DOCUMENT RESUME

ED 055 613 LI 003 167

TITLE	A Master Technical Plan for the National Mental Retardation Information and Resource Center.
INSTITUTION	Interuniversity Communications Council (EDUCOM), Boston, Mass.
SPONS AGENCY	President's Committee on Mental Retardation, Washington, D.C.
PUB DATE	Apr 69
NOTE	75p.; (0 References)
EDRS PRICE	MF-$0.65 HC-$3.29
DESCRIPTORS	*Information Centers; *Information Needs; *Information Systems; *Mental Retardation; National Programs; Planning; *Resource Centers
IDENTIFIERS	Medical Information Systems

ABSTRACT

The Master Technical Plan is divided into the following four main parts: (1) "Indroduction." (2) "A Description of the Proposed National Medical Retardation Information and Resource Center (NMRIRC)," consists of a series of descriptions of how the national center will serve its various organizational and individual constituents. This section explains the technical rationale that led to the construction of the technical plan for the National Medical Retardation Information and Resource Center (NMRIRC); (3) "Master Technical Plan for the NMRIRC." This is intended to be the durable vehicle of design for the eventual national center and also the master planning document for the President's Committee. Once reviewed, corrected, and approved by the President's Committee or the delegated representatives of the Secretary the plan should be the blueprint for the national center; and (4) "Proposed EDUCOM Support of the NMRIRC," includes some historical information on the Interuniversity Communications Council (EDUCOM), a roster of institutional members, a proposed staffing plan, and an estimate of costs for EDUCOM participation. (Author/MM)

A MASTER TECHNICAL PLAN

for the

NATIONAL MENTAL RETARDATION INFORMATION AND RESOURCE CENTER,

Prepared for

THE INFORMATION CENTER WORK GROUP

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

by

EDUCOM

The Interuniversity Communications Council

April 1969

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I. INTRODUCTION

The Interuniversity Communications Council (EDUCOM) was first introduced to the studies of the Secretary's ad hoc Task Force on the Feasibility of a National Mental Retardation Information and Resource Center in September 1968 when Mr. Francis Lynch of the staff of the President's Committee on Mental Retardation called on Mr. Tadashi Mayeda of EDUCOM's Bethesda office to discuss whether an information center could contribute in a central way to the national effort in combating and preventing mental retardation.

Given more time EDUCOM would have prevailed upon the expertise of the faculties of the 8 universities with facilities for the mentally retarded and the 6 universities with mental retardation research centers which are members of the EDUCOM consortium. In the limited time available, however, the critique was limited a staff opinion on generally accepted attitudes toward information systems and applied uses of information systems particularly from the viewpoint of information systems in health care.

Two years of project exposure to problems of information in health care under the contractual auspices of the National Library of Medicine and the guidance of the 46 medical school members of the consortium led EDUCOM to the solid conviction that patient care is a highly personal matter and indirectly and peripherally affected by information

systems. Information systems in a motivational vacuum can have no effect whatsoever on any patient. If, on the other hand, the clinician or person treating the patient needs and wants collateral information, the system can reach out and back for retrospective and remote materials which might be of assistance to him and the patient.

EDUCOM's comments on the proposed NMRIRC, consisting of 14 position statements, were based on this conviction. In effect, an information system is but a technological vehicle highly dependent upon the value of the information that it proposes to handle and the desire of the user to seek and apply that information.

The President's Committee on Mental Retardation is one of many commissions, task forces, and committees that have expressed interest in collecting, handling, and distributing information to expedite the transfer of capabilities, experiences and research results to practice.

The Regional Medical Program of the Public Health Service, established in October 1965 by the authority of Public Law 89-239, resulted from the 1964 study of the President's Commission on Heart Disease, Cancer, and Stroke. One of the needs was expressed as follows:

> A creative partnership must be formed among the Nation's medical scientists, practicing physicians, and all other of the Nation's health resources so that new knowledge can

> be translated more rapidly into better patient care. This partnership should make it possible for every community's practicing physician to share.....resources.

Dr. William Stewart, the Surgeon General, in a talk to the National Health Forum of the National Health Council in March 1967 on the subject of Public Law 89-749, the Comprehensive Health Planning Act, talked about comprehensive health as follows:

> Planning begins with the aspirations of society. The first step is to articulate these aspirations into meaningful goals.....The second step is to break these down into a set of objectives..... Information systems are the next indispensable ingredient of the planning process. Data are needed as to the nature, extent, and location of the problems identified as target objectives. We need to know the resources currently available to combat the problem, the resources that could be diverted from other purposes, the effect of this diversion, and the additional resources that could be developed.

Providing data and general information services to members of the Association of American Medical Colleges is recommended in the report, "Planning for Medical Progress Through Education" by Lowell T. Coggeshall.

> Certain basic data and general information services are essential.....By serving as a central agency for collection and distribution of information about trends and needs in education for health and medical sciences, the association can provide an important resource of objective data for the use of all organizations and agencies concerned with health. A broad variety of information should be gathered and disseminated on a clearinghouse basis.

The 1962 Airlie House "Conference on Health Communications" sponsored by the former Surgeon General, Dr. Luther Terry, addressed itself to the information explosion and the new techniques of communications. One of the recommendations read as follows:

> Support research and development directed toward establishing a coordinated network for automated biomedical information processing. The vast amount of biomedical communication which needs to be carried out can probably be facilitated by new electronic means. Eventually, a coordinated network may relieve the increasing pressure on libraries and speed the flow of information to scientists, practitioners, health administrators, and the public.

These and other reports show no evidence that the value of information is denied in any quarter. In almost every case, however, each phrasing of the problem includes some caution that information handling must lead to a clear gain in consumer service. In this regard the President's Committee on Mental Retardation and all other commissions and task forces interested in the possibilities that information systems have to offer are in complete agreement.

The President's Committee interest in information systems and Dr. Aldrich's later concern for an assessment of need are the guiding statements for this document. It is hoped that both of these are clearly and accurately reflected in the sections that follow.

The next section, "A Description of the Proposed NMRIRC", consists of a series of descriptions of how the

national center will serve its various organizational and individual constituents. This section explains the technical rationale that led to the construction of the technical plan for the NMRIRC.

Section III is the "Master Technical Plan for the NMRIRC". It is intended to be the durable vehicle of design for the eventual national center and also the master planning document for the President's Committee. Once reviewed, corrected, and approved by the President's Committee or the delegated representatives of the Secretary the plan should be the blueprint for the national center.

The final section, "Proposed EDUCOM Support of the NMRIRC", includes some historical information on EDUCOM, a roster of institutional members, a proposed staffing plan, and an estimate of costs for EDUCOM participation.

II. A DESCRIPTION OF THE PROPOSED NMRIRC

The National Mental Retardation Information and Resource Center effort should be a partnership of professional and voluntary workers, social and physical scientists, private and public institutions, and philanthropic and investment funds with the common goal of combating and preventing problems of mental retardation by extending the total national resource of formal and informal information into this diverse community of individuals.

The NMRIRC should be the organizing catalyst of dispersed resources so that these resources can be brought to bear on individual needs at the same time stimulating efforts to eliminate these needs in future generations. It should be an expansive partnership capable of regeneration through the highly motivated interests of private citizens and professional workers and it should seek ways and means to stimulate interest in the sector not now aware of or concerned with problems in mental retardation.

The NMRIRC organizational complex should consist of special information resource units, a publication production unit, various service outlets, and a central staff managing and supporting the various components concerned with information collection, handling, or distribution.

The special information resource unit for medical and health related literature in mental retardation and allied subjects will be one of the mental retardation research centers with an existing MEDLARS system. This resource component, acting on behalf of all medical research interests in mental retardation, will apply a deep vocabulary of MR terms to the supplemented MEDLARS data base to provide a complete literature resource to the (medical) researcher interested in problems of or related to mental retardation.

The special information resource unit for educational, testing, and training literature will be an institution with a basic ERIC capability. This institution will, on behalf of the educational community, assume the deep data base responsibility for all institutions and organizations concerned with educational and training methods and research in the field.

The functions of these and other special resource units will be the collection, storage, and retrieval of published literature. Literature citations will be retrieved by demand search to meet the information requirements of a user or by profile matching for current awareness notices to regular users.

The publication production unit will produce and distribute directories of service organizations, compendia of special interest research and service programs, catalogs

of films, and other publications of general interest based on information inputs received from resource units and service outlets.

The service outlets of the NMRIRC will be located in the offices of the community organization which receives the consent of participating mental retardation organizations to represent that group in communications with the national center. The local organization might be a regional office of the Department of Health, Education, and Welfare, the county or city Association for Retarded Children, a state vocational rehabilitation office, a state school, a state colony, a children's hospital, a university research center, or a public school special education office.

One or more members of the selected local office and staff members of other offices will receive special training and training materials on the best use of the national resource. The local staff member will stimulate and encourage use of national resources and act as the primary interface into the national system.

The local address and the telephone number of the community service outlet will be the point of entry into the national resource. Each community office will be provided with the directories and catalogs of the production unit including routinely updated directories on local and national diagnostic services, day care centers, nurseries, residential

facilities, vocational rehabilitiation programs, sheltered workshops, training materials, educational programs, and the conditions and limits of availability of this information or service for local use. In addition each local office will be advised of the specialized information services available to members of the professions serving the mental retardate, such as periodic individualized synopses of current awareness bulletins in research, deep searches for retrospective and distantly related literature citations dealing with mental retardation, and related subjects.

The NMRIRC in addition to providing resource materials and resource capabilities to local outlets will periodically conduct thrusts into specialty areas. For example, if exceptional resource materials on pediatric research ventures become available at a distant medical school, the local staff representative will contact the county or state medical association, the local pediatrics association, or community hospitals with advance material for the local medical director of continuing education.

By these methods the NMRIRC will serve the total national community concerned about or involved in MR problems. It will propose to serve:

The friend.....

...unaware of community support required by MR

...participating in community awareness ventures

The parent.....

...aware of anomalies in a childs growth and development

...seeking specialized medical diagnosis and conditions of availability

...will be told of specialized childrens' diagnostic centers and its services

The parent.....

...moving to a new area

...seeking a profile of community services

...will receive information on the nursery, day care, specialized education, and other services available within a 50 mile radius of the husband's new job location

The obstetrician...

...in solo practice in Montana

...removed from opportunities for formal continuing education

...may ask for monthly "alerts" on medical articles dealing with genetics, in utero diagnosis, etc.

The pediatrician.....

...conditioned to think of mental retardation as a non-hope situation

...observing an infant's unsatisfactory sensory motor development

...will be made aware of diagnostic and therapeutic services dealing with potentially handicapped children

The geneticist.....

...conducting research on a small population group

...concerned about the small population cross section

...will ask the central staff to include his data collection requirements in the MR incidence sample

The biochemist.....

...conducting primate research

...interested in related research in distant fields

...will request a deep literature search through other information systems

The on-the-job training specialist.....

...involved in job placement for trainees

...seeking trainee references

...will request updated listings of local vocational rehabilitation counselors, workshop supervisors, and other counselors.

The state legislative representative.....

...sympathetic to problems of mental retardation

...challenged on the fiscal priority of high overhead programs for the retardate

...will seek justification in a summary of various state laws, programs, and budgets

The NMRIRC will not be able to solve the problem of the experienced, highly competent, research specialist seeking collateral information from on-going research. Nor will the NMRIRC be able to tell a parent where to find diapers for a five year old child.

The NMRIRC will fail in the former because the publication trail introduces a one to two year delay between

completion of research and the appearance of research results in a scientific or medical journal. The system can, by employing the researcher-to-researcher contact technique employed by the World Health Organization Biomedical Research Information Service (WHOBRIS), put the requesting researcher in contact with people who have been doing similar work.

The NMRIRC will fail in the latter because data will not be collected down to the level of need for oversized diapers. The system will, on the other hand, be able to give the local staff a comprehensive snapshot of all local services having to do with MR. The system will not give the answer but will locate and identify likely reply sources.

Even within these limits the NMRIRC faces two major hurdles which must be overcome before the system can be effective and useful to the community of users. The first hurdle is the variety of information that the NMRIRC proposes to handle; the second, the accuracy of that information.

Existing information systems are generally limited to the collection, processing, and distribution of published information and various surrogates to that information. For a segment of the user population, mostly the researcher, this information serves a specific purpose. The practitioner or field worker, on the other hand, needs information not normally published. For various reasons of practicality and desirability

this type of information is not commonly handled in traditional systems. The NMRIRC is faced with the problem of including this reservoir of data into the files of the national center.

The second hurdle has to do with the accuracy of this information. One of the benefits of the traditional publication process is the editorial and review process which serves to validate the information before it is released to the public. Without this review there is no guarantee that the data in directories and catalogs will be up to date. In this regard it is hoped that the local outlet of NMRIRC will also play a role in data collection.

The Master Technical Plan for the NMRIRC is based on the various criteria described above.

III - MASTER TECHNICAL PLAN FOR THE NMRIRC

A master technical plan consisting of 32 project tasks and preliminary statements of work for key tasks were prepared for the proposed National Mental Retardation Information and Resource Center (NMRIRC). The object of the master plan is to:

a. Provide a detailed plan of action to the President's Committee on Mental Retardation to enable the Committee to assess the value of an information system for the community of persons concerned with problems in mental retardation

b. Provide information to a scientific council or a delegated review board of the Committee to permit specific task revisions

c. Provide a technical schematic to computer and information specialists to allow them to develop detailed task statements and design methods

d. Isolate a large number of self-standing technical tasks to allow project participation by as many different organizations as possible

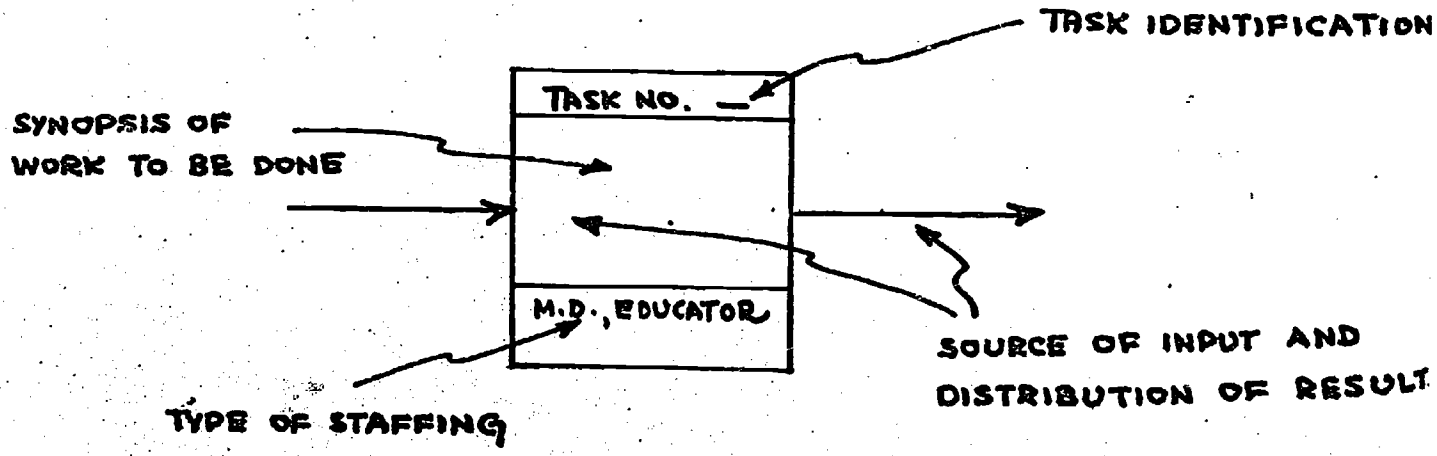
e. Lead to the establishment of an information center that could be financially self-sufficient while providing a needed service to the community.

The foldout page is the proposed NMRIRC Master Technical Plan. The two page statements are preliminary task descriptions corresponding to certain tasks on the master plan.

1. General Description

The master plan reads from left to right in the direction of the arrows. Each box represents a technical task. Dependency of one task on another is implied by the interconnecting lines. Specific comments on dependency are contained in each of the written task statements.

Each box contains a task identification number, synopsis of work, staffing recommendation, and an arrow leading to a succeeding task. Key data contained in each box include the following:



The horizontal ordinate of the master plan is not constructed on a time base. The task boxes are aligned in horizontal sequence to illustrate the fact that certain tasks necessarily come before others. However, tasks in vertical groupings need not be conducted within the same timeframe.

2. General Conditions and Governing Statements

The term "center" in NMRIRC describes an integrated capability rather than a building. This does not exclude the possibility that a single building some day might contain all of the machines, staff, and resources of a national mental retardation center which will be the focus and switching center of all mental retardation information inquiries. It does lay aside this scheme in favor of a plan to integrate, reinforce, and coordinate those information resources which are already near the centroid of mental retardation activity.

By this definition 12 institutions are at or near the centroid of research. If one of these is more qualified or willing than the others by virtue of facilities, staff, budgets, or affiliated capabilities to assume the function of processing mental retardation research literature in depth and providing a national access to that literature, it would be reasonable to assign that function to that institution on behalf of all other institutions. It is equally likely that the remaining 11 institutions might in some way participate in nationalizing their particular capabilities, thereby, making them national "centers" for other types of information.

The selection of one institution to act on behalf of all other institutions on a particular sub-set of an information system will be the prerogative of the President's Committee. It is assumed that the selection will be based on the extraordinary quality of that institution and its staff and not necessarily its physical facility or the location of that facility. No task for a communication cost trade-off (average line cost per unit inquiry) study is included in the master plan because the geographical location of that institution is not critical.

The overriding philosophy of design for the NMRIRC is the essential mission-oriented nature of mental retardation. It is an almost perfect antithesis of discipline orientation. No one subject field is dominant to the exclusion or subordination of another and no one profession is at the focus of all retardation activity. The field embraces, often successively the etiologist, epidemiologist, obstetrician, perinatalist, pediatrician, pediodontician, speech and hearing specialist, teacher, pychometrist, psychologist, neurologist, rehabilitation specialist, social worker, and a multitude of counselors and advisors. The unfortunate continuum through this trail of specialist and therapist is provided only by the retardate and the family.

It is doubtful whether an information system will ever be central to the purposes of mental retardation. The people who treat, serve, and counsel will probably always be the hub of activity in the field. What an information system can do is to provide the necessary continuum for researcher, teacher, parent, and retardate so that the retardate may obtain service easily, the trail of service is unbroken and lessons learned from past or parallel experiences can be passed on to the community as a whole.

This is the essential philosophy around which the master plan is developed. The plan is broader in scope than most plans for national information systems and yet it omits many of the traditional technical ingredients. In this regard it is more a master plan for information in MR service than an archival or formal information system.

3. Overall Criteria

There are five general criteria which apply to all tasks of the master plan.

a. Peer approval

b. Mission orientation

c. Phased implementation

d. Interdisciplinary participation and involvement

e. Design based on coordination and integration of existing resources

The purpose of these criteria are to define a practical perimeter for the design and operation of the NMRIRC. It is intended that these criteria will sufficiently restrict and focus the activities of the national center so that the information contained in it or accessed through it will serve a useful purpose at a reasonable cost and in a manner not otherwise available.

Peer approval is the outstanding ingredient for effective management and control of a national system. It consists of the deep involvement of the professionals in the field of mental retardation in the system that will collect, handle, and manipulate information for the ultimate benefit of the retardate. Other professionals will be available and willing to perform assigned tasks in the disciplines of computers, communications programming languages, and analytic techniques. Experience has taught the medical community that the hard sciences are not adaptable to the humane processes of personal dedication and service and that the scientist emphasizes statistical realization rather than personal accomplishment. It is the peer in the field of mental retardation, who must provide the review, direction, and assessment of value to the technologist in order to provide meaning to the system.

Mission-orientation, the second criterion, is the dedication of the system to a service role not focused on any one discipline or professional class of worker. It is the challenge

of why something is being done and for what purpose. If the intended purpose of a task is obscured by technological phenomena, alternate approaches must steer the effort toward a meaningful end.

The third criterion, phased implementation, means that the development of the national center will be gradual and accumulative. The earliest preliminary tasks will be designed in such a manner that the product of those tasks are immediately useful. It means doing things manually until enough data have been collected to warrant loading into a computer. It means establishing standards and protocols early in the effort to assure that data are compatible.

Participation and involvement are the criteria which will be applied to institutions and industries who have not been exposed to the personal character of the field of mental retardation. It means becoming involved in a task to be done because there are rewards other than profit for those who participate. It does not mean financial sacrifice because loss ventures hold low priorities. On the other hand it does not mean financial gain for profit alone. It does mean that a task should be central to the contracting organization while still being useful to the national center. It means amortization of development costs over two programs and the grievance that is bound to arise over this duality. An organization, while standing to lose nothing, in actuality stands to gain little by volunteering a task to dual usage.

Coordination and integration are the criteria mentioned in the ad hoc committee report. It means take advantage of what is currently available and what needs to be assembled into a coherent whole for the benefit of the total community. The elements of an information network - sources of information, service nodes, and various interfaces - exist in various forms and various locations. The information is not always compatible and easy means for extending the information from one source to a remote user are not always available. The information system would propose to establish a protocol for formalizing this information flow without sacrifice to the local recipient so that its benefit is extended to other persons without the resource

4. Schedules

The master plan is loosely scheduled over a three to five year period. With any fund raising (or joint participation) success at all the entire system can be in operation within two years. Parts of the system should be in operation within six months.

The reason for the omission of a stringent schedule is the unconventional method of financing proposed for the information center. Under normal circumstances legislative and fiscal authorities are known before any program is proposed. In this case only basic funds or seed monies are being solicited from the President's Committee. Operating funds will come from other sources. It is intended that subscriptions to directories, catalogs, and bibliographies will eventually defray some of the

costs of material distribution.

Certain tasks of the master plan are written in such a manner that information will be made available as it is being compiled. The tasks having to do with key personnel, MR facilities, and programs of interest to people in the field have already been formatted and names, places, and programs are being typed on cards which can be loaded into time-shared GE 265 and GE 635 computers by means of a portable teletypewriter. The danger of loading data into a computer early is the possibility that all data might have to be manually reloaded into a computer more efficient for the national center. The benefit is that data are available immediately and are not lost while waiting to be converted to machine format.

A master plan of this type will probably show a very slow rate of growth during the preliminary and formative phases because of its dependency on participation and involvement. There is reason to expect, however, that the rate of progress will increase rapidly as tasks are accepted and distribute to various participating institutions.

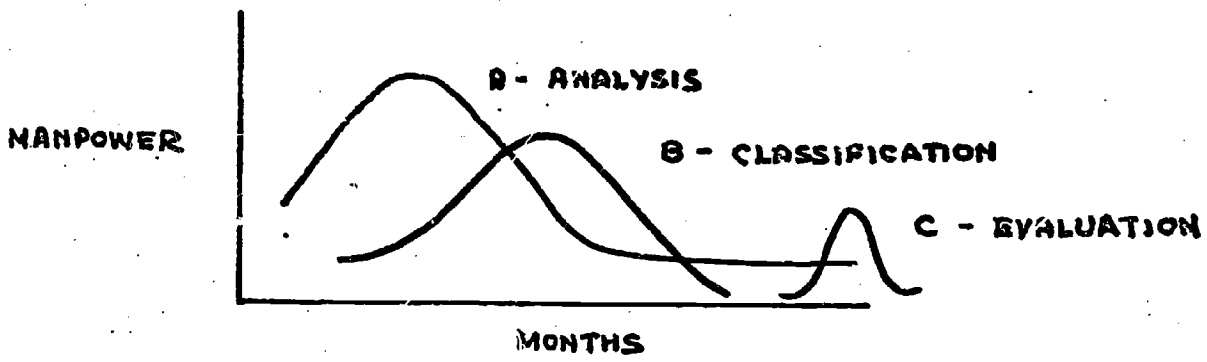
5. Staffing

A staffing estimate for the total plan has not been developed even though each written task statement contains an indication of the type of people required to do that job. Staffing estimates have not been compiled for the reason that many of the tasks will be performed by persons and institutions

who have not participated in the development of the plan. Actual staff assignments will be made by the person or organization performing the task and will be determined by local priorities, availabilities, and interests.

In each of the enclosed task statements there is a graph which indicates the type of manpower required for that task. Manpower is plotted as a function of time but there are no manpower numbers and no time marks.

The graph in Task No. 1 appears as follows:



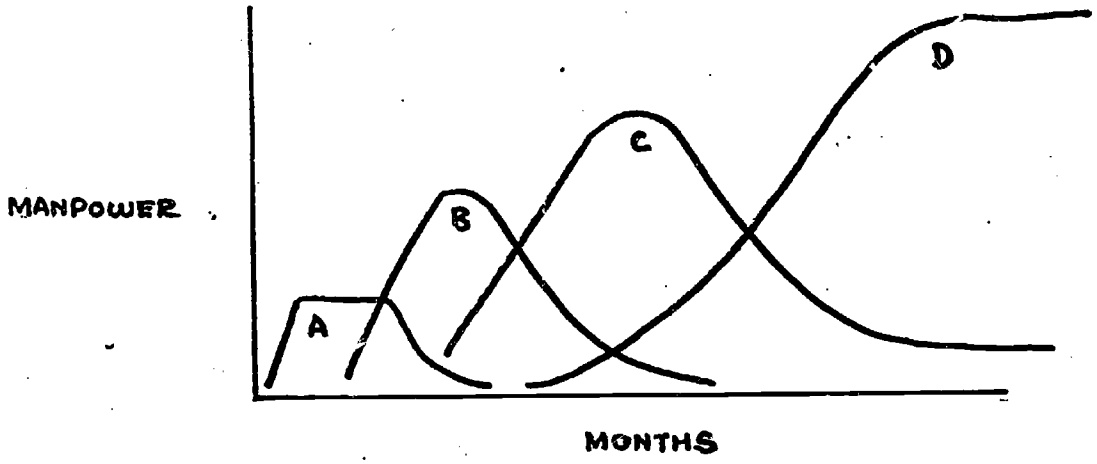
The graph tells the story that there are three specific sub elements of the terminology and classification task - analysis classification, and evaluation. The analysis sub-task, performed by specialists - physicians and educators - in mental retardation rises to a peak, diminishes, and then lingers at a constant, low level throughout the development effort. As the analytic work nears completion the task switches to the classificationist who

will catalog the terminology agreed upon by the team of specialists. The classificationist starts with the team of specialists as observer and then picks up as the analytic work is completed. During the period of observation the classificationinst lives with the essence of MR terminology while feeding in unalterable classification rules. The classification sub-task rises and declines. After a pause, while classification rules are being applied and tested an evaluation team moves in to verify the analysis and the classification scheme.

The graph describes the analytic sub-task as the major task, the classification sub-task as approximately half that of the analysis sub-task, and the evaluation sub-task as comparatively short and minor in terms of manpower.

For the most part the pattern of early and intense utilization of MR specialist manpower in the preliminary phases of the master plan holds true for all tasks. One intention of the master plan is to apply the experience and knowledge of specialists in mental retardation on critical tasks by drawing on their judgment and converting this judgment into a form communicable to the non-MR specialist. It is the intention of the plan to release the critical MR manpower as rapidly as possible to avoid burdening a field that is as manpower dependent as is the field of mental retardation.

In graphic form the shift of manpower on the master plan would appear as follows:



The "A" curve represents a brief but intense review of the entire master plan and all task statements. This is the initial peer evaluation suggested by Dr. D. Stedman. Six highly qualified specialists communicating with each other but isolated temporarily from daily administrative and project tasks will try to shape the master plan to account for as many of the nuances of the mental retardation field as possible. The revised master plan would then be the working document for the design and development of the national center.

The "B" curve represents the coordinating group who will be assigned the task of following up on task assignments and adjusting tasks for finish fit. The "B" team will be fitting, detailing, and looking for collateral funds for the national center. For example, one of the later tasks calls for the indexing of program summaries into machine searchable format Traditionally, this task is done by large teams of indexers. In this case, an attempt will be made to automatically index

program summaries with the help of a computer. The object of this effort will be to avoid the operational cost of support personnel.

Preliminary research on automatic indexing provides the confidence that this task can be done automatically. However, additional development funds might be required. In this case, the National Science Foundation will be asked to support this effort for the mutual benefit of both the NSF and the national center.

The "C" team is the MR specialist team. The team comes in early; their experiences are converted to specifications; they withdraw as the development work picks up; and they remain in small numbers throughout the life of the program to assure quality, consistency, and applicability to the purpose of MR.

The "D" team is the support team - computer designers, programmers, classificationists, communications engineers, reference specialists, systems designers, and operating personnel. The "D" team will be large in number but their MR decisional capability will be minimum. The object of this build up is to take advantage of personnel not currently associated with the field of MR.

6. Finances

Information systems - including libraries as well as computers - are expensive if for no other reason than information is acquired, cataloged, and otherwise handled in anticipation of use. In the traditional library it costs as

much to place a book on the shelf as it does to buy it. In the computer system the investment takes the form of fixed monthly machine costs and labor for organization and classification before data can be made available to the reading public.

The annual costs for a system as expansive as the NMRIRC might easily run over $1 to $2 million for the men and machines involved in center operations. Cost curbs will be effective only up to the point that there are diminishing returns to the users. In effect the national center will require a major investment even if attempts to minimize costs are successful.

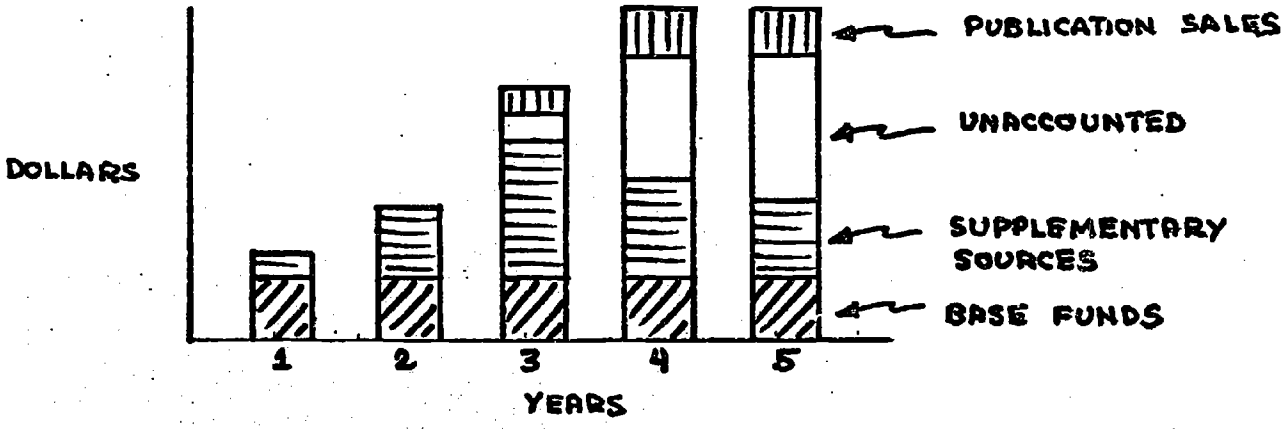
The investment can be amortized over a number of supporting agencies to reduce the cost to the MR community. Some of the 32 tasks listed in the master technical plan fall within the jurisdiction of agencies concerned with advances in certain subject fields. These agencies should be solicited for support.

The two most obvious sources for supplementary funds are discipline-oriented and support organizations. The National Science Foundation, Office of Science and Technology, Office of Naval Research, and Rome Air Development Center are examples of the former. The National Library of Medicine, National Medical Audiovisual Center, and various educational resources and materials organizations are examples of the latter. The obvious drawback to this venture for supplementary

funding is that these organizations tend to support advances in the state-of-the-art rather than applied efforts.

Sale of services to defray costs of operations are another possibility for financial support. The analysis and design phases of the master plan are clearly investment ventures and it is unlikely that any returns could be realized during this period from this source. When the system goes into operation, there is a possibility that the catalogs, compendia, and bibliographic listings could be offered to the public at base costs. It is unlikely that information searches for members of the immediate community could be or should be sold at any price.

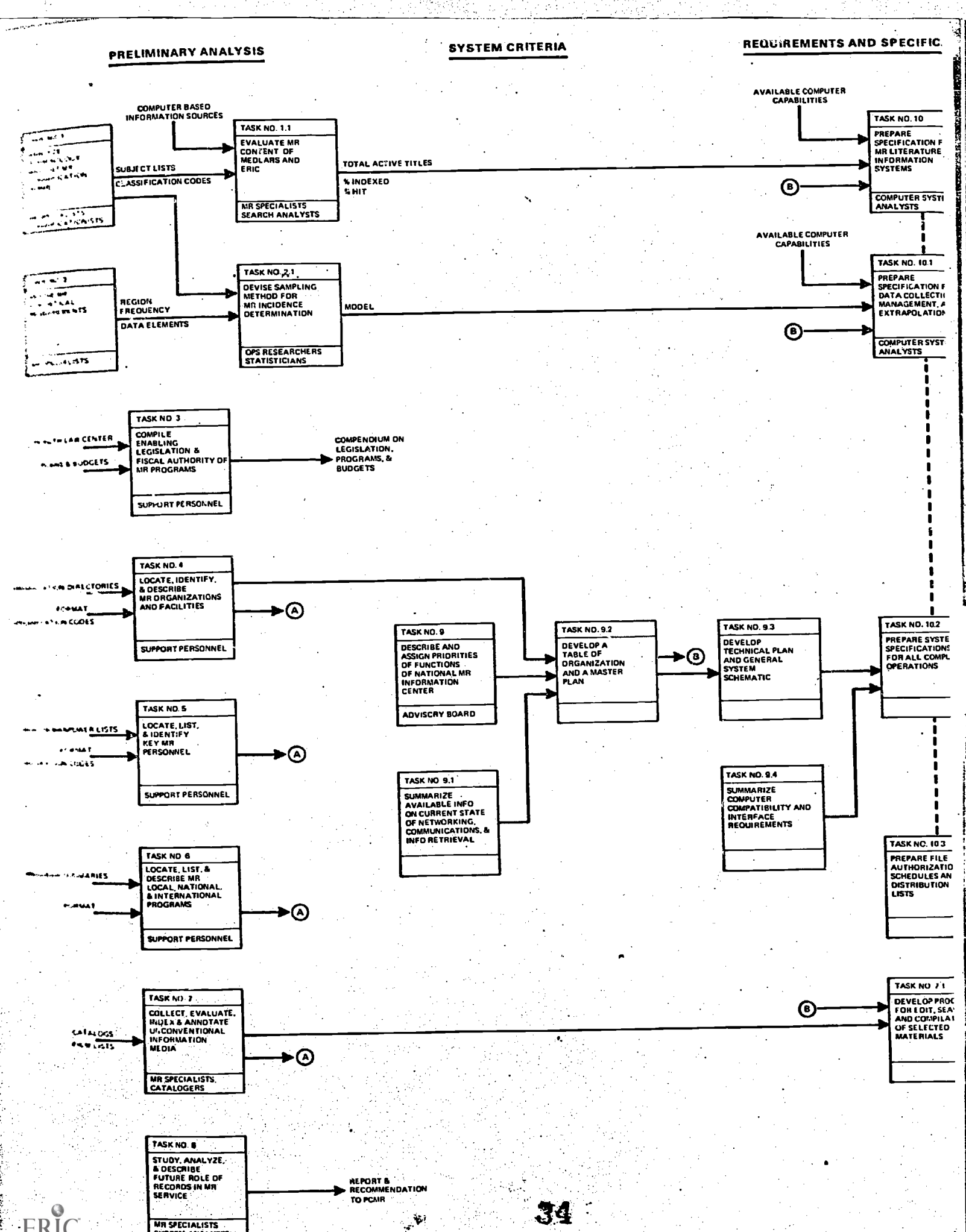
Various sources of support and how the level of support might change as a function of time is shown the following bar chart:

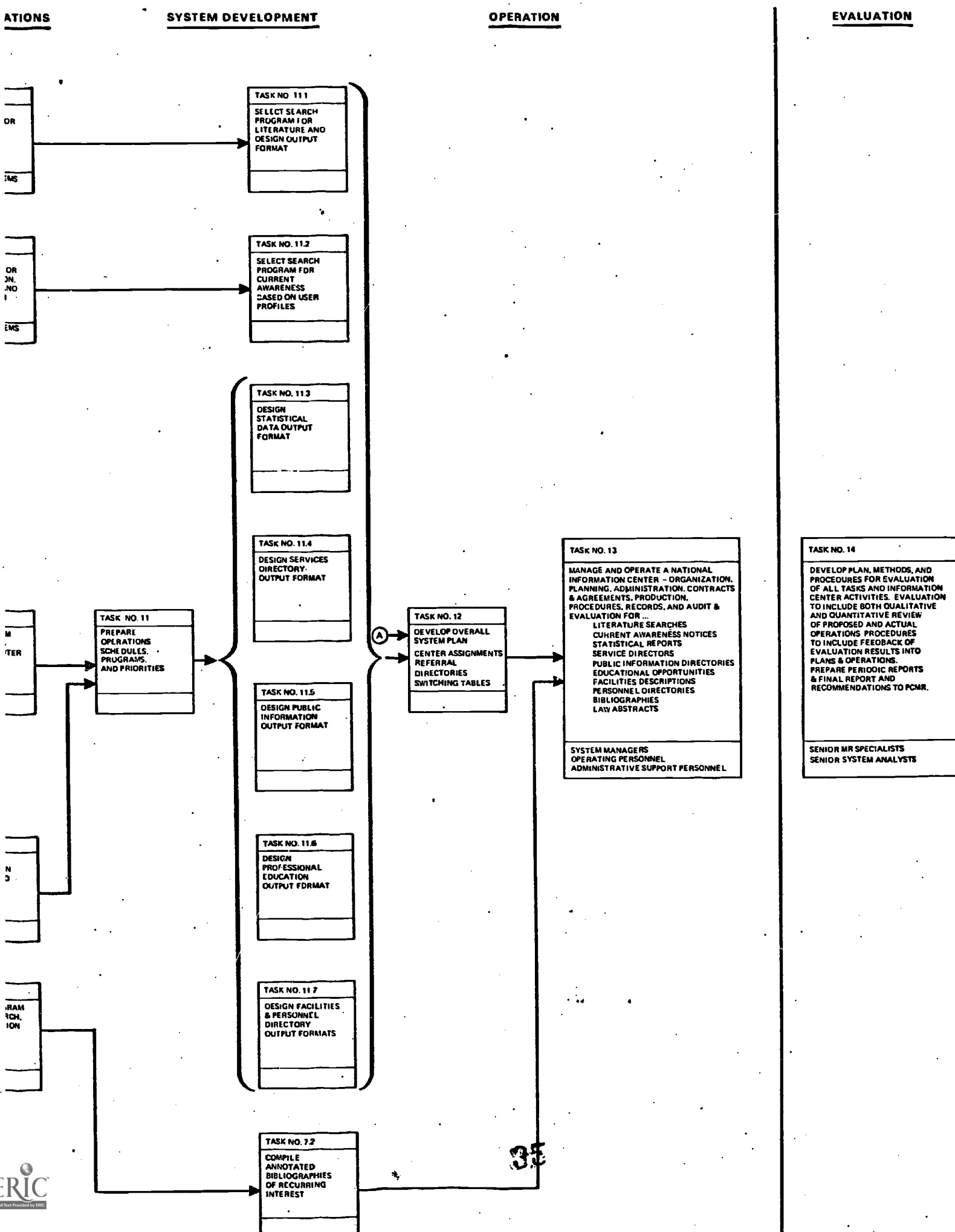


Base funds are those investments of the MR community. Supplementary sources are funds from other agencies. Publication sales are incomes from catalogs, compendia, etc. The unaccounted funds are the non-support monies which might have an operating investment of the MR community.

7. The Master Technical Plan

The foldout page is the master plan. The pages that follow are preliminary task descriptions. Those tasks on the master plan with staffing entries are enclosed as written tasks.


PRELIMINARY ANALYSIS
SYSTEM CRITERIA
REQUIREMENTS AND SPECIFIC
COMPUTER BASED INFORMATION SOURCES
SUBJECT LISTS
CLASSIFICATION CODES
TASK NO. 1.1
EVALUATE MR CONTENT OF MEDLARS AND ERIC
MR SPECIALISTS SEARCH ANALYSTS
TOTAL ACTIVE TITLES
% INDEXED
% HIT
AVAILABLE COMPUTER CAPABILITIES
TASK NO. 10
PREPARE SPECIFICATION F MR LITERATURE INFORMATION SYSTEMS
COMPUTER SYSTI ANALYSTS
B
REGION
FREQUENCY
DATA ELEMENTS
TASK NO. 2.1
DEVISE SAMPLING METHOD FOR MR INCIDENCE DETERMINATION
OPS RESEARCHERS STATISTICIANS
MODEL
AVAILABLE COMPUTER CAPABILITIES
TASK NO. 10.1
PREPARE SPECIFICATION F DATA COLLECTI MANAGEMENT, A EXTRAPOLATIO
COMPUTER SYST ANALYSTS
B
TASK NO 3
COMPILE ENABLING LEGISLATION & FISCAL AUTHORITY OF MR PROGRAMS
SUPPORT PERSONNEL
COMPENDIUM ON LEGISLATION, PROGRAMS, & BUDGETS
TASK NO. 4
LOCATE, IDENTIFY, & DESCRIBE MR ORGANIZATIONS AND FACILITIES
SUPPORT PERSONNEL
A
TASK NO. 9
DESCRIBE AND ASSIGN PRIORITIES OF FUNCTIONS OF NATIONAL MR INFORMATION CENTER
ADVISORY BOARD
TASK NO. 9.2
DEVELOP A TABLE OF ORGANIZATION AND A MASTER PLAN
B
TASK NO. 9.3
DEVELOP TECHNICAL PLAN AND GENERAL SYSTEM SCHEMATIC
TASK NO. 10.2
PREPARE SYSTE SPECIFICATIONS FOR ALL COMPL OPERATIONS
TASK NO. 5
LOCATE, LIST, & IDENTIFY KEY MR PERSONNEL
SUPPORT PERSONNEL
A
TASK NO 9.1
SUMMARIZE AVAILABLE INFO ON CURRENT STATE OF NETWORKING, COMMUNICATIONS, & INFO RETRIEVAL
TASK NO. 9.4
SUMMARIZE COMPUTER COMPATIBILITY AND INTERFACE REQUIREMENTS
TASK NO. 10.3
PREPARE FILE AUTHORIZATIO SCHEDULES AN DISTRIBUTION LISTS
TASK NO 6
LOCATE, LIST, & DESCRIBE MR LOCAL, NATIONAL, & INTERNATIONAL PROGRAMS
SUPPORT PERSONNEL
A
TASK NO. 7
COLLECT, EVALUATE, INDEX & ANNOTATE UNCONVENTIONAL INFORMATION MEDIA
MR SPECIALISTS, CATALOGERS
CATALOGS
A
B
TASK NO 7.1
DEVELOP PROC FOR EDIT, SEA AND COMPILA OF SELECTED MATERIALS
TASK NO. 8
STUDY, ANALYZE, & DESCRIBE FUTURE ROLE OF RECORDS IN MR SERVICE
MR SPECIALISTS SYSTEM ANALYSTS
REPORT & RECOMMENDATION TO PCMR


ATIONS
SYSTEM DEVELOPMENT
OPERATION
EVALUATION
TASK NO. 11.1
SELECT SEARCH PROGRAM FOR LITERATURE AND DESIGN OUTPUT FORMAT
TASK NO. 11.2
SELECT SEARCH PROGRAM FOR CURRENT AWARENESS BASED ON USER PROFILES
TASK NO. 11.3
DESIGN STATISTICAL DATA OUTPUT FORMAT
TASK NO. 11.4
DESIGN SERVICES DIRECTORY OUTPUT FORMAT
TASK NO. 11.5
DESIGN PUBLIC INFORMATION OUTPUT FORMAT
TASK NO. 11.6
DESIGN PROFESSIONAL EDUCATION OUTPUT FORMAT
TASK NO. 11.7
DESIGN FACILITIES & PERSONNEL DIRECTORY OUTPUT FORMATS
TASK NO. 11
PREPARE OPERATIONS SCHEDULES, PROGRAMS, AND PRIORITIES
TASK NO. 12
DEVELOP OVERALL SYSTEM PLAN
CENTER ASSIGNMENTS
REFERRAL DIRECTORIES
SWITCHING TABLES
A
TASK NO. 13
MANAGE AND OPERATE A NATIONAL INFORMATION CENTER - ORGANIZATION, PLANNING, ADMINISTRATION, CONTRACTS & AGREEMENTS, PRODUCTION, PROCEDURES, RECORDS, AND AUDIT & EVALUATION FOR ...
LITERATURE SEARCHES
CURRENT AWARENESS NOTICES
STATISTICAL REPORTS
SERVICE DIRECTORS
PUBLIC INFORMATION DIRECTORIES
EDUCATIONAL OPPORTUNITIES
FACILITIES DESCRIPTIONS
PERSONNEL DIRECTORIES
BIBLIOGRAPHIES
LAW ABSTRACTS
SYSTEM MANAGERS
OPERATING PERSONNEL
ADMINISTRATIVE SUPPORT PERSONNEL
TASK NO. 14
DEVELOP PLAN, METHODS, AND PROCEDURES FOR EVALUATION OF ALL TASKS AND INFORMATION CENTER ACTIVITIES. EVALUATION TO INCLUDE BOTH QUALITATIVE AND QUANTITATIVE REVIEW OF PROPOSED AND ACTUAL OPERATIONS PROCEDURES TO INCLUDE FEEDBACK OF EVALUATION RESULTS INTO PLANS & OPERATIONS. PREPARE PERIODIC REPORTS & FINAL REPORT AND RECOMMENDATIONS TO PCMR.
SENIOR MR SPECIALISTS
SENIOR SYSTEM ANALYSTS
TASK NO. 7.2
COMPILE ANNOTATED BIBLIOGRAPHIES OF RECURRING INTEREST

Task No. 1

Title: Information Terminology and Classification

Purpose and Objectives:

To devise and adopt an information classification system linking mental retardation terminology used in various disciplines; to extend the classification system to all information media; and to apply this classification system to the design and development of a computer based information system.

Preliminary Task Approach:

Analyze the subject organization of mental retardation as it is used in medicine, education, the social sciences and other fields to determine contextual variations of word use. Identify and define those words of particular interest to the field of mental retardation. Link these words with the subject headings of the various related disciplines. Identify gaps in terminology. Classify terminology in meaningful mental retardation groupings. Supplement the base classification system with additional terms and groupings to accommodate various media and the anticipated user population.

Background:

Classification systems of interest to this effort include those used by the American Association of Mental

Task No. 1 (Cont.):

Background:

Deficiency (Heber), the National Library of Medicine (MESH - Medical Subject Headings), Office of Education (ERIC - Clearinghouses on the Disadvantaged, Early Childhood Education, and Exceptional Children), World Health Organization, NICHD (Investigational Survey Format), and the Reiss-Davis Child Study Center (PSYCHES).

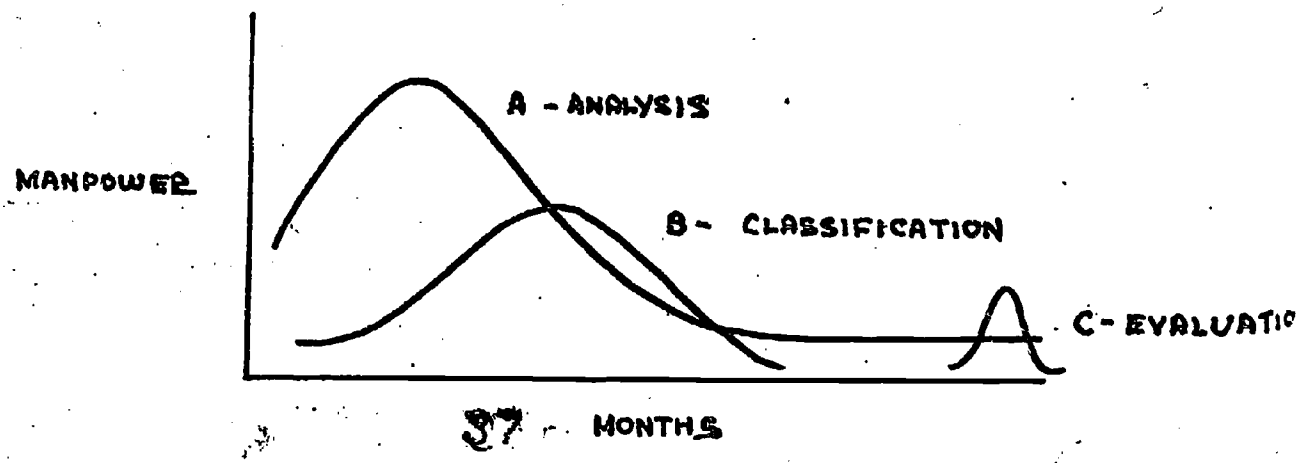
Priority and Relationship to Other Tasks:

Highest priority. Other tasks dependent on this task are data collection, statistics, and computer based information storage and retrieval.

Alternatives:

Establish discipline-oriented systems for medicine, education, social sciences, and voluntary service where each discipline handles requests. This alternative is contrary to the theme of focusing public attention on the problems of retardation.

Staffing:



Task No. 1 (Cont.):

Staffing:

A - Analysis. Medical doctor, educator, psychologist, psychometrist, and others who have devised and used MR subject structures.

B - Classification. Classificationists and information specialists who have devised library and computer subject classification lists.

C - Evaluation. Researchers, teachers, and social workers who are employed in MR.

Task No. 1.1

Title: MEDLARS/ERIC Evaluation

Purpose and Objectives:

To determine the effect of MEDLARS, ERIC and other information sources, and the services available through them, on an information system central to mental retardation; to determine the degree to which this information is applicable: to identify the retrieval "miss" conditions for MR that occur in these systems: and to identify additional actions required to make these systems fully supportive of MR.

Preliminary Task Approach:

Identify the position of the term "mental retardation" and other terms significant to MR in the classification word sets of pediatrics, neurology, pyschology, biology, education, welfare, psychiatry, occupational therapy, mental health and other directly and indirectly related disciplines. Examine the subject structure and classification organization of information systems with a recurring number of mental retardation related citations. Analyze the computer programs used in these systems. Estimate the existing file volume and potential monthly yield of MR citations. Compare the classification structures of these systems with the classification structure

Task No. 1.1 (Cont.):

Preliminary Task Approach:

for MR (Task No. 1) and determine the additional MR words needed to convert the file to MR purposes. Prepare a requirement for an MR information system based on available information supplemented with citations of particular interest to MR.

Background:

Index Medicus is a monthly and periodically accumulated indexed listing of citations from approximately 2,500 serials of a total of 18,000 serial title listings. Citations can be searched by MEDLARS using combinations of one or more 10,000 medical subject headings. MEDLARS and Index Medicus cover medicine and all related health fields. Three of the nineteen ERIC Clearinghouses abstract information of potential interest to MR. The three clearinghouses are on the Disadvantaged, Early Childhood Education, and Exceptional Children. ERIC abstracts are published monthly in "Research and Education". Search services are available through the various clearinghouses.

Priority and Relationship to Other Tasks:

Medium priority. Two to three month task. Will be used to define the capabilities of MR information system and

Task No. 1.1 (Cont.):

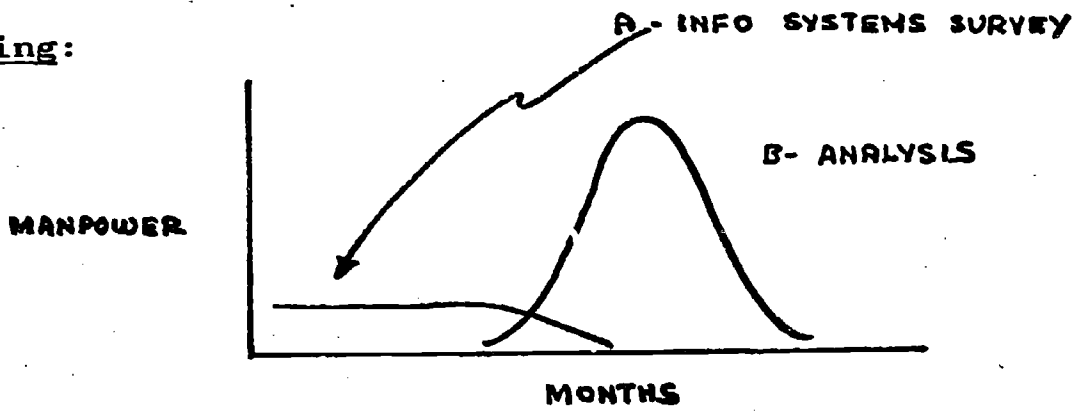
Priority and Relationship to Other Tasks:

the additional programs and information to make the file comprehensive in the subject of MR.

Alternatives:

Combine this task with the task for the MR information system specification and assign as a preliminary study of that task.

Staffing:



A - Information Systems Survey. Intermediate information specialist.

B - Analysis. Information systems specialists, search analysts.

k No. 2

le: Analysis of Statistics

pose and Objectives:

To focus the objectives of mental retardation programs on critical geographical areas, needy populations, and various areas of need based on incidences of mental retardation, incidences per unit population, rate increases, availability of services, or any deficiencies or anomalies in diagnostic and care services: to apply this data to the management of information systems: and to apply incidence statistics to the evaluation of information systems.

liminary Task Approach:

Analyze the availability, adequacy, and accuracy of statistics on mental retardation. This analysis will be conducted from the viewpoint of individuals and organizations concerned with problems of mental retardation including, but not limited to, the researcher - medical, educational, and allied professions - the administrator, the teacher, the social worker, the parent, the legislator, etc. Identify deficiencies and inadequacies of statistics both from the viewpoint of incidences and the medical-cumulative records normally used to record and register these incidences. Establish the requirements

Task No. 2 (Cont.):

Preliminary Task Approach:

of disease entities, physical stigmata, combinations of handicap, degree of handicap, environmental and ecological information, family data, diagnostic, test, and therapeutic data, and so forth which, if available, could focus the resources of research, service, and care on priority problems.

Background:

Sources of statistics include newborn records, pediatrics records, speech and hearing clinics records, disease indexes and registries, institution patient censuses, child study center records, cumulative records, nursery and day care center records, VR counselor records, and social service records. Census records are inadequate for this type of data.

Priority and Relationship to Other Tasks:

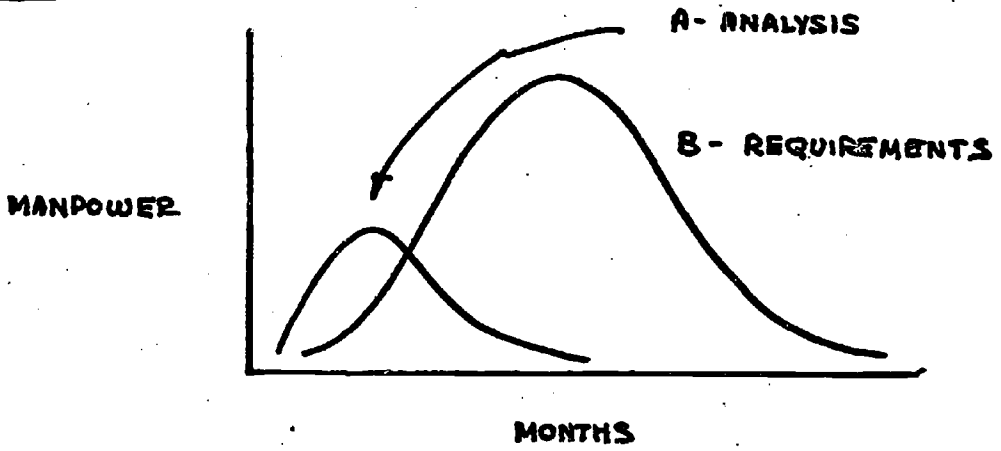
Highest priority. Distribution of information based on needs will be determined by population statistics and the workers employed to serve the handicapped. Statistics will determine network loading.

Task No. 2 (Cont.):

Alternatives:

MR incidences can be approximated by assuming even distribution of retardation according to the PCMR 3% of total population technique or Heber's one-standard-deviation method. Assuming that there is uniform distribution negates the possibility of geographical differences. Approximations are usually satisfactory only for broad administrative or legislative efforts to combat a problem.

Staffing:



A - Analysis. Same as team working on terminology and classification - MR specialists and professionals.

B - Requirements. Bio-statisticians, epidemiologists, MR researchers.

Task No. 2.1

Title: Statistics Sampling Method

Purpose and Objectives:

To devise a feasible method of statistical sampling capable of identifying significant MR events for the purpose of establishing service requirements and more closely linking cause and effect relationships: to identify significant indicators which will be sufficient to highlight potential problem areas in regions not observed in depth; and to devise a method of extrapolating data for national indications of MR events.

Preliminary Task Approach:

Devise a method of statistically sampling MR incidences and the services and care applied to these incidences. The sampling technique will be continuous and the data will be periodically compiled, correlated, and extrapolated for national indications. The primary thrust of the effort shall be to identify incidences of retardation and the effect of diagnostic, educational, and habilitative services. The technique shall consider the implications of geography, metropolitan, urban, and rural living, differences in socio-economic cultures, ages of retardates, the time and conditions of first entry of a retardate to diagnosis, the continuity of diagnosis and education/habilitation and the causes of discontinuities between

Task No. 2.1 (Cont.):

Preliminary Task Approach:

them, the cultural and nutritional effects of welfare aided and non-aided families, the availability and use of medical and MR professional vs. other diagnoses, the effect of programs and institutions on effective diagnosis and care, and the effects of perinatal or obstetric scrutiny on diagnosis and care.

Background:

Parental reluctance to acknowledge and accept retardation makes it difficult to apply standard registry techniques to MR. Data are recorded but the adequacy and accuracy of these data for MR are to be determined. Post diagnosis data are available to a limited degree. Health sampling techniques have been devised but few have been widely accepted due to the wide variety of disease manifestations in individuals. The difficulty of measuring retardation further complicates the problem.

Priority and Relationship to Other Tasks:

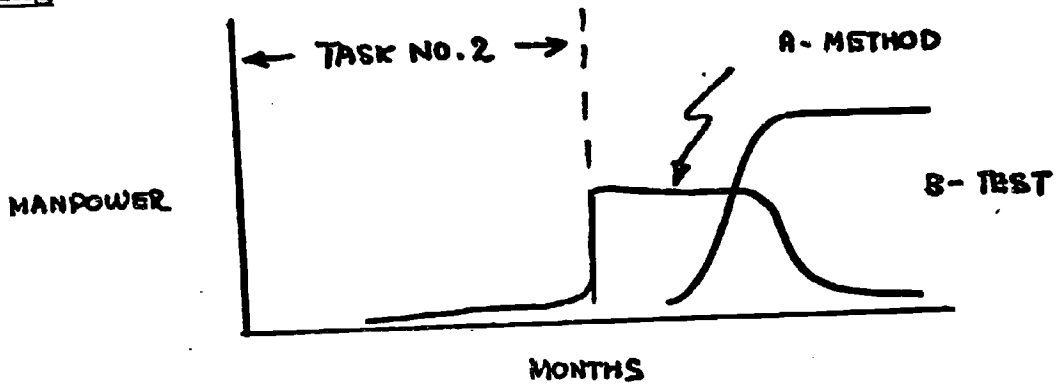
Medium priority. Must precede specification for computer maintenance of event records. Should be tested and evaluated prior to large scale collection of data.

Task No. 2.1 (Cont.):

Alternatives:

MR "registries" can be a function of the National Center for Health Statistics. The statistical method might be undertaken by the Health Statistics Center. The PCMR will be obliged to specify the criteria for the method to be devised.

Staffing:



A - Method. Statisticians, operations research analysts.

B - Test. Support personnel

Task No. 3

Title: Legislation and Fiscal Authority

Purpose and Objectives:

To locate and identify federal, state, and local mental retardation programs; and to identify legal barriers or fiscal inadequacies in areas of care or service to the mentally retarded.

Preliminary Task Approach:

Search the files of the Health Law Center for applicable appellate cases on welfare and uses of welfare monies. Collect federal and state legislative acts on mental retardation and related acts. Collect budget figures on federal and local investments in MR. Compile and collate these data and the sources of these data for the files of the MR information system. Identify persons or institutions in whom authority is vested.

Background:

Legislation and fiscal authority which might have an affect on the services provided to the retardate are state acts, state budgets, county rulings, decisions of educational boards, and other local rulings. Examples: admissibility of retardates into state institutions, legal age limit of youth in primary schools, services to multiple handicapped.

Task No. 3 (Cont.):

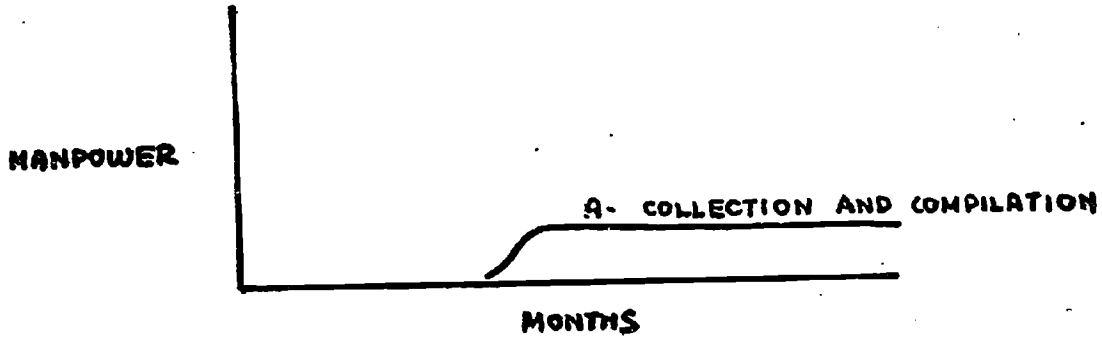
Priority and Relationship to Other Tasks:

Low priority from the viewpoint of information systems design. Medium priority from the viewpoint of viable operation of an information system in MR. Independent of other tasks.

Alternatives:

Encourage the Pittsburgh Health Law Center to collect and file background data over and above appellate rulings.

Staffing:



A - Collection and Compilation. Administrative staff personnel acquainted with MR

Task No. 4

Title: Organizations and Facilities

Purpose and Objectives:

To identify the organizations and key organizational components directly and indirectly involved in solving or serving problems of mental retardation: to identify organizational functions: and to determine the extent of the organizations' facilities and capabilities in this field.

Preliminary Task Approach:

Identify, list, and classify the organizations and organizational components involved in MR activities. Establish a format for a computer compatible listing. Establish a set of classification codes identifying the organizations and the functions performed by each. The types of organizations and some examples of each are as follows:

Type	Examples
Federal	NICHD, SRS Childrens' Bureau, NIMH, OE, OEO, Dept. of Labor, Vocational Rehabilitation
State	Public Health Services, Welfare, State Educational Boards, Depts of Vocational Rehabilitation
City, County	Boards of Education. Special Education Boards, County Workshops, Institutions

Task No. 4 (Cont.):

Preliminary Task Approach:

Type	Examples
Non-profit	WICHE, NEA, WHO, AAMD, IAMH
Foundations	Kennedy Foundation, Macey Jr. Foundation, Rosenberg, Eli Lilly, Ford, Kellogg, Commonwealth Fund
Voluntary	NARC, local ARC's
Others	Smith, Kline and French

Background:

The number of federal agencies involved in funding MR related programs has been reduced significantly in recent years. The major organizational components of the U.S. Government are easily identified, however, there are many agencies such as the Department of Labor which are indirectly involved in MR. The latter includes those agencies whose programs focus on other problems which spill over into MR related fields. Partnership for Health is one such program. Voluntary agencies and foundations whose investments are smaller compared to those of the federal government are significant to MR in that they are able to support innovative and sometimes far reaching programs which exceed the legislative authority of those agencies committed to the MR problem but sometimes hampered by the lack of ability to speculate on

Task No. 4 (Cont.):

Background:

potentially large returns for minor investments. These organizations with cadres of volunteers are sometimes able to commit manpower to individual problems which larger organizations cannot.

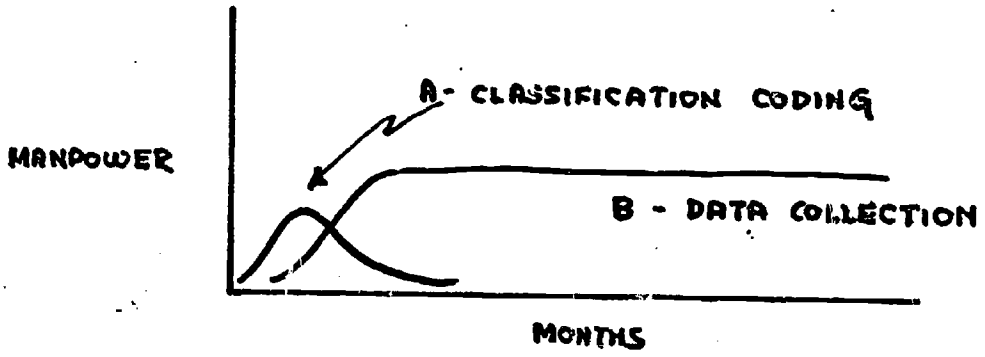
Priority and Relationship to Other Tasks:

Medium priority. Continuing effort. Organizational entries periodically loaded into the information system. A directory of MR organizations depends upon this input. An automatic call switching system, if such a function is to be adopted, will be highly dependent on this task.

Alternatives:

Collect mailing lists and organization tables. This would be adequate for general estimates of current activity but would not be accurate enough for consumer use.

Staffing:



A - Classification Coding. Information specialist

B - Data Collection. Support personnel

Task No. 5

Title: Key Personnel

Purpose and Objectives:

To identify key personnel directly and indirectly involved in solving and serving problems of mental retardation; to identify their fields of work and expertise; and to list their current and applicable past works in fields related to MR.

Preliminary Task Approach:

Identify, locate, and list the key individuals involved in MR research, education, administration, and service. Organizational tables will be a primary, but not exclusive, input. Researcher-to-researcher linkage via citations in the published literature will be used. Data on the individual will include organizational title, academic titles, organization, location, classification code of expertise, and references to past works and programs.

Background:

Key personnel can be identified in the fields of medicine, chemistry, biochemistry, physiology, human health, human development, speech, education, habilitation, and the supporting disciplines. These individuals are employed in MR research centers and residential facilities,

Task No. 5 (Cont.):

Background:

school systems not exclusively concerned with problems of retardation,, and organizations not involved in mental retardation.

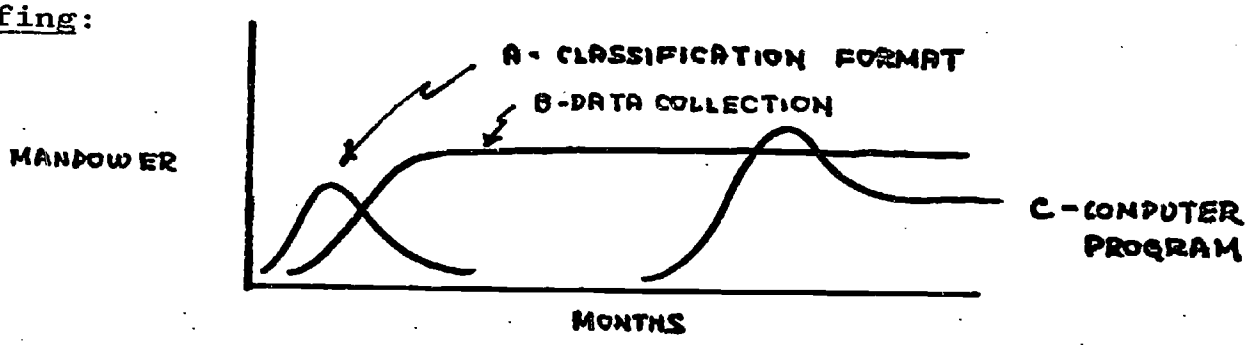
Priority and Relationship to Other Tasks:

Low priority. Continuing effort. This can be a by-product of an information storage and retrieval system which handles literature citations.

Alternatives:

Refer the user to the organization most likely to employ the person in question. Place a higher reliance on the organization to follow up on the requester's inquiry.

Staffing:



A - Classification Format. Information specialists

B - Data Collection. Support personnel

C - Computer Program for Researcher-to-Researcher link. Computer information specialist.

Task No. 6

Title: MR Projects and Programs

Purpose and Objectives:

To locate projects and programs directly or indirectly related to research in or service to the field of mental retardation; to highlight innovative programs; to identify significant and meaningful research and demonstration programs; and to make this information available to persons and organizations.

Preliminary Task Approach:

Identify, locate, and list local, national, and international projects and programs and the information and services available from them. Extract or prepare abstracts on the duration, objectives, and content of programs. Data on projects and programs will include program titles, source of funding, level of support, duration, content description, references, and other identifying data.

Background:

The PHS publishes lists of grants and awards annually for the fiscal year prior to the current calendar year. Data include title, project number, award recipient, and grant number. The NARC lists grants awarded by them in their

Task No. 6 (Cont.):

Background:

annual report. Other annual reports are indicators of project activity although the listings are insufficient for entry into a data file. Special listings, such as the programs supported by the Vocational Rehabilitation Administration, are also sources of data for this listing.

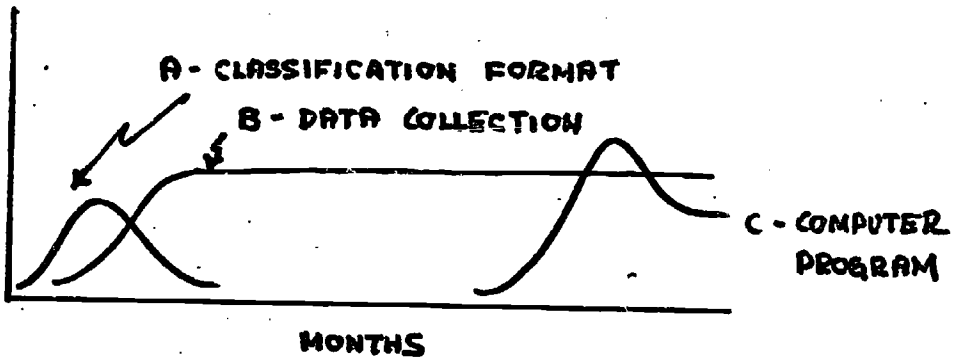
Priority and Relationship to Other Tasks:

Low priority. Continuing effort. Necessary if the data bank of an MR information system is to contain information on on-going programs.

Alternatives:

Refer the requesting individual to local project listings.

Staffing:



A - Classification Format. Information specialists.

B - Data Collection. Support personnel.

C - Computer Program. Computer information specialists.

Task No. 7

Title: Other Information Media

Purpose and Objectives:

To extend the utility of audio and audiovisual materials covering subjects of interest to the field of mental retardation to professionals and workers in MR and to others concerned with problems in MR; and to locate possible production sources for professional and public information materials in MR.

Preliminary Task Approach:

Locate, identify, classify, and index audio and audiovisual materials in subjects directly or indirectly related to problems of mental retardation. Establish a method of reviewing and evaluating these products. Format the descriptions of the material for a computer data bank. Prepare the requirements for a computer program to print a directory and to allow specific subject searches for various media.

Background:

The Mental Retardation Film List (undated) prepared by the National Medical Audiovisual Center, Atlanta, for the Social and Rehabilitation Service lists 151 titles for the use of professionals and nonprofessionals

Task No. 7 (Cont.):

Background:

concerned with problems of mental retardation. No single producer made a majority of these films. MEDCOM, a proprietary firm in NYC, is planning to produce a monthly videotape medical journal for pediatricians. RCA is now producing a monthly audiotape journal for the American Medical Association. Approximately 3/4ths of the medical schools in the U.S. are producing visualizations for the continuing education of physicians and allied professionals.

Priority and Relationship to Other Tasks:

Medium priority. Indexing and classifying audio and audiovisual materials is an expensive and tedious process. Generally unrelated to other information systems tasks.

Alternatives:

Only list producers and distributors of audio and audiovisual materials for the purpose of encouraging these producers to supply professional and public information on mental retardation. Do not classify and index titles.