CHARGES FOR RESIDENTIAL CARE OF THE MENTALLY RETARDED

A Section of the Study on Institutions and Institution Care

by The Committee on Residential Care

NATIONAL ASSOCIATION FOR RETARDED CHILDREN
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FOREWORD

The Need for the Survey

The advent of the parent movement in behalf of retarded children and subsequent organization of Associations for Retarded Children at a local, state and national level created an unprecedented increase of citizen interest in the welfare of thousands of mentally retarded individuals living in State-supported residential centers throughout the country. Members of the Committee on Residential Care of the NATIONAL ASSOCIATION FOR RETARDED CHILDREN believed that parents must become generally knowledgeable on the subject of institution care and well informed as to conditions, techniques and trends in the various States if they are to develop into the most effective co-workers with professional people in improving the quality of residential care.

In order to provide the basic Information on residential care, this Committee undertook a survey of the residential centers for the retarded throughout the nation.

Purpose of the Survey

The ultimate goal of the survey is to produce a report which might well be termed an instrument of understanding. Such an instrument should bring about a more intelligent understanding of the complex operations involved in residential centers for the retarded and a better understanding of the current programs, conditions and trends in the various States. In addition, the report should help those who work in this field to understand the specific aspects of institution care which are of importance to parents, and why.

How Was the Survey Developed and Carried Out?

This project was initiated and carried out by sixteen persons serving as the Committee on Residential Care of the NATIONAL ASSOCIATION FOR RETARDED CHILDREN. Specific aspects of institutional programming were assigned to various persons on the Committee. In 1961; a detailed questionnaire was prepared and submitted to the administrative officers

of 111 State-supported institutions for the retarded in fifty States. The questionnaire was preceded by a personal letter to the head of each institution which stated the reason for the project and asked for cooperation in giving the information for his institution. The questionnaires were divided into sections in order that they might be studied and answered by the various staff members responsible for a specific aspect of the total institutional program. Thus, instead of reflecting the opinions and ideas of only one or two persons in each institution, the questionnaires in many cases brought in replies from persons representing all disciplines on the institutional staff, thereby obtaining a broader, more comprehensive view of the total programs.

Of the 111 institutions polled, 99 or 89 percent returned the completed questionnaires. In several cases one or more institutions failed to return certain sections but the majority of those responding answered the entire questionnaire. Each individual Committee member then made a study of the returned questionnaire in his or her specific area of assignment. The data was organized and analyzed, and a report was written on each section by the responsible individual.

In addition to the questionnaires, other resource material was utilized by all committee men. This material included literature available from various sources pertaining to their specific area of study. The publications MENTAL HOSPITALS, THE AMERICAN JOURNAL OF MENTAL DEFICIENCY, and numerous other professional journals and articles relating to residential care were used as resource materials. Ideas were also drawn from numerous papers and talks presented by workers in the field of residential care and related areas. In addition, personal visits were made by NARC staff and/or members of the Committee on Residential Care to a majority of the 111 institutions. Conferences were held with administrative officials of the State, as well as with the administrative officials and staff members of the institutions themselves

Reporting of Results

The reports covering the various subjects of the survey will be published in separate parts in a series of volumes. Each report will present the data gathered on each subject, an interpretation of the data, the conclusions which are drawn from the survey, and the recommendations of the Committee on Residential Care on the particular facet of institution care involved.

Part I of the report contained in this volume presents the results of the study of the matter of charges for residential care. This is a matter which

has been under continuous study since 1956 when the first NARC study on this subject was begun. Published in 1958, the report Responsibility for Costs of Maintenance and Training in Public Institutions for the Mentally Retarded became the first available published compilation of data devoted exclusively to this vital problem.

This part of the overall survey is being published as a separate report because of its importance and somewhat unique nature. Basically this subject represents a reflection of public understanding and public attitude toward this enormous community problem.

John G Fettinger, President
National Association for Retarded Children

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I. INTRODUCTION

Many years ago, expenditures for the institution care of the mentally retarded in many States were relatively low, and efforts to collect charges from parents or relatives were weak or even non-existent. In more recent years the cost of institution care has risen throughout the country, as the States have improved and expanded their institution programs and as the general "cost of living" has increased. As a result, the matter of who should pay the cost of care has become an important issue.

The various States have demonstrated wide differences of opinion on the matter of reimbursement for care. A few States charge nothing; some charge a modest sum, but the majority seems inclined to continuously raise charges to very high levels. Inasmuch as the problem of mental retardation is the same in all States, these differences of opinion cannot be valid or justified. Some States may be correct in their views but the rest must be in error to some degree. The fact that many States have essentially the same reimbursement legislation or policies for the mentally retarded as for the mentally ill points up a lack of understanding of these widely divergent problems.

Because of the growing importance of Institution charges, this matter was included as a major item in the survey and study of residential institutions conducted by the NARC Committee on Residential Care.

II. BACKGROUND AND PREVIOUS INVESTIGATIONS

The matter of the responsibility for charges and the ability to pay them is a very complex matter with many factors to be considered.

On one side stands the retarded child in need of institutional care. He is handicapped through no fault of his own, forever dependent, or at least semi-dependent. His need for expensive institutionalization may be due to his own limitations, those of his family, or those of his community.

On the other side stands the community or the State. Traditionally, the burden for vital services which are too costly for citizens to handle on an individual basis is accepted by the community through taxes. The community, however, faces the continuous problem of finding funds for the ever-increasing demand for services.

In the middle stands the parent. He is not responsible, either, for the fact that this child is mentally retarded and that institutional care is necessary. His retarded child is only one of his responsibilities. He must also shoulder his responsibilities as a member of his community, his responsibilities to raise and educate his other children, and his responsibility for preparing adequately for his own retirement,

Who will pay the cost of institution care for this child? Who can pay it? If the cost is to be shared, who is to pay how much? Who is to say? How much sacrifice should a family or the other children in the family be expected to make? What is an adequate standard of living? What is "hardship"? Who is to say?

These are some of the questions with which researchers on the subject of institution charges have wrestled in studying the problem of charges (or reimbursement) for care.

The NARC report[1] published in 1958 was based upon a comprehensive survey of the matter of reimbursement in all States, The report stated:

1. Responsibility for Cost of Maintenance and Training in Public Institutions for the Mentally Retarded. A study by the Public Institutions Committee of the National Association for Retarded Children. New York: NARC, 1958. Price $1.00.

> "It is bitter irony to tax parents for the unavoidable misfortune of having a retarded child. We must wonder if it is consistent with American social philosophy to require that parents of mentally retarded children pay taxes to support public education facilities which exclude their children, when there is a price-tag on their attempts to obtain equal benefits for their children in public institutions."

The NARC report recommends that "Society should assist in bearing the expenses of this major calamity" and suggests that charges "should not be tied to the per-capita costs of Institutional programs" but instead "the maximum rate of payment (should) be established in relation to the cost of living of an individual member of family maintained in the community"

The report made many other pertinent recommendations, such as termination of all charges for children over 21 years of age, establishing uniformity and Justice in charges, limitation of accumulated liability for charges which a parent is deemed unable to pay.

The American Journal of Mental Deficiency published in 1960 a study by Dr. Edward Eagle into the matter of charges for care.2 In this report, the author points out that "there is little uniformity with respect to the magnitude of the maximum legal charges, the percent of parents required to pay the maximum, the procedure for determining the ability to pay, . . . the items included in per-capita costs, the amounts of per-capita costs, the amount required by various States from parents having the same gross income, etc."

The author concludes that one in thirty mentally retarded children ". . .will require full-time care for life. This major calamity is the problem not only of the parents, but of society as well."

A report published by the Virginia Association for Retarded Children[3] analyzed in its first section the hospitalization pattern of the mentally

2. Eagle, Edward. "Charges for Care and Maintenance in State Institutions for the Mentally Retarded." American Journal of Mental Deficiency, Vol. 65, No, 2, pp. 199-207. The American Association on Mental Deficiency. Willimantic, Connecticut: September, 1960. 3. Smith, Norman F., A Study of the System of Institution Charges for the Mentally Retarded in Virginia and the Nation. The Virginia Association for Retarded Children. Richmond, Virginia: March, 1961.

retarded and the mentally ill. Its conclusions said in part:

> "All conclusions drawn from this study of the institutionalization patterns of the retarded and the mentally ill must point to differences rather than to similarities . . . it is clear that the whole institutionalization pattern, the circumstances and problems involved, the family situations and the medical aspects, are all completely different."

The second part of the Virginia report analyzes the charge systems, using data from references 1, 2 and others, and concludes that the charge systems are unrealistic and inequitable. The report cites "the arbitrary nature of the administration of ability-to-pay", and states the principle that:

> "When an institution charge takes more from a family than that family would spend on that child maintained in the home, a hardship has been placed upon the standard of living of that family, upon its children, and upon the ability of the wage-earner to educate his other children and to provide adequately for his own retirement."

The work of the NARC Committee on Residential Care, as embodied in the present report, has concentrated on the broader over-all characteristics of the charge systems and has drawn from an analysis of these characteristics some definite conclusions and recommendations. These recommendations were embodied in a resolution which was proposed by the Committee and which was passed by the general membership meeting of the NARC at its 1962 annual convention in Chicago. The resolution is included at the end of the report.

. III. SOURCES OF DATA

The principle source of the 1960-61 data is the NARC questionnaire which was sent to the appropriate agency in each State. Appendix A contains a copy of the questionnaire, along with additional information on sources, uses, and qualification of the data.

IV. BASIC INFORMATION ON CHARGE SYSTEMS

Basic Data

Statutory charges. - The statutory annual charges for 1956 and for 1960-61 are shown in figure 1, The charge for each State in 1956 is indicated by the height of the solid bar, while the increase which occurred by 1960-61 can be read from the height of the cross-hatched bar, using the scales at either side of the figure.

Figure 2 summarizes the 1960-61 data and shows the number of States which charge nothing, low, high, and very high charges.

Per-capita cost of care. - The annual per-capita costs of care,1 or expenditures, in the various States are shown in figure 3 for 1956 and for 1960-61. The height of the solid bar indicates the cost of care in 1956, while the height of the cross-hatched bar indicates the cost of care in 1960-61. For States having several institutions with different per-capita costs, averages calculated for the entire State, weighted according to institution population, are shown.

Income distribution in the U.S. - The income distribution for U.S. families is shown in figure 4. This figure shows that 3.7 percent (3.7 in 100} of American families earn more than $15,000 per year, only 14 per-cent earn more than $10,000, while nearly half earn less than $5,000 per year.

Average family income and distribution of Income varies from one State to another. Figure 4(b) is a tabulation of values for each of the 50 States.

These data show that there is no large group in this country which can afford to pay large charges over a long period. On the contrary, a very large percentage of families are shown to have Incomes so low that they could not reasonably be expected to pay any charges other than for clothing and incidentals.

1. Generally defined as the institution budget divided by the total number of patients.

Trends

Comparison of cost and charges. - The data of figures 1 and 3 have been plotted in figure 5 to show the relationship between maximum statutory charge and per-capita cost of care for 1956 and 1960-61. Each State is one point (circle symbol) on these figures. Figure 5(a) shows that in 1956 some States charged the same as cost (points on the dashed line), two States charged slightly more than cost (points above the dashed line), while more than half charged less than cost (points below the dashed line). Also, most of the States with costs greater than $1300 per year charged substantially less than cost. The maximum cost of care (expenditures) is shown to be about $1700 in 1956,

By 1960-61 (figure 5(b)), a number of changes have occurred. About eighteen States spent more than $1700 per year. Only about seven of these States attempted to charge the full cost of care (points on or near the dashed line). The remainder charged substantially less than cost. The five States which spent a great deal more than $2000 per year had a maximum statutory charge of less than $1000. One of the five had a maximum statutory charge of less than $500 per year, and one charged nothing.

In the group of States which spent less than $1700 per year, the points are generally higher and closer to the dashed line in 1960-61, which indicates a significant general rise in maximum statutory charges.

Thus, figure 5(b) shows that in the upward movement of per-capita cost of care, many of the States have pushed maximum statutory charge upward along with expenditures. Some States have shown intention of collecting the full cost of care at levels approaching $2000 per year, A few States, however, have divorced statutory charge and cost of care by charging only a fraction of costs at the $1500 level and above.

Changes in statutory charges. - Figure 6 compares the maximum statutory charges in 1960-61 with those in 1956. Points on the dashed line indicate charges which were the same during both years. The points above the dashed line indicate increase in charges from 1956 to 1960-61 with the amount of increase equal to the vertical distance between the point and the dashed line.

Clearly, charges have been increased in over two-thirds of the States. The increases in most States are large, and occur for States which had high charges in 1956 as well as for States which had low charges. The level of statutory charges in about one-fourth of the States has reached the cost of maintaining a child in college.

The number of States making no charge is shown to be three in 1960-61, two less than in 1956.

Predicted future increases. - The NARC questionnaire asked, "Do you anticipate a change in present monthly charge?" The left portion of figure 7 shows the answers received. Twenty-four-States said "yes" (and indicated an increase), while twenty States said "no".

On the right portion of the figure, the present charges are plotted for those States which said "yes, a change (increase) is expected". Seventeen of the twenty-four States which predict increases are now charging between $1000 and $2000 per year, with eight of the seventeen already charging more than $1500 per year.

The solid black points on figure 7 have another interesting distinction - these points are for States which now collect the full charge from less than two percent (2 in 100) of the patients,

Thus, the information on this figure shows that almost half of the States are expecting to increase their maximum statutory charges, although many of these charges are already large, and although many of the States are actually collecting such charges from only a very small percentage of the residents involved.

Basis for Maximum Statutory Charge

It has been suggested by other research reports in this field (such as references 1 and 3) that the maximum rate should not be tied to the per-capita cost of the institutional program. Part of the justification for this suggestion is: that the per-capita costs contain numerous items which represent community services which are tax-based and for which there should be no charge.

States which base statutory charge on per-capita costs. - Figure 8 compares the number of States which based their maximum statutory charge on per-capita costs in 1956 and in 1960-61. This figure shows that the number of States which base their statutory charge on per-capita costs rose from 20 in 1956 to 28 in 1960-61. It is clear that more and more States are basing their maximum charge on the per-capita cost.

Content of per-capita cost. - The questionnaire asked each State to check the items which are included in per-capita cost (PCC) from a list of specific items. The following table shows the results for the 28 States which answered this question.

Item	States which include this item in PCC (28 States replying)
Food and lodging	28
Medical care	28
Staff salaries	28
Formal education program	27
Staff training	24
Rehabilitation	26
Bldg. repair and maintenance	24
Bldg. construction (capital outlay)	1

The arguments against including "Formal education program" and "Rehabilitation" in per-capita costs are formidable. The parents pay local and State taxes to help provide these services in their communities. In paying a charge based upon per-capita costs these parents are required to

pay a second time for these services. Twenty-seven out of twenty-eight States answered that they do include education in per-capita costs, the exception being Texas, which has legislation specifically forbidding the inclusion of this item.

Although the questionnaire did not probe these areas in detail, police and fire protection are also ordinarily included in per-capita costs, in spite of the fact that these, too, are services normally supplied by the community at no cost. Research is another item, which, according to reference 1, is included in the per-capita costs of two-thirds of the States which answered the 1956 NARC questionnaire. Research is an important function which should be sponsored directly by the State and should not be added to the burden of those who are striving to pay the cost of care for Institutionalized children.

Finally, the cost of clothing for indigent institution residents is included in the per-capita costs of many States. Parents who are paying part or full charge are therefore sharing the clothing bill for these residents while paying the clothing bill for their own children directly,

1. See footnote, pg. 6.

Some Conclusions for Section III

The foregoing information on costs, charges, trends, and income has been presented as the basic information necessary to an understanding of the charge systems. This information shows that maximum statutory charges are rising rapidly, as are per-capita costs or expenditures. Many States are attempting to keep charges tied to per-capita costs, while others, including some very high cost States, have abandoned this approach and are charging a great deal less than cost. Family-income data shows that a large percentage of American families have relatively modest incomes. There appears to be no large income group which can afford very high charges over a long period of time.

It is now appropriate to turn to a detailed study of the actual working of the charge systems, their performance and the impact which they are having upon parents of the mentally retarded. The next section of this report discusses these aspects of the problem in considerable detail.

V. THE PERFORMANCE AND IMPACT OF CHARGE SYSTEMS

Performance

In an examination of the performance of the existing charge systems, it is necessary to use general data covering all States and such specific data as is available from individual States. Where detailed data from an individual State is used, the State is not named. Such data are presented only to illustrate particular phenomena, and no claim to generalization is made.

The over-all performance from the standpoint of the State is shown by one simple item: the amount of money collected by each State, compared to the amount which the charge system intends or pretends to try to collect.

Portion of per-capita costs collected. - In figure 9 the total heights of the bars show the cost of care in the various States, repeated from figure 3. The solid black portion of each bar shows the amount of this cost collected, on the average, for the State. The height of this black portion, then, compared to the total height of the bar is a direct measure of the percentage of the total institution budget collected in charges in that State (see the example on figure 9).

This figure shows that in spite of high and steadily rising charges in many States which make a pretense of attempting to recover the cost of care, only a very small portion of the institution budget is actually recovered in charges. The maximum collected in any State is about 12 percent, and two-thirds of the States reporting collected less than 8 percent. An over-all reason for this situation is, of course, found in the data on income distribution in the U.S. previously presented in figure 4. The fact that the percentage recovered varies greatly from one State to another is an indication that the philosophy or intent of the State or its collection agency also varies greatly from one State to another.

Number of patients paying full, part, or nothing. - The performance of the charge systems, from the standpoint of the institution resident and the parents, is shown in figure 10. This figure shows the percentage of residents paying (or for whom is paid) the full-charge (white bar), part charge (cross-hatched bar) or nothing (black bar). It will be noted that only a very small percentage pays the full charge (not over 10 percent for any State, in some States no one). The percentage of residents which pay part of the statutory charge varies from 5 percent to 60 percent, depending upon the State. The percentage which pays nothing is very large, varying from about 25 percent

to more than 96 percent,

Figure 10 appears to support the conclusions drawn previously from the figure showing income distribution in the U.S., (fig. 4), the conclusion that there is no large income group which can afford large charges for institution care and only a relatively small group which has income sufficient to pay any charges at all.

This figure also illustrates the very great difference of opinion among the various States as to how many can or should pay. The procedures used in the various States for determining how much a particular family should pay is discussed in detail in a later section entitled "Ability-to-pay".

History of payments as charges rise. - Figure 11 shows what happened to collections in a high-charge Eastern State when the statutory charge was twice raised to higher levels. The rectangle drawn with a dashed line shows the amount of money which this State would collect if everyone paid the full statutory charge. This amount thus represents a sort of "target" amount. The cross-hatched areas show, to the same scale, the amount of money actually collected from those who pay full charge and part charge. The percentages and number of institution residents in each category are indicated at the bottom of the figure. This figure shows that in 1956-57 eight percent of the residents paid the full charge of $450 per year, while 21 percent paid a part payment which averaged $186 per year. When the statutory charge was raised to $780 per year in 1959-60, the same eight percent paid this amount, while 26 percent paid a part payment averaging $318. When the rate was raised to $1200 per year in 1960-61, only six percent paid this rate. Thirty-two percent paid a part payment averaging $373 per year.

It will be noted that the average payment rose substantially each time the statutory rate was increased, although presumably under the ability-to-pay system each person making a partial payment was already paying all that he could. Although some of the increase was undoubtedly due to tightening of the system and to increased collections from "third-party" sources, the evidence is strong that increased statutory charges result in increased pressure on parents all along the line.

The fact that the cross-hatched area showing full payments has become narrower when the charge was raised from $780 to $1200 (156 residents paying vs. 224} indicates that the revenue to be derived from full payments will probably not increase substantially in this State if rates are raised still further. The increased efforts at collection and the increased burden carried by this dwindling number of people are not justified by the small increased return to the State.[1]

1. Nevertheless, the statutory charge in this State was increased 25 percent on the following year.

Accounts in arrears. - Figure 12 shows the number of institution residents paying various charges and the amount by which these groups are in arrears in one midwest high-charge State. For example, the top section of the chart shows that 165 residents are paying the full charge. Ninety are paying $900 to $1800, etc. The bottom section of the chart shows the amount of payments in arrears for each group. Fifty residents, or nearly one-third of the 165 who are supposed to be paying the full charge, are in arrears $3000 or more, while 25 more are in arrears between $1000 and $3000. About one-fifth of the 90 which pay $900 to $1800 are in arrears $3000 or more. The number of residents in arrears for various amounts can be estimated for each payment group from the chart.

To look at this figure another way, the areas which comprise the top section show, to scale, the amount of money which the State is committed to collect from each group, while the areas which comprise the lower section of the chart show, to the same scale, the amount by which each group is in debt to the State. Clearly, a significant number of parents are in debt for significant amounts of money in this State.

Information from another (Eastern) State indicates that with collections from patients running about $2,800,000 per year (total of all mental hospitals), accounts in arrears total nearly $1,900,000. The reasons for these situations are not known; however, the existence of debts of this magnitude would appear to be incompatible with the concept, claimed by most reimbursement legislation or systems, that the amount charged a family shall be that which can be paid "without hardship". It seems likely, although it has not been proven, that similar situations exist in other States.

Ability-to-Pay

The foregoing data have shown that in no State is the full statutory charge paid by more than a very small percentage of the residents (parents). The rest come under some sort of administrative procedure which sets a rate of payment according to their "means" or "ability-to-pay". Because most parents of institutionalized children come under this administrative procedure, it will be treated in as much detail as is possible with the available data. It should be noted that detailed information which would permit a study of the true nature and inner workings of the ability-to-pay procedures are largely unavailable; consequently, an analytical and inferential approach based upon available data has been used.

Agency which determines ability-to-pay. - Figure 13 lists the various persons, agencies or authorities which make the ability-to-pay determination and the number of States in which each is used. Six different agencies or categories are seen to be performing this test, including various State agencies, local government, and local courts. The differences in the nature and Interests of these agencies suggest that their ability to perform this task might differ considerably, and that their determinations of ability-to-pay might vary greatly from one State to another as a result. That this is indeed the case is amply illustrated by the data which follows.

Example of charge determination in 40 States. - Figure 14 shows the annual charge which would be levied, based upon ability-to-pay, in 41 States for an identical family. These data were gathered by Dr. Edward Eagle, author of reference 2. The family was described as a family of 3 with no unusual debts or assets and with a gross income of $6000 per year. Nine States said that for this family there would be "no charge", (square symbols on the bottom line), eight States said that they could specify "no set charge", (square symbols to the right), twelve States gave a firm number or a range of numbers from $300 to $980 per year (squares and rectangles), while eleven States gave an amount which the charge would be "less than" (arrow symbols).

Even when allowance is made for the uncertainty of over half of the answers, it is clear that there is a very wide range of charges levied upon this "example family" by the 41 States. Inasmuch as mental retardation and the problems which it produces are quite similar in the various States, it is inconceivable that a charge of 0 in one State and a charge of $980 in another, for the same income, could both be Just and equitable. Consequently, the evidence shown must be taken to mean that ability-to-pay is not an absolute, measurable, definable quantity, but is rather an arbitrary opinion which varies

greatly from one authority to another and from one State to another.

Impact upon the family. - In considering the impact of institution charges upon the family, it should be remembered that the charges may come into the family budget after this budget has been strained for years by extra expenses in connection with the retarded child. Also, the Institution charges may continue for many years, perhaps for the lifetime of the parents, or longer.

Figure 15 provides information with which the impact of charges upon a family can be examined in detail. Shown on the right half of this figure is a typical budget for a family with a $6000 gross income. This budget, or the way in which the average family in this pay bracket spends its income, was determined by a research project of the United States Department of Labor (USDL).[4] This value of income is of particular interest because it is the mid-range of Incomes from $5370 to $6567 which are described by the USDL research as "modest but adequate" levels in various areas of the United States.

Shown on the left half of the figure, with dollars drawn to the same scale, is the institution charge in the range of a typical high-charge State (fig.14), taken as $800 per year for this income. Added to this value is an estimate of $350 for clothing, transportation and miscellaneous, making a total cost to the family of $1150.

To evaluate the impact which institution costs of $1150 have upon a $6000 income, one need only to attempt to find space for the cross-hatched column at the left in the column at the right. It will be noted that several of the budget items shown are fixed items, such as taxes, insurance, medical, etc. It will be noted also that the budget does not include an allowance for savings, education or contingencies. It is clear that $1150 cannot be taken from this budget without producing a serious decrease in the standard of living of this family.

The foregoing analysis suggests that institution charges which are collected from incomes in and below this "modest but adequate" level bear no relation to "ability-to-pay", but instead represent a serious and arbitrary

4. "The Interim City Worker's Family Budget." Monthly Labor Review, Report No. 2346, U.S. Department of Labor. Bureau of Labor Statistics, Washington, D.C.: August, 1960.

decrease in the standard of living for the family. Consequently, one of the strongest recommendations emanating from this study is the recommendation that this level of income be established as the limit below which no charges will be asked for other than clothing and incidentals.

Some quotes from reimbursement statutes. - While no effort was made to collect or analyze legislation from all States, a file of such information was accumulated and examined during the study. The legislation of many States appears to set forth the reimbursement procedures in only general terms, leaving, in effect, the policies, rates and procedures of reimbursement to the executive agency of the government. The following quotations are each from the statutes of 3 different State:

> "Whenever the parent, guardian or estate of the child is able to do so, the cost of maintenance in whole or in part shall be borne by them, the amount and payment thereof to be determined and arranged by the Board of Commissioners of state institutions from time-to-time as conditions and circumstances may permit... "

> "The county welfare boards shall investigate the financial circumstances of each patient and his relatives and shall report them to the Commissioner. The Commissioner shall make such further investigations as he deems necessary and shall determine, ... what part of the cost of care the patient is able to pay, if any. If, in the opinion of the Commissioner, the patient is unable to pay the full cost of care, he shall make a like determination as to the ability of the relatives to pay the charge provided in section 3 thereof. "

> "... the person legally liable for the support of any such person shall be liable for the expense of his care, treatment and maintenance in such Institution. Such expense shall not exceed the actual per-capita cost of maintenance and shall be fixed by the Department of Mental Hygiene and Hospitals... The Department may contract with any patient's parent, guardian, trustee, committee, or the person legally liable for his support and maintenance, and in arriving at the amount to be paid, the Department shall have due regard for the financial condition and estate of the patient or inmate, his present and future needs and

> the present and future needs of his lawful dependents, and, whenever deemed necessary to protect him, or his dependents, may agree to accept a monthly sum for his maintenance less than the actual per-capita cost of his maintenance."
>
> "'In exercising this right of reimbursement the director of mental health may, whenever it is deemed Just and expedient to do so, exonerate any person chargeable with such maintenance from the payment thereof in whole or in part, if the director finds that such person is unable to pay or that payment would work an undue hardship on him or on those dependent upon him... "
>
> "The department shall develop procedures to determine the ability of a patient or his legally responsible relative to pay all or a part of the costs of the patient's care and shall adopt rules and regulations for the assessment of charges in accordance with the ability to pay ..."

These samples illustrate the curious situation which prevails in many States with regard to reimbursement legislation. Legislation in these States does not spell out conditions of payment, nor does It give a policy or even define the terms (such as "due regard for the financial condition" or "works an undue hardship") used. Such legislation merely hands the whole affair over to an executive or judicial agency to run as it sees fit. As a result, nearly all of the parents of the institutionalized retarded come under an administrative ruling of a government agency for reimbursement purposes, rather than under the legislative ruling of the governing body.

In recognition of this situation, the NARC questionnaire sought Information on the methods used in determining ability-to-pay.

Curves and charts for determining charges, - The NARC questionnaire asked the question: "Are charts, tables or scales for determining adjusted charges published and/or available?" Figure 16 shows that 33 States answered "no", while only 9 States said "yes". A few of the States which answered "no" gave some explanation. Some quotations from these replies are of interest here.

> One State wrote: ". . .the system used to determine charges is rather complicated and cannot be determined by a table or scale alone but is made up of many factors involving a total family situation of which the resident is a member."
>
> From another: ". . . the system used to determine charges . . . is based on an individual's ability to pay . . .all Factors are considered . . . where charges are strictly on An ability-to-pay basis, without working an undue hard-ship, you can readily see that such a chart would not be practical or equitable in administering our reimbursement law."

Such well-meaning but vague statements were the only information which some States provided regarding their methods of determining charges under their reimbursement laws.

In denying that any system for determining ability-to-pay can be set forth in black-and-white, these statements seem to be saying that ability-to-pay is more an art than a science. That it is, in fact, neither art nor science but only an arbitrary opinion of the determining person, has been amply illustrated by figure 14 and others.

Further, if the States which deny having charts or tables for release to the public really do not have such, even for internal use, it seems unquestionable that differences in charges determined by different persons in different areas of the same State will be great, perhaps as great as those shown in figure 14.

Other researchers have reached similar conclusions regarding the elusiveness of ability-to-pay procedures. For example, Mernitz states: 5

> "Because of its elusive character, application of the ability-to-pay standard is subject to considerable manipulation, not infrequently resulting in unfairness and favoritism. Most statutes imposing private responsibility lack any standard of determination

5. Mernitz, David W. "Private Responsibility for the Costs of Care in Public Mental Institutions." Indiana Law Journal, Vol. 36, No. 4, pp. 443-482. Indiana University School of Law, Bloomington: Summer, 1961.

> at all other than the bare direction that charges be assessed in accordance with ability to pay."

All nine of the States which acknowledged that charts were available supplied copies. Eight of these have been plotted graphically on figure 17. {Data for the ninth, Colorado, was based upon State income-tax blanks and could not be readily plotted. Data for Kentucky have been added from information compiled by the Mental Health Commission in South Carolina.6) this figure shows the amount of charge asked (left scale) for various amounts of gross income (bottom scale). The step-shape which is characteristic of most tables is shown for those States where the steps are large enough to be significant. The rest are plotted as continuous lines,

For ease in reading, the fine solid lines have been added to show 5, 10, 15, 20 percent of gross income, as labeled. The percentage of gross income asked by the various States for various incomes can be readily estimated by the position of the charge curve with respect to these lines.

The great differences among these curves illustrate dramatically the large differences of opinion among the States as to what charges should be. It is astonishing to note that seven of these States levy charges upon families with incomes of less than $4000 per year. Taken as a group, these curves show that for incomes of $4000, charges in most of these States are around 5 percent of gross income, or about $200 per year. For incomes of $6000 charges run from about 6 percent to nearly 20 percent of gross income, or from about $400 to above $1000 per year. Above incomes of $7000 almost all of these States are charging between 10 and 20 percent of gross income.

The slope of the curves of figure 17 shows the rate at which charge is increased as income rises. The general slopes for all States on the first part of this figure (ignoring the step-shape of some) are seen to be quite similar and slightly steeper than the line labeled "30 percent of gross income". This slope means that for each additional $100 earned by the parent above about $5000 income, these States ask $30 to $36 more in institution charges until the maximum charge is reached. The slopes of the curves on the second part of figure 17 are varied, with a few approximating the 10 percent line. This slope means that approximately $10 is asked in charges for each $100 in additional gross income earned.

6. Information on Reimbursement - States of the. Southern Region. Compiled by Fiscal Section, South Carolina Mental Health Commission. Columbia, South Carolina: July, 1960.

Criteria for determination of ability-to-pay. - It is of interest to consider next the criteria for determining ability-to-pay, i.e., the information upon which the determination is based.

The NARC study[1] lists the results of a rather detailed inquiry into the factors considered by the various States. These data give some insight (for 1956) into the basis or criteria which is stated to be in use.

No effort was made in the present study to repeat this survey, nor to obtain detailed forms used by each State to document financial information on individual families. It is of interest, however, to consider the items on which information was asked by the blank forms sent to parents in one high-charge State. These items are:

Income	Assets
Debts and time payments	Rent or house payment
Food	Utilities
Heat	Taxes
Clothing	Retirement deductions
Insurance	Other (specify)
Transportation	

Entirely missing from the blank forms are such valid and vital budget Items as:

Medical expenses	Church and charities
Education and reserve for education	Vacation and recreation
	Christmas
Reserve for retirement	Savings and contingencies
Reserve for automobile replacement	Home maintenance

When questioned on the allow-ability of items on the latter list, the reimbursement officials in that State agreed that these items were probably allowable, and that the parents should list these items along with the others. In the discussion, it was pointed out that many parents were not including these items because they were not on the forms, and consequently were not giving a true account of their costs and obligations. In spite of this inquiry, however, no change or additions to the original list of items appeared on a reprinted version of the forms later issued in this State.

The above information is but one of numerous examples of the ways in which inequities can be injected into or can creep into the ability-to-pay procedures. Inasmuch as these procedures are dealing with a family's standard of living and may have a pronounced effect upon the long-term financial life of the family, such inequities should be regarded as a very serious matter.

A number of other questions come to mind in studying the list of items above. To what extent should assets be considered to enter into determination of ability-to-pay? If a family of modest income owns modest assets, should the family be required to liquidate these assets to pay charges? To what extent can assets be held as reserves for education or retirement? Who is to say? Inasmuch as a family's assets represent a degree of security for the future, should not only the income from these assets, if any, be considered to affect ability-to-pay?

How much reserve for education and reserve for retirement is allowable? What level of housing should a family enjoy? How much should a family give to church and charities, or spend on vacation and recreation? What is hardship? What is an adequate standard of living? How much sacrifice should a family or the other children in the family is expected to make? Who is to say?

A little reflection along the lines sketched above brings one quickly to the conclusion that those who determine "ability-to-pay" have much control over the standard of living, education of the children, and the present and future security of the whole family. It is disturbing to note that this very grave responsibility has in many cases been given without appreciable legislative direction, that it is reportedly executed without established charts, tables, or formal methods, and that the results are so inconsistent that they must be considered to be arbitrary opinions which vary greatly (fig.14) from one authority to another.

The inquiry into personal financial matters. - In general, parents of institutionalized retarded children who cannot afford to pay the full statutory charge are required to reveal the complete, intimate details of their financial status to the agency which determines ability-to-pay. In States in which the determination is made by the court (fig.13) these details may be thrown into open court. This practice is unacceptable for a number of obvious reasons and has been, according to a recent study,[7] ".. .almost universally condemned

7. Reimbursement for the Care of Mental Patients - A Compilation of State Programs and..Policies. House Order No, 3380, the Commonwealth of Massachusetts (February 19, 1962). Prepared by the Legislative Research Bureau. Wright and Potter Printing Co., Legislative Printers, 1962.

by both lawyers and psychiatrists."

In some States the parents are turned over to the welfare agency for investigation (fig. 13) and must endure the attendant indignity. In nearly all States, the financial life of the family is under continuous detailed scrutiny by the determining agency, with determinations being made sometimes as often as every six months.

In many States the parents who cannot pay the full charge are technically indigent, and in some States they are actually classified in the statute as legally indigent.

Unfortunately, it is not just a small portion of parents who are subjected to these procedures. Only the very small numbers which voluntarily pay the full charge without submitting to investigation are accepted. (fig. 10) The rest, which number from 90 to almost 100 percent of the parents, and which include a very large number of hard-working, responsible citizens, must endure the stigma of being labeled indigent, the indignity of welfare procedures, and the frustration of surrendering the right of planning the family's financial future. The addition of these burdens to the considerable burdens which the family already carries in having an institutionalized child would seem to indicate a lack of understanding of the basic facts about mental retardation and about the problems which it produces.

A few States have attempted to ease the matter of inquiry into personal financial matters by basing determination of ability-to-pay solely upon net income as computed on income-tax forms. This sort of system is considered to have much merit and its use is suggested in the Recommendations which appear at the end of this study.

Payments by "third parties". - An item which has become of increased importance in the area of reimbursement is payments by "third parties"; that is, sources other than the institution resident or the parents. These sources, which include social security, retirement benefits, and the like, can provide significant income in behalf of residents which might not otherwise be able to pay for care. As such, they are important to any reimbursement program, and must be taken into account when modifying or designing a charge system.

The availability of these "third party" payments, however, is sometimes used as an argument for setting the statutory charge as high as possible. Figure 18 shows some interesting information on the relative importance of "third party" sources in full and part payments in one high-charge State. The right portion of the figure shows that two-thirds (66 percent) of the full

payments are made solely by relatives, while relatives participated in another 16 percent of the full payments. Only 18 percent of the full payments are made solely by "third party" sources.

The left portion of the figure shows that nearly half (45 percent) of the part payments are made by "third party" sources, with relatives making the other half of the part payments.

This figure, though limited to one particular State, would seem to indicate that the largest burden of full payments is carried by relatives, and that "third party" sources are of far greater importance in the area of part payments. These part payments are, of course, fixed by the "third party" source itself, rather than by the statutory charge. Thus, raising the statutory charge serves principally to lay increased burdens directly upon the relatives, and would affect to a far smaller extent the amounts collected from "third party" sources.

Payments by hospitalization "insurance". - The payment by some hospitalization plans for the care of the institutionalized retarded, though not widespread, is nevertheless a significant item. The availability of such payments raises the question "What is the effect of the existence of hospitalization Insurance on ability-to-pay?"

One high-charge State does not mince words on this matter. Its legislation says:

> "If a patient has an insurance contract providing for payment of expenses at a hospital providing services for mental retardation, the other provisions of this division (on determining ability-to-pay) shall be suspended while such insurance is in force and such patient shall be charged the full amount of the average per capita cost for services at the type of institution at which the patient receives care."

In considering the equity of legislation or administrative policy such as this, it should be remembered that hospitalization Insurance is bought and paid for by the individual to protect himself from the unforeseen catastrophe of large medical bills. In a State having statute or policy that is quoted above, the following situation is conceivable:

A family with an Institutionalized child for whom the statutory rate is $125 per month has been examined and found "able to pay" $75 per month. It is then discovered that the family has a hospitalization policy which will pay $50 per month for a limited time. The State Immediately proceeds to collect $125 per

month, $75 from the parents and $50 from the Insurance Company. When the limited time period is over, the hospitalization payments cease and the charge continues at $75 per month from the parents.

Obviously, in this hypothetical case, the protection which the parent had purchased for his family has been denied him for this hospitalization and converted to the benefit of the State.

Legally, insurance can be looked upon as a contract between an individual and a company. There appears to be considerable question as to whether there is any legal or moral justification for taking into account an insurance contract in determining responsibility or charges, whether the insurance is automobile liability, hospitalization, burial insurance, or whatever.

Some Conclusions for Section IV.

The foregoing information on performance and impact of charge systems has shown that the percentage of parents who pay full charge is very small, in no State more than 10 percent. A larger group pays a part charge, but the largest group, which in most States is between 50 and 90 percent, pays nothing. This situation is a result of the level of family income, as described earlier in the report. As a consequence, the amount of money recovered in charges by the State is very small (in no State more than 12 percent) compared with the total expenditures.

The ability-to-pay procedures, which are used by most States to determine the amount of payment, demanded of all parents except the few who voluntarily pay the full charge, have been shown on a nationwide basis to be inconsistent, undefined, and inequitable. These procedures do not deal in measurable quantities but produce determinations which are only arbitrary opinions. Further, charges based upon these procedures are shown by the available data to be widely guilty of invading the basic standard of living of families of modest incomes.

VI. TOWARD A NEW PHILOSOPHY ON CHARGES

Background

The foregoing sections have presented and analyzed the technical aspects of charges for institution care, including the basic statistical data showing status, trends and performance. In distilling from this material the basis for improved charge systems, it is essential to add the ingredients of sociological; humanistic, and philosophical considerations. It is beyond the scope of this report to discuss or debate these considerations in any great detail. This section will therefore present only a few additional facts regarding the mentally retarded, their families, and their communities, and will then present the general conclusions and recommendations of the Committee.

Differences between the mentally retarded and the mentally i11. -A report on the matter of Institution charges would be Incomplete without consideration of the confusion which exists regarding the relationship between the mentally retarded and the mentally ill.

In the past these two groups have in many instances been treated alike. In many States, both groups were cared for in the same Institution. Although separation in different Institutions has now been effected in most States, the institutions for the mentally retarded are often administered by the same agency which administers the hospitals for the mentally ill. The reimbursement laws covering the two groups are often similar, if not identical. Legislation in the various States which sets the statutory maximum charge at the full cost of care often makes no differentiation between the two groups. Indeed, there is evidence that not only the general public, but also legislators and administrative agencies may not, in some cases, clearly understand the differences between these two groups.

The study by the Virginia Association for Retarded Children[3] presents a detailed analysis of this point, based upon the hospital records for one particular State. The results of this analysis showed that the number of patient movements (admissions, discharges, deaths) among the mentally ill was very large and showed that average lengths of stay were 10 months for first admissions, 20 months for re-admissions, and six years for persons who died in the hospital.

The mentally retarded patients, on the other hand, showed so little movement that average lengths of stay could not be computed directly. A deeper analysis of the data on the mentally retarded showed that most retarded were admitted as children, and that except for those highly defective children who died young, and except for the modest number of youths (mostly mildly-retarded educable) who left after their schooling was completed, a large number of patients stayed in the institution for a very long time - 20, 30, 40 years, or a lifetime.

This study concludes that the circumstances of hospitalization, family problems and the medical aspects are all completely different. Generally speaking, the patient coming now to a hospital for the mentally ill is, except for his period of hospitalization, an Independent adult, a competent wage earner, whose stay in the hospital is relatively short. The resident in the institution for the mentally retarded, on the other hand, enters at an early age for a long, perhaps a lifetime stay and is, generally speaking, dependent for life.

It is Imperative that these differences be carefully considered when designing a system of charges for institution care.

Attitudes of the parents. - In addition to the formal questionnaires which sought factual data from State agencies concerned with hospital administration and reimbursement, the NARC Committee performing the study asked for background information, parental attitudes, future trends, etc. from State Associations for Retarded Children. Letters containing helpful information were received from a majority of the States.

It is unfortunate that no means exists for readily presenting the composite of opinions which these letters contained. Collectively the letters provided the Committee with a fine feel for the grass-roots thoughts on the matter of charges for the residential care of the retarded.

Many letters expressed gratitude for the progress in the particular State, and a hope for better understanding of the problems faced by the parents of institutionalized children. Most letters spoke out against the particular symptom of lack of understanding in that State: lien laws, high charges, double taxation, collections in the hands of the wrong agency, inequities in setting charges, the lifetime burden laid on parents. Some mentioned that children with other handicaps (the blind, the deaf, etc.) are treated far differently from the retarded in their State (an item which is discussed in detail in the NARC study[1] and the article by Dr. Eagle.[2]) In short, a great many of the items which have been discussed in this report were brought up in these letters as items of grave concern.

One thought which appeared in many letters and which was very much in evidence in the discussions within NARC is the view that most parents expect and desire to participate in the care of their retarded children. They do not ask to be relieved of all responsibility, but expect to share in it, whether through payment of some measure of the costs or through providing for clothing, personal needs and incidentals. This philosophy runs through this report and is found firmly embodied in the formal NARC resolution which will be presented later in this section.

Having affirmed their intention to do their part, the parents ask, as they have asked on other subjects in the past, that the community also accepts a share of the responsibility, enough to make the burden manageable to the parents.

Attitudes of the community. - The attitude of the community (State), as revealed by the variety of policies on reimbursement described in the previous sections of this report, can be described as widely varying. At one end is the State which charges nothing for the residential care of the retarded. At the other end is the State whose legislation demands collection of the full cost of care, and perhaps prescribes pernicious methods to enforce collection,

such as the use of lien laws1 to cover the portion of costs which a family is deemed unable to pay.

It is clear from these differences that the community needs to make a new assessment of this matter. This new assessment should be based upon an understanding of the technical and economic information on reimbursement, such as is presented in this report, and upon a familiarity with the growing body of scientific information on mental retardation. It must be based also upon a careful consideration of the sociological and family aspects of the problem aspects which are only lightly touched upon in this report.

Based upon past experience, there is room for optimism that if the facts of the matter are brought before the community, a demand for improvement in this situation will result.

It should be mentioned that all States face the continuous requirement for obtaining the funds with which to implement their ever-increasing array of services. Consequently, the policies and legislation on reimbursements in many States are very highly revenue-oriented. While this need for revenue can be understood, it should not be considered a justification for placing undue financial burdens upon the parents of the institutionalized retarded. Although detailed data are not available upon which to base an analysis, it can be deduced from the data presented previously that modification of reimbursement systems to eliminate hardship and inequities would decrease the revenue to most States by an amount which is very small in terms of the total institution budget.

1. Not covered in this report. Some information will be found in references 1 and 2.

Conclusions and Recommendations from this Study

The following are the principal conclusions which have been produced by the NARC survey and study of charges for residential care. Each conclusion is followed by the general recommendation of the Committee on the particular point.

1. The maximum statutory charges for institution care of mentally retarded children have increased precipitously in the past 4 to 6 years. These charges now exceed in many States the cost of maintaining a child in college.

RECOMMENDATION: THAT THE STATES RECOGNIZE THAT THE STATUTORY CHARGES FOR INSTITUTION CARE OF MENTALLY RETARDED CHILDREN ARE TOO LARGE TO BE BORNE ALONE BY ANY APPRECIABLE SEGMENT OF OUR POPULATION, AND THAT THE MATTER OF REIMBURSEMENT BE STUDIED AND BE REALIGNED WITH REALITY.

2. More and more States are basing their statutory charges on per-capita costs; consequently, further increase in charges are predicted by 25 States, many of them already high-charge States,

RECOMMENDATION: THAT THE PRINCIPLE OF RESPONSIBILITY OF PARENTS FOR THE FULL COST OF CARE, OR PER-CAPITA COST, IS ABOLISHED, AND THAT THE COMMUNITY WILLINGLY ASSUMES A PORTION OF THE COST OF CARE OF ALL INSTITUTIONALIZED RETARDED.

3. The impact of institution charges actually levied upon parents in many States appears to be very great. There is evidence that significant reductions in standard of living are being produced, particularly among those parents who are in modest income brackets.

RECOMMENDATION: THAT MAXIMUM CHARGES TO THE PARENTS BE LIMITED TO THE COST OF REARING A NORMAL CHILD AT HOME, AND THAT NO CHARGE FOR OTHER THAN CLOTHING AND INCIDENTALS BE MADE TO FAMILIES WHOSE INCOME IS BELOW A MODEST BUT-ADEQUATE LEVEL.

4. In their performance, the charge systems of the various States demonstrate that the ability-to-pay determination is a vague and indefinable procedure which invades the private affairs of the family and which produces only arbitrary opinions. In spite of its claims of being based upon "ability" and "no hardship", the procedure is shown by the data to be widely guilty of invading the basic standard of living of families of very modest income.

RECOMMENDATION: THAT A SIMPLE SLIDING SCALE, FOR CASES IN WHICH PAYMENT LESS THAN THE MAXIMUM IS JUSTIFIED, SHOULD BE DEVELOPED BASED UPON NET TAXABLE INCOME, AND PUBLISHED.

5. The charge systems throughout the country, in spite of all efforts of the States to collect and all efforts of the parents to pay, succeed in collecting only a small percentage of institution costs. The reason is found in the income statistics which show that there is no large income group which can afford to pay large institution charges, and only a modest group which can afford to pay any charges at all.

RECOMMENDATION: THAT THE COMMUNITY RECOGNIZES THAT THE COSTS OF INSTITUTIONALIZATION ARE TOO GREAT TO BE CARRIED BY INDIVIDUALS, AND LIKE OTHER MAJOR ECONOMIC PROBLEMS, MUST BE SPREAD OVER THE COLLECTIVE TAX REVENUE OF THE COMMUNITY.

The NARC Resolution: A Guide for the Future

The conclusions and recommendations drawn from the work of the NARC Committee on Residential Care of the Mentally Retarded have been embodied in a resolution which was submitted by the Committee to the NARC annual convention in October, 1962, This resolution was passed by the membership in its general meeting. It will be noted that the resolution does not attempt to spell out what charges should be. Rather, it sets forth principles and limitations, which can be used in the design of a charge system for each State. A system designed on these principles will serve the requirements of the State and, at the same time, serve and protect the needs of families in whose hands has been placed one of society's great unsolved problems — a mentally retarded child.

The full text of the resolution follows:

Resolution

Whereas, mental retardation is a catastrophe which may befall a child in any family, at any economic level, in any community, and

Whereas, in the best interest of the retarded person, his family or his community it may become necessary that he be placed in an institution, and

Whereas, for a period of eight years NARC has conducted a comprehensive research and analysis of institution charges in the United States, and

Whereas, the conclusions drawn from this research have shown that great differences exist between the charges assessed parents in the various States, and that these charges result in damaging reductions in the standard of living of many families, particularly those families with modest incomes,

Now, Therefore, Be it

RESOLVED, that the National Association for Retarded Children recognizes and commends those States which have acknowledged that the cost of care of the mentally retarded is too great to be carried by the parents alone, and which

have assumed a substantial share, or all, such costs, and be it

FURTHER RESOLVED, that the National Association for Retarded Children recommends that in those States where payment for institutional care is required, the charge system should embody the following principles, limitations, and procedures:

1. The maximum responsibility of parents for the cost of care of the retarded in public institutions shall be limited to the cost of rearing a normal child at home.

2. Other than provision of clothing and incidentals, no charges for Institution care shall be made for families whose Incomes are below those described as "modest but adequate" by the Bureau of Statistics, U.S. Department of Labor.

3. For families with incomes above the minimum level, criteria and procedures for determining charges should be developed, based primarily upon net taxable Income.

4. Responsibility of parents for charges shall be reduced or cease if the period of institutional care is very prolonged or when the child reaches age 21.

5. No charges or debt shall accrue for other than the charges set by the procedures outlined above. There shall be a statute of limitations to provide that no charges can be recovered which are past due for more than five years,

6. Assets or entitlements of individuals residing in institutions may be applied toward reimbursement to the extent of average per-capita cost, with full consideration of his needs upon rehabilitation and release.

VII. REFERENCES

1. Responsibility for Costs of Maintenance and Training in Public Institutions for the Mentally Retarded. A study by the Public Institutions Committee of the National Association for Retarded Children. New York: NARC, 1958. Price $1.00

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5. Mernitz, David W. "Private Responsibility for the Costs of Care in Public Mental Institutions." Indiana Law Journal. Vol. 36, No. 4, pp. 443-482. Indiana University School of Law, Bloomington: Summer, 1961.

6. Information on Reimbursement - States of the Southern Region. Compiled by Fiscal Section, South Carolina Mental Health Commission. Columbia, South Carolina: July, 1960.

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APPENDIX A

Sources and Use of Data

The principal source of the 1960-61 data is the NARC questionnaire, a copy of which is included at the end of Appendix A. This questionnaire was designed to solicit information normally available to the State agency which administers institutions for the mentally retarded. It was, however, inadvertently sent to the various State institutions along with questionnaires on other subjects. Later it was also sent to the State agencies. Many State institutions provided what information they could on these questionnaires. Most State agencies also answered the questionnaire.

Some disagreement was found between answers from the individual institutions and from the State agency in the same State. Many of the discrepancies can probably be explained by minor differences in method of keeping records and the like, and are not sufficient to materially affect the analysis for which these data were used. In general, the data from the State agency were used. Where no reply was received from the agency or where the agency data were missing or obviously in error, the institution data were used.

Other sources of data and information were used to cross-check and fill blanks. These sources included legislative research reports (such as that of the U.S. Department of Labor[4]), material supplied by State Associations for Retarded Children, and publications (such as that by Mernitz 5). Except as otherwise indicated, the data presented are for 1960-61. Comparisons are made with data from the earlier NARC study 1 of 1956. Sources of data for 1956 include this study as well as that of the Virginia Association for Retarded Children.3

It is emphasized that the data contained in this report were not compiled to produce an utterly complete statistical report. Rather, the purpose was to produce a working document of respectable accuracy which illustrates the status and trends of charges for residential care, and which highlights the problems and the situations which are of concern to the parent and friends of the mentally retarded. Accordingly, graphical methods of presenting the basic data are used in preference to tabular methods.

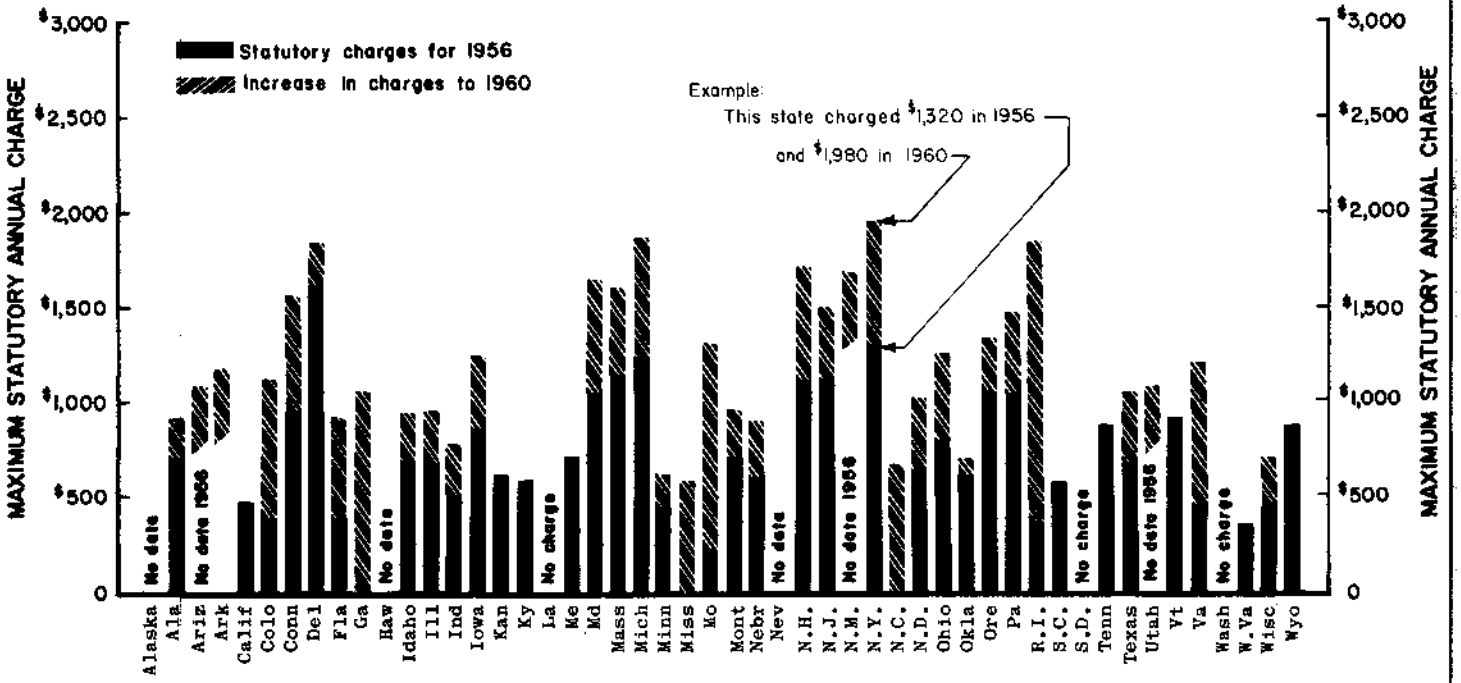


Figure 1.— Maximum statutory annual charges in 1956 and 1960–61. For states with several charge rates, calculated averages are shown.

MAXIMUM STATUTORY CHARGE	NO. OF STATES
None	3
Low (below $720 per year)	10
High ($720 to $1500 per year)	24
Very high (above $1500 per year)	10
No data or no institution	3

Figure 2. - Number of states having low, high, and very high maximum statutory charges in 1960-61.

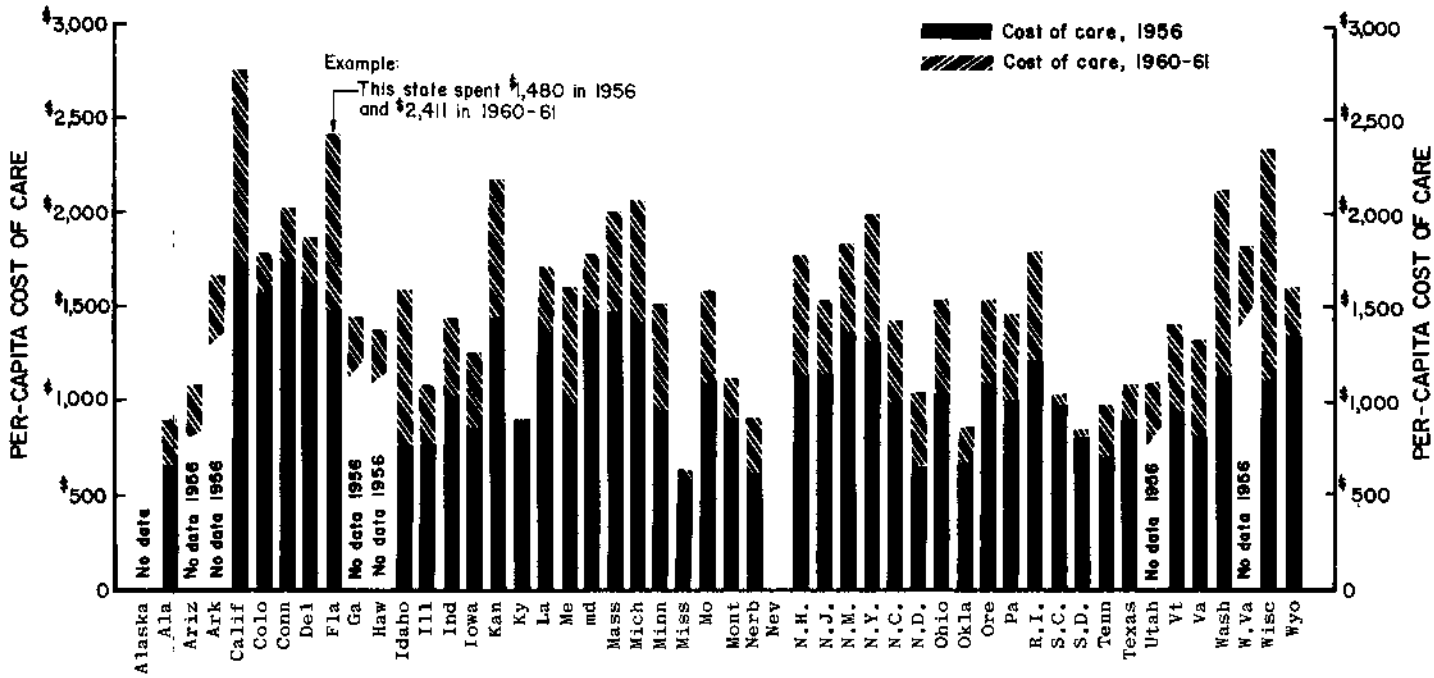


Figure 3.- Per-capita cost of care in 1956 and 1960-61. For states having several institutions with different per-capita expenditures, calculated averages are shown.

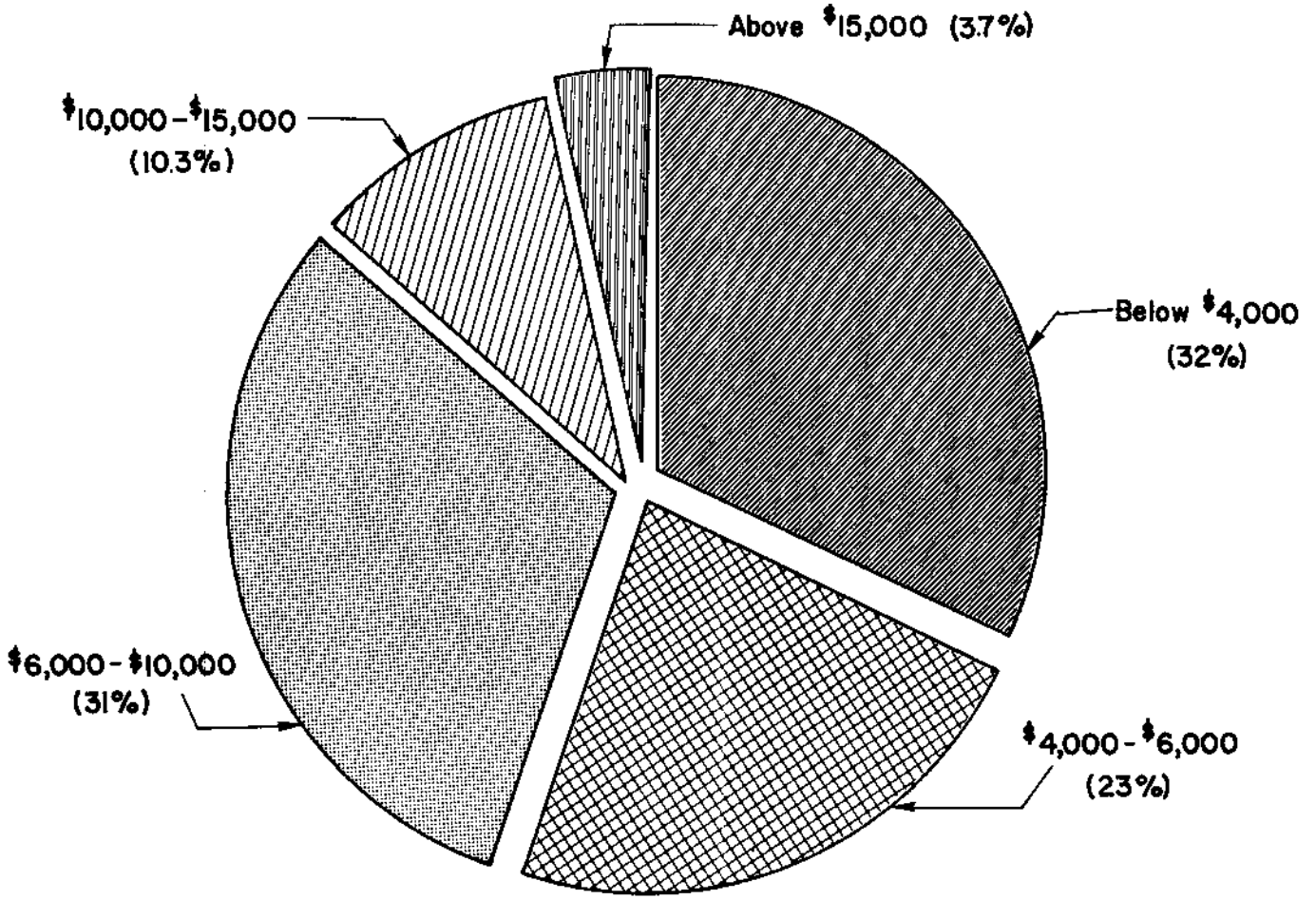
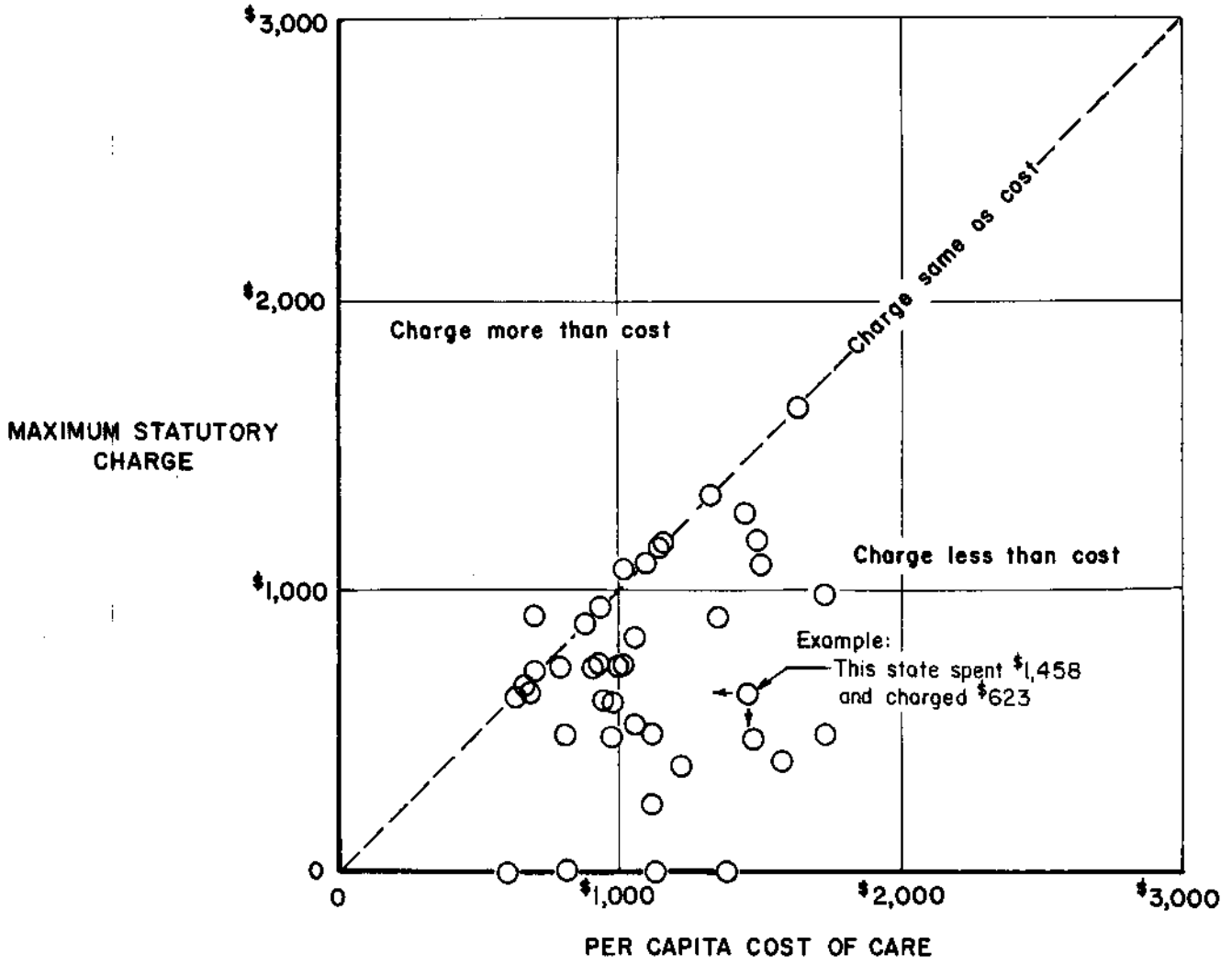


Figure 4.- Income distribution for U.S. families, 1960. Data from USIRS.

STATE	INCOME BRACKET								Median Income
	Under $2,000	$2,000 to $2,999	$3,000 to $3,999	$4,000 to $4,999	$5,000 to $5,999	$6,000 to $6,999	$7,000 to $9,999	$10,000 and Over	
Ala.	26.6	12.5	11.7	10.9	10.0	7.8	12.6	8.0	$ 3,937
Alaska	9.0	5.6	6.7	9.0	9.3	8.1	22.5	29.9	7,326
Ariz.	12.9	8.4	9.8	11.8	12.5	10.7	19.5	14.4	5,568
Ark.	32.5	15.2	12.7	10.3	8.6	6.1	9.1	5.5	3,184
Calif.	8.0	6.1	7.3	8.9	11.3	11.6	25.0	21.8	6,726
Colo.	9.6	8.7	9.8	11.7	13.1	11.3	21.2	14.6	5,780
Conn.	5.5	4.3	6.2	9.7	13.2	12.5	26.5	22.1	6,887
Del.	9.3	6.7	8.6	11.0	12.3	11.0	21.5	19.6	6,197
Fla.	16.2	12.2	12.9	12.0	11.4	8.9	15.2	11.1	4,722
Ga.	22.5	13.1	12.1	11.1	10.3	8.0	13.7	9.2	4,208
Hawaii	7.0	5.9	10.4	11.5	11.3	10.4	21.4	22.0	6,366
Idaho	11.5	9.3	11.4	14.1	13.9	11.0	18.2	10.5	5,259
Ill.	9.0	6.0	7.2	9.3	12.1	11.4	24.7	20.5	6,566
Ind.	10.6	7.4	9.4	11.8	13.6	11.6	21.5	14.1	5,798
Iowa	15.2	10.1	11.2	12.6	12.9	10.4	17.0	10.7	5,069
Kansas	12.9	9.4	11.1	12.7	13.4	10.6	17.9	12.1	5,295
Ky.	26.1	12.0	11.4	11.3	10.5	7.9	12.8	8.0	4,051
La.	23.0	12.6	11.5	10.8	10.0	8.2	14.0	9.9	4,272
Maine	11.8	11.0	14.3	14.7	14.1	10.7	15.7	7.7	4,873
Md.	8.8	6.5	8.5	10.6	12.2	11.0	22.6	19.8	6,309
Mass.	6.7	5.8	8.3	11.6	14.3	12.5	23.8	17.0	6,272
Mich.	9.5	6.3	7.2	10.4	13.7	12.0	23.7	17.4	6,256
Minn.	12.8	8.6	9.8	11.4	13.0	11.2	20.2	13.0	5,573
Miss.	37.7	13.9	11.2	9.3	7.9	5.8	9.0	5.2	2,884
Mo.	17.1	9.9	10.2	11.3	12.1	9.9	17.7	11.8	5,127

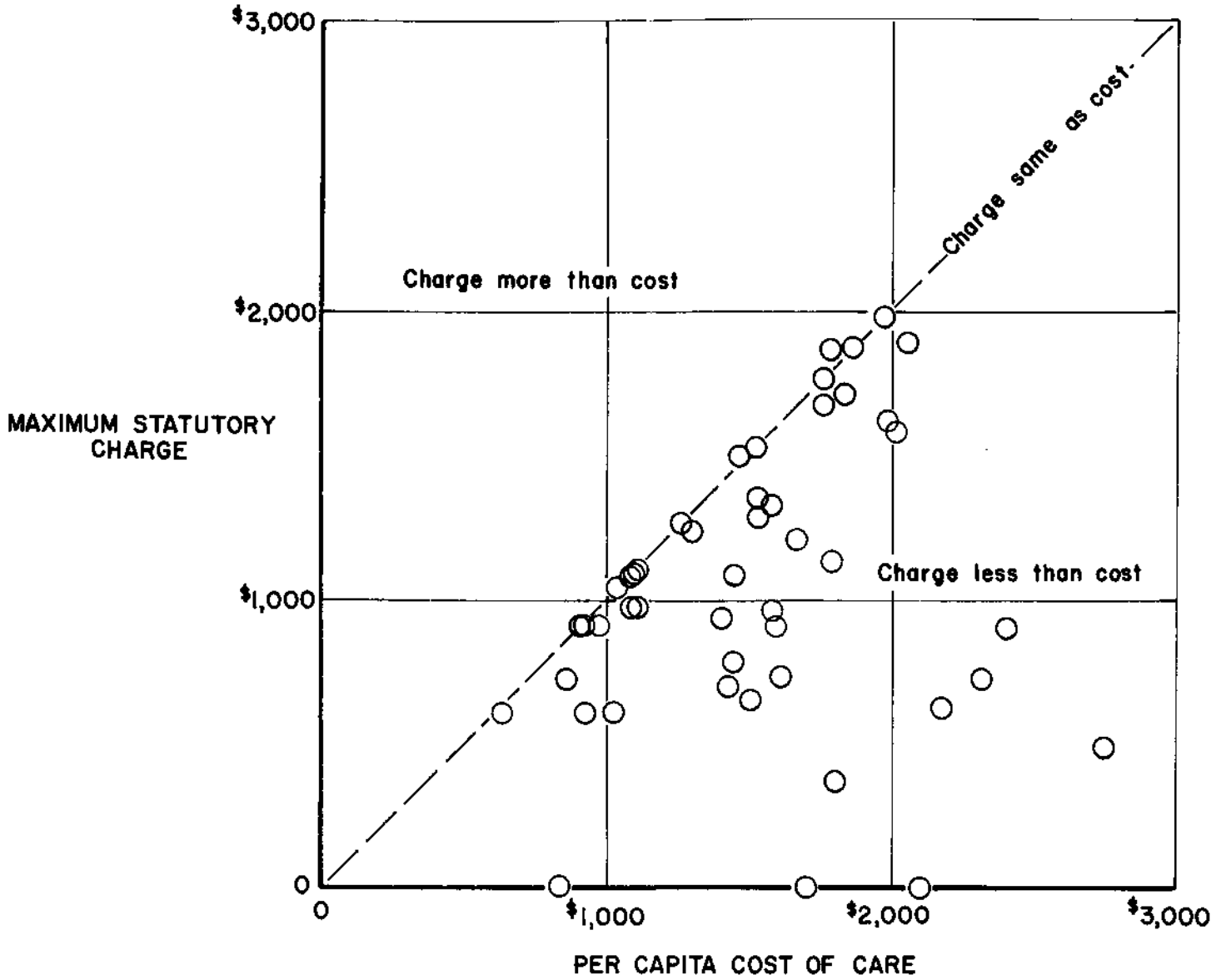
Figure 4(b) - Percentage of families in various income brackets in 1959 in the 50 states. Data from Statistical Abstract of the U.S., 1962, published by U. S. Dept.

STATE	INCOME BRACKET								Median Income
	Under $2,000	$2,000 to $2,999	$3,000 to $3,999	$4,000 to $4,999	$5,000 to $5,999	$6,000 to $6,999	$7,000 to $9,999	$10,000 and Over	
Mont.	11.4	8.8	11.3	12.8	14.1	11.3	18.8	11.5	$ 5,403
Nebr.	14.7	11.4	12.8	13.0	12.6	9.7	15.8	10.2	4,862
Nev.	6.9	5.4	7.6	10.0	11.6	11.5	25.1	21.9	6,736
N.H.	7.9	7.3	11.0	14.1	15.2	12.4	20.7	11.3	5,636
N.J.	6.5	4.9	6.8	9.5	12.8	12.0	25.4	22.0	6,786
N.Mex.	15.1	9.2	10.6	10.8	11.2	10.3	18.4	14.3	5,371
N.Y.	7.7	6.1	8.3	10.7	12.9	11.5	22.9	19.9	6,371
N.C.	23.9	13.2	13.4	11.8	10.3	8.0	12.3	6.9	3,956
N.Dak.	16.9	11.9	13.9	13.9	12.0	9.0	14.0	8.5	4,530
Ohio	9.4	6.3	7.7	10.7	13.8	12.4	23.5	16.2	6,171
Okla.	19.7	11.2	11.8	11.7	11.8	9.2	14.5	10.1	4,620
Ore.	9.9	7.2	8.4	11.8	14.3	12.4	22.1	13.9	5,892
Pa.	9.5	7.4	9.8	13.0	14.4	11.7	20.3	13.9	5,719
R.I.	9.5	7.2	11.0	13.3	15.1	12.0	20.2	11.7	5,589
S.C.	26.5	13.0	12.7	11.0	10.0	8.0	12.2	6.5	3,821
S.Dak.	20.9	12.6	13.3	12.8	11.4	8.8	12.6	7.6	4,251
Tenn.	25.4	12.9	12.3	11.1	10.1	7.9	12.5	7.8	3,949
Texas	18.0	10.7	11.3	11.2	11.1	9.4	16.4	11.8	4,884
Utah	8.3	6.5	8.7	12.6	15.6	13.1	21.5	13.8	5,899
Vt.	12.0	11.1	13.7	14.8	13.7	10.4	15.5	8.9	4,890
Va.	17.4	10.5	11.2	11.3	10.8	8.9	16.7	13.2	4,964
Wash.	8.6	6.6	7.8	10.4	13.7	12.5	23.7	16.6	6,225
W.Va.	21.9	10.7	10.7	11.7	12.2	9.6	14.8	8.4	4,572
Wisc.	10.0	7.4	8.6	11.2	13.9	12.6	22.1	14.3	5,926
Wyo.	9.0	7.5	10.0	11.7	13.5	12.4	21.4	14.6	5,877
United States	13.1	8.3	9.5	11.0	12.3	10.7	20.1	15.1	5,660



(a.) 1956

Figure 5.— Comparison of maximum annual statutory charges and annual per capita cost of care.



(b.) 1960-61

Figure 5.- Concluded

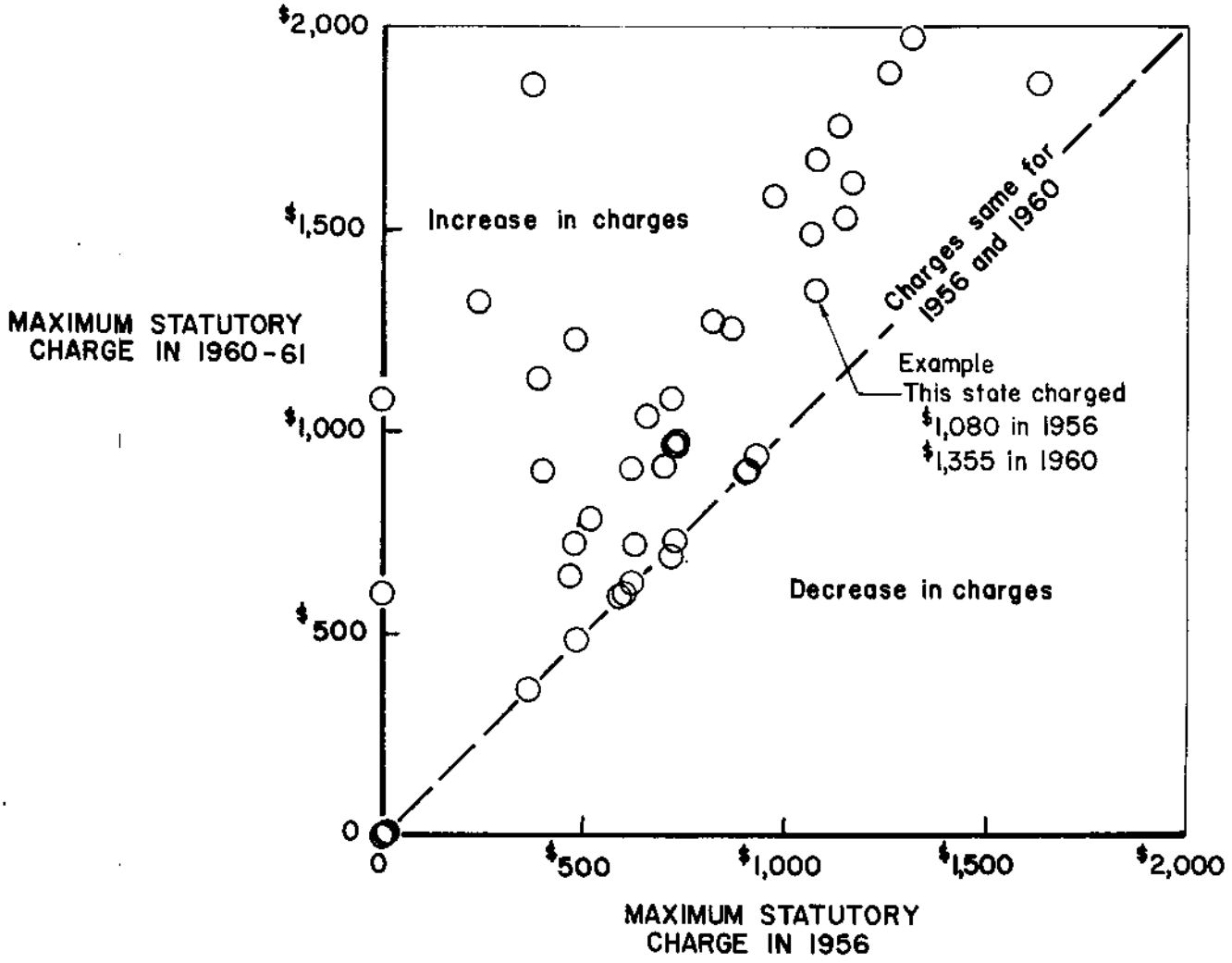
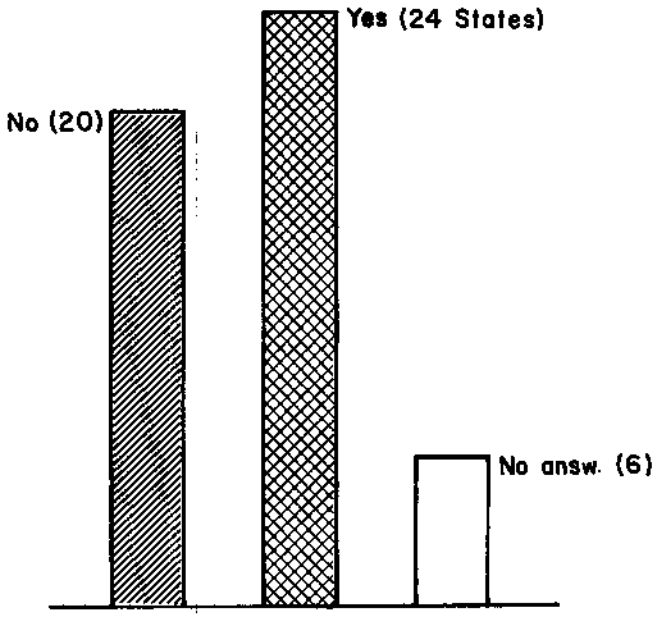
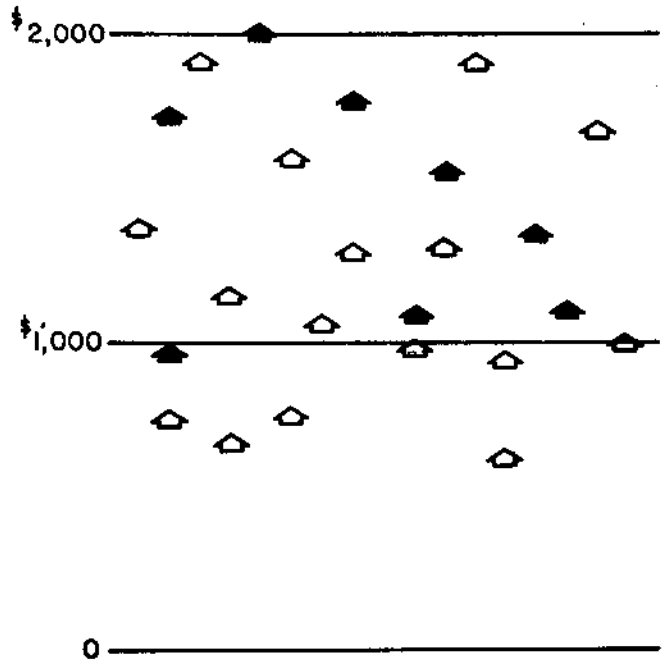


Figure 6.- Comparison of maximum statutory annual charges for 1956 and and 1960-61. Each point is for one state.

QUESTION: IS AN INCREASE IN STATUTORY CHARGE EXPECTED ?



(a) Answers to the question.



(b) Present charges of states answering "yes". Solid points indicate states in which less than 2% of patients are now paying the full statutory charge.

Figure 7.- Questionaire answers regarding anticipated increase in charges.

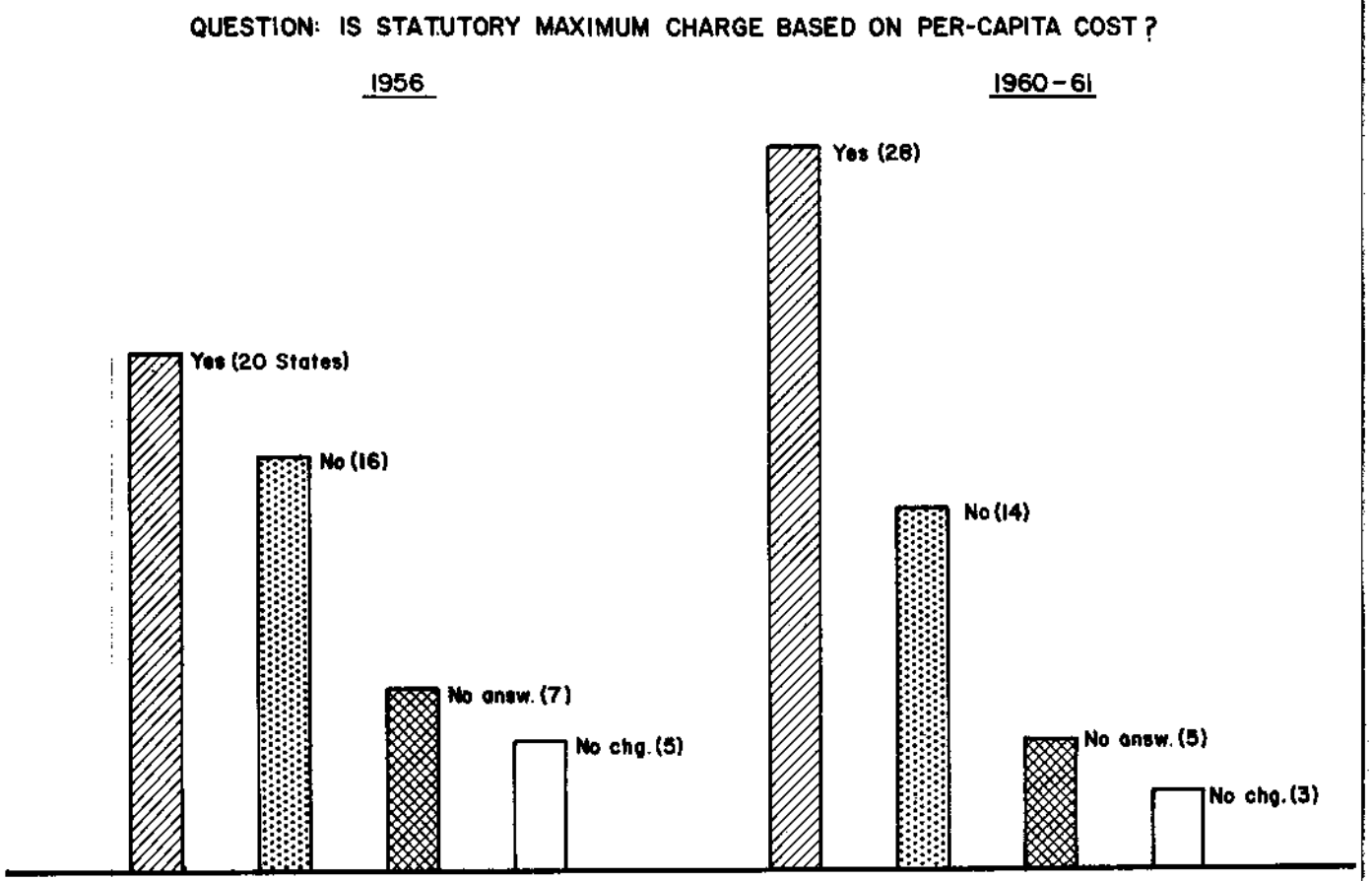


Figure 8.– Questionaire answers regarding basis of statutory maximum charge.

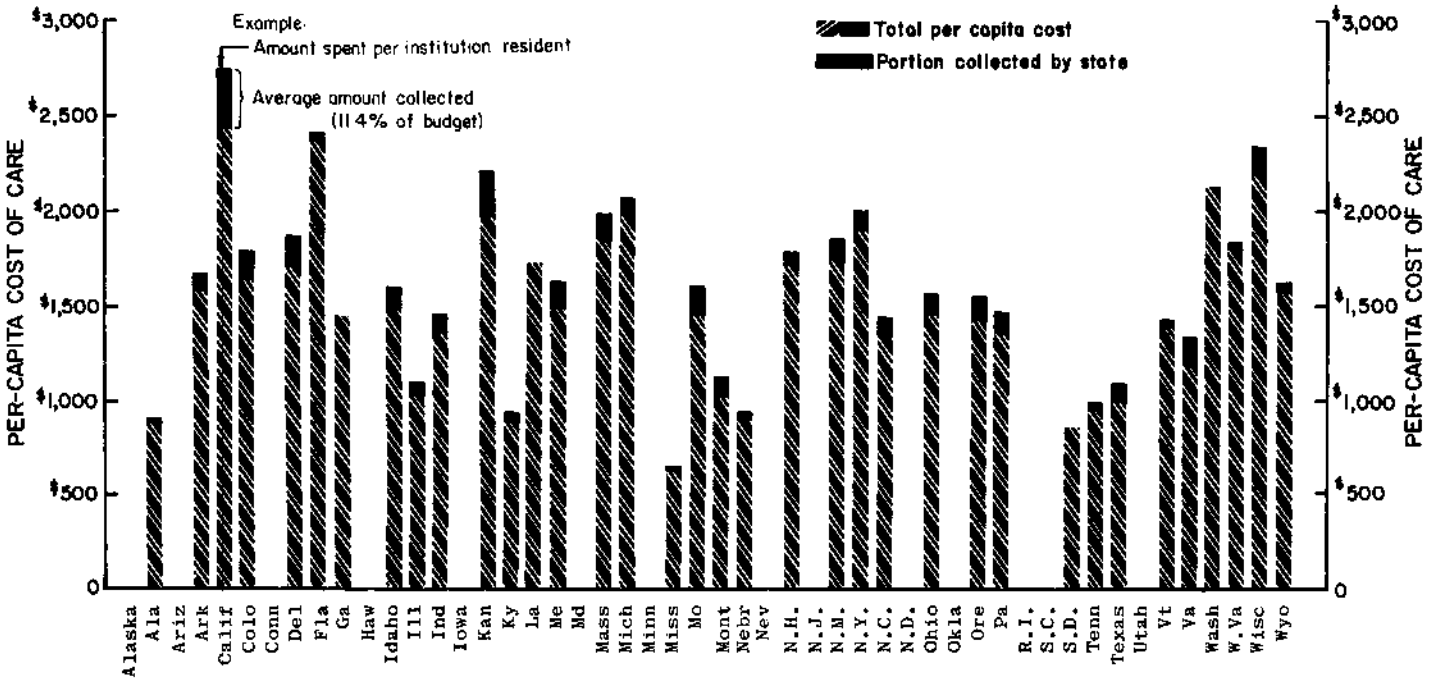


Figure 9.– Portion of per-capita costs collected in 36 states in 1960-61.

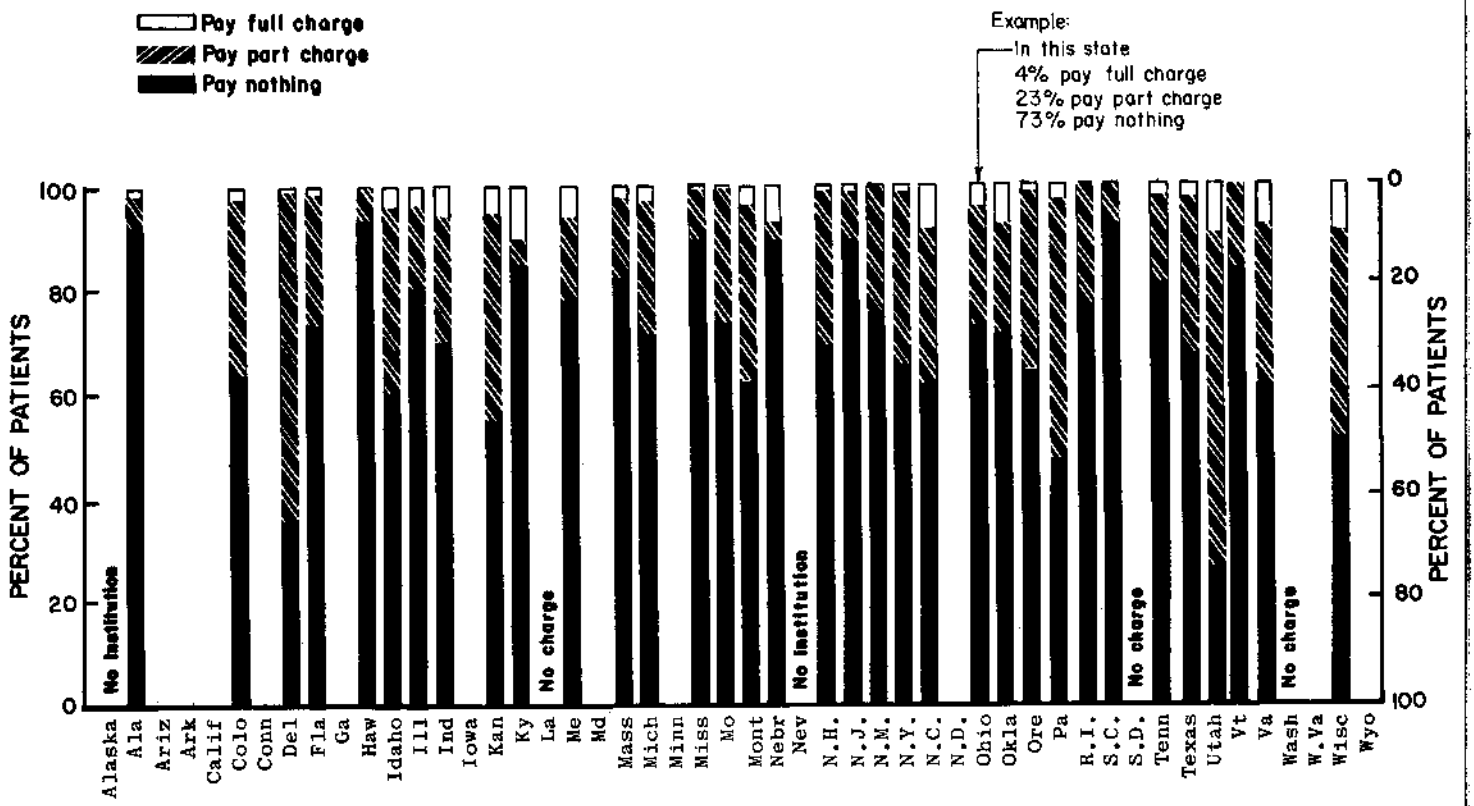


Figure 10.- Percentage of patients paying full charge, part charge, nothing, in 34 states.

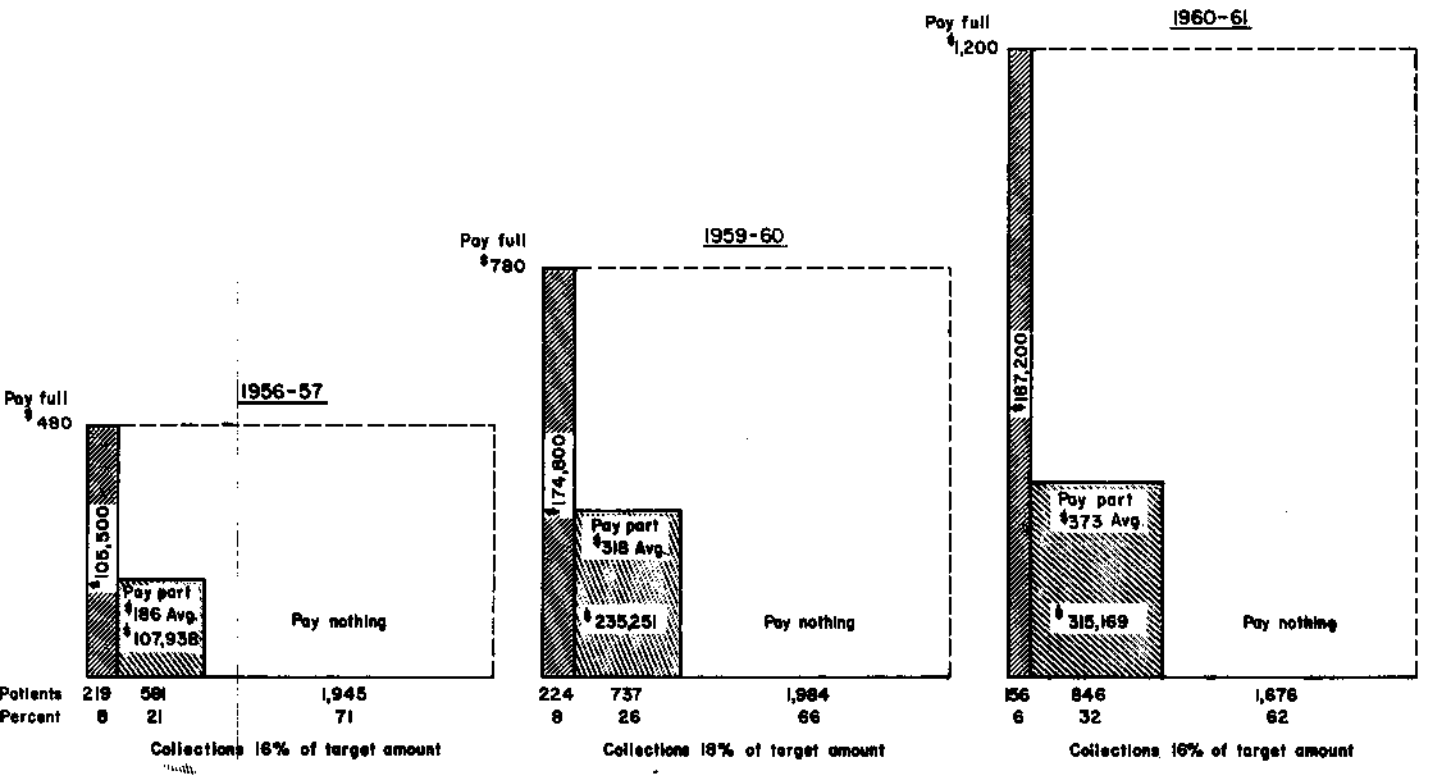


Figure 11.- Record of payment in one high-charge state as charges rise.

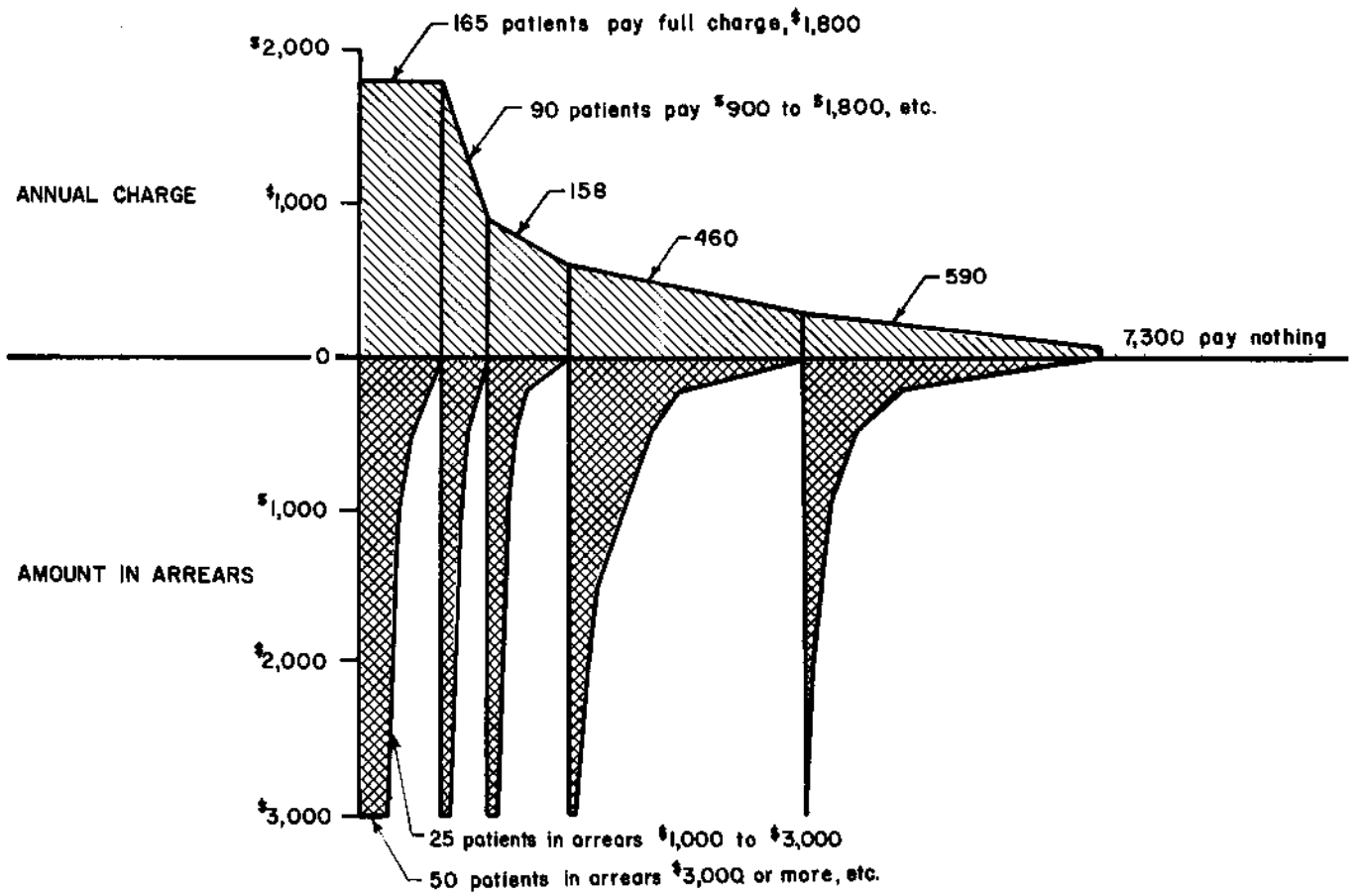


Figure 12.- The number of patients paying various charges in one high-charge state. Also shown are the amounts by which payments are in arrears for each group.

PERSON OR AGENCY	NO. OF STATES
Hospital or Superintendent	6
County or County Board	4
Court	9
Welfare Agency	6
Dept. of Mental Hygiene or Health or claims agency thereof	12
State Comptroller or Dept. of Revenue	3
No charge	3
No institution	2
No information	5

Figure 13. - The person or agency which performs ability-to-pay determinations in the various states.

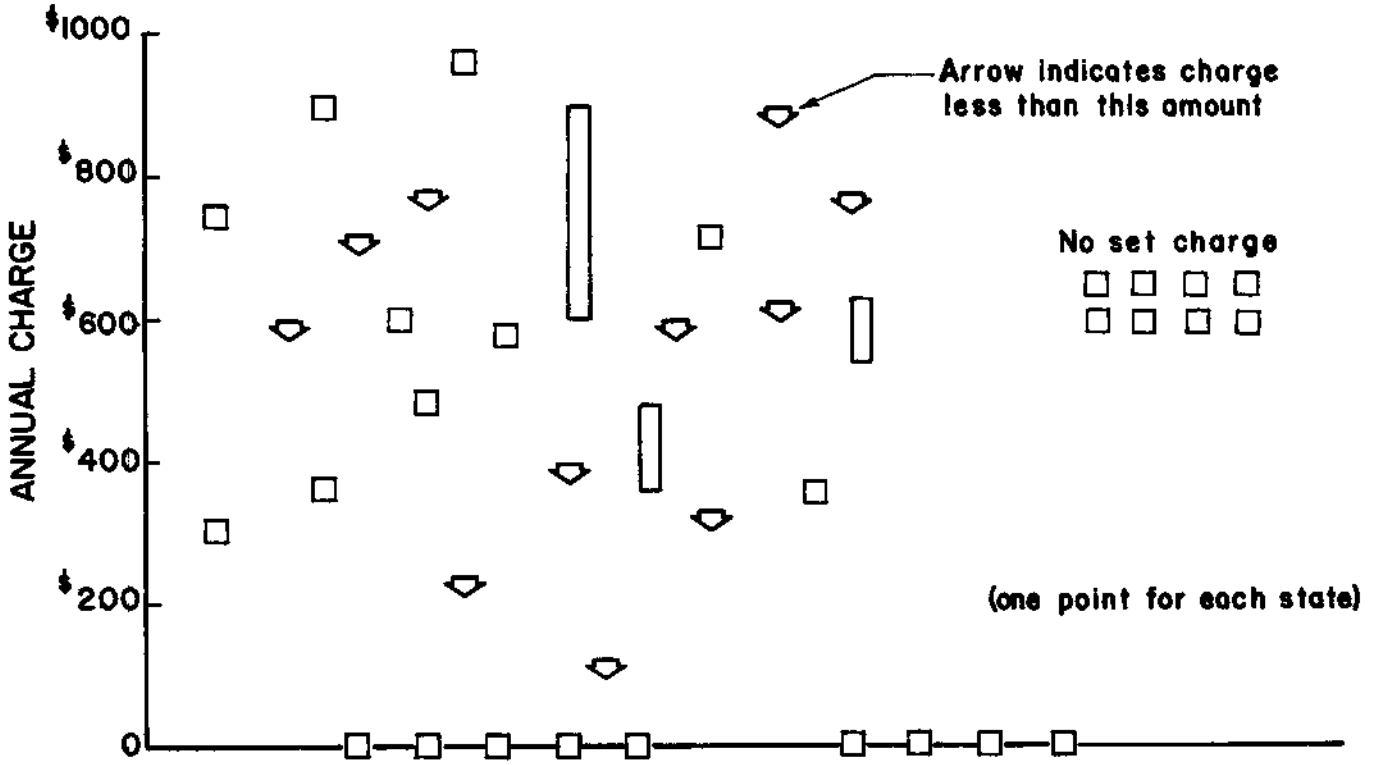


Figure 14.- Annual charge (based upon ability-to-pay) in 41 states for family of three with $6,000 gross income.

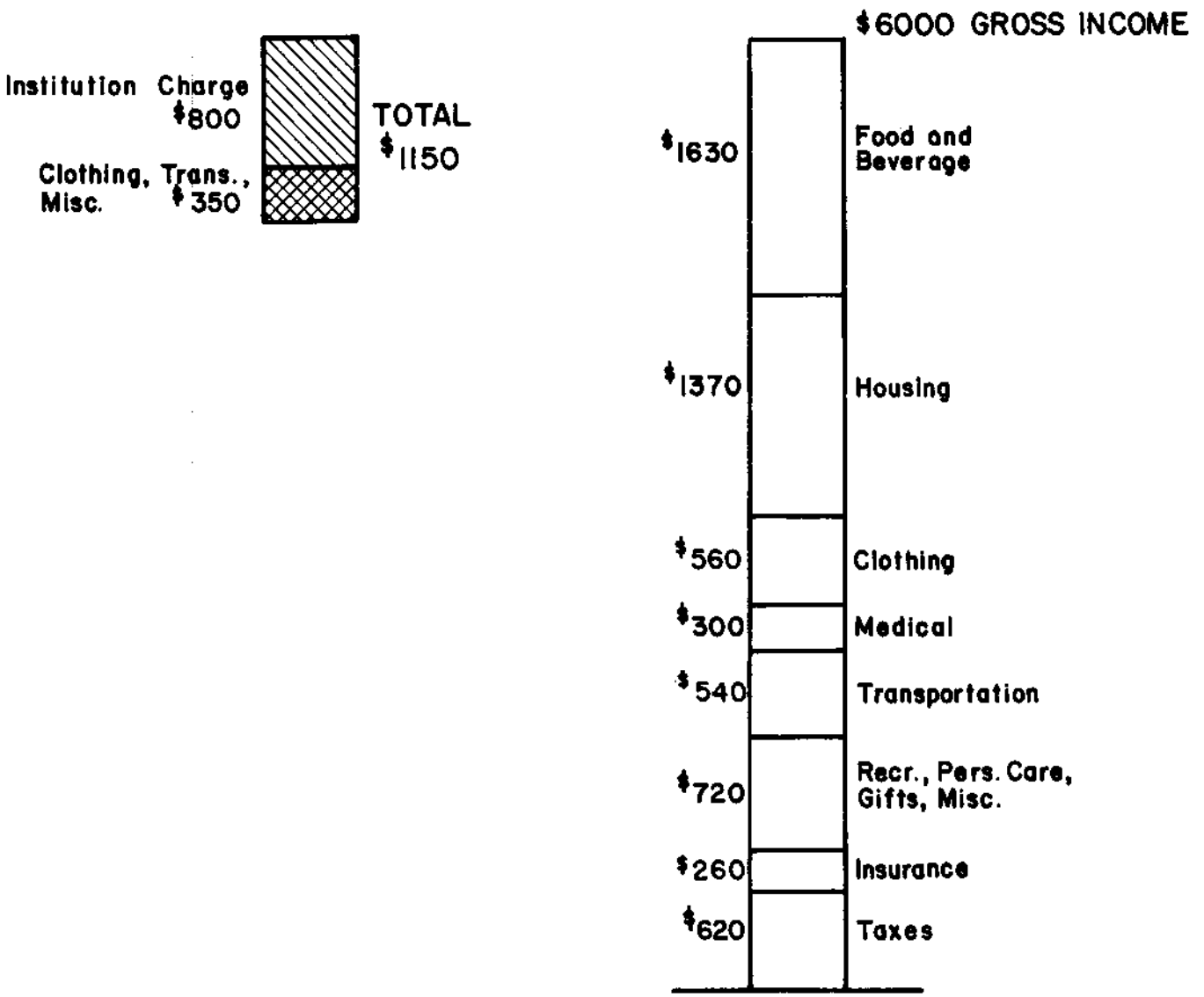


Figure 15.— Comparison of cost of institution care with family budget for a family of four with a $6,000 gross income. Budget data from reference 5. Institution charge is for typical high-charge state.

QUESTION: ARE CHARTS, TABLES OR SCALES FOR DETERMINING ADJUSTED CHARGES PUBLISHED AND/OR AVAILABLE ?

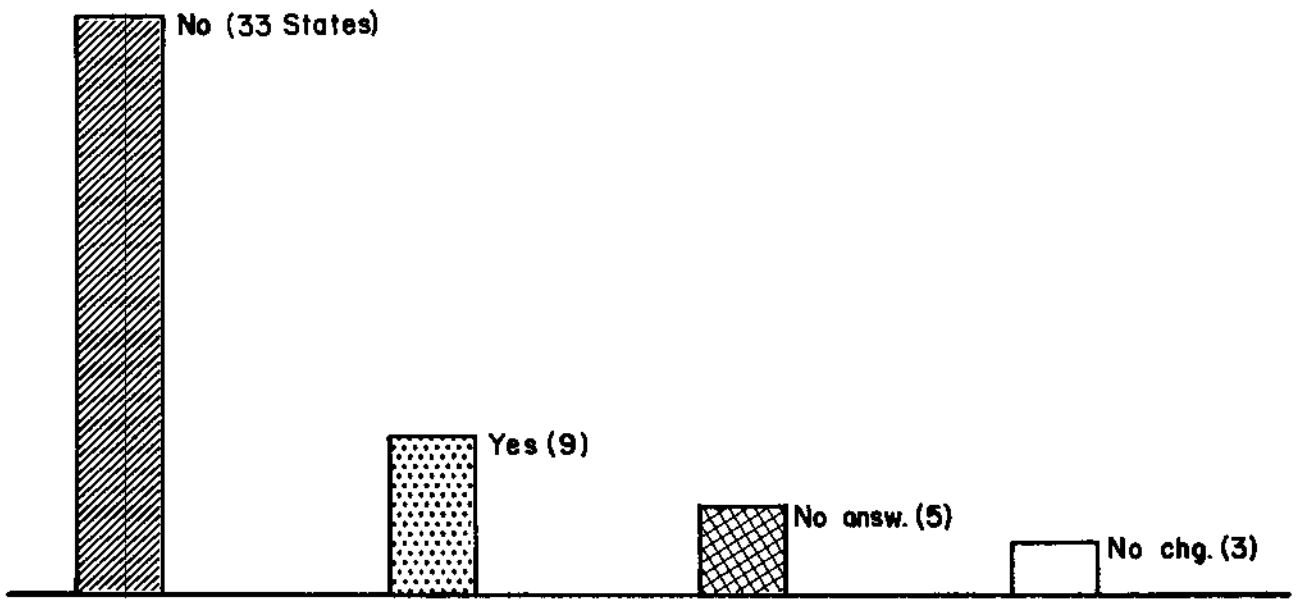


Figure 16.- Questionaire answers regarding availability of charts or tables for determining charges.

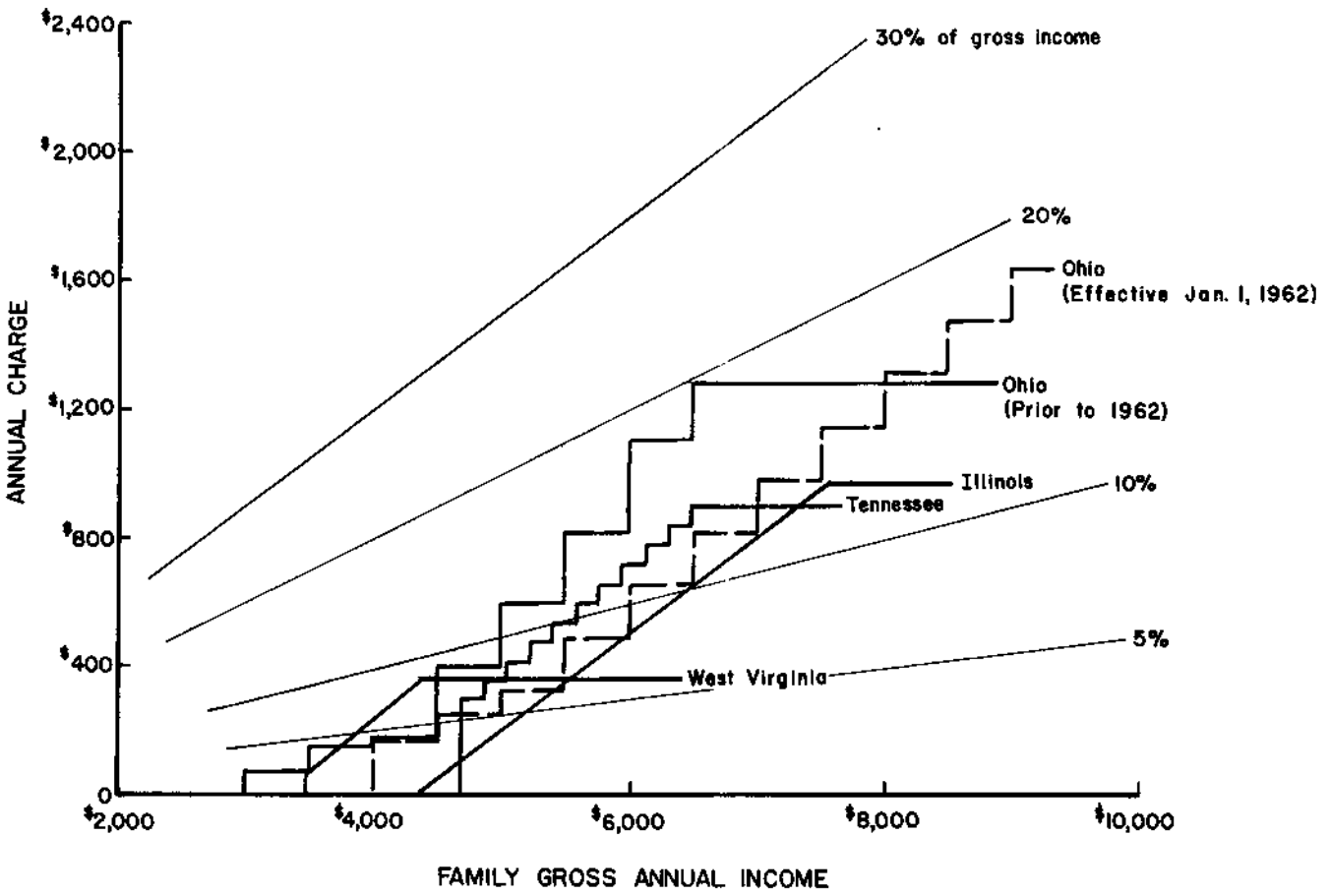


Figure 17.- Variation of charge with family gross income in nine states. Curves taken from schedule of charges, rate computation chart, responsibility scale, etc., supplied by these states. For family of four, including institution resident.

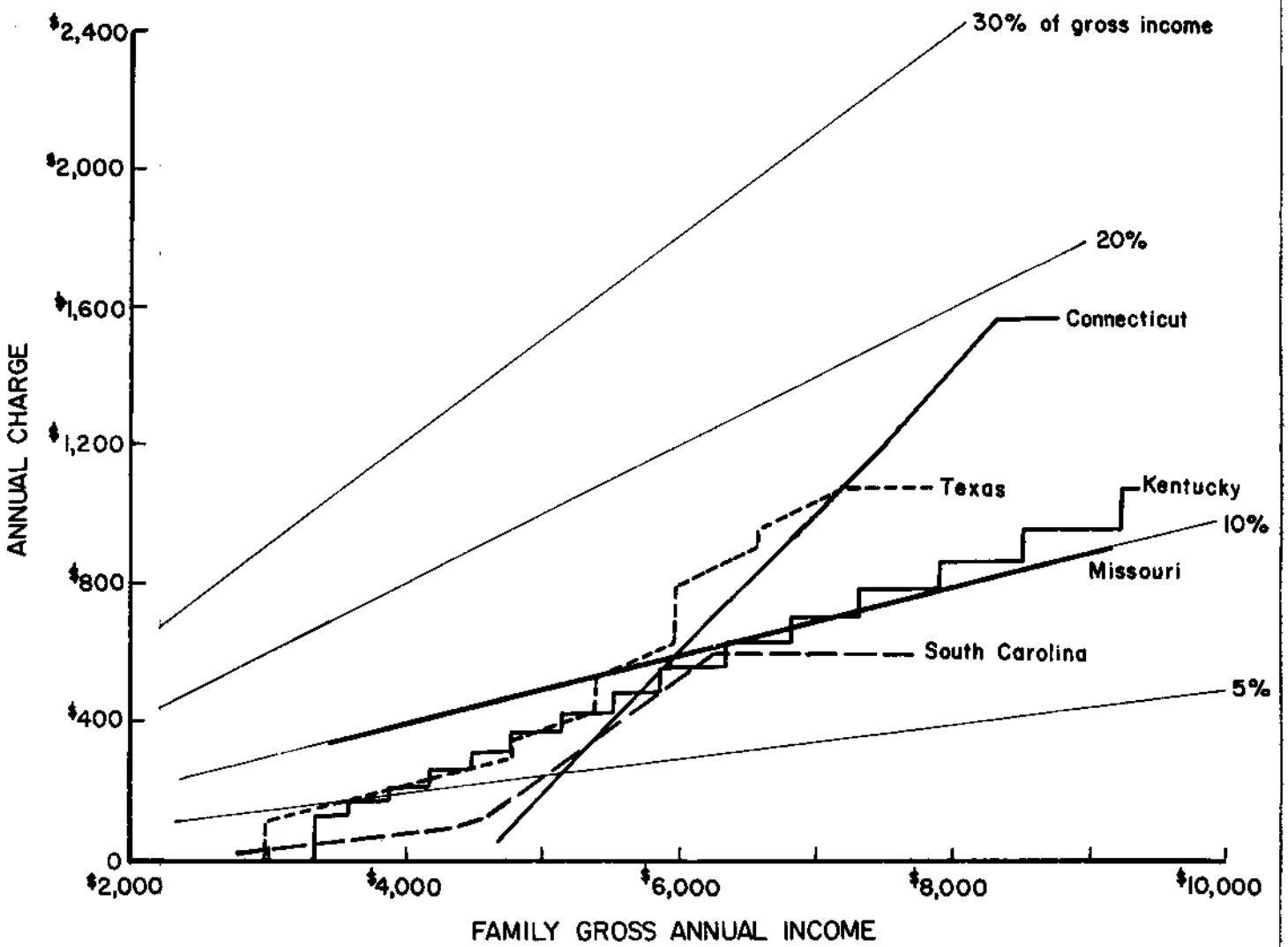


Figure 17.– Concluded.

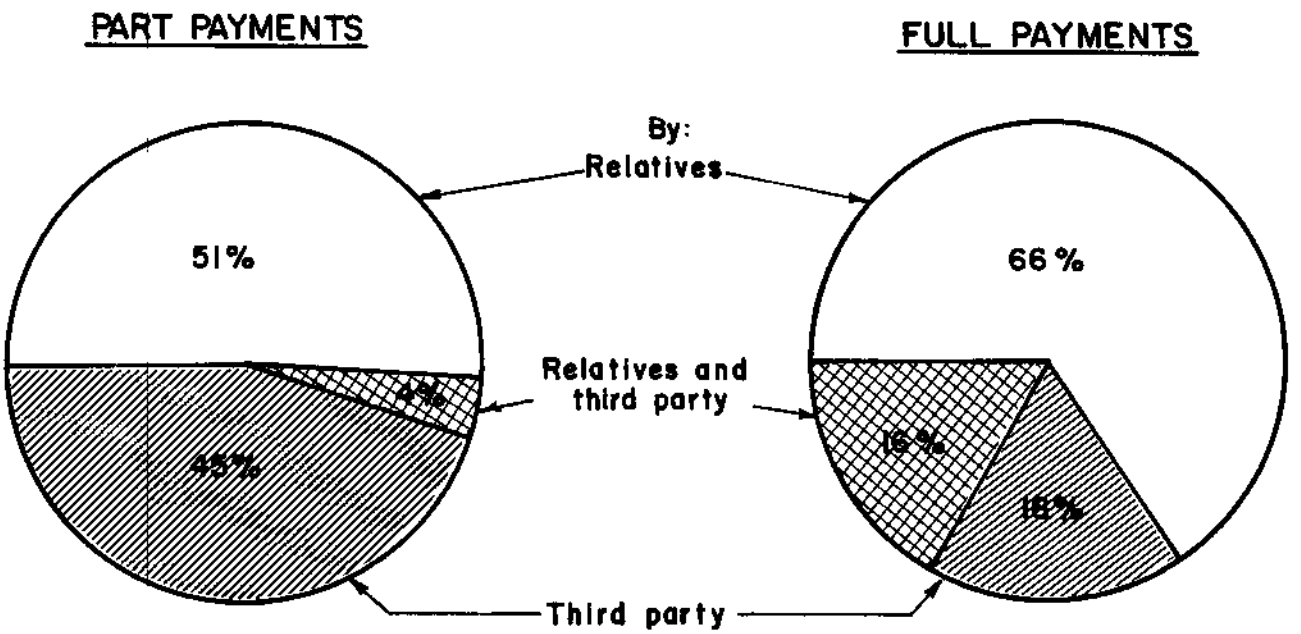


Figure 18.- Source of full and part payments in typical high-charge state.

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