewed by the State Policy Planning Group at meeting II.

During late December and early January the Department of Social Services and the Governor's Office considered delaying the whole Title XIX ICF/MR Program for several reasons--most critically, the requirement of guaranteeing a $9,000,000 appropriation for campus renovations and new construction and the uncertainty about the fiscal exposure of the community residential program. The net result of several meetings, was a decision to proceed with the campus program with a first year appropriation of $4,500,000 and a committment to carefully proceed with the community program based upon the community planning results.

Process: Prior to meeting II members of the Department of Social Services and the Campus Master Planners from Environmental Design Group prepared a set of revised Technical Plans of Correction based upon a two year, rather than five year schedule. This was presented to the State Policy Planning Group at Meeting II. Explained to the Group were the conditions under which the Technical Plans were revised. The importance of an immediate decision was brought out since to delay the decision would delay the Master Planning. Although the State Group expressed strong negative opinions about the changes they did approve the Technical Plans of Correction. (It should be noted that it was nearly another month before the plans were submitted due to the deliberations within the State government as to whether or not to enter into the program.)

During November and December the Master Planning process continued on the campus (see Campus Master Planning Report) with brief updates provided by the State Hospital School superintendents at each meeting.

At meeting VI the Campus Master Planning team made a formal presentation to the State Policy Planning Group and the DSS Management Team during the morning session. In the afternoon, a more informal presentation was made with an opportunity for the Group to make detailed comments and express their concerns about the progress to date. This process was continued during the afternoon session of meeting VII. A presentation sample of the Group's comments and concerns follows:

WILL THE PEOPLE REMAINING IN THE STATE HOSPITAL SCHOOLS BE THE LEAST FUNCTIONAL?

HOW DO WE INTERACT OVER THE NEXT SIX MONTHS TO HOLD BACK FURTHER CONSTRUCTION WHICH INCREASES THE INSTITUTIONAL CAPACITY?

HOW WILL PEOPLE BE GROUPED?

WHAT LOGIC SETS COTTAGE SIZE AT 16?

IS IT TRUE THAT A RESIDENCE SHOULD FIT ALL FUNCTIONAL LEVELS?

STATE HOSPITAL SCHOOLS ARE EASING THE WAY FOR COMMUNITY PROGRAMS.

The group evidenced difficulty in dealing with the issues raised by the Master Planning effort. A major cause of the difficulty was that this presentation was the first opportunity most members had to see the plans. The main concern of both the Group and the Master Planners was the projected functional level of the State Hospital Schools residents. Without being able to predict this, the master planners had to make their plans sufficiently flexible to meet a range of contingencies. It was clear that all involved were frustrated at being unable to predict the population. The frustration was further exacerbated by the uncertain knowledge of the future of the community program.

Resolution: The State Policy Planning Group reached no new conclusions; however, it has continued to emphasize a policy of responsible deinstitutionalization and promotion of community-based programs. It was clear that the

State Policy Planning Group desires over the next several months to avoid overbuilding on the campuses by promoting the development of community-based programs. The group has continually reaffirmed its policy direction: that the State Hospital Schools become resource centers to community-based programs and provide training, technical assistance, and low-demand, highly specialized programs.

Next Steps:

1. Monitor the progress of the State Hospital Schools on a regular basis and at key intervals.
2. Develop strategies for revising downward the residential populations called for in the Technical Plans of Correction.

LICENSURE AND CERTIFICATION (See Report of the Committee on Joint Licensure and Certification of ICF/MR Facilities)

History: As a result of a recommendation of the State Policy Planning Group, a project was developed to demonstrate that community residential facilities for the mentally retarded could be developed, document for the use of others how to develop facilities, and suggest changes in administrative procedures to assure such development. Key to the success of the project was a contract to supply technical services to an appropriate residential service provider in order that the procedures and rules could be tested. It was evident by Meeting II that the State would be unable to develop regulations for the community-based programs quickly enough and that no decision could be reached as to who the private provider might be or when the program would reach a stage that a private provider could begin development; thus, this project required major modification.

Process: At Meeting II, the status of the project was explained with a key set of policy issues which had to be decided before work could proceed. These were:

> Eligibility (level of retardation and program type) the vendor to be selected;
>
> Client group emphasis (State Hospital Schools, community, inappropriate placements.);
>
> Level of compliance (how much work had to be done to certify the program);
>
> Level of committment to community programming;
>
> Relationship to Model District Plans (vendor inside or outside the model district); and
>
> Implementation schedule.

At this meeting the suggestion was made to change the project to one of facilitation of a joint group to develop licensing and certification standards for ICF/MR programs.

At meeting III the above issues were spelled out more fully and discussed. Substantial agreement was reached that the emphasis of the project should be changed to focus on Joint Licensure and Certification Standards.

During Meeting IV, consensus was reached as to the composition and charge of the Joint Committee. This action was based on the opinion of the Group that the licensure and certification issues were so complex that the State Policy Planning Group could not recommend a singular direction. Subsequently, the Joint Committee was formed. At Meeting X, a status report and review of the Joint Committee's work was presented.

Resolution: The Joint Committee is proceeding on schedule at this writing.

The policy guidance which the State Policy Planning Group gave the Joint Committee was:

> Licensure and certification procedures and requirements should be integrated and consistent, and provide a clear delineation of responsibilities between the involved state agencies.
>
> Similarly licensed ICF/MR's should meet the same requirements, regardless of whether they participate in the Title XIX ICF/MR program.
>
> Procedures and a process should be developed which enables potential providers to understand the steps and requirements necessary to obtain a provider agreement for an ICF/MR.
>
> Licensure and certification standards should explicitly assure that the quality of services and programs for the retarded shall at least meet federal requirements (as indicated in the ICF/MR regulations, interpretive guidelines, and State Interim Certification Standards).
>
> Other standards shall provide at least implicit assurance of compliance with federal and interim State standards. Where the Committee believes departure from federal requirements is possible or advisable, the State Policy Planning Group shall be provided with a timely opportunity to review such departures.

Next Step:

Continue to review and monitor the development of final standards.

MODEL DISTIRCT PLANNING (See Model District Planning Report)

History: A major emphasis of the two week planning process was the development of a strong community care system for the mentally retarded and developmentally disabled. This was to be achieved through careful community planning at the local level throughout the State.

The Group recommended that a planning process be developed and tested in two model DSS districts. The results of this process were to be analyzed and the process revised and transferred to the other 14 DSS Districts.

The schedule for the Model District Planning paralleled in time this series of ten State Group meetings. At Meetings VI and VIII the State Policy Planning Group reviewed the status and products of the district planning. By March 1, 1976 both districts had completed their plans.

Process: During Meeting VI, a formal presentation was made by representatives of each of the district planning groups and the EDG consultants. The process was explained followed by a presentation of results. At that stage of the district process the products were "ideal model delivery systems" to which no real world constraints had been added. The reaction of the State Group was supportive of the district accomplishments. A sample of the comments of the Group follows:

> HOW DO YOU MAKE IT HAPPEN? WHAT DRIVES THE PLAN TO IMPLEMENTATION?
>
> THERE IS A HIGH REGARD FOR LOCAL AUTHORITY IN PLANNING AND DECISION-MAKING.
>
> PEOPLE WILL NOT BE SERVED OR POORLY UNTIL RESPONSIBILITY IS ASSIGNED.
>
> YOU MUST PLAN WITH COUNTY GOVERNMENT. THE COUNTY WILL ASSIST.

At Meeting VIII the districts again presented their planning products which were by then essentially complete. They included a needs assessment, model service delivery system, and a seven-year master plan. In addition the district groups presented a set of policy recommendations for the State Group's consideration and a schedule for implementing the district plans.

It is important to note that the results of the district plans helped to generate positions on state policy issues throughout the process. The best example of this is the placement policy guidelines (see Appendix 3) which parallel the district plans. In addition, the district administrators and two county supervisors from the model districts and a mental retardation supervisor from the district planning staff task force are members of the State Policy Planning Group.

Resolution: The Model District Plans are complete.

Next Steps: The State Policy Planning Group must review fully both plans during the month of April. They will make implementation recommendations to the Commissioner of Social Services and model districts.

Yet to be decided is how to transfer the planning process to the other 14 districts. Lack of funding and staff poses an obstacle to completing the process by the next state budget cycle, and, consequently, slows down the State Policy Planning Group's objective of fostering a strong community service system for the mentally retarded and developmentally disabled.

FUNDING MECHANISM

History: At a set-up meeting on October 24, 1975 the State Policy Planning Group established as a priority issue the development of policy recommendations for funding legislation. In order to sort out the issues and develop recommendations, Meetings I, II, and III were set aside for this purpose. The Technical Plans of corrections' crisis changed the Funding schedule to Meetings I, III, and IV.

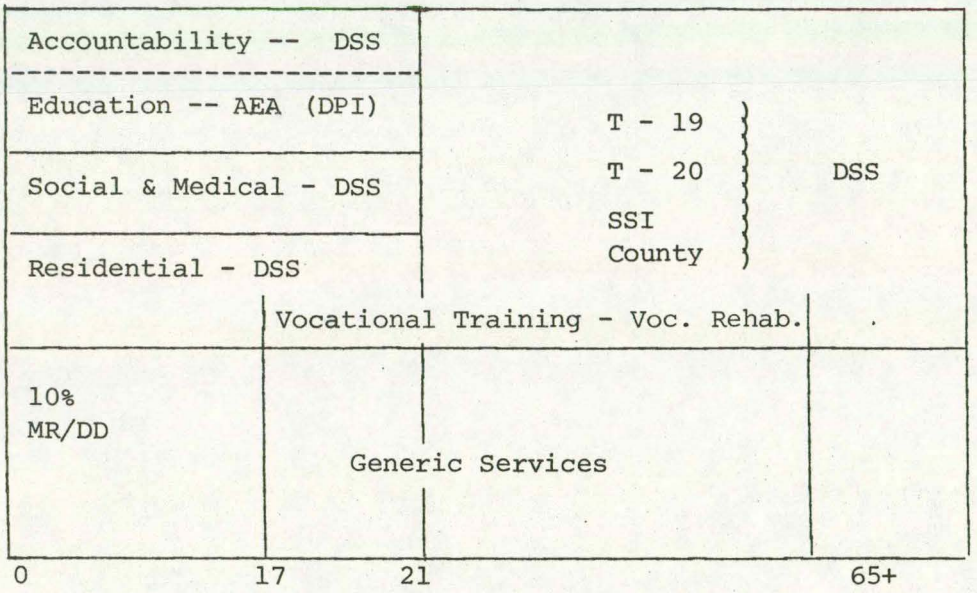
Process: Meeting I addressed the subject of background information. The Title XIX programs were discussed and compared. The relationship between residential services (Title XIX) and Social Services (Title XX) were explored. This discussion was followed by a discussion of the Developmental Disabilities Council Program. The DD Council spends its funds for planning and providing seed money for demonstration projects. A lengthy discussion followed a presentation of the program of the newly established Area Educational Agency. The State had passed a law which provides additional educational funds for the developmentally disabled. Since the program had only become operational in September, it was difficult to assess its impact. A key conclusion was that A.E.A. funded only educational and necessary support programs; it did not replace the need for funds for social, medical, and residential services. The Vocational Rehabilitation program was then explored. It was concluded that Vocational Rehabilitation services were limited to adults and young adults who "have potential for vocational planning" (i.e., competitive or sheltered employment). The next presentation explained that the counties were major contributors to MR/DD programs through their state institutions and mental health program (e.g., 80% of the support of

county residents at the State Hospital Schools). Finally, a brief presentation was made of Department of Health programs (mainly comprehensive Health Planning and Hill-Burton) which concluded that Hill-Burton funds might be used for construction of ICF/MR's.

At meeting III, EDG presented a simplified model of a funding mechanism for MR/DD services. The model broke services into two categories: MR/DD specific and generic services. The model charged the Department of Public Instruction with providing comprehensive MR/DD specific-services through age 21. At that point the Department of Social Services would provide comprehensive services. Generic services would remain as they were, but 10% of their programs would be required to be directed toward MR/DD persons.

This model was modified by the group to maintain within DSS responsibility for social, medical, and residential programs for those under 21 years of age.

REVISED FINANCIAL MODEL

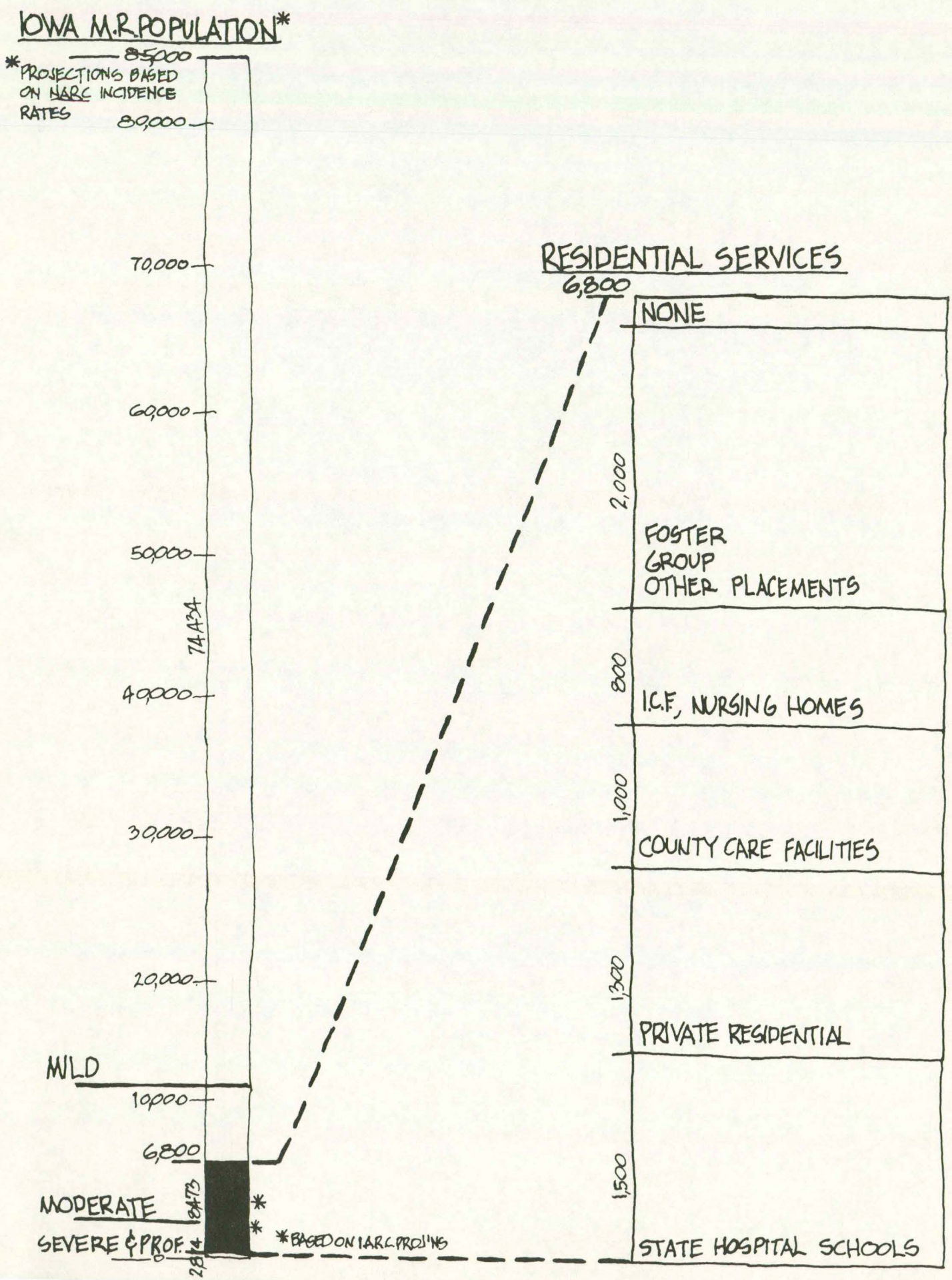


They further revised the model to break out service responsibility and fiscal responsibility.

SERVICE AND FISCAL RESPONSIBILITY

Service Responsibility	Fiscal Responsibility
DSS -- Accountability (D&E follow-along)	Personal, County tax (AEA, DSS), State (AEA, DSS) FED, SSI (T-19, T-20)
DSS -- Social Services	Same (Less T - 19)
DSS -- Residential Services (Maintenance)	Same (Less T - 20)
DSS -- Medical	Same (Less T - 20)
DPI -- Education & Training	Same (Less T - 19) (Stress AEA, Voc. Rehab.
DSS -- Generic Services	Same (Variety of Programs)

RESIDENTIAL SERVICES



The funding mechanism discussion was resumed when the Department, because of a lack of data, overestimated the fiscal exposure of a community program, and language in Section 222 of the Iowa code was found which suggested that the county could pay (through the same mechanism used for the State Hospital Schools) the state share for Title XIX ICF/MR. The Central Office Task Force recommended a cost study be done to accurately reflect the actual exposure of the State. These issues were taken up in meeting V.

At meeting V the following chart which had been developed by EDG and a sub-committee of the State Policy Planning Group was presented. The chart demonstrated that the maximum exposure of the state was limited to 6,800 possible residential placements. This projection was verified by the Group and encouraged the implementation of the cost study.

The details of the cost study were worked out in cooperation with DSS and a sub-committee of the State Policy Planning Group. The Department then tested the study in two counties. At meeting VII, the whole group received the test county results and made suggestions for revisions. These were incorporated, and the full study was begun during February. As of this writing the study has not been completed.

Resolution: No financial model has been recommended since the cost study is incomplete. The Group, however, would like to see a consistent policy for financing residential programs. They lean toward using the same financial mechanism for financing Title XIX in the community as is being used at the State Hospital Schools.

One policy which has been set and bears repeating:

-- FUNDS MUST FOLLOW THE CLIENT

Next Steps:

1. Continue to track the cost study.
2. Develop a funding model.
3. Develop legislative recommendations.

STRUCTURE AND FUNCTION OF THE STATE POLICY PLANNING GROUP

History: The State Policy Planning Group was formed in order to raise the issues surrounding the qualification of the State of Iowa for the ICF/MR Title XIX Program. Over the two weeks of July 29, to August 8, 1975 the Group developed the first part of this report. On October 24, 1975 they met to set an agenda for the next six months. Their scope of activities was:

Ongoing Title XIX ICF/MR Policy advice

Develop a Funding Mechanism

Develop Community Development policies

Monitor EDG Contract

District Planning
Vendor Demonstration Project
State Hospital School Master Planning

The committee structure at the beginning of the ten meeting agenda was: 14 state employees (10 from DSS), 3 public interest representatives, 2 private providers, 2 elected officials, and 2 consumers (see participant list appendix 1).

The structure of the Group was informal. There were no rules, formal procedures or officers. The only rule agreed upon was that recommendations would be determined by consensus with a provision for minority reports. The EDG consultants were contracted to facilitate the decision-making process of the Group and the ten meeting schedule.

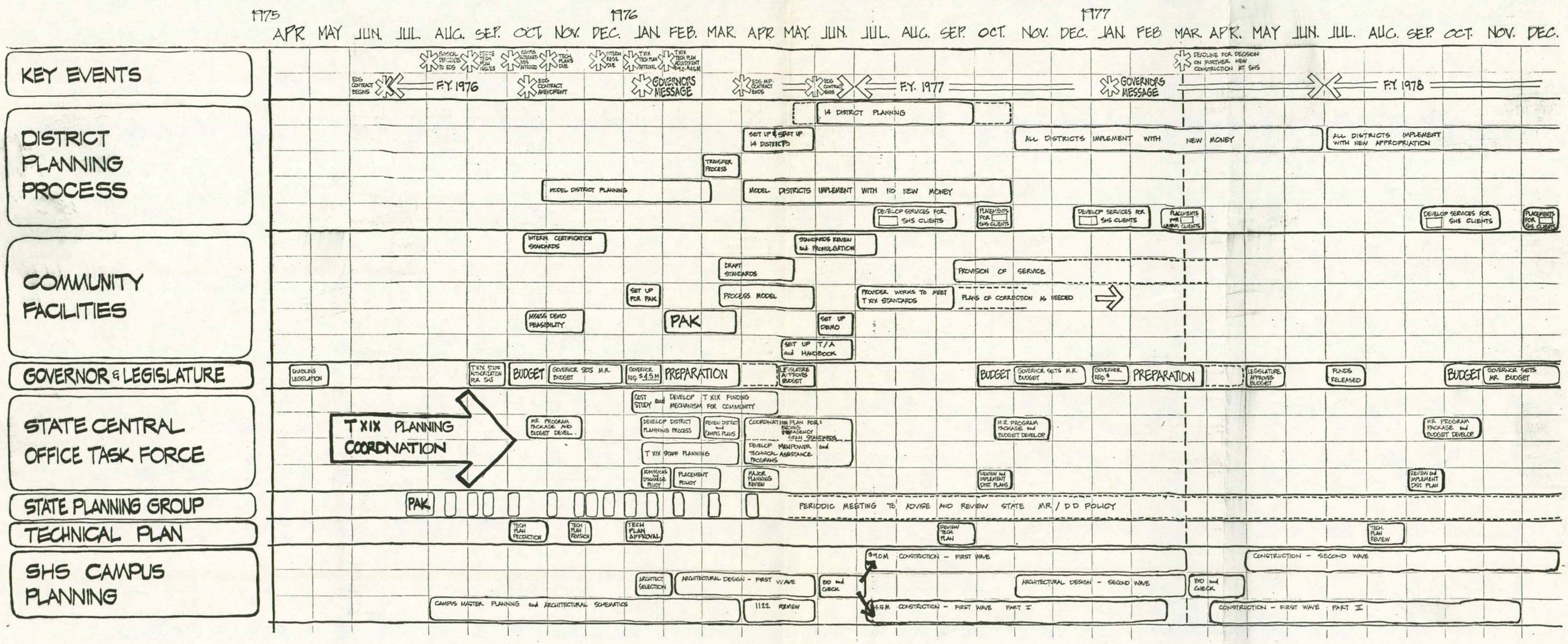
Process: For the initial three meetings, the Group stayed with the planning topics which had been established. At Meeting IV, however, events occurring within the Department (the delay or termination of the program, the Title XIX budget projections, and the maneuvering around the technical plans of correction) led to an undercurrent of frustration and pessimism. At that time the Department and facilitators were constrained from sharing the issues; however, several members of the Group were aware of these events, but they also felt they could not bring them before the Group.

The Group's concern was expressed obliquely by raising questions about the Group's role and DSS's responsibilities to the Group. The concerns expressed included:

> THE RELATIONSHIP OF THE DISTRICT MODELS TO THE DEPARTMENT'S POLICIES
>
> A REQUEST TO REVIEW (AND PERSONALLY HEAR FROM ALL DEPARTMENT HEADS) ALL STATE POLICIES REGARDING MR/DD.

The EDG consultants identified one problem as a lack of openness on the part of the Department and recommended that the Central Office Task Force, with the concurrance of the commissioner, work more openly and closely with the State Policy Planning Group. This recommendation was heeded.

MASTER SCHEDULE OF TITLE XIX PLANNING ACTIVITIES



After the Christmas break, EDG, the Central Office Task Force and a sub-committee of the Group developed a master two-year planning schedule covering all aspects of Title XIX ICF/MR system to highlight for the Group the magnitude of their task. The chart showed each critical decision point and planning activity for the local communities, the State Hospital Schools, the State Policy Planning Group, and the Central Office Task Force.

At Meeting V the Group heard an appraisal of the ICF/MR situation from the Central Office Task Force. This appraisal included a detailed chronology of the critical events which occurred between November, 1975 and Meeting V.

This presentation was followed by a brief discussion which raised the following points.

NEED A COMMITTMENT TO THE PROGRAM FROM THE COMMISSIONER.

WHEN MONEY BECAME A FACTOR, THE PICTURE CHANGED.

NEED TO PROVIDE A RATIONAL TIMETABLE FOR TITLE XIX.

NEGOTIATION OF TEHHNICAL PLANS OF CORRECTION IS NOW POSSIBLE BASED UPON THE AGREEMENT BETWEEN THE GOVERNOR AND THE REGIONAL DIRECTOR OF H.E.W.

NEED TO DEVELOP AN AGENDA TO PROMOTE THE PROGRAM.

TITLE XIX IS IMPORTANT TO INCREASE THE STANDARD OF ALL MR/DD PROGRAMS.

This discussion was followed by an assessment of the situation by the commissioner of Social Services.

The EDG facilitators then presented the chart showing the schedule of planning activities over the next two years. (Subsequently, the chart became the major focal point for the Group's activities).

The presentation was followed by a short discussion covering the following points:

WHAT IS THE OUTSIDE DOLLAR LIMIT FOR TITLE XIX?

WILL THE COMMISSIONER ENDORSE A COST STUDY?

CAN WE FACILITATE THE OPERATIONS OF THE JOINT STANDARDS COMMITTEE?

The EDG facilitators were impressed with the new spirit of cooperation as contrasted with the situation at the prior meeting. EDG attributes the change to the openness which occurred during this meeting, and the fact that the Governor had pledged funds and support to the program.

At meeting VI the State Policy Planning Group raised the following key issues about the Group's future:

WHAT IS THE POSITION OF THE DEPARTMENT TO PROVIDE LEADERSHIP ONCE EDG LEAVES? WHO? HOW?

STAFF DEFINITION BY THE END OF THE CONTRACT.

FEDERAL AND STATE SEARCH FOR FUNDS.

NEED TO MAKE PRESENTATIONS TO THE GOVERNOR AND THE LEGISLATURE.

The agenda for Meeting VIII included an item on the role and structure of the State Policy Planning Group. The first topic was a concern session which was used to generate ideas about revising the structure, leadership, and future role. The Group's concerns included:

THE GROUP SHOULD REMAIN A COMMUNICATION LINE AMONG THE DEPARTMENT OF SOCIAL SERVICES, OTHER STATE DEPARTMENTS, AND THE COMMUNITY.

THE GROUP DELINEATES LINKAGES BETWEEN PLANNING AND IMPLEMENTATION--A POLITICAL FORCE TO MAKE TITLE XIX WORK.

THE GROUP SHOULD REVIEW POLICIES AND PROCEDURES OR ALL STATE AGENCIES THAT IMPACT ON MR/DD PROGRAMS.

THE GROUP SHOULD BE FLEXIBLE. IT SHOULD HAVE VARIOUS ROLES; IT SHOULD NOT BE OVERLY STRUCTURED; THE ROLE SHOULD CHANGE OVER TIME.

THE GROUP SHOULD BE A PROVIDER OF VISION TO IMPROVE THE QUALITY OF SERVICE TO MR/DD PERSONS.

WHAT IS THE REASON FOR THE LACK OF INTEREST OF SOME GROUP MEMBERS?

PEOPLE GET TO KNOW AND UNDERSTAND EACH OTHER.

SHOULD SUPPORT THE DISTRICT PLANNING PROCESS.

As a result of this discussion a poster was developed to demonstrate the Group's current role and provide an opportunity for making changes (See chart next page).

Resolution: Although the Group has approved the above changes, no actions have been taken to formalize these changes.

ROLE AND FUNCTION OF STATEWIDE PLANNING AND POLICY GROUP

	TO DATE	FUTURE
MANDATE:	Advise Department on all MR/DD Planning and Policy Issues	Advise Department on all MR/DD Planning, Policy and Implementation Issues
AUTHORITY:	Letter of Agreement - Review all Policy and Planning Issues - Guided by Consensus of Group	Letter of Agreement - Review all Policy, Planning and Implementation Issues - Guided by Consensus of Group
COMPOSITION:	- 14 State Employees (10 DSS) - 3 Public Interest - 2 Private Providers - 2 Elected Officials - 2 Consumers	- 16 State Employees (10 DSS) - add 1 Department of Health - add 1 Controller's Office - 3 Public Interest - 3 Private Providers - add 1 Nursing Home - 2 Elected Officials
STRUCTURE:	- No By-Laws - No Officers - No Rules - No Work Program	Same as To Date
STAFFING:	EDG contract (end 3/31/76)	Extend EDG contract C.O. staffing unit
SCOPE OF ACTIVITIES:	- 2 week policy statement - On-going Title XIX ICF/MR Policy Advice - Licensing and Certification Standards - Funding Mechanism - Community Development - Monitor EDG Contract -District Planning -Demonstration -SHS Master Planning	Add Evaluation of District Plans

Next Steps:

1. Revise the letter of agreement with the Commissioner of Social Services.

2. Invite new members to participate on the State Policy Planning Group. (Note: EDG recommends that new members be fully briefed on the history and activities to date of the Group by the Central Office Task Force and members of the Group.)

3. Set up a new meeting agenda for the next six months.

4. Update the master schedule.

PLACEMENT POLICIES

History: Since early in this round of State Policy Planning Group meetings it was evident that placement policies were the "clutch" which would determine the balance between community-based and State Hospital School programs. There were varied opinions on placement policies (including admission, readmission, transfer, and discharge) for clients in residential programs. Without reaching a clear position on these policies, the community would be unable to predict who would be released from the State Hospital Schools under the Technical Plans of Correction. The community program developers further needed to understand these placement procedures in order to gear up for providing these clients quality services.

Process: The discussion of the placement policy issue was reassessed when the agenda for Meeting VII was changed. HEW representatives were to be present in order to present the District Plans in their final form. It was decided that two additional meetings (IX and X) would be required to accomplish the goal of making recommendations for placement policy guidelines.

At Meeting IX concerns and ideas were collected in six areas (initial evaluation, periodic evaluation, counseling and interpretation, rate determiniation, space and program availability and general concerns). Some key issues which were developed from this session were :

INITIAL EVALUATIONS

Need for a central point of entry into the system.

Evaluations must be of a high quality and multi-disciplinary.

The State Hospital Schools should act as a resource center for evaluations.

The client (or his/her representative) should play an active part in the evaluation.

PERIODIC EVALUATIONS

Should maintain the individual in the most appropriate setting based upon individual changes and program changes.

Client follow-along is essential.

Records should be maintained in the District.

COUNSELING AND INTERPRETATION

Need to fix responsibility for quality decision-making.

The allegiences of the interpreters are questionable (loyal to residential programs or budgets).

RATE DETERMINATION

Need for quality program and fiscal audits on a regular basis.

An average daily rate is used rather than an individual patient rate.

Rates should be uniform for the same service.

PROGRAM AND SPACE AVAILABILITY

Not enough community programs.

There should be regular program evaluations.

People are being place in State Hospital Schools because of poor (or no) community programs.

Need communication among the parts of the service system.

OTHER

Different jurisdictions must be clarified.

Need cooperation, coordination, and staff training.

Funding policies should be tailored to meet the clients' needs.

We have not placed enough emphasis on the MR/DD adult.

Following the generation of concerns and ideas three small groups were established to wrestle with the issues and develop recommendations for the consideration of the larger group. Group I met on evaluation and counseling; Group II on rate determination and program and space availability; Group III considered the general concerns which grouped around systems issues. Meeting X provided an opportunity for the small groups to report back their results. Group I presented a model for a community-based placement system. Group II provided instructions to policy procedures developers within DSS for cost and program control. Group III set the direction for future steps by the State Policy Planning Group and the Department of Social Services. These reports were followed by a discussion of recommended changes in order to bring the group report to consensus.

Resolution: (See Appendix B)

Next Steps:

(1) Refine guidelines where necessary.

(2) Develop a legislative and administrative strategy to accomplish the recommendations.

(3) Review the current administrative structure's ability to implement the above and make recommendations where necessary.

ANALYSIS OF SIX MONTH PLANNING PROCESS

Several factors impacted upon the deliberations of the State Policy Planning Group including the changes in the technical plans of correction required by Regional Office of HEW. The group had to face the fiscal realities of the Department of Social Services in a way that was unnecessary during the two week process. During this round of meetings, the Title XIX ICF/MR program became operational, meaning that the policy decisions made by the group were being implemented, but not always as the group has recommended.

In trying to strike a balance between the community program and the State Hospital School program certain trade-offs decisions have had to be made. While the community desperately needs funds to build up community programs, the State hospital Schools will receive the total appropriations for the next fiscal year. This was necessary in order to qualify the State for the program. It is now incumbent upon the State Policy Planning Group to insure that future allocations of funds are shared with the community programming effort.

The State Group has had to balance the need for quality services with the

fiscal realitites of the State. Original projections showed a need for a central administrative staff of six. This figure has been reduced to three, and there is a possibility it will become even less. It will be necessary for the group to press for adequate program resources from already scarce resources.

The State Policy Planning Group must continue to develop policies, but they must also concentrate their talents on promoting their policies within the State of Iowa. These policies and strategies must be based upon substantial data and facts; they must be reasonable and well developed. Ultimately, these policies must be acceptable to the Commissioner, Governor, Legislative, and the Citizens of Iowa. The care and planning which led to the presentations before the Governor and Legislative committee on Social Services must be continued.

The EDG facilitators have provided a degree of leadership in assisting the group to reach decisions, developing and substantiating information, and developing action strategies. Following Meeting X this leadership role falls upon the State Policy Planning Group itself. The individual members of the group and the group collectively must continue to press for adequate staff support for their activities. The group has taken a general position of providing guidance and review. In order to contine in this mode, the policy guidance must be transformed and refined by Department of Social Service staff. Further, the group is dependent upon DSS staff to point up policy issues in a timely manner.

The State Policy Planning Group has demonstrated significant change and growth over the last six months. They have changed from long-range blue-sky planning to a more careful "real world" analysis of policy issues. They have seen the need to consider and act in the political world--an absolute necessity if long range plans are to become a reality.

The EDG facilitators have been impressed throughout this process with the caliber of ideas and grasp of policy decision-making demonstrated by the group. EDG has been impressed by the dedication and committment of the group members, who are all busy people. It is unusual to see government so responsive to citizen input as has been the Department of Social Services at both the local and state levels. The group has attacked, head-on, hard issues and has dealt with them. EDG can only hope that this continues, for more often than not, quality programs get swept aside due to the failure to face difficult decisions.

SUMMARY OF NEXT STEPS

STATE HOSPITAL SCHOOL MASTER PLANNING

(1) Monitor on a regular basis and at key intervals the progress of the State Hospital Schools.

(2) Develop strategies for revising downward the residential populations called for in the technical plans of correction.

JOINT LICENSURE AND CERTIFICATION

(1) Continue to monitor and review the development of new standards.

MODEL DISTRICT PLANNING

(1) Review both plans and provide implementation recommendations to the Commissioner of DSS.

(2) Track the issue of the transferance of the process to the other 14 Districts.

FUNDING MECHANISM

(1) Continue to track the cost study.

(2) Develop a funding model.

(3) Develop legislative recommendation.

STRUCTURE AND FUNCTION OF THE STATE POLICY PLANNING GROUP

(1) Revise the letter of agreement with the Commissioner of Social Services.

(2) Invite new members to participate on the State Policy Planning Group.

(3) Set up a new meeting agenda for the next six months.

(4) Update the master schedule.

PLACEMENT POLICIES

(1) Refine guidelines where necessary.

(2) Develop a legislative and administrative strategy to accomplish the recommendations.

(3) Review the current administrative structure's ability to implement the above and make recommendations where necessary.

APPENDICIES

LIST OF PARTICIPANTS
SESSION SCHEDULES
PLACEMENT POLICY

LIST OF PARTICIPANTS

TWO WEEK TITLE XIX ICF/MR POLICY PLANNING POLICY

R. Bakke	Department of Health
Betty Barnes	Team Social Worker, Glenwood State Hospital-School
Howard Barton	Program Administrator, Woodward State Hospital-School
Frank Belke	Director, Social Services-Woodward State Hospital-School
Jim Bethel	Director, Bureau of Mental Retardation - Division of Community Services
Robert Boaz	Executive Director, Systems Unlimited - Iowa City
William Campbell	Superintendent, Glenwood State Hospital-School
*Rosemary Casey	Director, Planning & Operations - Division of Mental Health Resources
*Linda Cooper	(Co-Chairperson Title XIX Task Force), Director, Long Term Care Section
Richard Fischer	Assistant Director, Area Education Agency - Special Education Division
*Owen Franklin	Superintendent, Woodward State Hospital-School
Bruce Grogan	"1122" Coordinator, Comprehensive Health Planning Office of Planning & Programming, Des Moines
*Nicholas Grunzweig	(Co-Chairperson Title XIX Task Force), Acting Director, Division of Mental Health Resources, Department of Social Services, Central Office
Jack Harvey	Director, Bureau of Family & Adult Services Department of Social Services - Central Office
Helen Henderson	Executive Director, Iowa Association for Retarded Citizens, Des Moines
John Henry, M.D.	Assistant Superintendent, Professional Services, Glenwood State Hospital-School
Chad Hofbeck	Assistant Superintendent, Woodward State Hospital-School
Bill Howard	Human Resources Coordinator, Iowa State Association of Counties, Des Moines
S.B. Hussein, M.D.	Clinical Director, Woodward State Hospital-School
William C. Ketch	District Administrator, Des Moines District Department of Social Services
Bill Miles	Assistant Director, Developmental Disabilities, Office of Planning and Programming, Des Moines
Lloyd Munneke	Director, Adult Services - Hope Haven, Rock Valley
Linda Nerison	Team Social Worker, Glenwood State Hospital-School
Carroll Price	Director, Bureau of Architecture & Engineering, Department of Social Services - Central Office
Marv Sammons	Division of Community Services - Department of Social Services - Central Office (alternate)

*Title XIX Task Force

*Doug Settles	Program Administrator, Glenwood State Hospital-School
Bev Stubbee	Assistant Director, Division of Community Services, Department of Social Services - Central Office
Kay Svebakken	Mental Retardation Supervisor, Davenport District - Department of Social Services
F. Vance	Department of Public Instruction (alternate)
Barry Wills	Business Manager, Woodward State Hospital-School

*Title XIX Task Force

SIX MONTH TITLE XIX ICF/MR POLICY PLANNING PROCESS

J. Barfels	Department of Social Services
James Bethel	Department of Social Services
Robert Boaz	Systems Unlimited, Inc.
Robert Burke	Board of Supervisors, Clinton County Court House
*Rosemary L. Casey	Department of Social Services
William Campbell	Glenwood State Hospital-School
Larry Conrad	United Cerebal Palsy of Iowa
**Linda Cooper	Department of Social Services
Richard Fischer	Department of Public Instruction
*Owen Franklin	Woodward State Hospital-School
**Nicholas Grunzweig	Department of Social Services
Bruce Grogan	Office for Planning and Programming
Jack Harvey	Department of Social Services
Clell Hemphill	Office for Planning and Programming
Helen Henderson	Iowa Association for Retarded Citizens
William Howard	Iowa State Association of Counties
George Keiser	Department of Social Services
Rita Kline	Woodbury County Court House
Dudley Koontz	United Cerebral Palsy of Iowa
William Miles	Office of Planning and Programming
Kay Svebakken	Department of Social Services
Shiella Swanson	Department of Social Services
Charles Sweeney, Jr.	Department of Social Services
*William Turner	Department of Social Services

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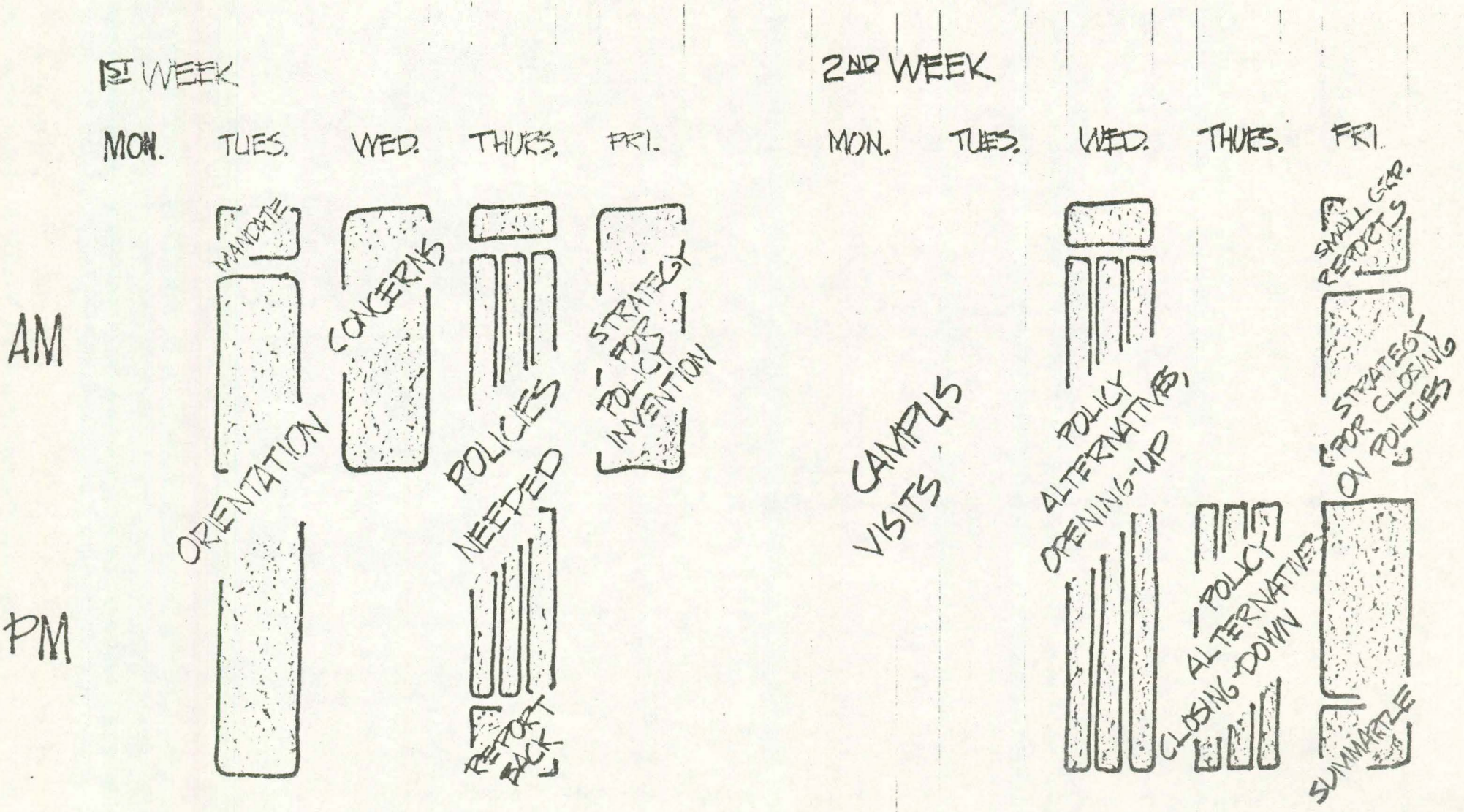
*Title XIX Task Force

**Co-Chairperson Title XIX Task Force

SESSION SCHEDULES

TWO WEEK T-19 PLANNING PROCESS



SIX MONTH PLANNING PROCESS

MAJOR MEETING ISSUES / DATE	I 11/10/75	II 12/1/75	III 12/10/75	IV 12/15/75	V 1/12/76	VI 1/19/76	VII 2/2/76	VIII 2/19/76	IX 3/3/76	X 3/11/76
STATE HOSPITAL SCHOOL MASTER PLANNING		REV. T.P.G.				REVIEW	REVIEW			
LICENSURE & CERTIFICATION		ISSUE	CONCEPT	RECOMM.						
MODEL DISTRICT PLANNING						REVIEW		REVIEW		
FUNDING MECHANISM	REVIEW		MODEL	REVIEW	COST STUD					
STRUCTURE & FUNCTION OF STATE POLICY PLANNING GROUP				DISCUSS	AGENDA		RECOMM.			
PLACEMENT POLICIES								AGENDA	DISCUSS	RECOMM

PLACEMENT POLICIES

STATE POLICY PLANNING GROUP

RECOMMENDED PLACEMENT POLICY GUIDELINES

Introduction

Over the last three meetings the Title XIX State Policy Planning Group has developed a set of placement policy guidelines for Iowa ICF/MR facilities.

These policies focus on three critical areas: evaluation and interpretation (to insure proper placement based on client needs), rate determination (to insure availability of appropriate placements), and space program availability (to insure quality programs).

In order to reach these guidelines, the State Policy Planning Group first listed their concerns and ideas. They then broke into three small groups to develop models and guidelines. These were returned to the large group for modification and approval. The following model for evaluation and interpretation was approved by the group along with the accompanying policy guidelines.

Although certain areas of these guidelines require refinement, they provide a starting point for developing departmental policy. The State Policy Planning Group realizes that the guidelines reflect what ought to be and that certain compromises may have to be made in the short run.

The State Policy Planning Group welcomes the opportunity to discuss these guidelines with policy developers within and without the Department of Social Services.

COUNSELLING AND INTERPRETATION GUIDELINES

Descriptive Statements About Model

- Every contact is reported to the MR supervisor who is responsible for the operation of the evaluation system and the welfare of the client.

- The residential QMRP along with DSS follow-along QMRP may redefine short-term objectives, but not long term goals, which must be changed by the team.

- The evaluation must be responsive to the developmental model, normalization principle, least restrictive environment, services close to home, etc.

Implications of Model

- The MR supervisor has the authority to incur the expense of evaluations and may delegate that authority to county QMRP's.

- The recommended procedure may require additional qualified staff.

- The MR supervisor has responsibility for and authority over DSS QMRP's.

- There must be ongoing staff training in all phases of evaluation, follow-along, counseling and interpretation, and case management.

- Team members must be trained in MR/DD evaluation.

- The role of the State Hospital Schools is (1) to assist at the request of local teams in evaluations, (2) to provide ongoing training to DSS staff and team members, (3) to provide technical assistance to DSS MR/DD staff.

- The team has a primary responsibility to the client beyond the responsibility to parents and guardian.

- On an interim basis, the SHS's will fill-in where qualified professionals are unavailable.

- Priority on community placements in quality community programs.

- Follow-along and funding rests at the local level. Even while client is at the State Hospital School.

Recommended Additional Guidelines

- DSS must establish standards format and procedures for evaluations.

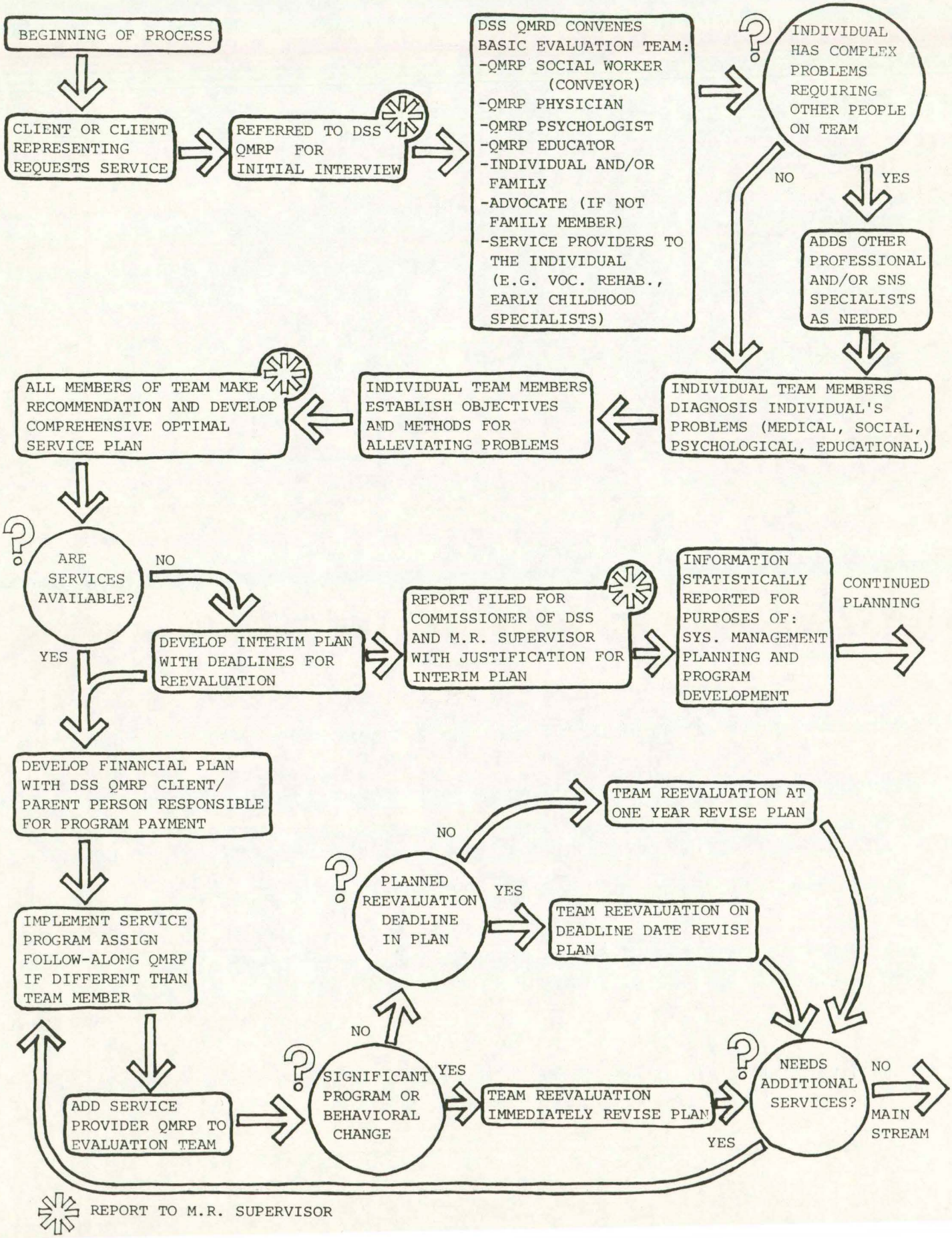
- Independent review and evaluation must be performed upon the district evaluation process.

  - Annual comprehensive evaluation
  - Use of a committee (DSS, Public Health, ARC, D.D. Council and DPI) or independent consultant.

- This process covers all MR/DD people, and should be expanded to cover all MR/DD services, not just residential programs.

- Responsibility and authority for placement policy rests with the commissioner of DSS not State Hospital Schools.
  - Delegated to district level.
  - Emphasis on community placement.
  - Change Section 222 accordingly.

CHART OF CLIENT FLOW THROUGH COMPREHENSIVE CARE & EVALUATION



RATE DETERMINATION GUIDELINES

1. There should be a program and fiscal audit every 12 months - Establish a prior review process of programs to cover major changes which take place more frequently than 12 months.
   - Establish accounting procedures.
   - Use same accounting procedure for all programs regardless of funding source (within Federal guidelines).
   - Develop a program audit capability - possibly using universities or other consultants. Put out an R.F.P.
   - Audit should be done by those who do not provide or finance services - in addition to audits which must be done by DSS.
   - Until an outside audit capability develops, use DSS resources.
2. There should not be an arbitrary ceiling on rates.
3. Rate consistency.
   - Regardless of the funding source, the rate should be the same for the same service at the same place.
   - Parents' financial responsibility should be the same regardless of the type of placement.
   - Service must be available to all regardless of family income and location.
4. Revise law to deal with problem of no county of legal settlement (Refer to 222 Committee to revise).
5. Insure money available for all types of placement.
6. Money should follow people.

SPACE AND PROGRAM AVAILABILITY GUIDELINES

1. Service as a matter of right.

2. Tie together placement, funding, and district plans.

3. There must be a certificate of need before DSS pays for care through any program.

4. Revise state law (Section 222).

5. No placement should be made without an assessment.
   - All currently placed people should be evaluated within 6 months from when comprehensive evaluations become operational in the District.

6. If necessary, an advocate should be identified at the time of placement.
   - Advocate is not synonymous with parent or guardian.
   - The advocate system should be available as needed (e.g., Developmental Disabilities Council).

7. Program and space availability must be coordinated with long-range District master plans. (Build into the 1122 review process.)

8. All providers and programs must be licensed.

9. Develop a system of appeals.

10. Formalize a policy for placement along District lines.

11. Assess individual needs and program availability. (A plan which follows the person.)

12. Implement a data collection and retrieval system.

13. Appoint a follow-along (case management) agency for direct service and resource development.

14. Need to educate agency people to what is available other than in their own County (or District).

15. Utilize the existing system to the maximum. People do not know where to go to access the system (services).

16. Policies should be department-wide with a system of quality control to monitor them.

Group I

Initial and Periodic Evaluation and
Counseling and Interpretation

(Concerns)

I. Initial Evaluations

- Beef up the evaluation process -- should be comprehensive and professional in nature.
- Travelling evaluation teams.
- There is a need for a central point of entry (particularly for adults).
    - Fix control and responsibility.
    - State-wide effort.
- Evaluations must be multidisciplinary in nature (e.g.,physician, psychologist, social worker, parent, and client).
    - Must be flexible for the client.
- Cannot arrive at a full level of service in all 16 districts.
- There should be a state resource center for (D&E) evaluations.
- Since there may be a difference of opinion between the parent and DSS, there must be an appeals procedure.
- The client should have an active part in the evaluation.
    - And the parents if they are an advocate for the client.
- Single point of entry defies normalicy.
- The individual performing the evaluation should be competent.
- All professionals should be qualified mental retardation professionals.
- Initial evaluations now being made on an ad noc basis.
- There is a lack of quality evaluation services.
- Travelling teams should enhance local efforts.

II. Periodic Evaluation

- Should keep client in an appropriate setting.
- Should be criteria for movement.
- Who makes (is responsible for) the decision?
- What works? (Periodic evaluation should reflect program success/ failure.)
- Records should be maintained in the district.
- Follow-along is essential.
- There is a lack of consistency in frequency and quality.
- Periodic evaluation should reflect changes in the individual and the program. (Highly variable)
- There is a need for a longitudinal capacity.
- Competency of the team.

III. Counseling and Interpretation

- Need to strengthen the abilities at the district and local levels. To make decisions. Need to fix responsibilities.
- There should be an appeals procedure (courts?).
- Counselors should be competent.
- Counseling should be interdisciplinary.
- The allegences of the interpreter are questionable.

State Planning Group
March 3, 1976

Group II

Rate Determination
(Concerns)

- Should be no charge or should be consistent.
- Sometimes we over-care or under-care for people.
- There is a need for serious program audits.
- Rates can drive quality.
- Must evaluate what we get for our money.
- Poor and rich get service. Middle gets hurt.
  - Need across the board people service.
- We should spend more on adults.
- Children of 18/adults over 40.
- Need balance between prevention and care.
- Rates should be set based upon program evaluation.
- People who set rates don't understand programs.
- Rates should vary based on programs.
- Reimbursement vs. rate setting.
- Average daily rate used rather than an individual patient rate.
- Money should follow people.
- Let individual buy care where he wants.
- Rate of state hospital schools is the maximum rate. Should this be? (222)
- Does high rate indicate high quality?
- Excess money leads to poor placement.
- County boards make decisions based upon money.
  - Boards do not get information/local worker just decides they won't provide funds.
- Multiple systems for payment -- rates should be uniform for the same service.
- Hospital schools funded under Title XIX/community facilities not under Title XIX.
  - This acts as an incentive to keep people in state hospital schools.
- County supervisors will respond if the need is made known.

State Planning Group
March 3, 1976

Group II

Program & Space Availability
(Concerns)

- Not enough space available in the community.
- Need to determine the range of disabilities and numbers of people needing service.
- Increase the state's ability to generate programs.
- Program evaluation -- people, objectives, staff/client ratio.
- The Districts accept responsibility for out of district referrals.
- What is meant by a community-based concept?
    - Use community sources first; only then consider institutional placement.
- Need a wider variety and more services.
- Placements are made based upon what is available.
- Unwillingness to use the client as a way to stimulate program development.
- Only if there is no space at state hospital schools are other alternatives explored.
- Need to assess the programs we have (poor, average, good).
    - Who is responsible for the assessment.
- We have to out-place from State Hospital School, but people are still being placed in the State Hospital Schools because of poor programs.
- Problem of the use of programs by people from outside the area.
- Identify needs - tell providers -- they'll develop service -- but must have payment.
    - Committment
- How do people end up in inappropriate placements?
- Mechanisms for accredidation? License?
- Control over system leads to placement policy.
- Any placement should be to a licensed/certified or otherwise approved setting.
- Can counties or a private individual do placement?
- Don't want control for control's sake.
- Advocacy, protective services should be legally tied down; now done voluntarily by DSS.
- Discharge obligation -- to see that person goes to someplace better.
- Never have placement without discharge.
- Need communication between parts of the system -- District control.
    - DSS assume leadership -- work with AEA.

- Placement outside of the District will be spurred as people are moved to appropriate AEA settings.
- Need to look closely at any placement outside of home community.
- Development of placements -- non-professional evaluations.
- Capacity to follow-along.
- County care facilities want information on what we want them to do.

Group III

Other Concerns

- There should be policies for all caring facilities.
- People get lost in the many jurisdictions.
- In Pennsylvania the rights of parents to place children is under question.
- There is a conflict between foster care and Title XIX.
    - Foster care program covers all substitute care for children.
- There is a conflict between state and county foster care.
- Policies for adults are worse than those for children.
- There needs to be an emphasis on adults.
- What is the impact of AEA?
- There should be equity in the distribution of resources.
- How do community programs and state hospital school programs key into Title XIX?
- What is the role of county care facilities?
- How do we get it done? Will we be able?
- Need:
    - Force of law
    - Responsibility, authority, accountability
    - Administrative structure
    - Legal issues resolved
- Funding sources should be tailored to meet clients' needs.
- Don't create another complicated system.
- Client outcomes should be the criteria for decisions.
- Use present policies as a model.