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Descriptors-Behavior, *Census Figures, Cooperative Programs, Data Collection, Educational Experience, Etiology, *Exceptional Child Research, Family Characteristics, Family Relationship, Individual Characteristics, *Institutionalized (Persons), Intelligence, *Mentally Handicapped, Mongolism, Research Utilization, Self Care Skills, Sex Differences, Statistical Data

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For 3 years, from 1966-68, data were collected representing the behavioral, social, and medical characteristics of over 20,000 retardates, the resident population of 22 state institutions for the mentally retarded in 13 western states. The data were returned to the institutions where they stimulated research, program development, evaluation, and inter- and intrainstitutional cooperation. Research uses and administrative uses of the data are discussed and illustrated by studies comparing phenylketonurics and mongoloid retardates with matched retarded controls, studies presenting characteristics for subgroups of mongoloids, and others. Twelve graphs and 40 tables present descriptive data and statistical analyses. (LE)



A Comprehensive Description of Institutionalized Retardates in the Western United States

WESTERN INTERSTATE COMMISSION FOR HIGHER EDUCATION

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE OFFICE OF EDUCATION

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A COMPREHENSIVE DESCRIPTION OF INSTITUTIONALIZED RETARDATES

IN THE WESTERN UNITED STATES

Dan Payne, Ronald C. Johnson, and Robert B. Abelson

A final report of progress on a program of regional cooperation in mental retardation research in institutions in the western United States. This program was sponsored by the National Institute of Child Health and Human Development under Contract Number PH 43-65-989.

Western Interstate Commission for Higher Education University East Campus, 30th Street Boulder, Colorado 80302

February, 1969



FOREWORD

The program described in this report has had considerable impact on the participating institutions. Past experience at the Western Interstate Commission for Higher Education (WICHE) indicates that the major impact and influence of this program is yet to be felt; there is always a substantial delay before the actual benefits of a regional program are realized.

The program would never have come about but for the vision and trust of the National Institute of Child Health and Human Development; Theodore D. Tjossem, Ph.D., Director, Mental Retardation Program, served as project officer for the program. The successes attributed to the program are due to the unprecedented cooperation of the administrators of all 22 participating institutions, and literally hundreds of their staff. Without their cooperation, no data could have been collected and there would have been no program.

The Research Advisory Committee is due special acknowledgement for their patient and untiring efforts to lend guidance to the program staff. In addition, Richard K. Eyman, Ph.D., Director, Socio-Behavioral Laboratory, Pacific State Hospital, and many of his staff are due special thanks for their generous assistance and spirit of cooperation.



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INTRODUCTION

For the three-year period 1966-68, the Western Interstate Commission for Higher Education (WICHE) collected data on the resident population of 22 state institutions for the mentally retarded throughout the 13 western states. These data represented the behavioral, social and medical characteristics of over 20,000 individual retardates. The institutions participated voluntarily. The data collected were identical at all institutions. The data for each institution was made available to all other institutions. The data stimulated research, program development and evaluation, and both inter- and intra-institutional cooperation. This level of achievement was due to the collective efforts of all the individuals and institutions involved. There was, however, a rich history of events which provided a solid foundation on which to build.

Background

In 1958, Pacific State Hospital at Pomona, California, initiated an effort to obtain a description of its residential population which would be useful in carrying out its treatment and rehabilitation function. This work was carried out under the direction of Dr. Harvey F. Dingman, psychologist and director of Pacific State Hospital's Socio-Behavioral Research Laboratory. The primary objective was to obtain data which would go far beyond the "cost per patient per day" description which had been adequate for custodial orientation (O'Connor & Hunter, 1965).

Pacific State Hospital's effort culminated in the creation of a "Population Census Form." This form had the virtues of collecting information which was useful to all departments of the institution and which could be completed quickly and reliably by staff at the ward level. Utility of these data were demonstrated in part by the fact that they stimulated or were referred to in a large number of papers covering a wide range of topics published by the staff at Pacific State.

Since usefulness of the data collection instruments and procedures had been demonstrated in one institution, it seemed likely that they would be equally useful in other institutions in the WICHE region. Dr. George Tarjan, then superintendent of Pacific State Hospital, agreed to provide the instruments and also offered to make his data processing facilities available.



With WICHE coordinating the activity, nine western institutions participated in a pilot joint data collection activity in the fall of 1963. Although there were numerous problems, the pilot effort was a success. The following year, 13 institutions joined the pilot project. The product of this joint effort was a four-page population census form on each of the 14,793 residents. The data were processed and tabulations of results for the individual institutions were prepared and returned to their superintendents. Each institution was invited to study the tabulations and request any breakdowns, lists, cross-tabulations, or other data displays which it felt would be useful to its own internal programming and patient management. Following this second effort to collect regional data, it was clear that the good offices, if not the facilities, of Pacific State Hospital were being overwhelmed by the success of the project. It was also clear that institutions in the region were vitally concerned with the data provided and wanted it to continue. Toward this end, WICHE secured a contract with the National Institute of Child Health and Human Development to develop and continue the Regional Joint Data Collection Project.

General Principles

Several general principles were basic to the way the project was conducted by WICHE. An enumeration of these principles follows.

- 1. Grass roots participation: A basic premise of this data system was that ward level personnel who have continuing contact with patients possess information about those patients which is important to planning and conducting of patient treatment programs.
- 2. Ordinary language: Insofar as ward level personnel understand and use sophisticated concepts, the words which stand for these concepts can be used in the instruments which collect the information. However, where ordinary common-sense descriptions are used by the ward personnel, the subtle differentiations of professional terminology are not understood by the personnel, probably do not influence their behavior toward the patients, and therefore are not useful in collecting information about patients. This does not rule out the use of more subtle concepts at the interpretation phase of data analysis.
- 3. Precision and reliability: Human behavior is sufficiently diverse so that no set of pre-established categories can describe all individual patients. The more narrow, rigid and precise the categories, the greater the number of "does not apply" responses. On the other hand, the more general and common sense the categories, the fewer the "does not apply" responses.



The discovery of inappropriate classification is the first step in correcting the perceptions of the respondent.

- 4. Multiple aims: While the primary objective of this kind of data collection system is information for the superintendent and his staff, there are several important by-products. First, there is an opportunity through inservice training to raise the level of sophistication and increase the sensitivity of ward level personnel to the phenomena they are observing and reporting. Second, there is an increased possibility of simple but important research activity. Third, there is an opportunity for increasing the quality of communications throughout the institution. Fourth, there should be an opportunity to improve staff morale through the use of feedback in association with the above.
- 5. Evolutionary system: Although the census form was used by all institutions participating, the form was subject to change each year. Similarly, the data processing system was subject to change each year. Thus, the kind and amount of information fed back to the institutions was somewhat different each year but with a core of longitudinal data.



THE DATA COLLECTION PROJECT

The data sought and most of the data collected relate directly to existing observable behaviors of the residents of state institutions for the retarded. The census form used in both 1967 and 1968 is presented as Figure 1. Although there are a number of items relating to basic demographic and institutional program variables, most relate to behavior.

Further, the behavior of interest will be seen as primarily maladaptive in nature. It is this type of behavior that prevents residents from engaging in institutional programs designed to enhance individual development. That is, a resident who is incontinent, nonambulatory, aggressive, etc., usually is not accepted in educational programs. The implication of this orientation is clear: these data highlight the behaviors which must be changed in order for residents to receive the benefit of institutional programming.

The Data Collection Form

The form used to collect the data was the product of evolution. The items contained in the original form used at Pacific State Hospital resulted from several years of experience. The items contained had been proven useful to that hospital. Under WICHE sponsorship, each institution was invited to review the items and suggest additions, deletions or changes. Many suggestions were received. The project staff met with an advisory committee to consider each suggestion. (Advisory Committee members are listed in Appendix A.) Suggestions were accepted if they represented information useful to all or most institutions, if it was information that would be readily available at each institution, and if the information could be readily coded and easily reported.

Initially, the data collection form was in standard questionnaire format. The amount of information collected, however, required computer processing. Thus, the information collected by questionnaire had to be punched onto cards. The manual punching effort proved to be slow, costly, and subject to high error rates. As a consequence, the questionnaire format was abandoned and the items were presented on a form compatible with an IBM 1231 Optical Mark Scanner (Figure 1).

The optical scanner is a device which "reads" the marks on the form, transfers the location of the marks to a small computer, and then punches the information on cards. The process is very much faster, more economical, and more accurate than manual key punching. These advantages are only minimally offset by the fact that there are a large number of items on one piece of paper and instructions for the items cannot appear on the form itself.



Gathering the Data

Prior to actual data collection, training programs were conducted. The first step in training was conducted by WICHE on a regional basis. Each participating institution nominated a representative who was to be responsible for the data collection effort at that institution. These representatives attended a meeting convened by WICHE. At the meeting, each item on the form was discussed. Item discussions continued until there was consensus as to the details of definition.

Procedures for collecting the data were then discussed. The institutions were given considerable latitude as to the details of procedure. This latitude was essential because of the differences in staff and organization among institutions. For example, the information items extracted from records was to be provided by records librarians. In many institutions, however, there are no records librarians. In such cases, a secretary or clerk was trained to extract the information. Several institutions had psychology and social service department personnel provide the data most relevant to their areas. Other institutions where records are kept at the ward level, had ward staff extract psychological and social service data.

The main emphasis on comparability of procedure had to do with the behavior items. The overriding issue here was that the data should be provided by the person most familiar with a given resident. In some cases, this person was the charge nurse or aide. In other cases, the person was an attendant.

The usual procedure was to have the record items completed first. The forms were then distributed to the wards where the remaining data was provided. The forms were then checked to insure that they were complete before being returned to WICHE. Only one institution significantly deviated from this procedure. The Arizona Children's Colony Psychology Department collected all the data. However, the behavior items were completed by interviewing ward staff.

At the conclusion of this regional training session, each representative e was responsible for training the institution data collectors. Further, the representative was available during the data collection period to answer specific questions as they arose.

Processing the Data

There were a maximum of 78 items of information to be recorded on each form. Forms were filled out on approximately 23,000 residents each year. Thus, for a given year, 1,794,000 bits of information had to be processed. Two steps were



Figure 1.

POPULATION CENSUS STANDARD FORM WICHE JOINT DATA COLLECTION PROJECT

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| UNKNOWN :: UNKNOWN :: | NO USE | YES TO ONE SIDE ONLY TO THE TITLE ONLY TO THE TI | FULL USE :: 6 | HAS THE RESIDENT EVER BEEN HAS THE RESIDENT EVER BEEN USE IN SELF CARE SERECT FOR MEDICAL REFERRED FOR MEDICAL EVALUATION OF HIS VISION? EVALUATION OF HIS HEARING? | (WITH GLASSES IF NEEDED) (WITH HEARING AID IF NEEDED) 25. ARM-HAND | 22. VISION 23. HEARING 24. DRESSING ABILITY | ORESSED II NO USEABLE VISION NO USEABLE HEARING NUST BE COMPLETELY 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 | DIFFICULTY REQU | NO DIFFICULTY NO DIFFICULTY REQUIRES LITTLE HELP 1 | | NOT TESTED | OTHER IO SCALES !! 9 | OTHER SO SCALES | THE | UNCLE/AUNT 6 6 6 SEPERE | A MENTAL 1Q OR SQ 9. TYPE OF TEST LATEST TEST (AAMD CLASSIF.) | S S S S S S S S S S S S S S S S S S S | GRANDPARENT 4 PEABODY 7 1 4 1 MILD | 3 3 CATTELL 9 3 3 BORDERLINE | BROTHER/SISTER 2 2 1 (1937, 1960) 2 1 2 1 NORMAL | WAIS, WISC OR BELLEYUE | |
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| UNKNOWN :: UNKNOWN :: | NO USE | YES YES ONE SIDE ONLY 7 7 7 7 7 | FULL USE | REFERRED FOR MEDICAL REFERRED FOR MEDICAL EYALUATION OF HIS VISION? EVALUATION OF HIS HEARING? | (WITH GLASSES IF NEEDED) (WITH HEARING AID IF NEEDED) 25. ARM-HAND | 22. VISION 23. HEARING 24. DRESSING ABILITY | ORESSED II NO USEABLE VISION NO USEABLE HEARING NUT BE COMPLETELY AND USEABLE HEARING ORESSED ASSISTANCE II NO USEABLE VISION NO USEABLE HEARING ORESSED NO USEABLE N | DIFFICULTY REQUIRES MUCH HELP 2 2 2 2 2 2 | NO DIFFICULTY NO DIFFICULTY REQUIRES LITTLE HELP 1 1 1 1 1 1 1 | : ::::: | NOT TESTED : UNKNOWN | OTHER 10 SCALES 9 9 1 | OTHER SO SCALES | THELAND | UNCLE/AUNT 6 6 6 SEPERE 3 6 6 SEPERE | A MENTAL 1Q OR SQ 9. TYPE OF TEST LATEST TEST (AAMD CLASSIF.) AAMD CODE | S S S S S S S S S S S S S S S S S S S | GRANDPARENT A PEABODY A MILD | CATTELL BORDERLINE | BROTHER/SISTER 2 2 (1937, 1960) 2 2 NORMAL 6 2 2 | WAIS WISC OR BELLEVUE 0 1 1 1 | |
| UNKNOWN :: UNKNOWN :: | NO USE | YES ONE SIDE ONLY II THE | FULL USE | HAS THE RESIDENT EVER BEEN HAS THE RESIDENT EVER BEEN USE IN SELF CARE REFERRED FOR MEDICAL REFERRED FOR MEDICAL EVALUATION OF HIS VISION? EVALUATION OF HIS HEARING? | (WITH GLASSES IF NEEDED) (WITH HEARING AID IF NEEDED) 25. ARM-HAND | 22. VISION 23. HEARING 24. DRESSING ABILITY | ORESSED IN OUSEABLE VISION NO USEABLE HEARING NUST BE COMPLETELY STATE ORESSED STATE ORESSED NO USEABLE HEARING NUST BE COMPLETELY STATE ORESSED NO USEABLE HEARING NUST BE COMPLETELY STATE ORESSED NO USEABLE HEARING NUST BE COMPLETELY STATE ORESSED NUST BE COMPLETELY STATE OR STATE | DIFFICULTY REQUIRES MUCH HELP 2 2 2 2 | NO DIFFICULTY NO DIFFICULTY REQUIRES LITTLE HELP 1 1 1 1 1 1 1 | | NOT TESTED | OTHER 10 SCALES 9 9 1 | OTHER SO SCALES | THE THE THE THE PROFOUND TO THE | UNCLE/AUNT 6 6 6 6 6 6 6 6 6 | A MENTAL 1Q OR SQ 9. TYPE OF TEST LATEST TEST (AAMD CLASSIF.) AAMD CODE | S S S S S S S S S S S S S S S S S S S | GRANDPARENT A PEABODY A MILD | CATTELL 9 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 3 | BROTHER/SISTER 2 2 (1937, 1960) 2 2 KORMAL 6 2 2 | WAIS WISC OR BELLEVUE 0 1 1 1 | |

| NEVER OR !! INFREQUENTLY !! WETS BED | OCCASIONALLY !! WETS | USUALLY WETS | UNKNOWN | 35. NIGHT | 38. CANDIDATE | AIREADY ON PROGRAM | DEFINITELY YES | POSSIBLY YES | 0 N | UNKNOWN | LESS THAN !! | 1 WEK- | 1 MONTY- | 1 YEAR 1 | 47. HOW LONG HAVE YOU | RESIDENT? 48. YOUR TITLE OR | | 7, 8, 8, | ATTENDANT | PSYCHIATRIC | OTHER : | |
|--|---|--------------------------------|--|---|-------------------|---|---------------------------------|--|--|------------|---|-------------------|--------------|--------------------------|--------------------------|---------------------------------------|------------------------------------|----------------------------------|------------------------|-------------------------|----------------------|---|
| BOWEL AND BLADDER TRAINED: | INDEPER PENT USE | MAKES TOILET !! | (RESPONDS TO TRAINED TRIP SCHEDULE, SHE BUT SOME DAYTIME | ON IDINESSS) | TRAINING | NO RESPONSE | TRAINING HAS NOT YET BEGUN | HAS Ph. SICAL DISABILITY WHICH !! PREVENTS TRAINING | HAS LIMITED MENTAL ABILITY :: PREVENTING :: IRAINING | UNKNOWN | APEROX, HOW OFTEN DID RESIDENT GO ON HOME LEAVE (OWN FAMILY) DURING THE LAST 12 MONTHS | NEVER | WEEKLY | MORE THAN ONCE A WEEK | EVERY OTHER | 46. HOME LEAVE | MONTHLY | EVERY OTHER | 3 OR 4 TIMES A YEAR | ONCE OR TWICE A YEAR | UNKNOWN | • |
| · | STAYS NEAT & | | CAN REMAIN NEAT & CLEAN WITH PROMPTING | | 33. GROOMING | MAKES NO ATTEMPT TO STAY | | | UNKNOWN | | APPROX. HOW OFTEN DID RESIDENT HAVE VISITORS BURING THE 1x** 12 MONTHS | NEVER | WEEKLY | MORE THAN !!! | EVERY OTHER !! | 45. VISITORS | MONTHLY | EVERY OTHER | 3 OR 4 TIMES A YEAR | ONCE OR II | UNKNOWN | |
| · · · · · · · · · · · · · · · · · · · | REGULAR DIET (SOLID) | | GROUND DIET | | 32. NUTRITION | SPECIAL DIETS: | WEIGHT CONTROL | MEDICAL | Dirknown | | APPROX. HOW OFTEN DID APP RESIDENT RECEIVE LETTERS OR RES PACKAGES FROM FAMILY DURING THE LAST 12 MONTHS MO | NEVER !! | WEEKLY : | MORE THAN | EVERY OTHER !! WEEK | PACKAGES | MONTHLY | EVERY OTHER | 3 OR 4 H | ONCE OR | UNKNOWN | |
| FEEDS SELF WITH: | | KNIFE, FORK & SPOON | SPOON | HANDS ONLY | 31. FEEDING | FED BY OTHERS: | RESIDENTS ONLY | RESIDENTS, EMPLOYEES, YOLUNTEERS | EMPLOYEES ONLY | UNKNOWN | APPROX. HE RESIDENT R. RESIDENT R. PACKAGES I PACKAGES I PROGRAM !! DURING THE | DEFINITELY YES !! | BLY YES | 2 | UNKNOWN | - | OUT EAVE/ EMENT/ | LEAVE EFERRED !! ROGRAM !! | DEFINITELY YES !! | POSSIBLY YES !!! | 9 | |
| | ES OWN TEETH | TEETH BRUSHED BY !!! OTHERS | GUMS (BLEEDS) | HAS BAD TEETH | RAL HYGIENE | HAS NO TEETH | WEARS DENTURES | KOUT:NELY | UNKNOWN | | ALREADY RI FOR/OK PR | DEFINIT | POSSIBLY | | | <u> </u> | | | | ==== | | |
| FROM | BRUSHES O | ==== | DRAL HAS BAD | | 30. 08 | 0/08 !! | | TO !! SEES DENTIST | | UNKNOWN !! | - | MALE | | FEMALE | 40, SEX | (FOSTER HOME GROUP COMMUNITY CARE) | ALREADY REFERRED FOR/ON PROGRAM | DEFINITELY YES | POSSIBLY YES | ON | UNKNOWN | |
| UNDERSTANDS | | UNDERSTANDS ORAL COMMUNICATION | HAS DIFFICULTY UNDERSTANDING (| | COMMUNICATION 29. | RESPONDS ON LY 1 TO GESTURES AND/OR 1 SIGNS | · | BOES NOT RESPUNO TO GESTURES AND/OR SIGNS | | ONKN | ~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~ | >- | ===== | ESCAPE | PRIVAILLY | | ==== | R CLOTHES | | WINDOWS | ON BOORS SECTUBED | • |
| COMMUNICATES TO OTHERS: | SPEECH UNDERSTANDABLE !! BY A STRANGER | | SPEECH SOMEWHAT DIFFICULT | | 28. COMMUN | MAKES NEEDS KNOWN | NO MEANINGFUL COMMUNICATION: | JABBERS-NO WORDS | MAKES NO SOUNOS | UNKNOWN | ZWZWZZ | E < → → → → | | 1 | MASTURBATES | SEXUAL ACTIVITY OTHERS-OPPOSITE SEX | ===== | REFUSES TO WEA | ATTACKS RE | EAKS | BANGS ON WHEN SEC | |
| I I I I I I I I I I I I I I I I I I I | MEDICATION FOR: | SLEEPING | | BEHAVIOR !! PROBLEMS !! | 27. DRUGS | OTHER DISORDERS | NONE | UNKNOWN | | | NM-1004 | | ::::: | GGRESSIVE | ASSIVE (KEEPS TO SELF) | MASTURBATES PUBLICLY 39. BEHAVIOR | | MOLESTS CHILDREN | ATTACKS EMPLOYEES | WARD PROPERTY | RUNS AND PACES | |
| | NONE OBSERVED | | HISTORY, BUT !! | | 26. SEIZURES | OBSERVED ONCE A !!! | _ | OBSERVED LESS !! THAN ONCE A !!! | | UNKNOWN | ZW>WE | | | ===== | CIIVE | SEX | ==== | ===== | | | | L RESTRAINTS |
| | : :::::: 2 :::::::::::::::::::::::::::: | :::0 | * | 2002 2002 2002 2002 2002 2002 2002 200 | N NUMBER | ::::: | 7 | | | | XM>MX NMJCOX | ⋞⋴⋴⋟ | ===== | HYPERACTIVE | SELF-DESTRUCT | SEXUAL ACTIVITY OTHERS-SAME SEX | | EXPOSES SEL | | امد | UPSETS FUENITURE | PEQUIRES MECHANICAL RESTRAINTS (BELTS, TIES, ETC.) |
| | | | | | 2-1. ADMISSION | | 200 | | | | ALREADY ON !! | DEFINITELY YES | POSSIBLY YES | 9 9 | UNKNOWN | | SYSTEM IS RESIDENT PAID | FUR WURK: | 2 | DOESN'T WORK | NXNO P. | 6H M81 |

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required in order to transform this amount of information into a form permitting efficient retrieval:

- 1. Automatic card-punching of the data collection form.
- 2. Constructing a magnetic tape file from the punched cards.

Step 1 involved the use of an IBM 1231 optical scanning device connected to an IBM 1401 computer with a card punch. The 1401 was programmed so that marks on the data collection form would result in appropriate punches on a card. There were two punch cards for each patient, one from each side of the form. In the case of uninterpretable information on the data form (such as multiple marks where only one was allowed), the 1401 program called for no punches to be recorded in that particular column of the card.

After the cards were punched, a single magnetic tape file was produced which would be suitable for quick and efficient retrieval of information. There were two major problems involved:

- Merging the two cards produced from the two sides of the form for each patient, and dealing with duplicate and missing cards.
- 2. Developing the data tape file in such a manner as to expedite future retrieval runs and minimize costs.

The first problem was handled as follows. The cards for each institution were first processed separately. The Side 1 cards were sorted into numerical order in terms of admission numbers. The Side 2 cards were similarly sorted. The cards were ther fed into a CDC 6400 computer programmed to: (1) check the order and abort the job if one or more cards were found out of order; (2) ignore all cards with duplicate admission numbers to prevent inadvertant merging of Side 1 from one individual with Side 2 from another (less than 1% of the cards processed has this problem); (3) merge the Side 1 and Side 2 cards for each resident in that institution; and (4) write a data tape.

Occasionally, one of the two cards for a given individual was missing. In that case, a "dummy" card was "inserted" containing all blanks for the missing side. This was done automatically, of course, by the program. About 2% of the residents had a missing card. Lists of these residents' admission numbers were kept, as well as lists of duplicate admission numbers, so that future updating and correcting of the data file would be possible if desired by the individual institutions.



The second major problem in creating the data tape was that of expediting future retrieval and minimizing costs. Because of the large number of retrieval runs which were expected, machine time to read the data tape became of critical importance in minimizing costs and maximizing efficiency. Thus, rather than writing the information on tape one individual at a time, the information was stored in the memory of the computer until the maximum amount of data that could be written on tape at one time was accumulated. This meant that when the tape was read during subsequent retrieval runs, a maximum amount of information could be brought into the machine at one time during each "read" operation. Furthermore, the tape was written in the computer's own internal code which resulted in immediate access to the information without the necessity of first converting the coding on the tape into machine coding. These and other factors resulted in extremely low cost retrievals.

Feedback

The data received from the institutions was routinely processed and the output returned to the institutions. In addition, requests for special processing services were honored where possible. The nature and extent of the routine output varied somewhat over the course of the project. Essentially, however, there were four kinds of output routinely provided to the institutions. These were

- 1. A frequency distribution for each variable for each institution. (Table I)
- 2. A frequency distribution for each variable for each ward or cottage at an institution. (Table II)
- 3. A frequency distribution for the combined population of all institutions. (Table III)
- 4. A frequency distribution in terms of percentages for all institutions and the combined populations. (Table IV)

Tables I through IV are illustrations of these outputs for the variable "Level of Retardation."

The special requests for data processing were many and varied. The most common requests fell into two categories: (1) selecting residents who met specified criteria; and (2) cross-tabulations of residents. An example of the first kind of request would be selecting residents at an institution who were blind, below 26 years of age, and with no other physical disability. Such a list would be useful in considering the development of a program for the visually handicapped. An example of the second category of requests would be determining the numbers of mongoloids by age and IQ groups. This information would be useful



Table I. Example of frequency distribution for the variable Level of Retardation for one institution.

| | | Number of Residents | Percent of Total |
|------------|-------|------------------------|---------------------|
| Normal | | 4 | .79 |
| Borderline | | 21 | 4.13 |
| Mild | | 54 | 10.63 |
| Moderate | | 102 | 20.08 |
| Severe | | 117 · | 23.03 |
| Profound | | 173 | 34.06 |
| Unknown ' | | 11 | 2.17 |
| | TOTAL | 508 | |

Table II. Example of frequency distribution for the variable Level of Retardation for each ward of one institution.

| | | _ | | | | Ward | Number | ^S | | | | |
|------------|----|----|----------|----|----------|------|--------|----|-----------|-----------|----|-----------|
| |] | 2 | <u>3</u> | 4 | <u>5</u> | 7 | 8 | 9 | <u>10</u> | <u>13</u> | 14 | <u>33</u> |
| Normal | 0 | 1 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 1 | 0 | 0 |
| Borderline | 2 | 3 | 0 | 4 | 8 | 1 | 1 | 1 | 0 | 1 | 0 | 0 |
| Mild | 2 | 10 | 0 | 11 | 15 | 3 | 9 | 0 | 0 | 1 | 3 | 0 |
| Moderate | 7 | 3 | 0 | 17 | 21 | 19 | 25 | 1 | 0 | 7 | 1 | 1 |
| Severe | 7 | 2 | 0 | 16 | 13 | 37 | 24 | 0 | 0 | 18 | 0 | 0 |
| Profound | 58 | 1 | 1 | 13 | 8 | 31 | 15 | 0 | 1 | 42 | 2 | 0 |
| Unknown | 6 | _0 | 0 | 1 | _2 | 2 | 0 | 0 | 0 | 0 | 0 | 0 |
| TOTAL | 82 | 20 | 1 | 62 | 69 | 96 | 74 | 2 | 1 | 71 | 6 | 1 |

Table III. Example of frequency distribution for the variable Level of Retardation for the total regional population.

| | Number of Residents | Percent of Total |
|------------|------------------------|---------------------|
| Normal | 128 | .53 |
| Borderline | 796 | 3.28 |
| Mild | 2,547 | 10.50 |
| Moderate | 4,436 | 18.29 |
| Severe | 5,999 | 24.73 |
| Profound | 8,619 | 35.53 |
| Unknown | 707 | 2.91 |
| TOTAL | 24,257 | |

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Example of frequency distribution for the variable Level of Retardation for each of the 22 institutions in percent. Table IV.

| | TOTAL | _ | က | 11 | 18 | 25 | 36 | က |
|-------------|-----------|---------|------------|--------------------|-------|----|----------|---------|
| | 22 | | 8 | 10 | 10 | 13 | 63 | _ |
| | 21 | 0 | 0 | 0 | 4 | 9 | 87 | က |
| | | 0 | വ | 2 | 22 | 53 | 34 | 4 |
| | 19 | | 0 | _ | _ | 14 | 44 | 33 |
| | 18 | 4 | 15 | 18 | 14 | 17 | 53 | 7 |
| | 17 | 0 | 4 | 1 | 19 | 40 | 22 | r- |
| | 16 | 0 | က | 10 | 12 | 22 | 47 | _ |
| | 15 | _ | 4 | 10 | 15 | 18 | 44 | 4 |
| | 14 | 0 | 5 | 91 | 20 | 18 | 36 | _ |
| irs | 13 | 0 | _ | 2 | 14 | 30 | 39 | 2 |
| Numbers | 12 | _ | 2 | 17 | 27 | 21 | 27 | _ |
| tion | = | 0 | 2 | 2 | 12 | 22 | 52 | 0 |
| Institution | 10 | က | _ | 4 | 31 | 53 | က | က |
| In | 6 | _ | 2 | 21 | 22 | 21 | 20 | 0 |
| | ∞l | 0 | _ | 15 | 28 | 32 | 22 | 0 |
| | 7 | _ | œ | 15 | 20 | 28 | 20 | 4 |
| | او | _ | 4 | 11 | 20 | 23 | 34 | 2 |
| | اک | 0 | 2 | 5 | 16 | 32 | 13 | 30 |
| | 41 | 0 | _ | 7 | 16 | 29 | 43 | 0 |
| | က | _ | 5 | 14 | 22 | 19 | 34 | 4 |
| | 2 | _ | 8 | ب- ب | 36 | 20 | 23 | _ |
| | ٦ | 0 | က | | | 25 | 35 | 0 |
| | | Normal | Rorderline | Mild | 2 - M | | Profound | Unknown |

in considering a research project with mongoloids.

There were a large number of other special requests which were quite varied. They ranged from the very simple to the very complex. While most requests of all kinds were specific to a given institution, many were concerned with the regional population. In addition to requests from outside, there were numerous processing requests initiated by the WICHE staff. Details of these requests and utilization of the data are discussed later.

Participating Institutions

The state mental retardation institutions participating in the regional data collection program are listed in Table V. The number of residents on whom data were collected in 1968 are indicated. This number may not precisely reflect the number of residents on the institutions' books. Usually, data were collected only on residents who were physically present in the institution on the day data were collected. Thus, residents on leave or otherwise absent from the institution were not included.

Most of the institutions are general in the sense that they serve a specified catchment area and offer services to all ranges and types of retardates. The exceptions and a very brief description of admissions policy follows:

Pueblo - This is the Special Education Division of the Colorado State Mental Hospital. Residents must be 16 years of age or over and able to serve themselves in a cafeteria. Preference is given retardates with emotional problems.

The Washington institutions all serve a specified category of residents. This policy is now in the process of change. At the time these data were collected, however, the restrictions were:

Fircrest - Residents of IQ 35 or below from the area west of the Cascade Mountains.

Rainier - Residents with IQ's above 35 from the area west of the Cascades.

Yakima - Profoundly retarded bed patients.

Interlake - Profoundly retarded bed patients.

Lakeland - All residents from east of the Cascades, not bed patients.

In Oregon, Fairview serves a general population, but there are also two institutions meeting special needs:

Columbia Park - Adult ambulatory retardates.

Eastern Oregon Hospital - A new division serves primarily profoundly retarded, multiply handicapped adult residents.



Table V. List of institutions.

| Institution | Institution Number | Number of Residents | Percent of Total |
|--------------------------|--------------------|------------------------|---------------------|
| Arizona | 1 | 973 | 4.01 |
| Pueblo, Colorado | 2 | 593 | 2.44 |
| Fairview, Oregon | 3 | 2,266 | 9.34 |
| Fairview, California | 4 | 2,498 | 10.30 |
| Fircrest, Washington | 5 | 922 | 3.80 |
| Idaho | 6 | 508 | 2.09 |
| Lakeland, Washington | 7 | 1,294 | 5.33 |
| Los Lunas, New Mexico | 8 | 718 | 2.96 |
| Montana | 9 | 1,184 | 4.88 |
| Nevada | 10 | 150 | .62 |
| Porterville, California | 11 | 2,486 | 10.25 |
| Rainier, Washington | 12 | 1,722 | 7.10 |
| Sonoma, California | 13 | 3,433 | 14.15 |
| Grand Junction, Colorado | 14 | 797 | 3.29 |
| Wheat Ridge, Colorado | 15 | 1,094 | 4.51 |
| Utah | 16 | 923 | 3.81 |
| Waimano, Hawaii | 17 | 767 | 3.16 |
| Wyoming | 18 | 709 | 2.92 |
| Yakima, Washington | 19 | 251 | 1.03 |
| Columbia Park, Oregon | 20 | 515 | 2.12 |
| Interlake, Washington | 21 | 78 | .32 |
| Eastern Oregon | 22 | <u>376</u> | 1.55 |
| TOTAL | | 24,257 | |

The state of Nevada presents an atypical case as far as these data are concerned. At the time these data were collected, Nevada did not have a separate facility for the retarded. The mentally retarded were housed at the mental hospital. Although this facility serves the entire state, the institutionalized mentally retarded were relatively few and data about them sometimes resembles a special purpose institution.



RELIABILITY OF THE DATA

The actual and potential usage of the census data is quite broad. As a consequence, the reliability of the data is of paramount importance. This is particularly true because the data were collected by non-professional ward staff. Abelson and Payne (in press) have conducted and reported on three reliability studies. The discussion is therefore a summary of their work.

Several investigators - Ellsworth et al. (1967); Jensen & Morris (1960); Gerjuoy et al. (1960); Charles & McGrath (1962) - have found that non-professionals are as reliable as professionals when rating observable behavior. Professionals excel when ratings require extensive or specialized knowledge, or when the judgments are complex, but non-professional ratings are accurate when based on behavior. There is, then, ample precedent for using ward staff as data collectors.

Three independent attempts were made to estimate reliability of the census data. Two studies were based on data collected in the spring of 1966, and one on 1967 data. Study I compared ward staff ratings with those made by professional staff. The ward staff collected data on the total population of the institutions - over 2,000 residents - in the usual manner. The professional staff - doctors, psychologists, and nurses - then rated a sample of 300 residents over a period of several months. Fifteen cases were unusable, leaving a matched sample of 285 cases.

Study II was essentially a complete replication of an institution population. Through an administrative error, it was necessary to repeat the entire data collection effort. After the replication, 646 matched cases were identified. Several months elapsed between the two sets of data. Study III involved comparisons on 287 residents made by both the morning and afternoon shifts on the same day.

The percent of items in absolute agreement was the measure chosen to indicate reliability. This measure is appropriate for all items and is also quite severe. No credit is given for nearly identical ratings or for low chance expectancies due to a large number of alternatives within an item.

Table VI lists in decreasing order the individual items rated. The scores listed for each item were averaged over the studies. The number of alternatives for each item is indicated. Items marked with an asterisk were used only in the 1967 study (Study III). Items marked with two asterisks were used in the 1966 studies. The other items were comparable overall studies.



Within each study, one-quarter of the items achieved a percent agreement of at least 93. The median scores for the three studies were 85, 83, 86 and 83.

Table VI indicates that about one-third of the items achieved a reliability of over 90%, and about half yielded scores above 85% agreement. About one-quarter of the items scored below 75% agreement.

In general, high reliability items are objective and have only a few alternatives. The least reliable items seem to require understanding of psychiatric concepts (e.g., psychotic, hyperactive, etc.) or prognostication (e.g., whether the resident could be in family care instead of institutionalized). Further, items which rely on long term memory seem to be hard to rate reliably.

While there are some weak items in the census, median scores in the mid-80's over the three studies indicate that the data warrant general confidence. This is particularly significant for future large-scale data collection efforts. Ward staff seem to be essential in any data collection effort on extremely large populations. For the present study, these findings suggest that the data are generally useable for any purpose. However, uses relying heavily on those lower reliability items should be interpreted with caution.



Table VI. Percent agreement scores for each item

| | Mean Percent | Number of |
|-------------------------------------|--------------|---------------------|
| <u>Item</u> | Agreement | <u>Alternatives</u> |
| Sex | 100 | 2 |
| **Uses hearing aid | 100 | 2 |
| **Uses prosthetic device | 100 | 2 |
| **Drugs - digitalis | 100 | 2 |
| **Drugs - insulin | 100 | 2 |
| *Drugs - unknown | 100 | 2 |
| **Diabetic | 100 | 2 |
| *Oral hygiene - unknown | 100 | 2 |
| **Special conditions - undetermined | 100 | 2 |
| *Special education for handicapped | 99 | 7 |
| **Criminal restraints | 99 | . 2 |
| **Drugs - benzedrine/dexedrine | 99 | 2 |
| *Oral hygiene - has bad gums | 98 | 2 |
| **Aids - walker | 98 | 2 |
| **Aids - other | 98 | 2 |
| **Runaway with others | 98 | 2 |
| Arm-hand use | 97 | 3 |
| **Aides - wheelchair | 97 | 2 |
| **Drugs - dilantin | 97 | 2 |
| **Drug sensitivity | 97 | 2 |
| Wears dentures | 96 | 2 |
| **Drugs - antibiotics | 96 | 2 |
| **Runaway alone | 96 | 2 |
| Has no teeth | 94 | 2 |
| **Candidate for group leader | 93 | 4 |
| *Masturbates publicly | 93 | 4 |
| **Aids - glasses | 93 | 2 |
| **Drugs -barbiturates | 92 | 2 |
| **Drugs - tranquilizers | 91 | 2 |
| Drugs - for sleep problems | 91 | 4 |
| Smears feces | 91 | 4 |

Table VI. (continued)

| | Mean Percent | Number of |
|-------------------------------------|--------------|---------------------|
| Item. | Agreement | <u>Alternatives</u> |
| Molests children | 91 | 4 |
| *Communication - understands | 91 | 4 |
| **Special conditions - other | 91 | 2 |
| **Language used | 90 | 3 |
| **Special conditions - has seizures | 90 | 2 |
| Ambulation | . 89 | 4 |
| Drugs - for seizures | 89 | 2 |
| *Teeth brushed by others | 89 | 2 |
| *Has bad teeth | 89 | 2 |
| *Requires restraints | 89 | 4 |
| Refuses to wear clothes | 89 | 4 |
| Attends school | 88 | 7 |
| Hearing ability | 88 | 3 |
| Toilet training | 86 | 7 |
| *Masturbates privately | . 86 | 4 |
| Breaks windows | 86 | 4 |
| **Aids - braces | . 86 | 2 |
| **Aids - none | 86 | 2 |
| **Difficulty falling asleep | 85 | 2 |
| Vision - referred for evaluation | 85 | 2 |
| *Nutrition | 84 | 4 |
| Night bedwetting | 84 | 3 |
| Exposes self | 84 | 4 |
| Height | 83 | - |
| *Drugs - for behavioral problems | 82 | 2 |
| Bangs doors when secluded | 82 | 4 |
| **Sleep habits | 81 | 7 |
| Dressing ability | 81 | 4 |
| Drugs - none | 80 | 2 |
| Ability to feed self | 80 | 6 |
| Attacks employees | 80 | 4 |
| Heterosexual activity | 80 | 4 |
| **Drugs - vitamins | 79 | 2 |



Table VI. (continued)

| | Mean Percent | Number of |
|-----------------------------------|--------------|---------------------|
| <u>Item</u> | Agreement | <u>Alternatives</u> |
| *Brushes own teeth | 70 | 2 |
| | 79 70 | 3 |
| Vision ability | 79 | _ |
| Exhibits seizures | 79 | · `4 |
| Destroys ward property | 78 | 4 |
| *Communication - to others | 77 | 6 |
| *Sees dentist regularly | 77 | |
| Destroys clothing | 77 | 4 |
| Upsets furniture | 77 | . 4 |
| Likely to escape | 77 | 4 |
| Could be in nursing home | 76 | 4 |
| Self-destructive | 76 | . 4 |
| Runs and paces | 75 | 4 |
| Could be placed out | 74 | 4 |
| Frequency of home leave | 73 | 8 |
| Drug - for other disorders | 72 | 2 |
| Weight | 69 | · • |
| Hearing - referred for evaluation | 69 | ` 2 |
| Homosexual activity | 69 | 4 |
| Considered for school program | 68 · | · 3 |
| Special conditions - none | 68 | 2 |
| Candidate for work project | 67 | 4 |
| Candidate for ward helper | 66 | 4 |
| Attacks residents | 62 | 4 |
| Could be in family care | 60 | 4 |
| Frequency of letters and packages | 59 | 8 |
| *Grooming ability | 58 | 3 |
| **Psychotic behavior | 56 | 4 |
| **Withdrawn | 55 | 4 |
| *Rewarded for work | 54 | 3 |
| Frequency of visitors | 49 | 8 , |
| Hyperactive | 48 | 4 |
| Passive | 46 | 4 |
| Aggressive | 44 | 4 |
| | • • | • |

GENERAL POPULATION DESCRIPTION

Various characteristics of the population will be described in three separate ways. The first summarizes the data for the entire region. The second compares residents of the various institutions on selected variables. The third indicates the importance of four major variables - sex, age, level of retardation, and diagnosis.

Regional Characteristics

The information in the census was obtained using a large number of discreet items. These items relate to general types of patient characteristics. Thus, the items relating to a given general characteristic can be considered simultaneously. Ten groups of items, relating to broad characteristics, account for most of the data and simplify presentation of the information. A description of the ten characteristics follows. The data presented were taken from the 1967 census.

Group 1: General Statistics. Table VII provides information regarding general statistics, such as mean age, height, weight, and so forth, of the entire population. The mean age is 24.07 years with a standard deviation of 13.96. The average patient has been institutionalized for slightly more than twelve years. About 70% have been court committed; and there are slightly more males than females in residence. The average height and weight (57.78 inches and 102.51 pounds, respectively) show the population is, as expected, physically smaller than what would be expected of a normal population.

Group 2: Intelligence Measures. In Table VIII are shown the variables relating to measured intelligence. The average patient has an IQ-SQ of 31.21. There is a large variability of intelligence, the standard deviation being slightly greater than 20 points. At the time the 1967 census was taken, it had been nearly six years since the average patient had been given an intelligence test. Table VIII also shows the percent of patients who were rated at each of the six levels of retardation. Over one-third of the population is profoundly retarded and about two-thirds are more than moderately retarded.

Group 3: Diagnosis. The numerous diagnostic categories as numbered by the American Association on Mental Deficiency (AAMD) classification system were grouped in terms of their first digit, and the percent falling within each group are shown in Table IX. The two largest groups, which together account for over



Table VII. General statistics for the regional population.

| <u>Items</u> | Percent | <u>Mean</u> | Standard Deviation |
|-------------------------|---------|-------------|-----------------------|
| Age in years | | 24.07 | 13.96 |
| Years institutionalized | | 12.04 | 10.03 |
| Court committed | 69.10 | | |
| Sex - Male | 56.90 | | |
| Weight in pounds | | 102.51 | 44.50 |
| Height in inches | | 57.78 | 9.62 |

Table VIII. Intelligence measures for the regional population.

| <u>Items</u> | Percent | Mean | Standard <u>Deviation</u> |
|-----------------------|---------------|-------|------------------------------|
| IQ-SQ | | 31.21 | 20.04 |
| Years since last test | | 5.82 | 5.88 |
| Level of retardation | | | |
| Normal | .52 | | |
| Borderline | 3.19 | | |
| Mild | 11.07 | | |
| Moderate | 22.51 | | |
| Severe | 27.82 | | |
| Profound | 34. 88 | | |
| _ ~ _ | | | |

Table IX. Diagnosis for the regional population.

| <u>Items</u> | Percent |
|----------------------------------|---------|
| Infection | 8.45 |
| Intoxication | 1.73 |
| Physical trauma | 12.37 |
| Metabolism, growth, or nutrition | 2.59 |
| New growths | .91 |
| Unknown prenatal influence | 31.94 |
| Unknown/structural | 18.08 |
| Psychogenic/functional | 23.93 |



half of the patients, were those with retardation due to unknown prenatal influence, or to psychogenic or functional causes. These data suggest that firm diagnosis is still extremely difficult to obtain and the problem of the etiology of mental retardation is unsolved in over 50% of the cases.

Group 4: Family Characteristics. The variables concerning the characteristics of the family are shown in Table X. Only a very small proportion of the patients are multiple births. (It should be noted that about one-third of the residents' data forms had this item marked "unknown." Similarly for the next item, "has institutionalized relatives," virtually no information was available to the institution; almost 90% marked this item "unknown." The percentages indicated in the tables are always percent of known.) Finally, over 90% of the residents are either Protestant or Catholic; and about 85% are white.

Group 5: Medical Problems. Table XI shows the extent to which special medical problems exist in the population, as indicated by three selected variables. Almost one-third of the patients require special diet and about two-thirds require drugs. These data provide some indication of the general level of impairment involving the entire organism rather than just intellectual ability.

Group 6: Sensorimotor Difficulties. In the same vein, Table XII shows the extensive impairment of sensorimotor functions. One-quarter of the patients cannot walk. Almost two-thirds have difficulty speaking. About a third of the residents have problems understanding speech, and a third have chronic enuresis. These figures demonstrate the enormity of the problems of simply caring for the basic needs of a large proportion of the population.

Group 7: Special Needs for Personal Care. This point is further emphasized by the data in Table XIII. Although four-fifths of the patients are able to feed themselves, about half of them require special attention in matters such as dressing, brushing teeth, and the use of the toilet.

Group 8: Outside Contact. The WICHE census was able to obtain data concerning the contact each patient had with the outside world - presumably family. Table XIV shows that about 40% are able to go home at least once in a while, but about 30% never have mail and 30% never have visitors.

Group 9: Participation - Is a Possible Candidate for Various Programs. Table XV provides information regarding participation, either actual or potential, in various institution programs. About one-quarter of the patients were in school at the time the 1967 census was taken or were considered candidates for a school program. About 40% were, or were considered candidates for, ward helpers, and



Table X. Family characteristics for the regional population.

| Items | Percent |
|---------------------------------|---------|
| Multiple birth | 2.40 |
| Has institutionalized relatives | 9.64 |
| Religion | |
| Protestant | 60.85 |
| Catholic | 30,66 |
| Race | |
| White | 84.85 |
| Negro | 3.09 |
| Spanish American | 6.58 |
| | |

Table XI. Medical problems for the regional population.

| | cent |
|-------------------|------|
| Observed seizures | .03 |
| - " | .21 |
| | .71 |

Table XII. Sensorimotor difficulties for the regional population.

| Items | Percent |
|----------------------------------|---------|
| Cannot walk | 25.25 |
| Impaired vision | 16.82 |
| Impaired hearing | 8.70 |
| Impaired arm-hand use | 23.62 |
| Impaired speech | 64.75 |
| Impaired comprehension of speech | 32.68 |
| Chronic enuresis | 32.25 |



Table XIII. Special needs for personal care for the regional population.

| <u>Items</u> | Percent |
|----------------------------|---------------|
| Needs help dressing | 59.51 |
| Needs help brushing teeth | 47.17 |
| Needs help with feeding | 19.39 |
| Needs help grooming | 72. 46 |
| Needs help with toilet use | 42.86 |
| | |

Table XIV. Lack of outside contact for the regional population.

| Items | Percent |
|--------------------------|---------|
| Never receives mail | 28.53 |
| Never has visitors | 30.13 |
| Never goes on home leave | 60.60 |

Table XV. Participation in, or possible candidate for, various programs for the regional population.

| Items | Percent |
|---------------------------|---------|
| School attendance . | 24.91 |
| Ward helper | 39.37 |
| Institution work projects | 29.86 |
| Work reward systems | 15.07 |
| Foster home placement | 28.99 |
| Nursing home placement | 18.69 |
| Outside work placement | 13.37 |



about 13% for outside work placement. The table shows the percentages for other institutions as well.

Group 10: Behavioral Characteristics. Table XVI presents data regarding the proportion of the residents which at least occasionally showed each of the behaviors listed. The census form called for ratings on 22 behaviors. These have been listed in six groups: (1) general activity level; (2) sexual activity; (3) infantile behavior; (4) destructive toward persons; (5) destructive toward property; and (6) other. About 40% of the patients were rated as hyperactive and 40% passive. The behavior which had the next highest proportion of occurrence was aggressiveness. In general, violent behavior toward persons, such as molesting children and attacking employees, was relatively rare; destructiveness toward property occurred a greater percentage of the time. Even so, fewer than one-fifth of the patients exhibited any type of destructiveness.

These ten tables taken together provide a profile of the population as a whole. It appears to be a fairly heterogeneous population regarding both abilities and problems. It is clear that a very significant proportion of the population has tremendous limitations bordering on virtual helplessness and requires constant care and supervision even for the simplest matters of selfcare. On the other hand, another type of patient is also apparent in significant number. This is the type which appears able to function independently to a high degree, even to the extent of working outside the institution. Thus, the tremendous diversity within the population is perhaps the first main characteristic to emerge from the data.

Comparison among Institutions: Selected Items

Detailed data describing the population characteristics of each institution as well as the regional totals is presented in Appendix B. These data are taken from the 1968 census. Figures 2 through 10 are graphic presentations of data for some items selected from the tables in the Appendix. Figures 2, 3 and 4 indicate the mean and the range of one standard deviation for age, IQ or SQ, and length of stay in years for each institution. The regional means are also indicated on each graph. Figure 5 indicates the percentage of each institutional population rated as either severely or profoundly retarded.

Figure 6 represents the percent of residents in each institution who are attending some kind of school program. The remaining figures are concerned with behavioral handicaps. The percent of residents who are nonambulatory, non-speaking, not toilet trained, and self-destructive are presented.



Table XVI. Occasionally or frequently occurring behaviors for the regional population.

| <u>Items</u> | Percent |
|-----------------------------|---------|
| General activity level | |
| Hyperactive | 39.45 |
| Passive | 40.32 |
| Runs and paces | 19.31 |
| Sexual activity | |
| Heterosexual behavior | 3.25 |
| Homosexual behavior | 11.00 |
| Masturbates privately | 22.72 |
| Masturbates publicly | 9.96 |
| Infantile behavior | |
| Smears feces | 11.30 |
| Exposes self | 10.25 |
| Refuses to wear clothing | 7.56 |
| Destructive toward persons | |
| Aggressive | 32.54 |
| Molests children | 4.62 |
| Attacks employees | 5.79 |
| Attacks residents | 17.88 |
| Destructive toward property | |
| Destroys clothing | 16.28 |
| Upsets furniture | 14.57 |
| Destroys ward property | 11.38 |
| Breaks windows | 5.58 |
| Bangs doors when secluded | 9.62 |
| 0 ther | |
| Self-destructive | 16.10 |
| Requires restraints | 9.79 |
| Likely to escape | 7.07 |

These figures illustrate the three categories of information included in the data collection program. Age, IQ, length of stay, and level of retardation are typical of the demographic variables; school attendance is the best program information obtained; ambulation, speech, toilet training, and self-destructive behavior are examples of the behavioral data.

Age. The mean age for all participating institutions is 24.4 years with a standard deviation of 14.06 years. This regional mean is somewhat below a national mean estimated at 26.5 years.* Figure 2 indicates the variation of institutional means about the regional mean, as well as inter-institution variability.

<u>IQ-SQ</u>. As before, IQ and SQ scores are combined in these data even though the scores reported are from a variety of tests. For example, 26.94% of all scores reported are from the Vineland, 16.35% of the scores were obtained from the Benet, 13.31% from one of the Wechsler tests, and the remainder from an assortment of other tests. The scores are combined based on the following rationale: The correlation of these tests with each other are well-known and considered acceptable; a study by Johnson and Abelson, to be reported later, indicates no difference in the power of IQ vs. SQ scores in predicting behavior. The mean IQ-SQ for the region is 31.42 with a standard deviation of 20.30. Figure 3 reflects the considerable variation in intelligence both within and across institutions.

Length of Institutionalization. The mean length of stay in institutions for the region is 12.33 years with a standard deviation of 10.40 years. Figure 4 indicates the great variation both within and between institutions. In this instance, the two institutions with the least mean length of stay both serve a general population. The two institutions with the greater mean length of stay are serving special populations.

Level of Retardation. Of the combined population of all institutions, 24.73% of the residents are severely retarded and 35.53% are profoundly retarded. Figure 5 indicates the percentage of the population of each institution falling within these two levels. While the special purpose institutions stand out, the variability among the remaining institutions is generally less than has been the case with the variables described thus far.

^{*} This estimate was calculated from grouped data presented in <u>Patients in Mental Institutions</u>, <u>1966</u>, <u>Part 1</u>, <u>Public Institutions for the Mentally Retarded</u>.

Public Health Service Publication No. 1818, Part 1. Washington, D.C. 1968.



Figure 2. Mean age, \pm one standard deviation, all institutions.

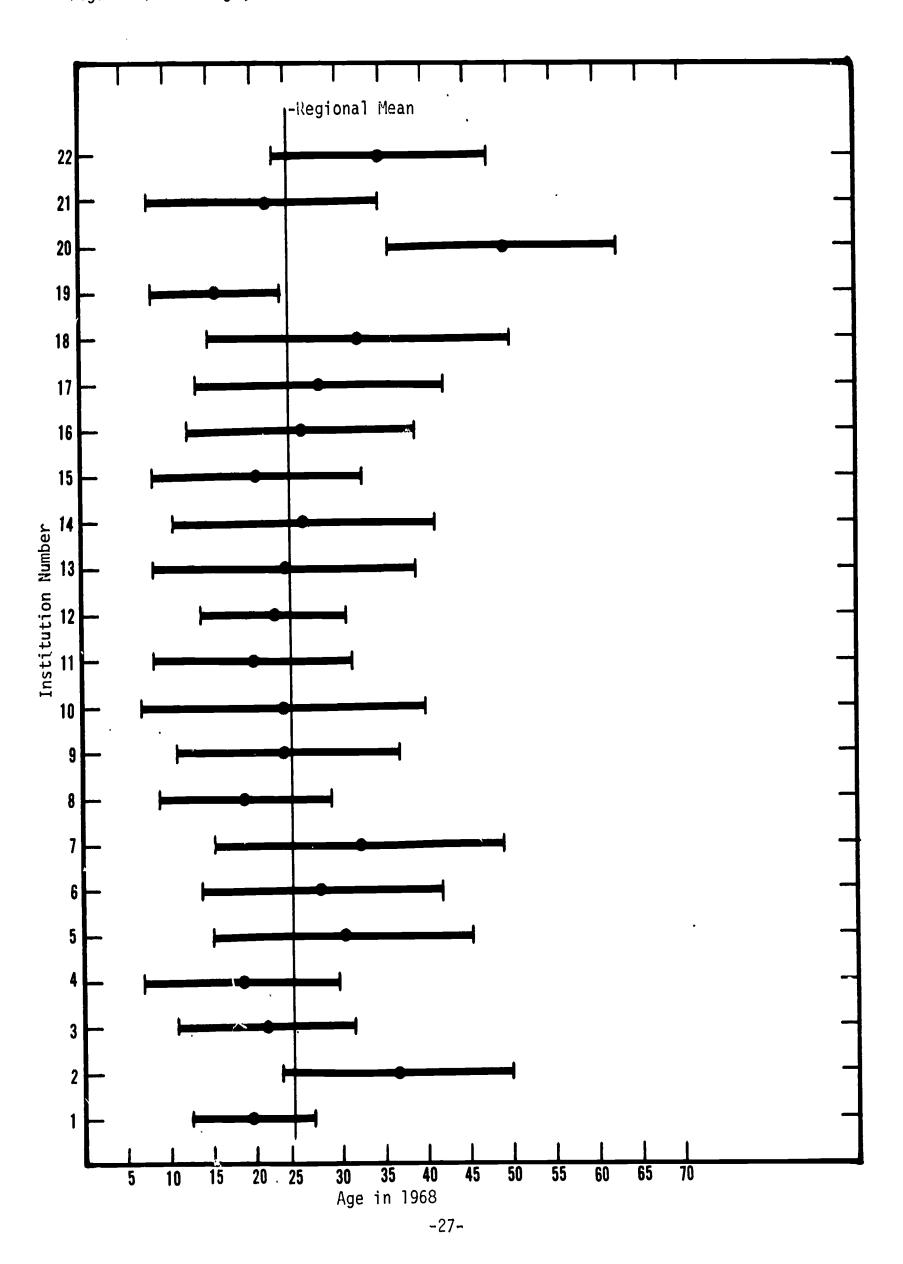


Figure 3. Mean IQ-SQ, \pm one standard deviation, all institutions.

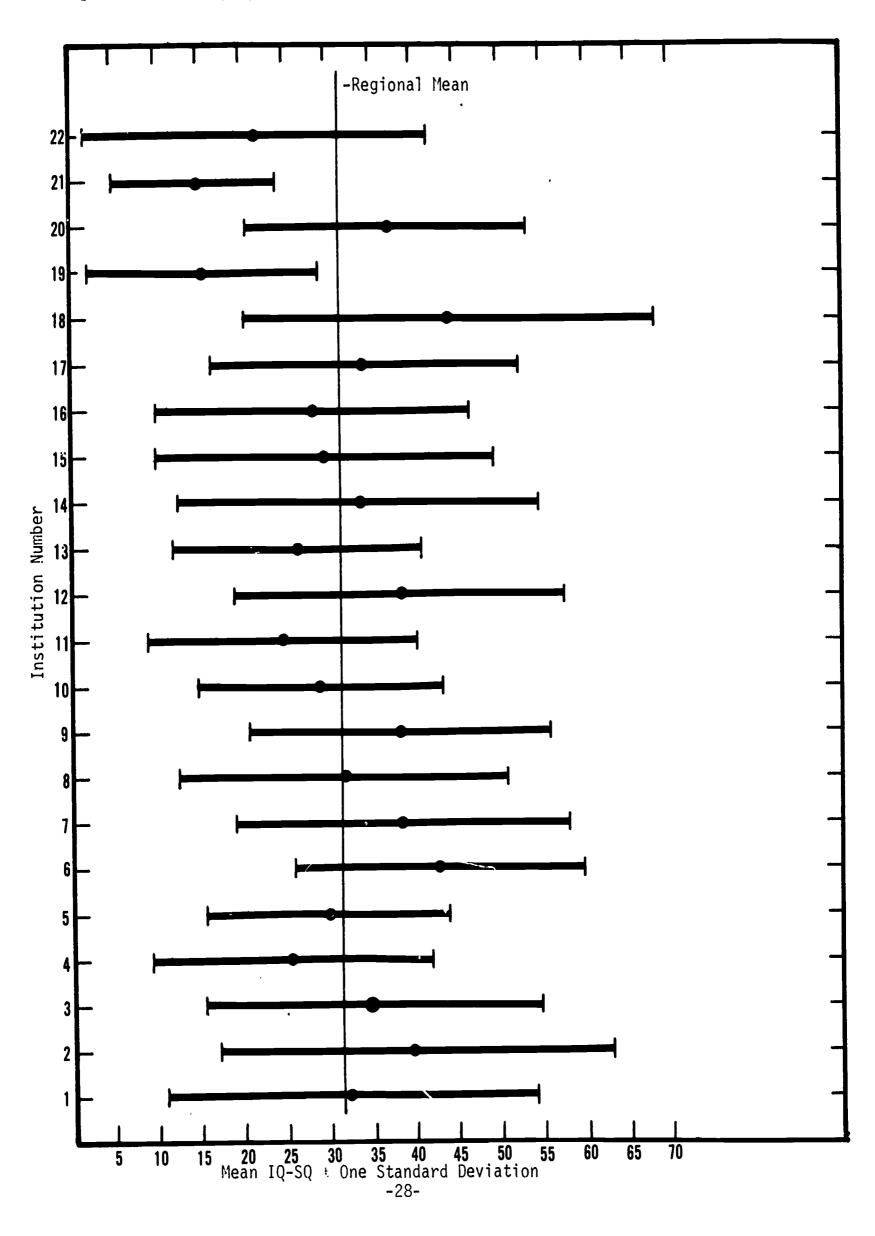




Figure 4. Mean years institutionalized, ± one standard deviation, all institutions.

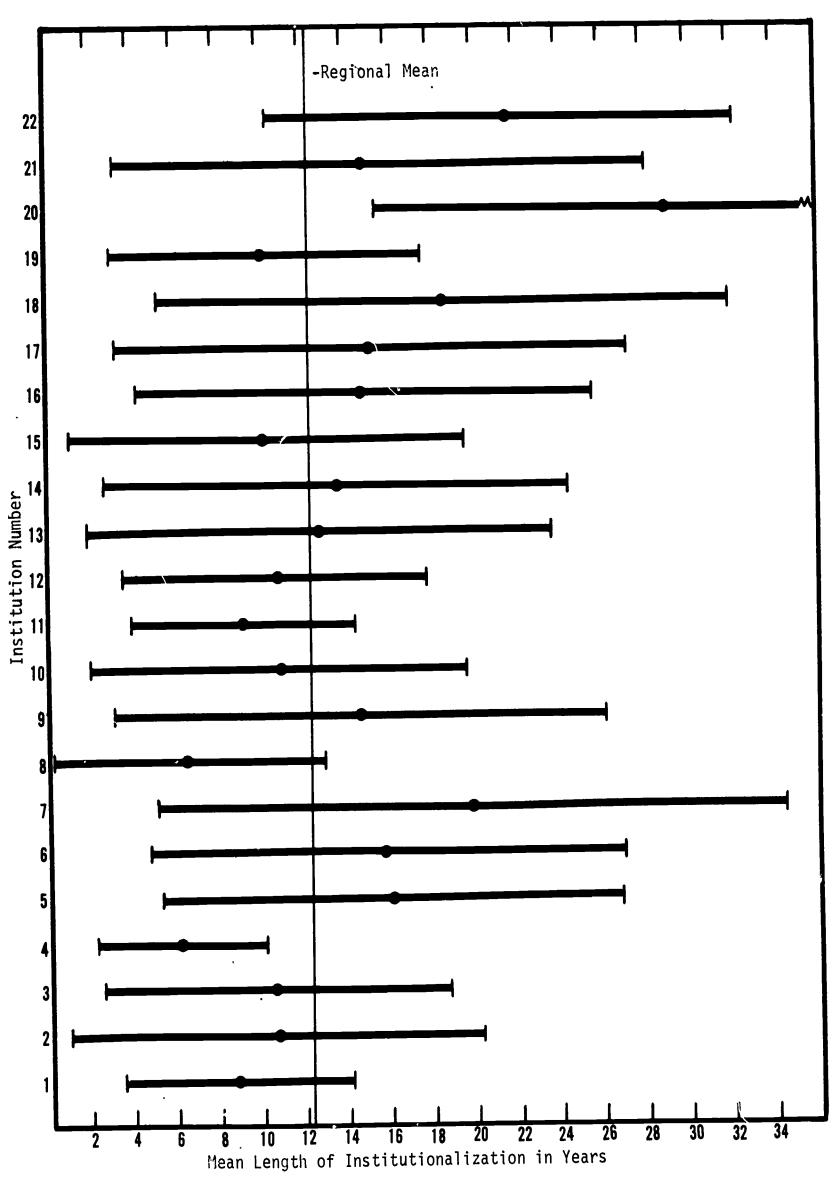
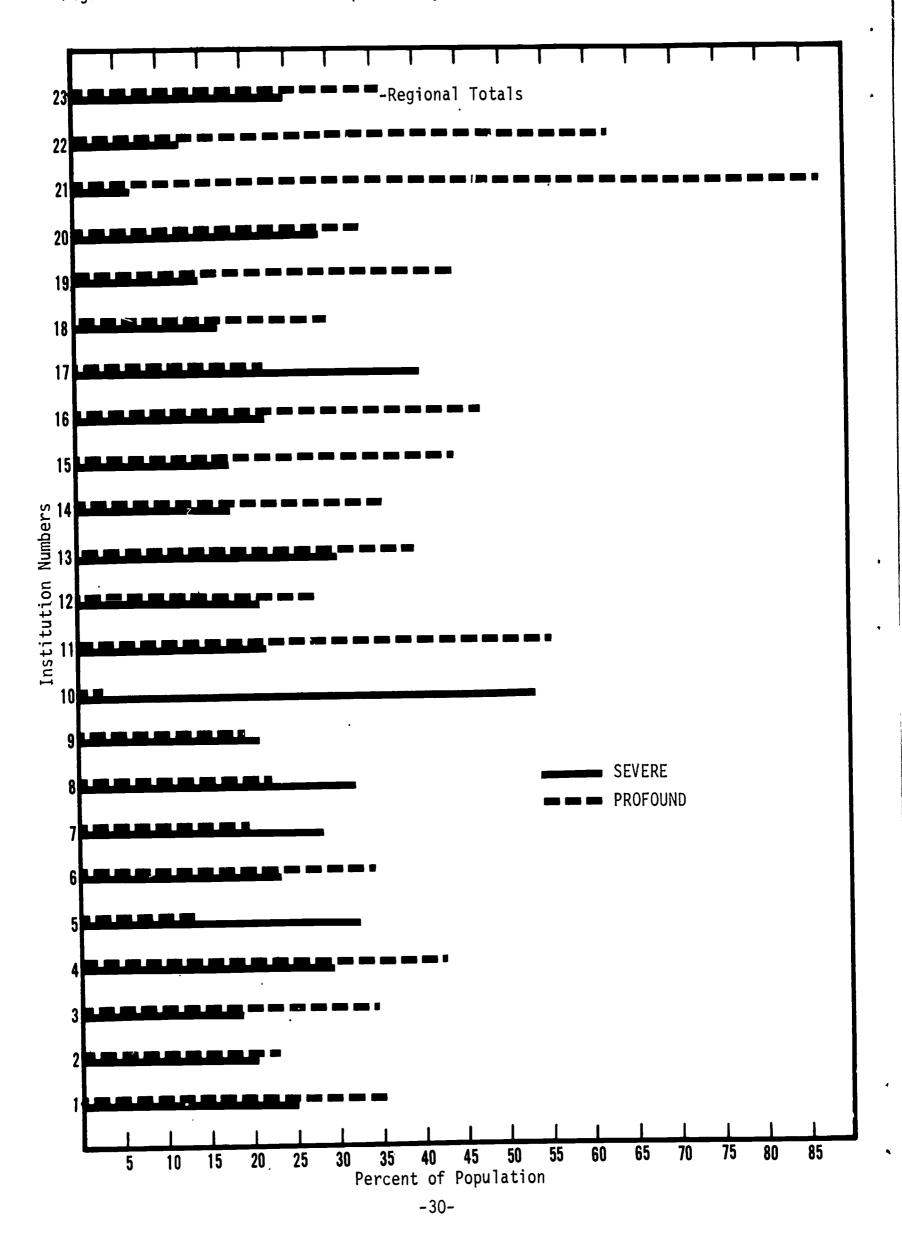


Figure 5. Percent of residents profoundly and severely retarded, all institutions.



<u>School Program Attendance</u>. In 1961 the National Association for Retarded Children's Committee on Residential Care conducted a survey of educational programs and attendance at 111 institutions across the country. The results, published in 1963, indicated that "25% of the mildly and moderately retarded residents in the eightynine institutions (responding to the survey) are enrolled in formalized education programs."

The data in Figure 6 indicate that most institutions in the West have considerably more than 25% of their residents in school programs. Of the regional population, 35.82% of the residents are in school programs. Two institutions, both serving special populations, do not have formal education programs.

The nature of these school programs was not considered when the data were

The nature of these school programs was not considered when the data were collected. In fact, the data in Figure 6 is the remainder when the number of residents <u>not</u> attending school programs of any kind is subtracted from the total population.

Nonambulatory Residents. Of the regional population, 24.5% are nonambulatory. In Figure 7, the special nature of some of the institutions is very apparent. There is relatively little variation in the distribution of this behavioral handicap among institutions serving a general population.

Non-speaking Residents. Figure 8 indicates the percentage of residents who do not speak at all. Of all residents, 42.85% do not speak. The variability of this particularly critical behavior handicap is considerable. The extent of this problem over all institutions seems greater than is generally recognized.

<u>Toilet Training</u>. This apparently mundane problem is seen to be of significance in Figure 9. Again, the special purpose institutions represent the extremes of the problem with the variability among institutions the major feature of the remaining data.

<u>Self-destructiveness</u>. Figure 10 indicates that self-destructive behavior is frequently observed with 5% of the total population. While this is not overpowering in terms of numbers, the nature of the behavior is severe.

It seems remarkable that there is so little inter-institutional variability. In this instance, the extremes are represented by institutions serving a general population.

As indicated earlier, these data were selected from Appendix B to illustrate the variety and depth of data collected and tabulated. The data contained in the Appendix is worthy of careful study since they represent a detailed description of the population of institutionalized retardates in the West. Scanning the figures for individual institutions, it is clear that there is considerable variability within each of the variables listed. It is apparent that, to the



Figure 6. Percent residents attending school programs, all institutions.

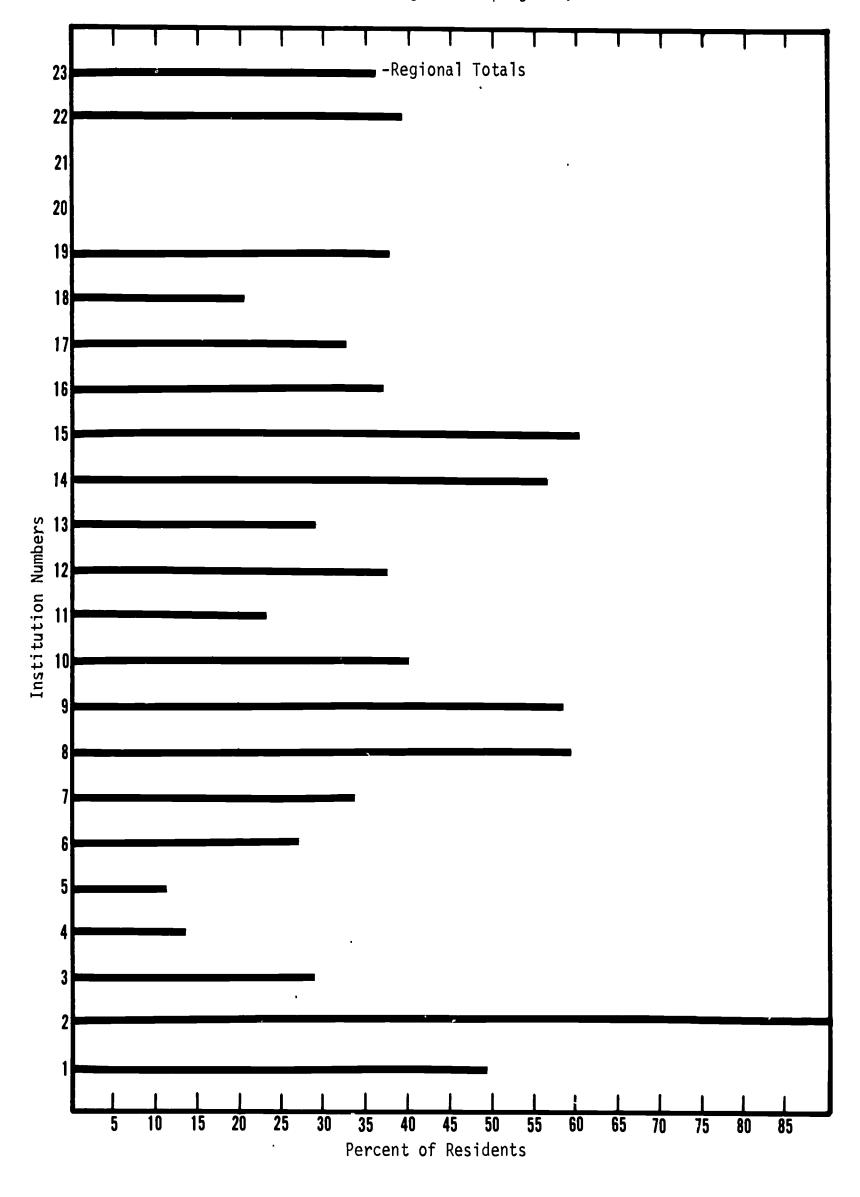




Figure 7. Percent residents unable to walk alone, all institutions.

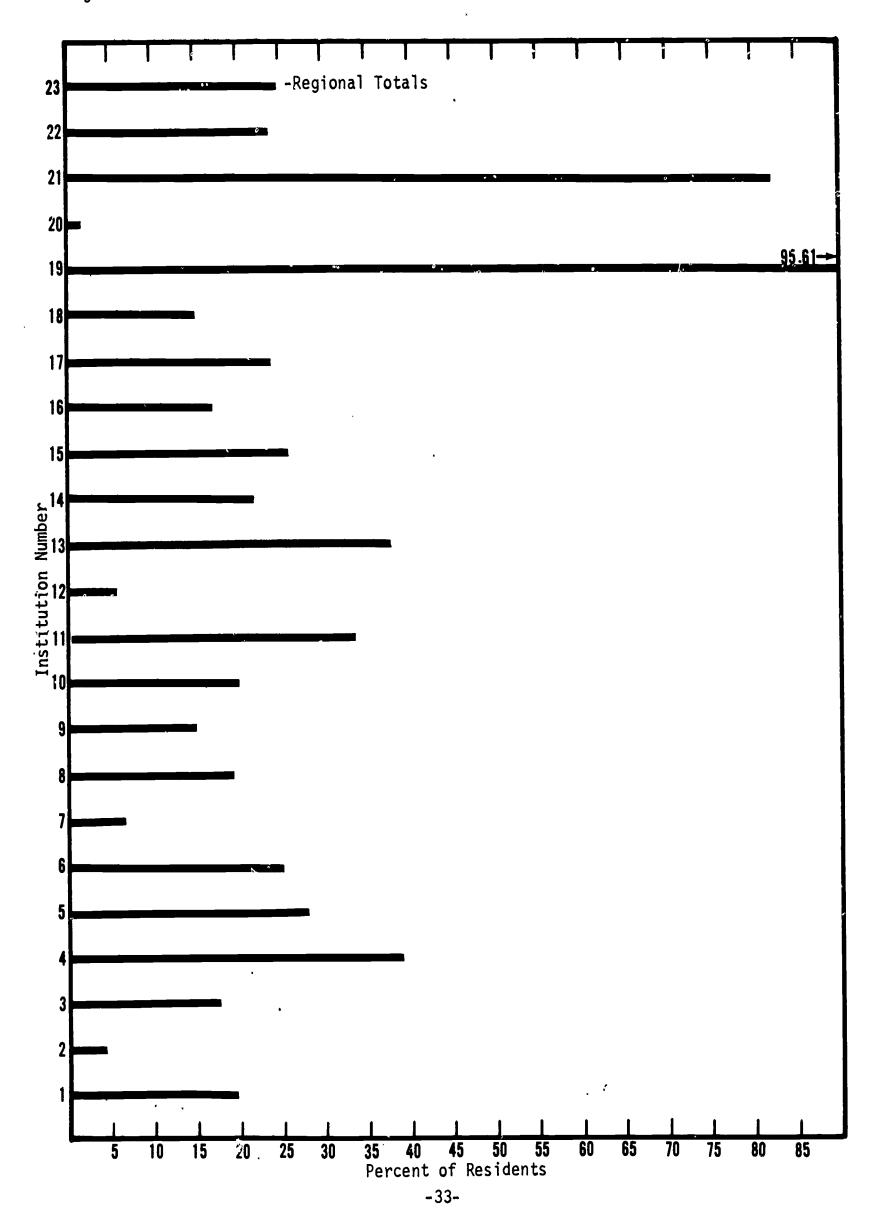




Figure 8. Percent residents with no speech, all institutions.

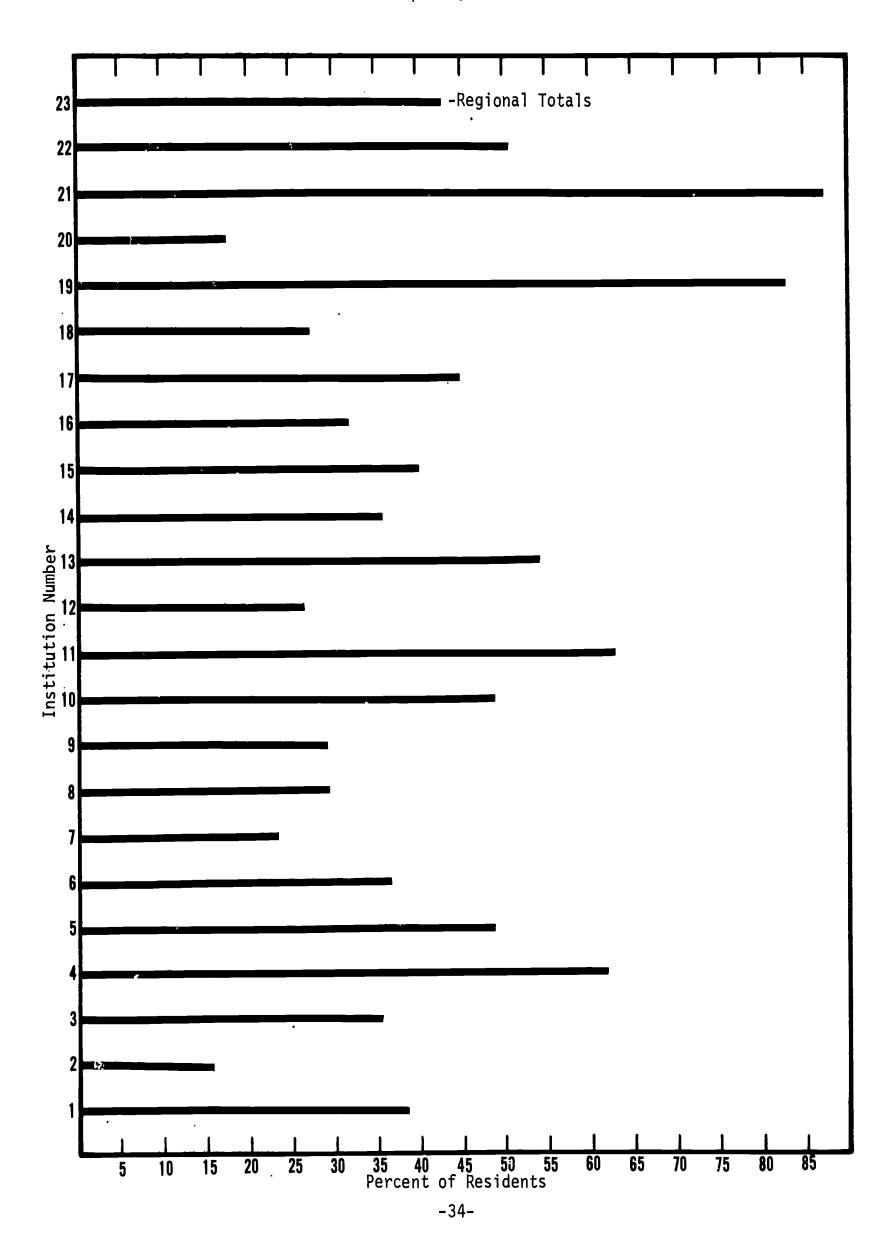




Figure 9. Percent residents not toilet trained, all institutions.

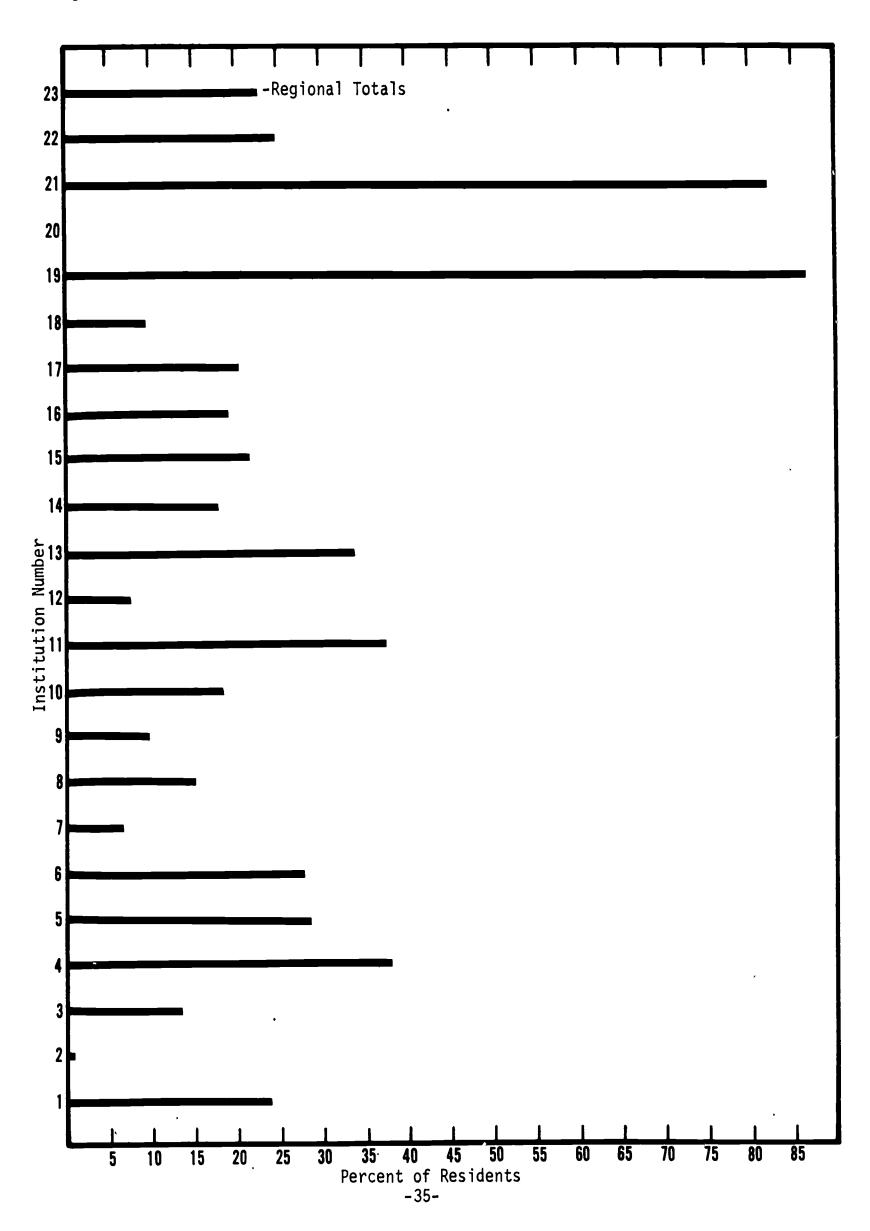
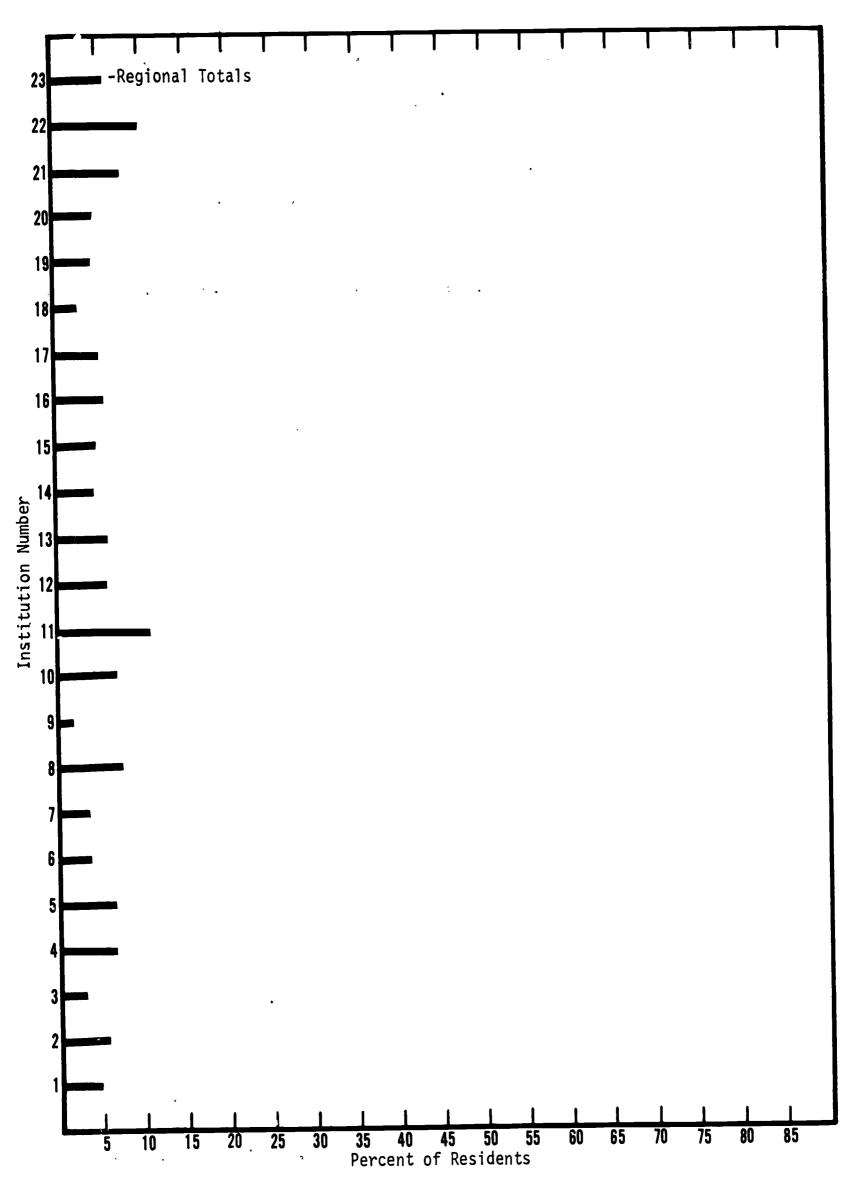




Figure 10. Percent residents frequently self-destructive, all institutions.



extent that these variables represent problems, the problems exist in all institutions. However, the magnitude of the problems varies across institutions.

It is logical to assume that state laws governing institutions accounts for a large part of the differences in population characteristics. But there are certainly other factors involved as well. The factors, and their relative contribution to the characteristics of institutional populations, is an empirical question that has not been adequately studied..

Effect of Four Major Variables

Because of the large number of variables involved in the census, it is impossible to describe all the possible relationships among all the variables. In a later section of this report, several studies relating specific variables to others are described. In this section, however, the attempt will be made to describe in general terms the effects of four major variables: sex, age, level of retardation, and diagnosis. These four variables were chosen for consideration for two reasons. First, these variables immediately come to mind as major general descriptive characteristics of a patient which might have considerable effects on his behavior and abilities. Secondly, it was empirically determined that two of these variables - sex and diagnosis - have a surprisingly little effect on any of the other variables and, conversely, the other two have a surprisingly profound effect.

Sex. Each of the variables comprising the ten groups described on pages 19 to 24 were investigated in terms of sex differences. The lack of any difference due to sex in most of these variables is remarkable. For example, it can be seen from Table XVI that about 33% of the total population are rated as at least occasionally exhibiting aggressive behavior. A breakdown in terms of sex showed the 32% of the males are so rated as are 33% of the females. Similarly, almost all the other variables showed no significant difference between males and females; in fact, the figures are virtually identical for the two sexes, i. e., within two or three percentage points. Only one variable showed a difference of more than ten percentage points: 27% of the males and 39% of the females are on a special diet.

<u>Diagnosis</u>. The relation of diagnostic category to the other variables is a bit more complex. In this case, the major diagnostic categories were investigated and, with some exceptions, found to be remarkably similar in their general characteristics, their abilities, and their behavior. The exception may be summarized as follows:



- 1. Phenylketonurics and those patients diagnosed as cultural-familial have a far greater number of relatives in mental institutions. The percentages are 25 and 40 respectively, whereas no other group shows greater than 9%.
- 2. Mongoloids and cultural-familial have virtually no seizures, whereas every other type of mental deficiency show at least 10% and sometimes as much as 34% of the patients with seizure problems.
- 3. Mongoloids and the psychogenic-functional disorders have virtually no basic ambulatory or arm-hand problems, and although these groups have considerable speech difficulties, they are impaired to a lesser extent than the other groups.
- 4. Similarly, mongoloids and the psychogenic-functional groups are generally better able to care for themselves.

There are surprisingly little differences in the behavior ratings (Group 10) among all the diagnostic groups. Specific differences in this area with respect to mongoloids and phenylketonurics are described later in this report.

Age and Level of Retardation. By far, the greatest effect upon virtually all the variables was found to be due to age and level of retardation of the patient. These two variables will be discussed together because they show considerable interaction such that, if treated separately, they sometimes mask each other's effects.

In general, difficulties increase directly with level of retardation (with the exception of the normals), and inversely with age. Tables XVII and XVIII show the typical relationship. Table XVII deals with the effect of level of retardation upon the extent to which help is required in the use of the toilet. Table XVIII presents similar data for age.

When the two variables are combined, a new aspect of the relationship appears. The data are shown in Table XIX. Within each cell is shown the percent of those residents needing help. For example, 51% of the profoundly retarded patients, age 36 to 88, are not able to use the toilet without help, whereas only 19% of the severely retarded in this same age group need help. The dotted line divides each column such that above the line, fewer than the total (42%) need help, while below the line a greater percent need assistance. (The normals in each age group are not considered in this division since they represent a special problem.)



Table XVII. Relationship between level of retardation and independent toilet use.

| Level of Retardation | Percent within Each Level Requiring Help |
|----------------------|--|
| Normal | 19 |
| Borderline | 7 |
| Mild | 6 |
| Moderate | 13 |
| Severe | 40 |
| Profound | 77 |
| Total population | 42 |
| | |

Table XVIII. Relationship between age and independent toilet use.

| Age Group | Percent within Each Age Group Requiring Help |
|------------------|--|
| 1- 5 | 93 |
| 6-10 | 84 |
| 11-15 | 58 |
| 16-20 | 44 |
| 21-35 | 29 |
| 36-88 | 19 |
| Total population | 42 |

Table XIX. Effect of age and level of retardation on independent toilet use.

| Level of Retardation | 1-5 | 6-10 | <u>Ago</u> 11-15 | <u>16-20</u> | 21-35 | <u>36-88</u> | Total Population |
|----------------------|------|------|---------------------|--------------|-------|--------------|---------------------|
| Normal | 80 | 100 | 40 | 11 | 15 | 12 | 19 |
| Borderline | 100 | 39 | 13 | 6 | 5 | 4 | 7 |
| Mild | 50 | 44 | 9 | 5 | 4 | 4 | 6 |
| Moderate | 78 | 54 | 18 | 12 | 7 | 7 | 13 |
| Severe | 93 | 83 | 55 | 39 | 22 | 19 | 40 |
| Profound | 100 | 98 | 91 | 81 | 63 | 51 | 77 |
| Total population | n 93 | 84 | 58 | 44 | 29 | 19 | 42 |

It can be seen from Table XIX that while age and level of retardation each have a profound effect on toilet ability they compensate for each other to some extent. That is, a severely retarded individual, for example, is likely to attain independence at a later age than a moderately retarded individual. This principle applies to virtually all the abilities; in fact, the pattern exists to at least some extent within most of the WICHE data.

The implications of the data presented in this entire section are clear. Diagnosis tells one far less about the abilities and potentials of a mentally retarded patient than does level of retardation. This finding, together with the finding that over half of the patients are diagnosed as either "unknown prenatal influence" or "psychogenic-functional," shows that diagnosis is a major difficulty and that prediction and prognosis on the basis of diagnosis alone is extremely difficult.

On the other hand, level of retardation consistently leads to good prediction and taken together with age provides an excellent indication of the performance of the individual. Finally, the fact that age and level of retardation seem to compensate for each other tends to support a developmental theory of retardation as opposed to a "type" theory based upon the characteristics of the different types of retardation. That is, one of the apparent main effects of retardation is to arrest or slow down the rate of development rather than prevent it.



RESEARCH USES OF THE REGIONAL DATA

There is no question as to the wealth of information contained in the regional data. However, these data are descriptive and not usually sufficient for hypothesis testing. Unless it is possible to get back to individual residents, a correlational rather than an experimental approach is imposed by the nature of the data. However, data relating to research problems in mental retardation is available from the census and is useful in approaching many of these problems. The following examples of uses of the data are presented in the order that variables involved occur on the data collection form.

Birth Date - and Mental Retardation

MacMahon and Sowa (1961) provide a thorough review of the literature having to do with monthly and seasonal variations in the frequency that mentally retarded individuals are born. They cite research by Knoblock and Pasamanick (1958) who report a heightened incidence of retardation among those born in January, February or March, and a lowered incidence among those born in June, July and August, and further show an increased frequency of retarded individuals born in those years when summer temperatures are warmer. MacMahon and Sowa, in summarizing their discussion of Knoblock and Pasamanick, state that, "These observations are, in our opinion, among the most significant recent observations in this general area (1961, p. 51)."

Knoblock and Pasamanick believe that the higher the temperature that the mother is exposed to during the eighth to twelfth week of gestation, the more likely it is for retardation to occur in the offspring. A reverse position can be taken.

It is known that some kinds of maternal illness produce developmental anomalies in the fetus. The maternal illness most closely associated with retardation is rubella, but a wide variety of diseases including respiratory infections significantly increase the frequency with which developmental anomalies including retardation occur (American Medical Association, 1964, pp. 17-18; Shapiro, Ross, & Levine, 1965), with the probability of fetal damage being greatest in the first trimester -- possibly in the first eight weeks -- following conception (AMA, 1964, pp. 17-18). Epidemiological evidence (e.g., Gordon, 1965, Rosenbaum, Edwards, Frank, Pierce, Crawford, & Miller, 1965) suggests that children conceived in fall or winter (October through March), far more frequently than children conceived in spring or summer (April through



September), should have had mothers who had one of the diseases known to be associated with retardation (along with other developmental anomalies) during the first three months of the offspring's fetal life. If so, a greater proportion of those individuals conceived in October through flarch should be found in the categories of retardation that pertain to prenatal causes of retardation than those conceived in April through September.

The 1967 WICHE census provides data concerning 23,211 residents. Of these residents, 2,672 are in AAMD categories 11, 22, 31, and 61, all of which involve prenatal causes for retardation. Month of birth is available for 2,666 of these persons. The frequency and percentage of individuals in these diagnostic categories born in each month is presented in Table XX.

If one compares by month those conceived in the fall and winter (October through March) and born July through December with those conceived in the spring or summer (April through September) and born January through June by means of a sum of ranks test (Walker & Lev, 1953, pp. 434-435), those conceived in the October through March period show a significantly higher proportion of retardation resulting from prenatal influences (z = 2.56, p = <.01).

The data reported herein are in opposition to those reported by Knoblock and Pasamanick, possibly because Knoblock and Pasamanick studied <u>all</u> individuals admitted to a school for the retarded born in half of the months of the year, while the present study is only of those retarded as a result of prenatal causes (thus excluding nearly 90% of the entire institutional population) for all of the months of the year.

Birth Date - and Down's Syndrome

Some researchers have suggested significant seasonal variations in birth rate among individuals with Down's Syndrome. The monthly distributions for all cases of Down's Syndrome in the 1967 census, as well as for karyotyped trisomies, translocations, mosaics, and multiple chromosomal anomalies (trisomy plus sex chromosomal anomaly) are presented in Table XXI.

These data do not appear to offer support for the belief that individuals with Down's Syndrome show significant seasonal variations in birth rate.

Sex of Residents: On the Preponderance of Males among Individuals Diagnosed as Mentally Retarded.

Significantly more males than females are found at each level of retardation, including the "severe" and "profound" levels. These data suggest that explanations for the preponderance of males based



Table XX. Month of birth, frequency, and percent of retarded in AAMD categories 11, 22, 31, 61.

| | <u>Frequency</u> | Percent |
|-----------------------------------|------------------|---------|
| January | 216 | 8.08 |
| February | 214 | 8.01 |
| March | 209 | 7.82 |
| April | 188 | 7.04 |
| May | 212 | 7.93 |
| June | 206 | 7.71 |
| July | 239 | 8.94 |
| August | 213 | 7.97 |
| September | 252 | 9.43 |
| October | 257 | 9.62 |
| November | 229 . | 8.57 |
| December | 231 | 8.65 |
| Unknown or errors in key punching | 6 | 0.22 |

Table XXI. Birth months of mongoloids (Down's Syndrome).

| | | | Karyotyped | Cases | _ |
|------------------------|------------------|---------|---------------|-----------------|------------------|
| <u>Month</u> | <u>All Cases</u> | Trisomy | Translocation | Mosaic | Multiple Anomaly |
| January | 221 (8.48%) | 26 | 3 | | |
| February | 183 (7.02%) | 18 | | 2 | |
| March | 219 (8.40%) | 23 | 3 | 2 | 1 |
| April | 196 (7.52%) | 20 | 2 | | 1 |
| May | 212 (8.14%) | 18 | | 1 | |
| June | 216 (8.29%) | 15 | 1 | 1 | |
| July | 220 (8.44%) | 19 | 3 | 2 | |
| August | 209 (8.02%) | 28 | | 1 | 1 |
| September | 227 (8.71%) | 26 | 1 | 2 | |
| October | 222 (8.52%) | 21 | 3 | 3 | |
| November | 227 (8.71%) | 21 | 2 | 3 | |
| December | 246 (9.44%) | 18 | 3 | 1 | |
| Mispunched or blank | 8 (0.31%) | 1 | | | |
| TOTAL | 2606 | 254 | 21 | 18 [,] | 3 |

on the notion of differential environmental demands or on sex differences in aggression or in ability to communicate are not sufficient. It is suggested that males may be more susceptible to extrinsic agents causing retardation or else that some forms of retardation have a sex linked genetic basis.

One of the most reliably obtained findings in the area of mental retardation with regard to studies conducted in the United States, is that there are more males than females among the retarded, whether in institutions (New York State Department of Mental Hygiene, 1958; U. S. Office of Health, Education, and Welfare, 1966) or in epidemiological studies of retardates in the community (New York State Department of Mental Hygiene, 1955). The 1966 data were examined in order to present data on sex differences in frequency at various levels of retardation among the 19,752 retarded <u>Ss</u> of known level (borderline, mild, moderate, severe, profound) of retardation. These data will serve as the basis for a discussion of various explanations for the preponderance of males among the retarded. The number of <u>Ss</u> of each sex, at each level of retardation, along with the male-female ratio at each level, are presented in Table XXII.

Binomial tests (Siegel, 1956, pp. 36-42) show males to be significantly over-represented (z=(6.00 at each level, p=(.000001))) at each level of retardation. It should be noted too that the U. S. Department of Health, Education, and Welfare report (1966) of a 1964 patient census of over 68,000 patients shows males to be more frequent in each of the twelve major categories of retardation (including an "unclassified" category) used therein.

Explanations for the higher proportion of males than females among retardates include the following:

- 1. Boys are more aggressive than girls. They get in trouble more often, therefore are studied more often, and their mental defect discovered in the course of their being studied (Lemkau, 1956).
- 2. Boys are retarded as compared with girls in communication skills and are more often diagnosed as retarded for this reason (Lemkau, 1956).
- The culture places greater demands on boys than girls (Masland, Sarason, and Gladwin, 1958, p. 263).
- 4. Brain damaged girls die at a higher rate (Gruenberg, 1964, p. 277).
- 5. Males are more susceptible to the extrinsic factors or agents which produce retardation (Gruenberg, 1964, p. 277).



Table XXII. Frequency of $\underline{S}s$, by sex, at various levels of retardation. 1

| Level of Retardation | <u>Sea</u> Male | <u>X</u> <u>Female</u> | Ratio of males to Females |
|----------------------|--------------------|---------------------------|---------------------------|
| Borderline | 465 | 278 | 1:0.60 |
| Mild | 1524 | 1079 | 1:0.71 |
| i1oderate | 2479 | 1952 | 1:0.79 |
| Severe | 3033 | 2414 | 1:0.80 |
| Profound | 3531 | 2997 | 1:0.85 |

1. The total number is less than the 23,443 in the 1966 WICHE census, since for some $\underline{S}s$, level of retardation was not indicated on the census form, and other residents of the institutions for the retarded were of normal ability.



Explanations 1, 2 and 3 appear to have relevance only at the higher levels of retardation and would not account for the preponderance of males at lower levels since it seems unlikely that sex differences in aggression, communication skills, or cultural demands would cause one sex more than the other to escape detection as being retarded when the retardation is severe or profound. One wonders whether they hold at the upper levels. For example, the supposed superiority of girls in communication skills appears to be largely a result of the fact that most language testing has been done by women experimenters (Cowan, Weber, Hoddinott and Klein, 1967) since sex of the experimenter is a more important source of variance than sex of S. Explanation 4 appears to run contrary to known data since, as Gruenberg notes, far more males are aborted than females, and male mortality rates (e.g., in this WICHE sample) clearly are higher than female at each age level. Gruenberg says, "Nonetheless, it's possible that certain conditions such as mongolism and hydrocephaly produce higher fetal and neonatal mortality in girls than in boys (1964, p. 277)." This may be true, but the fact that males are over-represented in each major diagnostic category suggests that this explanation is partial at best. Explanation 5, that boys are more sensitive than girls to the extrinsic factors or agents that produce retardation, would seem to be the best suited of the five explanations given above to account for the sex x level data presented herein. Another explanation perhaps complementary to Explanation 5 is that one or more as yet undiagnosed and relatively frequent varieties of mental retardation have a sex linked genetic basis.

IQ-SQ - The Predictive Utility of Psychometric Tests

Psychometric tests have been attacked from a number of points of view. This study investigates the degree to which one can predict the likelihood of an individual manifesting each of a variety of adaptive and problem behaviors from psychometric test scores in general, from IQ scores, and from SQ scores. The data reveal that psychometric scores are of considerable predictive power and that IQ is of approximately the same predictive value as is SQ. Most of the variance in behavior between diagnostic groups can be predicted from IQ as can the variance in adaptive behavior between residents of different institutions.



The use of psychometric tests in general, and of IQ tests in particular, as a means of establishing an individual's present level of competence and of predicting present and future levels of performance has been subjected to considerable criticism in recent years. Some of this criticism (e.g., Jastak, 1967) comes from those who state that no presently available tests adequately assess mental competence. Other criticism have come from those espousing the operant conditioning position. For example, Buddenhagen (1967), writing from an operant point of view, says that "...the IQ score is the most trivial bit of information that can be known about a person (1967, p. 40)." Others are not opposed to psychometric tests in general, but believe that tests of social maturity provide more meaningful information than do IQ tests.

The 1967 WICHE IQ-SQ data was employed to determine the utility of IQ tests as opposed to other methods of classifying individuals in the prediction of the behavior of individuals. The data is uniquely suited to this kind of study since it is with the mentally retarded group that the controversy concerning the utility of psychometric tests is chiefly concerned.

Of the <u>Ss</u> studied, 7,619 have IQ scores from the Binet or one of the Wechsler tests; 6,599 have SQ scores, nearly all of them from the Vineland Social Maturity Scale; and 5,919 have IQ scores from tests other than the Binet or one of the Wechsler tests.

These data were used in a number of analyses. First, the relative effectiveness of IQ vs. SQ scores in predicting behavior was established. Second, the degree to which differences in ability between diagnostic groups are predictive of behavioral differences between these groups was investigated. Third, the often expressed idea that big institutions are bad institutions (see Cleland, 1965, for a review of this literature) was examined in terms of differences in mean ability level of residents that are associated with institutional size.

Table XXIII consists of the following columns of data: (1) the relation of resident's ability, whether measured in terms of IQ or SQ, to the occurrence of adaptive and maladaptive behaviors; (2) the relation of Wechsler and Binet IQ scores to the same behaviors; (3) the relation of SQ scores to these behaviors; (4) the relation of IQ to behavior in a single institution in which 98.5% of the residents had IQ test scores; (5) the relation of SQ to behavior in a single institution where 100% of the residents had SQ scores; (6) the relation of the mean IQ-SQ of individuals in each to ten different diagnostic categories to the proportion of individuals in these diagnostic groups exhibiting these behaviors; and (7) the relation of mean institutional IQ-SQ to the proportion of residents

in these institutions capable of a number of adaptive behaviors. Column 1 deals with the general question of whether one can predict behavior from psychometric test scores. Columns 2 and 3 compare the power of IQ and SQ in predicting behaviors. Columns 4 and 5 also deal with the predictive power of IQ vs. SQ, in this case using two comparable institutions. (The institution in Column 4 had a census population of 898 with a mean IQ of 28.20 and a standard deviation of 20.15; the institution in Column 5 had a census population of 915 with a mean SQ of 31.11 and a standard deviation of 20.99.) Column 6, in establishing the amount of the variance in behavior between diagnostic groups that can be accounted for in terms of IQ-SQ, is, in a sense, a means of evaluating the utility of the present system of diagnostic categorization. The last column, when considered along with data regarding the relation of institutional size to mean institutional IQ-SQ, sheds some light on the effects of institutional size on adaptive behavior.

The correlations in column 1, 2 and 3 suggest that psychometric data can tell us a fair amount about a resident. They allow one to predict at a far greater than chance level of success the probability of the \underline{S} emitting certain adaptive behaviors and of being exposed to or judged capable of learning from certain varieties of training experience. Test scores tell far less about the probability that certain "problem" behaviors will occur, but still in a number of instances allow prediction at a considerably better than chance probability of success. The writers had believed that a combined \underline{S} pool of IQ and SQ tested $\underline{S}s$ would show more substantial correlations than either the IQ or SQ $\underline{S}s$ alone since they believed that IQ tests were used chiefly with high ability \underline{S} s; SQ with the more severely retarded. This was not the case: the correlations were of the same magnitude for either the IQ or the SQ $\underline{S}s$ alone as they were for the combined group of $\underline{S}s$. It was discovered that IQ tests often are used with quite severely retarded $\underline{S}s$ and SQ tests with comparatively bright ones. Despite the fact that SQ tests directly measure social behavior (e.g., dresses self), and were constructed as a result of the belief that IQ tests did not adequately measure social behavior, the IQ is almost as adequate a predictor of socially adaptive behavior and seems slightly superior to the SQ as a predictor of "problem" behavior. The same conclusions concerning the predictive power of IQ vs. SQ are supported by the comparisons of institutions using IQ (column 4) and SQ (column 5) measures. The correlations are of the same magnitude but generally are larger than those presented in the first three columns, probably because inter-institutional variation in treatment and in rating behavior is eliminated. Column 6 has to do with the relation of mean IQ-SQ of individuals



Table XXIII. IQ-SQ as predictors of behavior.

| <u>Behavior</u> | 1 (r _{pb}) <u>(N=20,137)</u> | 2 (r _{pb)} (N=7619) | 3 (r _{pb}) (N=6599) | 4 (r _{pb}) (N=898) | 5 (r _{pb}) (N=915) | 6 (r) (N=10) | 7 (rho) <u>(N=18)</u> |
|--|--|------------------------------------|-------------------------------------|------------------------------------|------------------------------------|--------------------|-----------------------------|
| Does not speak understandably* | 58** | 54 | 49 | 61 | 62 | 97 | 78 |
| Does not understand speech of others | 49 | 46 | 42 | 56 | 62 | 93 | 77 |
| Night bedwetting | 50 | 45 | 47 | 55 | 57 | 85 | 83 |
| Requires help in dressing | 59 | 53 | 53 | 64 | 67 | 96 | 84 |
| Does not brush own teeth | 56 | 50 | 50 | 52 | 66 | 95 | 72 |
| Cannot feed self with implements | 43 | 37 | 43 | 48 | 62 | 66 | 66 |
| Requires help in grooming | 41 | 37 | 38 | 38 | 52 | 97 | 61 |
| Not toilet trained | 56 | 47 | 55 | 61 | 69 | 92 | 75 |
| Is in school | .40 | .31 | .53 | .31 | .69 | .75 | |
| Is, or is candidate for, ward helper | .55 | . 46 | .55 | .51 | .64 | .94 | |
| Is on, or is candidate for, work project | .54 | .47 | .51 | .60 | .62 | .96 | |
| Is on, or is candidate for, work reward system | .36 | .30 | .40 | .61 | .51 | .97 | |
| Could be placed in family care | .33 | .22 | .37 | . 47 | .56 | .83 | |
| Could be placed out | . 40 | .37 | .36 | .48 | . 47 | .95 | |
| Hyperactive | 08 | 11 | 03 | 08 | .04 | 54 | |
| Passive | .15 | 16 | 18 | .05 | 07 | 87 | |
| Runs and paces | 08 | 12 | 02 | 13 | .04 | 56 | |
| Sex with opposite sex | .16 | .16 | .08 | . 17 | .10 | .77 | |
| Sex with same sex | .13 | .06 | .14 | .26 | . 19 | .69 | |
| Masturbates privately | .06 | .03 | .01 | 01 | .02 | .51 | |
| Masturbates publicly | 14 | 17 | 12 | 24 | 10 | 90 | |
| Smears feces | 23 | 26 | 17 | 36 | 18 | 88 | |
| | | | | | | | |



N

Table XXIII. (continued)

| Behavior | 1 (r _{pb}) (N=20,137) | 2 (r _{pb}) (N=7615) | 3 (r _{pb}) (N=6599) | 4 (r _{pb}) (N=898) | PD | 6 (r) (N=10) | 7 (rho) (N=18) |
|---------------------------|---------------------------------------|-------------------------------------|-------------------------------------|------------------------------------|-----|--------------------|----------------------|
| Exposes self | 16 | 16 | 12 | 28 | 09 | 82 | |
| Refuses to wear clothing | 17 | 19 | 13 | 19 | 15 | 83 | |
| Aggressive | .07 | .04 | .11 | .06 | .18 | 23 | |
| Holests children | .00 | 04 | .04 | 02 | 04 | 47 | |
| Attacks employees | 02 | 04 | 01 | 03 | 03 | 46 | |
| Attacks fellow residents | .04 | 01 | .11 | .01 | .12 | 37 | |
| Destroys clothing | 16 | 21 | 09 | 14 | 08 | 78 | |
| Upsets furniture | 05 | 10 | .01 | 04 | .08 | 71 | |
| Destroys property | 04 | 09 | .02 | 06 | .06 | 72 | |
| Breaks windows | .02 | 02 | .07 | 06 | .12 | 34 | |
| Bangs doors when secluded | 01 | 07 | .02 | 05 | .04 | 38 | |
| Self-destructive | 16 | 18 | 12 | 10 | 16 | 70 | |
| Requires restraints | 17 | 15 | 18 | 08 | 20 | 77 | |
| Likely to escape | 02 | 05 | .01 | 05 | .09 | 34 | |
| | | | | | | | |

^{*} Each behavior was pitted against other alternatives in the census item. For example, the item "Communicates to others" has the following alternatives: understandable, difficult to understand, makes sounds or signs, jabbers, no sounds, unknown. The first alternative was pitted against all others except "unknown," with <u>Ss</u> in the unknown category (103 of 23,211) being discarded.



^{**}With sample sizes of the magnitude of those in the first five columns, a very small correlation is significant in a statistical though not in any real-world sense. Therefore, the significance of correlations in these columns is not reported; correlations in column 6 are significant at the .05 level when the correlation reaches .60. Correlations in column 7 all are significant at the .01 level of confidence.

in different diagnostic groups (postnatal cerebral infections, mechanical birth injuries, asphyxia at birth, postnatal birth injury, phenylketonuria, congenital cerebral defect, mongolism, unknown structural defect, cultural-familial, functional retardation) to the proportion of individuals in each of these categories rated as behaving in each of a variety of ways. While some diagnostic categories, such as Down's cases, do differ from IQ-SQ matched controls (Moore, Thuline, & Capes, 1968; Johnson & Abelson, in press) it seems clear from these data that most of the variance in behavior between groups can be accounted for in terms of ability level without further concern for diagnostic category. Finally, the correlation between mean institutional IQ-SQ and institutional size for the 18 institutions in the WICHE census (the nineteenth institution was excluded since it takes only severely neurologically damaged, multiply handicapped individuals) is .40, with larger institutions having duller residents. When the correlation between institutional size and mean institutional IQ-SQ is partialled out, only "speaks understandably" is significantly associated with institutional size. The correlations of mean institutional IQ-SQ and behaviors remain significant with institutional size partialled out. The major share of the variance between big and small institutions can be attributed to differences in IQ between big and small institutions rather than to size per se. (It would take a longitudinal study to determine whether the fact that big institutions have residents lower in ability level than do small institutions is a result of admittance practices or of what happens to the resident once admitted.)

These data demonstrate that one can predict a good deal from IQ-SQ, and that one can predict socially adaptive and maladaptive behaviors approximately as well from IQ as from SQ scores. Most of the variance in behavior between diagnostic groups can be attributed to differences between these groups in ability level, as can most of variance in behavior between residents of different institutions. Somewhat surprisingly, IQ allows one to predict problem behaviors slightly more adequately than does SQ, though neither measure is as powerful in prediction as it is with regard to adaptive behavior -- perhaps because maladaptive behaviors have a lesser cognitive component than do adaptive behaviors; certainly because maladaptive behaviors are rated less reliably (Abelson & Payne, in press). The data as a whole support the position that ability level, whether measured by IQ or SQ, is a useful predictor of a variety of behaviors in the retarded.



IQ-SQ - Institutional Residents with Normal Intelligence

Szasz (1961, 1963) has taken the position that many individuals committed to institutions for the mentally disturbed are not, in fact, so disturbed as to require hospitalization. Rather, they are bothersome to someone, have few resources of their own with which to defend themselves, and are institutionalized as a result of the pressure exerted by those to whom they are bothersome.

The same may be true for a portion of those individuals institutionalized as mentally retarded. If one looks at data concerning first admissions to institutions for the mentally retarded, it comes as something of a surprise to find that 7.06% (N = 754 of a total group of 10,683 Ss) of the individuals admitted to institutions for the retarded in 1964 are of borderline or higher ability (U. S. Department of Health, Education & Welfare, 1966, 1-48). Further, in the 1966 census it was found that of the 23,443 residents, 83 were of IQ 90 or above, and 259 were in the IQ 80-89 range. In all, IQ 80-plus residents made up 1.45% of the institutional population for whom IQs were available.

Since most individuals in this ability range function adequately in general society and are not institutionalized, it is of some interest to determine why these particular individuals are institutionalized. More specifically, two questions present themselves: How is it that these individuals are committed in the first place? Once committed, why are they retained within the institutions to which they were committed? The U. S. Department of Health, Education and Welfare (HEW) publication cited above provides data concerning the first question; the WICHE census provides information concerning the second.

The HEW census provides information about the ability level of individuals admitted during the year 1964, the total number of patients admitted in 1964, the average number patients institutionalized during 1964, and the money expended during 1964, for 41 of the 50 states. The writers determined, by state, the total number of patients admitted, the percent of this number that fell in the normal and borderline group, and the average expenditure per year for each patient. The correlation between amount of money spent per patient in a given state in 1964 and the percent of borderline and normal individuals admitted in 1964 is of zero order, despite the fact that the ranges of percents of normal and borderline individuals admitted (0.00% for Arkansas, Hawaii, Idaho, Oklahoma, Rhode Island, South Carolina, Utah, and West Virginia to 32.00% for Mississippi) and of money spent per year per patient (\$4,524 for West Virginia to \$863 for Mississippi) are large ones. However, if one looks at the number of patients per state and the number of new patients admitted during 1964, a clear relation may be discerned, as shown in Table XXIV.



Table XXIV. Number of residents per state, number of new admissions, and percent of normal and borderline individuals admitted.

| | Number of Residents | | | | |
|---|--------------------------|-------------|-------------|--------------|--|
| | 1-750 | 751-1500 | 1501-3000 | 3001 or more | |
| | (8 states) | (11 states) | (9 states) | (13 states) | |
| Median % normal and 1 borderline admitted | 0.40 | 3.39 | 4.75 | 6.96 | |
| | Number of New Admissions | | | | |
| | 1-75 | 76-150 | 151-300 | 301 or more | |
| | (11 states) | (7 states) | (14 states) | (9 states) | |
| Mediar % normal and borderline admitted | 2.18 | 3.39 | 5.21 | 6.96 | |

Median, rather than mean, scores were used because the percent of admissions of normal and borderline individuals by states was markedly skewed.

Table XXV. Comparison of IQ 80-plus group with other ambulatory male residents regarding general statistics.

| <u>Variable</u> | IQ 80-plus | Other Ambulatory Males |
|------------------------|------------|------------------------|
| Number of residents | 59 | 9,538 |
| Age (years) | | |
| Mean | 28.1 | 25.0 |
| Standard deviation | 12.7 | 13.3 |
| Length of stay (years) | | |
| Mean | 11.4 | 12.3 |
| Standard deviation | 10.4 | 10.1 |
| IQ | | |
| Mean | 86.5 | 36.3 |
| Standard deviation | 4.8 | 19.3 |
| Height (inches) | | |
| i·1ean | 67.1 | 61.3 |
| Standard deviation | 6.0 | 8.7 |
| Weight (pounds) | | |
| ı1ean | 152.6 | 120.3 |
| Standard deviation | 39.5 | 42.3 |

Kruskal and Wallis (1952) H tests, corrected for ties, show each of these relations to be significant beyond the .01 level. These data demonstrate that normal and borderline individuals are more likely to be institutionalized if they come from states with large numbers of residents in institutions for the retarded and/or high numbers of new admissions. Perhaps, as number of patients and number of new admissions increases, concern for the individuals decreases. Possibly, too, in states with large populations, usually urban in character, more rigorous criteria exist for being considered intellectually normal.

Obviously, someone must have felt that each of these normal or borderline persons was sufficiently inept or socially incompetent to require removal from society. The HEW data provide no information on this point. The WICHE data deal not with first admissions but rather with individuals residing in institutions at the time the yearly census was taken. It seems reasonable to assume that of those individuals of this relatively high level of ability that are committed, the more inept, incompetent, or troublesome would be more likely to be retained in the institution.

It was first suspected that those individuals of IQ 80 or above who reside in institutions for the mentally retarded are problem individuals -- criminal, aggressive, psychotic, or generally socially incompetent. When the 1967 WICHE census became available, 288 persons (1.37%) were reported with an IQ of 80 or above. Most of these individuals were found to have one or more difficulties, including problems with ambulation, speech, vision, hearing, arm-hand use, and seizures. While these difficulties do not necessarily imply intellectual impairment to the point of requiring residency in an institution for the mentally retarded, they do indicate problems which conceivably might be best handled by institutionalization. (Whether an institution for the mentally retarded is the appropriate place for these individuals is a separate question.)

When patients with one or more of the above difficulties are deleted along with any residents who were rated as below borderline level of retardation, 74 of the original 288 patients with IQ 80 and above remain. Of these, 59 were male and were selected for comparison with the 9,538 other male ambulatory patients in the WICHE population. (It was felt that the number of IQ 80-plus females was too small to allow a meaningful assessment of their characteristics as a group.)

Table XXV shows a comparison between the two groups regarding certain general statistics. The differences in age and length of stay in the institution are relatively small. On the other hand, the height and weight of the IQ 80-plus group appear to be approximately those of the general population in the United States, while the other ambulatory male residents are markedly smaller at about



the same age.

An examination of the diagnoses of the two groups is revealing. Table XXVI shows this information. Of the 59 individuals with IQ 80 or more, 83% have been diagnosed as either psychogenic/functional or unknown/unclassified. This compares with 34% of the other ambulatory males in these two categories. Thus, in the vast majority of cases, no structural or metabolic defect has been found in the higher IQ group. The lack of a discernible medical difficulty in this group is further borne out by the relatively small proportion of these residents who are being treated with drugs. Only 28% receive medication compared to 61% of the other ambulatory group. (The medication includes vitamins and drugs to aid sleep, and it is likely that a good proportion of the 28% who do receive medication are given it for these purposes.)

The possibility exists that the IQ 80-plus individuals are for some reason unable to care for themselves. Table XXVII provides information regarding the need for help in dressing, eating, grooming and toilet use. It can be seen that the IQ 80-plus group is almost completely self-sufficient in these matters, whereas the other ambulatory males have considerable difficulty.

The general picture which emerges then is that these residents are normal regarding height and weight, a large proportion of them are adults institutionalized for over ten years, their difficulty is diagnosed as psychogenic/functional or uncertain, and they have no problem caring for themselves. It was thought that perhaps these individuals were rejected by family or were from underprivileged groups. No support for either of these hypotheses was found. Table XXVIII shows that a smaller than expected number of these residents show no evidence of family contact. The percent of cases who never receive letters or packages, get visitors, or go on home leave is considerably less than for the other institutionalized ambulatory male residents. Nor is there evidence that these individuals come from minority groups; 93% of them are white, and 96% are either Protestant or Catholic.

An examination of the behavioral items in the WICHE census fails to reveal any pronounced behavioral problems among the IQ 80-plus group. Table XXIX shows the percent of each of the two groups which at least occasionally exhibits the various behaviors listed. There is a tendency for the IQ 80-plus group to be more sexually active toward members of the opposite sex, a finding which is not particularly surprising. On the whole, these patients seem to exhibit the various behaviors at a level one would expect, and in general do not appear to present any unusual problems. In fact, in certain areas they are "better behaved" than the comparison group: their activity level is less extreme, they engage in



Table XXVI. Diagnosis for the IQ 80-plus group and for other ambulatory males.

| Diagnostic Category | IQ 80-plus | Other Ambulatory Males |
|------------------------|------------|------------------------|
| Psychogenic/functional | 61% | 28% |
| Unknown/unclassified | 22% | 6% |
| All others | 17% | 66% |
| | | |

Table XXVII. Percent of the IQ 80-plus group and the other ambulatory males requiring help in caring for themselves.

| <u>Item</u> | IQ 80-plus | Other Ambulatory Males |
|-------------|------------|------------------------|
| Dressing | 2% | 46% |
| Eating | 0% | 3% |
| Grooming | 0% | 26% |
| Toilet use | 0% | 25% |
| | | |

Table XXVIII. Percent of the IQ 80-plus group and the other ambulatory males showing no evidence of family contact.

| <u>Item</u> | IQ 80-plus | Other Ambulatory Males |
|---------------------------------|------------|------------------------|
| Never receives letters/packages | 14% | 25% |
| Never has visitors | 17% | 29% |
| Never goes on home leave | 30% | 52% |

Table XXIX. Percent of the IQ 80-plus group and the other ambulatory males exhibiting various behaviors at least occasionally.

| Behavior Item | IQ 80-plus | Other Ambulatory Males |
|------------------------|------------|------------------------|
| General activity level | | |
| Hyperactive | 32% | 43% |
| Passive | 31% | 40% |
| Runs and paces | 12% | 40% |
| Sexual behavior | | |
| Heterosexual | 25% | 14% |
| Homosexual | 15% | 3% |
| Masturbates privately | 16% | 17% |
| Masturbates publicly | 10% | 9% |

Table XXIX. (continued)

| <u> Sehavior Item</u> | IQ 80-plus | Other Ambulatory Males |
|-----------------------------|------------|------------------------|
| Infantile behavior | | |
| Exposes self | 8% | 10% |
| Smears feces | 0% | 8% |
| Refuses to wear clothes | 0% | 6% |
| Destructive toward persons | | |
| Aggressive | 41% | 37% |
| Molests children | 3% | 5% |
| Attacks employees | 7% | 6% |
| Attacks residents | 17% | 20% |
| Destructive toward property | | |
| Destroys clothing | 5% | 15% |
| Upsets furniture | 5% | 16% |
| Destroys ward property | 12% | 13% |
| Breaks windows | 5% | 7% |
| Bangs doors when secluded | 10% | 8% |
| Other | | |
| Self-destructive | 3% | 14% |
| Requires restraints | 0% | 6% |
| Likely to escape | 12% | 8% |

Table XXX. Percent of the IQ 80-plus group and the other ambulatory males either already on work programs or possibly able to qualify.

| Program | IQ 80-plus | Other Ambulatory Males |
|--------------------------|------------|------------------------|
| Ward helper | 95% | 53% |
| Work outside institution | 61% | 19% |
| Work project | 80% | 40% |
| Work reward system | 54% | 19% |

fewer infantile acts and, in general, they are slightly less destructive, although they are somewhat aggressive. None requires restraints.

Since the characteristics of these residents did not provide an explanation for their institutionalization, the institutions themselves were examined. Of the 20 institutions taking part in the 1967 census, three had mixed (psychotic as well as retarded) or specialized (only cases of severe neurological damage) populations and were excluded from the present analysis. Information was obtained concerning the amount of money spent per day per resident for 16 of the 17 remaining institutions. (Despite a good deal of effort, information concerning one of the institutions was unobtainable.) The cost per day per resident ranged from \$4.76 to \$13.33. The percent of residents of IQ 80 or above ranged from 0.40 to 4.49. The rank order correlation between cost per resident and the percent of residents of IQ 80 or above was .69 (p = $\langle 0.02 \rangle$). The direction of the correlation is such that the lower the outlay per resident, the higher the percent of residents in the comparatively high IQ group.

One explanation of the obtained relation is that the higher the proportion of high ability residents, the higher the proportion capable of self-help; hence, less money need be expended for each patient. However, the IQ 80 and above group makes up less than two percent of the total institutional sample with a range between institutions of from 0.40 to 4.49 percent. It seems unlikely that this small a difference between institutions in individuals more often capable of self-help could result in a correlation of the obtained magnitude. It seems more likely that the negative relation between institutional costs and the percent of patients of comparatively high ability does not result from the fact that these patients can help themselves but rather that they are used by the institution to help others. The less money the institution receives per patient, the less willing this institution may be to release into the community its unpaid workers.

Evidence that this may be the case can be seen in Table XXX: 95% of the IQ 80-plus group was rated as either already acting as ward helper or a possibility for such a position. This compares to only 53% of the remaining ambulatory males. Similarly, 61% of the IQ 80-plus group was rated as probably or definitely able to work outside the institution or already on such a program, as compared to only 19% of the comparison group. The same sort of situation exists for the capacity for these patients to participate in institution work projects and work reward systems.

Szasz's writings (1961, 1963) have raised serious questions regarding commitment procedures in mental hospitals. The material presented herein would



seem to raise equally serious questions concerning commitment procedures for the retarded. The HEW census shows that a relatively high percent of persons committed as retarded are of borderline or normal ability, and that the probability of being so committed varies greatly from state to state. The WICHE data demonstrate that those borderline or normal individuals retained in institutions for the retarded are not necessarily "troublesome," so that even this explanation for commitment and retention does not appear to hold. The substantial relation between amount expended per patient and percent of normal or borderline individuals residing in an institution suggests that the retention of these individuals raises a moral or ethical issue.

Diagnosis - General

The American Association on Mental Deficiency is preparing to establish a new system of diagnostic classification. If it can be assumed that even when holding ability level constant one still should be able to discern behavioral differences between diagnostic types, then the WICHE data suggest that the present system is in fact inadequate. We have obtained frequency printouts for each major diagnostic category (that is, contrasting AAMD categories 11 through 19 with 21 through 29, etc.), and found few differences between groups. As noted above, most of the variance between diagnostic categories can be accounted for by differences in the mean ability level of these categories. One might argue that the mere fact of being mentally retarded and institutionalized overrides any differences resulting from the causal nature of the defect. This position seems doubtful. When the diagnostic categories are firm ones, differences are present, as discussed below.

Diagnosis - Behavioral Characteristics of Phenylketonurics and Matched Controls

Two hundred two individuals with phenylketonuria (FKU) were compared with a control group on 22 rated behaviors. The PKU group differed markedly in behaviors indicative of activity and aggressiveness but did not differ appreciably on other behaviors rated.

It is commonly believed that different diagnostic types of retarded individuals vary from one another in patterns of social behavior. For example, individuals with Down's Syndrome generally are believed to be sunny and affectionate persons. Research data (Moore, Thuline & Capes, 1968) supports this belief. Phenylketonuric individuals are far less frequently represented in institutional



populations than are Down's cases and have not been recognized as a separate diagnostic group until comparatively recently. Yet a set of beliefs concerning the behavior of PKU individuals also has come into being, with PKU's being considered irritable and hyperactive behavior problems (Carver & Wittson, 1960; Centerwall, Centerwall, Armon, & Mann, 1961; Garfield & Carver, 1960; Knox, 1966; Koch, Fishler, Schild, & Ragsdale, 1964). These traits appear to be more common among older, duller individuals and do not appear to be characteristics of individuals with PKU who are of normal ability (Siegel, Balow, Fisch, & Anderson, 1968). The 1967 census was utilized to provide a systematic behavioral comparison of a large number of institutionalized phenylketonurics with other institutionalized retarded individuals matched in ability level.

<u>Procedure</u>. Of the 23,211 residents, 202 are diagnosed as having PKU. A computer program was devised in order to randomly select <u>Ss</u> in different frequencies at differing ability levels from the remainder of the sample in order to provide a control group matched to the PKU group in ability.

Sex ratios were as follows: PKU, male, 54.46%; female, 44.55%, no entry on census form, 00.99%; control, male, 54.63%; female, 45.37%. These data demonstrate that the PKU and control groups are closely matched in sex and ability level.

The WICHE census contains information concerning 22 behaviors (the behaviors appear in Table XXXII) with each behavior being rated as being exhibited "never," "seldom," "occasionally," or "frequently" by a given resident. Responses of "never" and "seldom" were considered negative and combined. Ratings of "occasionally" and "frequently" were considered positive and combined. Positive and negative responses for the PKU and control groups were tabulated and transformed into percents.

Results and Discussion. The behaviors, as well as the frequencies and percents of PKU and control <u>Ss</u> showing each behavior, are shown in Table XXXII. The significance of difference between percents was determined by a formula from McNemar (1949, p. 79).

Fourteen of the behaviors (1, 2, 6, 7, 8, 9, 10, 13, 14, 15, 16, 20, 21 and 22) have to do with activity/aggressiveness. PKU Ss were significantly higher than controls on ten of the fourteen behaviors and approached significance on the eleventh. The other eight behaviors have to do with sexuality or else with infantile or psychotic behavior (e.g., smears feces). Although PKU Ss were higher than controls on more of these behaviors, no differences were significant. It appears that institutionalized PKU Ss are different from matched controls in



Table XXXI. Ability level of PKU and control $\underline{S}s$.

| Latest | Pk | PKU | | <u>Control</u> | | |
|------------------|--------|---------|--------|----------------|--|--|
| IQ or SQ | Number | Percent | Number | Percent | | |
| 1- 9 | 42 | 20.79 | 1990 | 22.36 | | |
| 10-19 | 76 | 37.62 | 3540 | 39.78 | | |
| 20-29 | 35 | 17.33 | 1695 | 19.04 | | |
| 30-39 | 17 | 08.42 | 791 | 08.89 | | |
| 40-49 | 12 | 05.94 | 449 | 05.04 | | |
| 50-59 | 6 | 02.97 | 336 | 03.78 | | |
| 60-69 | 2 | 00.99 | 99 | 01.11 | | |
| No score entered | 12 | 05.94 | | | | |
| | | | | | | |

Table XXXII. Behaviors of PKU and control \underline{Ss} .

| | Behavior | <u>PKU (</u> | (N=202) <u>%</u> | Control <u>N</u> | (N=9800) <u>%</u> | Significant Critical Ratios |
|-----|---------------------------|--------------|---------------------|---------------------|----------------------|-----------------------------|
| 1. | Hyperactive | 129 | 63.9 | 3576 | 40.2 | 6.92*** |
| 2. | Self-destructive | 71 | 35.2 | 1633 | 18.4 | 4.95*** |
| 3. | Homosexual activity | 19 | 09.4 | 629 | 07.1 | |
| 4. | Exposes self | 33 | 16.4 | 1109 | 12.5 | |
| 5. | Smears feces | 39 | 19.3 | 1359 | 15.3 | |
| 6. | Destroys clothing | 52 | 25.8 | 1673 | 18.8 | 2.25** |
| 7. | Upsets furniture | 42 | 20.8 | 1202 | 13.5 | 2.53** |
| 8. | Requires restraints | 27 | 13.4 | 1080 | 12.1 | |
| 9. | Aggressive | 93 | 46.0 | 2619 | 29.4 | 4.68*** |
| 10. | Passive | 94 | 46.5 | 3767 | 42.3 | |
| 11. | Masturbates publicly | 29 | 14.4 | 997 | 11.2 | |
| 12. | iMolests children | 9 | 04.5 | 353 | 04.0 | |
| 13. | Attacks employees | 18 | 08.9 | 480 | 05.4 | 1.73* |
| 14. | Destroys ward property | 38 | 18.8 | 890 | 10.0 | 3.18*** |
| 15. | Runs and paces | 85 | 42.1 | 1676 | 18.8 | 6.65*** |
| 16. | Likely to escape | 14 | 06.9 | 612 | 06.9 | |
| 17. | Masturbates privately | 27 | 13.4 | 1195 | 13.4 | |
| 18. | Heterosexual activity | 5 | 02.5 | 123 | 01.4 | |
| 19. | Refuses to wear clothes | 26 | 12.9 | 884 | 09.9 | |
| 20. | Attacks residents | 59 | 29.2 | 1371 | 15.4 | 4.28*** |
| 21. | Breaks windows | 18 | 08.9 | 428 | 04.8 | 2.03** |
| 22. | Bangs doors when secluded | 25 | 12.4 | 626 | 07.0 | 2.32** |
| | | | | | | |



*P = > .05 < .10

P = **<.05

***P = **<.**01

the direction that would be predicted from generalizations made from clinical observations and case studies and that these differences are especially great in the area of activity and aggression.

Diagnosis - The Behavioral Competence of Mongoloid and Non-Mongoloid Retardates

Mongoloids (cases of Down's Syndrome) show greater social competence as measured in terms of frequency with which they are capable of certain adaptive behaviors than do non-mongoloids. However, mongoloids do appear to have a special problem in communicating to others, an area where the mongoloid - non-mongoloid comparison is markedly at variance with all other comparisons.

Moore, Thuline, and Capes (1968) compared 536 mongoloid (Down's Syndrome) with 536 matched control residents of institutions for the retarded. They compared the frequency with which members of each of the two groups of <u>Ss</u> exhibited each of 21 maladaptive behaviors, obtaining their rating data from the 1966 regional census of 23,443 residents of institutions for the retarded. Moore et al. found mongoloids to show significantly less maladaptive behavior on 14 of the 21 rated behaviors, thus confirming the generally held belief that mongoloids usually are better adjusted than other types of retarded individuals. Other data are available in the census that may shed further light on the general level of behavioral competence of mongoloids as compared with non-mongoloids.

Procedure. There were 2,606 individuals with Down's Syndrome and 20,605 individuals who did not fall into this diagnostic category in the 1967 regional census. The mean age of the Down's cases was 21.18 and for the remainder of the census population was 24.45. The mean IQ of the Down's cases was 28.61, and for the remainder of the sample was 32.07. The Down's cases are somewhat younger and duller than those in other diagnostic categories but the differences are relatively slight.

The two groups of <u>Ss</u> were compared in the frequency with which they exhibited the following behaviors, all of which pertain to areas of social competence: dresses self; communicates to others understandably; understands others; brushes own teeth; feeds self with knife, fork and spoon; grooming - stays neat; independent use of toilet; never or infrequently wets the bed; is candidate for ward helper or work project (already on program or definitely should be); and is on work reward system. The frequencies are shown in Table XXXIII.



Table XXXIII. Competence of mongoloids and non-mongoloids.

| | Mongoloid (N=2606) | | Non-Mongoloid (N=206 | | |
|--|--------------------|---------|----------------------|---------|--|
| Behavior Exhibited | Frequency | Percent | Frequency | Percent | |
| *Dresses self | 1167 | 44.78 | 7947 | 38.57 | |
| *Communicates to others understandably | 490 | 18.80 | 7261 | 35.24 | |
| *Understands others | 1839 | 70.57 | 12904 | 62.63 | |
| *Brushes own teeth | 1275 | 48.93 | 8702 | 42.23 | |
| *Feeds self with knife, fork and spoon | 1293 | 49.62 | 8308 | 40.32 | |
| Grooming - stays neat | 727 | 27.90 | 5404 | 26.23 | |
| *Independent use of toilet | 1747 | 67.04 | 11023 | 53.50 | |
| *Never or infrequently wets bed | 1700 | 65.23 | 10204 | 49.52 | |
| *Candidate for ward helper | 822 | 31.54 | 5807 | 28.18 | |
| Candidate for work project | 550 | 21.11 | 4584 | 22.25 | |
| Work reward system | 385 | 14.77 | 2817 | 13.67 | |



^{*}Differences between percents significant at .01 level of confidence.

Results and Discussion. Tests of the significance of difference between percents (McNemar, 1949) show the Down's cases to exhibit higher proportions of socially adaptive, socially competent behavior in seven of the eleven comparisons despite the fact that they are slightly younger and duller than the group with which they were compared. The differences in favor of the Down's cases are large in the area of self-help (e.g., dresses self) and either small or nonsignificant in the area of helping others (e.g., candidate for ward helper). A striking departure from the general tendency for Down's cases to be more competent than the comparison group is found for the item "communicates to others understandably." This item shows the largest difference of any of the comparisons, and here the Down's cases are inferior. This finding is in general agreement with the research reported by Spreen (1965).

The present report may be viewed as being supplementary to that of Moore et al. While they found mongoloids to exhibit maladaptive behaviors less frequently, the present paper demonstrates that mongoloids more frequently exhibit a variety of adaptive, socially competent behaviors.

<u>Diagnosis - Intellectual, Behavioral, and Physical Characteristics Associated</u> <u>with Trisomy, Translocation, and Mosaic Types of Down's Syndrome</u>

Two hundred fifty-four trisomy, twenty-one translocation, and eighteen mosaic Down's Syndrome cases were compared on intelligence test scores and on rated behavior. The translocations were highest, trisomies intermediate, and mosaics lowest in intellectual ability. Translocation cases tend to be more active and aggressive than trisomies and mosaics. The three groups do not differ in the number or kind of stigmata exhibited.

Individuals with Down's Syndrome may have any one of three major genetic defects: trisomy - the presence of an extra chromosome 21; translocation - the presence of extra chromosomal material, ranging from a portion of one arm to a whole extra chromosome attached to another chromosome; and mosaicism in which a portion of the blood or skin cell analyses conducted on a given individual reveal the existence of a normal complement of 46 chromosomes, while the remainder of the analysis reveals the presence of a chromosomal anomaly, trisomy 21.

Recent literature suggests that individuals with Down's Syndrome who are comparatively high ability are far more often cases of mosaicism than one would



expect by chance (Rosecrans, 1968). Individuals with Down's Syndrome generally are believed to be better adjusted and less aggressive than individuals with other kinds of retardation, and recent research (Moore, Thuline, & Capes, 1968) supports this belief. Yet one hears, from ward attendants particularly, that some Down's cases are quite aggressive and difficult. A study was therefore undertaken to compare the three major types of Down's Syndrome on intellectual or behavioral characteristics in order to investigate further ability differences between the three types, to compare their behavior, and to obtain more information on stigmata of each of the three types...

<u>Procedure</u>. Of the 23,211 individuals in the 1967 census, 2,606 are cases of Down's Syndrome. A computer printout of the admission number, institution, and ward number of each of those persons listed as having Down's Syndrome was obtained, and each institution was asked for all karyotypic information available for each individual for whom karyotyping had been performed. Two hundred ninety-six individuals had been karyotyped. Of these, 254 were trisomy 21, 21 were translocations, 18 were mosaics, and 3 were individuals with two different chromosomal anomalies (e.g., trisomy 21 plus XO sex chromosome). All but six of these 296 karyotyped cases (4 trisomies, 1 translocation and 1 mosaic) came from the five institutions in the WICHE census area that have had in the past or presently have established routine karyotyping programs.

All Down's cases in one of the five institutions have been tested. In three of the five, not all have been tested, apparently because the program depended on an interested individual or individuals who had moved, thus causing the karyotyping to be discontinued, or else because karyotyping was only recently initiated. In the fifth institution, nearly all cases have been karyotyped and those not karyotyped appear to be a backlog of cases. Admission policies of these institutions is not different than that of other institutions in the WICHE census. The remaining six individuals were karyotyped at other institutions before arriving at their present one or else karyotyped at parental expense.

The mean IQ of the entire WICHE census population of 2,606 Down's cases is 28.61, while the mean of the karyotyped subjects (excluding the three with two genetic anomalies) is 32.33. It appears, therefore, that the karyotyped group is somewhat brighter than institutionalized Down's cases in general, but the bias is relatively slight. A reader has commented that the proportion of translocations and mosaics is higher than one might expect. The sources of this bias, if it in fact exists, is not known.

The fourth group of three Ss was discarded, and the remaining three groups



of Down's cases compared on a number of variables for which information was available in the WICHE census data. (For discussion of the reliability - generally very high - of these census data, see Abelson & Payne, 1968.)

The means and standard deviations of the IQ's for those members of each of the three groups for whom IQ's were recorded is as follows: Trisomy, $\overline{X}=32.11$, $S\overline{X}=13.21$ (N = 238); Translocation, $\overline{X}=37.83$, $S\overline{X}=12.47$ (N = 21); and Mosaic, $\overline{X}=28.94$, $S\overline{X}=13.43$ (N = 18). The translocations are significantly higher in ability than either the trisomies (C.R. of $D_m/\sigma_{D_m}=2.02$, P = <.05) or or mosaics (C.R. of $D_m/\sigma_{D_m}=2.14$, P = <.05), while the trisomies and mosaics do not differ significantly from one another.

The WICHE census also contains 22 items of rated behavior for each individual with each behavior being rated as being never, seldom, occasionally, or frequently present. Fourteen of these items have to do with activity and aggressiveness. They are: hyperactive, self-destructive, destroys clothing, upsets furniture, requires restraints, aggressive, passive, attacks employees, destroys ward property, runs and paces, likely to escape, attacked residents, breaks windows, bangs doors when secluded. The other eight behaviors fall into two groups, one having to do with infantile or psychotic behavior (e.g., smears feces) and the other with sexual activity (e.g., sex with others of the same sex). The translocation cases were higher than trisomies on 12 of the 14 measures of activity and aggression (with passivity scored in reverse). A sign test (Siegel, 1956, pp. 68-75) shows this difference to be significant (P = (.02). Translocation cases were higher than mosaics on 10 of 13 untied measures of activity and aggression. A sign test shows this difference to approach significance (P = .092). Trisomies and mosaics show little difference in activity and aggressiveness, with the trisomies having higher scores on 5 of the 14 measures. No differences of any appreciable magnitude were observed between groups for the remaining eight behaviors that did not have to do with activity and aggression.

As a next step, the translocations and mosaics were compared on "problem behaviors" with trisomies matched in age (\pm 1 year) and IQ (\pm 2 points). A rating of "never" for a given behavior was scored "1"; seldom, "2"; dccasionally, "3"; and frequently, "4." Only five \underline{S} s had scores of 28 or more on the 14 behaviors having to do with activity-aggression. All of these were translocations. Three were male and two were female. They were 8, 16, 17, 21, and 52 years of age with a mean IQ of 36.20.

The admission number and ward number of each translocation and mosaic, as well as the matched trisomies described in the paragraph above, were sent to the



institutions involved along with a request for information concerning the stigmata of each resident. Deaths and transfers reduced the \underline{N} somewhat so that 37 trisomies, 19 translocations, and 15 mosaics remained for whom the institution provided information. The stigmata studied, the number of \underline{S} s in each group having each of stigmata, and the mean for each group is shown in Table XXXIV.

The three types of Down's Syndrome do not differ in number or in kind of stigmata. Attempts to discern a differential pattern of stigmata for any one type as compared with the other two were unsuccessful. It appears that with institutionalized Down's cases, type of Down's Syndrome cannot be predicted from number or kind of stigmata.

Results and Discussion. Previous reports have suggested that within the general category of Down's Syndrome, mosaics are likely to be among the brightest group. The present data show translocation cases to be higher in IQ than trisomies or mosaics and show mosaics to be lower in ability than either trisomies or translocations.

Previous reports, for the most part, have dealt with individuals whose comparatively high ability has caused them to be selected for karyotyping. The present $\underline{S}s$ were tested as part of routine testing programs. It may be that mosaics show a high amount of variation in ability so that if, for example, one were testing the brightest 1% of Down's cases, one would find many of them to be mosaics, despite the fact that the mean for all mosaics is below that of the other two types of Down's cases. Some support is found for this interpretation within the present group of $\underline{S}s$. Mosaics comprise only 6% of the total sample. Yet, of the five cases with IQ above 60, one was a mosaic.

Many people in daily contact with the retarded talk about two kinds of Down's cases: one kind that fits the most common pattern of being happy, somewhat passive, and affectionate; and another kind that is more active and is easily angered. It would appear that trisomies, mosaics, and most translocations are of the first type, and that the relatively few Down's cases that are of the second type are translocations.

Finally, an examination of the number and kind of stigmata does not allow one to differentiate between individuals on the basis of type of Down's Syndrome.

Diagnosis - Ethnic Background and Phenylketonuria

When clear and objective criteria exist for the inclusion of <u>Ss</u> within given diagnostic groups as is the case for mongolism (Down's Syndrome) and phenylketonuria, behavioral differences between diagnostic groups and, in the



Table XXXIV. Type of Down's Syndrome and number showing each of 14 stigmata.

| | Stigmata | Trisomy (N=37) | Translocation (N=19) | Mosaic (N=15) |
|-------|--|----------------|----------------------|------------------|
| 1. | Back of head flat, not curved | 31 | 13 | 10 |
| 2. | Cheeks noticeably redder than average patient. | 14 | 5 | 8 |
| 3. | Iris of eye speckled (e.g., blue eyes with speckles or spots of brown | n) 24 | 5 | 8 |
| 4. | Has epicanthic folds (skin at inner corner of eye forms fold, making eye look somewhat slanted) | 25 | 12 | 7 |
| 5. | Ears are malformed | 9 | 9 | 5 |
| 6. | Bridge of nose looks flat or "pushed in" | 13 | 8 | 5 |
| 7. | Nostrils noticeably tilted upward | 14 | 6 | 8 |
| 8. | Furrowed or fissured tongue (furrows across the tongue) | 27 | 12 | 8 |
| 9. | Broad, short hand as compared with the average person's hand | 29 | 16 | 11 |
| 10. | Clubbed, short fingers (broad, stubby, little taper to them) | 20 | 11 | 8 |
| 11. | Little finger noticeably more curved than other three fingers | 18 | 10 | 9 |
| 12. | Simian line or fold in palm (a deep line from area of thumb to close to ring finger) | 13 | 8 | 4 |
| 13. | Third toe longer than second toe | 1 | 0 | 1 |
| 14. | Noticeably larger gap between the big toe and next toe than that found between other pairs of toes | 29 | 13 | 9 |
| ilean | number stigmata | 7.22 | 6.74 | 6.73 |

*Table XXXV. Obtained and expected frequencies of phenylketonuria in ethnic groups.

| Race | Obtained Frequency | Expected Frequency |
|------------------|--------------------|---------------------------|
| White | 212 | 189 |
| Negro | 1 | 7 |
| Spanish-American | 3 | 14 |
| Indian | 1 | 3 |
| Oriental | 1 | 4 |
| Polynesian | 0 | 0 |

^{*}No data was available regarding the ethnicity of one PKU S.



case of Down's Syndrome, between sub-types within a diagnostic group do exist. Another study was conducted using a single diagnostic group, phenylketonurics, which was not directed toward the study of behavior, but instead had to do with basically demographic data.

Two hundred nineteen known phenylketonurics were reported in the 1966 census. It should be noted that some other <u>Ss</u> in the total institutional group may be phenylketonurics, but have not been tested. However, the frequency is quite close to that which one would predict from Jervis' (1954) data, so that it would appear that relatively few undiagnosed phenylketonurics are to be found among the <u>Ss</u> of the 1966 census. Census data were compared with previous data concerning ethnic background, age, and sex as related to PKU.

Knox (1963) reviewed the literature having to do with the ethnic background of individuals with phenylketonuria and concluded that "with the exception of Japan, all cases of phenylketonuria have been recognized in north and western European countries or countries whose populations derived from this part of Europe (Knox, 1963, p. 14)." However, he later noted (p. 16) that "a few isolated patients of other origins have been reported."

The ethnic background of the 22,427 individuals of known ethnic background (ethnic data reported for \underline{S} ; \underline{S} not reported as being of "mixed" within each ethnic category) is as follows: White, 19,457 (86.75%); Negro, 707 (3.15%); Spanish-American, 1,445 (6.44%); Indian, 316 (1.41%); Oriental, 443 (1,98%); and Polynesian, 59 (0.26%). The frequency of \underline{S} s in each racial group being diagnosed as phenylketonurics, along with the number of \underline{S} s within each racial group who would be expected to manifest the disorder in terms of the percent of \underline{S} s in the entire institutional population, is shown in Table XXXV.

A Chi square comparison of white vs. all other racial groups shows the white group to contribute significantly ($\chi^2 = 8.22$, 1df, p = <.005) more than their expected frequency of cases of phenylketonuria. However, cases are found in other racial groups as well. These data strongly indicate the existence of a different recessive gene frequency for phenylketonuria across ethnic groups, but also show the genetically based disorder to be present in other than European groups.

Diagnosis - Age, Sex, and Phenylketonuria

Jervis (1954) obtained data regarding 48,536 institutionalized individuals and found no disparity between sexes in the frequency of phenylketonuria. Hence, it was concluded that the gene producing phenylketonuria was transmitted on an



autosomal chromosome. As will be shown below, one interpretation of the age by sex data calls this conclusion to question. Age data from Lang (1955) are presented in Knox (1963). The Lang data are in terms of percents with the base being the 100% figure for male <u>Ss</u> at birth or shortly thereafter and all other percents being proportions of this figure (Knox, 1963, p. 17); the present data are in terms of numbers. Therefore, the data are not directly comparable, but the shape of the curves can be compared between the two studies. The curves by age are shown in Figure 11. The actual frequency of PKU in the WICHE sample by age and sex is shown in Table XXXVI.

Figure 11 is of some interest. The differences in curves between the Lang study show a most considerable difference in the frequency of PKU in the age 0-9 group. Most of the institutions whose residents make up the present sample are somewhat reluctant to admit children under age 5. Therefore, some of the reduced frequency is clearly a result of admission policies. However, the number of residents in the age 0-9 group were approximately half as many as those in the 10-19 year old group. Yet PKU in the 0-9 group is less than a fifth of the incidence of the 10-19 group. Even when the number of phenylketonurics in the 0-9 group is corrected for the lesser frequency of all patients in this age range, a binomial expansion (Siegel, 1956, pp. 36-42) shows that, compared with the 10-19 year old $\underline{S}s$, phenylketonurics are significantly (z = 5.22, p = 4.001) under-represented in the younger age group. It would seem likely that a considerable proportion of the reduction in incidence of PKU in the 0-9 year old group may be a result of screening and early dietary therapy.

As noted above, the data presented by Jervis show no sex differences and therefore have been used to support the position that the gene producing PKU is transmitted on an autosomal chromosome. The total number of PKU $\underline{S}s$ of each sex in the present study does not differ significantly. However, when $\underline{S}s$ are divided by sex into those at or below the median in age (0-19 years old) and those above (20 years old or older), significantly more males fall in the younger group and females in the older group ($X^2 = 5.29$, $P = \langle .02 \rangle$) than chance expectancy. These data may demonstrate that more male phenylketonurics are born and that the total frequency for each of the sexes is equal only because of a higher death rate among males.

Other interpretations of the sex X age data come to mind. Perhaps testing for PKU yields more false negatives for males than for females. No evidence for this possibility has been found. Perhaps untreated males are more severely handicapped (and hence more likely to be institutionalized) than untreated females. This is not so, at least for those who are institutionalized in the



WICHE (1966) Lang (1955) Age of Residents

ERIC Full text Provided by ERIC

Age of PKU <u>Ss</u> in two sturies.

Figure

*Table XXXVI. Age, sex, and PKU.

| | <u>Age</u> | | | | | | | |
|------------|------------|-------|-------|-------|-------|--------------|-------|-------|
| <u>Sex</u> | 0-9 | 10-19 | 20-29 | 30-39 | 40-49 | <u>50-59</u> | 60-69 | 70-79 |
| Male | 14 | 54 | 24 | 14 | 5 | 1 | 0 | 0 |
| Female | 3 | 40 | 25 | 14 | 9 | 5 | 1 | 1 |

^{*}Age or sex data were not available for 18 of the 219 PKU $\underline{S}s$.



WICHE area. The mean IQ for males is 19.55; for females, 19.56. Perhaps dietary therapy is more effective for females than for males. An examination of all cases treated before I year of age, treated between I and 3 years of age, and treated after 3 years of age, that were described in studies cited in Baumeister's (1967) review shows small and insignificant sex differences in IQ within each of the three groups, so that this explanation does not appear to be a correct one. At least two possible explanations for the over-representation of males in the younger group remain: more male than female phenylketonurics are born and/or testing yields more false negatives (and hence untreated individuals) a Jag males than females.

Height - and XYY Males

New case histories of chromosomally aberrant XYY males are flooding the literature. These individuals with two male chromosomes first were discovered in a survey of Scottish prisons (Jacobs, Brunton, Melville, Brittain, & McClemont, 1965). They typically are big, dull, and aggressive. (Richard Speck, the convicted mass murderer, is appealing his conviction on the grounds that he is an XYY and XYY's are generally disposed toward violence.) One could make a double selection of residents, selecting on the basis of height and ratings on the aggression items of the behavior rating scale, so as to obtain all of the tall and aggressive males in the census, and then determining sex chromosomal type to further select out the XYY's. This procedure would very likely provide one with the largest sample of XYY's ever obtained. They would be of some interest since sex chromosome anomalies are associated with factor-specific defects in intellectual ability. Females with Turner's Syndrome (XO sex chromosome type) generally are normal in intellectual ability except that they are markedly deficient in spatial ability (Money, 1966), so that they could be separated as a distinct group on the basis of score profiles on factor pure intelligence tests. Since physical stigmata make Turner's cases an easily discernible group, accurate diagnosis preceded this psychometric discovery. Other types as distinct in terms of causation as the Turner's cases may exist, but without the easily identifiable physical stigmata. In this case, test profile scores might be the only means available to separate out a specific genotype. A test of XYY males is in a sense a test of the feasibility of this proposition since here one has a known genotype and might reasonably expect a profile in abilities common to all individuals with this genotype. Although generally dull, XYY males should be higher in spatial ability than on any other factors (e.g., number ability, memory) of factor pure tests. While the WICHE census data



could be used in screening individuals for karyotyping, it has not been used in this way as yet.

Behavior Ratings - Heterosexual and Aggressive Behaviors among Institutionalized Retardates

Institutionalized retarded individuals identified in a census as frequently aggressive or as frequently engaging in heterosexual behavior were compared. The two groups show almost no overlap in individuals comprising them, and differ markedly on a number of other census items. The heterosexual group appears to demonstrate superior social competence in a variety of areas when compared with members of the aggressive group, and also appears more competent than the census population at large.

Both heterosexual and aggressive behavior on the part of residents may be viewed as problems by institutional personnel. Relatively little is known about the personal attributes of retarded individuals showing either of these behaviors. The present paper compares residents reportedly manifesting heterosexual or aggressive behavior.

In the 1967 census of 23,211 residents, the census form contains a number of items having to do with aggression: aggressive, molests children, attacks residents, attacks employees, destroys clothing, upsets furniture, destroys ward property, breaks windows, and bangs doors when secluded. The item used in selecting the present group of aggressive individuals was "breaks windows," since prior analysis of the aggression items indicated that if the \underline{S} breaks windows, \underline{S} also is likely to engage in all or at least most of the other aggressive behaviors as well. The census form contains one item concerning heterosexual behavior - "sex others, opposite sex." Individuals who were described in the census as frequently breaking windows formed the aggressive sample; individuals who were described as frequently engaging in sex with others of the opposite sex formed the heterosexual sample. Only nine' \underline{S} s of the total census group of 23,211 residents fell into both categories and these individuals were discarded prior to the analyses discussed below.

Characteristics of male and female aggressive and heterosexual residents are shown in Table XXXVII.



Table XXXVII. Characteristics of male and female aggressive and heterosexual residents.

| | <u>Male</u> | <u>Female</u> | <u>Male</u> | <u>Female</u> | <u>Total</u> |
|---|-------------|-------------------|---------------------|---------------------|--------------|
| <u>Item</u> | Aggressive | <u>Aggressive</u> | <u>Heterosexual</u> | <u>Heterosexual</u> | Sample |
| <u>N</u> | 150 | 86 | 59 | 66 | 23,211 |
| Mean age | 20.83 | 23.49 | 24.51 | 25.57 | 24.07 |
| Mean IQ-SQ | 30.97 | 24.96 | 42.48 | 46.27 | 31.66 |
| Mean height | 61.03 in. | 59.62 in. | 62.87 in. | 60.21 in. | 58.74 in. |
| Mean weight | 115.55 lb. | 118.46 lb. | 123.71 lb. | 115.92 lb. | 102.79 lb. |
| % court commitment | 57.14 | 69.88 | 75.44 | 82.81 | 66.99 |
| <pre>% diagnosis psychogenic/ functional (AAMD categories 81-89)</pre> | 28.57 | 22.37 | 36.36 | 49.02 | 21.50 |
| Level of retardation | * | | | | |
| % normal | 00.00 | 00.00 | 01.79 | 00.00 | 00.50 |
| % borderline | 02.05 | 01.23 | 12.50 | 03.13 | 03.01 |
| % mild | 08.22 | 04.94 | 23.21 | 32.81 | 10.47 |
| % moderate | 24.66 | 16.05 | 21.43 | 39.06 | 21.29 |
| % severe | 32.88 | 27.16 | 12.50 | 14.06 | 26.30 |
| % profound | 32.19 | 50.62 | 28.57 | 10.94 | 32.97 |
| % with history of seizures | 20.71 | 24.39 | 15.52 | 10.77 | 30.43 |
| % receiving drug nedication | 90.67 | 96.51 | 57.63 | 95.61 | 32 ., 80 |
| <pre>% now or candidate for ward helper</pre> | 35.66 | 23.17 | 63.79 | 75.38 | 28.56 |
| <pre>% taking part in or candidate for work reward system</pre> | 10.56 | 04.71 | 31.48 | 19.70 | 22.12 |
| <pre>% referred or candi- date for referral fo foster home placemen</pre> | r | 07.23 | 41.51 | 55.56 | 26.48 |
| % non-white | 06.12 | 10.98 | 15.79 | 18.75 | 17.72 |
| % never goes on home leave | 63.64 | 70.24 | 50.00 | 37.10 | 55.66 |
| | | | | | |

^{*}Figures in columns total less than 100 percent since some $\underline{S}s$ were of unknown ability and some cards were mispunched.



As may be seen in Table XXXVII, sex differences on other variables within a given problem group generally are minimal, while differences across problem groups, regardless of sex of \underline{S} , are much more substantial. These data, like the infrequency of overlap between membership of the two problem groups, suggest that the heterosexually active and the aggressive groups are essentially independent populations.

Significant differences are presented in Table XXXVIII, with significance (.05 or less) being determined by a binomial test, in the case of sex differences in the frequency of given problem behaviors of males vs. females, and in terms of significance of differences between means or percents in all other comparisons.

Differences across sexes within problem groups are smaller than differences between problem groups. The comparison across problem groups suggests, as noted above, that the two groups are very different from one another, with the heterosexual group being judged to be generally better adapted to social interaction (e.g., ward helper, foster home placement) than the aggressive group despite the fact that they may have been more frequently viewed as problems within the community, if percent of court commitment is any criterion. Despite the fact that heterosexual behavior may be believed by institutional personnel to be a "problem" within the institution, these data suggest that heterosexuality is a positive indication that the individual so engaged is a relatively intact individual capable of a number of socially competent behaviors. An examination of the final column of Table XXXVII indicates that this is the case, not only when heterosexual residents are compared with aggressive residents, but also when heterosexual residents are compared with the entire census population.

Behavior Ratings - Institutional Size and Institutional Effectiveness

The proportion of residents of eighteen institutions who are capable of certain self-help behaviors was compared. Residents of large institutions generally are less competent than residents of small institutions. However, differences in mean IQ-SQ and of mean age of residents are associated with institutional size. Differences between institutions in mean IQ-SQ seem most closely related to variation between institutional residents in competence, with institutional size playing a relatively minor role.



Table XXXVIII. Significant differences in comparisons.

Males vs. females within problem groups

- 1. More males than females are aggressive
- 2. More aggressive males than females are or are potential candidates for ward helper.
- 3. More aggressive females than males are profoundly retarded.
- 4. More heterosexual males than females are profoundly retarded.
- 5. More heterosexual females than males are on drug medication.

Combined male and female, heterosexual problems vs. male and female, aggressive problems

- 1. Heterosexuals are higher in ability than aggressive <u>Ss</u>.
- 2. Heterosexuals are more often court committed.
- 3. Heterosexuals are more often psychogenic/functional mental retardates.
- 4. Heterosexuals are more often mild or above in defect, less often severe or profound in defect.
- 5. Fewer heterosexuals have or have had seizures.
- 6. Fewer heterosexuals are on drug medication.
- 7. More heterosexuals are, or are candidates for, ward helper.
- 8. More heterosexuals are on, or are candidates for, a work reward system.
- 9. More heterosexuals are candidates for foster home placement.
- 10. More heterosexuals are non-white.
- 11. More heterosexuals go on home leave.



Cleland (1965) presents a review of the literature having to do with the relation between institutional size and institutional effectiveness. He notes the contemporary parental and professional opposition to large institutions for the retarded, discusses other variables associated with institutional size (e.g., quality of work force), and concludes with the statement that "It may be possible that at some future date it will be proved as it is now assumed that the big institution is a bad institution, but it has not been proven yet!"

Census data are used below to present data bearing on the problem of the relation between size and effectiveness, and to discuss possible confounding factors associated with institutional size.

Of the 19 state institutions included in the 1967 census, one of the institutions was for a specialized, severely neurologically damaged population and, therefore, was not included in the present analysis. No such selective factors operated in placement in the other 18 institutions. The relative influence of institutional size, mean latest IQ or SQ of residents, and mean age of residents on adaptive behavior forms the basis of the present discussion. The characteristics of the 18 institutions are shown in Table XXXIX.

The correlations between the three independent variables are as follows: institutional size and IQ-SQ, rho = .32; institutional size and age, rho = .44; IQ-SQ and age, rho = .40. The directions of the correlations are such that residents of smaller institutions tend to be brighter and older than residents of larger institutions, and that institutions with residents obtaining higher mean IQ-SQ scores also tend to have residents who are older.

It would appear reasonable to operationally define institutional effectiveness in terms of the degree to which residents have been trained in certain socially adaptive behaviors. The WICHE census contains eight items of this sort: dresses self; speaks understandably; understands others; brushes own teeth; feeds self with knife, fork and spoon; keeps self neat in grooming; independent use of toilet; never or infrequently wets the bed. The correlations between institution size, mean IQ-SQ in each institution, and mean age of residents of each institution with the proportion of residents capable of each of these eight self-help behaviors are presented in Table XL.

The direction of the correlativeness is as follows: small institutional size, high IQ-SQ, and high mean age are in each case associated with a high proportion of residents capable of performing a given behavior.

The correlations of IQ-SQ and age with behavior had been obtained because previous work with the WICHE census had led to the belief that these two variables account for a very high proportion of the variance on other census items. Even



Table XXXIX. Number, mean IQ-SQ, and mean age of residents of 18 institutions.

| Institution | Number | Mean IQ-SQ | Mean Age |
|-------------|--------|------------|----------|
| 1 | 2428 | 24.32 | 20.77 |
| 2 | 915 | 31.11 | 18.92 |
| 3 | 573 | 44.50 | 38.54 |
| 4 | 2615 | 26.39 | 19.51 |
| 5 | 719 | 43.13 | 31.75 |
| 6 | 1690 | 37.79 | 22.07 |
| 7 | 898 | 28.20 | 26.91 |
| 8 | 919 | 24.32 | 29.32 |
| 9 | 843 | 34.85 | 25.63 |
| 10 | 2270 | 36.27 | 21.40 |
| ·11 | 689 | 32.34 | 17.94 |
| 12 | 683 | 41.10 | 31.01 |
| 13 | 1255 | 38.30 | 32.51 |
| 14 | 818 | 42.34 | 27.86 |
| 15 | 162 | 32.53 | 24.79 |
| 16 | 1005 | 29.34 | 20.96 |
| 17 | 3359 | 27.31 | 23.54 |
| 18 | 884 | 39.85 | 27.04 |
| | | | |

Table XL. Correlations of institution size, mean IQ-SQ, and mean age with proportion of residents exhibiting adaptive behaviors.

| Behavior | <u>Size</u> | <u> 10-SQ</u> | Age |
|---------------------------------|-------------|---------------|--------|
| Dresses self | .55*** | .84*** | .54*** |
| Speaks understandably | .87*** | .78*** | .40* |
| Understands others | . 32 | .77*** | .52** |
| Brushes own teeth | .41* | .72*** | .30 |
| Eats with knife, fork and spoon | .33 | .66*** | .38 |
| Neat in grooming | .40* | .61*** | .06 |
| Independent use of toilet | .40* | .75*** | .38 |
| Never or infrequently wets bed | .40* | .83*** | .54*** |

^{***} Significant at .01 level of confidence, 2 tailed test.



^{**} Significant at .05 level of confidence, 2 tailed test.

^{*} Significant at .10 level of confidence, 2 tailed test.

so, it came as something of a surprise to find such substantial correlations between IQ-SQ and proportion of residents capable of performing various self-help behaviors, even within this limited range of mean IQ-SQ scores.

Institutional size and mean age show less substantial and consistent relations with adaptive behavior. IQ-SQ, age, and institutional size are related to one another. A partial correlational approach would appear to be a means of determining the separate effects of each on adaptive behavior. In the present situation the correlations between institutional size and self-help that were significant at the .01 level of confidence remain significant at the .05 level of confidence (two tailed test of significance), the correlations between mean institutional IQ-SQ and self-help all remain significant at the .01 level of confidence (two tailed test), and the correlations between mean age of institutional residents that were significant at the .01 or .05 levels of confidence fall to slightly below the .05 level (two tailed test).

The present data suggest that institutional size is consistently negatively related to proportion of residents capable of a variety of self-help behaviors, but that the relations are comparatively weak, and are statistically significant in only two of the eight correlations. Far more important in the case of this set of institutions is the variation in mean institutional IQ-SQ that was associated with institutional size. Even so, these data do support the position that large institutions are somewhat deleterious, even though they are more expensive to maintain (rho = .52 between institutional size and cost per day per patient for the 14 institutions for which cost per day per patient was known), if institutional effectiveness is measured in terms of self-help capacities of residents.

Perhaps only a longitudinal study of a matched cohort of individuals admitted to institutions differing in size can provide solid data concerning the supposed "badness" of big institutions. These correlational data provide only hints.

Finally, with regard to institutions, their make-up over the period 1964-68 was studied. These data are presented in the first section of this report.



ADMINISTRATIVE USES OF THE WICHE CENSUS DATA

Despite the fact that administrators generally have considerable contact with residents, the census data contained surprises for them, since it was typically the first systematic description of the entire institutional population that had been available to them. The administration sometimes is alerted to special problems. For example, the superintendent of one institution wrote WICHE mentioning his great surprise at the number of residents at his institution who were borderline or normal in ability. He had assumed that almost all individuals of relatively high ability who were without physical or severe emotional handicaps were on some sort of work release program, yet found through the census that 40 of these individuals still were in the institution. He obtained outside placement for nearly all of them within a few months.

Broken down by institution, the census provides institutional personnel with comparative data by which they can judge their own efforts. For example, the mean number of years since residents have been tested is 5.82; the standard deviation is 5.88. Differences between institutions are great - several institutions obtain an IQ and/or SQ for each resident at least once a year while in another institution the mean length of time since last testing is more than eleven years. In the same vein, two institutions that do not differ appreciably in the age or intellectual level of residents or in budget, vary quite considerably in the proportion of residents who are toilet trained with less than half of the residents of one institution and over three-quarters of the residents of the other institution being capable of independent use of the toilet. One of these two institutions appears to be far more effective than the other in a large number of training functions, including toilet training.

One finds comparatively little in the mental retardation literature having to do with multiply handicapped retarded. It came as something of a surprise to most institutional personnel to find such a high proportion of handicaps.

The census data provide a clear and full description of the individuals residing in an institution. These data are sufficiently compelling that legislatures respond in terms of them.

Examples of administrative and institutional research program planning uses of the WICHE data have been collected from letters and reports sent to WICHE and are presented on the following pages. It is impossible to establish mutually exclusive categories for the ordering of these comments, but the attempted general



ordering is as follows: (1) general demographic uses of WICHE data; (2) effects of WICHE data on general policy; (3) effects of WICHE data on record keeping, (4) WICHE data in program planning and evaluation and institutional research; (5) WICHE data in lobbying and public relations; (6) the identification of special research problems through intra- and inter-institutional data comparisons; and (7) uses of WICHE data in staff training.

General Demographic Uses of WICHE Data

First of all, it was the first organized data collection program that we had in our institution for the retarded. Before the onset of the WICHE program, there was no reliable data gathered. The impetus of the program has gotten the Hospital staff used to the idea and advantages of data collection. Indeed, we have even had some influence on the Neuropsychiatric part of the Hospital, and they have recently instituted, with our assistance, a program that will put admission data and discharge data on an IBN system.

Our primary use of this data to date has been to confirm and more exactly define the change in our hospital population. Though we have been aware for some time that our patients were becoming on the average younger, more severely retarded and with more and more associated physical and sensory nandicaps, it is only in the past two years, since the availability of the data from your project, that we have been able to clearly determine the degree and rate of this change. With this information available we are able to intelligently plan for changes in the use of our pe sonnel, buildings and materials to accommodate a more handicapped population.

, like many of its contemporary institutions, is in a frustratingly slow process of evolving from a custodial to treatment-oriented facility. WICHE's role, and its information system, has served as a catalyst for this process and has greatly hastened the transition. I for one would like to see the process completed as soon as possible, and in my opinion this is dependent to a great extent upon the continuation of Joint Data Collection Project.

The data has been of value in documenting areas which are in need of greater attention by the clinical services. It has helped to pinpoint areas which require further diagnostic investigation and clinical research. In many areas it corroborates impressions which were already extant, and which could be verified by institutional staff even without WICHE. However, due to the stark reality of institutional



life, that much needs to be done, but resources and qualified manpower are limited, such surveys would rarely be carried out by institutions. In one full swoop a cross sectional view of the institutional population is obtained, without significantly disrupting the function of the institution. At the same time, it induces the individuals who fill out the IBM card, to think of the institutional resident in specific terms. This process in itself may influence the resident's relationship with the attendant, and his institutional course.

Effects of WICHE Data on General Policy

Generally speaking, I believe the continuation of the Regional Joint Data Collection Project is fundamental to a better understanding essential to expansion of services and programs for the mentally retarded in the west. I believe that it is only at such time that we have a precise understanding of the scope of our problems with the mentally retarded that we can work effectively to resolve these. There seems to be little question but what there will be an increasing amount of interchange between states as time goes on and as population needs demand more modern approaches to meet the special circumstances provided by increased mobility of families. There are many differences between state programs at the present time and these can be resolved or circumvented when we know more about what one another is doing and as we learn from one another. Also much emphasis is now being placed upon the development of mental retardation services in communities rather than in large isolated institutions. To adequately prepare many community resources for assuming responsibility for meeting the multipurpose needs of the mentally retarded it will be necessary to give communities accurate information regarding those we will refer. I believe the WICHE Data Project has made possible a significant step in the right direction through providing us with "legs to stand on" in our arguments for improved services.

The foregoing lists some of the ways the data has been used directly and probably is not entirely complete. An evaluation as to the extent of value of the data project to our institution can be measured somewhat in terms of research studies done or dollar amounts of funded projects. The overall real value however, is a combination of factors almost impossible to analyze. For example, how does one measure the effects of ____'s and _____'s visits to stimulate our staffs' thinking, or of the Data Utilization meetings where we made contacts, discussed various program problems and aspects and found out a little of what was going on in other states, or the whole concept of using data in making decisions and formulating treatment programs? The project has served as a tremendous impetus to get our insti-



tution moving and has made information available to us in a form not previously possible. The data had been used a great deal directly bearing on our population and programs, however has served us indirectly in many more ways such as program evaluation, staff stimulation and growth, more effective treatment, programs, increased funding, etc.

Effects of WICHE Data on Record Keeping

We use the information in the annual evaluations of our residents. It gives us a very solid, objective measurement by which to report about this particular person. This acts as a springboard for the more subjective judgments that can be made as a result of having an objective definition telling us where we are as far as this particular patient is concerned. When the data comes back to us, we let each ward attendant have the data sheet and he writes a paragraph, not describing the questions, but the answers to the questions made concerning each individual resident. As a result, we obtain a pretty good paragraph of description about this particular patient. This is for the use of the ward technician and is kept in the ward file; it is not kept in our central records file, but it is literally kept on the hall where it can be used year after year to make growth comparisons. Such a method facilitates the collecting of data each year when WICHE asks us to cooperate with them because we have the technician's full support and cooperation due to the fact that the technician gets something in return for his extra labors.

The data has stimulated the initiation of our own primitive data processing system, (i.e., key punch and card sorter) which has opened up new avenues of analyzing data: as well as development of data systems for other departments such as inventory, purchasing, genetic/chromosome data, etc.

The WICHE data system has been a vivid example of what can be done with statistics throughout the state. A similar procedure is now being undertaken by the State Health Department with the Mental Health Registry.

Institution staff members have become increasingly aware of the importance of accurate records as well as the need to collect data which are essential for studies and research.

This project has also stimulated our staff to the greater awareness of, and definitions of, data terms, and in an attempt to develop a common language in the field of mental retardation. It has led to an awareness of the need to



update patient care through the quality of the medical record.

The information contained on the WICHE Data Collection Form served as a basis for our McBee Card System. The same information collected annually on the Data Collection Form is used to update the McBee Card System (some catagories of the McBee Card System are updated several times a year).

Mental Health Division. _____ and the other state MR facilities are now engaged in a dialogue with the MHD regarding institution goals and roles. One of our tasks is to develop an inter-institutional patient classification system. It is interesting to note that, although no one is sure what the system should be, all are agreed that the system should be related to a data collection instrument -- individual classifications should be based on profiles of variables as reported by cottage/ward personnel.

With cooperation of Biometrics Section, Board of Control, have arranged for staff to have direct access to a sorter primarily to familiarize itself with information available in the WICHE deck -- a necessary first step in utilizing data in the area of patient management. Program heads, Unit Staff, and cottage personnel are now being encouraged to use the "tool." Interesting results expected.

WICHE Data in Program Planning and Evaluation and Institutional Research

Statistical basis for program planning. This furnishes the fundamental rationale for development of special programs for:

- 1. different age groups
- 2. different IQ groups
- different diagnostic groups
- 4. the blind, the deaf, the infirm, etc.

The analysis of this year's data on a hall-by-hall basis should allow us much more information for analysis of hall needs, problems and programs. It should provide data on which to base decisions about requests for increased staff, program changes, etc.

To illustrate further the usefulness of the WICHE data, let me point out a specific area in which it will certainly be put to excellent use. As in any institution such as ours, there are a considerable number of residents who show self-destructive behavior such as head banging, self-hitting, etc. Since this is such a serious problem from both a medical and



psychological standpoint, we were interested in learning more about how our attendant counselors dealt with the very serious problem of self-inflicted injury. Thus, an optional item was used which raised the question of how a counselor typically responded to a resident while the resident was engaged in self-destructive behavior. The data which we received from WICHE very clearly pointed out areas of information needed by our counselors to enable them to deal more effectively with this problem. Thus, as a result of this data, we have been able to pinpoint a problem and can now initiate action in terms of additional training for our counselors to reduce self-inflicted injury by residents.

As you know, I am frequently called upon to provide information to other departments regarding our population. For example, questions may be asked as to the number of residents with hearing difficulties so that a speech and hearing program may be more adequately planned. Information on self-help skills enables us to program more effectively and use our manpower in those areas where it will do the most good.

The data was used to support an application for a service project for MR aged at this institution. The project was funded (\$21,000) to serve 105 aged MR residents in an activity and training program aimed at rehabilitating cottage sitters into productive involvement, and nursing home placement.

The data was used for the planning of our new facility for our mentally retarded children. As part of our information to the architects, we made "mock-ups" of typical cottage populations that might be expected to occur in the new facility. Since we gave a detailed behavioral description of these children and their capabilities, the architects have found this extremely useful in the design of the physical plant.

The data was used to identify critical needs for the "under 21" age group in support of an ESEA Title I project application. The project has been funded for the past three years (\$270,000) and has resulted in addition and expansion of numerous programs such as Speech Therapy, Music Therapy, Occupational Therapy, Physical Therapy, Special Education, Vocational Counseling and Training, and Physical Education and Recreation.

Currently interested in relationship of demographic and behavior variables to necessary decision-making regarding (1) individual patient assignment/removal from programs,



(2) projected need for specific programs at least 3 years in the future, (3) evaluation of institution programs, and (4) makeup of a research "bank" or supplemental file of selected characteristics for use in research projects and other short-term programs.

Education. Education Department is currently studying patients identified in the 1967 inventory as eligible for school program to learn (a) what profile(s) attendants used in making this assessment, and (b) if a profile of inventory variables can be used to screen school eligibles from the general institution population.

Our School Department has used WICHE for the following reasons and occasions:

- 1. Assessment of inclusion of all students with IQ's above 30.
- 2. Assessment of status of special programs. (Data indicates Progress)
- 3. Determination of inclusiveness in school programs.

The data was used in 1967 to expand special education programs and identify students who had not previously participated. In addition to adding some 70 students in the academic program, 2 classes for emotional disturbed, 1 for blind and 2 classes for severely retarded were initiated.

Evaluation of existing programs is possible by comparing data from two successive years (i.e., % toilet trained in 1966 vs. % toilet trained in 1967) or by comparing _____'s data with those from other institutions. (I thought we used a huge amount of tranquilizers around here until the 1966 data showed _____ 18th in the list of 19.)

WICHE Data in Lobbying and Public Relations

The data has been very helpful to us in budget making. Some institutions may say, "Gee, I'd like to have a 2 to 1 staffing ratio, or, I'd like to have a 3 to 1 staffing ratio." Combining our need for staff with our unit system instead of merely asking for 150 technicians or 300 technicians we are able to say that we need this many technicians, these sorts of technicians, and we know we need them because our data says that we have this kind and that kind of patient; we know what we need and can verify our request. Thus, we are able to relate our staffing ratio more closely to those ratios recommended by AAMD, and we are able to do this because we made a unit system from the data and because we have the data to justify the system and the request for



personnel. Of course, there are locs of other budgetary implications within this collected data.

The past 4 years data on types of population movement and admission trends was analyzed to determine immediate and long range building needs.

Projections of hospital needs in terms of patient population - this requires that the census be continued annually for several years so that trend lines can be established and developing patient needs can be anticipated. For example, predicted changes in the following would necessitate changes in budget:

- 1. number of infirm patients
- 2. number of profoundly retarded
- 3. number of infant patients
- 4. etc.

The data have been most helpful to administrative, business and personnel staff in the formulation of programs and budgets affecting our total operation. Social service and placement specialists have made more effective use of limited staff in both admission and placement programs through the selective use of the data.

Preparation of annual budget, especially those items which tell us the "story" of the severity of the handicaps and all services required. These data have been used to justify dramatically to the legislative bodies the needs of the institution.

The data was used to depict program, personnel and building needs for presentation to Appropriation Committee of 1967 Legislature. Presentation resulted in 37% budget increase of \$1,000,000 appropriation for new buildings.

The WICHE Data printout on the ______ population has been extremely helpful to me and the staff in evaluating our general population problems and needs and the projection of programs to meet these needs. I have used the data extensively in determining budget requirements for personnel and programs in special problem areas and justifying same with the Department of Finance and the Legislature.

In addition, we have been able to utilize this "hard" data to point out to our Legislators, parent groups and professional groups reasons for changes in our budgetary requests, admission policies, etc. As you know we have requests for this data from groups outside the _____; the recent



request of the ____ as an example, as are others emanating from County School and Public Health agencies.

I have almost daily need for the printout information on the in answering the many questions directed to me regarding the nature of our population, program, etc. I find the data to be an excellent factual source of information for public relations purposes and for utilization in classes taught by _____ personnel.

We have made much use of this data. I have personally used the data in talks and lectures to the community such as to service clubs, parent groups, professional groups, etc.

The Identification of Special Research Problems through Intra- and Inter-Institutional Data Comparisons

The census indicated that there were 40 patients in our hospital with IQ's greater than 70. A study is being initiated to discover the circumstances of these patients' hospitalization.

In the area of services, the data collection has clearly indicated that overall seizure control, although good was not quite as good as we thought. As a direct result, the methodology for reporting and following up convulsive disorders has been modified.

The same sort of misconception was discovered regarding enuresis, and has stimulated professional interest in proper diagnostic investigation, remediation, and follow-up of this problem.

The height and weight data has helped to direct our attention to the many residents with short stature, and has also delineated two distinct groups: 1) with excessive stature, 2) extreme obesity. These three groups are currently being investigated both diagnostically and from a clinical research point of view, and have led to the establishment of an extra clinic to study and classify these problems.

A study of the data has also forced a considerable amount of program development. The first year, through perusal of the data which is concerned with resident contact with parents, relatives, and families, we discovered that 74 percent of our people had contact with no one. This revelation flooded us with great feelings of horror. Of course, we found out who that 74 percent of our population were and have now reduced the number to 44 percent. Credit for this decrease can only



be given to a very active social services division whose members went out and searched until they found someone who related to a resident in some way, but they might have gone in a different direction had the data not dictated this particular need.

A study was done comparing visitation rates from western and eastern sections of state to determine extent of limitations imposed on visitations and parental involvement due to distance. Results were used in planning a new MR community centered facility in eastern part of state.

The incidence of hearing loss reported in the census is significantly lower than that reported by intensive audiometric testing of selected hospital populations. A project has been developed to screen an unselected sample of the hospital population with objective audiometric tests to check the accuracy of the census.

nere are some people who think we have a lot of regressed schizophrenics in our population. As a result of the WICHE data we found out that 30 of the 550 residents are regressed schizophrenics, at least in the minds of our psychiatric technicians, but it gives us a direction in which to point our psychiatrists and our psychologists as far as defining them is concerned.

The behavioral inventory has helped to stimulate several professionals to spend more time on the halls and to develop programs which attendants can carry out. This is particularly true of the efforts of the OT and PT department.

Identification of program needs. For example, each year as we collect the psychological test data we list those residents who have not been re-evaluated for a period of years. Then, as the year progresses, supposedly we work them into the testing schedule. If not, then their names reappear on next year's list - and we are readily aware of departmental effectiveness or lack thereof.

Similarly, it is possible to determine the major gaps in other areas: number in school vs. those eligible; number blind or with limited vision vs. those enrolled in special programs for the visually handicapped; number needing speech therapy (or anything else) vs. those exposed to it, etc.

This data also allows us to have a kind of distant form of supervision of our professional employees. If we are not getting a psychometric, for example, on this person every year, it lets us know if someone is not doing his job or at least keeps us alert to such things.



The option columns are proving to be a great help. We used some to define more specifically multi-handicaps; we have used others to investigate medication given. We asked our technicians whether, in their opinion, our residents were on too much medication. We have a rather unique problem -- being associated with a hospital and having the type of people we have -- 83 percent of our residents are on tranquilizing medication as compared to 24 percent of the WICHE region as a whole. Such statistics seem to validate and necessitate a medication question. These statistics have also alerted our technicians to question the need for any medication presently being given.

Hospital Improvement Project. Getting ready to do longitudinal study of patients who are, or have been, subjects of HIP at _____ to determine the extent of improvements in behavior. Will utilize WICHE data gathered in 1964, 1966, and 1967.

Because is isolated from other states, the comparative data of western institutions have been invaluable in helping us to upgrade patient care. For example, a question arises as to why there are so much more dental problems in when dental and oral dental problems in appear to be similar with some of the western states.

The combined printout of all western institutions has been very helpful in giving our program perspective and I am very hopeful that as the WICHE Joint Data Collection Project continues we will be able to have more specific information of the developmental progress of retarded children who are receiving specialized programs elsewhere so that we can put this information to work at the

Many persons on our staff have used the WICHE printouts to compare our population characteristics with other mentally retarded hospitals operating within the region as well as comparison between one year's operation and the next.

Printouts of the results of Data Collection received from your office are used to prepare annual comparisons of this institution and other institutions. This comparison not only furnishes information but is used in program planning and budget preparation. Enclosed are copies of this year and last year's comparison.

Comparison of the Hospital population with other state hospitals and with the region - this forms a basis for comparing local programs with those of other hospitals.

discover unique problems.

2. profit from other programs if applicable.



Communication with our sister institutions, _____ and ____, is facilitated to some extent by the data collected. We find that we can talk more knowledgeably, with a common vocabulary, about the kinds of people we have in our populations, and I'm reasonably sure that the superintendents of those two institutions can do the same as the result of having the WICHE data.

Research projects are possible within this institution and between several institutions, intra and inter-state, via the joint data collection project. One that occurs to me is an examination of similarity of behavior and character-istics of those people given the same diagnosis at several institutions. Another is a comparison of reported behavior of retarded persons of various diagnoses at succeeding age levels; that is, at what ages/do behavior problems develop in cultural-familial retarded? in Mongoloids? etc. Are behavior problems characteristic of the diagnosis, of the specific environmental setting, or are they developmental and exaggerations of normal developmental changes?

The census indicated that there are 2606 mongoloids in the region. A project has been initiated to develop a demographic description of this population.

The Behavior Scales on the 1966 Data Collection are being used to assess whether mongoloids fall on a continuum or into two groups with respect to behavior characteristics.

As an example of a question raised by the data, why were there only five cases of "encephalopathy associated with other disorders of carbohydrate metabolism" among 23,443 institutional residents? Was this a true prevalence or was the diagnosis being missed? Doctors _____ and ____ of ___ School's staff felt that the diagnosis of hypoglycemia might be missed and set up a study to test this. Among 1200 residents screened using a simple glucose oxidase strip test for blood glucose after a 24 hour fast, they have found a frequency of 1 percent and 9 percent possibly with hypoglycemia. Further studies are in progress, but this illustrates one rewarding use of the data on medical diagnosis.

Many research studies depend on the census to locate subjects for specific projects. This has been true for

- head-bangers
- blind
- 3. IQ greater than 70
- 4. deaf
- 5. etc.



The data collection form has also provided us with an opportunity to devise a technician training curriculum. We have a seven and a half month training program for technicians prior to their starting work, and we have leaned rather heavily on the WICHE data to try to discern what we should teach these technicians. This provides us with a concise curriculum or, better, a concise portion of that curriculum.

Many other departments make use of project data and we anticipate much greater utilization in the future by our recently revamped In-Service Training Department.

Evaluation of Utility of the Data in Institutions

A questionnaire was developed in order to more systematically evaluate the usefulness of the WICHE data to the staffs of the participating institutions. The questionnaire used is presented as Figure 12. The responses made to it by individuals in four different categories (category 1 - directors or superintendents; 2 - assistant or associate directors or superintendents; 3 - supervisory personnel at the department [e.g., cottage life] level; 4 - non-supervisory professionals [e.g., psychologists, speech correctionists]) are indicated in the Figure and are discussed.

In general, the data appear to be judged as useful. It appears that the less specialized the role of the individual respondent, the more likely he was to believe the census to be useful in the contexts presented in the questionnaire. This is easily understandable since as specialization increases, certain problems no longer are germane to the individual's role. For example, few non-supervisory professionals are directly involved in preparing budgets; hence, most of them say that the census has been of little use to them in preparing budgets.

There is no way of estimating from this questionnaire the effects of the census on legislative appropriations. However, administrators believe it had an impact.

The last item of the questionnaire had to do with comments concerning the ways the census had or had not been useful. One comment, made by seven different people, is that more copies of the census should be sent to each institution since they had trouble finding a copy when it was needed. If the census continued, it seems clear that more copies should be sent out. A second comment, made by nearly a third of the respondents, was that although the data were useful, they would have been far more useful if the institutions themselves had data process-



ing equipment - even a card sorter. A third comment, made by a good number of respondents, was that the data were worthless because they had been collected by non-professionals. This comment was made by nearly all respondents from one institution, and by few others, so that it appears that this belief was quite localized. As indicated by research cited in the first section, this belief reveals an ignorance concerning the relevant literature as well as an ill-founded conviction of professional superiority.



Figure 12. Questionnaire on USES OF CENSUS DATA.

Part of the charge given me by the federal granting agency is to establish the ways in which the WICHE regional census has been of use to the various state institutions. For this reason, I would be most appreciative if you would complete the enclosed questionnaire.

Rate the usefulness, to you, of the WICHE census data by encircling the most appropriate letter in each category. If useful, please give an example in each category of how the census provided information not otherwise available (if this was, in fact, the case) and how this information was used.

| | | | , | Responde | nt Group | | |
|-----|------|-------------------|-----|-------------|----------|----------|---|
| | | | 1 | 2 | <u>3</u> | 4 | |
| 1. | Pro | gram Planning | | | | | |
| | Α. | Frequently useful | 6 | 6 | 13 | 6 | |
| | В. | Sometimes useful | 7 | 0 | 13 | 12 | |
| | С. | Rarely useful | 0 | 2 | 5 | 3 | |
| | D. | Never useful | 0 | . 0 | 5 | 2 | • |
| | *Le | ft blank | 0 | 0 | 7 | 1 | , |
| Exa | mple | : | | | | , | |
| 2. | Pro | gram Evaluation | | | | | |
| | Α. | Frequently useful | 2 | 3 | 1 | 2 | |
| | В. | Sometimes useful | 4 | 2 | 8 | 7 | |
| | С. | Rarely useful ' | 5 | 2 | 10 | 4. | |
| | D. | Never useful | 1 | 0 | 13 | 8 | |
| | *Le | ft blank | 1 | 1 | 11 | 3 | |
| Exa | mple | : | | | | | |
| 3. | Bud | lgeting | | | | * | |
| | Α. | Frequently useful | 7 | 5 | 7 | 2 | |
| | В. | Sometimes useful | 4 | 2 | 14 | 8 | |
| | С. | Rarely useful | 1 | 1 | 4 | 2 | |
| | D. | Never useful | . 0 | 0 | 12 | 9. | |
| | *Le | eft blank | 1 | 0 | 11 | 3 | |
| Exa | mple | :: | | | | | |



| | | | Responde | nt Group | | |
|------|----------------------------|--------------|--------------|-------------|-------------|--|
| | | 1 | 2 | <u>3</u> | 4 | |
| ١. | Public Education and Infor | rmation | | | | |
| | A. Frequently useful | 8 | 4 | 14 | 11 | |
| | B. Sometimes useful | 2 | 2 | 15 | 5 | |
| | C. Rarely useful | 3 | 1 | 4 | 2 | |
| | D. Never useful | 0 | 1 | · 7 | 1 | |
| | *Left blank | 0 | 0 | 8 | 5 | |
| xar | mple: | | | | | |
| · | Providing Information for | the Legislat | ure | | | |
| | A. Frequently useful | 8 | 4 | 4 | 1 | |
| | B. Sometimes useful | 3 | 1 | 7 | 6 | |
| | C. Rarely useful | 0 | 2 | 2 | 3 | |
| | D. Never useful | 0 | 0 | 15 | 7 | |
| | *Left blank | 2 | 1 | 20 | 7 | |
| Exai | mple: | | | | | |
| j. | Staff Training | | | | | |
| | A. Frequently useful | 2 | 3 | 5 | 4 | |
| | B. Sometimes useful | 7 | 2 | 11 | 7 | |
| | C. Rarely useful | 3 | 2 | 5 | 4 | |
| | D. Never useful | 1 | 0 | 14 | 3 | |
| | *Left blank | 0 | 1 | 13 | 6 | |
| Exa | mple: | | | | | |
| 7. | Staff Evaluation | | | | | |
| | A. Frequently useful | 0 | 2 | 3 | 0 | |
| | B. Sometimes useful | 3 | 2 | 3 | 4 | |
| | C. Rarely useful | 5 | 3 | 4 | 4 | |
| | D. Never useful | 4 | 0 | 22 | 9 | |
| | *Left blank | 1 | 1 | 16 | 7 | |
| Exa | ample: | | | | | |
| 8. | Placement of Residents . | | | | | |
| | A. Frequently useful | 1 | 3 | 5 | 5 | |
| | B. Sometimes useful | 2 | 0 | 7 | 6 | |
| | C. Rarely useful | 2 | 4 | 4 | 2 | |
| | D. Never useful | 6. | 0 | 15 | 7 | |
| | *Left blank | 2 | 1 | 17 | 4 | |
| Fya | ample: | | _ | | | |



| | | Re | spond | lent Group | | |
|-----|--|----------------|-------------|--------------|---------|-------------|
| | | <u>1</u> | 2 | <u>3</u> | 4 | |
| 9. | Research | | | | | |
| | A. Frequently useful | 3 | 4 | 8 | 5 | • |
| | B. Sometimes useful | 3 | 1 | 6 | 7 | |
| | C. Rarely useful | 4 | 2 | 7 | 4 | |
| | D. Never useful | 3 | 0 | 10 | 4 | |
| | *Left blank | 0 | 1 | 17 | 4 | |
| Exa | mple: | | | | | |
| 10. | Promoting Interdepartmental | Communication | and | Cooperation | within | Institution |
| | A. Frequently useful | 0 | 3 | 3 | 2 | • • |
| | B. Sometimes useful | 5 | 2 | 13 | 3. | v |
| | C. Rarely useful | 4 | 2 | 3 | 3 | |
| | D. Never useful | 3 | 0 | 12 | 10 | |
| | *Left blank | 1 | 1 | 17 | 6 | |
| Exa | mple: | | | | | |
| 11. | Promoting Inter-Institution | al Cooperation | า | | | |
| | A. Frequently useful | 3 | 2 | 1 | 2 | |
| | B. Sometimes useful | 4 | 1 | 4 | 5 | |
| | C. Rarely useful | 2 | 3 | 4 | 2 | |
| | D. Never useful | 3 | 0 | 19 | 7 | |
| | *Left blank | 1 | 2 | 20 | 8 | |
| Exa | mple: | | | | | |
| 12. | Promoting New Systems of Re Statewide Basis | cord Keeping | withi | n the Instit | ution o | r on a |
| | A. Frequently useful | 1 | 1 | 1 | 0 | |
| | B. Sometimes useful | 5 | 2 | 4 | 5 | |
| | C. Rarely useful | 3 | 3 | 6 | 0 | |
| | D. Never useful | 3 | 0 | 15 | 7 | |
| | *Left blank | 1 | 2 | 22 | 12 | |
| Exa | umple: | | | | | |

^{*}This was not an alternative on the form, but occurred rather frequently.

| Ì |
|---|



FURTHER RESEARCH PROBLEMS

A prime objective of the large scale data base described in this report has been to foster the development of an understanding of the important research issues relevant to institutionalized retardates. Many of the questions raised by the data have been at least partially answered by the studies discussed earlier in this report. Other questions, which probably would require additional data, can be generated in substantial numbers.

In the opinion of the program staff, most of the pressing questions fall into four broad categories:

- 1. Reasons for and effect of institutionalization.
- 2. Problems of testing and diagnosis.
- 3. Handicaps, self-care limitations, and behavioral characteristics.
- 4. Effectiveness and relevance of rehabilitation and training programs.

Reasons for and Effect of Institutionalization

The main concern within this group of questions is to what extent the environment of the institution interacts with both the problems and the prognosis of its residents. In this regard, what is needed is a large scale, long-term study of a cohort of newly admitted residents (plus, if possible, a control group of non-residential retardates matched in age, sex, IQ, and diagnosis) to determine the effects over time of institutionalization. This longitudinal approach could provide data concerning the question of whether institutionalization generally has an adverse effect on development or whether the effects of institutionalization may be positive or negative depending on the characteristics of the resident (e.g., ability level), the institution (e.g., institutional size), or of the interaction between resident and institutional characteristics. A longitudinal study of this sort could provide data concerning what type of ward population (homogeneous or heterogeneous) should be constructed in order to provide the most effective ward environment. Factors contributing to institutional admission and discharge also could be assessed.

One of the factors possibly contributing to the institutionalization of an individual is the lack of mental retardation services within the community. This, too, could be assessed. It could best be investigated longitudinally, but some data concerning the effect of community services on rate of institutionaliza-



tion also could be obtained cross-sectionally from any given yearly census.

A longitudinal study would permit investigation of many other related questions. For example, what factors contribute to institutional retention of residents with normal intelligence, or of borderline or mild retardation? The entire question of admission and discharge policy needs investigation. Additionally, the effect of outside retardation services at the community level on admission and discharge practices needs to be assessed, as well as the effect that outside contact in general (e.g., home leave) has on the progress of the retardate himself.

Problem of Testing and Diagnosis

Despite the fact that many persons in the field of retardation reject the idea of IQ, and some reject the whole idea of testing, data presented earlier provides convincing evidence that test scores are relatively adequate predictors of behavior. Therefore, a number of further questions could be asked concerning test scores. They include:

- a. Are there maximum abilities associated with IQ level? That is, can one construct a Guttman-like scale of abilities that relates to IQ scores?
- b. Some individuals have Loth IQ and SQ scores (though only one score is entered on the census form). It would be possible to find those individuals for whom both IQ and SQ scores are available. It might be of some interest then to select out those whose two scores show a substantial (perhaps 10 point) discrepancy in order to determine what is associated with this discrepancy (e.g., we would expect older residents to more often have high SQ's than IQ's).
- c. Research discussed earlier in this report suggests that differences between diagnostic types are very slight (except in the cases of Down's Syndrome and PKU), once differences in IQ-SQ between diagnostic groups has been controlled for. Even individuals with encephalitis do not differ significantly in problem behavior from others, popular beliefs to the contrary. Yet, it seems that <u>some</u> diagnostic scheme should work. With further time, the WICHE data might provide leads as to how to develop another diagnostic system. Additional research on



further diagnostic aids, such as chromosome analysis, would also be helpful.

- d. How do IQ-SQ scores change over time? What causes this change, and what may be done to accelerate improvement? Is such change an artifact of the testing procedures generally utilized, or does this represent a maturation or development process for retardates that is different than for normals?
- e. In this same regard, the question may be asked as to whether a "specific impairment" theory, or an "arrested development" theory is most appropriate to retardation. The whole issue of the relation between learning and maturation as they apply to retardation needs further study.

Handicaps, Self-Care Limitations, and Behavioral Characteristics

The whole area of handicaps might be investigated further. It seems clear from a pilot screening program conducted at Fairview, Oregon, that a substantial number of sensory defects go unrecognized. Full use of the WICHE data by institutions might well provide them with cues concerning the proportion of handicapped persons not known to be so handicapped, and also perhaps with information concerning the effectiveness of various screening procedures. Institutions also might examine their residential population in terms of motor handicap. For example, two institutions in the census are very similar in terms of the mean age, mean ability level, and diagnosis of residents. Yet one institution has twice as many nonambulatory residents than the other. Why? This appears to be a question worth examining, if only because ambulatory residents are easier and cheaper to care for.

The cost of caring for the basic needs of the institutionalized represents a huge proportion of the total cost of institutionalization. A rough illustration will emphasize this point. Of the 24,257 residents in the 1968 census, 3,216 occasionally, and 7,307 usually wet their beds. For illustration, assume the 10,523 residents wet the bed at least once a day. Further assume that it takes paid employees 15 minutes to change the bed, that they are paid \$1.50 per hour, and that a pair of sheets can be laundered for a penny each. Simple arithmetic indicates that it costs \$4,106.49 per day to simply change and launder sheets due to bedwetting. In a year, this figure increases to \$1,498,859.95!



Research is most definitely needed to develop training methods to increase self-care abilities. Successful programs toward this end would not only free large amounts of money and employee time, but would most likely have a profound effect on the self-image and motivation of the patient himself. The effects of such a benefit can scarcely be underestimated.

A different sort of problem lies with the investigation of the behavioral characteristics of the residents. The WICHE census recorded information related to behaviors most often mentioned by the staff as representing problems. These need further analyses such as factoring these characteristics to reveal kinds of behavior, as well as studies to determine what these behaviors really mean. That is, while certain behaviors may represent problems for the institution staff, they may also represent healthy and encouraging behavior on the part of the patients. For example, as was reported earlier, overt heterosexual behavior was almost always associated with higher than average functioning, and those residents engaging in this type of sexual behavior were almost never destructive. Thus, the various behaviors mean something about the patient; the meaning should be investigated and staff personnel trained to understand and interpret what the patient is communicating (though admittedly in a primitive way) through these behaviors.

Effectiveness and Relevance of Rehabilitation and Training Programs

Finally, a series of questions might be asked regarding the school programs, outside placement, and other institution programs. Trading of information among the various institutions might be of particular use in this area. Questions to be investigated include: What are the requisite criteria for participation? What are the determinants for "graduation"? What kinds of progress can be expected from the various programs, and what are the limitations which interfere with progress?



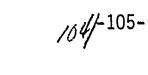
APPENDIX A

RESEARCH ADVISORY COMMITTEE



RESEARCH ADVISORY COMMITTEE

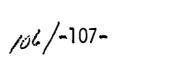
- William B. Beach, Jr., M.D., Deputy Director, Division of Local Programs, California State Department of Mental Hygiene.
- Dr. Harvey F. Dingman, Professor, Department of Psychology, University of Texas.
- Dr. Harry Martin, Professor, Department of Psychiatry, University of Texas School of Medicine.
- Dorothy Smylie, Assistant Chief, Crippled Children's Service, Child Health Division, Idaho State Department of Health.
- Gareth Thorne, Superintendent, Rainier School, Washington.
- Horace Thuline, M.D., Director of Laboratories, Rainier School, Washington.





APPENDIX B

POPULATION CHARACTERISTICS OF PARTICIPATING INSTITUTIONS





3 I.FNGTH OF STAY-YEARS

| ₹0 | | 0 | • | 14 | 31 | 10 | w | N | ~ | 0 | 0 | 0 |
|------------|----------|---|--------------|------------|------------|-----|----------------|----------|----------|------------|----------|----------|
| 22 | | 0 | - | æ | € | 53 | 10 | ທ | m | 0 | 0 | 0 |
| 21 | | • | 0 | 33 | 9 | 13 | m _. | - | • | 0 | 0 | 0 |
| 20 | | 0 | - | ~ | 23 | .55 | 21 | 18 | c | 0 | | 0 |
| 19 | | 0 | N | 4 3 | 4 3 | 12 | 0 | 0 | 0 | 0 | | 0 |
| 18 | | 0 | ~ | 62 | 31 | 1, | 16 | _ | - | 0 | 0 | • |
| 17 | | 0 | 4 | 42 | 22 | 19 | 60 | ហ | 0 | 0 | 0 | 0 |
| 16 | | - | • | 36 | 32 | 15 | 13 | 0 | 0 | 0 | 0 | 0 |
| 15 | | 0 | 8 | 59 | 27 | 9 | • | - | 0 | 0 | 0 | 0 |
| 1 | | 0 | m | * | 31 | 13 | • | • | 0 | 0 | 0 | 0 |
| 13 | | 0 | • | 43 | 33 | 11 | • | ~ | - | 0 | 0 | 0 |
| 12 | | 0 | ~ | 25 | 31 | 14 | - | 0 | 0 | 0 | 0 | 0 |
| 11 | | 0 | 4 | 9 | 20 | 0 | 0 | 0 | 0 | 9 | 3 | э |
| 10 | | 0 | - | 55 | 59 | Φ | 4 | N | 0 | 0 | 0 | 0 |
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17 SCHOOL ATTENDANCE

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HEARING-ABILITY

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23 HEARING-REFERRED FOR EVAL.

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25 ARM-HAND USE

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27 DPUGS-FOR SLEEP PRORLEMS

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27 DRUGS-FOR SETZURES

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COMMUNICATION-UNDERSTANDS

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33 GROCMING

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34 INILET TRAINING

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6 CANDIDATE FOR WARD HELPER

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37 CANDIDATE FOR WORK PROJECT

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38 WORK REWARD SYSTEM

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39 BFH 4-EXPOSES SELF

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39 BEH 6-DESTROYS CLOTHING

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39 BFH 8-REQUIRES RESTRAINTS

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| | لما ا | ^ | 17 | 16 | 16 | 91 | 18 | 16 | 16 | ~ | 11 | 17 | 16 | 12 | 12 | 12 | Φ | 19 | 12 | N | 50 | 9 | 20 | 14 |
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39 BFH 11-MASTURBATES PUBLICLY

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| | | - | ~ | m | • | ហ | • | ~ · | © | • | . 10 | - | 12 | 13 | 14 | 15 | 16 | 11 | 18 | 19 | 20 | 23 | 22 1 | ‡ ∨ ‡ |
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| NEVER | - | 85 | 73 | 75 | * | 82 | 72 | 7 | 82 | 26 | 16 | 70 | 11 | 57 | 82 | 73 | 63 | 92 | 92 | 89 | 69 | 95 | 76 | 72 |
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39 BFH 12-MOLESTS CHILDREN

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| ERROR. | ĩ | 53 | m | Ŋ | m | • | ហ | Φ | 11 | 36 | ហ | 4 | ~ | 0 | m | 22 | 19 | S | 16 | 1.0 | m | 0 | * | 10 |
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| NEVER | , . | 63 | 80 | 12 | 86 | 85 | 18 | 68 | 80 | j. | 48 | 80 | 75 | 63 | 85 | 69 | 65 | 82 | 17 | 87 | 61 | 96 | 88 | 73 |
| SELDOM | ~ | N | 7 | 4 | 4 | ~ | 4 | Ö | 'n | 4 | m | 8 | • | m | ß | 8 | • | m | 0 | 0 | 0 | - | - | ო |
| OCCASTONALLY | la. | m | 0 | Ŋ | N | ~ | m | * | ώ | Ņ | m | 8 | m | N | * | N | N | ~ | a | 0 | 0 | - | - | 0 |
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| NEVER | ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,, | 77 | 69 | 87 8 | 808 | 82 80 | 0 79 | | 26 | Β. | 49 | 4 | 69 | 89 | 77 (| 62 8 | 81 8 | 81 92 | 98 | 95 | 71 | 7. |
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39 BFH 14-DESTROYS WARD PROPERTY

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| CLANK | 0 | 7 | ო | ~ | N | m | • | 4 | ~ | * | - | m | ~ | 10 | ~ | m | ~ | m | - | N | - | 0 | N | m |
| NEVER | , | 57 | 63 | 73 | 99 | 75 | 2 | 29 | 11 | 64 | 89 | 28 | 57 | 22 | * | 29 | 6 | 20 | * | 78 | 68 | 16 | 63 | 63 |
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| ERROR | ĩ | - | | - | 0 | 0 | - | ~ | N | 58 | m | - | m | ហ | 0 | 9 | 12 | ~ | - | - | - | 0 | 0 | 4 |
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| NEVER | ••• | 81 | 58 | 11 | 99 | 72 | 11 | 65 | 18 | 20 | Ľ | 59 | 49 | 09 | 81 8 | 80 | 57 6 | 67 8 | 81 9 | 97 8 | 81 9 | 95 6 | 60 6 | -89 |
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39 BFH 16-LIKELY TO ESCAPE

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| | | ~ | N | m | • | ம | 9 | ^ | œ | 6 | 10 11 | 1 12 | 2 13 | 3 14 | 15 | 16 | 17 | .18 | 19 | 20 | 2 | 22 | ToT |
| ERROR | ï | 9 | S | - | - | 0 | Ņ | M. | m | 31 | e | - | | | 11 | œ | 4 | • | m | 0 | 0 | - | • |
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| NEVER | - | 80 | 99 | 85 | 69 | 86 | . 28 | 62 | 81 | 58 7 | 78 6 | 11 69 | 99 1 | 87 | 16 | 69 | * | 83 | 66 | 98 | 96 | 86 | ic O |
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| FREGUFNTLY | 4 | ហ | m . | - | • | ∾. | - | - | ო. | - | ന . , | · · · | 3 | ~ | ω | m | - | - | 0 | 0 | 0 | ~ | m |
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39 BFH 17-MASTUPBATES PRIVATELY

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| | | - | N | m | 4 | ß | • | ~ · | co | • | 10 | 7 | 12 | 13 1 | 14 1 | 15 16 | 5 17 | 18 | 19 | 20 | 12 | 22 | ŤoŤ |
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| ZEVER | - | 55 | 23 | 21 | 51 | 50 | 31 | 52 | 22 | 20 | 6 43 | 30 | 21 2 | 23 2 | 27 4 | 40 22 | 2 41 | 31 | 4 | 15 | 72 | 18 | 35 |
| SELDOM | C ! | - | Φ | σο | 9 | 4 | • | • | 00 | 8 | - | 4 | _ | S | la) | 4 11 | | 9 | 0 | 12 | 0 | • | • |
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| UNKNOWN. | w . | 0 | 42 | 50 | 27 | 56 | 37 | 4 3 | co | 24 | 42 | 1, 1, | 7 7 7 | 4 3 5 | 53 1 | 16 21 | 1 31 | 23 | | 8 0 | 19 | * | 35 |

39 BFH 18-SEX OTHERS, OPP SEX

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| NEVER | | 82 | 98 | 63 | 4 | 85 | 65 | 92 | 87 | 52 | 70 | 29 | 54 | 54. | 77 | 71 6 | 66 7 | 76 7 | 75 8 | 88 7 | 70 79 | 79 | 68 | • |
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| FREQUENTLY | 4 | c | ~ 1 | - | 0 | ~ | 0 | 0 | - | 9 | 4 | • | 0 | - | - | | - | _ | - | 0 | m | 0 | ~ | |
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39 BFH 19-REFUSES TO WEAR CLOTHES

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| ERROR | 7 | 34 | 4 | 4 | • | ß | ហ | 11 | 01 | 41 | m | • | o , | • | Φ | 25 | 24 | • | 18 | 13 | • | • | 3 . 11 | · 🚙 |
| BLANK | . | - | m | ~ | ~ | m | • | • | - | • | - | m | - | 10 | ~ | m | ~ | 6 | - | ~ | - | 0 | N | 'n |
| NEVER | , | 9 | 18 | 83 | 67 | 48 | 85 | 75 | 4 | 50 | 77 | 11 | 11 | 61 | 89 | 99 | 29 | . 22 | | 81 | 92 9 | 95 7 | 7 0 7 | 11 |
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| OCCASTONALLY | m | 4 | 4 | m | 00 | N | N | m | 4 | ~ | c o | 7 | • | ம | 8 | ~ | m | • | ~ | N | - | - | ~ | • |
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| FREQUENTLY | r | 0 | • | 0 | 0 | 0 | 0 | Ο, | 0 | • | 0 | • | 0 | - | 0 | 0 | 0 | - | ഗ | 0 | 0 | 0 | 0 | 0 |
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39 BFH 20-ATTACKS RESIDENTS

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| | 1 | - | N | m | 4 | ഗ | • | ~ · | a | J | 10 | 11 | 12 1 | 13 1 | 14 15 | 5 16 | 17 | 18 | 61 | 20 | 21 | 22 | 101 |
| ERROR | ĩ | 16 | - | N | m | 8 | , W | Φ | . ~ | 36 | • | N | 4 | ~ | 1 18 | 8 18 | m | • | • | ~ | 0 | ~ | |
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| NEVER . | - | SS | 4 | 72 | 49 | 89 | 72 | 56 | 69 | 14 | 69 | 20 | 56 | 53 7 | 70 63 | 3 52 | 58 | 7.1 | 95 | 69 | 96 | 51 | 9 |
| SELDOM | מי | ^ | 21 | 12 | 13 | = | Φ. | 13 | • | ທ ີ | 11 | 19. | 17 | 13. 1 | 11. | ហ | 9 17 | 7 | 0 | 15 | 0 | 13 | 12 |
| OCCASTON-4LLY | m | 12 | 19 | 07 | 12 | 11 | _ | 16 | 10. | 7 | 13 | 16 | 14 1 | Q٠. | 11 | 60 | 8. 13 | S. | 0 | 15 | • | 19 | 12 |
| FREQUENTLY | 4 | 6 | • | N | Ŋ | ហ | N | m | m | N | - | Φ. | ~ | m | S | ω. | ر 4 | N | o | ហ | • | ^ | 6 0 |
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