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FACILITIES FOR THE DEVELOPMENTALLY DISABLED

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DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
SOCIAL AND REHABILITATION SERVICE
REHABILITATION SERVICES ADMINISTRATION

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INDIVIDUALIZED DATA BASE FOR DEVELOPMENTAL DISABILITIES

Grantee: UCLA

Grant Number: 54-P-71020/9

Project Title: "Individualized Data Base for Developmental Disabilities"

Project Direction: Richard Eyman, Ph.D., Principal Investigator
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Project Site: Pacific State Hospital, Pomona, California

UCLA Neuropsychiatric Institute Research Group

Project Period: September 1, 1972 - August 31, 1975

Project Amount: \$515,542

Grant Period: September 1, 1973 - August 31, 1974

Grant Amount: \$173,731

Descriptive Background Information: The purpose of the project is to establish a model individualized data system for tracking development ally disabled individuals from a variety of states through, a continuum of services. An evaluation will be made of the type and range of services including living arrangements used in terms of subsequent changes in the status of the developmentally disabled. Also, an analysis will be made of the relative cost for services received which will be related to developmental outcome.

The project entails identifying the developmentally disabled receiving services in participating states; establishing a tracking system, utilizing standard forms; assessing individual progress through a continuum of services, i.e., longitudinal evaluation of client progress; evaluating services and living arrangement in 'relationship to individual outcome; and conducting cost effectiveness and cost-benefit analyses. A computer will be utilized to process data.

Current Status: A three day multi-state Individualized Data Base (IDB) •for the Developmentally Disabled Conference was held on February 20, 21, 22, 1974. There were some 92 participants with representatives from many different states across the country. This was the second working conference held by the IDB staff in order to bring state and project staff together • to communicate on successes and problems relating to design and implementation. Two concurrent workshops were conducted, one relating to design and the other to extension. Technical and management personnel attended appropriate workshops. In general sessions, the various participating states reported on the status of the data system in their respective states. In the final general session, the results and recommendations of the two workshop groups were presented for a give and take session. (A Conference Report is being prepared which will give details as to the participants and the content of this Conference.)

Current Status (continued):

INDIVIDUALIZED -DATA BASE
PROGRESS REPORT NO. 5
DECEMBER 1, 1973

In accordance with the objectives of the grant, year two of the Individualized Data Base project will focus on maintaining the data base in an effort to maximize utilization of the data collected by agencies included in the project. In compliance with past tradition, it also seems feasible to divide the following report into three sections—collection effort, reporting effort and future directions—which are reflective of new avenues when the project is currently exploring. Each section has its own focus, but the combination of the three demonstrates the broad scope of our recent activities.

I. Current Status of the Collection Effort

All geographical areas presently participating in the project, as well as those areas still considering participation, are discussed below in order of their respective status within the collection effort. Table 1 summarizes the project effort to date.

California

1. Inland Counties Regional Center: This regional center has completed data collection and conversion for 1500 clients and is expected to complete conversion on the remaining 2,000 clients by the beginning of 1974.

2. Orange County Regional Center: Orange County initiated data collection, in September, and is currently collecting data at one of four sub-offices. The remaining three offices are expected to initiate collection procedures by January 15, 1974. It is expected that this regional center will complete data collection for 2,000 - 4,000 clients by March 1974.

3. South Central Regional Center: This is a newly formed regional center. Due to staff recruitment problems this center has not yet started operating. They have just recently completed recruitment and are expected to start operation by the end of November. Data collection will commence then also. Data collection and conversion, for the approximately 1,200 - 2,000 clients, within the South Central L.A. area, is projected for April 1, 1974.

4. Harbor Regional Center: Another newly formed regional center, this agency has also experienced minor staffing problems. This center is expected to become operational by years end and has indicated a desire to begin data collection at that time, for their 1,000 - 2,000 client initial caseload.

5. Fresno Regional Center: The concept of "regionalization" was adopted early by Fresno and the surrounding areas. This regional center is well established, having been in operation for four years. Just recently responsible persons from the Fresno Regional Center contacted the project concerning possible inclusion in the data base. Project staff visited Fresno in November and presented the project to the regional center. They expressed great interest in the data base and agreed to make a decision regarding commitment by years end. Currently, Fresno Regional Center has a caseload of approximately 3,000 clients.

6. Sacramento Regional Center: This regional center, though keenly interested in the project, has had considerable internal problems and, as a result, has indicated they will not be prepared to initiate data collection until well into the new year.

Colorado: All institutions and community centers have completed conversion of the states 5,000 current clients to the system. We are currently involved with supplying reports and replying to requests based on their data base.

Montana: Montana has completed data collection and conversion for the 1,200 cases known to the institutions community and department of vocational rehabilitation. Requests and reports are now being processed for Montana's data base.

Nevada: Nevada has completed collections and conversion for 300 of its 600 clients. Collection and conversion is expected to be completed January 1, 1974.

Virginia: Virginia has begun data collection, and is expected to complete conversion for 5,000 of the states 9,000 clients by the end of December. The remaining 4,000 community clients will be added to the system during the first quarter of 1974.

Oregon: Due to some procedural difficulties they have incurred, Oregon has not yet implemented the modified data system described in our last report. It is expected that they will begin incorporating the modified system during the first part of the new year.

Arizona: Arizona has still not been implemented into the data base, due to their current service structure, which does not coordinate hospital and community services. Project personnel periodically monitor this states progress as related to their effort to coordinate the service structure within the state.

Washington: This state is still having some internal difficulties due to some major organizational and personnel changes. Representatives of the state met with project personnel in November, and demonstrated continued interest in the project on behalf of the state of Washington at that time.

South Dakota: South Dakota recently contacted us and expressed interest in being included in the project. Project staff visited the state in October. As a result of that meeting, South Dakota is now included in the project. Representatives from the Department of Mental Health of South Dakota will visit us early in January to confirm a starting date.

Illinois: This state is still working toward maintaining, with our assistance, their own data base. We anticipate a computer interface--based on their data--to be available early in 1974.

II. Current Status of Data Reporting Effort

A significant milestone which occurred during this quarter was the acquisition and installation of our computer. The entire computing system was installed in our facility in September. Since then the data reporting effort has taken an upward swing as we have been better able to process and respond to user requests for data reports, as well as, generate reports of our own conception. This occurrence has added considerable enthusiasm among the user's, as it has afforded them the opportunity of actually experiencing--through reports and request--benefits of the data base.

As mentioned in previous reports, a major effort of the project during the first year was the development of computer programs to coordinate and analyze the data. A significant task during this first quarter of our second project year has been the utilization of these reports for the purpose of supplying our reporting agencies with current, frequent, and viable reports. Table 2 is a list of the regular monthly reports being provided to affiliate state and local agencies. In addition to the above, project staff respond to approximately 20 special requests each month for data retrieval or manipulation from the various affiliated agencies. As we are

quickly approaching the point where we will have two data measures on all subjects, we are currently preparing a number of special reports that will exhibit and analyze developmental aspects of the data. Figure 1 is an example of one such report. This report depicts developmental progress (or regression) made in an individual's Adaptive Behavior for a 2, 3, 4, or 5 year period. In this case two measures are shown.

Another major effort which began this quarter is the preparation of a training manual to assist the various agencies in interpreting the numerous and various computerized reports. Our feeling here is that the better understanding our users have of the data base, and subsequently the reportings being provided from it, the more capable they will become at utilizing it to its fullest potential.

III. Other Directions

A. Education. During the months of September and October meetings were held with the following consultants: Martha Smith of the El Camino School for the Educationally Handicapped; Martha Leedy of the Los Angeles District Special Education Office; Barbara Keough of the U.C.L.A. School of Education; and Marilyn Parsley of the University of Denver. As a result of these meetings a model system was developed which was adopted from, and closely resembles the model used for the current data base. The educational model is designed specifically for EMR, TMR, and L.D. clients in the public school systems. Preliminary data collection forms have been constructed and are now being evaluated by the above named consultants. Project staff expect to initiate a preliminary testing of the system in sample school districts during the next quarter.

B. Cost Accounting. In order to further assess the current state of the art in relation to cost accounting, meetings were held during September and October with Tom Frazier, an originator of the "Jenkins" cost accounting

system; Delbert Messner of the American Hospital Association; Bob Edwards, Director of Inland Counties Regional Center; and Bob Stephens of Colorado. As a result of these meetings, it became apparent to project staff that considerably more research must be done prior to initiating a cost accounting system into our data base. As a first step, project staff plan to field test a small scale "model system" at the Inland County Regional Center during the first part of the new year- ,.

Table I
Data Effort Summary

REGION	COLLECTION COMPLETED	COLLECTION IN PROGRESS	CONVERSION COMPLETED	CONVERSION IN PROGRESS	REPORTING IN PROGRESS	UNDER DISCUSSIO
Calif., Inland Counties		X		X	X	
Calif., Fresno						X
Calif., Sacramento						X
Calif., Orange County		X				
Calif., South Central						X
Calif., Harbor						X
Colorado	X		X		X	
Montana	X		X		X	
Oregon				X		
Arizona						X
Ohio						X
Nevada		X		X	X	
Washington						X
Hawaii						X
Virginia		X				
Illinois				X		
Florida						X
Connecticut						X
South Dakota						X

TABLE II

MONTHLY COMPUTER REPORTS

Resident Roster by Case Number

Resident Roster *by* Cottage

Case Control Totals

Caseload Listing by Case Number

Caseload Listing by Case Number within Location

Caseload Listing by Case Number within Service Code

Caseload Listing by Service code within Location Code

Caseload Listing by Location code within Living Plan

Caseload Listing by Case Number within Living Plan

Resident Roster of selected birthmonth by Case Number within Cottage

Resident Roster of Birthdate sorted in descending order

Listing of Residents needing Adaptive Behavior Test by Case Number

Listing of Residents needing Adaptive Behavior Test by Location within Living Plan

Adaptive Behavior Profiles (Individual)

Activities Planned for Next Four Months: The staff of the individualized data base project will be continuing in their efforts to develop and test the model data system in various states and provide consultation to states interested in considering such a system. A special analysis will be made of the transactions that have taken place at the recent February 20-22, 1974 DD data base conference, reviewing for new information and identifying the problems in setting up and operating a data system. Preparation of the DD IDB Conference Report will be made and distributed, including members of the National Advisory Council for Developmental Disabilities. Serious consideration is being given to prepare an application for a supplementary grant to help resolve the problem presented in collecting valid and reliable data *by* training of local personnel who are involved in the initial steps of data collection. This seems to be a special problem in the state of Colorado) one of the states which is furthest along in development of a data system. In addition, contact is being made relating to cost accounting systems.

Addendum: A periodical survey of states for data systems is needed.

The AAMD Data Bank Committee did conduct a survey of states to identify data systems a couple of years ago. (Dr. Richard Eyman is the Chairman of the AAMD Data Bank Committee, *as well as* being the Principal Investigator on the DD Data Base Project.) Recently, as suggested by the Director* Division of Developmental Disabilities* a survey of existing state client progress systems was conducted through the DD regional office staff. The results were presented to the DD data base project staff. A review will be conducted by the project staff. (Unfortunately, it appears that the Nebraska Client Progress System may be inoperative as originally conceived. An analysis and evaluation needs to be made on the NCPS to better understand the problems met by that system.) It should be noted that an application for project grant to conduct a detailed survey of developing and operating data systems was submitted in the Summer of 1973 by Dr. James Budde, University of Kansas, in collaboration with Dr. Richard Eyman. This application for a small grant was not funded.

Project Officer's Comments:

The project is being conducted in an excellent manner. The project staff and consultants represent competent specialists in their field, measurement statistics* epidemiology, system analysis* as well as medicine, psychology, and other service-oriented professionals. Project progress has been quite satisfactory considering the necessity to obtain state and local approval and cooperation to set-up the data project* and operating a coordinated system once it has been established* besides the designing, testing, and modifying of a state system. One of the problems which has arisen is the need to support and demonstrate the training of local personnel in the on-going collection of data to ensure valid and reliable data for the system. Colorado is well on its way toward an operating system but is in need of some assistance in the preceding area. *The* project's resources are too limited to provide assistance in this area.