

SUPPLEMENTARY FACTUAL REPORT #2

(Data relative to: A Preliminary Proposal to Eliminate
Waiting Lists for State Hospitals for the Mentally Retarded")

A survey of Families with Children on the Waiting List

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INTRODUCTION

In January 1964, a subcommittee of the Assembly Ways and Means Committee began a review of State services for mentally retarded persons unable to live in their own homes. Since that time the committee and its staff have visited and studied California's public and private facilities; consulted with numerous professionals; conducted public hearings; studied literature pertaining to mental retardation; and published two reports: "A Preliminary Proposal to Eliminate Waiting Lists for State Hospitals for the Mentally Retarded," and a companion document, "Supplementary Factual Report #1."

For many years, the State has assumed responsibility for certain retarded persons by offering care in State hospital facilities. Since the time when the State hospital system was first designed, new knowledge of the problem of mental retardation has been developed. The committee's study has had a two-fold purpose: to produce recommendations for improving State hospital services, and to determine if California's system is properly organized in the light of current knowledge.

In addition to analysing information provided by agencies, professional persons, and organizations, the committee has probed another dimension. Of major importance, in reviewing the present system, is the attitude of the individuals who use these services. What do parents of retarded children want the State to do? How do they view their problem and what solutions are they seeking? During the past few months the committee has attempted to find answers to

these questions. The committee corresponded with over 100 families with retarded children and gathered factual information from more than 1,200 families with children on the waiting list for State hospitals.

The results of that investigation are summarized in this report.

SUMMARY OF FINDINGS

1. Half the families with children on the current waiting list for State hospitals for the retarded would not place their children in a State hospital if other alternatives were available.

These families state they would prefer to hire help to assist them in caring for their children at home, or would elect to place their children in foster homes or private institutions if funds were available to help them pay for these services.

The present State system does not offer such alternatives to State hospital care. The following quote from one of the many letters to the committee illustrates the dilemma:

"Our son is 4 years old, and living for the past few months in a foster home licensed by the State Department of Mental Hygiene.

"He was diagnosed by Dr. _____, at the Birth Defect Center at Children's Hospital in San Francisco, as neurologically damaged and severe sensory receptive aphasia. We were advised to make an application for him at Sonoma State Hospital The hospital told us that he was eligible but not suitable--that they could not duplicate the care and education he was receiving in San Francisco.

"Naturally we were delighted that he can be here in San Francisco where we can visit him, and that he is showing progress in the classes for aphasic children at the San Francisco Hearing and Speech Center."

"But, I'm afraid we are classic examples of the middle-income family unable to afford the \$150 a month for his care. My husband makes an adequate salary for a family of seven with normal expenses we are not eligible for any aid from Public Welfare We're a bit stymied at this point. We are praying that funds will be made available as a result of new legislation and it is on that premise that we are taking a loan to help us take care of our son for the next several months"

2. Half the families with children on the waiting list prefer State hospital care to any of the suggested alternatives.

These families prefer the State hospital because of its permanency and complete spectrum of services. Some families have also expressed a distrust of the motives of private agencies and foster parents and suggest that until more adequate standards and inspection procedures are developed they would not feel secure about placing their children in community facilities.

This information confirms the continuing need for State hospitals for those children whose special needs cannot now be met by community agencies and for those whose families prefer State hospital care for a variety of reasons.

3. There is a direct relationship between family income and the willingness or ability to utilize private care facilities.

Among the families with children on the State hospital waiting list, the families in the high income range do utilize private facilities at a much greater rate than the families in the low income range. This confirms the belief that financial reasons alone may be a significant reason why more families do not use private facilities to help them deal with their problems.

4. Of the children on the waiting list who are in private facilities until a vacancy occurs in the State hospital, nine out of ten are supported in the private facilities at a monthly cost of less than \$300.

5. Three out of four children presently on the waiting list for State hospitals are living in their own homes.

Even though the retarded who are on the waiting list represent the more severely retarded in a community, over three-fourths of them are living at home. The cost of private care very likely prevents many parents from placing their child in a private facility, but the fact that such a large percentage are cared for at home may also indicate that with some type of assistance to the parents, some of these children could continue to live at home, utilizing such services as day care centers and homemaker service, rather than being placed away from the family.

GENERAL FINDINGS

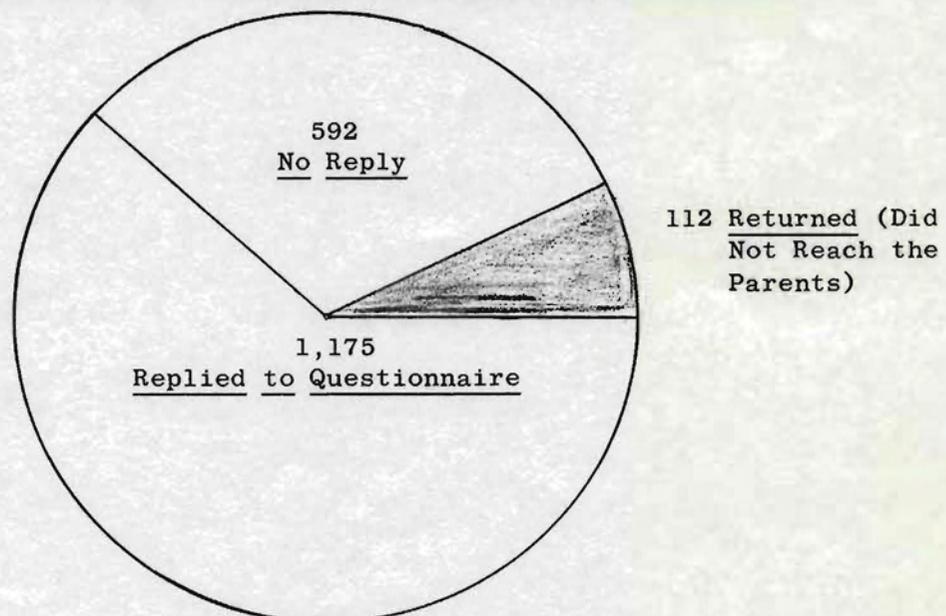
1. Over half of the parents with a child on the waiting list for a State hospital responded to the questionnaire. With the cooperation of the Department of Mental Hygiene, a total of 1,879 questionnaires were mailed. One hundred twelve questionnaires were returned because the family had moved and left no forwarding address. Of the 1,767 who received questionnaires, a total of 1,175 (66.4%) replied.

The conclusions drawn in the main body of this study are based on 1,023 of the 1,175 responses. (A total of 152 responses could not be used because they were incomplete, were answered in an ambiguous manner, or were returned late.*)

The 1,023 questionnaires upon which conclusions are based represent 57.8% of the parents with children on the waiting list.

FIGURE I

Rate of Reply to 1,879 Questionnaires Mailed to Parents of Children on the State Hospital Waiting List



* The 152 responses not included in the main report are analysed and discussed in the appendix.

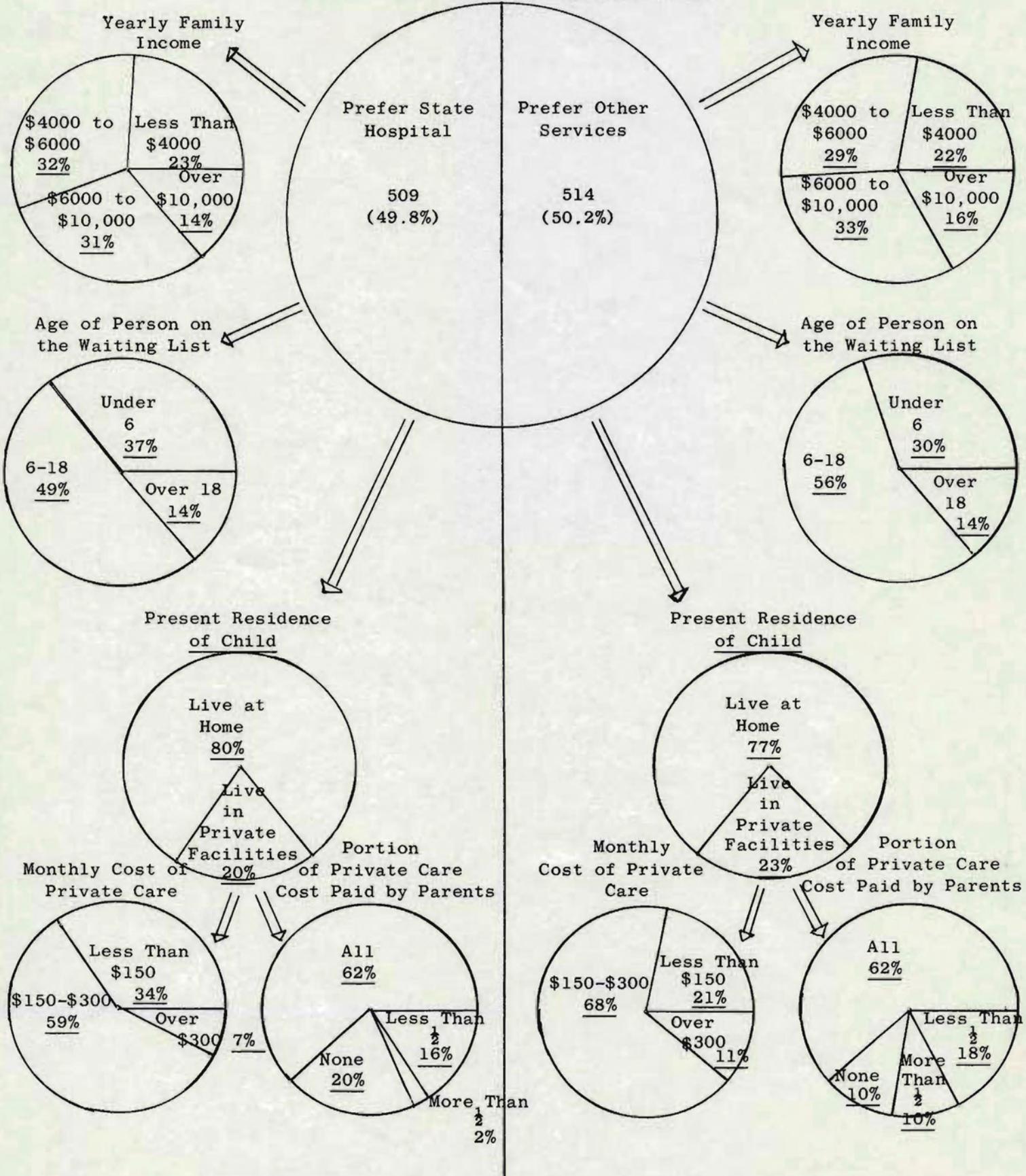
2. About half the parents with retarded children on the waiting list would prefer hiring help at home or placing the child in a foster home or private institution, rather than place the child in a State hospital, if funds could be made available to help pay for these services. Of the 1,023 responses used to draw conclusions for the study, 514 stated a preference for private or home care services, while 509 preferred the State hospital.

3. A breakdown of the two groups (those preferring State hospitalization and those preferring community care) according to yearly family income indicates that the economic position of the two groups is almost identical. A breakdown according to the age of the child also fails to show any significant difference between the groups.

A comparison of the percentage of those whose children are living at home to those who have placed their children in private care facilities likewise fails to show any significant difference between the groups. Further, whether the child is now at home or in a private facility seems to have no bearing on the preferences of the family, nor do we find any evidence that the portion of the cost of private care now paid by these families is related to their choice of community care or State hospitalization. (See Figure II)

FIGURE II

Placement Preference of Families With Children on the Waiting List



4. Three out of four children presently on the waiting lists for the State hospitals are living in their own homes. Of the 1,023 in the study, 802 (78.4%) are now living at home, while 221 (21.6%) are living in foster homes, nursing homes, or other types of private care facilities in the community. Some children living at home utilize day care facilities in the community, but the rate of utilization of these types of facilities by persons on the waiting list could not be determined from the available data.

The retarded persons on the waiting list represent the more severely retarded in the community, yet three out of four are cared for in their homes until a vacancy occurs in the State hospital. The cost of care in private facilities, a desire to keep the child at home as long as possible, and, in some cases, a general distrust of those who operate the private facilities "for profit" are some of the reasons cited by parents for not utilizing private services.

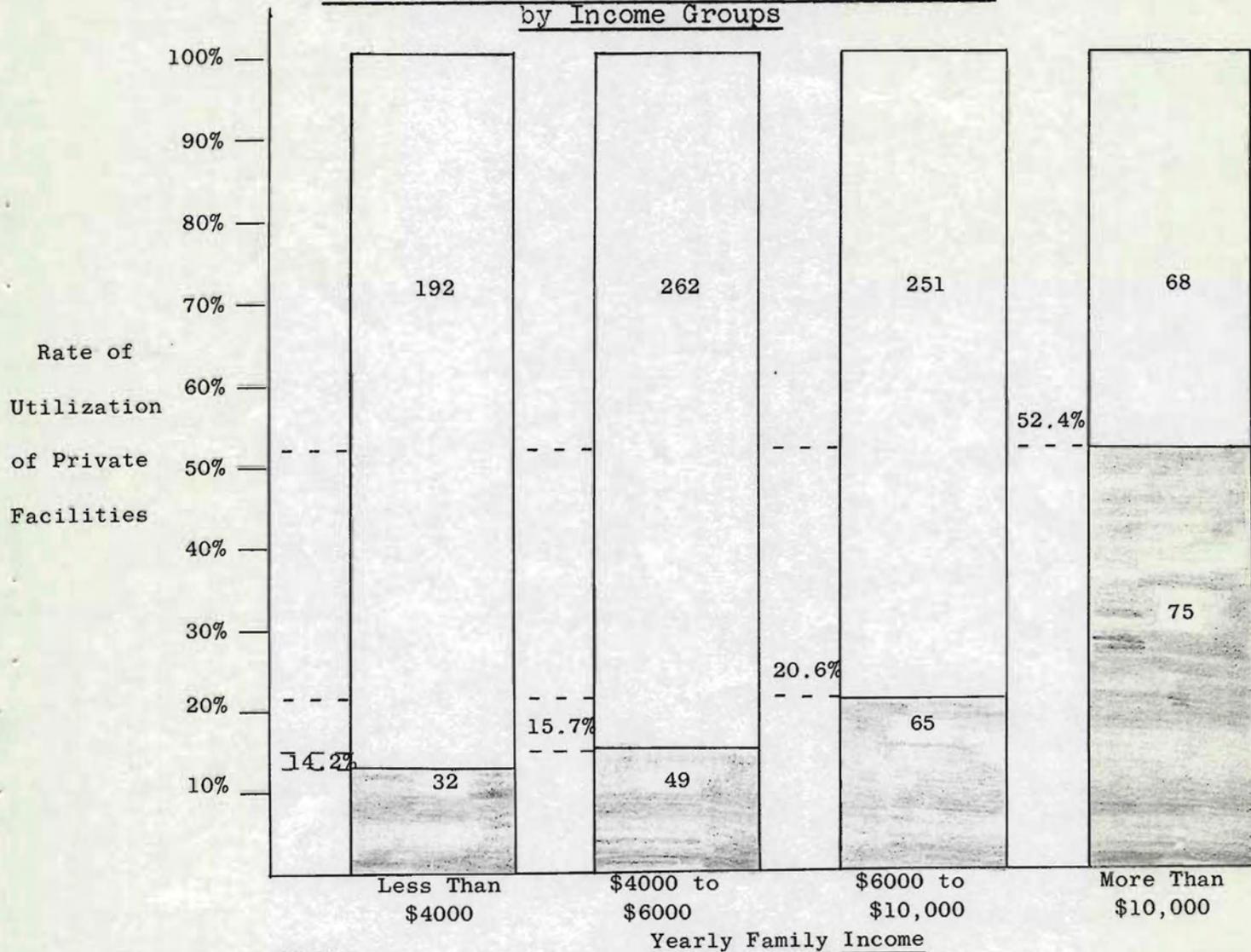
A recent report by the Committee, "Supplementary Factual Report #1," gives the results of a study of the 225 private facilities licensed to care for the retarded in California. That report indicated that there are many vacancies in these existing facilities-- primarily because of the prohibitive cost for many middle-income families.

Reasons such as the desire to keep the child at home as long as possible and feelings of distrust for those operating private care facilities are some of the reasons given for not placing a child in a private facility. Such reasons, based on feelings and attitudes, are very difficult to measure. Intensity of feelings cannot be translated into numbers and compared as easily and reliably as the cost of care factor.

The cost factor has been analysed and it is clear that there is a direct relationship between yearly family income and whether or not the family of a child on the waiting list will place the child in a private facility until a vacancy occurs in the State hospital. Figure III illustrates the sharp increase in the rate of utilization of private facilities that accompanies an increase in yearly family income.

FIGURE III

Rate of Utilization of Private Facilities
by Income Groups



Legend:

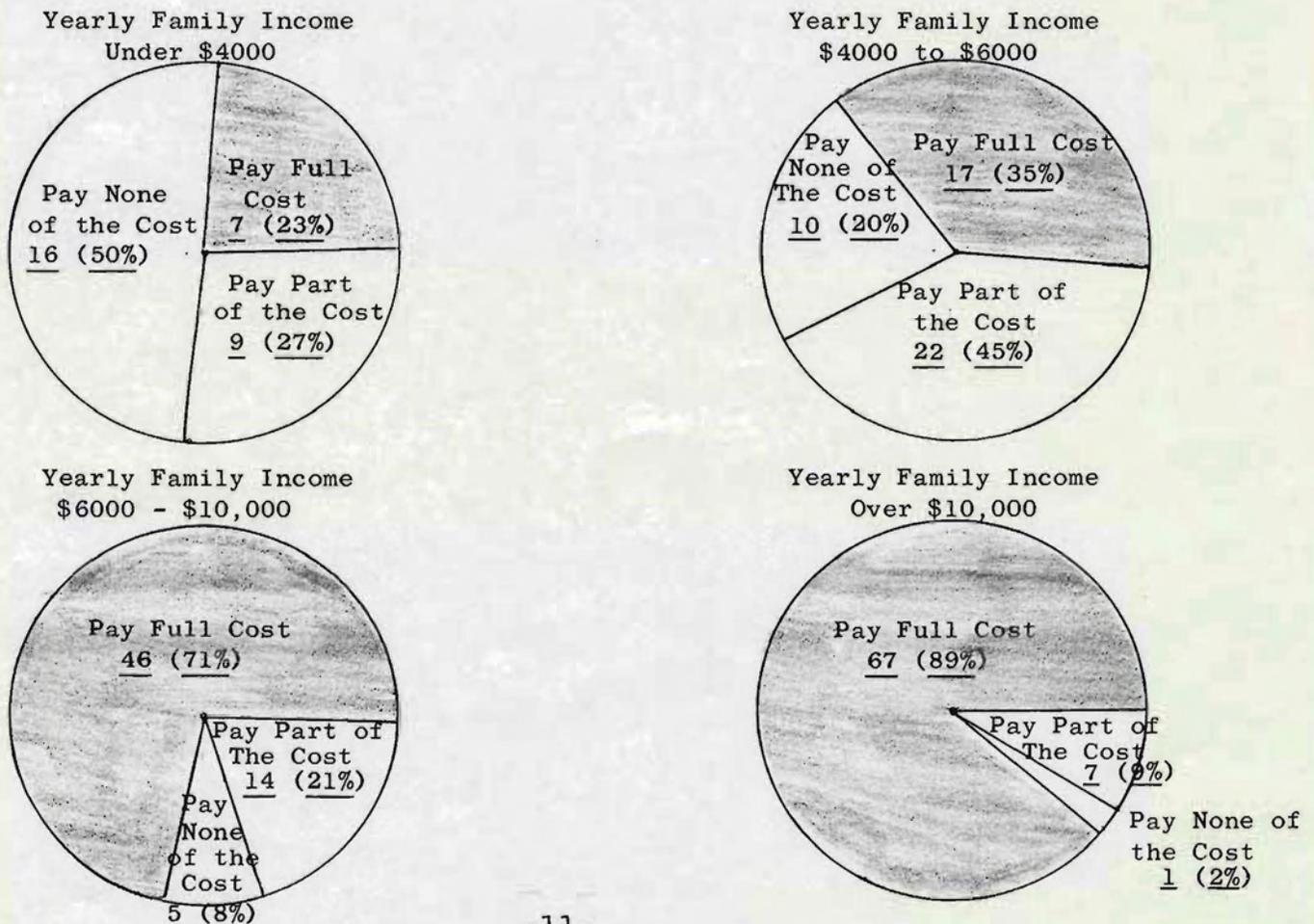
- Live at Home
- Live in Private Facilities

Figure III indicates that a yearly family income of \$10,000 or more is necessary before many persons are able to afford private care. Although there is a steady increase in the rate of utilization of private facilities as one goes from the low income to the high income groups, a significant change in the rate of utilization occurs in the over \$10,000 group.

Figure IV further clarifies the relationship between yearly family income and placements in private facilities. Of the families with children in private facilities, the portion of the cost of private care paid by the parents increases sharply with an increase in yearly family income.

FIGURE IV

Portion of Private Care Costs Paid by
Parents of Children on the Waiting List
Who Live in Private Facilities



Among families who have a yearly family income under \$4,000 per year who have a child placed in a private facility, 23% pay the full cost of private care. The percentage of those paying the full cost of private care rises as one goes up the income scale, and among those who have a yearly family income of more than \$10,000, 89% pay the full cost of private care.

As expected, we find a decrease in the percentage of those paying none of the cost of private care as income increases. Among the families with a yearly income under \$4,000, 50% pay none of the cost of private care. In the \$4,000-\$6,000 bracket, 20% pay none of the cost of private care. In the \$6,000-\$10,000 group, only 8% pay nothing towards the cost of private care. In the over \$10,000 category, only 2% fail to contribute in some part to the cost of private care for their child.

Although it is not surprising to find that those who have a larger income pay more towards the support of their child in a private institution, these facts prove the direct relationship between family income and the ability to utilize private facilities. Over 80% of the families in the study have a yearly family income of less than \$10,000, and these families clearly cannot afford the total cost of private care.

5. Nine out of ten children on the waiting list who are presently in private facilities are being cared for in these facilities at a monthly cost of less than \$300. (A total of 221 patients on the waiting list were living in private facilities at the time of the study.) The monthly cost for maintenance in private facilities for 201 (91%) of these patients was less than

\$300. Since \$300 represents a minimal estimate of the cost of maintaining a person in a State hospital, it is apparent that the cost of maintaining these 201 children will increase when they are transferred to the State hospital. (A transfer desired by only half the families.)

SOME IMPLICATIONS FOR PLANNING

This report emphasizes the need for a new dimension in planning. Until this time considerable planning has been based on facts and attitudes provided by professional personnel. Lacking in most projections was the ingredient of the feelings and desires of the users of service - families with retarded children.

It is now possible to add this new information to that already known, to arrive at more significant estimates of the impact of possible legislation which may increase the number of State sponsored alternatives to hospital care:

A survey of the mentally retarded patients' needs done by the Department of Mental Hygiene in 1963* indicates that 59.9% of those on the waiting list could be "more appropriately cared for in facilities other than the State hospital." In that report, the Department also stated that 63.2% of those presently in the State hospital could be better served in other facilities. The other facilities specified were 24-hour nursing homes, foster homes, and home care (parental or a relative's home with some homemaker or day care assistance).

Since the publication of that study, the Department has re-evaluated those patients who were categorized in the "need 24-hour nursing care" category, and they now feel that many of the persons

* Bio-statistical report No. 34, Department of Mental Hygiene, 1963, pp. 33.

so classified in 1963 (about 4,000 people) are actually in need of State hospital care.*

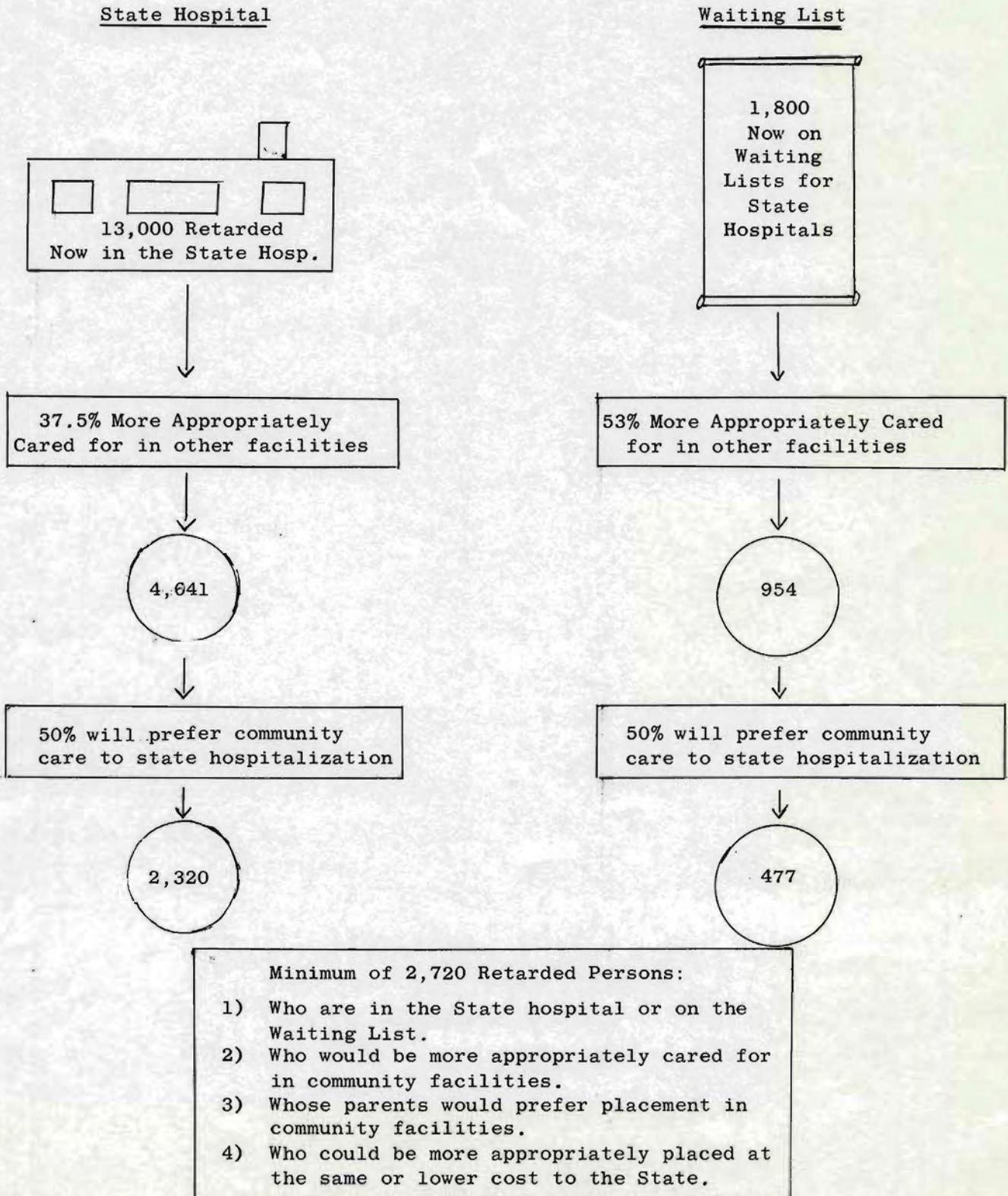
For the purpose of the following projections we will assume that those "needing 24-hour nursing care" do belong in the State hospital, and we will include only the "foster home" and "home care" categories of patients. Considering only these two categories reduces the percent of patients who could be served in community facilities to 53% of the waiting list, and 35.7% of those in the hospitals. (It is important to note that these are minimum figures based on a re-definition of the problem by the Department of Mental Hygiene.) Based on the above assumptions and the new knowledge concerning family preferences, the following projections can be made:

There are approximately 1,800 persons now on the waiting list for State hospitals. According to the Department of Mental Hygiene 954 (53%) of these could be more appropriately cared for in facilities other than the State hospital. Our figures indicate that about 50% of the persons on the waiting list would prefer placement in community facilities if financial help was available. Therefore, 477 persons who are presently on the waiting lists could be more appropriately cared for in a facility other than the State hospital, and would be

* Interview with Dr. William Beach, Jr., Department of Mental Hygiene, September 11, 1964. (This re-evaluation is open to some question in view of the fact that over 100 patients needing 24-hour nursing care have been satisfactorily placed in private nursing homes in a four-year pilot program conducted by the Department. It is reasonable to assume that many patients in this category now being re-defined as needing State hospital care could also be properly served in community facilities.)

FIGURE V

Minimum Number of Retarded Persons
For Whom Immediate Community Care is Indicated



APPENDIX

A total of 152 questionnaires were returned, but could not be used in drawing conclusions for the study. Most were returned too late and some were incomplete.

Although the data from these 152 questionnaires were not included in the conclusions, the purpose of this appendix is to show that the exclusion of this data did not significantly alter any of the conclusions. Since one of the reasons for exclusion from the main body of the study was failure to answer one or more questions, the number of responses added to the totals found in the main conclusions will vary, depending on how many of the 152 questionnaires being considered in the appendix gave an answer for the particular question of concern. For the most part, the appendix will compare percentages, rather than numbers of responses, since most of the conclusions were based on data that had been converted into percentage form.

A) Conclusion 1 deals with the rate of response, and the 152 cases in the appendix are included.

B) Conclusion 2 stated that about one-half of the parents who have retarded children on the waiting list would prefer community based care, rather than State hospitalization. Of the 1,023 replying to the questionnaire, 514 (50.2%) preferred community care, while 509 (49.8%) preferred State hospitalization. By adding the preferences of the 152 questionnaires under consideration in the appendix, we find that 563 (47.9%) preferred community care, 573 (48.7%) preferred State hospitalization, and that 39 (3.4%) had no preference.

The inclusion of the 152 cases makes no difference in the conclusion. Those preferring State hospitalization and those preferring community care are still separated by less than 1% and those having no preference make up only 3.4% of the total number of responses.

C) Conclusion 3 pointed out that three out of four persons on the waiting list are living in their own homes. Of the 1,023 in the study, 802 (78.4%) were living at home, while 221 (21.6%) were living in private facilities. The addition of those cases being considered in the appendix makes little difference in these percentages. A total of 888 (76.2%) were living at home at the time of the study, and 276 (23.8%) were living in private facilities when we include the cases in the appendix. The inclusion of these figures does not alter the conclusion that three out of four persons on the waiting list live in their own homes.

D) Conclusion 4 indicated that there is a direct relationship between yearly family income and rate of utilization of private facilities. Of those with a yearly family income of less than \$4,000, 14.2% had their children placed in a private facility, 15.7% with income of \$4,000-\$6,000 had their children under private care, 20.6% of those with income of \$6,000-\$10,000 had their children placed in private facilities, while 52.4% of those with a yearly income of more \$10,000 were utilizing private care facilities. By taking into consideration the cases in the appendix, the rate of utilization of private facilities for those with a yearly family income of less than \$4,000 goes up slightly to 19.1%, the rate of

utilization for the \$4,000-\$6,000 group also rises slightly to 18.4%, the utilization rate for the \$6,000-\$10,000 group rises to 22.4%, while the rate for the over \$10,000 group drops to 51.2%. These variations are insignificant, and still result in the conclusion that rate of utilization of private facilities is closely connected to yearly family income, especially when one reaches the \$10,000 per year income group.

E) Conclusion 5 points out that nine out of ten children who are on the waiting list and are presently in private facilities are being cared for in these facilities at a cost of less than \$300 per month. A total of 201 (91%) of the 221 in private facilities were found to be maintained at a monthly cost of less than \$300. By including the data from the responses included in the appendix, we find that 89.3%, still approximately nine out of ten, are being cared for at a cost of less than \$300 per month.

The purpose of this appendix has been to point out that although some data was excluded from consideration in drawing the general conclusions, the exclusion of the data did not alter any of the conclusions drawn. The exclusion of the data, on the other hand, facilitated the drawing of conclusions because the data was more workable and consistent. Since no change in content occurred as a result, it is felt that the exclusion of these cases was justified. In fact, it appears that the cases reviewed in the appendix represent a fairly reliable sample and tend to confirm the conclusions.

