

---

A Study of  
**Cerebr  
al Palsy**



---

**Helen M. Wallace, M.D. • Curtis L. Meinert • Philip J. Englund**

---

# **A STUDY OF CEREBRAL PALSY**

## **A REPORT ON THE STATE-WIDE CEREBRAL PALSY SURVEY IN MINNESOTA**

**By**

**Helen M. Wallace, M.D.; Curtis Meinert, M.S.; and**

**Philip J. Englund**

**Dr. Wallace is Chief, Child Health Studies, Children's Bureau, Washington, D.C. Mr. Meinert is at the University of Minnesota, School of Public Health. Mr. Englund is Executive Director of UCP of Minnesota.**

**Part of this investigation was carried out during the tenure of a Pre-doctoral Fellowship (No. MF-7995- C2) by Mr. Meinert from the National Institute of Mental Health; Public Health Service, Washington, D.C.**

## **FOREWORD**

**The first two Chapters of this report deal with the background and study design employed. While this information is of importance in the ultimate interpretation given to the material in Chapter Three, some readers may desire to go directly to Chapter Three omitting or scanning the first two Chapters of this report.**

## **ACKNOWLEDGMENTS**

We gratefully acknowledge the support, assistance and cooperation of United Cerebral Palsy of Minnesota. Acknowledgment is also made to the Minnesota State Departments of Education, Health and Welfare and to the many other agencies which provided special assistance in the various steps of this study.

In addition the authors would like to acknowledge the efforts of Virginia Belcher and Charlotte Shine in editing and coding the questionnaires, Beverly Anderson in punching the information onto cards, Frances Palmer and Ruth King for valuable secretarial assistance in the preparation of this manuscript and the Statistical Services of the University of Minnesota for checking the calculations. The authors also wish to acknowledge the efforts of Thyra Ostrand and Lois Eckstein in the preparation of this manuscript.

Finally, we are grateful to all cerebral palsied patients and their parents or guardians who completed and returned the questionnaires.

## TABLE OF CONTENTS

<b>Chapter 1:</b>	<b>INTRODUCTION AND BACKGROUND</b>	<b>Page No.</b>
1.1.	Introduction .....	1
1.2.	The Method of Case Finding .....	1
1.3.	The Reports .....	2
1.4.	Completeness of Case Finding .....	4
1.5.	Completeness of Reporting .....	5
1.6.	Accuracy and Adequacy of the Reports.....	8
<b>Chapter 2:</b>	<b>THE MAIL SURVEY</b>	
2.1.	The Research Design.....	15
2.2.	Development of the Questionnaire and Pre testing .	16
2.3.	The Mailings .....	17
2.4.	Response to the Mailings .....	18
2.5.	The Population Studied .....	20
2.6.	Coding the Questionnaire .....	36
2.7.	"Inter and Intra" Respondent Reliability.....	37
2.8.	Sources of Bias .....	40
2.9.	Comparison of Finding With Other Studies .....	43
<b>Chapter 3:</b>	<b>ANALYSES OF THE COMPLETED QUESTIONNAIRES</b>	
3.1.	Method of Analysis.....	45
3.2.	Source of Information on the Form .....	45
3.3.	Place of Birth and Present Place of Residence of Patients with Cerebral Palsy .....	46
3.3.1.	Place of Birth.....	46
3.3.2.	Place of Residence of Patients with Cerebral Palsy .....	48
3.4.	Age at Time of Diagnosis .....	49
3.5.	Frequency and Severity of Handicaps.....	50
3.5.1.	General Status of Patients .....	50
3.5.2.	Walking Status of Patients .....	52
3.5.3.	Feeding Status of Patients.....	54
3.5.4.	Dressing Status of Patients .....	55
3.5.5.	Status Regarding Caring for Toilet Needs .	56
3.5.6.	Speech Status of Patients .....	57
3.5.7.	Eye Status.....	58
3.5.8.	Hearing Status .....	60
3.5.9.	Status of Patients Regarding Convulsions .	62
3.5.10.	Presence of Other Health Problems.....	66
3.6.	Present Medical Care of the Patient.....	67
3.6.1.	Type of Present Medical Care .....	67

Chapter Three (Com.)	Page No.
3.6.2. Types of Physicians Currently Caring for Cerebral Palsied Patients .....	69
3.6.3.* Number of Sources of Present Medical Care	71
3.6.4. Resency of Last Visit to a Physician . . . .	72
3.7. Care by Certain Medical Specialists .....	74
3.7.1. Orthopedic Care .....	74
3.7.2. Eye Care .....	75
3.7.3. Status of Care for those with Hearing Impairment .....	77
3.8. Dental Care .....	78
3.8.1. Dental Care During Patient's Entire Lifetime .....	78
3.8.2. Dental Care During Past Year .....	79
3.9. Use of Public Health Nursing Service .....	81
3.10. Therapy Status of Patients .....	82
3.10.1. Therapy Summary .....	82
3.10.2. Status of Present Physical Therapy .....	85
3.10.3. Status of Present Occupational Therapy Service .....	86
3.10.4. Status of Present Speech Therapy Service .	87
3.11. Educational Status of Patients .....	89
3.11.1. Ability of the Patient to Learn .....	89
3.11.2. Education of School-Aged Children (under 21) .....	90
3.11.2.1. Type of Class or School in Current School Attendance .....	93
3.11.2.2. Home Instruction .....	96
3.11.2.3. Level of Education of School-Aged Children not Presently in School .....	97
3.11.3. Previous Education of Adult Patients . . . .	99
3.12. Vocational Assistance and Status .....	101
3.12.1. Vocational Assistance .....	101
3.12.2. Current Employment Status .....	104
3.13. Participation in Recreational Activities .....	106
3.14. Assistance Needed by Families .....	108
3.15. The Presence of Cerebral Palsy in Other Members of the Patient's Family .....	109
<b>Chapter 4: RECOMMENDATIONS .....</b>	<b>111</b>
<b>APPENDICES</b>	
Appendix 1 Copy of the Questionnaire Used .....	119
Appendix 2 Selected Tables .....	133
Appendix 3 Definitions .....	155

# CHAPTER 1: INTRODUCTION AND BACKGROUND

## 1.1 INTRODUCTION

The Minnesota Cerebral Palsy Study was undertaken jointly by the University of Minnesota School of Public Health and the United Cerebral Palsy of Minnesota. It was jointly co-sponsored by the Minnesota State Departments of Education, Health, and Welfare, and in addition the study was approved by the State Medical Association and the State Hospital Association.

The first part of this project, namely the part dealing with the development of the register and the description of the study population, has already been reported upon. However, because of changes in the register since the time of that report, it will be necessary to re-present many tabulations given in that report.

The emphasis of this report will be placed upon the findings with respect to the current status of the reported patients and the services received by them in the past and at present, as indicated from the questionnaires returned.

The purpose of this study can be summarized as follows:

- (1) To determine the reported prevalence of cerebral palsy among children and adults in the state;
- (2) To determine the geographic location of reported patients;
- (3) To portray a picture of the current status of the reported patients and the services received by them in the past and at present,  
and
- (4) To make a plan for comprehensive services to meet the needs of patients with cerebral palsy.

## 1.2 THE METHOD OF CASE FINDING

Since no roster of cerebral palsied patients existed prior to this study, one of the first steps was to develop a list of cerebral palsied in the state. To this end it was necessary to embark upon a state-wide case finding program. For various reasons the method of choice in this case was to rely upon voluntary reports of known cerebral palsy patients. Various sources were contacted either directly or by written communication

*Wallace, H. M.; Meinert, C; Deiter, R.; and Bearman, J., Cerebral Palsy in Minnesota, Part I - Method of Study, Prevalence, and Distribution. American Journal of Public Health, Vol. 51: 417/426, March, 1961.*

and were asked to supply the names and addresses of known cerebral palsied patients. Sources contacted included:

- 1) all licensed practicing physicians in Minnesota during the year 1958,
  - 2) all State and private hospitals licensed in Minnesota during the year 1959,
  - 3) rehabilitation services,
  - 4) all licensed nursing and boarding care homes in the state,
  - 5) local affiliates of the United Cerebral Palsy of Minnesota,
  - 6) State Office of Vocational Rehabilitation,
  - 7) school census data from the State Department of Education,
  - 8) caseloads known to the State Department of Welfare including the Crippled Children's program, aid to the disabled, aid to dependent children, general public assistance, aid to the blind, and patients hospitalized in state hospitals,
  - 9) children's institutions,
  - 10) county welfare agencies,
  - 11) county superintendents of schools,
- and
- 12) county public health nurses.

In addition, the local health departments, the local boards of education and the visiting nurse agencies were contacted in the metropolitan areas of Minneapolis, St. Paul and Duluth.

This phase of the project resulted in the creation of a register of reported cerebral palsy patients, all presumably alive and living in the state at the time of reporting. A total of 4,035 patients were reported.

### **1.3 THE REPORTS**

As indicated in the previous section, a total of 4,035 individuals were reported. The source of these reports, as well as the number of reports obtained from each source, is given in Table 1.3.1.

Inspection of Table 1.3.1. reveals a total of 6,627 reports were submitted, an average of 1.64 per patient. The duplication of reporting on a per patient basis is indicated by Table 1.3.2.

Inspection of this table reveals that nearly 56% of the patients were reported by one agency only. The remainder of the patients were reported by two or more agencies. Four patients were reported by eight different sources.

TABLE 1.3.1. Distribution of Reports Obtained by Source

<u>Source</u>	<u>No. of Patients Reported</u>
<b>1. Official Agencies</b>	
A. State Department of Welfare, including:	
(a) Crippled Children's program.....	1,330
(b) State Hospitals.....	451
(c) County Welfare Boards.....	496
B. State Department of Education, including:	
(a) Reports from the State Department of Education.....	752
(b) 20-County Survey.....	136
(c) Public School Reports.....	792
C. State Department of Health	
Public Health Nurses.....	129
D. State Division of Vocational Rehabilitation.....	
	<u>108</u>
Subtotal	4,194
<b>2. Nonofficial Agencies</b>	
A. Voluntary Health Agencies, including:	
(a) Curative Workshop.....	701
(b) United Cerebral Palsy.....	297
(c) State Society for Crippled Children.....	150
(d) Other*.....	129
B. Hospital - not including State Hospitals.....	
	588
C. Physicians.....	
	232
D. Mayo Clinic.....	
	145
E. Rehabilitation Centers.....	
	<u>140</u>
Subtotal	2,382
3. Source Unknown.....	
	<u>51</u>
Grand Total	6,627

\*Includes reports from Goodwill Industries, Minnesota Retarded Children's Association, Minnesota School for the Deaf, Nursing Care homes and Boarding Care homes and others.

TABLE 1.3.2. Number of Agencies Reporting a Patient

No. of Agencies Reporting	No. of Patients Reported	Percent
1	2,248	55.71
2	993	24.61
3	397	9.84
4	219	5.43
5	105	2.60
6	51	1.26
7	18	0.45
8	4	.10
Total	4,035	100.0%

#### 1.4 COMPLETENESS OF CASE FINDING

It is difficult to assess the completeness of reporting of any chronic disease since any method of case finding will fail to locate a certain proportion of the cases. Cerebral palsy is no exception. Even the most complete case finding program available would probably under-report the total number of cases present in a community. Unfortunately, it was not possible to make any extensive evaluation of the completeness of reporting. Nevertheless, an estimate of the extent of under-reporting for the state-wide project was possible as a result of a survey conducted for the purpose of locating all orthopedically handicapped children, between the ages of zero and twenty-one, in a twenty-county area in southwestern Minnesota.

The survey was carried out by the Division of Special Education of the Minnesota State Department of Education. It was carried out independently of the state-wide project and was actually completed about six months prior to the beginning of this project. The procedure followed was to have each county school superintendent obtain the names and addresses of all handicapped children known to the district school superintendents, school boards, county and school nurses and state and county welfare boards. This procedure identified 526 orthopedically handicapped children, of whom 136 were reported to be cerebral palsied. One hundred and nine of these 136 were also reported by some other reporting source in the State-wide Cerebral Palsy Study, while the remaining 27 were reported by the twenty-county survey alone. On the other hand, an additional 200 patients under 21 years of age were identified by the State-wide Cerebral Palsy Study, reported to have cerebral palsy and to be residing in the twenty-county area, but were not reported in the twenty-county survey. In other words, a total of 336 reported cerebral palsy patients between the ages of 0-21 years were found to be residing in the twenty-county area, of whom 8.0% were reported by the twenty-county survey alone.

TABLE 1.4.1. Comparison of Reporting in State-Wide Survey with 20-County Survey

Source	Number Reported	Percent
Reported by 20-County Survey alone	27	8.04
Reported by State-Wide Study alone (excluding the 20-County Survey)	200	59.52
Reported by both 20-County Survey and the State-Wide Study	109	32.44
Total	336	100.0

On the basis of these figures we may estimate that the state-wide study has at least an 8% under-reporting error in the 0-21 age group.

### 1.5 COMPLETENESS OF REPORTING

A second consideration in a project of this sort is the completeness of reporting. That is, of those asked to submit reports of all cerebral palsied known to them, how many actually did? Here, in particular, you will recall from section 1.2 that we contacted all licensed physicians in the state, as well as all the hospitals, nursing and boarding care homes, and county welfare boards in the state. The letter used for contacting members of each group requested the names and addresses of all known cerebral palsied patients. The results of the initial contact of these four groups are summarized in Table 1.5.1 below.

TABLE 1.5.1. Results of Initial Requests for Reports of Cerebral Palsied Made to Physicians\*, Hospitals\*\*, Nursing Homes and Boarding Care Homes\*\*, and County Welfare Boards in the State at the Time of this Survey.

Group	Total Number in State	Number Responding	Percent Responding	Number of Patients Reported
Physicians	4,337	189	4.4	174
Nursing Homes and Boarding Care Homes	442	6	1.4	6
Hospitals	213	31	14.6	345
County Welfare Boards	87	75	86.2	496

*Ms listed in the 1958 State of Minnesota Directory of Licensed Physicians and Surgeons.*

*\*Ms listed in the 1959 Minnesota Directory of Licensed Hospitals and Related Institutions.*

In order to attempt to estimate the number of new patients left un-reported by those units not responding to the letter, a second mailing was made in which all the hospitals not responding to the first mailing were contacted. A ten percent systematic sample of physicians who failed to respond to the first letter was contacted during the second mailing, and a 50% systematic sample of the non-responding nursing and boarding care homes was contacted during the second mailing. Table 1.5.2 gives the total number of units contacted in the second mailing (the denominators are given in Table 1.5.1), the number responding to the second mailing, and the number of new patients reported.

TABLE 1.5.2. Results of the Follow-up Mailing to the Physicians, Hospitals, Nursing Homes and Boarding Care Homes in the State at the Time of the Survey.

Group	Number contacted in Follow-up Mailing	No. Responding (Percent responding given in parentheses)*	Number of New Cases Reported*	Number of Patients Reported, Already Known to Register*
Physicians	414	182 (44.2)	21	37
Nursing Homes and Boarding Care Homes	223	114 (51.1)	6	3
Hospitals	182	115 (63.2)	74	169

*\*A total of 30 responding units have been excluded from this tabulation because it was not possible to determine to which group the response should be allocated (i.e., physician, nursing and boarding care homes or hospitals). These 30 units, if added to the table, would account for an additional 13 new patients and 22 patients who were already known to the register.*

Using the figures given in this and Table 1.5.1, we can derive an estimate of the under-reporting existing in the state-wide study among physicians, nursing and boarding care homes, and hospitals. If we assume that the units responding to the follow-up mailing are the same as those not responding to the follow-up mailing in terms of the number of patients they would report, then we may estimate the number of patients yet un-reported, still existing in these three groups. That is, approximately 450 patients would remain un-reported by physicians after the second mailing, 20 by nursing and boarding care homes and 40 by hospitals, for a total of 510. On this basis we would estimate that the under-reporting based upon the total number of patients reported is about thirteen (13) percent. This is somewhat higher than the estimate reported in the previous section, but you will recall the former estimate was only for patients under 21, whereas this estimate is for patients of all age groups.

However, it should be pointed out that this is most likely an over-estimate of the under-reporting. That is, the assumption that those not responding to the follow-up mailing are the same as those responding to the mailing with respect to patient reports is probably not justified. It seems reasonable to believe that those not responding to the follow-up mailing would have fewer patients to report than those who respond. As a matter of fact, one reason for non-response to the request for reports may be due to the fact that they had no patients to report. Evidence that this may indeed be the case is given in Table 1.5.3.

TABLE 1.5.3. Comparison of the First Mailing Results with Second Mailing Results.

Group	Number of Reports per Reporting Unit on Initial Mailing	Number of Reports per Reporting Unit on Follow-up Mailing
Physicians	$\frac{174}{189} = .92$	$\frac{51}{182} = .32$
Hospitals	$\frac{345}{31} = 11.13$	$\frac{200}{115} = 2.11$

A comparison of effectiveness of the initial mailing with the follow-up mailing in producing reports on a per unit basis indicates that those units which respond initially produce a larger yield of cases than those which respond to the follow-up mailing. This trend would probably continue over subsequent mailings. For example, the average yield per report from physicians on the first mailing was .92 as compared to .32 per physician on the second mailing.

Of course, the above comparison assumes the design of the first and second mailing was comparable. This in fact is not true because the letter used with the first mailing did not provide a return envelope and negative responses were not specifically requested, whereas the second mailing did provide a return envelope and the letter used did specifically request negative responses. The specific request of negative responses on the second mailing, but not on the first, will tend to increase the difference between the first and second mailing with respect to the yield of reports on a per unit basis.

The comparison of the yield per unit reporting among nursing and boarding care homes was not made because of the small numbers involved.

Finally, it should be pointed out that the estimate of 13% given above deals only with the under-reporting in the three groups contacted in the follow-up mailing. It is not possible to estimate the additional under-reporting existing in those sources consisting of multiple reporting units such as schools, U.C.P. chapters, county welfare boards, and re-

habilitation centers since the non-responding units were not contacted with a second mailing. However, in each of the cases just cited, the reporting on a per unit basis was relatively complete on the initial contact.

#### **1.6 ACCURACY AND ADEQUACY OF THE REPORTS**

Several considerations enter into the discussion of the accuracy of reports. One factor that must be considered is the number of false reports (i.e., those patients reported as being cerebral palsied, but who actually are not). Secondly, it is necessary to consider the number of reports obtained in which the patient's address is not adequate. In connection with this, reports of patients residing outside of the state must be considered as superfluous, since only reports of patients within the state were requested. Finally, the number of patients deceased, although reported as living, must also be considered as superfluous.

First, consider the problem of the false reporting. Ideally, each report should have been verified by a direct evaluation of a physician or team of physicians. In this manner the number of false reports could have been minimized. However, for various reasons it was impossible to obtain a medical evaluation of the reported patients. For this reason a possible false report could not be identified until the diagnosis was questioned by the respondent to the mail questionnaire. In such a case the reporting agencies were contacted and asked to supply the diagnostic information available on the patient. In general, it was possible to obtain reasonably good diagnostic information in this manner. This information was then reviewed by the physician associated with the study, and a decision reached as to whether or not the patient could be considered cerebral palsied according to the information available. If the diagnostic information furnished by a recognized treatment agency included any of the conditions listed below, the patient was considered cerebral palsied.

**TABLE 1.6.1. Conditions Accepted as Cerebral Palsy.**

- Abscess of brain
- Ataxia
- Birth injury
- Birth stroke
- Blood clot on brain
- Brain injury
- Brain injury from car accident
- Cerebellar ataxia atypical spastic
- Cerebral atrophy
- Cerebral degeneration
- Cerebral hemorrhage, cause of brain damage
- Cerebral palsy spastic hemiplegia congenital
- Cerebral palsy right hemiplegia
- Cerebral palsy spastic monoplegia
- Cerebral palsy spastic paraplegia

TABLE 1.6.1. (Cont'd)

Cerebral spastic hemiplegia  
Cerebral spastic infantile monoplegia  
Cerebral spastic paraplegia  
Cerebrospastic infantile hemiplegia, due to encephalitis  
Chronic brain syndrome  
Chronic brain syndrome with brain trauma  
Chronic brain syndrome with epidemic encephalitis  
Chronic brain syndrome with encephalitis, behavior reaction  
Chronic brain syndrome following meningitis  
Congenital anomalies and cerebral palsy  
Congenital cerebrospastic quadriplegia  
Encephalitis  
Encephalitis with brain damage  
Encephalitis from scarlet fever  
Epilepsy and spastic  
Erythroblastosis  
Hemiparesis secondary to cerebral vascular accident  
Hemiplegia  
Idiot with congenital cerebral spastic  
Infantile quadriplegia  
Jaundice at birth  
Little's disease  
Measles encephalitis  
Mentally retarded and spastic due to brain injury  
Myxedema and cerebral palsy  
Paralyzed from birth  
Paraplegia  
Partially paralyzed and epileptic seizures  
Post traumatic with athetoid  
Post traumatic spastic  
Residual hemiparesis  
Retarded and spastic  
Rh incompatibility  
Spastic  
Spastic palsy  
Spastic paralysis  
Spastic and deaf  
Spastic diplegia  
Tendencies of cerebral palsy  
Tension Athetoid

The diagnosis of cerebral palsy of 378 patients was questioned. The follow-up diagnostic efforts indicated that of these, 228 could be classed as cerebral palsy in accordance with the conditions listed in Table 1.6.1. The remaining 150 patients had to be re-classified as non-cerebral palsy either because their diagnostic information was inadequate or because the information furnished indicated that the patient did not have cerebral palsy. Some of the conditions not accepted as cerebral palsy are listed below in Table 1.6.2.

Those who were classed as cerebral palsied were urged to complete a questionnaire in the subsequent mailing, if a completed questionnaire had not already been obtained. The agencies reporting the patients that were ultimately classed as not cerebral palsied, as well as the agencies reporting the patients who questioned their diagnosis but remained classed as cerebral palsied, are given in Table 2.5.8 of Chapter 2, under the heading "Not C.P." and "Claimed Not C.P.", respectively.

The reliability of the diagnostic information furnished is probably quite variable depending on its source. Further, the elimination of the non-cerebral palsied from the population in the fashion employed here is no guarantee that, the remaining study population consists entirely of cerebral palsied patients. Further, one wonders about the group that failed to respond to the mail questionnaire. There may be a disproportionate number of false reports in this group. This, as a matter of fact, may be one of the reasons for not answering the questionnaire.

As an aside, it is interesting to note that a relatively large number of respondents claimed the patient in question was not cerebral palsied, but had Little's Disease or was spastic. Such responses may be indicative of the need for further education among cerebral palsy families.

A second consideration in the accuracy of reporting is the adequacy of the address information furnished by the reporting agency. This is particularly important since the study is based upon a mail survey. As might be expected, a sizable proportion of those reported could not be located. Of the total 4,035 patients reported, 613 could not be located. The agencies reporting these patients are given in Table 2.5.8 of Chapter 2, under the heading "Imp. Locate".

TABLE 1.6.2. Conditions, if Given Without Any Other Qualifying Information, That Were not Accepted as Cerebral Palsy.

Accident  
Agenesis of cerebellum and corpus callosum  
Amyotonia  
Amyotonia- congenital  
Arrested hydrocephalus  
Bilateral ocular nystagmus  
Brachial nerve injury  
Brain tumor  
Brachial palsy  
Brachial plexus paralysis  
Cerebral atrophy  
Cerebral dysgenesis  
Chickenpox-encephalitis  
Club foot-talipes calcaneovalgus

**TABLE 1.6.2. (Con't)**

**Congenital abnormality of speech muscle**  
**Congenital arthrogryposis**  
**Congenital deformity**  
**Convulsive disorder**  
**Coronary thrombosis**  
**Degenerative brain disease**  
**Emotionally disturbed**  
**Encephalitis**  
**Epilepsy**  
**Epileptic and mentally retarded**  
**Equinovarus**  
**Erb's palsy**  
**Facial diplegia**  
**Friedrich's ataxia**  
**Grand Mal**  
**Hardening of arteries and ear condition**  
**Hemophilia**  
**Hurler's disease (lipochondrodystrophy)**  
**Legg-Perthes disease**  
**Marie-tooth's disease**  
**Meningitis**  
**Mentally retarded**  
**Mental retardation, idiopathic**  
**Mental retardation, strabismus**  
**Microcephaly**  
**Mongoloid**  
**Multiple neurosis**  
**Multiple sclerosis**  
**Muscular dystrophy**  
**Occult spina bifida**  
**Paralysis agitans**  
**Parkinson's disease**  
**Partial paralysis due to congenital meningitis**  
**Phenylketonuria**  
**Polio**  
**Postencephalitic parkinsonism**  
**Pronation of calcaneus, bilateral**  
**Psychosis with epidemic encephalitis**  
**Retarded, idiopathic with convulsion disorder**  
**Schilder's disease**  
**Spina bifida, meningocele, hydrocephalus**  
**Spinal meningitis**  
**Strept. tonsillitis**  
**Strept. meningitis**  
**Stroke**  
**Transverse myelitis**  
**Traumatic psychosis and mental deterioration**  
**Vogt-Spielmeyer syndrome**

Whenever a questionnaire was returned by the post office because of an insufficient or inadequate address, efforts were made to locate the patient. In general, the reporting agencies were contacted and asked to provide the most recent address available for the patient. In addition, other aides such as telephone books and city directories were employed when possible.

Table 1.6.3 gives the reasons given by the post office for returning the original questionnaire to the sender.

TABLE 1.6.3. Reasons Given by the Post Office for Returning a Piece of Mail to the Sender.

Reason	Frequency
Unclaimed*	450
Insufficient address**	110
No reason given	53
Total	613

\* Unclaimed includes any piece of mail that could be delivered but the person for whom the form was meant no longer lived at the address listed, and further, no forwarding address was available.

\*\*Insufficient address includes any piece of mail that Could not be delivered because the street or city address was inadequate.

Table 1.6.4 gives the number of additional addresses tried in addition to the original one. The additional addresses tried were frequently the result of research in telephone and/or city directories as well as the result of subsequent addresses furnished by the reporting agencies.

TABLE 1.6.4. Number of Additional Addresses Tried in Addition to the Original.

Number of Additional Addresses Tried	Frequency
0	495
1	100
2 or more	18
Total	613

The accuracy of address information with respect to residence within the state must also be considered. That is, a number of patients were reported to be living in the state, but information obtained during the mailings indicated the patient did not reside in the state.-(For a definition of what is meant by residence within the state see section 2.5.) A total of 119 such cases were identified. These individuals were obviously excluded from the final study population since the project was concerned only with residents of the state.

**Another reflection of reporting inaccuracy is the number of patients reported who in fact were deceased. A total of 142 such reports were received.**

**The agencies reporting the patients actually residing outside the state are given in Table 2.5.8 under the heading of "Out State". The agencies reporting the deceased patients are given in the same Table under the heading of "Deceased". Several other Tables in section 2.5 are also closely related to the discussion of this section and should be inspected at this time.**

## CHAPTER 2: THE MAIL SURVEY

### 2.1 THE RESEARCH DESIGN

One of the purposes of this study was to evaluate the nature of patient care and needs in Minnesota. To accomplish this end a mail questionnaire was used. Every person reported as being cerebral palsied was to receive a questionnaire along with a covering letter explaining the purpose of the study and urging their cooperation. If the patient named in the questionnaire had an address similar to his parents, the form was addressed to the patient's parents. In those few cases where the patient was either married or supporting himself independently of his parents, the form was addressed *to* the patient himself.

A total of three mailings were planned. During the first mailing all patients known to the project were contacted. All those not responding to the first mailing received a second questionnaire. This form, like the first form, was accompanied with a covering letter. Finally, those individuals not responding to the first or second questionnaire were mailed a third form. Again this form was accompanied with a covering letter. Those not responding to this form were then considered non-respondents.

The covering letter and questionnaire used in the second and third mailing were mailed first class with first-class return postage provided. However, the first mailing was conducted in a slightly different manner in order to assess the relative merits of first class mailing versus third class mailing. That is, approximately half of the forms during the first mailing were mailed via first class mail and the other half were mailed via third class mail. Still another part of this ancillary mailing project was to attempt *to* assess the effectiveness of return postage prepaid as compared with no return postage provided. (In either case, however, a return envelope was enclosed.) Approximately half of the forms mailed had return postage provided, whereas the remaining half had no such provision. This latter split was made independent of the first grouping. Hence, approximately one-quarter of the patients received the first mailing form via first class mail and had return postage provided, while another one-quarter of the patients received their forms via first class mail but had to provide the return postage. Still another quarter of the patients received their forms via third class mail and had return postage provided, while the remaining quarter of the patients received their forms via third class mail and had to provide their own return postage.

A similar type design was employed during the third mailing in

*Actually non-respondents to the third mailing, if residing in the metropolitan area of Minneapolis and St. Paul, were contacted by telephone if possible and asked to complete the questionnaire.*

order to evaluate the relative effect of a personal versus an impersonal salutation on the covering letter and a signed versus an unsigned covering letter.

The results of these ancillary studies will be reported at a later date in a separate paper.

## **2.2 DEVELOPMENT OF THE QUESTIONNAIRE AND PRETESTING**

One of the difficulties in developing any mail questionnaire is the desirability of making it as short as possible, but yet obtaining all the information necessary to achieve the objectives of the study. The limitation of length, although not as serious here as in some other projects because of the motivation of the group contacted, definitely was an influencing factor in the development of the questionnaire. Construction of the actual format of the questionnaire and individual items on the form must be done in such a manner as to insure intelligibility. This is particularly difficult where the population of respondents, is as heterogeneous as they are in a study of this sort. In addition, the reliability with which information requested can be obtained, must be kept in mind when designing a form. It does little good to construct an elaborate questionnaire if no assurance can be given that the information obtained from it is reasonably reliable.

Because of the necessity of considering such factors as the intelligibility of an item, its reliability, and general format of a questionnaire, it was necessary to pretest. For this purpose a list of thirty families, each with a known cerebral palsy patient, was furnished by United Cerebral Palsy of Minneapolis. Each of these families was mailed a questionnaire accompanied by a typewritten covering letter explaining the purpose of the study. No return envelope was provided.

During the second and third mailing the forms were mailed first class and return postage provided. A typewritten covering letter also accompanied each form mailed during these mailings.

Seventeen forms were returned as a result of the first mailing, eight as a result of the second mailing, and three as a result of the third mailing. Altogether twenty-eight out of the thirty families responded to the mail questionnaire.

An inspection of the returned forms revealed some of the obvious defects of the questionnaire. In order to pick up some of the more subtle defects, however, it was necessary to interview a sample of the respondents.

The respondent was initially contacted by telephone for the purpose of arranging an appointment. No one contacted refused an appointment. Also at this time an attempt was made to select a time when both parents of the patient would be present, since it was felt that the com-

pletion of the questionnaire was usually a family project. If such arrangements were not possible, a meeting with the person largely responsible for filling out the form was planned. In most such cases this turned out to be the mother of the patient. All interviews were conducted in the home of the patient. The procedure employed during each interview was held as uniform as possible.

The technique employed during the interview was first to hand the respondent the questionnaire that he had filled out, asking him to refresh his memory as to the difficulties encountered. After completion of this phase of the interview, the respondent was asked to return the form and was given a blank questionnaire in exchange. The interviewer then went over the form very carefully with the respondent. During this aspect of the interview, specific questions were asked in order to establish the meaning of his responses and locate possible areas of ambiguity. Although based on a relatively small number of respondents, the pretest was useful in pointing up some obvious shortcomings of the form. The changes suggested by the pretest were then incorporated in the final form of the questionnaire. A copy of the final questionnaire used can be found in Appendix 1 of this report. It will be noted that in its final form, the covering letter was incorporated with the questionnaire in that it made up the first page of the form.

The same form was used in each of the three mailings. The only difference was in the covering letter used. Only the copy of the covering letter used during the first mailing is included in the appendix. The covering letter used during the second as well as the letter used during the third mailing differ from the first mailing letter primarily in motivational aspects.

### **2.3 THE MAILINGS**

The first mailing began on January 29, 1959, and was completed on April 18, 1959. The second mailing began May 18, 1959, and was completed June 2, 1959. The third mailing began on August 18, 1959, and was completed August 31, 1959. A total of 4,407 questionnaires was mailed during the first mailing. The reason for this figure being larger than the total number of patients listed in the registry is that it included duplicate mailings. That is, in those cases in which a patient was institutionalized, a form was mailed to the institution and one to the patient's home address as well.

Sixteen hundred and five forms were mailed during the second mailing. In general, only one form per patient was mailed. That is, for those patients who were institutionalized, where neither the institution nor the parents had responded to the first mailing, forms were sent only to the parents of the patients during the second mailing. Of course, those

patients who could not be located on the initial mailing had to be eliminated from subsequent mailings unless a new address could be obtained. In addition, those patients deceased, those residing outside of the state, as well as those patients who had been falsely reported as cerebral palsied, had to be excluded.

A total of 1156 forms was mailed during the third mailing. This figure is somewhat larger than the actual number of non-respondents remaining at the time of the third mailing, because here again duplicate mailings occurred. This time all available addresses were tried for patients from whom a completed questionnaire had not yet been received. Also, as in the first mailing, forms were mailed to the patient's parents as well as the institution in those cases in which the patient was institutionalized. As a general note, it should be pointed out that efforts were made to obtain a completed questionnaire from both the parents and the institution in these cases. Hence, if a completed form was received from the parents during an earlier mailing, the institution was nevertheless urged to fill out the questionnaire during the third mailing.

#### 2.4 RESPONSE TO THE MAILINGS

Any questionnaire received prior to the start of the second mailing was considered due to the first mailing. Similarly, a form received after the second mailing began, but before the third mailing started, was considered due to the second mailing. Any form received after the start of the third mailing was considered due to it. According to these definitions, 1,353 forms were received during the first mailing, 408 questionnaires during the second mailing and 330 during the third mailing. In all, a total of 2,141 completed questionnaires was received. (See Table 2.4.1.)

TABLE 2.4.1. Number of Forms Received From Mailings.

Mailing	No. of Forms Received	Percent
First	1,353	63.19
Second	408	19.06
Third	330	15.41
Telephone Follow-up*	50	2.34
Total	2,141	100.0

*\*Actually non-respondents to the third mailing, if residing in the metropolitan area of Minneapolis and St. Paul, were contacted by telephone, if possible, and asked to complete the questionnaire.*

In general, the questionnaires were completed by the patient's family, the institution in which the patient was residing, or by the patient himself. Table 2.4.2 gives the source of the information provided on the questionnaire.

TABLE 2.4.2. Source of Information Provided on the Questionnaire.

Source of Information on the Form	Number of Forms Received	Percent
Patient's parents	1,751	81.79
Institution	273	12.75
The patient	75	3.50
Other*	42	1.96
Total	2,141	100.0

\*Including such sources as a friend of the patient, staff member at a boarding home and so forth.

In those cases in which a questionnaire was received from both the patient's family and the institution to which the patient was committed, only the form from the patient's family was used in the analysis discussed in Chapter 3.

The 2,141 completed questionnaires represent 53.06% of the total number of patients originally reported. However, a meaningful evaluation of the response to the mailing cannot be based upon the total, 4,035. It will be recalled, this figure includes 142 patients who were in fact deceased, 119 patients who did not reside in the state at the time of the mail survey, 613 patients who could not be located because of inadequate address, and 150 patients who were ultimately classed as non-cerebral palsied. None of the above mentioned groups can be considered eligible to respond to the mail questionnaires. Therefore, if these groups are

TABLE 2.4.3- Comparison of the Calculated Effectiveness of the Mail Survey by Mailing, When Based on the Total Reported Population and the Total "Eligible" Population.

Mailing	Percent Responding Based on Original Reported Population (4,035)		Percent Responding Based on "Eligible" Population (3,011)	
	Based on Total Reported (4,035)	Based on Total Remaining After Each Mailing	Based on Total "Eligible" (3,011)	Based on Total Remaining After Each Mailing
1st	$\frac{1353}{4035} = 33.53$	$\frac{1353}{4035} = 33.53$	$\frac{1353}{3011} = 44.94$	$\frac{1353}{3011} = 44.94$
2nd	$\frac{408}{4035} = 10.11$	$\frac{408}{2682} = 15.21$	$\frac{408}{3011} = 13.55$	$\frac{408}{1658} = 24.61$
3rd	$\frac{330}{4035} = 8.18$	$\frac{330}{2274} = 14.51$	$\frac{330}{3011} = 10.96$	$\frac{330}{1250} = 26.40$
Telephone Follow-up	$\frac{50}{4035} = 1.24$	$\frac{50}{1944} = 2.57$	$\frac{50}{3011} = 1.66$	$\frac{50}{920} = 5.43$
Total	$\frac{2141}{4035} = 53.06$		$\frac{2141}{3011} = 71.11$	

eliminated, the new base for evaluating the mailing is 3,011. The 2,141 completed questionnaires represent 71.11% of this total. Table 2.4.3 provides a comparison of the calculated effectiveness of the survey by mailing when based on the total "eligible" population and the total reported population.

## **2.5 THE POPULATION STUDIED**

As indicated in the previous section, the original population, as a result of the mailings, could be divided into various groups according to their response to the questionnaire. Because of the nature of some of these groups, it was necessary to eliminate them from the study population. For example, the patients living outside the state, the deceased, and the non-cerebral palsied all must be eliminated in order to arrive at the final study population.

The basic characteristics of the study population, such as the sex distribution, place of residence, age distribution and reporting sources, are given in the tables below. Each of these tables provides the breakdown of the results by response to the questionnaire. The subgroups that are listed in the tables of this section are:

- 1) Completed questionnaire received (Q. Rec'd),
- 2) Unable to locate (Imp. Locate),
- 3) Claimed to be not cerebral palsied (Claim not CP),
- 4) Questionnaire not answered (Q. Not Ans.),
- 5) Patient deceased (Deceased),
- 6) Patient resides outside of the state (Out State),
- and
- 7) Patient is not cerebral palsied (Not CP).

In order to avoid any confusion about these classifications, it is necessary to define them. The completed questionnaire group will consist of those patients for whom a completed questionnaire has been received and who, according to the diagnostic information furnished, are cerebral palsied. The unable to locate group consists of those patients who could not be located, and hence no completed questionnaire could be obtained from this group. The third group consists of those patients who claimed not to be cerebral palsied, but the diagnostic information subsequently furnished did not substantiate this claim. This group also contains those cases which could not definitely be classed as cerebral palsied on the basis of the diagnostic information furnished. In either case, however, in order to be classified in this group, no completed questionnaire could be received for the patient. Finally, the fourth group consists of those patients for whom a completed questionnaire could not be obtained and the information available on the patient gave no reason to believe that the patient belonged to any of the three groups previously defined.

These four groups comprise what will be referred to as the study population. It is really this population that we are interested in. Of course, the only group that we can make extensive statements about is the first group, namely the group for which we have completed questionnaires. The information on the remaining three groups is much less extensive.

The remaining three groups not included in the study population are the "Deceased" group, the "Out State" group and the "Not CP" group. The "Deceased" group consists of those individuals who were originally reported as cerebral palsied, but were later found to be deceased. The second group, those residing outside the state — the "Out State" group — consists of those patients who were reported to be residing in the state but subsequent information revealed that this was not correct. A patient was considered to reside outside the state if:

- 1) The patient's parents, as well as the patient himself, resided outside the state;
- or
- 2) The patient's parents resided in the state, but the patient resided outside the state and was over 21 years of age and/or self supporting.

A patient was considered to reside in the state if:

- 1) The patient's parents resided in the state, even though the patient may reside outside the state, provided he was not 21, and/or self supporting;
- or
- 2) The patient was in an institution in the state regardless of where his parents reside (i.e., in or out of the state).

The last group, the "Not CP", consists of those patients who, on the basis of subsequent diagnostic information furnished, could not be considered cerebral palsied.

The seven groups defined above will form the basis for several of the tables to follow in this section. The groups will be referred to by the abbreviations appearing in parentheses in the listing of the groups above.

As indicated, the study population totals in each of these tables will be obtained by summing the values for the following groups: Q. Rec'd., Imp. Locate, Claim Not CP, and Q. Not Ans. The total population values will be obtained by summing the value for the study population plus the values for the remaining three groups, namely the Deceased, Out State, and Not CP groups.

TABLE 2.5.1. Sex Distribution by Response to the Questionnaire (Totals).

Sex	Q Rec'd.	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out State	Not CP	Original Pop. Total
Male	1,222	340	142	329	2,033	80	64	82	2,259
Female	919	255	84	295	1,553	62	50	68	1,733
Sex un-Known	0	18	2	18	38	0	5	0	43
Total	2,141	613	228	642	3,624	142	119	150	4,035

TABLE 2.5.2. Sex Distribution by Response to the Questionnaire (Percent)\*.

Sex	Q Rec'd.	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out State	Not CP	Original Pop. Total
Male	57.08	57.14	62.83	52.72	56.69	56.34	56.14	54.67	56.59
Female	42.92	42.86	37.17	47.28	43.31	43.66	43.86	45.33	43.41
Total	100%	100%	100%	100%	100%	100%	100%	100%	100%

\*In this Table as well as subsequent Tables of percentages in this section, the the unknown group will be eliminated from the computation.

TABLE 2.5.3. Age\* Distribution by Response to the Questionnaire (Totals).

Age Group	Q Rec'd.	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out State	Not CP	Original Pop. Total
0-4	362	29	21	67	479	16	17	20	532
5-9	505	69	37	139	750	33	30	29	842
10-14	475	121	39	123	758	20	24	23	825
15-19	332	114	41	116	603	18	14	21	656
20-24	140	69	18	48	275	17	13	7	312
25-29	93	54	12	34	193	8	5	3	209
30-34	61	31	8	23	123	2	3	0	128
35-39	55	10	9	10	84	3	2	5	94
40-44	46	4	6	11	67	0	1	8	76
45-49	21	8	2	7	38	1	1	7	47
50-54	16	6	5	5	32	3	0	8	43
55-59	12	3	0	8	23	9	0	8	40
60-64	6	1	0	8	15	0	0	3	18
65-69	7	1	0	3	11	2	0	5	18
70-74	3	1	0	3	7	3	0	2	12
75+	3	0	0	0	3	3	0	1	7
Age Unknown	4	92	30	37	163	4	9	0	176
Total	2,141	613	228	642	3,624	142	119	150	4,035

\*Based upon the assumption that all reporting was obtained on January 1, 1958.

Table 2.5.4. Percent Age\* Distribution by Response to the Questionnaire.

Age Group	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out State	Not CP	Percent of Original Pop.
0-4	16.94	5.57	10.61	11.07	13.84	11.59	15.45	13.33	13.79
5-9	23.63	13.24	18.69	22.99	21.67	23.92	27.28	19.34	21.82
10-14	22.23	23.23	19.69	20.33	21.90	14.49	21.82	15.33	21.38
15-19	15.54	21.88	20.70	19.17	17.42	13.04	12.73	14.00	17.00
20-24	6.55	13.24	9.09	7.93	7.95	12.32	11.82	4.67	8.08
25-29	4.35	10.36	6.06	5.62	5.58	5.80	4.55	2.00	5.42
30-44	7.58	8.64	11.62	7.27	7.92	3.62	5.45	8.67	7.72
45-59	2.29	3.26	3.54	3.31	2.69	9.42	0.91	15.33	3.37
60+	0.89	0.58	-	2.31	1.04	5.80	-	7.33	1.43
Percent of Total Pop.**	53.06	15.19	5.65	15.91	89.81	3.52	2.95	3.72	100.0

\*Based upon the assumption that all reporting was obtained on January 1, 1958.

\*\*With age unknown group included.

Tables 2.5.1 and 2.5.2 provide the sex distribution by response to the questionnaire. Tables 2.5.3 and 2.5.4 provide the age distribution of the various sub-populations as determined by the response to the questionnaire. Table 2.5.5 gives the geographic distribution of patients by county as related to response to the questionnaire.

The county of residence is difficult to determine for the impossible - to-locate group. In this group the county of residence was based upon the patient's most recent address. This most certainly introduces some errors in our tabulation since the assumption that a patient is still residing in the county in which he was reported to have resided is certainly not valid.

Inspection of the table below reveals that 28.23 percent of the originally reported population resided in Hennepin county and 28.39 percent of the study population resided in Hennepin county. Forty-three percent of the originally reported population had addresses indicating residence in the five county metropolitan area composed of Anoka, Dakota, Hennepin, Ramsey and Washington counties. About the same proportion (43.54%) of the study population resided in the five county metropolitan area.

Table 2.5.6 gives the county and state prevalence ratios per 1000 population. Ratios are given for the originally reported population, the study population and for the study population assuming a ten percent under-reporting error in each county. This figure seems reasonable on the basis of the discussion given in section 1.5 of Chapter 1. The Minnesota population figures used for Table 2.5.6 are from the 1950 census.

TABLE 2.5.5. Distribution by County of Residence According to the Response to the Questionnaire.

County of Residence	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Decreased	Out State	Not CP	Orig. Pop. Total
Aitkin	2	2	-	2	6	-	-	-	6
Anoka	30	6	1	4	41	1	-	-	42
Becker	15	2	1	7	25	1	1	1	28
Beltrami	29	4	2	4	39	-	1	2	42
Benton	21	5	1	7	34	1	-	1	36
Big Stone	4	1	1	1	7	-	-	-	7
Blue Earth	26	2	6	3	37	1	-	-	38
Brown	13	3	3	4	23	2	-	2	27
Carlton	24	4	3	5	36	-	-	3	39
Carver	16	1	4	1	22	-	1	2	25
Cass	7	3	2	8	20	-	-	2	22
Chippewa	10	-	2	6	18	-	2	-	20
Chisago	-	1	2	3	6	-	-	1	7
Clay	20	5	2	5	32	-	5	1	38
Clearwater	12	-	-	2	14	-	2	1	17
Cook	5	-	-	1	6	-	-	-	6
Cottonwood	13	-	2	3	18	-	-	2	20
Crow Wing	23	1	2	5	31	2	-	1	34
Dakota	39	10	1	5	55	5	-	-	60
Dodge	8	1	1	1	11	1	1	2	15
Douglas	18	-	3	5	26	1	2	1	30
Faribault	18	1	2	1	22	1	-	1	24
Fillmore	8	4	2	4	18	-	2	1	21
Freeborn	16	8	3	7	34	3	3	4	44
Goodhue	19	2	1	3	25	2	-	1	28
Grant	10	2	-	-	12	1	-	1	14
Hennepin	531	283	60	155	1,029	40	40	30	1,139
Houston	14	2	-	2	18	-	4	-	22
Hubbard	10	-	-	1	11	-	-	-	11
Isanti	5	-	1	3	9	-	-	-	9
Itasca	26	5	4	9	44	2	-	6	52
Jackson	9	-	-	2	11	-	-	-	11
Kanabec	5	-	-	-	5	-	-	1	6
Kandiyohi	14	5	1	3	23	-	-	2	25
Kittson	9	-	-	-	9	-	-	-	9
Koochiching	11	1	4	-	16	2	-	1	19
Lac qui Parle	11	3	1	2	17	-	-	1	18
Lake	7	-	-	4	11	1	4	-	16
Lake of Woods	1	-	-	-	1	-	1	-	2
LeSueur	9	1	-	3	13	-	1	1	15
Lincoln	7	-	2	4	13	-	-	-	13
Lyon	24	6	-	5	35	-	1	-	36

TABLE 2.5.5. (Cont'd)

County of Residence	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out State	Not CP	Orig. Pop. Total
McLeod	14	2	1	4	21	-	-	1	22
Mahnomen	5	2	-	4	11	1	-	1	13
Marshall	10	-	-	1	11	-	-	-	11
Martin	10	2	-	2	14	1	1	1	17
Meeker	16	3	1	4	24	-	-	-	24
Mille Lacs	15	1	1	5	22	1	-	2	25
Morrison	17	2	1	3	23	-	2	2	27
Mower	30	6	3	8	47	3	1	4	55
Murray	7	-	-	2	9	1	-	1	11
Nicollet	11	3	2	1	17	1	-	-	18
Nobles	16	3	2	2	23	5	1	-	29
Norman	8	1	-	2	11	1	-	-	12
Olmsted	23	3	3	9	38	1	4	5	48
Otter Tail	28	1	6	8	43	2	-	3	48
Pennington	12	1	1	4	18	1	1	1	21
Pine	9	1	2	3	15	1	1	-	17
Pipestone	11	3	-	5	19	-	-	-	19
Polk	23	7	3	14	47	2	1	-	50
Pope	4	1	3	1	9	-	-	-	9
Ramsey	238	74	22	72	406	13	11	15	445
Red Lake	3	1	-	3	7	-	-	1	8
Redwood	14	3	4	5	26	1	1	-	28
Renville	19	2	4	1	26	1	-	1	28
Rice	19	5	2	6	32	1	-	1	34
Rock	6	-	-	2	8	1	-	1	10
Roseau	8	2	-	3	13	-	-	-	13
St. Louis	148	44	18	53	263	6	6	8	283
Scott	10	1	1	1	13	-	1	3	17
Sherburne	8	1	-	4	13	-	-	-	13
Sibley	14	1	1	2	18	-	-	2	20
Searns	75	9	7	30	121	10	1	4	136
Steele	13	1	1	7	22	2	2	-	26
Stevens	7	2	-	6	15	-	-	1	16
Swift	12	1	1	5	19	3	3	-	25
Todd	12	4	2	7	25	1	1	-	27
Traverse	4	1	-	4	9	-	-	-	9
Wabasha	4	1	3	5	13	-	-	-	13
Wadena	8	1	1	3	13	-	-	-	13
Waseca	15	-	2	4	21	-	1	1	23
Washington	32	7	1	7	47	2	-	3	52
Watsonwan	6	2	3	4	15	2	-	4	21
Wilkin	8	-	1	4	13	1	-	1	15
Winona	20	7	-	8	35	3	4	2	44
Wright	11	3	-	8	22	1	-	-	23

TABLE 2.5.5. (Cont'd)

County of Residence	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ana.	Study Pop. Total	Deceased	Out State	Not CP	Orig. Pop. Total
Yellow Medicine	9	-	-	2	11	1	1	1	14
Parents residing out of state, but patient in Inst. in state	24	-	-	-	24	-	3	-	27
County of residence unknown	26	24	5	14	69	5	1	8	83
Total	2,141	613	228	642	3,624	142	119	150	4,035

TABLE 2.5.6. Prevalence Ratios by County for the Originally Reported Population and the Study Population.

County	Prevalence Ratio for Originally Reported Population	Prevalence Ratio for Study Population	Prevalence Ratio for Study Pop. Assuming 10% Under-reporting	Minnesota Population 1950 Census
Aitkin	.42	.42	.49	14,327
Anoka	1.18	1.15	1.26	35,579
Becker	1.13	1.01	1.13	24,836
Beltrami	1.68	1.56	1.72	24,962
Benton	2.26	2.14	2.33	15,911
Big Stone	.73	.73	.83	9,607
Blue Earth	.99	.97	1.07	38,327
Brown	1.04	.89	.97	25,895
Carlton	1.59	1.46	1.63	24,584
Carver	1.38	1.21	1.32	18,155
Cass	1.13	1.03	1.13	19,468
Chippewa	1.19	1.08	1.19	16,739
Chisago	.55	.47	.55	12,669
Clay	1.25	1.05	1.15	30,363
Clearwater	1.67	1.37	1.47	10,204
Cook	2.07	2.07	2.41	2,900
Cottonwood	1.27	1.14	1.27	15,763
Crow Wing	1.10	1.00	1.10	30,875
Dakota	1.22	1.12	1.24	49,019
Dodge	1.19	.87	.95	12,624
Douglas	1.41	1.22	1.36	21,304
Faribault	1.01	.92	1.01	23,879
Fillmore	.86	.74	.82	24,465
Freeborn	1.27	.99	1.07	34,517

TABLE 2.5.6. (Cont'd)

County	Prevalence Ratio for Originally Reported Population	Prevalence Ratio for Study Population	Prevalence Ratio for Study Pop. Assuming 10% Under-reporting	Minnesota Population 1950 Census
Goodhue	.87	.78	.87	32,118
Grant	1.47	1.26	1.36	9,542
Hennepin	1.68	1.52	1.67	676,579
Houston	1.52	1.25	1.39	14,435
Hubbard	.99	.99	1.08	11,085
Isanti	.74	.74	.82	12,123
Itasca	1.56	1.32	1.44	33,321
Jackson	.67	.67	.74	16,306
Kanabec	.65	.54	.65	9,192
Kandiyohi	.87	.80	.87	28,644
Kittson	.93	.93	1.04	9,649
Koochiching	1.12	.95	1.06	16,910
Lac Qui Parle	1.24	1.17	1.31	14,545
Lake	2.06	1.41	1.54	7,781
Lake of Woods	.40	.20	.20	4,955
LeSueur	.79	.68	.73	19,088
Lincoln	1.28	1.28	1.38	10,150
Lyon	1.62	1.57	1.75	22,253
McLeod	.99	.95	1.04	22,198
Mahnomen	1.84	1.56	1.70	7,059
Marshall	.68	.68	.74	16,125
Martin	.66	.55	.58	25,655
Meeker	1.27	1.27	1.37	18,966
Mille Lacs	1.65	1.45	1.58	15,165
Morrison	1.05	.89	.97	25,832
Mower	1.30	1.11	1.23	42,277
Murray	.74	.61	.68	14,801
Nicollet	.86	.81	.91	20,929
Nobles	1.29	1.03	1.11	22,435
Norman	.93	.85	.93	12,909
Olmsted	1.00	.79	.87	48,228
Otter Tail	.94	.84	.92	51,320
Pennington	1.62	1.39	1.54	12,965
Pine	.93	.82	.93	18,223
Pipestone	1.29	1.29	1.43	14,003
Polk	1.39	1.31	1.45	35,900
Pope	.70	.70	.78	12,862
Ramsey	1.25	1.14	1.26	355,332
Red Lake	1.18	1.03	1.18	6,806
Redwood	1.27	1.18	1.31	22,127
Renville	1.17	1.09	1.21	23,954

TABLE 2.5.6. (Cont'd)

County	Prevalence Ratio for Originally Reported Population	Prevalence Ratio for Study Population	Prevalence Ratio for Study Pop. Assuming 10% Under-reporting	Minnesota Population 1950 Census
Rice	.94	.88	.96	36,325
Rock	.89	.71	.80	11,278
Roseau	.90	.90	.97	14,505
St. Louis	1.37	1.28	1.40	206,062
Scott	1.03	.79	.85	16,486
Sherburne	1.22	1.22	1.31	10,661
Sibley	1.26	1.14	1.26	15,816
Stearns	1.92	1.71	1.88	70,681
Steele	1.23	1.04	1.13	21,155
Stevens	1.44	1.35	1.53	11,106
Swift	1.58	1.20	1.33	15,837
Todd	1.06	.98	1.10	25,420
Traverse	1.12	1.12	1.24	8,053
Wabasha	.77	.77	.83	16,878
Wadena	1.02	1.02	1.09	12,806
Waseca	1.54	1.40	1.54	14,957
Washington	1.51	1.36	1.51	34,544
Watonwan	1.51	1.08	1.22	13,881
Wilkin	1.42	1.23	1.32	10,567
Winona	1.10	.88	.98	39,841
Wright	.83	.79	.87	27,716
Yellow Medicine	.86	.68	.74	16,279
Total	1.35	1.22	1.34	2,982,483

The prevalence ratios given in Table 2.5.6 indicate a wide degree of variability among the various counties. However, a comparison of the prevalence ratios based on the originally reported population with the prevalence ratios based on the study population, assuming a ten percent under-reporting, shows a striking degree of similarity, indicating that the exclusions from the study population on a county basis tend to be uniform for all counties.

Figure 2.5.1 shows the geographic distribution of cerebral palsy patients by county. It is interesting to note the variation within the five county metropolitan area of Anoka, Dakota, Hennepin, Ramsey and Washington counties. Further, it should be noted that the two counties having the highest prevalence ratios are Benton and Cook. Possible explanations for the great variation in the prevalence ratios are that: (1) the variation is an artifact of reporting and/or (2) there is a true difference in the prevalence of cerebral palsy requiring further epidemiological study.



Table 2.5.7 below condenses the results of Table 2.5.6 by grouping the prevalence ratios into intervals of length .15.

TABLE 2.5.7. Distribution of Prevalence Ratios of Cerebral Palsey in the Eighty-seven Counties of Minnesota Based on 1950 Census Data.

Prevalence Ratio Interval	Frequency Based on Original Pop.	Frequency Based on Study Pop.	Frequency Based on Study Pop. Assuming a 10% Under-reporting
Less than .45	2	2	1
.45 - .59	1	3	3
.60 - .74	8	10	6
.75 - .89	9	15	11
.90 - 1.04	14	16	13
1.05 - 1.19	13	13	14
1.20 - 1.34	15	13	15
1.35 - 1.49	7	8	10
1.50 - 1.64	9	4	7
1.65 - 1.79	4	1	4
1.80 - 1.94	2	-	1
1.95 - 2.09	2	1	-
2.10 - 2.24	-	1	-
2.25 or more	1	-	2
<b>Total</b>	<b>87</b>	<b>87</b>	<b>87</b>

Inspection of Table 2.5.7 reveals that over one-half of the counties have prevalence ratios (based on the study population) below 1.05, while only seven counties have prevalence ratios in excess of 1.50.

TABLE 2.5.8. Distribution of Original Reports by Source of Report (Totals).

Source	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out-State	Not CP	Orig. Pop. Total
<b>I. Official Agencies</b>									
<b>A. State Dept. of Welfare</b>									
a) Crippled Children's Program	754	186	45	197	1,182	54	37	57	1,330
b) State Hospitals	309	16	22	50	397	16	2	36	451
c) County Welfare Boards	325	28	21	88	462	7	14	13	496
<b>B. State Dept. of Education</b>									
a) Dept. of Education	453	158	10	94	715	9	21	7	752
b) 20-County Survey	91	12	8	21	132	2	1	1	136
c) Schools	606	37	23	102	768	5	11	8	792

TABLE 2.5.8. (Cont'd)

	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	De- ceased	Out- State	Not CP	Orig. Pop. Total
C. State Dept. of Health Public Health Nurses	92	2	5	26	125	-	1	3	129
D. State Division of Vocational Rehabilitation	68	6	5	21	100	-	6	2	108
Subtotal	2,698	445	139	599	3,881	93	93	127	4,194
2. Nonofficial Agencies									
A. Voluntary Health Agencies									
a) Curative Workshop	319	192	33	92	636	28	29	8	701
b) United Cere- bral Palsy	219	17	10	37	283	2	8	4	297
c) State Society for Crippled Children	128	6	-	16	150	-	-	-	150
d) Other	89	4	7	23	123	2	-	4	129
B. Hospitals	341	55	31	103	530	31	13	14	588
C. Physicians	168	14	5	30	217	2	4	9	232
D. Mayo Clinic	78	15	12	27	132	4	9	-	145
E. Rehabilitation Centers	102	5	4	20	131	1	4	4	140
Subtotal	1,444	308	102	348	2,202	70	67	43	2,382
3. Unknown	20	2	9	17	48	-	1	2	51
Grand Total	4,162	755	250	964	6,131	163	161	172	6,627

TABLE 2.5.9. Percent Distribution of Original Reports by Response to the Questionnaire.

Source	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	De- ceased	Out- State	Not CP	Orig. Pop. Total
1. Official Agencies									
A. State Dept. of Welfare									
a) Crippled Children's Program	18.12	24.64	18.00	20.43	19.28	33.13	22.98	33.14	20.07

TABLE 2.5.9. (Cont'd)

Source	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	De- ceased	Out- State	Not CP	Orig. Pop. Total
b) State Hospitals	7.42	2.12	8.80	5.19	6.48	9.82	1.24	20.93	6.81
c) County Welfare Boards	7.81	3.71	8.40	9.13	7.54	4.29	8.70	7.56	7.48
B. State Dept. of Education									
a) Dept. of Education	10.88	20.93	4.00	9.75	11.66	5.52	13.04	4.07	11.35
b) 20-County Survey	2.19	1.99	3.20	2.18	2.15	1.23	.62	.58	2.05
c) Schools	14.56	4.90	9.20	10.58	12.53	3.07	6.83	4.65	11.95
C. State Dept. of Health									
Public Health Nurses	2.21	.26	2.00	2.70	2.04	-	.62	1.74	1.95
D. State Division of Vocational Rehabilitation	1.63	.79	2.00	2.18	1.63	-	3.73	1.16	1.63
Subtotal	64.82	58.94	55.60	62.13	63.30	57.05	57.77	73.84	63.28
2. Nonofficial Agencies									
A. Voluntary Health Agencies									
a) Curative Workshop	7.66	25.43	13.20	9.54	10.37	17.18	18.01	4.65	10.58
b) United Cerebral Palsy	5.26	2.25	4.00	3.84	4.62	.23	4.97	2.33	4.48
c) State Society for Crippled Children	3.08	.79	-	1.66	2.45	-	-	-	2.26
d) Other	2.14	.53	2.80	2.39	2.01	1.23	-	2.33	1.95
B. Hospitals	8.19	7.28	12.40	10.68	8.64	19.02	8.07	8.14	8.87
C. Physicians	4.04	1.85	2.00	3.11	3.54	1.23	2.48	5.23	3.50
D. Mayo Clinic	1.87	1.99	4.80	2.80	2.15	2.45	5.59	-	2.19
E. Rehabilitation Centers	2.45	.66	1.60	2.07	2.14	.61	2.48	2.33	2.11
Subtotal	34.69	40.79	40.80	36.10	35.91	42.94	41.61	25.00	35.94
3. Unknown	.48	.26	3.60	1.76	.78	-	.62	1.16	.77
Grand Total	100%	100%	100%	100%	100%	100%	100%	100%	100%

Tables 2.5.8, 2.5.9 and 2.5.10 give the breakdown by sources originally reporting the population. Inspection of Table 2.5.8 reveals that on the average 1.64 reports per patient were received. When this calculation is made on the basis of the study population rather than the originally reported population, the figure becomes 1.72 (i.e., total number of reports received of study patients over the number of patients in the study population).

TABLE 2.5.10. Percent Distribution of Original Reports for Each Source, by Response to the Questionnaire.

Source	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	De- ceased	Out- State	Not CP	Orig. Pop. Total
<b>1. Official Agencies</b>									
<b>A. State Dept. of Welfare</b>									
a) Crippled Children's Program	56.70	13.98	3.38	14.81	88.87	4.06	2.78	4.29	100%
b) State Hospitals	68.51	3.55	4.88	11.09	88.03	3.55	.44	7.98	100%
c) County Welfare Boards	65.52	5.65	4.23	17.74	93.14	1.41	2.82	2.62	100%
<b>B. State Dept. of Education</b>									
a) Dept. of Education	60.24	21.01	1.33	12.50	95.08	1.20	2.79	.93	100%
b) 20-County Survey	66.91	8.82	5.88	15.44	97.06	1.47	.74	.74	100%
c) Schools	76.52	4.67	2.90	12.88	96.97	.63	1.39	1.01	100%
<b>C. State Dept. of Health</b>									
Public Health Nurses	71.31	1.55	3.88	20.16	96.90	-	.78	2.32	100%
<b>D. State Division of Vocational Rehabilitation</b>									
	62.96	5.56	4.63	19.44	92.59	-	5.56	1.85	100%
<b>Subtotal</b>	<b>64.33</b>	<b>10.61</b>	<b>3.31</b>	<b>14.28</b>	<b>92.53</b>	<b>2.22</b>	<b>2.22</b>	<b>3.03</b>	<b>100%</b>
<b>2. Nonofficial Agencies</b>									
<b>A. Voluntary Health Agencies</b>									
a) Curative Workshop	45.51	27.39	4.71	13.12	90.73	3.99	4.14	1.14	100%
b) United Cerebral Palsy	73.74	5.72	3.37	12.46	95.29	.67	2.69	1.35	100%

TABLE 2.5.10. (Cont'd)

Source	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out-State	Not CP	Orig. Pop. Total
c) State Society for Crippled Children	85.33	4.00	-	10.67	100.0	-	-	-	100%
d) Other	68.99	3.10	5.43	17.83	95.35	1.55	-	3.10	100%
B. Hospitals	58.00	9.35	5.27	17.52	90.14	5.27	2.21	2.38	100%
C. Physicians	72.41	6.03	2.16	12.93	93.53	.86	1.72	3.89	100%
D. Mayo Clinic	53.79	10.34	8.28	18.62	91.03	2.76	6.21	-	100%
E. Rehabilitation Centers	72.85	3.57	2.86	14.29	93.57	.71	2.86	2.86	100%
Subtotal	60.62	12.93	4.28	14.61	92.44	2.94	2.81	1.81	100%
3. Unknown	39.22	3.92	17.65	33.33	94.12	-	1.96	3.92	100%
Grand Total	62.80	11.39	3.77	14.55	92.51	2.46	2.43	2.60	100%

It is interesting to note the percent distributions of Tables 2.5.9 and 2.5-10. Table 2.5.9 gives the percent distribution of reports for each subclass of the population. Official agencies accounted for nearly 65% of the total number of reports received for the study population. The two largest contributors to this total were the Crippled Children's Program and schools. On the other hand, official agencies accounted for about 74% of the Not CP reports, while the non-official agencies only accounted for 25% of these.

Table 2.5.10 gives an indication of the nature of the reports received from a particular source. For example, the 20-county survey produced the highest yield of usable reports in that 97.06% of their reports identified patients who were ultimately considered to be part of the study population. The corresponding percentages for the official and non-official agencies are 92.53% and 92.44%, respectively.

TABLE 2.5.11. Number of Sources Reporting a Patient as Broken down by Response to the Questionnaire.

Number of Sources	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out-State	Not CP	Orig. Pop. Total
1	1,018	358	177	394	1,947	104	66	131	2,248
2	512	205	44	151	912	28	38	15	993
3	276	34	6	56	372	9	12	4	397
4	183	8	1	23	215	1	3	-	219
5	90	5	-	10	105	-	-	-	105
6	40	3	-	8	51	-	-	-	51
7	18	-	-	-	18	-	-	-	18
8	4	-	-	-	4	-	-	-	4
Total	2,141	613	228	642	3,624	142	119	150	4,035

Tables 2.5.11, 2.5.12 and 2.5.13, all deal with the number of agencies reporting a patient. Inspection of Table 2.5.12 reveals that over one-half (55.71%) of the patients originally reported were reported by a single agency. This percentage becomes 53.72 when we consider the reports of patients ultimately classed in the study population.

TABLE 2.5.12. Percent Distribution of the Number of Sources Reporting a Patient as Broken down by Response to the Questionnaire.

Number of Sources	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out-State	Not CP	Orig. Pop. Total
1	47.55	58.40	77.63	61.37	53.72	73.24	55.46	87.33	55.71
2	23.91	33.44	19.30	23.52	25.17	19.72	31.93	10.00	24.61
3	12.89	5.55	2.63	8.72	10.26	6.34	10.09	2.67	9.84
4	8.55	1.30	.44	3.58	5.93	.70	2.52	-	5.43
5	4.20	.82	-	1.56	2.90	-	-	-	2.60
6	1.87	.49	-	1.25	1.41	-	-	-	1.26
7	.84	-	-	-	.50	-	-	-	.45
8	.19	-	-	-	.11	-	-	-	.10
Total	100%	100%	100%	100%	100%	100%	100%	100%	100%

TABLE 2.5.13. Percent Distribution of the Response to the Questionnaire as Broken down by Number of Sources Reporting a Patient.

Number of Sources	Q Rec'd	Imp. Locate	Claim Not CP	Q Not Ans.	Study Pop. Total	Deceased	Out-State	Not CP	Orig. Pop. Total
1	45.28	15.93	7.87	17.53	86.61	4.63	2.93	5.83	100%
2	51.56	20.64	4.43	15.21	91.84	2.82	3.83	1.51	100%
3	69.52	8.56	1.51	14.11	93.70	2.27	3.02	1.01	100%
4	83.56	3.65	.46	10.50	98.17	.46	1.37	-	100%
5	85.72	4.76	-	9.52	100.00	-	-	-	100%
6	78.43	5.88	-	15.69	100.00	-	-	-	100%
7	100.00	-	-	-	100.00	-	-	-	100%
8	100.00	-	-	-	100.00	-	-	-	100%
Total	53.06	15.19	5.65	15.91	89.81	3.52	2.95	3.72	100%

Inspection of Table 2.5.12 reveals that in general a higher percentage of patients in the "Q Rec'd" group were reported by three or more agencies than the patients in any other group.

Table 2.5.13, among other things, reveals that the more sources by which a patient was reported the more likely he was to be classed in the study population and, for that matter, the more likely we were to have a completed questionnaire for the patient.

## 2.6 CODING THE QUESTIONNAIRE

Each completed questionnaire was edited before coding. The code employed was quite complex and it is therefore reasonable to question how consistently the information can be coded. It is not the purpose of this paper to go into detail on the method of ascertaining the coding consistency<sup>1</sup>, but it is essential that this topic be considered at least briefly at this point, because the data presented in the next chapter cannot be considered independent of the coding consistency.

Two coders were responsible for coding all questionnaires. After completion of coding the 2,141 forms, a systematic sample of 68 forms was selected and re-coded. Comparing the second coding with the original coding enabled us to make estimates of the "inter" and "intra" coder consistency. The latter is a measure of how well Coder A (or B) agrees with herself on a repeat coding of the same form ("intra" consistency), while the former is a measure of how well Coders A and B agree on forms both have coded on separate occasions ("inter" consistency).

The material contained on each questionnaire was divided into three parts, each part being coded and punched onto a separate IBM card. Coder A was responsible for coding card 1. Coder B was responsible for coding card 2. Both Coders A and B were trained for coding card 3.

Item by item comparison of the coding on the first and second coding shows that for card 1 Coder A had a 98.77% consistency coefficient (based on repeat codings of 3,808 individual items where each item is presented by a column on an IBM card). That is to say, Coder A agreed with herself 98.77% of the time. Incidentally, an inconsistency is defined as any case where the code for a particular column on the IBM card on the first coding did not correspond with the coding for that column on the second coding. Coder B had a 98.13% consistency coefficient (based on repeat codings of 3,672 individual items).

The consistency coefficient for card 3 for Coder A, where Coder A did both codings of card 3, is 99.40% (based on repeat codings of 836 individual items), while the corresponding coefficient for Coder B is 96.49% (based on repeat codings of 570 individual items). The consistency coefficient ("inter" consistency) for card 3 where Coder A coded card 3 on the first coding and Coder B coded card 3 on the second coding (or vice versa) was 97.45% (based on repeat codings of 1,178 individual items).

*1We have used, the word consistency rather than reliability here because agreement on the first and second coding of a form does not imply that the information was correctly coded in the first place. It merely implies the information was coded in the same way on two separate occasions.*

It should be noted that the comparison between Coder A and B must be made with caution even when such a comparison is based on card 3 because the "intra" consistency coefficient for Coders A and B is based on different subsets of forms, and the comparison would only be valid if the subset of repeat codings for A was of the same difficulty as the subset of forms repeat coded by B. Although the subset was determined on a chance basis, it is nevertheless possible that the two sets may differ with respect to difficulty. Unfortunately the appropriate design (one in which Coder A and B re-coded the same subset) was not employed.

Finally, it should be noted that most of the inconsistencies on all three cards occurred in the columns requiring a judgment by the Coder. Those columns in which the code was objective resulted in relatively few errors.

## 2.7 "INTER" AND "INTRA" RESPONDENT RELIABILITY

Another question that comes to mind is how reliable is the information that is provided by the respondent on the form? This is a difficult question to answer properly. However, a crude measure of respondent reliability can be obtained from the data already available from this study.

The "intra" reliability may be estimated on the basis of duplicate questionnaires obtained on two separate occasions from the same source. This type of duplication was relatively rare and primarily the result of a respondent's receiving a subsequent form after having completed an earlier form. The respondent, thinking that the preceding form had either been lost in the mail or that it had not been mailed, filled out and mailed a second form. In general a patient was taken off subsequent mailing lists when a completed form was received; however, an occasional recording error was made, hence explaining subsequent contact of a respondent and the occasional duplication of forms from the same source. In all, a total of thirty-two (32) such duplications occurred. Incidentally, when such duplications occurred the first form received was the one included in the analysis given in the next chapter.

Before looking at the agreement between these two forms, it is necessary to point out that the measure of reliability obtained in this manner is likely to be an overestimate of the true "intra" respondent reliability. Those respondents who take the time to fill out a second copy of the questionnaire after having already filled out one form, are obviously quite conscientious, and the care with which such respondents answer the questionnaire may in no manner be representative of the entire group from which we have completed questionnaires.

Using a definition similar to the one given in the previous section, the "intra" reliability coefficient is  $100 - (768)100/4416 = 82.61\%$ . In other

words, 82.61% of the items coded on the first form agreed with the corresponding item on the coding of the second form. It should be noted, however, that since the average time lapse between receipt of the first and second forms was a little over five months, some of the apparent disagreements observed may actually be a reflection of true changes. For example, the item dealing with present medical care shows a relatively large degree of disagreement, part of which may be explained by actual changes in medical care. However, most of the differences observed cannot be explained in this way. For example, ten of the thirty-two comparisons of the age at time of diagnosis indicate disagreement. Other items showing large differences are given below in Table 2.7.1 as well as the number of disagreements observed.

Inspection of the table below reveals that the items requiring the respondent to recall information are particularly subject to disagreement over time. The more objective information, such as patient's age, place

TABLE 2.7.1. Items Showing Ten or More Disagreements Out of the Thirty-two Comparisons. Both Questionnaires Received From the Same Source.

Item	Number of Disagreements
Number of sources of previous medical care	25
Sources of present occupational therapy	18
Frequency of present speech therapy	18
Need for assistance and service	18
Number of general practitioners previously treating the patient	17
Convulsions	17
Frequency of present occupational therapy	17
Sources of present speech therapy	17
Ability to learn	16
Frequency of previous* physical therapy	16
Frequency of present physical therapy	16
Sources of present physical therapy	15
Number of sources of present medical care	13
Treatment by an otologist	13
Other health problems listed	13
Frequency of previous* speech therapy	13
Treatment by an ophthalmologist	12
Types of vocational assistance	12
Types of summer recreational activities attended	12
Visual defects	11
Sources of previous* physical therapy	11
Age at time of diagnosis	10
Treatment by an orthopedic surgeon	10
Frequency of previous* occupational therapy	10
Sources of previous* speech therapy	10

\*Defined as before 9/1/58.

**TABLE 2.7.2. Items Showing 30 or More Inconsistencies for the 73 Patients for Whom a Form was Received From Two Different Sources.**

Item	Number of Disagreements
Time last seen by a physician	67
Place born	65
Reason for not having been seen by a P.H. nurse	65
Treatment by orthopedic surgeon	60
Family's need for service and assistance	56
Number of sources of previous medical care	54
Convulsions	54
Reason for not seeing dentist in last year	53
Recreational activities attended during the summer	52
Age at time of diagnosis	51
Ability to learn	49
Sources of previous occupational therapy	49
Frequency of present occupational therapy	49
Treatment by an ophthalmologist	48
Other health problems	48
Sources of physical therapy before 9/1/58	48
Frequency of previous physical therapy	48
Sources of present occupational therapy	48
Employment status	47
Vision problem	46
Frequency of previous occupational therapy	46
Treatment by an otologist	45
Ability to care for toilet needs	43
Source of previous speech therapy	43
Frequency of previous speech therapy	42
Source of present speech therapy	42
Number of general practitioners previously treating the patient	41
Ability to speak clearly	40
Frequency of present speech therapy	40
Ability to dress self	39
Sources of present physical therapy	38
Frequency of present physical therapy	38
Type of present vocational assistance given employment status	38
Reason for not seeing dentist in past	36
Ability to feed self	36
Recreational activities attended	36
Hearing problem	33
Name of hospital born at	32
Ability to walk	31
Source of vocational assistance given	31
Type of previous vocational assistance given	30

of birth, as well as the physical status items such as the respondent's assessment of the patient's ability to walk, feed himself, dress himself and speak, did not show large inconsistencies.

It should be emphasized that any difference between the first and second forms in the code for a particular column is listed as a disagreement regardless of how small the disagreement is. This definition is quite strict because a particular item may be punched differently on the first form as compared with the second form, whereas an inspection of the item and the codes punched may reveal relatively insignificant difference between the two forms.

In addition to the "intra" reliability estimate, we may also obtain an "inter" reliability estimate in which completed questionnaires for a particular patient were received from two different sources (73 in all)<sup>1</sup>. In every case one of the sources was the patient's parents. The other source was the institution in which the patient was residing. In other words, in those cases in which the patient was institutionalized, sometimes both the patient's parents and the institution returned a completed questionnaire. Such duplications were compared and the areas of agreement and disagreement recorded to provide an "inter" reliability estimate.

Table 2.7.2 lists those items in which the major disagreements arose. As might be expected, the reliability estimate for this type of comparison is lower than for the "intra" reliability estimate. The "inter" reliability coefficient is  $100(28659100)/9775 = 70.69\%$  as compared to the

"intra" consistency coefficient of 82.61%.

It is important to note, however, that the "inter" reliability estimate, like the "intra" reliability estimate is likely to be lowered somewhat because of the manner in which it is computed. That is, in one respect these estimates tend to be conservative in that many of the disagreements so noted may not always indicate particularly dissimilar information. In addition, a disagreement would be recorded if one source was able to provide a particular piece of information while the other source had to leave the item unanswered.

## 2.8 POSSIBLE SOURCES OF BIAS

One must invariably be concerned with the sources of bias in a study of this nature. The primary purpose of this study was to provide an accurate picture of the current status of the reported patients and the services received by them in the past and at present. However, since

*In these cases the form from the patient's parents was the one included in the analysis discussed in the next chapter.*

everyone in the study population did not respond to the questionnaire, this goal, in a sense, was not achieved. However, no valid inferences can be made from the respondent group to the non-respondent group unless additional information can be obtained for the non-respondent group. Certainly it would be hazardous to assume the non-respondents are no different than the respondents with respect to the characteristics under investigation.

Therefore, it is either necessary to qualify the findings of this study by restricting all findings to the population of reported cerebral palsy patients from whom we have completed questionnaires, or it is necessary to identify the sources of bias and take them into account when inferring to the total study population of patients reported. The latter, however, is rather difficult to do because of the very nature of the non-respondents.

The non-respondents of this study can be divided into two groups, namely,

- 1) those who could not be located and hence did not have an opportunity to respond to the questionnaire,
- and
- 2) those who could presumably be located but did not answer the questionnaire.

These two groups of non-respondents can, however, be compared with the group of respondents with respect to such characteristics as sex, age, and place of residence, if we are willing to assume that the information available for these three groups for such characteristics is equally reliable. Making this assumption, comparisons can be made by consulting Tables 2.5.1, 2.5.3, and 2.5.5 respectively. The sex ratios do not differ significantly for the three groups ( $P > .10$ ). However, the age distributions for the three groups as determined by the  $\chi^2$  distribution do differ significantly ( $P < .0005$ ). Similarly, when comparing the place of residence for the two non-respondent groups with the respondent group, rather large differences are noted. The  $\chi^2$  obtained has a probability of .0005 associated with it when each of the three groups is classed as to urban — rural home address. (See Appendix 3 for a definition of urban — rural status.)

A second method of identifying the possible sources of bias is to attempt to describe the non-respondents by considering the respondent population. That is, if one assumes that it would be possible to achieve a 100% (or nearly 100%) response rate to a questionnaire if continuing efforts were made, then the only difference between the respondents and non-respondents at any given time is in the resistance that remains to be overcome in order to produce a response. If, then, resistance can reasonably be measured by the number of mailings necessary to obtain a completed questionnaire, we could divide the groups for which we have com-

pleted questionnaires into resistance groups. That is, the group responding to the first mailing would represent the lowest resistance group, and so forth. The groups requiring a third mailing and a telephone call<sup>1</sup> before a completed questionnaire could be obtained would represent the highest resistance group among the respondents. If the second type of non-respondents (i.e., the "Not Ans." group) outlined above can be considered as a group whose resistance has not yet been broken down, then the characteristics of the highest resistance group, if anything, should approximate those of the non-respondent group more closely than those of the lowest resistance group. If there is no significant difference between the lowest and highest resistance groups with respect to a particular variable, then our confidence that the non-respondent ("Not Ans.") group does not differ from the respondent group with respect to this variable is increased. On the other hand, if there is a difference among the resistance groups, our guess would be that the non-respondent group would resemble the highest resistance group more closely than the lowest resistance group. Of course, this analysis assumes that a non-respondent is such because he merely failed to respond to the questionnaire and not because the patient does not belong to the study population (i.e., is not cerebral palsied, deceased, or out of the state).

Although it is not the purpose of this study to go into the technical aspects of data analysis, it is nevertheless of interest to at least demonstrate this method. To illustrate, let us consider the age breakdown by mailing group. For simplicity we will consider by mailing, the number of patients who are under (or over) ten years of age. (See Table 2.8.1). The telephone follow-up group has been eliminated because it was restricted to patients residing in the metropolitan area and living at home.

TABLE 2.8.1. Number of Patients Under 10 by Mailing. Percentages Given in Parentheses.

Mailing	Under 10	Over 10	Total
1st	598 (44.2)	754 (55.8)	1,352 (64.75)
2nd	151 (37.1)	256 (62.9)	407 (19.49)
3rd	99 (28.1)	230 (71.9)	329 (15.76)
Total	848 (40.61)	1,240 (59.39)	2,088 (100.0)

Theoretically we would expect the proportion under 10 to remain constant over all three mailings if age of the patient did not influence when the questionnaire was filled out. However, in fact, we see a larger proportion of patients under 10 are accounted for by the first mailing than

<sup>1</sup>The families of 166 patients were contacted by telephone after failing to respond to the third questionnaire and were urged to fill one out. This entire group consisted of families residing in the Minneapolis and St. Paul area.

by subsequent mailings. The first mailing breakdown, when compared with the remainder (i.e., respondents to the second and third mailing), yields a significant  $\chi^2$  ( $P < .0005$ ).

These results suggest that the trend observed is real and not the result of chance variation. Hence, the conclusion that forms for young patients (under 10) tend to be received earlier than for older patients seems to be valid, and in turn suggests that the remaining individuals for whom we did not receive completed questionnaires are older on the average than the group from whom we have completed questionnaires. Inspection of Table 2.5.4 reveals in fact that this is the case, with 34% of the "Not Ans/" group under 10 while about 41% of the "Q Rec'd" group were under 10.

## 2.9 COMPARISON OF FINDINGS WITH OTHER STUDIES

Table 2.9.1 compares the reported prevalence in Minnesota with that of other community studies. As can be seen from the table, values for the Minnesota Study are given for the entire population originally reported, for the study population (see section 2.5 for a definition of the study population) and for the study population assuming a 10% under-reporting error. These values can be compared with those obtained in Schenectady County, New York<sup>1</sup>, a two county area in Georgia<sup>2</sup>, Texas<sup>3</sup>, and Connecticut<sup>4</sup>/\*.

The reader should remember when making comparisons of the prevalence data listed in Table 2.9.1 that the studies listed cover a ten year interval and that the method of case finding varied from study to study. Differing case finding techniques may indeed account for a large share of the variability observed in Table 2.9.1.

<sup>1</sup>*Report of the New York State Joint Legislative Committee to Study the Problem of Cerebral Palsy. Legislative Document No. 55, 1949, 67 pp.*

<sup>2</sup>*Wishik, Samuel M. Handicapped Children in Georgia. A.J.P.H. 46:195-203 (Feb.), 1956.*

<sup>3</sup>*Wolfe, W. G., and Reid, J. J. A Survey of Cerebral Palsy in Texas. The United Cerebral Palsy of Texas (1010 Lacava, Austin, Tex.), (May), 1958, 326 pp.*

<sup>4</sup>*The Study of Cerebral Palsy in Connecticut, Hartford, Conn.: Connecticut State Department of Health, 1951, 120 pp.*

TABLE 2.9.1. Comparison of Prevalence With Other Studies. All Rates are per 1000 Population.

Study	Year	All Ages	Under 5 Years	Under 20 Years	20 Years & Over
Minnesota Study					
Total Reports	1958	1.35	1.60	2.77	.51
Study Population Reports	1958	1.22	1.44	2.51	.45
Study Population Reports Corrected for 10% under Reporting	1958	1.34	1.59	2.76	.49
Schenectady Co., N.Y.	1948	1.5	2.7	3.8	.8
Georgia (Two Counties)	1955	--	2.95	5.0*	--
Texas	1953	1.1 - 3.1	.8	1.8	.3
Connecticut	1950		1.0 - 1.2	1.6 - 1.8*	--

\*Under 21 years.

## CHAPTER 3: ANALYSES OF COMPLETED QUESTIONNAIRES

### 3.1 METHOD OF ANALYSIS

As indicated previously, all complete questionnaires were edited and coded. The code was then punched onto IBM cards and the tabulations summarized in this chapter were done on IBM machines.

Certain tabulations such as severity and urban-rural status are summary punches of other information punched on the card. The definition of such summary punches will be given in the text of the report when the variable is first introduced, as well as in Appendix 3.

The remainder of this chapter is devoted to findings based on the completed questionnaires received. The tabulations given by no means exhaust the number of tabulations originally made. However, as one might guess, many of these tabulations, once studied carefully, were considered not of sufficient interest to warrant inclusion in this report. On the other hand, certain tabulations, although interesting, could not be included in the text of the report because of space limitations. Certain of these tables have been selected and included in Appendix 2. Such tables will always be denoted with the letter "A" in the table number.

A large number of the tables included in this report will be accompanied by a simple chi square analysis.<sup>1</sup> The results of the analysis will be given as a footnote of the table to which it applies. In addition the probability associated with the observed  $X^2$  will also be given.

Again it should be emphasized that the statements made in this chapter must be restricted to the sub-population from which we received completed questionnaires. Inference to the entire study population would in general require additional information about the non-respondents.

### 3.2 SOURCE OF INFORMATION ON THE FORM

In general, the questionnaires received were from one of three sources, namely, the patient's family, the institution in which the patient was residing, or the patient himself. Table 3.2.1 gives the breakdown by source of information on the form.

Table 3.2.1 A shows the relationship of source of information on the form with the place of residence of the patient. Table 3.2.2A shows the relationship of source of information on the form with severity of handicap, and Table 3.2.3A gives the relationship of source of information on the form with the patient's present age.

<sup>1</sup>*Dixon, W.J.; Massey, F.J.; Introduction to Statistical Analysis. McGraw-Hill Book Company, Inc., New York, 1957.*

TABLE 3.2.1. Source of Information Provided on the Questionnaire. Percentage Given in Parentheses.

Source	Frequency
Patient's family	1,749 (81.69)
Institution	275 (12.84)
The patient	75 ( 3.50)
Other	42 ( 1.96)
Total	2,141 (100.0)

### 3.3 PLACE OF BIRTH AND PRESENT PLACE OF RESIDENCE OF PATIENTS WITH CEREBRAL PALSY

#### 3.3.1 Place of Birth

Nearly eighty-six percent of the patients from whom we have information on place of birth were born in a hospital. In addition, inspection of Table 3.3.1.1 reveals that a higher proportion of patients presently residing in rural areas<sup>1</sup> were born at home than patients presently residing in urban areas. ( $\chi^2 = 32.84$ ,  $P < .005$ ).

Table 3.3.1.2 gives the breakdown as related to severity<sup>2</sup> of handicap. The data indicate that relatively more mildly handicapped individuals were born at home than severely handicapped individuals. However, this trend may, to some extent, be a reflection of the age bias in responding to this item. The fact that place of birth information was not furnished for 27.68% of the severely handicapped while these percentages are 10.65% and 4.46% for the moderately and mildly handicapped groups, respectively, suggests that the three age groups differed in the manner in which this item was answered. If we considered only those forms filled out by the parents of the patient the trend observed in Table 3.3.1.2 is reduced. This classification shows less difference among the three severity groups with respect to place of birth. See Table 3.3.1.3.

<sup>1</sup>Geographic distribution as used in this report will refer to urban versus rural distribution. A patient is considered to reside in an urban area if he has a home address in the five county metropolitan area of Anoka, Dakota, Hennepin, Ramsey and Washington counties. Patients not having a home address in this area were considered to be residing in a rural area. See Appendix 3 for additional details.

<sup>2</sup>Severity is a composite measure based on the response to five items on the form. The items deal with the patient's ability to walk, his ability to feed himself, his ability to dress himself, his ability to speak clearly, and his ability to care for his toilet needs. Additional details on how this measure was derived are given in Appendix 3.

Table 3.3.1.4 gives the relationship of place of birth with the present age of the patient. As expected the proportion of patients born in a hospital decreases with the present age of the patient.

Table 3.3.1.1 A in the appendix gives the relationship of the place of birth with the sex of the patient.

TABLE 3.3.1.1. Place of Birth as Related to Home Address of the Patient. Percentages Given in Parentheses.

Where Born	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
In a hospital	699 (90.54)	891 (80.78)	1,590 ( 85.80)
At home	73 ( 9.46)	212 (19.22)	285 ( 15.20)
Total	772 (41.17)	1,103 (58.83)	1,875 (100.00)

$$\chi^2_1 = 32.84, P < .005$$

TABLE 3.3.1.2. Place of Birth as Related to Severity of Handicap. Percentages Given in Parentheses.

Where Born	SEVERITY			Total
	Mild	Moderate	Severe	
In a hospital	499 (84.01)	810 (84.99)	168 (88.42)	1,477 ( 85.03)
At home	95 (15.99)	143 (15.00)	22 (11.58)	260 ( 14.97)
Total	594 (34.20)	953 (54.86)	190 (10.94)	1,737 (100.00)

$$\chi^2_2 = 2.21, .30 < P < .40$$

TABLE 3.3.1.3. Place of Birth as Related to Severity of Handicap, Where all Forms Were Completed by the Parents of the Patient. Percentages Given in Parentheses.

Where Born	SEVERITY			Total
	Mild	Moderate	Severe	
In a hospital	457 (87.21)	756 (87.30)	159 (88.33)	1,372 ( 87.39)
At home	67 (12.79)	110 (12.70)	21 (11.67)	198 ( 12.61)
Total	524 (33.38)	866 (55.16)	180 (11.46)	1,570 (100.00)

$$\chi^2_2 = .16, .90 < P < .95$$

TABLE 3.3.1.4. Place of Birth as Related to Present Age of the Patient. Percentages Given in Parentheses.

Place Born	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
In a hospital	356 (99.44)	1,090 (89.42)	142 (48.14)	1,588 ( 84.83)
At home	2 ( .56)	129 (10.58)	153 (51.86)	284 ( 15.17)
Total	358 (19.12)	1,219 (65.12)	295 (15.76)	1,872 (100.00)

$$\chi^2_2 = 32.83, P < .005$$

### 3.3.2 Place of Residence of Patients with Cerebral Palsey.

The present location of the patients with cerebral palsy in Minnesota is one of the basic factors determining the types of programs and services to be developed in the future.

Almost three-quarters of the patients are living at home (73.03%), and one-fifth (20.30%) are living in institutions. A small percentage (4.04%) are living in foster or boarding homes. There was no significant difference in location of patients either by sex or geographic distribution. (See Tables 3.3.2.1A and 3.3.2.2A in Appendix 2). On the other hand, as might be expected the age of the patient is an important factor. The younger the patient, the more likely he is to be at home. In the adult group (over 21) only one-half (54.99%) of the patients are residing at home, and two-fifths (39.17%) are in institutions, as opposed to 90.58% and 2.22%, respectively for the under 5 year age group (See Table 3.3.2.1).

The severity of the patient's handicap also is a factor. Most of the mildly handicapped patients are living at home (89.06%), while only 42.07% of the severely handicapped are living at home (See Table 3.3.2.2.)

Thus, a comprehensive program for patients with cerebral palsy in Minnesota needs primarily to be geared to meet the needs of patients living at home with their families. Such a program must be so planned that it can meet the needs of patients of all ages at home. At the same time, because a fifth of the patients are in institutions, especially the severely handicapped, the quality of institutional care needs to be considered and planned for as well.

TABLE 3.3.2.1. Present Place of Residence of Patients as Related to the Patient's Present Age. Percentages Given in Parentheses.

Place of Residence	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Home	327 (90.58)	998 (73.82)	226 (54.99)	1,551 ( 73.02)
Institution	8 ( 2.22)	262 (19.38)	161 (39.17)	431 ( 20.29)
Foster or Boarding Home	24 ( 6.65)	48 ( 3.55)	14 ( 3.41)	86 ( 4.05)
Other*	2 ( .55)	44 ( 3.25)	10 ( 2.43)	56 ( 2.64)
<b>Total</b>	<b>361 (17.00)</b>	<b>1,352 (63.65)</b>	<b>411 (19.35)</b>	<b>2,124 (100.00)</b>

$$\chi^2_4 = 169.78, P < .0005$$

\*Other includes such things as living with friends, living with relatives, etc. This group was eliminated for the  $\chi^2$  analysis.

TABLE 3.3.2.2. Present Place of Residence of Patients as Related to the Severity of Handicap. Percentages Given in Parentheses.

Place of Residence	PRESENT AGE			Total
	Mild	Moderate	Severe	
Home	554 (89.06)	776 (71.99)	114 (42.07)	1,444 ( 73.26)
Institution	39 ( 6.27)	217(20.13)	135 (49.81)	391 ( 19.84)
Foster or Boarding home	9 ( 1.45) 20 ( 3.22)	56 ( 5.19) 29 ( 2.69)	18 ( 6.64) 4( 1.48)	83 ( 4.21) 53 ( 2.69)
Other*				
Total	622 (31.56)	1,078 (54.69)	271 (13.75)	1,971 (100.00)

$$X^2/4 = 253.98, P < .0005$$

\*This group was eliminated for the  $X^2$  analysis.

### 3.4 AGE AT TIME OF DIAGNOSIS

As would be expected, the more severe the degree of handicap the earlier the diagnosis (See Table 3.4.3.). However, the relationship of present age of the patient with age at time of diagnosis is not so clear cut. It is true that 40.69% of the patients under five years of age were diagnosed in the first year of life, while only 34.10% of the total number of patients in the age group 5 to 21 were diagnosed within the first year of life. However, if in the latter group we consider only the patients who were diagnosed within the first five years of life, we then notice that 40.46% of this total were diagnosed in the first year of life. The comparable figure for the "over 21" age group is 56.19%. These figures certainly do not indicate that case finding has improved over the years. (See Table 3.4.2.) Although this statement may be disturbing, it is good to keep in mind that the data on age at diagnosis may be quite unreliable, and further, the reliability of this information may very well vary with the present age of the patient. For instance, it is interesting to note that the percent of patients who were diagnosed in the first year of life is about the same for the "under 5" age group as for the "5 to 21" age group (Table 3.4.2.), and then increases in the "over 21" age group.

TABLE 3.4.1. Age at Time of Diagnosis as Related to the Patient's Present Age. Percentages Given in Parentheses.

Age at Time of Diagnosis	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Under 1 yr.	129 (40.69)	384 (34.10)	118 (44.03)	631 ( 36.88)
1 to 5 yrs.	188 (59.31)	565 (50.18)	92 (34.33)	844 ( 49.33)
5 to 10 yrs.	0	141 (12.52)	18 ( 6.72)	160 ( 9.35)
Over 10 yrs.	0	36 ( 3.20)	40 (14.92)	76 ( 4.44)
Total	317 (18.53)	1,126 (65.81)	268 (15.66)	1,711 (100.00)

In any case, efforts must be made to promote early case finding since 13.79% of the total number of patients from whom we have time of diagnosis information did not have their condition diagnosed until after age 5. (See Table 3.4.1.)

TABLE 3.4.2. Age at the Time of Diagnosis During the First Five Years of Life as Related to the Patient's Present Age. Percentages Given in Parentheses.

Age at Time of Diagnosis	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Under 1 yr.	129 (40.69)	384 (40.46)	118 (56.19)	631 ( 42.75)
1 to 5 yrs.	188 (59.31)	565 (59.54)	92 (43.81)	845 ( 57.25)
Total	317 (21.48)	949 (64.29)	210 (14.23)	1,476 (100.00)

$$\chi^2_{2} = 18.07, P < .0005$$

TABLE 3.4.3. Age at Time of Diagnosis as Related to the Severity of Handicap. Percentages Given in Parentheses.

Age at Time of Diagnosis	SEVERITY			Total
	Mild	Moderate	Severe	
Under 1 yr.	121 (23.82)	327 (37.24)	148 (70.14)	596 ( 37.32)
1 to 5 yrs.	276 (54.33)	447 (50.91)	57 (27.01)	780 ( 48.84)
5 to 10 yrs.	77 (15.16)	71 ( 8.09)	4 ( 1.90)	152 ( 9.52)
Over 10 yrs.	34 ( 6.69)	33 ( 3.76)	2 ( .95)	69 ( 4.32)
Total	508 (31.81)	878 (54.98)	211 (13.21)	1,597 (100.00)

$$\chi^2_{4} = 154.74, P < .0005$$

The fact that 197 of the families (11.51% of the total from whom we have diagnostic information) did not know that the patient had cerebral palsy is significant. (As indicated in a previous section, each such instance was later verified by follow-up work to ascertain the diagnosis.) One explanation for this is that the family may not have understood the meaning of the diagnosis. Such cases certainly point out the need for improved parent education and the need for a careful explanation of the child's condition to the parents.

There was no important difference in age of diagnosis when related to geographic distribution, but a significant sex difference was observed. (See Tables 3.4.1A and 3.4.2A respectively.)

### 3.5 FREQUENCY AND SEVERITY OF HANDICAPS

#### 3.5.1 General Status of Patients

One of the major factors in planning services for patients with cerebral palsy is the frequency and severity of their handicaps. For the total group, approximately one-third (31.73%) of the patients were mildly handicapped, one-half (54.58%) were moderately handicapped, and one-

eighth (13.69%) were severely handicapped. See Appendix 3 for definition of the terms used to classify severity of handicap.

There were some differences in severity of handicap as related to present age of the patient. That is, a lower percentage of children under five years of age were mildly handicapped and a higher percentage of them were severely handicapped than in the other two age groups. (See Table 3.5.1.1.) This may be due to the increasing salvage of babies who formerly did not survive, and who now are presenting more severe forms of disability upon survival. If this is the case, the Minnesota program can probably look forward to the need of providing services for an increasing number of severely disabled cerebral palsied patients, until more effective preventive measures are applied and until more is known about prevention. On the other hand, it may be a selection in reporting and/or the respondents' use of differing standard in assessing the degree of handicap as related to the age of the patient.

There was no difference found in the severity of handicaps of patients as related to their present geographic location. See Table 3.5.1.1A in Appendix 2.

A difference in the severity of handicaps was found by present place of residence of the patients. A higher percentage of patients living at home were mildly handicapped and a lower percentage of them were severely handicapped. The reverse was true for patients living in institutions. (See Table 3.5.1.2.) Thus, as is well known, the institutional program should be geared primarily for the care of severely disabled patients.

It is curious that, of the 391 institutionalized patients who appear in Table 3.5.1.2, 39 were reported to be mildly physically handicapped and 217 (55.50%) moderately physically handicapped. Unless these patients were seriously mentally retarded as well, the question ought to be raised about the reason and appropriateness of their placement.

See Table 3.5.1.2A in the appendix for the relationship of severity of handicap to sex of the patient. Table 3.5.1.3A gives the relationship of severity of handicap to place of birth of the patient.

TABLE 3.5.1.1. Severity of Handicap by Present Age of the Patient. Percentages Given in Parentheses.

Severity of Handicap	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Mild	30 ( 9.90)	496 (38.54)	102 (26.49)	628 ( 31.80)
Moderate	211 (69.64)	637 (49.49)	228 (59.22)	1,076 (54.48)
Severe	62 (20.46)	154 (11.97)	55 (14.29)	271 ( 13.72)
Total	303 (15.34)	1,287 (65.16)	385 (19.49)	1,975 (100.00)

$$\chi^2_4 = 100.75, P < .0005$$

TABLE 3.5.1.2. Severity of Handicap by Present Place of Residence of the Patient. Percentages Given in Parentheses.

Severity of Handicap	PLACE OF RESIDENCE			Total
	Living at Home	Living in a Foster Home	Living in an Inst.	
Mild	554 (38.37)	9 (10.84)	39 ( 9.97)	602 ( 31.39)
Moderate	776 (53.74)	56 (67.47)	217 (55.50)	1,049 ( 54.69)
Severe	114 ( 7.89)	18 (21.69)	135 (34.53)	267 ( 13.92)
Total	1,444 (75.29)	83 ( 4.33)	391 (20.38)	1,918 (100.00)

$\chi^2_4 = 253.97, P < .005$

### 3.5.2. Walking Status of Patients

About two-thirds (66.30%) of the total number of patients from whom we have walking status information were able to walk without help, while almost one-quarter (24.29%) of the patients were unable to walk at all (i.e., either confined to a wheelchair or bed).

Inspection of Table 3.5.2.1 reveals some rather striking differences by age. In looking at the table it should be noted that those patients considered too young to walk by the respondent were eliminated from the "under 5" age group, provided the patient was less than two years old. However, even after eliminating this obvious source of bias the distribution observed in the "under 5" age group is markedly different from the distribution obtained for the "5 to 21" age group and the "over 21" age group. The  $X^2$  for the comparison of the "under 5" group with the other two groups combined is highly significant ( $P < .0005$ ). In addition, the comparison of the "5 to 21" age group with the "over 21" age group also yields a significant  $X^2$  ( $P < .0005$ ).

The results of Table 3.5.2.1 indicate that fewer patients under 5 are able to walk and a larger proportion confined to bed than in the other two age groups. This finding is, at least in part, related to the fact that the most severely handicapped are likely to be diagnosed quite early in life. The major difference between the "5 to 21" age group and the "over 21" age group is in the number of patients confined to wheelchairs. This may indicate a difference in the facilities available for the severely handicapped after age 21. For example, a larger number of patients over 21 tend to be admitted to institutions than patients under 21.

Tabulations of walking information with geographic location (urban-rural) as well as sex were also made. The results are given in Tables 3.5.2.1A and 3.5.2.2A, respectively, in the appendix. Table 3.5.2.3A gives the relationship of walking status information to physical therapy.

Table 3.5.2.2 provides a breakdown of the walking status information with present place of residence. As can be noted from the table,

patients unable to walk without help are less likely to be living at home than patients who are able to walk without help. Of course, this result should not be considered independent of the results given in Table 3.5.2.1.

TABLE 3.5.2.1. Patient's Status Regarding Ability to Walk as Related to Present Age. Percentage Given in Parentheses.

Walking Status	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Able to walk without help	189 (54.00)	948 (72.31)	227 (57.04)	1,364 (66.25)
Able to walk with braces	16 ( 4.57)	16 ( 1.22)	10 ( 2.51)	42 ( 2.04)
Able to walk with crutches	12 ( 3.43)	51 ( 3.89)	18 ( 4.52)	81 ( 3.93)
Able to walk with crutches and braces	23 ( 6.57)	40 ( 3.05)	8 ( 2.01)	71 ( 3.45)
Confined to wheelchair	43 (12.29)	167 (12.74)	112 (28.14)	322 (15.64)
Confined to bed	67 (19.14)	89 ( 6.79)	23 ( 5.78)	179 ( 8.69)
Total	350 (17.00)	1,311 (63.67)	398 (19.33)	2,059 (100.00)

Overall:  $\chi^2_{10} = 133.84$ ,  $P < .0005$

Under 5,

Over 5 age groups:  $\chi^2_8 = 90.97$ ,  $P < .0005$

5 to 21,

Over 21 age groups:  $\chi^2_8 = 60.03$ ,  $P < .0005$

TABLE 3.5.2.2. Ability to Walk as Related to Place of Residence. Percentages Given in Parentheses.

Ability to Walk	PLACE OF RESIDENCE				Total
	Living at Home	Living in Inst.	Living in Foster Home	Other*	
Able to walk without help	1,092 (72.22)	193 (48.25)	3 ( 6.52)	30 (55.55)	1,318 ( 65.50)
Able to walk with braces	29 ( 1.92)	10 ( 2.50)	0	3 ( 5.56)	42 ( 2.09)
Able to walk with crutches	65 ( 4.30)	6 ( 1.50)	7 (15.22)	3 ( 5.56)	81 ( 4.03)
Able to walk with crutches and braces	50 ( 3.31)	12 ( 3.00)	7 (15.22)	2 ( 3.70)	71 ( 3.53)
Confined to wheelchair	199 (13.16)	95 (23.75)	15 (32.61)	12 (22.22)	32 ( 15.95)
Confined to bed	77 ( 5.09)	84 (21.00)	14 (30.43)	4 ( 7.41)	179 ( 8.90)
Total	1,512 (75.15)	400 (19.88)	46 ( 2.29)	54 ( 2.68)	2,012 (100.00)

$\chi^2_{10} = 238.68$ ,  $P < .001$

\*This group has been eliminated for the  $\chi^2$  analysis.

Information on the walking status of patients may help to serve as an indication of the need for physical therapy services. While it is evident that a careful clinical evaluation of each patient is necessary before any aspect of the rehabilitation program is prescribed, it is possible that the potential physical therapy caseload for cerebral palsied patients in Minnesota, from whom we have walking status information, may represent as many as 695 patients (695/2141 = 33.69%).

### 3.5.3 Feeding Status of Patients

Nearly three-fourths (71.02%) of all the patients were able to feed themselves completely while 14.61% were unable to feed themselves at all. A higher percentage in the age group 5 to 21 years were able to feed themselves independently than in the other two age groups, while a higher percentage of children under 5 years of age were totally dependent for feeding than in the other two age groups. (See Table 3.5.3.1.) It should be added that patients whom their parents felt were too young for an evaluation of feeding ability were eliminated from this tabulation, provided such a child was under two years of age.

Tables 3.5.3.1A and 3.5.3.2A in the appendix give the distribution of feeding status with respect to geographic location of the patient and sex of the patient. Table 3.5.3.3A gives the relationship of feeding ability as related to whether or not the patient has had occupational therapy.

TABLE 3.5.3.1. Feeding Status as Related to Present Age of the Patient. Percentages Given in Parentheses.

Feeding Status	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Feed self completely	207 (59.14)	998 (75.72)	260 (65.82)	1,465 ( 71.01)
Feed self partly	47 (13.43)	89 ( 6.75)	48 (12.15)	184 ( 8.92)
Feed self poorly or very little	28 ( 8.00)	53 ( 4.02)	31 ( 7.85)	112 ( 5.43)
Unable to feed self at all	68 (19.43)	178 (13.51)	56 (14.18)	302 (14.64)
Total	350 (16.96)	1,318 (63.89)	395 (19.15)	2,063 (100.00)

Under 5, over 5 age groups:  $\chi^2 = 29.70, P < .0005$

5 to 21, over 21 age groups:  $\chi^2 = 24.31, P < .0005$

Information on a patient's ability to feed himself may also serve as an indication of the need for occupational therapy. While it is evident that a careful evaluation of each patient is necessary before any aspect of the rehabilitation program is prescribed, it is possible that the potential occupational therapy caseload among cerebral palsied patients in Minnesota, from whom completed questionnaires were received, may represent as many as 599 patients (27.99% of 2,141) in regard to the need for training in self-feeding (i.e., all those patients who could not feed themselves.)

### 3.5.4 Dressing Status of Patients

About one-half (50.37%) of the patients for whom we have dressing status information can dress themselves completely, while one-quarter (25.48%) of the patients could dress themselves very little or not at all. It should be noted that children under four years of age for whom the respondent felt it was too early to make an evaluation of dressing ability were eliminated from the tabulation for this item. This may, however, not have been adequate to remove the age bias from the tabulation given in Table 3.5.4.1. At any rate, the "under 5" age group is either quite handicapped with respect to dressing ability or this information is particularly unreliable for patients under 5 years of age. Because of the latter possibility, the age group under 5 has been eliminated from consideration in the analysis of the data of Table 3.5.4.1. When this is done the  $\chi^2$  for the remaining data does not show a difference between the two remaining age groups ( $P = .16$ ).

Tables on dressing status as related to geographic location of the patient and sex of the patient are given in Appendix 2. (See Table 3.5.4.1A and 3.5.4.2A.) Table 3.5.4.3A gives the relationship of dressing status with whether or not the patient has had occupational therapy.

TABLE 3.5.4.1. Dressing Status as Related to Present Age of the Patient. Percentages Given in Parentheses.

Dressing Status	PRESENT AGE			Total
	Under 5*	5 to 21	Over 21	
Dress self completely	48 (15.48)	754 (57.29)	215 (54.43)	1,017 ( 50.32)
Dress self partly	59 (19.03)	205 (15.58)	62 (15.70)	326 ( 16.13)
Dress self poorly or very little	41 (13.23)	83 ( 6.31)	38 ( 9.62)	162 ( 8.02)
Unable to dress self at all	162 (52.26)	274 (20.82)	80 (20.25)	516 ( 25.53)
Total	310 (15.34)	1,316 (65.12)	395 (19.54)	2,021 (100.00)

$$\chi^2_3 = 5.21, P \doteq .16$$

\*This age group has been eliminated for the  $\chi^2$  analysis.

Information on patients' ability to dress themselves may serve as an indication of a need for occupational therapy. While it is evident that a careful evaluation of each patient is necessary before any aspect of the rehabilitation program is prescribed, it is possible that the potential occupational therapy caseload for cerebral palsied patients in Minnesota, among the group from whom we have completed questionnaires, may represent as many as 1,005 patients (46.94% of 2,141).

### 3.5.5 Status Regarding Caring for Toilet Needs

Inspection of Table 3.5.5.1 reveals that 59.04% of the patients were able to take care of their toilet needs completely, but 23.24% were able to do so poorly or not at all. Again an age restriction was placed on the response to this item. That is, any child under the age of 4 years was not considered abnormal if the respondent felt the patient was too young to assess his ability to care for his toilet needs. However, as in the previous section, it appears obvious that this was not adequate to remove the age bias from this item. Therefore, analysis of the data of Table 3.5.5.1 is restricted only to the age groups "5 to 21" and "over 21". The  $\chi^2$  for the comparison of these two age groups yields a value that is significant at the .0005 level, again seeming to indicate the older patients are more severely handicapped than younger patients. Or, at least, we have completed questionnaires from more severely handicapped patients in the "over 21" age group than in the "5 to 21" age group.

Assuming that all patients who cannot care for their toilet needs completely at the age of five are in need of training, we may say that 35.56% (608 patients) of the total number over 5 years of age, for whom we have toilet care information, are in need of such training. This represents a minimum number of patients in need of training in toilet care, since it does not include any children under 5 years of age.

TABLE 3.5.5.1. Toilet Care Status as Related to Present Age of the Patient. Percentages Given in Parentheses.

Toilet Care Status	PRESENT AGE			Total
	Under 5*	5 to 21	Over 21	
Able to care for needs completely	106 (31.74)	874 (66.51)	224 (57.14)	1,207 ( 59.04)
Able to care for needs partly	64 (19.16)	134 (10.20)	47 (11.99)	246 ( 12.04)
Able to care for needs poorly	25 ( 7.49)	54 ( 4.11)	37 ( 9.44)	116 ( 5.68)
Not able to care for needs at all	139 (41.61)	252 (19.18)	84 (21.43)	475 ( 23.24)
Total	334 (16.34)	1,314 (64.28)	392 (19.18)	2,044 (100.00)

$$\chi^2_3 = 21.88, P < .0005$$

\*This group eliminated from the  $\chi^2$  analysis.

Tables 3.5.5.1 A and 3.5.5.2A give the toilet care status as related to the geographic location of the patient and to the sex of the patient, respectively. No significant differences are noted.

### 3.5.6 Speech Status of the Patients

Over four-tenths of the patients (43.02%) were able to speak clearly while one-fifth (18.86%) were not able to speak at all. A child, who the respondent felt was too young to make an evaluation of his speaking ability, was excluded from the tabulations provided in this section, if he was under three years of age. Even this restriction, however, may not have been adequate to remove the age bias associated with this item. There certainly is a marked difference between the "under 5" age group and the remaining two groups, particularly in the number of patients not able to speak at all. However, even if we eliminate the "under 5" age group and compare the two remaining groups we observe a  $\chi^2$  which is significant at the .0005 level.

Speech status as tabulated by the patient's geographic location and sex is given in Tables 3.5.6.1A and 3.5.6.2A, respectively. Table 3.5.6.3A gives the relationship of speech status with whether or not the patient has had speech therapy.

If all patients unable to speak completely are considered to be in need of speech therapy, we may say that the minimum potential caseload for training in speech is 54.86% (943 patients) of the total number of patients over 5 for whom we have speech status information. (See Table 3.5.6.3A for the proportion of patients who have actually had speech therapy.) However, this must be considered as a minimum estimate of the total number of patients in need of training since children under 5

TABLE 3.5.6.1. Speech Status as Related to Present Age of the Patient. Percentages Given in Parentheses.

Speech Status	PRESENT AGE			Total
	Under 5*	5 to 21	Over 21	
Able to speak clearly	107 (32.04)	621 (46.97)	155 (39.05)	883 (43.01)
Able to speak partly clear	55 (16.47)	304 (23.00)	122 (30.73)	481 (23.43)
Able to speak very little	53 (15.87)	172 (13.01)	76 (19.14)	301 (14.66)
Not able to speak at all	119 (35.62)	225 (17.02)	44 (11.08)	388 (18.90)
Total	334 (16.27)	1,322 (64.39)	397 (19.34)	2,053 (100.00)

$$\chi^2_3 = 26.46, P < .0005$$

\*This group eliminated for the  $\chi^2$  analysis.

are not included; certainly a proportion of these children as well are likely to be in need of speech therapy.

### 3.5.7 Eye Status

Of the total group of patients providing eye care information, 877 (43.33%) were reported to have an eye defect, including 37 (1.83%) who were reported to be blind. It is of some interest that, while 43% of the patients were reported to have an eye defect, only 17.52% of the group from whom we have completed questionnaires were reported to have been seen by a qualified ophthalmologist. There was no difference reported in the frequency of eye defects by geographic distribution. (See Table 3.5.7.1A in the appendix.) A lower percentage of young children were reported with eye defects than older children or adults, (see Table 3.5.7.1) although the  $X^2$  for Table 3.5.7.1 does not suggest a significant age dependence. Only 32.39% of the severely physically handicapped patients were reported to have an eye defect, compared with 46.86% of the mildly physically handicapped and 44.17% of the moderately physically handicapped. (See Table 3.5.7.2.) Whether this difference is a true one, due to reporting, or due to the frequency of use of an ophthalmologist is unknown.

Of those with eye defects, after eliminating the blind, a total of 68.62% have glasses. As would be expected there is a tendency for older patients to have glasses more frequently than younger patients.

TABLE 3.5.7.1. Eye Defects as Related to the Patient's Present Age. Percentages Given in Parentheses.

Eye Condition	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Has eye defect	133 (38.66)	568 (44.00)	174 (45.19)	875 (43.32)
Has no eye defect	211 (62.34)	723 (56.00)	211 (54.81)	1,145 (56.68)
Total	344 (17.03)	1,291 (63.91)	385 (19.06)	2,020 (100.00)

$X^2 = 3.83, 10 < P < .20$

TABLE 3.5.7.2. Eye Defects as Related to Severity of Handicap of the Patient. Percentages Given in Parentheses.

Eye Condition	SEVERITY			Total
	Mild	Moderate	Severe	
Has eye defect	291 (46.86)	462 (44.17)	80 (32.39)	833 (43.52)
Has no eye defect	330 (53.14)	584 (55.83)	167 (67.61)	1,081 (56.48)
Total	621 (43.45)	1,046 (54.65)	247 (12.90)	1,914 (100.00)

$X^2 = 15.45, P < .0005$

(See Table 3.5.7.3.) A higher percentage of the mildly handicapped group had glasses than did the moderately or severely physically handicapped. (See Table 3.5.7.4.).

Ninety-four percent of the patients having glasses wore them. The older the patient, the more likely that he wore the glasses he had. (See Table 3.5.7.5.). However, the trend is not significant at the 5% level. A higher percentage of the mildly physically handicapped group wore the glasses they had than did the severely physically handicapped. (See Table 3.5.7.6.)

There were no differences in the eye status of patients by sex or geographic distribution (urban and rural). These two tables, as well as others related to the discussion of this section, are given in Appendix 2. (See Tables 3.5.7.1A through 3.5.7.6A).

TABLE 3.5.7.3. Ownership of Glasses Among Those Patients Who Listed an Eye Defect, as Related to the Present Age of the Patient, After Eliminating the Blind and Those Who Did Not Answer This Portion of the Question on Eye Care. Percentages Given in Parentheses.

Has Glasses	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	34 (31.78)	380 (72.38)	124 (81.58)	538 (68.62)
No	73 (68.22)	145 (27.62)	28 (18.42)	246 (31.38)
Total	107 (13.65)	525 (66.96)	152 (19.39)	784 (100.00)

$$\chi^2_2 = 82.77, P < .0005$$

TABLE 3.5.7.4. Ownership of Glasses Among Patients Who Listed an Eye Defect, as Related to Severity of Handicap, After Eliminating the Blind and Those Who Did Not Answer This Portion of the Question on Eye Care. Percentages Given in Parentheses.

Has Glasses	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	244 (86.83)	264 (64.08)	10 (18.18)	518 (69.25)
No	37 (13.17)	148 (35.92)	45 (81.82)	230 (30.75)
Total	281 (37.57)	412 (55.08)	55 ( 8.35)	748 (100.00)

$$\chi^2_2 = 113.34, P < .0005$$

<sup>1</sup>*Committee on Child Health, American Public Health Association. Services for Children with Cerebral Palsy. New York, 1955. Page 14.*

The percentage (40.96%) of patients reported to have an eye defect among the patients from whom we have received questionnaires is low compared with other studies. It may be related to the fact that only 17.52% of the patients for whom we have eye care information had been seen by a qualified ophthalmologist. Because of the high frequency of eye defects in individuals with cerebral palsy<sup>1</sup>, a complete eye examination by a qualified ophthalmologist should be incorporated into the diagnostic evaluation of each patient.

TABLE 3.5.7.5. Does or Does Not Wear Glasses Among Those Patients Who Have Glasses, as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Wears Glasses	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	29 (85.29)	357 (93.95)	118 (95.16)	504 (93.68)
No	5 (14.71)	23 ( 6.05)	6 ( 4.84)	34 ( 6.32)
Total	34 ( 6.32)	380 (70.63)	124 (23.05)	538 (100.00)

$$\chi^2_2 = 4.54, .10 < P < .20$$

TABLE 3.5.7.6. Does or Does Not Wear Glasses Among Those Patients Who Have Glasses, as Related to Severity of Handicap. Percentages Given in Parentheses.

Wears Glasses	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	234 (95.90)	248 (93.94)	5 (50.00)	487 (94.02)
No	10 (4.10)	16 ( 6.06)	5 (50.00)	31 ( 5.98)
Total	244 (47.10)	264 (50.97)	10 ( 1.93)	518 (100.00)

$$\chi^2_2 = 35.87, P < .0005$$

### 3.5.8 Hearing Status

Of the total group of patients from whom we have hearing status information, 202 (9.95%) were reported to have a hearing defect. It is of some interest that, while nearly 10% of the patients were reported to have a hearing defect, only 7.15% of the patients from whom we received completed questionnaires were seen by a qualified otologist or audiologist. The frequency of reported hearing defects was higher in older children and in adults than in young children (under five years of age.) (See Table 3.5.8.1.) It was higher in the moderately and mildly physically handicapped groups than in the severely physically handicapped group. (See Table 3.5.8.2.) Whether this is due to differences in the diagnosis of hearing defects or to a true difference is unknown. There was no difference between urban and rural areas (see Table 3.5.8.1A). Similarly there were no important sex differences. (See Table 3.5.8.2A.)

Three percent (3.04%) of the total group of patients from whom we had completed questionnaires had a hearing aid. The percentage (based on the total from whom we have completed questionnaires) was higher in urban areas (4.37%) than in rural areas (2.12%). It was highest in the moderately physically handicapped group, and lowest in the severely physically handicapped group.

We find that 41.67% of the patients with hearing defects had a hearing aid. The percentage was higher in urban (52.05%) than in rural areas (32.53%). (See Table 3.5.8.3.) Possession was highest in the moderately physically handicapped group (47.22%) and lowest in the severely physically handicapped group (16.67%). (See Table 3.5.8.4.)

It should be noted that Tables 3.5.8.3, 3.5.8.4 and 3.5.8.3A do not include the 19 individuals who were considered deaf by the respondents, because of inadequate information as to the nature of their condition.

TABLE 3.5.8.1. Presence or Absence of Hearing Defects as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Hearing	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Has hearing defect	21 ( 6.14)	137 (10.54)	44 (11.46)	202* ( 9.97)
Has no hearing defect	321 (93.86)	1,163 (89.46)	340 (88.54)	1,824 (90.03)
Total	342 (16.88)	1,300 (64.17)	384 (18.95)	2,026 (100.00)

$\chi^2_2 = 7.00, .025 < P < .05$

*\*19 of these patients were considered deaf by the respondent.*

TABLE 3.5.8.2. Presence or Absence of Hearing Defects as Related to Severity of Handicap. Percentages Given in Parentheses.

Hearing Status	SEVERITY			Total
	Mild	Moderate	Severe	
Has hearing defect	47 ( 7.59)	139 (13.24)	11 ( 4.49)	197* (10.29)
Has no hearing defect	572 (92.41)	911 (86.76)	234 (95.51)	1,717 (89.71)
Total	619 (32.34)	1,050 (54.86)	245 (12.80)	1,914 (100.00)

$\chi^2_2 = 27.57, P < .0005$

*\*19 of these were considered deaf by the respondent.*

The fact that only 10% of the patients were reported to have a hearing defect is a low finding compared with other studies. For example, the Committee on Child Health of the American Public Health Association<sup>1</sup> reports that over 25% of cerebral palsied children with moderate to severe disability may have hearing problems. The low percentage found in this study may be related to the fact that only 7.15% of the patients were seen by a qualified otologist or audiologist, or it may be due to differences among those who responded to the questionnaire.

TABLE 3.5.8.3. The Relationship of Home Address of the Patient to the Possession of a Hearing Aid, After Eliminating Those for Whom we Had Inadequate Information on Ownership. Percentages Given in Parentheses.

Ownership	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Has hearing aid	38 (52.05)	27 (32.53)	65 (41.67)
Does not have hearing aid	35 (47.95)	56 (67.47)	91 (58.33)
Total	73 (46.79)	83 (53.21)	156 (100.00)

$\chi^2_1 = 5.31, .001 < P < .025$

TABLE 3.5.8.4. The Relationship of Severity of Handicap to the Possession of a Hearing Aid, After Eliminating Those for Whom We Had Inadequate Information on Ownership. Percentages Given in Parentheses.

Ownership	SEVERITY			Total
	Mild	Moderate	Severe	
Has hearing aid	9 (24.32)	51 (47.22)	1 (16.67)	61 (40.40)
Does not have hearing aid	28 (75.68)	57 (52.78)	5 (83.33)	90 (59.60)
Total	37 (24.50)	108 (71.52)	6 ( 3.97)	151 (100.00)

$\chi^2_2 = 7.45, .01 < P < .025$

### 3.5.9 Status of Patients Regarding Convulsions

A total of 1,085 patients (52.59%) gave a negative history of convulsions. The families of 323 patients (15.66%) reported that the patient currently has convulsions and 312 patients (15.12%) had convulsions in the past but none now.

<sup>1</sup>Committee on Child Health, American Public Health Association. *Services for Children with Cerebral Palsy*. New York, 1955. Page 14.

Table 3.5.9.1 breaks the above figures down by age group. As can be seen, a smaller proportion of patients over 21 have convulsions presently than in the other two age groups. However, this may in part be an artifact of the reliability of the data. With respect to this point, inspection of Table 3.5.9.1 reveals that no information was furnished about the past history of convulsions for 23.33% of patients over 21, while the percentage was 15.85 and 12.32 for the "5 to 21" age group and the "under 5" age group, respectively. However, if such patients are eliminated and the remaining data analyzed (see Table 3.5.9.2), we still obtain a  $X$  that is significant at the .01 level, indicating that the three age groups are different with respect to history of convulsions. It would be interesting to know the proportion, by age group, of individuals eliminated from Table 3.5.9.2 who actually have a history of convulsions. This information would possibly make the three age groups of Table 3.5.9.2 comparable.

Tables 3.5.9.3 and 3.5.9.4 reveal that the mildly handicapped gave a lower proportion of positive histories than the moderately and severely handicapped. In turn, the moderately handicapped gave fewer positive histories than the severely handicapped. These percentages as recorded

TABLE 3.5.9.1. Presence or Absence of Convulsions as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Convulsion Status	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
No history of convulsions	202 (56.58)	669 (50.99)	211 (54.10)	1,082 ( 52.55)
No convulsions at present, no information about past	44 (12.32)	208 (15.85)	91 (23.33)	343 ( 16.66)
Had convulsions in the past, none now	54 (15.13)	209 (15.93)	49 (12.57)	312 ( 15.15)
Has convulsions now	57 (15.97)	226 (17.23)	39 (10.00)	322 ( 15.64)
Total	357 (17.34)	1,312 (63.72)	390 (18.94)	2,059 (100.00)

TABLE 3.5.9.2. Presence or Absence of a History of Convulsions as Related to Age of the Patient, After Eliminating Those for Whom we Have Inadequate Information. Percentages Given in Parentheses.

Convulsion History	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Negative history of convulsions	202 (64.54)	669 (60.60)	211 (70.57)	1,082 ( 63.05)
Positive history of convulsions	111 (35.46)	435 (39.40)	88 (29.43)	634 ( 36.95)
Total	313 (18.24)	1,104 (64.34)	299 (17.42)	1,716 (100.00)

$$X^2 = 10.40, .05 < P < .01$$

in Table 3.5.9.4 are 29.56, 36.93 and 58.22, respectively. The comparison of the history groups of this table as classed by severity yields a  $X^2$  that is significant at the .0005 level.

TABLE 3.5.9.3. Presence or Absence of Convulsions as Related to Severity of Handicap. Percentages Given in Parentheses.

Convulsion History	SEVERITY			Total
	Mild	Moderate	Severe	
No history of convulsions	367 (59.00)	557 (52.40)	94 (36.43)	1,018 ( 52.39)
No convulsions at present, no information about past	101 (16.24)	181 (17.03)	33 (12.79)	315 ( 16.21)
Had convulsions in the past, none now	86 (13.83)	173 (16.27)	39 (15.12)	298 ( 15.34)
Has convulsions now	68 (10.93)	152 (14.30)	92 (35.66)	312 ( 16.06)
Total	622 (32.01)	1,063 (54.71)	258 (13.28)	1,943 (100.00)

TABLE 3.5.9.4. History of Convulsions as Related to Severity of Handicap, After Eliminating Those for Whom We Have Inadequate Information. Percentages Given in Parentheses.

Convulsion History	SEVERITY			Total
	Mild	Moderate	Severe	
Negative history of convulsions	367 (70.44)	555 (63.07)	94 (41.78)	1,016 ( 62.48)
Positive history of convulsions	154 (29.56)	325 (36.93)	131 (58.22)	610 ( 37.52)
Total	521 (32.04)	880 (54.12)	225 (13.84)	1,626 (100.00)

$$X^2 = 55.36, P < .0005$$

TABLE 3.5.9.5. Presence or Absence of Convulsions as Related to Present Place of Residence of the Patient. Percentages Given in Parentheses.

Convulsion History	PLACE OF RESIDENCE			Total
	Living at Home	Living in an Inst.	Living in a Foster Home	
No history of convulsions	853 (55.82)	155 (40.26)	44 (52.38)	1,052 ( 52.69)
No convulsions at present, no information about past	236 (15.45)	79 (20.52)	15 (17.86)	330 (16.52)
Had convulsions in the past, none now	249 (16.30)	45 (11.69)	8 ( 9.52)	302 (15.12)
Has convulsions now	190 (12.43)	106 (27.53)	17 (20.24)	313 (15.67)
Total	1,528 (76.51)	385 (19.28)	84 ( 4.21)	1,997 (100.00)

Tables 3.5.9.5 and 3.5.9.6 show that patients with negative histories of convulsions are more likely to be living at home or in a foster home than patients with positive histories. Sixty-six percent of the patients living at home have a negative history of convulsions, while 50.65 percent of the patients living in institutions have such a history.

TABLE 3.5.9.6. History of Convulsions as Related to Present Place of Residence, After Eliminating Those Patients for Whom We Have Inadequate Information. Percentages Given in Parentheses.

Convulsion History	PLACE OF RESIDENCE			Total
	Living at Home	Living in an Inst.	Living in a Foster Home	
Negative history of convulsions	853 (66.02)	155 (50.65)	44 (63.77)	1,052 ( 63.11)
Positive history of convulsions	439 (33.98)	151 (49.35)	25 (36.23)	615 ( 36.89)
Total	1,292 (77.50)	306 (18.36)	69 ( 4.14)	1,667 (100.00)

$$\chi^2_2 = 25.11, P < .0005$$

TABLE 3.5.9.7. Frequency of Convulsions When Given. Percentages Given in Parentheses.

Frequency of Convulsion	Number of Patients
Daily	36 ( 24.00)
One to six times weekly	11 ( 7.33)
One to four times monthly	45 ( 30.00)
Less than once a month	58 ( 38.67)
Total	150 (100.00)

The need for diagnostic and treatment services for ambulatory seizure patients can be demonstrated by the fact that 60.70% of the patients (190 out of 313) who currently have convulsions are living at home, and 5.43% of the patients (17 out of 313) are living in foster homes. Since the others are living in institutions (33.87%), similar services are needed for this group. (See Tables 3.5.9.5 and 3.5.9.6.)

Of the 323 patients who have convulsions now, 51 were receiving medication. Table 3.5.9.7 gives the frequency of seizures for those not under medication. The data of Table 3.9.5.8 reveals the tendency is for the more severely handicapped to have seizures more frequently than the less handicapped, but the trend was not significant.

Additional tables of related interest may also be found in the appendix (Tables 3.5.9.1A through 3.5.9.3A).

TABLE 3.5.9.8. Frequency of Convulsions When Given as Related to Severity of Handicap. Percentages Given in Parentheses.

Frequency	SEVERITY			Total
	Mild	Moderate	Severe	
One or more times a week	6 (20.69)	21 (29.58)	17 (38.64)	44 (30.56)
Less than once a week	23 (79.31)	50 (70.42)	27 (61.36)	100 (69.44)
Total	29 (20.14)	71 (49.30)	44 (30.56)	144 (100.00)

$$\chi^2 = 2.70, P \hat{=} .26$$

### 3.5.10 Presence of Other Health Problems

A total of 433 patients (20.22% of the total from whom we have completed questionnaires) reported having other health problems in addition to those specifically listed on the questionnaire. Table 3.5.10.1 gives the frequency distribution of health problems listed. They total to more than 433 because some respondents listed more than one health problem. Inspection of the table reveals that the most frequently listed problems were related to the respiratory tract (25.25%), the gastro-intestinal tract (16.43%), bone and muscle (14.63%), and neuro-psychological problems (14.83%).

Other health problems were more frequently reported in the severely physically handicapped group, than in the mildly handicapped group. (See Table 3.5.10.1A in the appendix.)

TABLE 3.5.10.1. Frequency Distribution of Other Health Problems Present in Addition to Those Already Discussed in Previous Parts of This Section. Percentages Given in Parentheses.

Problem Related to:	Number Reporting Such Problems
Respiratory tract	126 (25.25)
Gastro-intestinal tract	82 (16.43)
Neuro-psych problems	74 (14.83)
Bone and muscle	73 (14.63)
Skin	27 ( 5.41)
Genitourinary tract	27 ( 5.41)
Allergy	23 ( 4.61)
Cardiovascular system	22 ( 4.41)
Endocrine-metabolic	21 ( 4.21)
Other organs	13 ( 2.61)
Congenital	11 ( 2.20)
Total	499 (100.00)

The fact that one-fifth of the patients were reported to have other health problems demonstrates the need for continuous medical care and supervision of cerebral palsied patients.

### 3.6 PRESENT MEDICAL CARE OF THE PATIENT

#### 3.6.1 Type of Present Medical Care

Thirty-three percent of the total number of patients for whom we have information on present medical care were under the care of a medical specialist. On the other hand, 28.00% of those for whom we have information were under no present medical care, while 21.27% were under the care of a general practitioner only. The remainder (17.81%) were receiving their present medical care from "Other hospitals". (See footnote to Table 3.6.1.1.).

Table 3.6.1.1 shows a variation in the type of current medical care as related to present urban-rural status of the patient. All patients not currently living at home have been eliminated from this comparison since their home address, in these cases, is not indicative of the type of medical care presently available to them. Comparison of the two residence groups produces a  $X^2$  that is significant at the .0005 level. As might be expected, more patients residing in an urban area were cared for by medical specialists than patients residing in a rural area.

TABLE 3.6.1.1. Type of Present Medical Care as Related to Geographic Location of the Patient, Restricted to Patients Presently Living at Home. Percentages Given in Parentheses.

Type of Medical Care	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Medical specialty care*	285 (45.97)	286 (33.81)	571 (38.95)
General Practitioner only**	125 (20.16)	252 (29.79)	377 (25.72)
Other hospital***	14 ( 2.26)	4 ( .47)	18 ( 1.23)
No present medical care	196 (31.61)	304 (35.96)	500 (34.10)
Total	640 (42.29)	846 (57.71)	1,466 (100.00)

$$X^2_{11} = 37.73, P < .0005$$

\*Includes physicians who are certified by a medical specialty board, certain hospitals (e.g., Gillette, University Hospital, Mayo Clinic, Kenny Institute) and the State Crippled Children's Clinics. A patient was classed in this group regardless of whether or not he was also presently being seen by a general practitioner.

\*\*General practitioner includes all physicians who were not certified by a medical specialty board but were licensed to practice medicine in the State of Minnesota.

\*\*\*Other hospital includes all hospitals (other than those included in \* above) in which it was not certain if a patient being cared for in such a hospital either on an in-patient or outpatient basis, would have specialty care available to him.

- 3) The disadvantageous position of older children and adults regarding current medical care;
- and
- 4) The special problems of the severely handicapped individual.

### 3.6.2. Types of Physicians Currently Caring for Cerebral Palsied Patients

In planning services for patients with cerebral palsy, the quality of such services is equally as important as the quantity. The types of physician and hospital care are most important factors.

Nearly seventy-two percent of the current medical care (among those from whom we have medical care information) was being provided by practicing physicians, and the remainder by hospitals and the State Crippled Children's Clinics. Over one-half (52.97%) of the physicians were general practitioners. One-fifth (21.44%) were orthopedic surgeons and about one-sixth (15.15%) were pediatricians. Small percentages were ophthalmologists, otologists, neurologists, and physiatrists. (See Table 3.6.2.1.)

TABLE 3.6.2.1. Count of Type and Number of Physicians Currently Caring For the Patients as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Type	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
<b>Physicians</b>				
General practitioners	187(42.79)	441(35.91)	113(39.10)	741(37.92)
Orthopedist	67(15.33)	227(18.49)	6( 2.08)	300(15.35)
Pediatrician	87(18.53)	129(10.50)	2( .69)	212(10.85)
Ophth-otologist	20( 4.58)	27( 2.20)	2( .69)	49( 2.51)
Neurologist	5( 1.14)	31( 2.52)	2( .69)	38( 1.95)
Physiatrist	9( 2.06)	11( .90)	0( 0 )	20( 1.02)
Neurosurgeon	3( .69)	5( .41)	2( .69)	10( .51)
Internist	0( 0 )	6( .49)	3( 1.04)	9( .46)
Other specialist	4( .92)	12( .98)	4( 1.38)	20( 1.02)
				1,399(71.60)
<b>Hospitals and Clinics</b>				
Gillette Hospital	15( 3.43)	56( 4.56)	1( .35)	72( 3.69)
University Hospital	21( 4.81)	30( 2.44)	9( 3.11)	60( 3.07)
State C.C. Clinics	9( 2.06)	29( 2.36)	0( 0 )	38( 1.94)
Mayo Clinic	5( 1.14)	7( .57)	1( .35)	13( .67)
Kenny Institute	1( .23)	2( .16)	0( 0 )	3( .15)
Other hospital	10( 2.29)	219(17.51)	144(49.83)	369(18.89)
				555(28.40)
<b>Total</b>	457(22.56)	1,228(62.85)	289(14.79)	1,954(100.00)

Of the care furnished by hospitals and clinics, two-thirds (66.49%) was furnished by the group classed as "Other hospital". It is of interest that Gillette Hospital comprised 12.97% of the total for hospitals and clinics and the University Hospitals provided 10.81% of this total. (See Table 3.6.2.1.)

Age of the patient proved to be a source of variation. (See Table 3.6.2.1.) As would be expected, pediatricians, Gillette Hospital and the State Crippled Children's Clinics were more likely to be caring for children, while general practitioners and hospitals other than specialty hospitals were more likely to be caring for adults.

Table 3.6.2.2 gives the type of physicians caring for the patient as related to present geographic location of the patient, where all patients not currently living at home have been eliminated from this table. As expected, patients residing in urban areas were more likely to be cared for by pediatricians and other types of medical specialists than patients

TABLE 3.6.2.2. Count of Type and Number of Physicians Currently Caring for the Patients as Related to the Present Geographic Location of the Patient (i.e., Eliminating all Patients Not Presently Living at Home).

Type	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
<b>Physicians</b>			
General Practitioners	238(30.20)	401(41.34)	639(36.35)
Orthopedist	143(18.15)	123(12.68)	266(15.13)
Pediatrician	132(16.75)	59( 6.08)	191(10.68)
Ophth-otologist	29( 3.68)	16( 1.65)	45( 2.56)
Neurologist	21( 2.66)	9( .93)	30( 1.71)
Physiatrist	4( .51)	16( 1.65)	20( 1.14)
Neurosurgeon	6( .76)	2( .21)	8( .46)
Internist	5( .64)	4( .41)	9( .51)
Other specialist	10( 1.27)	7( .72)	17( .97)
			1,225(69.68)
<b>Hospitals and Clinics</b>			
Gillette Hospital	21( 2.66)	40( 4.12)	61( 3.47)
University Hospital	25( 3.17)	25( 2.58)	50( 2.84)
State C. C. Clinics	0( 0 )	38( 3.92)	38( 2.16)
Mayo Clinic	1( .13)	11( 1.13)	12( .68)
Kenny Institute	1( .13)	2( .21)	3( .17)
Other hospitals	152(19.29)	217(22.37)	369(20.99)
			533(30.32)
<b>Total</b>	<b>788(44.82)</b>	<b>970(55.18)</b>	<b>1,758(100.00)</b>

residing in rural areas, where the general practitioner is playing a more frequent role. The State Crippled Children's Clinics are seeing children living in rural areas only.

There were no large differences in the pattern of present medical care as related to the sex of the patient. (See Table 3.6.2.1A.)

Certain problems and needs are evident from the above data. They are as follows:

- 1) The large role played by the physician in general practice in the rural areas, as opposed to urban areas, points up an area difference in the type of medical care available to cerebral palsied patients;
  - 2) The large role played by hospitals, other than those providing specialized orthopedic and rehabilitation care, points out the relative importance of such sources of medical care;
- and
- 3) The special problems of medical care of patients over 21 years of age.

### 3.6.3 Number of Sources of Present Medical Care

Approximately 63% of the patients who were presently under medical care were being cared for by only one source of medical care, 25.32% by two sources of medical care, and the remainder by three or more sources of medical care.

There was some variation in the number of sources of medical care by age of the patient. Young children (under five years of age) were more likely to be under medical care, and were more likely to be under multiple sources of medical care, than were the older age groups. (See Table 3.6.3.1.)

Table 3.6.3.2 reveals that the severely handicapped patient was more likely to be under one source of medical care than were the mildly

TABLE 3.6.3.1. Number of Sources of Present Medical Care as Related to Age of the Patient. Percentages Given in Parentheses.

Number of Sources	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
No present medical care*	66(18.80)	389(30.46)	103(27.11)	558(27.79)
1	127(36.19)	542(42.44)	245(54.47)	914(45.51)
2	98(27.92)	244(19.11)	25( 6.58)	367(18.28)
3 or more	60(17.09)	102( 7.99)	7( 1.84)	169( 8.42)
<b>Total</b>	<b>351(17.48)</b>	<b>1,277(63.60)</b>	<b>380(18.92)</b>	<b>2,008(100.00)</b>

$$\chi^2_4 = 125.72, P < .0005$$

\*This group was eliminated for the  $\chi^2$  analysis.

or moderately handicapped groups. This difference among the three handicapped groups with respect to source of medical care (excluding those not presently under medical care) was significant at the .0005 level.

The fact that one-third (36.96%) of all patients giving information on present medical care were under more than one source of current medical care is of interest. Regardless of the underlying reason for this, it is clear from the point of view of the patient that, where multiple sources of medical care are used at any given time, coordination of such care is necessary.

There was no difference in the number of sources of present medical care by geographic location of the patient, nor was there a significant difference by sex of the patient. (See Tables 3.6.3.1A and 3.6.3.2A in the appendix.)

TABLE 3.6.3.2. Number of Sources of Present Medical Care as Related to Severity of Handicap. Percentages Given in Parentheses.

Number of Sources	SEVERITY			Total
	Mild	Moderate	Severe	
No present medical care*	241(40.23)	243(23.85)	46(18.04)	530(28.29)
1	216(36.06)	455(44.65)	181(70.98)	852(45.49)
2	104(17.36)	214(21.00)	30( 7.84)	348(18.05)
3 or more	38( 6.34)	107(10.50)	8( 3.14)	153( 8.17)
Total	599(31.98)	1,019(54.40)	255(13.61)	1,873(100.00)

$$\chi^2_4 = 46.78, P < .0005$$

\*This group has been eliminated for the  $\chi^2$  analysis.

### 3.6.4 Recency of Last Visit to a Physician

No recommended standard exists for the frequency of medical care for patients with cerebral palsy. However, it might be reasonable to hope

TABLE 3.6.4.1. Time the Patient was Last Seen by a Physician. Percentages Given in Parentheses.

Time Last Seen	Number of Patients
Within one month	520(29.43)
Two thru three months	402(22.75)
Four thru six months	265(15.00)
Seven thru nine months	155( 8.77)
Ten thru twelve months	74( 4.19)
One to two years	190(10.75)
Two to three years	67( 3.79)
Three to four years	43( 2.43)
Five years or more	51( 2.89)
Total	1,767(100.00)

that patients would be seen at least once every six months by a physician. Over 67% of the patients for whom we have information meet this condition. On the other hand 12.96% of the patients providing information had last been seen by a physician 6 to 12 months ago, 10.75% of the patients had last been seen by a physician one to two years ago. Finally, 9.11% of the patients were last seen by a physician over two years ago. (See Table 3.6.4.1.).

Some variation was found by age of the patients. Patients under 5 were more likely to have been seen within the past six months than the age group "over 21". A higher percentage of adults than children under 5 had been without medical care for at least one year. (See Table 3.6.4.2.)

Some variation was also found by severity of handicap. A higher percentage of the severely handicapped had seen a physician within the past one month, and a smaller percentage of them had been without medical care for over one year than the other two age groups. Seventy-eight

TABLE 3.6.4.2. Time Last Seen by a Physician as Related to Present Age of the Patient. Percentages Given in Parentheses.

Time Last Seen	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Within one month	84(25.23)	280(25.23)	154(47.98)	518(29.37)
2 thru 6 months	188(56.45)	413(37.20)	66(20.56)	667(37.81)
7 thru 12 months	36(10.81)	168(15.14)	25( 7.79)	229(12.98)
1 to 2 years	20( 6.01)	141(12.70)	28( 8.72)	189(10.71)
Over 2 years	5( 1.50)	108( 9.73)	48(14.95)	161( 9.13)
Total	333(18.88)	1,110(62.92)	321(18.20)	1,764(100.00)

$$\chi^2_2 = 162.23, P < .0005$$

Note: This  $\chi^2$  was computed by grouping time last seen by a physician into two groups, i.e., within 6 months and over 6 months.

TABLE 3.6.4.3. Time Last Seen by a Physician as Related to Severity of Handicap. Percentages Given in Parentheses.

Time Last Seen	SEVERITY			Total
	Mild	Moderate	Severe	
Within one month	101(18.10)	276(30.84)	106(52.22)	483(29.17)
2 thru 6 months	224(40.14)	344(38.44)	52(25.62)	620(37.44)
7 thru 12 months	85(15.23)	117(13.07)	17( 8.37)	219(13.22)
1 to 2 years	69(12.37)	95(10.61)	20( 9.85)	184(11.11)
Over 2 years	79(14.16)	63( 7.04)	8( 3.94)	150( 9.06)
Total	558(33.70)	895(54.04)	203(12.26)	1,656(100.00)

$$\chi^2_2 = 31.91, P < .0005$$

Note: This  $\chi^2$  was computed by grouping time last seen by a physician into two groups, i.e., within 6 months and over 6 months.

percent of the severely handicapped had been seen by a physician within the past six months. These percentages for the mildly and moderately handicapped groups are 58.24 and 69.28, respectively. (See Table 3.6.4.3.)

There was no significant difference found in the frequency of patients being seen by a physician as related to the geographic location or sex of the patient. (Tables 3.6.4.1A and 3.6.4.2A in the appendix.) Table 3.6.4.3A gives the relationship of time last seen by a physician with the type of present medical care.

In conclusion, the facts of this section highlight certain problems and needs. They are:

- 1) A considerable proportion of patients had not recently been seen by a physician;
- and
- 2) The disadvantageous position of older children and adults in regard to continuing medical care.

### 3.7 CARE BY CERTAIN MEDICAL SPECIALIST

As can be seen from inspection of the questionnaire in Appendix 1, in addition to the general question on previous and present medical care, single specific questions relating to care of the patient by an orthopedic surgeon, ophthalmologist and otologist were included on the form. The following three sections deal with the response to these three items, respectively.

#### 3.7.1 Orthopedic Care

As can be seen from Table 3.7.1.1, over one-third (37.87%) of the patients for whom we have information on orthopedic care had been seen

TABLE 3.7.1.1. Orthopedic Care of Patients with Cerebral Palsy. Percentages Given in Parentheses.

Type of Care	Number of Patients
Qualified orthopedic surgeon	704(37.87)
Orthopedic care given:	
1. By a physician	140*( 7.53)
2. By a hospital	258**(13.88)
Not given any orthopedic care	757(40.72)
Total	1,859(100.00)

*\*The physician listed in response to item 2.F on the questionnaire was not listed in the Directory of Medical Specialties as a qualified orthopedic surgeon.*

*\*\*The source of orthopedic care was given as a hospital in these cases and it was not clear whether or not the patient had actually received care by a qualified orthopedic surgeon.*

by a qualified orthopedic surgeon at some time. The percentage seen by an orthopedic surgeon was higher in urban areas than in rural areas, 43.99% and 33.43%, respectively. (See Table 3.7.1.2.)

Care by orthopedic surgeon, as one might expect, was also related to the age of the patient. Over 42% of the patients in the "5 to 21" age group had been seen by an orthopedic surgeon, as compared with 36.84% and 22.67% for the "under 5" age group and the "over 21" age group, respectively. (See Table 3.7.1.3.)

There was no significant difference at the five percent level in usage of the sources of an orthopedic surgeon by sex of the patient. (See Table 3.7.1.1 A in the appendix.)

Although neuro-muscular abnormality is common in these patients, only a third had been seen by an orthopedic surgeon. Adults and patients living in rural areas were in a disadvantageous position. Further, since most patients with cerebral palsy have neuromuscular abnormalities, and many have a disability, it is essential that they be seen by an orthopedic surgeon and/or a physiatrist.

TABLE 3.7.1.2. Care by Orthopedic Surgeon as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Seen by Orthopedic Surgeon	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	344(43.99)	360(33.43)	704(37.87)
No	438(56.01)	717(66.57)	1,155(62.13)
Total	782(42.07)	1,077(57.93)	1,859(100.00)

$\chi^2_1 = 21.04, P < .0005$

TABLE 3.7.1.3. Care by Orthopedic Surgeon as Related to Age of the Patient. Percentages Given in Parentheses.

Seen by Orthopedic Surgeon	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	119(36.84)	507(42.53)	78(22.67)	704(37.87)
No	204(63.16)	685(57.47)	266(77.33)	1,155(62.13)
Total	323(17.37)	1,192(64.13)	344(18.50)	1,859(100.00)

$\chi^2_2 = 44.92, P < .0005$

### 3.7.2 Eye Care

In Minnesota 19.81% of the respondents who gave information on eye care reported that the patient had been seen by a qualified ophthalmologist. (See Table 3.7.2.1.) The percentage in urban areas (26.05%) was almost twice as high as that in rural areas (14.87%). (See Table

3.7.2.2.) While the percentages in all age groups seen by a qualified ophthalmologist were low, they were higher in children under five (19.17%) and in children aged 5 to 21 (21.68%) than in the adult age group (14.00%). (See Table 3.7.2.3.)

There was no difference in usage of services of an ophthalmologist by sex of the patient (Table 3.7.2.1A in the appendix).

TABLE 3.7.2.1. Eye Care of Patients with Cerebral Palsy. Percentages Given in Parentheses.

Type of Eye Care	Number of Patients
Seen by a qualified ophthalmologist	375(19.81)
Eye care, but given by	
1. a physician	247*(13.05)
2. a hospital	244**(12.89)
3. optometrist	13* *(.69)
Not seen by anyone for eye care	1,014(53.56)
<b>Total</b>	<b>1,893(100.00)</b>

\*The physician listed in response to item 2.D on the questionnaire was not listed in the Directory of Medical Specialties as a qualified ophthalmologist.

\*\*The source of eye care was given as a hospital in these cases and it was not clear whether or not the patient had actually received care by a qualified ophthalmologist.

TABLE 3.7.2.2. Care by an Ophthalmologist as Related to Geographic Distribution of the Patient. Percentages Given in Parentheses.

Seen by Ophthalmologist	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	218(26.05)	157(14.87)	375(19.81)
No	619(73.95)	899(85.13)	1,518(80.19)
<b>Total</b>	<b>837(44.22)</b>	<b>1,056(55.78)</b>	<b>1,893(100.00)</b>

$\chi^2_1 = 36.72, P < .0005$

TABLE 3.7.2.3. Care by an Ophthalmologist as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Seen by Ophthalmologist	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	65(19.17)	261(21.68)	49(14.00)	375(19.81)
No	274(80.83)	943(78.32)	301(86.00)	1,518(80.19)
<b>Total</b>	<b>339(17.91)</b>	<b>1,204(63.60)</b>	<b>350(18.49)</b>	<b>1,893(100.00)</b>

$\chi^2_2 = 10.17, P < .01$

In spite of the frequency of eye abnormalities in cerebral palsied patients, only a small percentage had been seen by a qualified ophthalmologist. Patients living in rural areas and adults were in the most disadvantageous position. A large proportion of patients with cerebral palsy have eye abnormalities; in some studies, as many as two-thirds of the patients have such a condition. For this reason, it is usually recommended that they be seen by a qualified ophthalmologist, preferably beginning during the early preschool period because of the frequency of strabismus.

### 3.7.3 Status of Care for Those with Hearing Impairment

In Minnesota 8.30% of the patients for whom we have received hearing impairment information were seen by a qualified otologist or audio-logist (See Table 3.7.3.1.). The percentage was higher in urban areas (13.31%) than in rural areas (4.06%).(See Table 3.7.3.2.) The percentage was higher in the age group "5 to 21" (9.97%) than in young children (3.63%) or in adults (4.73%). (See Table 3.7.3.3.)

TABLE 3.7.3.1. Status of Care for Hearing Impairment. Percentages Given in Parentheses.

Type of Care	Number of Patients
Qualified hearing care by:	
1. On otologist	145 ( 7.87)
2. An audiologist	8 ( .43)
Hearing care, but given by:	
1. A physician	240* (13.03)
2. A hospital	190** (10.32)
Not seen by anyone for hearing care	1,259 (68.35)
<b>Total</b>	<b>1,842 (100.00)</b>

\*The physician listed in response to item 2.E on the questionnaire was not listed in the Directory of Medical Specialties as a qualified otologist.

\*\*The source of hearing care was given as a hospital in these cases and it was not clear whether or not the patient had actually received care by a qualified otologist.

TABLE 3.7.3.2. Care by an Otologist as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Seen by Otologist	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	101 (13.31)	44 ( 4.06)	145 ( 7.87)
No	658 (86.69)	1,039 (95.94)	1,697 (92.13)
<b>Total</b>	<b>759 (41.21)</b>	<b>1,083 (58.79)</b>	<b>1,842 (100.00)</b>

$$\chi^2 = 51.32, P < .0005$$

There was no difference in the usage of the services of an otologist by sex of the patient. (See Table 3.7.3.1A in the appendix.)

The percentage of patients seen by a qualified otologist or audiologist is low. Patients in rural areas, adults, and young children are in a disadvantageous position. Nevertheless, a significant percentage of patients with cerebral palsy were reported to have hearing impairment, and thus should be seen by a qualified otologist and/or audiologist for diagnostic work-up, and for treatment and rehabilitation when indicated.

TABLE 3.7.3-3. Care by an Otologist as Related to Present Age of the Patient. Percentages Given in Parentheses.

Seen by Otologist	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	12 ( 3.63)	117 ( 9.97)	16 ( 4.73)	145 ( 7.87)
No	319 (96.37)	1,056 (90.03)	322 (95.27)	1,697 (92.13)
Total	331 (17.97)	1,173 (63.68)	338 (18.35)	1,842 (100.00)

$\chi^2_2 = 19.97, P < .0005$

### 3.8 DENTAL CARE

Dental abnormalities are frequent in patients with cerebral palsy especially dental caries and malocclusions. For this reason, information on dental care was requested on the form. Information on dental care over the patient's entire lifetime, as well as dental care during the past 12 months was requested. The following two parts deal with information obtained from these items.

#### 3.8.1 Dental Care During Patient's Entire Lifetime

Eighty-six percent of the patients had been seen by a dentist at least once some time in their lives. The percentages were higher in older children and adults (90.49 and 97.95, respectively) than in children under five years of age (50.35%). (See Table 3.8.1.1.) Table 3.8.1.2 gives

TABLE 3.8.1.1. Dental Care History of the Patient as Related to Present Age of the Patient. Percentages Given in Parentheses.

Ever Seen by a Dentist	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	145 (50.35)	1,180 (90.49)	383 (97.95)	1,708 (86.13)
No	143 (49.65)	124 ( 9.51)	8 ( 2.05)	275 (13.87)
Total	288 (14.52)	1,304 (65.76)	391 (19.72)	1,983 (100.00)

$\chi^2_1 = 39.02, P < .0005$

NOTE: This analysis was performed after eliminating the under 5 age group.

the relationship of severity of handicap with the patient's dental care history. Note that a smaller proportion of the severely handicapped have been seen by a dentist than in the other two age groups.

TABLE 3.8.1.2. Dental Care History of the Patient as Related to Severity of Handicap. Percentages Given in Parentheses.

Ever Seen by a Dentist	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	601 (93.32)	870 (82.62)	167 (70.17)	1,638 (84.65)
No	43 (6.68)	183 (17.38)	71 (29.83)	297 (15.35)
Total	644 (33.28)	1,053 (54.42)	238 (12.30)	1,935 (100.00)

$\chi^2_2 = 79.04, P < .0005$

TABLE 3.8.1.3. Dental Care History of the Patient as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Ever Seen by a Dentist	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	719 (89.10)	993 (84.15)	1,712 (86.16)
No	88 (10.90)	187 (15.85)	275 (13.84)
Total	807 (40.61)	1,180 (59.39)	1,987 (100.00)

$\chi^2_1 = 9.41, P < .005$

As indicated by Table 3.8.1.3 urban patients have a better dental care history than rural patients. This difference was significant at the .005 level.

There was no difference in the pattern of past dental care by sex of the patient or by source of present medical care. (See Tables 3.8.1.1A and 3.8.1.2A, respectively.)

Reasons given by families for not seeking dental care for their cerebral palsied family member were most frequently: 1) lack of belief dental care was necessary; 2) inability to afford it; 3) fear on the part of the patient; 4) institutionalization of the patient; and 5) lack of availability of the services of a dentist.

### 3.8.2 Dental Care During Past Year

It is recommended that there be at least annual visits to a dentist. Nearly seventy-two percent of the patients for whom we have dental care information met this condition. Table 3.8.2.1 indicates that children under 5, relative to the other two age groups, were less likely to have been seen by a dentist during the past year. This is not unexpected since this group contains the very young, who, even under the best possible conditions probably would not see a dentist until the age of two.

TABLE 3.8.2.1. Dental Care Within the Past 12 Months as Related to Present Age of the Patient. Percentages Given in Parentheses.

Seen by a Dentist in Last 12 Months	PRESENT AGE			Total
	Under 5*	5 to 21	Over 21	
Yes	127 (44.25)	968 (76.04)	293 (76.70)	1,388 (71.47)
No	160 (55.75)	305 (23.96)	89 (23.30)	554 (28.53)
Total	287 (14.78)	1,273 (65.56)	382 (19.67)	1,942 (100.00)

$\chi^2_2 = 122.47, P < .0005$

\*This analysis was performed after eliminating the under 5 age group.

TABLE 3.8.2.2. Dental Care Within the Past 12 Months as Related to Severity of Handicap. Percentages Given in Parentheses.

Seen by a Dentist in Last 12 Months	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	521 (81.41)	703 (68.12)	130 (56.28)	1,354 (71.15)
No	119 (18.59)	329 (31.88)	101 (43.72)	549 (28.85)
Total	640 (33.63)	1,032 (54.23)	231 (12.14)	1,903 (100.00)

$\chi^2_2 = 62.31, P < .0005$

TABLE 3.8.2.3. Dental Care Within the Past 12 Months as Related to Present Place of Residence of the Patient, Eliminating Those Patients Not Living at Home. Percentages Given in Parentheses.

Seen by a Dentist in Last 12 Months	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	475 (76.86)	550 (63.95)	1,025 (69.35)
No	143 (23.14)	310 (36.05)	453 (30.65)
Total	618 (41.81)	860 (58.19)	1,478 (100.00)

$\chi^2_2 = 27.88, P < .0005$

Table 3.8.2.2 shows that the less severe the physical handicap, the more likely the patient was to see a dentist. Table 3.8.2.3 reveals a tendency for urban patients to see a dentist more frequently within the period of one year than rural patients.

There was no significant difference between present dental care and sex of the patient. There was, however, a difference at the .05 level between present dental care and present medical care. (See Tables 3.8.2.1A and 3.8.2.2A.)

It would appear from these findings that there is need for increased interpretation of the importance of continuing dental care for cerebral palsied patients, with special emphasis upon young children and the more severely handicapped.

### 3.9 USE OF PUBLIC HEALTH NURSING SERVICE

It is generally recognized that the community public health nursing service can be of considerable assistance in the home care of cerebral palsied patients.

In Minnesota, 44.77% of the patients from whom we have information had been visited at home by a public health nurse at some time. The percentage visited was considerably higher in rural areas (58.61%) than in urban areas (25.00%). (See Table 3.9.1.) The younger the patient was, the more likely he had been visited by a public health nurse; the percentages were 51.40% in the age group under five, 46.14% in the age group 5 to 21, and 31.08% in the adult group. (See Table 3.9.2.)

TABLE 3.9.1. Visits by a Public Health Nurse as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Visit by Public Health Nurse	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	194 (25.00)	650 (58.61)	844 (44.77)
No	582 (75.00)	459 (41.39)	1,041 (55.23)
Total	776 (41.17)	1,109 (58.83)	1,885 (100.00)

$\chi^2_1 = 207.23, P < .0005$

TABLE 3.9.2. Visits by a Public Health Nurse as Related to Present Age of the Patient. Percentages Given in Parentheses.

Visit by Public Health Nurse	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	184 (51.40)	568 (46.14)	92 (31.08)	844 (44.77)
No	174 (48.60)	663 (53.86)	204 (68.92)	1,041 (55.23)
Total	358 (18.99)	1,231 (65.31)	296 (15.70)	1,885 (100.00)

$\chi^2_2 = 29.72, P < .0005$

Reasons given by families for not using the public health nursing service were: 1) lack of need for a public health nurse; 2) lack of knowledge how the public health nurse might help; 3) lack of knowledge that a public health nurse made home visits; and 4) lack of knowledge how to obtain such service. (See Table 3.9.3.)

There was no significant difference in usage of public health nursing service by sex of the patient or by the source of present medical care (Tables 3.9.1A and 3.9.2A in the appendix).

In view of the fact that many cerebral palsy patients have multiple health problems, it is surprising to find that only 45% of those patients for whom we have information had actually been seen by a public health nurse. There is need for further promotion of the use of this service,

with emphasis on interpreting to families the contribution which the service can make and with information on how it can be secured. The lower usage of the service for urban patients is a special point in need of further emphasis.

TABLE 3.9.3. Reason Given for not Having a Public Health Nurse Visit as Related to the Home Address of the Patient. Percentages Given in Parentheses.

Reason	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Did not need one	403 (53.67)	269 (57.48)	672 (55.13)
Did not know what a Public Health Nurse could offer	175 (23.30)	106 (22.65)	281 (23.05)
Did not know Public Health Nurse made home visits	93 (12.38)	64 (13.67)	157 (12.88)
Did not know how to arrange a visit	80 (10.65)	29 ( 6.20)	109 ( 8.94)
<b>Total</b>	<b>751 (61.61)</b>	<b>468 (38.39)</b>	<b>1,219 (100.00)</b>

$\chi^2_3 = 7.59, .05 < P < .10$

### 3.10 THERAPY STATUS OF PATIENTS

#### 3.10.1 Therapy Summary<sup>1</sup>

Nearly seventeen percent of the patients for whom we have summary therapy information received a combination of physical, occupational, and speech therapy, 33.79% received physical therapy only, 5.47% received speech therapy only, and 1.42% received occupational therapy only. Over 18% of the patients have never received any therapy of any type.

It is of some interest that 73.56% of the patients for whom we have summary information have received physical therapy at some time, 36.40% have received speech therapy at some time, and 29.36% have received occupational therapy at some time.

<sup>1</sup>The findings of this section are a summary of a patient's history with respect to therapy including previous as well as present therapy. Previous therapy is defined as any therapy received prior to 9-1-58 and present therapy is defined as any therapy received after that date. Only those individuals for whom we had information on all three therapy items on the form were included in this summary. For example, if a respondent provided information on physical therapy and speech therapy, but left the occupational therapy items unanswered, no summary information was punched.

There are some differences reported by geographic location. A higher percentage of patients in rural areas have never received any therapy of any type than in urban areas. On the other hand, patients living in urban areas were more likely to have had combinations of therapy. For example, 25.97% of the urban patients for whom we have summary information have received all three types of therapy, whereas the corresponding percentage for rural patients was only 9.57%. The therapy differences between urban and rural communities were highly significant. (See Table 3.10.1.1.)

TABLE 3.10.1.1. Therapy Summary\* as Related to the Geographic Location of the Patient, Restricted to Patients Presently Living at Home. Percentages Given in Parentheses.

Summary	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
No Therapy	77 (12.98)	169 (22.78)	246 (18.43)
Physical therapy only	155 (26.14)	296 (39.90)	451 (33.79)
Occupational therapy only	6 ( 1.01)	13 ( 1.75)	19 ( 1.42)
Speech therapy only	26 ( 4.38)	47 ( 6.33)	73 ( 5.47)
Physical & occupational therapy	82 (13.83)	51 ( 6.87)	133 ( 9.96)
Physical & speech therapy	83 (14.00)	90 (12.13)	173 (12.96)
Occupational & speech therapy	10 ( 1.69)	5 ( .67)	15 ( 1.12)
All three types of therapy	154 (25.97)	71 ( 9.57)	225 (16.85)
<b>Total</b>	<b>593 (44.42)</b>	<b>742 (55.58)</b>	<b>1,335 (100.00)</b>

$$\chi^2 = 111.67, P < .0005$$

\*Summarizes physical, occupational and speech therapy.

Table 3.10.1.2 provides the therapy summary as related to the age of the patient. As might be expected the age group 5 to 21 was more likely to have received therapy than the age group under 5. However, since this is a summary of past as well as present therapy, it is natural to expect that the "over 21" age group should have the lowest percentage of patients who have not had any therapy, if the availability of therapy was the same for patients over 21 as for the other two age groups. However, the percentage for this group is 37.33% as compared to 21.79% for the "5 to 21" age group. This suggests either a change in the availability of therapy sources over the last twenty years and/or a difference in the reliability of therapy information furnished as related to the patient's age.

TABLE 3.10.1.2. Therapy Summary\* as Related to Present Age of the Patient. Percentages Given in Parentheses.

Summary	PRESENT AGE			Total
	Under	5 to 21	Over 21	
No therapy	87 (28.15)	243 (21.79)	109 (37.33)	439 (25.58)
Physical therapy only	129 (41.75)	337 (30.22)	63 (21.58)	529 (30.83)
Occupational therapy only	7 ( 2.27)	11 ( .99)	14 ( 4.79)	32 ( 1.86)
Speech therapy only	6 ( 1.94)	77 ( 6.91)	9 ( 3.08)	92 ( 5.36)
Physical & occupational therapy	33 (10.68)	100 ( 8.97)	26 ( 8.91)	159 ( 9.27)
Physical & speech therapy	18 ( 5.83)	141 (12.64)	29 ( 9.93)	188 (10.96)
Occupational & speech therapy	0 ( 0 )	13 ( 1.17)	4 ( 1.37)	17 ( .99)
All three types of therapy	29 ( 9.38)	193 (17.31)	38 (13.01)	260 (15.15)
Total	309 (18.01)	1,115 (64.97)	292 (17.02)	1,716 (100.00)

\*Summarizes physical, occupational and speech therapy.

$$\chi^2_4 = 103.13, P < .0005$$

Note: This  $\chi^2$  was computed after grouping in the following manner: no therapy; physical, occupational or speech therapy only; and combinations of therapy.

TABLE 3.10.1.3. Therapy Summary\* as Related to Severity of Handicap. Percentages Given in Parentheses.

Summary	SEVERITY			Total
	Mild	Moderate	Severe	
No therapy	113 (20.81)	212 (22.65)	108 (50.95)	433 (25.61)
Physical therapy only	237 (43.65)	225 (24.04)	54 (25.47)	516 (30.51)
Occupational therapy only	13 ( 2.39)	17 ( 1.82)	1 ( .47)	31 ( 1.83)
Speech therapy only	28 ( 5.16)	61 ( 6.52)	2 ( .94)	91 ( 5.38)
Physical & occupational therapy	64 (11.79)	76 ( 8.12)	17 ( 8.02)	157 ( 9.28)
Physical & speech therapy	42 ( 7.73)	135 (14.42)	10 ( 4.72)	187 (11.06)
Occupational & speech therapy	4 ( .74)	12 ( 1.28)	0 ( 0 )	16 ( .95)
All 3 types of therapy	42 ( 7.73)	198 (21.15)	20 ( 9.43)	260 (15.38)
Total	543 (32.11)	936 (55.35)	212 (12.54)	1,691 (100.00)

\*Summarizes physical, occupational and speech therapy.

$$\chi^2_4 = 197.00, P < .0005$$

Note: This  $\chi^2$  was computed after grouping in the following manner: no therapy; physical, occupational or speech therapy only; and combinations of therapy.

Table 3.10.1.3 gives the relationship of therapy with severity of handicap. Inspection of the table reveals that the severely handicapped were less likely to have received therapy of any sort than were the other two severity groups. On the other hand, the mildly handicapped were more likely to have received physical therapy only, than were the other two severity groups, and the moderately handicapped were more likely to have received all three types of therapy, than were the other two groups.

There was a significant difference in the relationship between the therapy summary and sex of the patient (Table 3.10.1.1A in the appendix).

With the high frequency of neuromuscular and speech involvement among cerebral palsy patients, one might have expected the percentage of patients having therapy to be greater. The special need for services of patients in rural areas is again demonstrated.

### 3.10.2 Status of Present Physical Therapy Service

A total of 22.36% of the patients were currently receiving therapy (i.e., since 9-1-58). The percentage was slightly higher (Table 3.10.2.1) in urban areas (23.87%) than in rural areas (21.18%), but the difference is not significant. Most patients receiving physical therapy received it at least once a week, and the majority received it daily. (See Table 3.10.2.2.) The sources of current physical therapy are listed in Table 3.10.2.3. The most frequent source was the school, which provided therapy more in urban than in rural areas.

In conclusion, slightly more than one-fifth of the patients were receiving physical therapy currently. The largest source was the schools, which means that this source is restricted to children of school age. Rural patients are again demonstrated to be at a disadvantage.

TABLE 3.10.2.1. Present\* Physical Therapy Status as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Present Physical Therapy	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	185(23.87)	209(21.18)	394(22.36)
No	590(76.13)	788(78.82)	1,368(77.64)
Total	775(43.98)	987(56.02)	1,762(100.00)

$$\chi^2_1 = 1.67, .10 < P < .20$$

\*Defined as therapy after September 1, 1958.

TABLE 3.10.2.2. Frequency of Physical Therapy Sessions for Those who are Presently\* Receiving Therapy. Percentages Given in Parentheses.

Frequency of Therapy	Number
Daily	180(57.69)
3 to 6 times per week	36(11.54)
2 times per week	46(14.74)
Once a week	30( 9.62)
4 or fewer times a month	20( 6.41)
Total	312(100.00)

\*Defined as therapy after September 1, 1958.

TABLE 3.10.2.3. Source or Sources of Current\* Physical Therapy as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Source	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
School	84(53.16)	47(30.32)	131(41.85)
Private**	31(19.62)	30(19.35)	61(19.49)
Public hospital	23(14.56)	28(18.06)	51(16.29)
Private hospital	3( 1.90)	18(11.61)	21( 6.71)
**Other private***	2( 1.27)	16(10.32)	18( 5.75)
Public health agency	3( 1.90)	11( 7.10)	14( 4.47)
State hospital	9( 5.70)	1( .65)	10( 3.19)
Camp	1( .63)	0( 0 )	1( .32)
Other	2( 1.27)	4( 2.58)	6( 1.92)
Total	158(50.48)	155(49.52)	313(100.00)

\*Defined as therapy after September 1, 1958.

\*\*Therapy given by a registered therapist on a private basis.

\*\*\*Therapy given on a private basis in which it was not certain as to whether or not a registered therapist was involved.

### 3.10.3 Status of Present Occupational Therapy Service

A total of 11.29% of the patients from whom we had occupational therapy information were currently receiving occupational therapy (i.e., since 9-1-58). The percentage was higher in urban (16.91%) than in rural (6.85%) areas (Table 3.10.3.1.). Nearly all patients receiving occupational therapy received it at least once a week (Table 3.10.3.2 ). The sources of current occupational therapy are listed in Table 3.10.3.3. The most frequent source is the school, predominantly for children in urban areas.

Slightly more than one-tenth of the total number of patients from whom we have occupational therapy information were currently receiving occupational therapy. Because the most frequent source is the schools, this particular service is concentrated to a large extent on children of school age. Rural patients are again shown to be at a disadvantage.

TABLE 3.10.3.1. Present\* Occupational Therapy Status as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Present Occupational Therapy	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	115(16.91)	59( 6.85)	174(11.29)
No	565(83.09)	802(93.15)	1,367(88.71)
Total	680(44.13)	861(55.87)	1,541(100.00)

$$\chi^2 = 37.38, P < .0005$$

\*Defined as therapy after September 1, 1958.

TABLE 3.10.3.2. Frequency of Occupational Therapy Sessions for Those Who are Presently\* Receiving Therapy. Percentages Given in Parentheses.

Frequency of Therapy	Number
Daily	51(36.69)
3 to 6 times weekly	32(23.02)
2 times weekly	41(29.50)
Once weekly	12( 8.63)
4 or fewer times monthly	3( 2.16)
Total	139(100.00)

\*Defined as therapy after September 1, 1958.

TABLE 3.10.3.3. Source or Sources of Current\* Occupational Therapy as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Source	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
School	63(54.31)	19(35.19)	82(48.24)
Private	35(30.17)	15(27.78)	50(29.41)
Public hospital	6( 5.17)	9(16.67)	15( 8.82)
State hospital	5( 4.31)	6(11.11)	11( 6.47)
Public health agency	2( 1.72)	4( 7.41)	6( 3.53)
Private hospital	4( 3.45)	1( 1.85)	5( 2.94)
"Other private"	1( .86)	0( 0 )	1( .59)
Total	116(68.24)	54(31.76)	170(100.00)

\*Defined as therapy after September 1, 1958

### 3.10.4 Status of Present Speech Therapy Service

A total of 12.95% of the patients for whom we have information were currently receiving speech therapy (i.e., since 9-1-58). The percentage was higher in urban (16.19%) than in rural (10.46%) areas. (See Table 3.10.4.1.) Most patients receiving speech therapy received it at least once a week. (See Table 3.10.4.2.) The sources of current speech therapy

are listed in Table 3.10.4.3 and indicates that the school is the most frequent source of speech therapy.

Slightly more than one-tenth of the total number of patients from whom we have speech therapy information were currently receiving speech therapy. Rural patients are at a disadvantage. Here again, the schools represent the primary source of speech therapy, and the service, therefore, is concentrated on children of school age to a large extent.

TABLE 3.10.4.1. Present\* Speech Therapy Status as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Present Speech Therapy	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	108(16.19)	91(10.46)	199(12.95)
No	559(83.81)	779(89.54)	1,338(87.05)
Total	667(43.40)	870(56.60)	1,537(100.00)

$$\chi^2_1 = 10.50, P \leq .001$$

\*Defined as therapy after September 1, 1958.

TABLE 3.10.4.2. Frequency of Present\* Speech Therapy Sessions. Percentages Given in Parentheses.

Frequency of Sessions	Number
Daily	40(24.39)
3 to 6 times per week	29(17.68)
2 times per week	60(36.59)
Once a week	25(15.24)
4 or fewer times a month	10( 6.10)
Total	164(100.00)

\*Defined as therapy after September 1, 1958.

TABLE 3.10.4.3. Sources of Current\* Speech Therapy as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Source	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
School	83(74.10)	52(57.72)	135(66.82)
Private	16(14.28)	12(13.33)	28(13.86)
Public hospital	5( 4.46)	5( 5.56)	10( 4.95)
"Other private"	2( 1.79)	8( 8.89)	10( 4.95)
Public health agency	2( 1.79)	7( 7.78)	9( 4.46)
Camp	1( .89)	3( 3.33)	4( 1.98)
State hospital	2( 1.79)	1( 1.11)	3( 1.48)
Other	1( 1.89)	2( 2.22)	3( 1.48)
Total	112(55.43)	90(44.55)	202(100.00)

\*Defined as therapy after September 1, 1958.

### 3.11 EDUCATIONAL STATUS OF PATIENTS

#### 3.11.1 Ability of the Patient to Learn

The questionnaire contained an item requesting information on the patient's ability to learn. The respondent was asked to classify the patient's ability to learn as either a "Fast Learner", "Normal Learner", "Slow Learner", "Moderately Retarded", or "Severely Retarded". It is recognized that the data reported must be questioned with respect to reliability and that the response to an item like this is probably not made independently of other considerations, such as severity of handicap.

With these remarks in mind, Tables 3.11.1.1 and 3.11.1.2 are presented. Inspection of Table 3.11.1.2 shows the relationship between severity of handicap and ability to learn. Few patients who were considered to be fast learners were severely handicapped while very few severely retarded patients were mildly handicapped.

There was no difference in the reported ability of the patient to learn, by geographic location or by sex of the patient (Tables 3.11.1.1A and 3.11.1.2A in the appendix).

TABLE 3.11.1.1. Ability of the Patient to Learn as Related to Age of the Patient. Percentages Given in Parentheses.

Ability to Learn	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Fast	52(15.48)	119( 9.20)	45(12.16)	216(10.80)
Normal	101(30.06)	391(30.24)	112(30.27)	604(30.22)
Slow	49(16.58)	287(22.20)	61(16.49)	397(19.86)
Moderately Retarded	67(19.94)	237(18.33)	66(17.84)	370(18.51)
Severely Retarded	67(19.94)	259(20.03)	86(23.24)	412(20.61)
Total	336(16.81)	1,293(64.68)	370(18.51)	1,999(100.00)

$\chi^2 = 22.81, P < .005$

TABLE 3.11.1.2. Ability of the Patient to Learn as Related to Severity of Handicap. Percentages Given in Parentheses.

Ability to Learn	SEVERITY			Total
	Mild	Moderate	Severe	
Fast	109(17.78)	88( 8.48)	8( 3.21)	205(10.79)
Normal	285(46.49)	266(25.63)	16( 6.43)	567(29.84)
Slow	150(24.47)	220(21.19)	10( 4.02)	380(20.00)
Moderately Retarded	62(10.11)	257(24.76)	29(11.65)	348(18.32)
Severely Retarded	7( 1.14)	207(19.94)	186(74.70)	400(21.05)
Total	613(32.26)	1,038(54.63)	249(13.11)	1,900(100.00)

$\chi^2 = 702.25, P < .0005$

### 3.11.2 Education of School-Aged Children (5 to 21 years)

At the time the information on these patients was collected slightly less than two-thirds (63.48%) were currently in school. Nearly twenty-eight percent were in elementary school (kindergarten through grade 6) while nearly eighteen percent were in junior or senior high school. About two percent were presently in college (Table 3.11.2.1).

There were some differences in the various age groups. While almost 70% of the children aged 5 to 10 years and 10 to 15 years were in school, only 48% of those in the age group 15 to 21 were in school. (See Table 3.11.2.1.)

There were some differences by severity of handicap. Nearly 86% of the mildly handicapped were in school, in contrast to 59.74% of the moderately handicapped and only 8.39% of the severely handicapped. A small percentage of the children and youth who were moderately handicapped were in junior high school or beyond. None of the severely handicapped were beyond the kindergarten level (Table 3.11.2.2).

There were some differences by geographic distribution. Slightly over 40% of the rural children were not attending school, in contrast to 31.45% of the urban children. Nearly 23% of the children in urban areas were ungraded while this percentage was 11.75 for children in rural areas. This probably indicates an area difference in facilities available for ungraded children. (See Table 3.11.2.3.)

TABLE 3.11.2.1. Relationship of Present Grade in School with Present Age of the Patient. Percentages Given in Parentheses.

Present Grade	PRESENT AGE				Total
	Under 5*	5 to 10	10 to 15	15 to 21	
Not presently attending school	46(47.42)	144(30.12)	138(30.53)	157(52.16)	485(36.52)
Ungraded	9( 9.28)	87(18.20)	98(21.68)	24( 7.97)	218(16.42)
Kindergarten	33(34.02)	16( 3.35)	0( 0 )	0( 0 )	49( 3.69)
1st or 2nd grade	9( 9.28)	92(19.24)	3( .66)	1( .33)	105( 7.91)
3rd or 4th grade	0( 0 )	97(20.29)	16( 3.54)	0( 0 )	113( 8.51)
5th or 6th grade	0( 0 )	41( 8.58)	58(12.83)	1( .33)	100( 7.53)
7th or 8th grade	0( 0 )	1( .21)	74(16.37)	4( 1.33)	79( 5.95)
High school	0( 0 )	0( 0 )	64(14.16)	92(30.56)	156(11.75)
College	0( 0 )	0( 0 )	1( .22)	22( 7.31)	23( 1.73)
Total	97( 7.30)	478(35.99)	452(34.04)	301(22.67)	1,328(100.00)

\*The individuals under 5 in this group, particularly those in the 1st and 2nd grade, suggest a classification error on our part. Age was determined under the assumption that all forms were filled out on January 1, 1958. Certainly this assumption introduces slight errors in age classification, particularly for those forms received well after that date.

Analysis of present school attendance as related to presence of visual defects produced a significant  $\chi^2$  (Table 3.11.2.4). The comparison of present school attendance as related to the presence or absence of hearing defects shows little variation, although children with hearing defects were more likely to be ungraded than children free of such defects (Table 3.11.2.5).

As would be expected, analysis of school attendance by reported ability to learn revealed some differences. The fast and normal learners were more likely to be attending school than the other three groups. Only 13.96% of the severely retarded and 58.62% of the moderately retarded

TABLE 3.11.2.2. Relationship of Present Grade in School with Severity of Handicap. Percentages Given in Parentheses.

Present Grade	SEVERITY			Total
	Mild	Moderate	Severe	
Not presently attending school	65(13.77)	265(40.26)	142(91.61)	472(36.72)
Ungraded	37( 7.84)	164(24.92)	12( 7.74)	213(16.58)
Kindergarten	9( 1.91)	38( 5.78)	1( .65)	48( 3.74)
1st or 2nd grade	43( 9.11)	59( 8.97)	0( 0 )	102( 7.94)
3rd or 4th grade	72(15.25)	39( 5.93)	0( 0 )	111( 8.64)
5th or 6th grade	62(13.14)	33( 5.02)	0( 0 )	95( 7.39)
7th or 8th grade	51(10.81)	20( 3.04)	0( 0 )	71( 5.53)
High school	115(24.36)	35( 5.32)	0( 0 )	150(11.67)
College	18( 3.81)	5( .76)	0( 0 )	23( 1.79)
Total	472(36.73)	658(51.21)	155(12.06)	1,285(100.00)

TABLE 3.11.2.3. Relationship of Present Grade in School with Geographic Location of the Patient. Percentages Given in Parentheses.

Present Grade	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Not presently attending school	173(31.45)	316(40.36)	489(36.68)
Ungraded	126(22.91)	92(11.75)	218(16.35)
Kindergarten	27( 4.91)	22( 2.81)	49( 3.68)
1st or 2nd grade	45( 8.18)	61( 7.79)	106( 7.95)
3rd or 4th grade	50( 9.09)	63( 8.05)	113( 8.48)
5th or 6th grade	41( 7.45)	59( 7.53)	100( 7.50)
7th or 8th grade	24( 4.36)	55( 7.02)	79( 5.93)
High school	55(10.00)	101(12.90)	156(11.70)
College	9( 1.64)	14( 1.79)	23( 1.73)
Total	550(41.26)	783(58.74)	1,333(100.00)

$$\chi^2_B = 42.16, P < .0005$$

attended school, in contrast to 75.52% of the slow learners and about 84% of the normal and fast learners. It is interesting to note that even 15% of those reported with normal or above normal ability to learn did not attend school. (See Table 3.11.2.6.)

No significant difference was found when school attendance was classed by sex of the patient. (See Table 3.11.2.1A.)

TABLE 3.11.2.4. Relationship of Present Grade in School with Presence or Absence of Eye Defects. Percentages Given in Parentheses.

Present Grade	EYE DEFECT		Total
	Yes*	No	
Not presently attending school	182(32.27)	276(37.81)	458(35.39)
Ungraded	96(17.02)	120(16.44)	216(16.69)
Kindergarten	18( 3.19)	31( 4.25)	49( 3.79)
1st thru 6th grade	129(22.87)	186(25.48)	315(24.34)
7th or 8th grade	38( 6.74)	40( 5.48)	78( 6.03)
High school	84(14.89)	71( 9.73)	155(11.98)
College	17( 3.01)	6( .82)	23( 1.78)
Total	564(43.59)	730(56.41)	1,294(100.00)

$$\chi^2_{\text{df}} = 21.19, P < .005$$

\*Classed in this group are 18 individuals who were considered blind; 14 of whom did not presently attend school; 1 who was ungraded, and 3 who were in elementary school.

TABLE 3.11.2.5. Relationship of Present Grade in School with Presence or Absence of Hearing Defects. Percentages Given in Parentheses.

Present Grade	HEARING DEFECT		Total
	Yes*	No	
Not presently attending school	36(27.27)	432(37.08)	468(36.08)
Ungraded	32(24.24)	181(15.54)	213(16.42)
Kindergarten	3( 2.27)	44( 3.78)	47( 3.62)
1st thru 6th grade	35(26.51)	280(24.03)	315(24.29)
7th or 8th grade	9( 6.82)	68( 5.84)	77( 5.94)
High school	16(12.12)	139(11.93)	155(11.95)
College	1( .76)	21( 1.80)	22( 1.70)
Total	132(10.18)	1,165(89.82)	1,297(100.00)

$$\chi^2_{\text{df}} = 10.36, .10 < P < .20$$

\*Classed in this group are 8 patients who were considered deaf; 1 of whom was ungraded; 2 who were in elementary school, and 5 who did not presently attend school.

It is significant that about one-third of the school-aged group were currently not attending school, including 15% of the children reported to be normal with respect to ability to learn. The special needs of the teenage group for more school sources are demonstrated. Rural school children are at a disadvantage, as are the moderately and severely physically disabled.

TABLE 3.11.2.6. Relationship of Present Grade in School with Ability to Learn. Percentages Given in Parentheses.

Present Grade	ABILITY TO LEARN					Total
	Fast Learner	Normal Learner	Slow Learner	Moderately Retarded	Severely Retarded	
Not presently attending school	19(15.97)	59(15.21)	71(24.48)	96(41.38)	222(86.04)	467(36.29)
Ungraded	5( 4.20)	22( 5.67)	50(17.24)	95(40.95)	35(13.57)	207(16.08)
Kindergarten	8( 6.72)	21( 5.41)	15( 5.17)	4( 1.72)	0( 0 )	48( 3.73)
1st thru 6th grade	50(42.02)	143(36.86)	95(32.76)	25(10.78)	1( .39)	314(24.40)
7th or 8th grade	13(10.92)	43(11.08)	18( 6.21)	3( 1.29)	0( 0 )	77( 5.98)
High school	20(16.81)	84(21.65)	38(13.10)	9( 3.88)	0( 0 )	151(11.73)
College	4( 3.37)	16( 4.12)	3( 1.03)	0( 0 )	0( 0 )	23( 1.79)
Total	119( 9.25)	388(30.15)	290(22.53)	232(18.03)	258(20.05)	1,287(100.00)

### 3.11.2.1 Type of Class or School in Current School Attendance

Fifty-eight percent of the children for whom we have education information were attending a regular class in regular schools, 30.40% were in a special day school, and the remainder, 11.38%, in a special class in a regular school.

TABLE 3.11.2.1.1. Type of School Presently Being Attended as Related to the Geographic Location of the Patient. Percentages Given in

Type of School Attended	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Regular class in regular school	155(40.90)	341(72.09)	496(58.22)
Special class in a regular school	41(10.82)	56(11.84)	97(11.38)
Special day school	183(48.28)	76(16.07)	259(30.40)
Total	379(44.48)	473(55.52)	852(100.00)

$$\chi^2_2 = 107.22, P < .0005$$

There were some differences by geographic distribution. A higher percentage of children in rural areas were in regular class and a lower percentage in special day schools than urban children (See Table 3.11.2.1.1.)

There are also differences by age of the children, although the distribution for patients aged 5 to 10 and 10 to 15 is quite similar. The majority of youth aged 15 to 21 years were in regular class (73.95%), and a lower percentage (15.49%) were in a special day school, compared with children aged 5 to 10 or children aged 10 to 15 (Table 3.11.2.1.2).

The relationship of severity of handicap to type of school attended is given in Table 3-11.2.1.3. Most of the mildly handicapped children were in regular class, (82.81%), while 50.38% of the moderately handicapped were in a special day school and one-third (33.84%) were in a regular class.

It is of some interest that there is no large difference in the school

TABLE 3.11.2.1.2. Type of School Presently Being Attended as Related to Present Age of the Patient. Percentages Given in Parentheses.

Type of School Attended	PRESENT AGE				Total
	Under 5*	5 to 10	10 to 15	15 to 21	
Regular class in regular school	22(42.31)	188(54.81)	181(57.46)	105(73.95)	496(58.22)
Special class in a regular school	3( 5.77)	46(13.41)	33(10.48)	15(10.56)	97(11.38)
Special day school	27(51.92)	109(31.78)	101(32.06)	22(15.49)	259(30.40)
Total	52( 6.10)	343(40.26)	315(36.97)	142(16.67)	852(100.00)

$$\chi^2_4 = 30.78, P < .0005$$

\*This group was eliminated for the  $\chi^2$  analysis.

TABLE 3.11.2.1.3. Type of School Presently Being Attended as Related to Severity of Handicap. Percentages Given in Parentheses.

Type of School Attended	SEVERITY			Total
	Mild	Moderate	Severe	
Regular class in regular school	342(82.81)	133(33.84)	1( 8.33)	476(58.19)
Special class in a regular school	32( 7.75)	62( 7.75)	0( 0 )	94(11.49)
Special day school	39( 9.44)	198(50.38)	11(91.67)	248(30.32)
Total	413(50.49)	393(48.04)	12( 1.47)	818(100.00)

$$\chi^2_4 = 227.29, P < .0005$$

placement of those children with and without an eye defect. This may be due to the fact that some of the eye defects may be of a very mild nature. A special study is indicated, including a study of the 223 children with an eye defect who are in regular class and the 112 children with an eye defect who are in a special day school. Incidentally, it is of interest also that two blind children were in regular class. (See Table 3.11.2.1.4.)

Over 39% of those with hearing defects were in regular class, 19.59% were in a special class in a regular school and 41.23% were in a special day school. These percentages may be compared with the group free of hearing defects. There are some marked differences. (See Table 3.11.2.1.5.) It would be of some interest to study the children with hearing defects who were in special day schools.

As would be expected, the more retarded the child, the more frequent the placement in a special class or special day school. Nevertheless, 128 "slow learners" and 26 moderately retarded children were in regular class, reflecting a need for additional special classes or more careful placement of children within a school. (See Table 3.11.2.1.6.)

TABLE 3.11.2.1.4. Type of School Patient is Presently Attending as Related to Presence or Absence of Visual Defects. Percentages Given in Parentheses.

Type of School Attended	EYE DEFECT		Total
	Yes*	No	
Regular class in regular school	223(58.38)	268(58.26)	491(58.31)
Special class in regular school	47(12.30)	50(10.87)	97(11.52)
Special day school	112(29.32)	142(30.87)	254(30.17)
Total	382(45.37)	460(54.63)	842(100.00)

$$\chi^2 = .54, .70 < P < .80$$

*\*This includes a total of 5 blind individuals, 2 of whom attended regular class in regular school, 2 who attended special class in regular school and 1 who attended a special day school.*

TABLE 3.11.2.1.5. Type of School Patient is Presently Attending as Related to Presence or Absence of Hearing Defects. Percentages Given in Parentheses.

Type of School Attended	HEARING DEFECT		Total
	Yes	No	
Regular class in regular school	38(39.18)	451(61.03)	489(58.50)
Special class in regular school	19(19.59)	77(10.42)	96(11.48)
Special day school	40(41.23)	211(28.55)	251(30.02)
Total	97(11.60)	739(88.40)	836(100.00)

$$\chi^2 = 17.88, P < .0005$$

There is no difference in type of school attended as related to sex of the patient. (Table 3.11.2.1.1A in the appendix.)

In conclusion some special needs are demonstrated. They are:

- 1) The need of rural children for more special classes;
  - 2) The need of the moderately disabled for special classes;
- and
- 3) A study of the services needed by cerebral palsied children with visual or hearing impairment.

TABLE 3.11.2.1.6. Type of School Patient is Presently Attending as Related to Ability to Learn. Percentages Given in Parentheses.

Type of School Attended	ABILITY TO LEARN					Total
	Fast Learner	Normal Learner	Slow Learner	Moderately Retarded	Severely Retarded	
Regular class in regular school	77(75.49)	257(76.94)	128(57.66)	26(19.40)	0( 0 )	488(59.07)
Special class in regular school	1( .98)	20( 5.99)	27(12.16)	40(29.85)	5(14.71)	93(11.26)
Special day school	24(23.53)	57(17.07)	67(30.18)	68(50.75)	29(85.29)	245(29.67)
Total	102(12.35)	334(40.43)	222(26.88)	134(16.22)	34( 4.12)	826(100.00)

### 3.11.2.2 Home Instruction

The number of children reported to have a home teacher was small, totaling only 38. The largest group was ungraded (23). Since many of these children have multiple handicaps (e.g., visual, hearing, and intellectual) this group of children should be studied. (See Tables 3.11.2.2.1 through 3.11.2.2.3.)

It is of interest that of the 38 children with home instruction, 3 lived in an urban area and 33 in a rural area. Of the 38 children one was under five years of age, fourteen were 5 to 10 years of age, fifteen were 10 to 15 years of age, and eight were 15 to 21 years of age.

Of the 262 school-aged children (5 to 21) in institutions, only 50 were reported to be receiving any education (19.08%). This situation should be reviewed.

It is desirable that as many children as possible receive their education in school. Nevertheless, home instruction can serve a useful purpose for certain children. When the entire educational plan for children with cerebral palsy is reviewed, the question of provision of home instruction should be included.

TABLE 3.11.2.2.1. Visual Status Among Patients Reported to Have a Home Teacher. Percentages Given in Parentheses.

Present Grade	EYE DEFECT		Total
	Yes	No	
Ungraded	14(77.78)	9(45.00)	23(60.52)
1st thru 8th grade	4(22.22)	10(50.00)	14(36.84)
High school	0( 0 )	1( 5.00)	1( 2.63)
<b>Total</b>	<b>18(47.37)</b>	<b>20(52.63)</b>	<b>38(100.00)</b>

$\chi^2_2 = 4.56, P = .10$

TABLE 3.11.2.2.2. Hearing Status Among Patients Reported to Have a Home Teacher. Percentages Given in Parentheses.

Present Grade	HEARING DEFECT		Total
	Yes	No	
Ungraded	1(25.00)	22(64.71)	23(60.52)
1st thru 8th grade	3(75.00)	11(32.35)	14(36.84)
High school	0( 0 )	1( 2.94)	1( 2.63)
<b>Total</b>	<b>4(10.53)</b>	<b>34(89.47)</b>	<b>38(100.00)</b>

$\chi^2_2 = 2.83, .20 < P < .30$

TABLE 3.11.2.2.3. Learning Ability Among Patients Reported to Have a Home Teacher. Percentages Given in Parentheses.

Present Grade	LEARNING ABILITY			Total
	Fast or Normal Learner	Slow Learner	Moderately Retarded	
Ungraded	7(46.67)	6(50.00)	7(87.50)	20(57.14)
1st thru 8th grade	7(46.67)	6(50.00)	1(12.50)	14(40.00)
High school	1( 6.67)	0( 0 )	0( 0 )	1( 2.86)
<b>Total</b>	<b>15(42.86)</b>	<b>12(34.29)</b>	<b>8(22.86)</b>	<b>35(100.00)</b>

### 3.11.2.3 Level of Education of School-Aged Children not Presently in School

Of the 1,403 school-aged patients for whom we have education information, 297 had never attended school, while 146 patients, although not presently attending school, had attended school in the past. (See Tables 3.11.2.3.1 through 3.11.2.3.3.) As would be expected, the more mild the degree of handicap, the greater the proportion who have ever attended school. None of the moderately handicapped attended school beyond high school, and none of the severely handicapped beyond the sixth grade. The proportion who attended school was greater for urban than for rural children. There was no sex difference in school attendance. (See Table 3.11.2.3.1A.)

TABLE 3.11.2.3.1. Highest Grade Completed as Related to Present Age of the Patient. Percentages Given in Parentheses.

Highest Grade Completed	PRESENT AGE				Total
	Under 5	5 to 10	10 to 15	15 to 21	
Never attended school	41(97.62)	106(79.70)	98(79.03)	52(36.11)	297(67.04)
Ungraded	1( 2.38)	20(15.04)	19(15.32)	31(21.53)	71(16.03)
Kindergarten	0( 0 )	3( 2.26)	1( .81)	2( 1.39)	6( 1.35)
1st thru 6th grade	0( 0 )	4( 3.00)	4( 3.23)	11( 7.64)	17( 4.29)
7th or 8th grade	0( 0 )	0( 0 )	2( 1.61)	10( 6.94)	12( 2.71)
High school	0( 0 )	0( 0 )	0( 0 )	37(25.70)	37( 8.35)
College	0( 0 )	0( 0 )	0( 0 )	1( .69)	1( .23)
Total	42( 9.48)	133(30.02)	124(27.99)	144(32.51)	443(100.00)

TABLE 3.11.2.3.2. Highest Grade Completed as Related to Severity of Handicap. Percentages Given in Parentheses.

Highest Grade Completed	SEVERITY			Total
	Mild	Moderate	Severe	
Never attended school	6( 9.84)	164(67.21)	117(94.35)	287(66.90)
Ungraded	10(16.39)	53(21.72)	6( 4.84)	69(16.08)
Kindergarten	1( 1.64)	5( 2.05)	0( 0 )	6( 1.40)
1st thru 6th grade	15( 8.20)	12( 4.92)	1( .81)	18( 4.20)
7th or 8th grade	9(14.75)	3( 1.23)	0( 0 )	12( 2.80)
High school	29(47.54)	7( 2.87)	0( 0 )	36( 8.39)
College	1( 1.64)	0( 0 )	0( 0 )	1( .23)
Total	61(14.22)	244(56.88)	124(28.90)	429(100.00)

TABLE 3.11.2.3.3. Highest Grade Completed as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Highest Grade Completed	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Never attended school	94(60.65)	203(70.49)	297(67.04)
Ungraded	39(25.16)	32(11.11)	71(16.03)
Kindergarten	1( .65)	5( 1.74)	6( 1.35)
1st thru 6th grade	5( 3.23)	14( 4.86)	19( 4.29)
7th or 8th grade	3( 1.94)	9( 3.12)	12( 2.71)
High school	13( 8.39)	24( 8.33)	37( 8.35)
College	0( 0 )	1( .35)	1( .23)
Total	155(34.99)	288(65.01)	443(100.00)

$$\chi^2_6 = 16.45, P < .025$$

### 3.11.3 Previous Education of Adult Patients

Nearly 32% of the total group of adult patients on whom there is information had never attended school. Eleven and one-half percent had spent 1 to 5 years in school, 7.66% had spent 6 to 7 years in school, and 7.89% had spent eight years in school. Nine and one-half percent had spent 9 to 11 years in school, 11.72% had spent 12 years in school, and 20.09% had spent 13 or more years in school. (See Table 3.11.3.1.)

There were some geographic differences. There was a higher percentage of rural adults (38.47%) who had never attended school than urban adults (22.82%). Furthermore, patients with urban home addresses were more likely to have attended school longer than rural patients. (See Table 3.11.3.1.)

TABLE 3.11.3.1. Total Number of Years Spent in School as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Total No. of Years Spent in School	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Never attended school	42(22.82)	90(38.47)	132(31.59)
1 - 5 years	22(11.96)	26(11.11)	48(11.48)
6 - 7 years	13( 7.07)	19( 8.12)	32( 7.66)
8 years	11( 5.98)	22( 9.40)	33( 7.89)
9 - 11 years	19(10.33)	21( 8.97)	40( 9.57)
12 years	25(13.58)	24(10.26)	49(11.72)
13 years	13( 7.07)	7( 2.99)	20( 4.78)
14 - 20 years	39(21.19)	25(10.68)	64(15.31)
<b>Total</b>	<b>184(44.02)</b>	<b>234(55.98)</b>	<b>418(100.00)</b>

$\chi^2 = 21.92, P < .005$

TABLE 3.11.3.2. Total Number of Years Spent in School as Related to Severity of Handicap. Percentages Given in Parentheses.

Total No. of Years Spent in School	SEVERITY			Total
	Mild	Moderate	Severe	
Never attended school	5( 4.46)	72(31.03)	50(89.28)	127(31.75)
1 - 5 years	6( 5.36)	38(16.38)	2( 3.57)	46(11.50)
6 - 7 years	9( 8.04)	22( 9.48)	0( 0 )	31( 7.75)
8 years	10( 8.93)	22( 9.48)	0( 0 )	32( 8.00)
9 - 11 years	16(14.29)	17( 7.33)	2( 3.57)	35( 8.75)
12 years	25(22.31)	21( 9.05)	1( 1.79)	47(11.75)
13 years	14(12.50)	6( 2.59)	0( 0 )	20( 5.00)
14 - 20 years	27(24.11)	34(14.66)	1( 1.79)	62(15.50)
<b>Total</b>	<b>112(28.00)</b>	<b>232(58.00)</b>	<b>56(14.00)</b>	<b>400(100.00)</b>

There were some differences by severity of handicap. Most of the severely handicapped (89.28%) never attended school, while 31.03% of the moderately handicapped and 4.46% of the mildly handicapped had never done so. In general, the mildly handicapped had attended school for more years than the moderately or severely handicapped. (See Table 3.11.3.2.)

Fourteen percent of the adults for whom we had information had attended college; an additional 14.18% had completed senior high school. The proportion completing senior high school and attending college was greater among urban patients than among rural patients. (See Table 3.11.3.3.) The proportion completing high school and attending college was also higher for the mildly handicapped than for the moderately or

TABLE 3.11.3.3. Highest Grade Completed as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Highest Grade Completed	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Never attended school	42(22.83)	90(37.66)	132(31.21)
Ungraded	33(17.93)	31(12.97)	64(15.13)
1st - 5th grade	9( 4.89)	17( 7.11)	26( 6.15)
6th - 7th grade	9( 4.89)	20( 8.37)	29( 6.86)
8th grade	11( 5.98)	19( 7.95)	30( 7.09)
9th - 11th grade	12( 6.52)	10( 4.18)	22( 5.20)
12th grade	33(17.93)	27(11.30)	60(14.18)
1st year college	13( 7.07)	11( 4.60)	24( 5.67)
2nd - 5th year college	22(11.96)	14( 5.86)	36( 8.51)
Total	184(43.50)	239(56.50)	423(100.00)

$$\chi^2_B = 22.24, P < .005$$

TABLE 3.11.3.4. Highest Grade Completed as Related to Severity of Handicap. Percentages Given in Parentheses.

Highest Grade Completed	SEVERITY			Total
	Mild	Moderate	Severe	
Never attended school	5( 4.35)	72(30.90)	50(89.28)	127(31.44)
Ungraded	8( 6.96)	48(20.60)	4( 7.14)	60(14.85)
1st - 5th grade	4( 3.48)	20( 8.58)	0( 0 )	24( 5.94)
6th - 7th grade	11( 9.57)	16( 6.87)	0( 0 )	27( 6.68)
8th grade	15(13.04)	15( 6.44)	0( 0 )	30( 7.43)
9th - 11th grade	10( 8.70)	8( 3.43)	0( 0 )	18( 4.46)
12th grade	28(24.34)	30(12.88)	1( 1.79)	59(14.60)
1st year college	15(13.04)	9( 3.86)	0( 0 )	24( 5.94)
2nd - 5th year college	19(16.52)	15( 6.44)	1( 1.79)	35( 8.66)
Total	115(28.47)	233(57.67)	56(13.86)	404(100.00)

severely handicapped. Only two severely handicapped adults completed senior high school, and one of these had attended college. (See Table 3.11.3.4.)

Table 3.11.3.5 gives the relationship of highest grade reached as compared to the number of years necessary to reach that grade. The mean number of years spent in reaching a given grade are given in the right hand column of the table.

There was no sex difference in the previous education of adult patients (Table 3.11.3.1A).

Only 9 adults had ever had home instruction; of this number, 6 lived in urban areas, and 3 in rural areas.

It is significant that about one-third of the adult group had never attended school. The rural group was at a greater disadvantage than the urban group. Few severely handicapped ever attended school, while about one-third of the moderately handicapped and 4.5% of the mildly handicapped had never attended school. On the other hand, 14% of the adults had attended college, and another 14% had completed senior high school.

TABLE 3.11.3.5. Relationship of Highest Grade Completed to Total Number of Years Spent in School.

Highest Grade Completed	YEARS SPENT IN SCHOOL							Mean No. of Years
	1-5	6-8	9-11	12	13	14-20	Total	
Ungraded	23	16	9	1	0	4	53	6.38
1st - 5th grade	18	4	0	0	0	0	22	4.14
6th - 8th grade	1	41	12	2	0	1	57	8.05
9th - 11th grade	0	0	15	2	1	4	22	11.59
12th grade	0	0	2	43	4	9	58	12.40
1st year college	0	0	0	0	14	10	24	13.58
2nd - 5th year college	0	0	0	0	0	36	36	15.86
<b>Total</b>	<b>42</b>	<b>61</b>	<b>38</b>	<b>48</b>	<b>19</b>	<b>64</b>	<b>272</b>	

### 3.12 VOCATIONAL ASSISTANCE AND STATUS

#### 3.12.1 Vocational Assistance

Only 8.81% of the patients from whom we have information have ever received any vocational assistance. The percentage is higher for urban patients (11.76%) than for rural patients (6.57%), although it is small in both groups. (See Table 3.12.1.1.) Only 22.22% of the adult patients (over 21 years of age) have ever received any vocational assistance. (See Table 3.12.1.2.) Only fifteen and one-half percent of the mildly handicapped, 6.46% of the moderately handicapped, and 1.81% of severely handicapped have ever received such assistance. (See Table 3.12.1.3.) There was no sex difference in vocational assistance received (Table 3.12.1.1A in the appendix).

The State Office of Vocational Rehabilitation provided vocational assistance for 91 patients, voluntary health agencies (the UCP Centers, and Kenney Institute, etc.) for 31 patients, the schools for 11 patients, sheltered workshops for 2 patients, and miscellaneous sources for 11 patients. (See Table 3.12.1.4.)

It is of some interest that of the patients employed full time, 47 out of 97 had received vocational assistance; of those employed part time, 11 out of 35 had received vocational assistance.

The types of vocational assistance most frequently received include training, testing and job placement. (See Table 3.12.1.5.)

In response to the item whether vocational assistance is needed now, 11.41% of respondents indicated such a present need. (See Table

TABLE 3.12.1.1. History of Vocational Assistance Status as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Has Patient Ever Had Vocational Assistance	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	80(11.76)	59( 6.57)	139( 8.81)
No	600(88.24)	839(93.43)	1,439(91.19)
Total	680(43.09)	898(56.91)	1,578(100.00)

$$\chi^2_1 = 12.36, P < .0005$$

TABLE 3.12.1.2. History of Vocational Assistance Status as Related to the Age of the Patient. Percentages Given in Parentheses.

Has Patient Ever Had Vocational Assistance	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	3*( 1.22)	70( 6.78)	66(22.22)	139( 8.82)
No	243(98.78)	963(93.22)	231(77.78)	1,437(91.18)
Total	246(15.61)	1,033(65.54)	297(18.84)	1,576(100.00)

$$\chi^2_2 = 89.39, P < .0005$$

*\*These three reports are most likely the result of an error by the respondent in filling out the form or an age classification error (see Appendix 3, part 3).*

TABLE 3.12.1.3. History of Vocational Assistance Status as Related to Severity of Handicap. Percentages Given in Parentheses.

Has Patient Ever Had Vocational Assistance	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	79(15.49)	52( 6.46)	3( 1.81)	134( 9.05)
No	431(84.51)	753(93.54)	163(98.19)	1,347(90.95)
Total	510(34.44)	805(54.35)	166(11.21)	1,481(100.00)

$$\chi^2_2 = 42.86, P < .0005$$

3.12.1.6.) Specification of such a need by age of the patient indicates that a slightly higher proportion of adults listed such needs (17.16%) than in the group aged 5 to 21 years (12.76%). Specification of such needs was highest in the mildly handicapped (21.38%), next highest in the moderately handicapped (10.26%), and lowest in the severely handicapped (2.44%). The types of vocational assistance most frequently needed now include training, job placement and guidance. (See Table 3.12.1.7.)

In conclusion, a low percentage of adult patients have received vocational assistance. Rural patients are at a disadvantage. The need for increased vocational assistance services is demonstrated.

TABLE 3.12.1.4. Source of Vocational Assistance as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Source	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Office of Vocational Rehabilitation	42(49.41)	49(80.32)	91(62.34)
Voluntary health agencies*	26(30.59)	5( 8.20)	31(21.23)
School	8( 9.41)	3( 4.92)	11( 7.53)
Sheltered Workshop	2( 2.35)	0( 0 )	2( 1.37)
Other**	7( 8.24)	4( 6.56)	11( 7.53)
Total	85(58.22)	61(41.78)	146***(100.00)

\*Includes such agencies as Sister Kenny Institute, Cerebral Palsy Centers, and Minnesota Homecraft Center.

\*\*Other includes such sources as state institutions, public hospitals and Goodwill Industries.

\*\*\*This totals more than 139 because some patients were receiving assistance from more than one source.

TABLE 3.12.1.5. Type of Vocational Assistance Given as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Type of Assistance	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Training	24(26.08)	22(30.56)	46(28.05)
Testing	11(11.96)	15(20.82)	26(15.85)
Job placement	20(21.74)	3( 4.17)	23(14.02)
Tuition payment for training	9( 9.78)	13(18.06)	22(13.41)
Guidance	8( 8.70)	8(11.11)	16( 9.76)
Sheltered Workshop (employment)	11(11.96)	2( 2.78)	13( 7.93)
Financial	5( 5.43)	8(11.11)	13( 7.93)
Other	4( 4.35)	1( 1.39)	5( 3.05)
Total	92(56.10)	72(43.90)	164*(100.00)

\*This totals more than 139 — the number of patients who have had vocational assistance — because some patients received more than one type of assistance.

TABLE 3.12.1.6. Need for Vocational Assistance Now, as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Is Vocational Assistance Needed Now	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	61(12.30)	67(10.70)	128(11.41)
No	435(87.70)	559(89.30)	994(88.59)
Total	496(44.21)	626(55.79)	1,122(100.00)

$$\chi^2_1 = .55, .40 < P < .50$$

TABLE 3.12.1.7. Type of Vocational Assistance Needed Now as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Type	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Training	26(36.11)	32(38.55)	58(37.42)
Testing	5( 6.94)	6( 7.23)	11( 7.10)
Job placement	20(27.78)	14(16.87)	34(21.94)
Tuition payment for training	1( 1.39)	4( 4.82)	5( 3.23)
Guidance	14(19.44)	16(19.28)	30(19.35)
Sheltered Workshop employment	2( 2.78)	2( 2.41)	4( 2.58)
Financial	4( 5.56)	7( 8.43)	11( 7.10)
Other	0( 0 )	2( 2.41)	2( 1.29)
Total	72(46.45)	83(53.55)	155*(100.00)

*\*This totals more than 128 because some patients listed more than one type of vocational assistance needed.*

### 3.12.2. Current Employment Status

Only 7.71% of the total group of patients from whom we have employment information were currently employed. Among those who were employed, about two-thirds (67.53%) were employed on a full-time basis. The percentage of patients employed was higher in urban areas (11.71%) than in rural areas (4.94%). (See Table 3.12.2.1.) Over 22% of the adult patients for whom employment status information was available were currently employed, predominantly on a full-time basis. It is of some

TABLE 3.12.2.1. Employment Status as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Employment Status	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Not employed	724(88.29)	1,120(95.06)	1,844(92.29)
Employed part time	24( 2.93)	26( 2.21)	50( 2.50)
Employed full time	72( 8.78)	32( 2.72)	104( 5.21)
Total	820(41.04)	1,178(58.96)	1,998(100.00)

$$\chi^2_2 = 37.57, P < .0005$$

interest that only 15.14% of the mildly handicapped were currently employed. (See Tables 3.12.2.2 and 3.12.2.3.) Table 3.12.2.4 gives the employment status as related to sex of the patient.

The majority of the patients earned less than \$1,000, although five patients earned more than \$5,000 in 1958. (See Table 3.12.2.5).

The types of current employment are listed in Table 3.12.2.6. It is of interest that 62 of the 147 patients were described as doing manual labor.

In summary, about one-fifth (21.41%) of the entire adult group from whom we have completed questionnaires, were reported to be currently employed. The further need for increased vocational rehabilitation sources is demonstrated.

TABLE 3.12.2.2. Employment Status as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Employment Status	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Not employed	339(100.00)	1,207(94.89)	297(77.54)	1,840(92.28)
Employed part time	0( 0 )	32( 2.52)	18( 4.70)	50( 2.51)
Employed full time	0( 0 )	33( 2.59)	71(18.56)	104( 5.22)
Total	339(17.00)	1,272(63.79)	383(19.21)	1,994(100.00)

TABLE 3.12.2.3. Employment Status as Related to Severity of Handicap. Percentages Given in Parentheses.

Employment Status	SEVERITY			Total
	Mild	Moderate	Severe	
Not employed	499(84.86)	958(94.11)	242(99.59)	1,699(91.89)
Employed part time	30( 5.10)	18( 1.77)	0( 0 )	48( 2.60)
Employed full time	59(10.03)	42( 4.13)	1( .41)	102( 5.52)
Total	588(31.80)	1,018(55.06)	243(13.14)	1,849(100.00)

TABLE 3.12.2.4. Employment Status as Related to the Sex of the Patient. Percentages Given in Parentheses.

Employment Status	SEX		Total
	Male	Female	
Not employed	1,026(90.55)	818(94.56)	1,844(92.29)
Employed part time	36( 3.18)	14( 1.62)	50( 2.50)
Employed full time	71( 6.27)	33( 3.82)	104( 5.21)
Total	1,133(56.71)	865(43.29)	1,998(100.00)

$$\chi^2_2 = 6.51, P < .05$$

TABLE 3.12.2.5. Annual Earnings of Patients Employed Either Part Time or Full Time in 1958. Percentages Given in Parentheses.

Amount of Annual Earnings in 1958	Number of Patients
Less than \$1,000	72(55.82)
Between \$1,000 and \$2,000	24(18.60)
Between \$2,000 and \$3,000	16(12.40)
Between \$3,000 and \$4,000	12( 9.30)
\$5,000 and over	5( 3.88)
Total	129

TABLE 3.12.2.6. Type of Employment of Patients Employed Either Part Time or Full Time in 1958. Percentages Given in Parentheses.

Type	Number of Patients
Professional and Executive	10( 6.80)
Managerial	1( .68)
White collar	25(17.01)
Skilled labor	17(11.56)
Manual labor	62(42.18)
Homemaker	1( .68)
Farmhand	10( 6.80)
Other	21(14.29)
Total	147

### 3.13 PARTICIPATION IN RECREATIONAL ACTIVITIES

Over one-third (37.35%) of the patients who provided recreation information had participated in some type of recreational activity either at present or at some time in the past. The percentage was higher in urban than in rural areas. (See Table 3.13.1.) It was highest in the adult group (47.38%) and lowest in the group under 5 (9.40%). See Table 3.13.2. Table 3.13.3 shows the relationship of participation in recreational activities with severity of handicap. A higher percentage (54.10%) of the mildly handicapped participated in recreational activities than did the other two severity groups.

There is a sex difference in the attendance at recreational activities at the 5% level. (See Table 3.13.1A in the appendix.)

TABLE 3.13.1. Recreational Activities as Related to Geographic Location of the Respondent. Percentages Given in Parentheses.

Attends Activities	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	300(40.71)	351(34.89)	651(37.35)
No	437(59.29)	655(65.11)	1,092(62.65)
Total	737(42.28)	1,006(57.72)	1,743(100.00)

$$\chi^2_1 = 5.90, .01 < P < .025$$

The types of activities attended or performed are listed in Table 3.13.4. Note the high percentage of community activities that are furnished by athletic events.

In conclusion, the need for further provision of recreational activities is demonstrated. While it is needed for all patients, there is special need for more recreational services for rural patients and for the moderately and severely disabled. The special needs of children under 5 years of age must also be considered. Some consideration might also be given to increasing summer recreational activities.

TABLE 3.13.2. Recreational Activities as Related to Present Age of the Patient. Percentages Given in Parentheses.

Attends Activities	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	25( 9.40)	454(40.83)	172(47.38)	651(37.39)
No	241(90.60)	658(59.17)	191(52.62)	1,090(62.61)
Total	266(15.28)	1,112(63.87)	363(20.85)	1,741(100.00)

$\chi^2_2 = 110.12, P < .0005$

TABLE 3.13.3. Recreational Activities as Related to Severity of Handicap. Percentages Given in Parentheses.

Attends Activities	SEVERITY			Total
	Mild	Moderate	Severe	
Yes	284(54.10)	294(32.78)	46(21.20)	624(38.07)
No	241(45.90)	603(67.22)	171(78.80)	1,015(61.93)
Total	525(32.03)	897(54.73)	217(13.24)	1,639(100.00)

$\chi^2_2 = 94.04, P < .0005$

TABLE 3.13.4. Type of Recreational Activities Attended or Performed. Percentages Given in Parentheses.

Types of Activity	Frequency
Athletic activities	162(19.11)
Hospital or institutional activities	158(18.64)
School activities	129(15.21)
Community activities	100(11.79)
Spectator sports	73( 8.61)
Family activities	56( 6.60)
Church events	56( 6.60)
Voluntary agency activities	47( 5.54)
Camp	15( 1.77)
Television	15( 1.77)
Handiwork	5( .59)
Other	32( 3.77)
Total	848(100.00)

### 3.14 ASSISTANCE NEEDED BY FAMILIES

Almost one-half (46.40%) of the families responding to the item on need for services and assistance expressed some need for assistance. The expressed need was most frequent in urban areas and for children under five years of age. (See Tables 3.14.1 and 3.14.2, also Table 3.14.1A in the appendix.)

Five hundred and ten families listed one need, 209 listed two needs, 75 listed three needs and 32 listed four or more needs.

The types of specific needs are listed in Table 3.14.3. The most frequent were medical and related care and educational services.

It is significant that 46% of the families expressed the need for some type of assistance. From the list of needs expressed by families, it is evident that comprehensive, non-fragmented services are needed. It is also interesting to note that several families said they were unaware of the facilities available to them, indicating a need for community education as to the resources available.

TABLE 3.14.1. Need for Assistance or Service as Related to the Present Age of the Patient. Percentages Given in Parentheses.

Assistance Needed	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Yes	161(52.61)	533(47.17)	132(38.60)	826(46.46)
No	145(47.39)	597(52.83)	210(61.40)	952(53.54)
Total	306(17.21)	1,130(63.55)	342(19.24)	1,778(100.00)

$\chi^2_{\frac{2}{2}} = 13.40, P < .005$

TABLE 3.14.2. Need for Assistance or Service as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Assistance Needed	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	373(49.54)	453(44.11)	826(46.40)
No	380(50.46)	574(55.89)	954(53.60)
Total	753(42.30)	1,027(57.70)	1,780(100.00)

$\chi^2_{\frac{1}{1}} = 4.93, .025 < P < .05$

TABLE 3.14.3. Types of Assistance or Service Requested by Respondents to the Questionnaire.

Type	No. of Requests	Type	No. of Requests
<u>1. Medical &amp; Related Care</u>		<u>4. Institutional Care</u>	
Physical therapy	149	Institution	22
Speech therapy	94	Home for handicapped	17
Rehabilitation	50	Custodial care	9
Occupational therapy	42	<u>5. Vocational</u>	
Diagnostic service	27	Vocational	71
Dental care	23	Employment	48
Medical care	22	Sheltered Workshop	5
Psychiatric care	20	<u>6. Recreational</u>	
Surgery	18	Recreation	99
Testing	14	Nursery school	7
Nursing	11	<u>7. Equipment</u>	
Hearing	7	Equipment	35
Medication	5	Braces	13
Vision	5	Wheelchair	7
Convulsions	5	Glasses	3
<u>2. Educational Services</u>		<u>8. Transportation</u>	
Education	138	40	
Tutoring	42	<u>9. Miscellaneous</u>	
<u>3. Social Service Assistance</u>		Guidance	41
Financial	75	Do not know resources	25
Temporary home	11	Service for retarded	22
Housekeeper	9	General Assistance	14
Case worker	6	Other	9
Housing	4		

### 3.15 THE PRESENCE OF CEREBRAL PALSY IN OTHER MEMBERS OF THE PATIENT'S FAMILY

A total of 89 families, (4.16% of the total from whom we had completed questionnaires) had at least one other family member with cerebral palsy. Of this group, 79 families had one other family member with cerebral palsy, 7 families had two other family members, and 3 families had three other family members with cerebral palsy.

There were 11 sets of twins, both of whom had cerebral palsy, known to the study.

## CHAPTER 4: RECOMMENDATIONS

### RECOMMENDATIONS

One of the primary purposes of the Minnesota Cerebral Palsy Study was to present facts to provide a picture of the present status of the patients and the care they were receiving. It was the hope and intent that services for cerebral palsied patients would be expanded and improved, if the study showed that this was indicated.

From the facts presented in Chapter 3 of this report, certain needs are evident, and the following recommendations are made.

A. It is recommended that a coordinating committee, representing all of the agencies concerned with the prevention of cerebral palsy and the care of the cerebral palsied in Minnesota, be established to review the findings of the study and to develop and implement the plans of action.

B. It is recommended that specific steps be taken to improve case finding of cerebral palsied patients. Some steps to be considered include the follow-up of the more vulnerable groups (i.e., those more likely to develop cerebral palsy). They include:

1. Infants born prematurely (birth weight of 5 1/2 pounds or less);
2. Infants born after prolonged (more than 24 hours), precipitate (less than 3 hours), or difficult labor;
3. Infants born of mothers who have had certain complications (bleeding and toxemia);
4. Infants delivered by high or low forceps;
5. Infants requiring resuscitation at birth;
  
6. Infants and children who have had—
  - a. a head injury,
  - b. a bacterial or viral infection of the central nervous system,or
  - c. lead poisoning.

C. It is recommended that each patient with cerebral palsy have the opportunity for a comprehensive evaluation by a team. As a minimum, this should be made available to all patients moderately or severely disabled. Certain specifics should be considered:

1. The need for a comprehensive initial evaluation and for frequent periodic re-evaluations;

2. The need to develop teams consisting of medical specialists, therapists, a psychologist, a social worker, a vocational counselor, a dentist, a nurse and teacher (An ophthalmologist, an otologist, and an audiologist routinely should be members of such teams.) such teams.);
3. The need to provide these services, not only in the larger urban areas, but also on a regional or district basis to bring the services closer to the patients to be served;
4. The need for evaluation on.
  - a. prior to planning the treatment and rehabilitation program for the patient,
  - b. prior to school placement,
  - c. prior to providing vocational assistance,and
  - d. prior to recommending long term institutional care.
5. The need to coordinate such comprehensive evaluation services with the combined diagnostic and rehabilitation services;
6. The need for a complete ophthalmological examination on young preschool children, because of the frequency of strabismus and because of the need for early diagnosis and treatment to prevent loss of vision in the crossed eye;
7. The need for careful interpretation to parents and for counseling of them following the diagnostic evaluation.

**D. It is recommended that comprehensive diagnostic and rehabilitation services be planned and developed to meet primarily the needs of ambulatory patients, since most of these patients are living at home. At the same time, consideration should be given to the quality of institutional care for those patients in institutions.**

**E. In making plans for the further development of diagnostic and rehabilitation services, consideration must be given to the fact that, until more effective preventive measures are known and employed, an increasing proportion of patients will be more disabled.**

**F. There is need to promote and provide continuous medical supervision for all individuals with cerebral palsy. Other equally important recommendations concerning medical care include:**

1. The need to provide practical refresher courses for physicians in general practice because of their prominent role in treating the cerebral palsy;

2. The need to make available the services of medical specialists to patients, especially in rural areas (The provision of regional or district teams will assist in meeting this need.);
3. The need to coordinate medical care, because of the multiple sources of care for a significant percentage of patients.

G. There is need to promote and provide continuous dental care for all individuals with cerebral palsy.

H. There is need to promote and provide public health nursing service for patients with cerebral palsy and their families, especially where the patient is moderately or severely disabled.

I. It is recommended that special school services, primarily special classes, be provided on a county basis for children living away from the larger urban areas. Such services need to be staffed by a team consisting of teachers of special education, therapists, public health nurses, psychologists, and medical personnel. For the teenage group, vocational assistance is essential. Special attention is needed for those cerebral palsied children with visual or hearing impairment. Transportation to and from school is necessary.

J. It is recommended that vocational assistance be expanded, including testing, guidance, training, and placement and should begin during adolescence in the schools. More sheltered workshop services are needed for the moderately to severely disabled.

K. It is recommended that recreational activities be increased, especially for the moderately and severely disabled, for patients in rural areas, and for young children.

L. For those patients in the study whose families have indicated the need for assistance, it is recommended that a team review each patient and his family individually and make plans to provide the necessary assistance. It would be desirable that the reviewing team be drawn from the official and voluntary agencies concerned.

M. In making plans for the further development of services for patients with cerebral palsy and their families, it is recommended that separate services for the cerebral palsied not be established. The individual with cerebral palsy may have multiple types of problems, e.g., neuromuscular, visual, hearing, psychological, and so forth. Thus, a comprehensive diagnostic and rehabilitation program for patients with all types of handicaps is indicated.

# APPENDICES

# **APPENDIX 1**

**COPY OF THE QUESTIONNAIRE USED**

MINNESOTA CEREBRAL PALSY STUDY  
Co-sponsors UNIVERSITY OF  
MINNESOTA SCHOOL OF PUBLIC HEALTH  
UNITED CEREBRAL PALSY OF MINNESOTA  
MINNESOTA STATE DEPARTMENT OF EDUCATION  
MINNESOTA STATE DEPARTMENT OF HEALTH  
MINNESOTA STATE DEPARTMENT OF PUBLIC WELFARE

Dear Reader:

A study of the needs of people with cerebral palsy in the State of Minnesota is presently being carried on by the University of Minnesota School of Public Health, the United Cerebral Palsy of Minnesota, and the Minnesota State Departments of Health, Education and Welfare. This project has been approved by the Minnesota State Medical Society. The purpose of this study is to determine the services which patients with cerebral palsy are already receiving, and the necessary services not now provided. In order to accomplish this we need YOUR help!

For this reason, we would greatly appreciate your filling out the attached questionnaire and returning it in the enclosed addressed envelope. Please read each question CAREFULLY and answer each one as COMPLETELY and ACCURATELY as possible. Be sure to answer questions one through eight, and eleven through sixteen for patients of all ages. Question nine should be answered if the patient is BETWEEN five and twenty-one years old. Question ten should be answered only if the patient is OVER twenty-one years old. Answers to all questions should be written in this booklet on the appropriate space provided. If more space is needed for certain questions you may use page eleven of this booklet. Be sure to identify your remarks with the number of the question to which the remarks apply. Should you need more space than is provided on page eleven you should feel free to enclose an extra page or two for your added comments.

Your providing us with the information asked for on this questionnaire will help us in planning and developing more services and facilities to help people with cerebral palsy and their families. All information will, of course, be kept strictly confidential.

Thank you for your assistance and cooperation.

Very sincerely yours,

Helen M. Wallace, M.D.  
Professor of Maternal and Child Health  
School of Public Health  
University of Minnesota  
Minneapolis 14, Minnesota

P.S. If we are mistaken and this questionnaire does not apply to the person whose name is typed near the top of page two, or if that person named does not belong to your family, please check one of the following three items. If you have checked items one or three, fill in the corresponding blank, then mail the questionnaire back to us unanswered.

1. Person named does not live at this address. His address is (if known) \_\_\_\_\_ ( )
2. Patient is no longer living - - - - - ( )
3. Other reasons (specify) \_\_\_\_\_ ( )

**STUDY OF SERVICES AND NEEDS OF  
PEOPLE WITH CEREBRAL PALSY**

**NOTE TO PERSON OR PERSONS FILLING OUT THIS FORM**

This is a questionnaire dealing with cerebral palsy and applies to the person whose name is typed below. The questions on this form should be read carefully and answered as accurately and completely as possible. While filling out this form please disregard the numbers written below the parenthesis on the right side of these sheets. They will be used in a later part of this project. **REMEMBER** — the success of this study depends on you. Your cooperation will be greatly appreciated.

**HISTORY OF PATIENT**; Please indicate the patient's present address, his date of birth and sex, in the appropriate spaces below.

Last	First	Middle	Street or RFD	City	County	State
Does the patient live within the city limits of Duluth, Minneapolis or St. Paul			DATE OF BIRTH			
----- Yes ( ) No ( )			Month	Day	Year	
			SEX ----- Male ( ) Female ( )			

**I. PLACE OF BIRTH AND PRESENT LOCATION OF PATIENT**

A. Was the patient born in a hospital ----- Yes ( ) No ( )

If YES, give name and address of hospital. \_\_\_\_\_

If NO, was patient born at home? ----- Yes ( ) No ( )

Patient was born somewhere other than at home or in a hospital? ----- Yes ( ) No ( )

B. Is the patient living at home now? Yes ( ) No ( )

If NO, where is the patient living? (Fill in the proper blank below.)

a. In a foster or boarding home \_\_\_\_\_  
(Person in charge and address)

b. In an institution \_\_\_\_\_  
(Name of place and address)

c. Living elsewhere \_\_\_\_\_  
(Please state with whom living and address)

d. Other \_\_\_\_\_  
(Place and address)

2. MEDICAL CARE

A. How old was the patient when diagnosis of cerebral palsy was first made?

\_\_\_\_\_

B. List the NAMES and ADDRESSES of PRESENT medical care. Be sure to list all the names and addresses of doctors that are presently seeing the patient. Also, if the patient is presently in a hospital please give its name and address. If the patient has no PRESENT medical care, please indicate this by writing NONE in the space below. You may use the last page of this booklet if more space is required.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

On what date was the patient last seen by a doctor? \_\_\_\_\_  
Month Day Year  
Please give today's date. -----  
Month Day Year

C. List the NAMES and ADDRESSES of PREVIOUS medical care. Be sure to list all the names and addresses of doctors that have seen the patient in the past, EVEN IF some of these were listed above. Also, give the names and addresses of any hospitals that the patient has been in for treatment. You may use the last page of this booklet if more space is needed.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

D. Has the patient ever been seen by an ophthalmologist (doctor specializing in eye disorders)? ----- Yes ( ) No ( )  
If YES, give name(s) of doctor(s) \_\_\_\_\_

E. Has the patient ever been seen by an otologist (doctor specializing in ear, nose and throat disorders)? ----- Yes ( ) No ( )  
If YES, give name(s) of doctor(s) \_\_\_\_\_

2. MEDICAL CARE (continued)

F. Has the patient ever been seen by an orthopedic surgeon  
(doctor specializing in bone and joint diseases)? ----- Yes ( ) No ( )  
If YES, give name(s) of doctor(s) \_\_\_\_\_

3. DENTAL CARE

A. Has the patient ever been to a dentist? ----- Yes ( ) No ( )  
If NO, give reason (s) \_\_\_\_\_

B. Has the patient been to a dentist within the past twelve  
(12) months? ----- Yes ( ) No ( )  
If NO, give reason(s) \_\_\_\_\_

4. NURSING CARE

A. Has a public health nurse ever visited the patient at  
home? ----- Yes ( ) No ( )

B. If NO, please check as many of the following statements as are necessary  
to BEST describe your reason or reasons for not having a visit by a public  
health nurse. Use the indicated space on the right for checking.

- a. Did not know what a public health nurse could offer in the way  
of help. ----- ( )
- b. Did not know how to arrange a visit. ----- ( )
- c. Did not know public health nurses made home visits ----- ( )
- d. Did not have a need for a public health nurse. ----- ( )
- e. Other reasons. (Specify.) \_\_\_\_\_

5. PRESENT CONDITION OF PATIENT

A. Does the patient have ANY eye defects? ----- Yes ( ) No ( )  
Does the patient need glasses? ----- Yes ( ) No ( )  
Does the patient have glasses? ----- Yes ( ) No ( )  
Does the patient wear glasses? ----- Yes ( ) No ( )

5. PRESENT CONDITION OF PATIENT (continued)

- B. Does the patient have hearing difficulty? ----- Yes ( ) No ( )  
Does the patient need a hearing aid? ----- Yes ( ) No ( )  
Does the patient have a hearing aid? ----- Yes ( ) No ( )  
Does the patient use a hearing aid? ----- Yes ( ) No ( )

- C. Does the patient have convulsions of "fits"? ----- Yes ( ) No ( )  
If YES, how often? \_\_\_\_\_  
If NO, has the patient ever had them in the past? ----- Yes ( ) No ( )

- D. Please check ONLY ONE of the following four sentences that BEST describes the patient's walking ability. Place your check at the right.  
a. The patient is usually able to walk along without help. ----- ( )  
b. The patient is usually able to walk only with braces. ----- ( )  
c. The patient is usually able to walk only with crutches ----- ( )  
d. The patient is usually able to walk only with braces and crutches. ----- ( )  
If the patient is NOT able to walk at all, please check the ONE sentence e or f, below that BEST describes the patient's condition.  
e. The patient is usually confined to a wheelchair. ----- ( )  
f. The patient is usually confined to bed. ----- ( )

- E. Please check ONLY ONE of the following four sentences that BEST describes the patient's ability to feed himself. Place your check at the right.  
a. The patient is usually able to feed himself completely. ----- ( )  
b. The patient is usually partly able to feed himself. ----- ( )  
c. The patient is usually able to feed himself only poorly or very little. ----- ( )  
d. The patient is usually not able to feed himself at all. ----- ( )

- F. Please check ONLY ONE of the following four sentences that BEST describes the patient's ability to dress himself. Place your check at the right.  
a. The patient is usually able to dress himself completely. ----- ( )  
b. The patient is usually partly able to dress himself. ----- ( )  
c. The patient is usually able to dress himself only poorly or very little. ----- ( )  
d. The patient is usually not able to dress himself at all. ----- ( )

5. PRESENT CONDITION OF PATIENT (continued)

- G. Please check ONLY ONE of the following four sentences that BEST describes the patient's ability to speak. Place your check at the right.
- a. The patient is usually able to speak clearly. ----- ( )
  - b. Usually the patient speaks clearly enough to be clearly understood. ----- ( )
  - c. The patient is usually able to speak only poorly or very little. ----- ( )
  - d. The patient is usually not able to speak at all. ----- ( )
- H. Please check ONLY ONE of the following four sentences that BEST describes the patient's ability to care for his toilet needs. Place your check at the right.
- a. The patient is usually able to care for his toilet needs completely. ----- ( )
  - b. The patient is usually partly able to care for his toilet needs. ----- ( )
  - c. The patient is usually able to care for his toilet needs only poorly or very little. ----- ( )
  - d. The patient is usually not able to care for his toilet needs at all. ----- ( )
- I. Please check ONLY ONE of the following five sentences that BEST describes the patient's ability to learn. Place your check at the right.
- a. The patient is considered a fast learner. ----- ( )
  - b. The patient is considered a normal learner. ----- ( )
  - c. The patient is considered a slow learner. ----- ( )
  - d. The patient is considered moderately retarded. ----- ( )
  - e. The patient is considered severely retarded. ----- ( )
- J. Does the patient have any other health problems? ----- Yes ( ) No ( )  
If YES, please describe them. You may use the last page of this booklet if more space is needed.

---

---

---

---

**NOTE:** In Part B of questions 6, 7 and 8; 9/1/58 is used as a shorthand expression for September 1, 1958.

**6. PHYSICAL THERAPY**

A. Did the patient ever receive physical therapy before September 1, 1958? ----- Yes ( ) No ( )  
If YES, state source\* or sources of physical therapy. (see footnote)

---

---

If YES, how often did the patient receive physical therapy?

---

B. Has the patient received physical therapy since 9/1/58? Yes ( ) No ( )  
If YES, state source\* or sources of physical therapy. (see footnote)

---

---

If YES, how often does the patient receive physical therapy?

---

**7. OCCUPATIONAL THERAPY**

A. Did the patient ever receive occupational therapy before September 1, 1958? ----- Yes ( ) No ( )  
If YES, state source\* or sources of occupational therapy. (see footnote)

---

---

If YES, how often did the patient receive occupational therapy?

---

B. Has the patient received occupational therapy since 9/1/58? Yes ( ) No ( )  
If YES, state source\* or sources of occupational therapy.

---

---

If YES, how often does the patient receive occupational therapy?

\* Please tell us from which agency or agencies the patient received or receives the therapy in question.

8. SPEECH THERAPY

A. Did the patient ever receive speech therapy before

September 1, 1958? ----- Yes ( ) No ( )

If YES, state source\* or sources of speech therapy. (see footnote)

\_\_\_\_\_

If YES, how often did the patient receive speech therapy?

B. Has the patient received speech therapy since 9/1/58? -- Yes ( ) No ( )

If YES, state source\* or sources of speech therapy.

\_\_\_\_\_

If YES, how often does the patient receive speech therapy?

\_\_\_\_\_

9. EDUCATION FOR SCHOOL-AGED PATIENTS (If the patient is between 5 and 21 years old, please answer all parts of this question, otherwise skip this question and go on to 10.)

A. Does the patient attend school? ----- Yes ( ) No ( )

If YES, in what grade is the patient now? (If the patient was never graded, please indicate this by writing UNGRADED in the space provided.)

\_\_\_\_\_

B. If the patient is attending school this year, please check the ONE sentence, a, b, or c, that BEST describes the school the patient is attending.

a. The patient is attending regular class in a regular school. ----- ( )

b. The patient is attending a special class in a regular school. ----- ( )

c. The patient is attending a special school. ----- ( )

C. If the patient does not attend school, has he EVER attended school? ----- Yes ( ) No ( )

If YES, what was the highest grade completed? (If the patient was never graded, please indicate this by writing UNGRADED in the space provided.)

\_\_\_\_\_

\* Please tell us from which agency or agencies the patient received or receives the therapy.

9. EDUCATION FOR SCHOOL-AGED PATIENTS (continued)

- D. If the patient has attended school in the past, please check as many of the three sentences a, b and c, below, that you need in order to BEST describe the school or schools previously attended.
- a. The patient has attended regular class in regular school. ----- ( )
  - b. The patient has attended special class in regular school. ----- ( )
  - c. The patient has attended special school. ----- ( )
- E. Does the patient have a home teacher? ----- Yes ( ) No ( )  
If YES, in what grade is the patient now? (If the patient was never graded, please indicate this by writing UNGRADED in the space provided.)  
\_\_\_\_\_
- F. Is the patient being taught in an institution other than a school? ----- Yes ( ) No ( )
- G. Is the patient receiving any teaching at present? ----- Yes ( ) No ( )

10. EDUCATION FOR ADULTS (If the patient is over 21 years old please answer this item, otherwise skip this question and go on to question 11.)

- Has the patient ever attended school? ----- Yes ( ) No ( )  
If YES, please answer ALL of the following five items, a, b, c, d, and e.
- a. Please give the years of elementary school completed.  
(If UNGRADED, indicate this in the space on the right.) \_\_\_\_\_
  - b. Please give the years of high school completed. (If NONE, write the number zero in the space on the right.) \_\_\_\_\_
  - c. Please give the years of undergraduate college completed. (If NONE, write the number zero in the space on the right.) -----
  - d. Please give any other education the patient has had, by specifying it in the space below. (If NONE, please indicate this also.)  
\_\_\_\_\_  
\_\_\_\_\_
  - e. Please give the total number of years the patient has attended school. -----

NOTE: The rest of the items are to be answered for PATIENTS OF ALL AGES.

11. VOCATIONAL ASSISTANCE (job placement, job training, testing and so forth)

A. Has vocational assistance ever been given the patient? Yes ( ) No ( )

If YES, by what agency or agencies? \_\_\_\_\_  
\_\_\_\_\_

Type of assistance given. \_\_\_\_\_

B. Is vocational assistance needed now? ----- Yes ( ) No ( )

If YES, what kind(s)? \_\_\_\_\_

12. EMPLOYMENT

A. Is the patient employed? ----- Yes ( ) No ( )

If YES, give the type of work done.

If YES, check ONLY ONE of the sentences, a or b, below.

a. Is the patient employed part time. ----- ( )

b. Is the patient employed full time. ----- ( )

If employed at any time during the calendar year 1958, check ONLY ONE of the five sentences, below, that BEST describes the patient's yearly earnings.

c. The patient earns less than \$1000.00 a year. ----- ( )

d. The patient earns between \$1000.00 and \$2000.00 a year. ----- ( )

e. The patient earns between \$2000.00 and \$3000.00 a year. ----- ( )

f. The patient earns between \$3000.00 and \$4000.00 a year. ----- ( )

g. The patient earns over \$5000.00 a year. ----- ( )

B. During the past year how many weeks was the patient employed? (If the patient was not employed during the past year, write the number zero in the space provided.)

13. RECREATION (Use the last page of this booklet if more space is needed.)

Does the patient attend any recreational activities? ----- Yes ( ) No ( )

If YES, give the place and type. \_\_\_\_\_

Please list any other recreational activities the patient attended last summer. (If none, write the word NONE in the space below.)  
\_\_\_\_\_

**NOTE:** The rest of the items are to be answered for PATIENTS OF ALL AGES.

14. NEED FOR ASSISTANCE (If more space is needed you may use the last page of this booklet.)

Does the patient need any kind of help not previously mentioned in this questionnaire? ----- Yes ( ) No ( )

If YES, please describe. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

15. NEED FOR SERVICES (If more space is needed for this item you may use the last page of this booklet.)

Do you or the patient need any services which your community might provide? ----- Yes ( ) No ( )

If YES, please describe. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

16. Do any other members of the patient's family have cerebral palsy? ----- Yes ( ) No ( )

If YES, please give name, address and date of birth.

_____	_____	_____
NAME	ADDRESS	DATE OF BIRTH
_____	_____	_____
NAME	ADDRESS	DATE OF BIRTH
_____	_____	_____
NAME	ADDRESS	DATE OF BIRTH

Date this questionnaire was filled in. -----  
MONTH DAY

Now that you have finished filling out this form check it over carefully. Make sure you have answered each part of questions one through eight, eleven through sixteen and nine or ten. Then, fold this questionnaire and place it in the envelope that you received and drop it in the mail box.

**APPENDIX 2**

**SELECTED TABLES**

TABLE 3.2.1A. Source of Information Provided on the Questionnaire as Related to the Patient's Present Place of Residence. Percentages Given in Parentheses.

Source of Information	PLACE OF RESIDENCE			Total
	Living at Home	Living in a Foster or Boarding Home	Living in an Inst.	
Patient's family	1,449(93.24)	60(69.77)	179(41.82)	1,688( 81.62)
Institution	3( 0.19)	21(24.42)	246(57.48)	270( 13.06)
The patient	66( 4.25)	3( 3.49)	0( 0 )	69( 3.34)
Other	36( 2.32)	2( 2.32)	3( 0.70)	41( 1.98)
<b>Total</b>	<b>1,554(75.14)</b>	<b>86( 4.16)</b>	<b>428(20.70)</b>	<b>2,068(100.00)</b>

TABLE 3.2.2A. Source of Information Provided on the Questionnaire as Related to Severity of Handicap. Percentages Given in Parentheses.

Source of Information	SEVERITY			Total
	Mild	Moderate	Severe	
Patient's family	539(85.83)	890(82.41)	189(69.74)	1,618( 81.76)
Institution	30( 4.78)	142(13.15)	80(29.52)	252( 12.73)
The patient	48( 7.64)	24( 2.22)	1( 0.37)	73( 3.69)
Other	11( 1.75)	24( 2.22)	1( 0.37)	36( 1.82)
<b>Total</b>	<b>628(31.73)</b>	<b>1,080(54.58)</b>	<b>271(13.69)</b>	<b>1,979(100.00)</b>

TABLE 3.2.3A- Source of Information Provided on the Questionnaire as Related to Present Age of the Patient. Percentages Given in Parentheses.

Source of Information	PRESENT AGE			Total
	Under 5	5 to 21	Over 21	
Patient's family	350(96.68)	1,201(88.31)	196(47.23)	1,747( 81.75)
Institution	9( 2.49)	130( 9.56)	135(32.53)	274( 12.82)
The patient	0( 0. )	19( 1.40)	56(13.49)	75( 3.51)
Other	3( 0.83)	10( 0.73)	28( 6.75)	41( 1.92)
<b>Total</b>	<b>362(16.94)</b>	<b>1,360(63.64)</b>	<b>415(19.42)</b>	<b>2,137(100.00)</b>

TABLE 3.3.1.1A. Place of Birth as Related to Sex. Percentages Given in Parentheses.

Place of Birth	SEX		Total
	Male	Female	
Born in a hospital	885(83.41)	705(86.61)	1,590( 84.80)
Born at home	176(16.59)	109(13.39)	285( 15.20)
<b>Total</b>	<b>1,061(56.59)</b>	<b>814(43.41)</b>	<b>1,875(100.00)</b>

$$\chi^2_1 = 3.41 \quad .05 < P < .10$$

TABLE 3.3.2.1A. Present Place of Residence as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Present Place of Residence	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Home	644(74.3)	910(72.2)	1,554( 73.03)
Institution	171(19.7)	261(20.7)	432( 20.30)
Foster or Boarding Home	40( 4.6)	46( 3.6)	86( 4.04)
Other*	12( 1.4)	44( 3.5)	56( 2.63)
<b>Total</b>	<b>867(40.74)</b>	<b>1,261(59.26)</b>	<b>2,128(100.00)</b>

$$\chi^2_2 = 1.50, .40 < P < .50$$

\*This group was eliminated for the  $\chi^2$  analysis.

TABLE 3.3.2.2A. Present Place of Residence as Related to Sex of the Patient. Percentages Given in Parentheses.

Present Place of Residence	SEX		Total
	Male	Female	
Home	881(72.39)	673(73.88)	1,554( 73.03)
Institution	257(21.12)	175(19.21)	432( 20.30)
Foster or Boarding Home	58( 4.77)	28( 3.07)	86( 4.04)
Other*	21( 1.72)	35( 3.84)	56( 2.63)
<b>Total</b>	<b>1,217(57.19)</b>	<b>911(42.81)</b>	<b>2,128(100.00)</b>

$$\chi^2_2 = 4.56, P = .10$$

\*This group was eliminated for the  $\chi^2$  analysis.

TABLE 3.4.1A. Age at Time of Diagnosis as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Age at Time of Diagnosis	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Under 1 yr.	269(37.57)	362(36.35)	631( 36.86)
1 to 5 yrs.	342(47.77)	502(50.40)	844( 49.30)
5 to 10 yrs.	75(10.47)	85( 8.53)	160( 9.35)
Over 10 yrs.	30( 4.19)	47( 4.72)	77( 4.50)
<b>Total</b>	<b>716(41.82)</b>	<b>996(58.18)</b>	<b>1,712(100.00)</b>

$$\chi^2_3 = 2.69, .40 < P < .50$$

TABLE 3.4.2A. Age at Time of Diagnosis as Related to Sex of the Patient. Percentage Given in Parentheses.

Age at Time of Diagnosis	SEX		Total
	Male	Female	
Under 1 yr.	353(36.81)	278(36.92)	631( 36.86)
1 to 5 yrs.	454(47.34)	390(51.79)	844( 49.30)
5 to 10 yrs.	103(10.74)	57( 7.57)	160( 9.34)
Over 10 yrs.	49( 5.11)	28( 3.72)	77( 4.50)
Total	959(56.02)	753(43.98)	1,712(100.00)

$\chi^2_3 = 8.04, P \hat{=} .05$

TABLE 3.5.1.1A. Severity of Handicap as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Severity of Handicap	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Mild	261(32.14)	367(31.45)	628( 31.73)
Moderate	447(55.05)	633(54.24)	1,080( 54.58)
Severe	104(12.81)	167(14.31)	271( 13.69)
Total	812(41.03)	1,167(58.97)	1,979(100.00)

$\chi^2_2 = .94, .60 < P < .70$

TABLE 3.5.1.2A. Severity of Handicap as Related to Sex of the Patient. Percentages Given in Parentheses.

Severity of Handicap	SEX		Total
	Male	Female	
Mild	373(33.07)	255(29.97)	628( 31.73)
Moderate	603(53.46)	477(56.05)	1,080( 54.58)
Severe	152(13.47)	119(13.98)	271( 13.69)
Total	1,128(57.00)	851(43.00)	1,979(100.00)

$\chi^2_2 = 2.18, .30 < P < .40$

TABLE 3.5.1.3A. Severity of Handicap as Related to Place of Birth. Percentages Given in Parentheses.

Severity	PLACE OF BIRTH		Total
	Born in Hospital	Born at Home	
Mild	491(33.72)	95(36.54)	586( 34.15)
Moderate	798(54.81)	143(55.00)	941( 54.84)
Severe	167(11.47)	22( 8.46)	189( 11.01)
Total	1,456(84.85)	260(15.15)	1,716(100.00)

$\chi^2 = 2.33, .30 < P < .40$

TABLE 3.5.2.1A. Ability to Walk as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Ability to Walk	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Able to walk without help	565(67.02)	803(65.82)	1,368( 66.30)
Able to walk with braces	16( 1.90)	26( 2.13)	42( 2.04)
Able to walk with crutches	37( 4.39)	44( 3.61)	81( 3.93)
Able to walk with crutches and braces	31( 3.68)	40( 3.28)	71( 3.44)
Confined to wheelchair	130(15.42)	192(15.74)	322( 15.61)
Confined to bed	64( 7.59)	115( 9.42)	179( 8.68)
Total	843(40.86)	1,220(59.14)	2,063(100.00)

$$\chi^2_{\text{B}} = 3.29, .60 < P < .70$$

TABLE 3.5.2.2A. Ability to Walk as Related to Sex of the Patient. Percentages Given in Parentheses.

Ability to Walk	SEX		Total
	Male	Female	
Able to walk without help	799(67.77)	569(64.36)	1,368( 66.31)
Able to walk with braces	21( 1.78)	21( 2.38)	42( 2.04)
Able to walk with crutches	42( 3.56)	39( 4.41)	81( 3.93)
Able to walk with crutches and braces	40( 3.39)	31( 3.51)	71( 3.44)
Confined to wheelchair	181(15.36)	141(15.95)	322( 15.61)
Confined to bed	96( 8.14)	83( 9.39)	179( 8.68)
Total	1,179(57.15)	884(42.85)	2,063(100.00)

$$\chi^2_{\text{B}} = 3.68, P \approx .60$$

TABLE 3.5.2.3A. Walking Status of the Patient as Related to Whether or Not The Patient Has Had Physical Therapy. Percentages Given in

Walking Status	THERAPY STATUS		Total
	Had Physical Therapy	Not Had Physical Therapy	
Able to walk without help	732(65.53)	381(66.84)	1,113( 66.97)
Able to walk with braces	24( 2.15)	11( 1.93)	35( 2.07)
Able to walk with crutches	69( 6.18)	7( 1.23)	76( 4.51)
Able to walk with braces and crutches	55( 4.92)	8( 1.40)	63( 3.73)
Confined to wheelchair	179(16.03)	90(15.79)	269( 15.95)
Confined to bed	58( 5.19)	73(12.81)	131( 7.77)
Total	1,117(66.21)	570(33.79)	1,687(100.00)

$$\chi^2_{\text{B}} = 61.34, P < .0005$$

TABLE 3.5.3.1A. Feeding Status of Patients as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Feeding Status	GEOGRAPHI LOCATION		Total
	Urban	Rural	
Feed self completely	614(72.75)	854(69.83)	1,468( 71.02)
Feed self partly	73( 8.65)	112( 9.16)	185( 8.95)
Feed self poorly or very little	43( 5.09)	69( 5.64)	112( 5.42)
Not able to feed self at all	114(13.51)	188(15.37)	302( 14.61)
Total	844(40.83)	1,223(59.17)	2,067(100.00)

$$\chi^2/3=2.21, .05 < P < .10$$

TABLE 3-5.3.2A. Feeding Status of Patients as Related to Sex of the Patient. Percentages Given in Parentheses.

Feeding Status	SEX		Total
	Male	Female	
Feed self completely	842(71.29)	626(70.66)	1,468( 71.02)
Feed self partly	107( 9.06)	78( 8.80)	185( 8.95)
Feed self poorly or very little	64( 5.42)	48( 5.42)	112( 5.42)
Not able to feed self at all	168(14.23)	134(15.12)	302( 14.61)
Total	1,181(57.14)	886(42.86)	2,067(100.00)

$$\chi^2_3 = .35, P \approx .95$$

TABLE 3.5.3.3A. Feeding Status as Related to Whether or Not the Patient Has Had Occupational Therapy. Percentages Given in

Feeding Status	THERAPY STATUS		Total
	Had Occup. Therapy	Not Had Occup. Therapy	
Feed self completely	343(73.60)	885(72.06)	1,228( 72.49)
Feed self partly	52(11.16)	95( 7.74)	147( 8.68)
Feed self poorly or very little	23( 4.94)	67( 5.46)	90( 5.31)
Not able to feed self at all	48(10.30)	181(14.74)	229( 13.52)
Total	466(27.51)	1,228(72.49)	1,694(100.00)

$$\chi^2_3 = 9.77, .01 < P < .025$$

TABLE 3.5.4.1A. Dressing Status as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Dressing Status	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Dress self completely	431(52.30)	589(49.04)	1,020( 50.37)
Dress self partly	134(16.26)	193(16.07)	327( 16.15)
Dress self poorly or very little	63( 7.65)	99( 8.24)	162( 8.00)
Unable to dress self at all	196(23.79)	320(26.65)	516( 25.48)
Total	824(40.69)	1,201(59.31)	2,025(100.00)

$$\chi^2_{\frac{2}{3}} = 2.83, .40 < P < .50$$

TABLE 3.5.4.2A. Dressing Status as Related to Sex of the Patient. Percentages Given in Parentheses.

Dressing Status	SEX		Total
	Male	Female	
Dress self completely	604(52.25)	416(47.87)	1,020( 50.37)
Dress self partly	166(14.36)	161(18.53)	327( 16.15)
Dress self poorly or very little	90( 7.79)	72( 8.28)	162( 8.00)
Unable to dress self at all	296(25.60)	220(25.32)	516( 25.48)
Total	1,156(57.09)	869(42.91)	2,025(100.00)

$$\chi^2_{\frac{2}{3}} = 7.40, .05 < P < .10$$

TABLE 3.5.4.3A. Dressing Status as Related to Whether or Not the Patient Has Had Occupational Therapy. Percentages Given in Parentheses.

Dressing Status	THERAPY STATUS		Total
	Had Occup. Therapy	Not Had Occup. Therapy	
Dress self completely	215(46.84)	631(52.76)	846( 51.11)
Dress self partly	95(20.70)	178(14.88)	273( 16.50)
Dress self poorly or very little	41( 8.93)	97( 8.11)	138( 8.34)
Unable to dress self at all	108(23.53)	290(24.25)	398( 24.05)
Total	459(27.73)	1,196(72.27)	1,655(100.00)

$$\chi^2_{\frac{2}{3}} = 9.40, P = .025$$

TABLE 3-5.5.1A. Toilet Care Status as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Toilet Care	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Able to care for needs completely	510(61.01)	697(57.70)	1,207( 59.04)
Able to care for needs partly	106(12.68)	140(11.59)	246( 12.04)
Able to care for needs poorly	43( 5.14)	73( 6.04)	116( 5.68)
Not able to care for needs at all	177(21.17)	298(24.67)	475( 23.24)
Total	836(40.90)	1,208(59.10)	2,044(100.00)

$\chi^2_3 = 4.72, .10 < P < .20$

TABLE 3.5.5.2A. Toilet Care Status as Related to Sex of the Patient. Percentages Given in Parentheses.

Toilet Care	SEX		Total
	Male	Female	
Able to care for needs completely	693(59.28)	514(58.74)	1,207( 59.04)
Able to care for needs partly	133(11.38)	113( 5.53)	246( 12.04)
Able to care for needs poorly	78( 6.67)	38( 1.86)	116( 5.68)
Not able to care for needs at all	265(22.67)	210(10.27)	475( 23.24)
Total	1,169(57.19)	875(42.81)	2,044(100.00)

$\chi^2_3 = 6.17, P = .10$

TABLE 3-5.6.1A. Speech Status as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Speech Status	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Able to speak clearly	378(44.84)	507(41.76)	885( 43.02)
Able to speak partly clear	204(24.20)	279(22.98)	483( 23.48)
Able to speak very little	122(14.47)	179(14.74)	301( 14.63)
Not able to speak at all	139(16.49)	249(20.51)	388( 18.86)
Total	843(40.98)	1,214(59.02)	2,057(100.00)

$\chi^2_3 = 5.70, .10 < P < .20$

TABLE 3.5.6.2A. Speech Status as Related to Sex of the Patient. Percentages Given in Parentheses.

Speech Status	SEX		Total
	Male	Female	
Able to speak clearly	508(43.09)	377(42.94)	885( 43.03)
Able to speak partly clear	285(24.17)	198(22.55)	483( 23.48)
Able to speak very little	184(15.61)	117(13.33)	301( 14.63)
Not able to speak at all	202(17.13)	186(21.18)	388( 18.96)
Total	1,179(57.32)	878(42.68)	2,057(100.00)

$$\chi^2_{3} = 6.73, .05 < P < .10$$

TABLE 3.5.6.3A. Speech Status as Related to Whether or Not the Patient Has Had Speech Therapy. Percentages Given in Parentheses.

Speech Status	THERAPY STATUS		Total
	Had Speech Therapy	Not Had Speech Therapy	
Able to speak clearly	169(30.56)	593(52.43)	762( 45.24)
Able to speak partly clear	226(40.87)	170(15.03)	396( 23.52)
Able to speak only poorly	110(19.89)	138(12.20)	248( 14.73)
Not able to speak at all	48( 8.68)	230(20.34)	278( 16.51)
Total	553(32.84)	1,131(67.16)	1,684(100.00)

$$\chi^2_{3} = 190.18, P < .0005$$

TABLE 3.5.7.1A. Eye Defect as Related to the Geographic Location Patient. Percentages Given in Parentheses.

Eye Condition	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Has eye defect	373(44.99)	504(42.18)	877(43.33)
Has no eye defect	456(55.01)	691(57.82)	1,147(56.67)
Total	829(40.96)	1,195(59.04)	2,024(100.00)

$$\chi^2_{1} = 1.47, .20 < P < .30$$

TABLE 3.5.7.2A. Eye Defect as Related to the Sex of the Patient. Percentages Given in Parentheses.

Eye Condition	SEX		Total
	Male	Female	
Has eye defect	489(42.48)	388(44.44)	877(43.33)
Has no eye defect	662(57.52)	485(55.56)	1,147(56.67)
Total	1,151(56.87)	873(43.13)	2,024(100.00)

$$\chi^2_{1} = .70, P = .40$$

TABLE 3.5.7.3A. Ownership of Glasses Among Patients who Listed an Eye Defect, as Related to the Geographic Location of the Patient, After Eliminating the Blind and Those Who Did Not Answer This Portion of the Question on Eye Care. Percentages Given in Parentheses.

Glasses Status	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Has glasses	229(66.76)	309(70.07)	538(68.62)
Does not have glasses	114(33.24)	132(29.93)	246(31.38)
Total	343(43.75)	441(56.25)	784(100.00)

$$\chi^2_1 = .83, .30 < P < .40$$

TABLE 3.5.7.4A. Ownership of Glasses Among Patients Who Listed an Eye Defect, as Related to the Sex of the Patient, After Eliminating the Blind and Those Who Did Not Answer This Portion of the Question on Eye Care. Percentages Given in Parentheses.

Ownership	SEX		Total
	Male	Female	
Has glasses	282(66.35)	256(71.31)	538(68.62)
Does not have glasses	143(33.65)	103(28.69)	246(31.38)
Total	425(54.21)	359(45.79)	784(100.00)

$$\chi^2_1 = 1.94, .10 < P < .20$$

TABLE 3.5.7.5A. Does or Does Not Wear Glasses Among Those Patients Who Have Glasses as Related to the Geographic Location of the Patient. Percentages Given in Parentheses.

Wears Glasses	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Yes	219(95.63)	285(92.23)	504(93.68)
No	10( 4.37)	24( 7.77)	34( 6.32)
Total	229(42.57)	309(57.43)	538(100.00)

$$\chi^2_1 = 2.03, .10 < P < .20$$

TABLE 3.5.7.6A. Does or Does Not Wear Glasses Among Those Patients Who Have Glasses as Related to Sex of the Patient. Percentages Given in Parentheses.

Ownership	SEX		Total
	Male	Female	
Wears glasses	266(94.33)	238(92.97)	504(93.68)
Does not wear glasses	16( 5.67)	18( 7.03)	34( 6.32)
Total	282(52.42)	256(47.58)	538(100.00)

$$\chi^2_1 = .22, .60 < P < .70$$

TABLE 3.5.8.1A. Presence or Absence of Hearing Defects as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Hearing Status	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Has hearing defect	86(10.35)	116( 9.67)	202( 9.95)
Has no hearing defect	745(89.65)	1,083(90.33)	1,828(90.05)
Total	831(40.94)	1,199(59.06)	2,030(100.00)

$\chi^2_1 = .18, .60 < P < .70$

TABLE 3.5.8.2A. Presence or Absence of Hearing Defects as Related to the Sex of the Patient. Percentages Given in Parentheses.

Hearing Status	SEX		Total
	Male	Female	
Has hearing defect	113( 9.71)	89(10.28)	202( 9.95)
Has no hearing defect	1,051(90.29)	777(89.72)	1,828(90.05)
Total	1,164(57.34)	866(42.66)	2,030(100.00)

$\chi^2_1 = .87, .30 < P < .40$

TABLE 3.5.8.3A. The Relationship of Sex of the Patient to the Possession of a Hearing Aid, After Eliminating Those for Whom We Have Inadequate Information. Percentages Given in Parentheses.

Ownership	SEX		Total
	Male	Female	
Has hearing aid	39(43.82)	26(38.81)	65(41.67)
Does not have hearing aid	50(56.18)	41(81.19)	91(58.33)
Total	89(57.05)	67(42.95)	156(100.00)

$\chi^2_1 = .22, .60 < P < .70$

TABLE 3.5.9.1A. Presence or Absence of Convulsions as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Convulsion History	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Has no history of convulsions	447(53.15)	638(52.21)	1,085(52.59)
Has no convulsions at present and no information about past	138(16.41)	205(16.77)	343(16.63)
Had convulsions in the past, but none now	128(15.22)	184(15.06)	312(15.12)
Has convulsions now	128(15.22)	195(15.96)	323(15.66)
Total	841(40.77)	1,222(59.23)	2,063(100.00)

$\chi^2_3 = .30, P = .96$

TABLE 3.5.9.2A. Presence or Absence of Convulsions as Related to Sex of the Patient. Percentages Given in Parentheses.

Convulsion History	SEX		Total
	Male	Female	
Has no history of convulsions	642(54.37)	443(50.23)	1,085(52.59)
Has no convulsions at present and no information about past	202(17.10)	141(15.99)	343(16.63)
Had convulsions in the past, but none now	163(13.80)	149(16.89)	312(15.12)
Has convulsions now	174(14.73)	149(16.89)	323(15.66)
<b>Total</b>	<b>1,181(57.25)</b>	<b>882(42.75)</b>	<b>2,063(100.00)</b>

$$\chi^2_3 = 6.71, .05 < P < .10$$

TABLE 3.5.9.3A. Frequency of Convulsions (Where Given) for Patients Who Have a Present History of Convulsions as Related to Place of Residence. Percentages Given in Parentheses.

Frequency	PLACE OF RESIDENCE		Total
	Living at Home	Living in an Inst.	
One or more times a week	33(36.67)	8(16.00)	41(29.29)
Less than once a week	57(63.33)	42(84.00)	99(70.71)
<b>Total</b>	<b>90(64.29)</b>	<b>50(35.71)</b>	<b>140(100.00)</b>

$$\chi^2_1 = 5.67, P \dot{=} .02$$

TABLE 3.5.10.1A. Frequency Distribution of Other Health Problems (In Addition to Those Already Discussed in Previous Parts of This Section) as Related to Severity of Handicap. Percentages Given in

Problem Related to:	SEVERITY			Total
	Mild	Moderate	Severe	
Respiration	12(10.17)	68(26.05)	36(41.86)	116(24.95)
Gastro-intestinal tract	5( 4.24)	42(16.09)	23(26.75)	70(15.05)
Neuro-psych problems	37(31.36)	36(13.79)	1( 1.16)	74(15.91)
Bone and muscle	19(16.10)	41(15.71)	7( 8.14)	67(14.41)
Skin	13(11.02)	11( 4.21)	2( 2.33)	26( 5.59)
Genitourinary tract	5( 4.24)	16( 6.13)	4( 4.65)	25( 5.38)
Allergy	7( 5.93)	14( 5.36)	2( 2.33)	23( 4.95)
Cardiovascular system	9( 7.63)	11( 4.22)	1( 1.16)	21( 4.52)
Endocrine-metabolic	7( 5.93)	9( 3.45)	5( 5.81)	21( 4.52)
Other organs	2( 1.69)	8( 3.07)	1( 1.16)	11( 2.36)
Congenital	2( 1.69)	5( 1.92)	4( 4.65)	11( 2.36)
<b>Total</b>	<b>118(25.38)</b>	<b>261(56.13)</b>	<b>86(18.49)</b>	<b>465(100.00)</b>

Parentheses.

TABLE 3.6.1.1A. Type of Present Medical Care as Related to the Sex of the Patient. Percentages Given in Parentheses. (See footnote for Table 3.6.1.1.)

Type	SEX		Total
	Male	Female	
Medical specialty care	352(30.77)	304(35.81)	656(32.92)
General Practitioner only	236(20.63)	188(22.14)	424(21.27)
Other hospital	211(18.44)	144(16.96)	355(17.81)
No present medical care	345(30.16)	213(25.09)	558(28.00)
<b>Total</b>	<b>1,144(57.40)</b>	<b>849(42.60)</b>	<b>1,993(100.00)</b>

$$\chi^2_3 = 9.36, .025 < P < .05$$

TABLE 3.6.2.1 A. Count and Type of Physicians Currently Caring for the Patients as Related to the Sex of the Patient. Percentages Given in Parentheses.

Type	SEX		Total
	Male	Female	
<b>Physicians</b>			
General practitioner	408(38.27)	333(37.50)	741(37.92)
Orthopedist	154(14.45)	146(16.44)	300(15.35)
Pediatrician	106( 9.94)	106(11.94)	212(10.85)
Ophth-otologist	29( 2.72)	20( 2.25)	49( 2.51)
Neurologist	21( 1.97)	17( 1.92)	38( 1.95)
Physiatrist	7( .66)	13( 1.46)	20( 1.02)
Neurosurgeon	6( .56)	4( .45)	10( .51)
Internist	3( .28)	6( .68)	9( .46)
Other specialist	8( .75)	12( 1.35)	20( 1.02)
			<b>1,399(71.60)</b>
<b>Hospitals and Clinics</b>			
Gillette Hospital	34( 3.19)	38( 4.28)	72( 3.69)
University Hospitals	36( 3.38)	24( 2.70)	60( 3.07)
State C.C. Clinics	24( 2.25)	14( 1.58)	38( 1.94)
Mayo Clinic	8( .75)	5( .56)	13( .67)
Kenny Institute	3( .28)	0( 0 )	3( .15)
Other hospital	219(20.55)	150(16.89)	369(18.89)
			<b>555(28.40)</b>
<b>Total</b>	<b>1,066(54.55)</b>	<b>888(45.45)</b>	<b>1,954(100.00)</b>

TABLE 3.6.3.1A. Number of Sources of Present Medical Care as Related to Geographic Location of the Patient After Eliminating Those Patients not Presently Living at Home. Percentages Given in Parentheses.

Number of Sources	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
No present medical care*	196(31.56)	304(35.72)	500(33.97)
1	214(34.46)	292(34.31)	506(34.37)
2	141(22.71)	179(21.04)	320(21.74)
3 or more	70(11.27)	76( 8.93)	146( 9.92)
Total	621(42.19)	851(57.81)	1,472(100.00)

\*This group has been eliminated for the  $\chi^2$  analysis.

$$\chi^2_2 = 1.49, .40 < P < .50$$

TABLE 3.6.3.2A. Number of Sources of Present Medical Care as Related to Sex of the Patient. Percentages Given in Parentheses.

Number of Sources	SEX		Total
	Male	Female	
No present medical care*	345(30.00)	212(24.65)	557(27.71)
1	517(44.96)	399(46.40)	916(45.57)
2	197(17.13)	171(19.88)	368(18.31)
3 or more	91( 7.91)	78( 9.07)	169( 8.41)
Total	1,150(57.21)	860(42.79)	2,010(100.00)

\*This group has been eliminated for the  $\chi^2$  analysis.

$$\chi^2_2 = 1.08, .50 < P < .60$$

TABLE 3.6.4.1A. Time Last Seen by a Physician as Related to the Geographic Location of the Patient, After Eliminating all Patients not Presently Living at Home. Percentages Given in Parentheses.

Time Last Seen	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Within one month	121(20.86)	142(17.73)	263(19.04)
2 thru 6 months	236(40.69)	345(43.07)	581(42.07)
7 thru 12 months	87(15.00)	123(15.35)	210(15.21)
1 to 2 years	78(13.45)	97(12.11)	175(12.67)
Over 2 years	58(10.00)	94(11.73)	152(11.01)
Total	580(42.00)	801(58.00)	1,381(100.00)

$$\chi^2_2 = 3.61, .10 < P < .20$$

Note: This  $\chi^2$  was computed by grouping time last seen by a physician into two groups, i.e., within 6 months and over 6 months.

TABLE 3.6.4.2A. Time Last Seen by a Physician as Related to Sex of the Patient. Percentages Given in Parentheses.

Time Last Seen	SEX		Total
	Male	Female	
Within one month	288(28.57)	232(30.57)	520(29.43)
2 thru 6 months	379(37.60)	288(37.95)	667(37.75)
7 thru 12 months	130(12.90)	99(13.04)	229(12.96)
1 to 2 years	114(11.31)	76(10.01)	190(10.75)
Over 2 years	97( 9.62)	64( 8.43)	161( 9.11)
Total	1,008(57.05)	759(42.95)	1,767(100.00)

$$\chi^2_2 = 1.95, .30 < P < .40$$

Note: This  $\chi^2$  was computed by grouping time last seen by a physician into two groups, i.e., within 6 months and over 6 months.

TABLE 3.6.4.3A. Time Last Seen by a Physician as Related to Type of Present Medical Care. Percentages Given in Parentheses.

Time Last Seen	TYPE OF MEDICAL CARE				Total
	No Present Medical Care	Specialty Care	Care by G. P. Only	Care by "Other Hospital"	
Within one month	26*( 5.57)	157(25.74)	102(27.05)	223(88.14)	508(29.76)
2 thru 6 months	140(29.98)	302(49.51)	185(49.07)	20( 7.91)	647(37.90)
6 thru 12 months	77(16.49)	89(14.59)	47(12.47)	6( 2.37)	219(12.83)
1 to 2 years	110(23.55)	45( 7.38)	26( 6.90)	2( .79)	183(10.72)
Over 2 years	114(24.41)	17( 2.78)	17( 4.51)	2( .79)	150( 8.79)
Total	467(27.36)	610(35.73)	377(22.09)	253(14.82)	1,707(100.00)

\*These 26 individuals raise a question as to the reliability of the information furnished by them.

TABLE 3.7.1.1A. Care by Orthopedic Surgeon as Related to Sex of the Patient. Percentages Given in Parentheses.

Seen by Orthopedic Surgeon	SEX		Total
	Male	Female	
Yes	385(36.15)	319(40.18)	704(37.87)
No	680(63.85)	475(59.82)	1,155(62.13)
Total	1,065(57.29)	794(42.71)	1,859(100.00)

$$\chi^2_1 = 2.96, .05 < P < .10$$

TABLE 3.7.2.1A. Care by an Ophthalmologist as Related to Sex of the Patient. Percentages Given in Parentheses.

Seen by Ophthalmologist	SEX		Total
	Male	Female	
Yes	200(18.69)	175(21.26)	375(19.81)
No	870(81.31)	648(78.74)	1,518(80.19)
Total	1,070(56.52)	823(43.48)	1,893(100.00)

$\chi^2_1 = 1.78, .10 < P < .20$

TABLE 3.7.3.1A. Care by an Otologist as Related to Sex of the Patient. Percentages Given in Parentheses.

Seen by Otologist	SEX		Total
	Male	Female	
Yes	85( 8.07)	60( 7.60)	145( 7.87)
No	968(91.93)	729(92.40)	1,697(92.13)
Total	1,053(57.17)	789(42.83)	1,842(100.00)

$\chi^2_1 = .079, .70 < P < .80$

TABLE 3.8.1.1A. Dental Care History as Related to the Sex of the Patient. Percentages Given in Parentheses.

Ever Seen by a Dentist	SEX		Total
	Male	Female	
Yes	971(85.6)	741(86.9)	1,712(86.2)
No	163(14.4)	112(13.1)	275(13.8)
Total	1,134(57.1)	853(42.9)	1,987(100.00)

$\chi^2_1 = .53, .40 < P < .50$

TABLE 3.8.1.2A Dental Care History as Related to Present Medical Care of the Patient. Percentages Given in Parentheses.

Ever Seen by a Dentist	PRESENT MEDICAL CARE		Total
	No Present Medical Care	Has Present Medical Care	
Yes	469(86.7)	1,158(85.0)	1,627(85.5)
No	72(13.3)	205(15.0)	277(14.5)
Total	541(28.4)	1,363(71.6)	1,904(100.00)

$\chi^2_1 = .80, .30 < P < .40$

TABLE 3.8.2.1A. Dental Care Within the Past 12 Months as Related to the Sex of the Patient. Percentages Given in Parentheses.

Seen by a Dentist in Last 12 Months	SEX		Total
	Male	Female	
Yes	786(70.30)	606(73.19)	1,392(71.53)
No	332(29.70)	222(26.81)	554(28.47)
Total	1,118(57.45)	828(42.55)	1,946(100.00)

$$\chi^2_1 = 1.80, .30 < P < .40$$

TABLE 3.8.2.2A. Dental Care Within the Past 12 Months as Related to Present Medical Care of the Patient. Percentages Given in Parentheses.

Seen by Dentist in Last 12 Months	PRESENT MEDICAL CARE		Total
	No Present Medical Care	Has Present Medical Care	
Yes	362(67.04)	971(71.93)	1,333(70.53)
No	178(32.96)	379(28.07)	557(29.47)
Total	540(28.57)	1,350(71.43)	1,890(100.00)

$$\chi^2_1 = 4.20, .025 < P < .05$$

TABLE 3.9.1A. Visits by a Public Health Nurse as Related to the Sex of the Patient. Percentages Given in Parentheses.

Visit by Public Health Nurse	SEX		Total
	Male	Female	
Yes	461(43.70)	383(46.14)	844(44.77)
No	594(56.30)	447(53.86)	1,041(55.23)
Total	1,055(55.97)	830(44.03)	1,885(100.00)

$$\chi^2_1 = 1.03, .30 < P < .40$$

TABLE 3.9.2A. Visits by a Public Health Nurse as Related to Present Medical Care. Percentages Given in Parentheses.

Visits by Public Health Nurse	MEDICAL CARE		Total
	No Present Medical Care	Has Present Medical Care	
Yes	232(42.11)	565(45.71)	797(44.60)
No	319(57.89)	671(54.29)	990(55.40)
Total	551(30.83)	1,236(69.17)	1,787(100.00)

$$\chi^2_1 = 1.86, .10 < P < .20$$

TABLE 3.10.1.1A. Therapy Summary\* as Related to the Sex of the Patient. Percentages Given in Parentheses.

Summary	SEX		Total
	Male	Female	
No therapy	262(26.84)	178(23.99)	440(25.62)
Physical therapy only	300(30.74)	230(31.00)	530(30.85)
Occupational therapy only	22( 2.25)	10( 1.35)	32( 1.86)
Speech therapy only	59( 6.05)	33( 4.45)	92( 5.36)
Physical & occupational therapy	72( 7.38)	87(11.72)	159( 9.25)
Physical & speech therapy	96( 9.84)	92(12.40)	188(10.94)
Occupational & speech therapy	13( 1.33)	4( .54)	17( .99)
All 3 types of therapy	152(15.57)	108(14.55)	260(15.13)
Total	976(56.81)	742(43.19)	1,718(100.00)

$$\chi^2_4 = 19.31, P < .001$$

\*Summarizes physical, occupational and speech therapy.

Note: This  $\chi^2$  was computed after grouping in the following manner: no therapy; physical, occupational or speech therapy only; and combinations of therapy.

TABLE 3.11.1.1A. Ability of the Patient to Learn as Related to Geographic Location of the Patient. Percentages Given in Parentheses.

Ability to Learn	GEOGRAPHIC LOCATION		Total
	Urban	Rural	
Fast	87(10.66)	129(10.88)	216(10.79)
Normal	242(29.66)	363(30.60)	605(30.22)
Slow	170(20.83)	229(19.31)	399(19.93)
Moderately retarded	160(19.61)	210(17.71)	370(18.48)
Severely retarded	157(19.24)	255(21.50)	412(20.58)
Total	816(40.76)	1,186(59.24)	2,002(100.00)

$$\chi^2_4 = 2.87, .50 < P < .60$$

TABLE 3.11.1.2A. Ability of the Patient to Learn as Related to Sex of the Patient. Percentages Given in Parentheses.

Ability to Learn	SEX		Total
	Male	Female	
Fast	117(10.20)	99(11.58)	216(10.79)
Normal	331(28.86)	274(32.05)	605(30.22)
Slow	242(21.10)	157(18.36)	399(19.93)
Moderately retarded	216(18.83)	154(18.01)	370(18.48)
Severely retarded	241(21.01)	171(20.00)	412(20.58)
Total	1,147(57.29)	855(42.71)	2,002(100.00)

$$\chi^2_4 = 4.76, P \approx .30$$

TABLE 3.11.2.1A. Relationship of Present Grade in School with Sex of the Patient. Percentages Given in Parentheses.

Present Grade	SEX		Total
	Male	Female	
Not presently attending school	283(38.03)	206(34.97)	489(36.68)
Ungraded	117(15.72)	101(17.15)	218(16.35)
Kindergarten	24( 3.23)	25( 4.24)	49( 3.68)
1st or 2nd grade	57( 7.66)	49( 8.32)	106( 7.95)
3rd or 4th grade	57( 7.66)	56( 9.51)	113( 8.48)
5th or 6th grade	59( 7.93)	41( 6.96)	100( 7.50)
7th or 8th grade	42( 5.64)	37( 6.28)	79( 5.93)
High school	91(12.23)	65(11.04)	156(11.70)
College	14( 1.88)	9( 1.53)	23( 1.73)
<b>Total</b>	<b>744(55.81)</b>	<b>589(44.19)</b>	<b>1,333(100.00)</b>

$$\chi^2_8 = 4.95, .70 < P < .80$$

TABLE 3.11.2.1.1A. Type of School Presently Being Attended as Related to the Sex of the Patient. Percentages Given in Parentheses.

Type of School Attended	SEX		Total
	Male	Female	
Regular class in regular school	279(59.36)	217(56.81)	496(58.22)
Special class in regular school	53(11.28)	44(11.52)	97(11.38)
Special school	138(29.36)	121(31.67)	259(30.40)
<b>Total</b>	<b>470(55.16)</b>	<b>382(44.84)</b>	<b>852(100.00)</b>

$$\chi^2_2 = .63, .70 < P < .80$$

TABLE 3.11.2.3.1A. Highest Grade Completed as Related to Sex of the Patient. Percentages Given in Parentheses.

Highest Grade Completed	SEX		Total
	Male	Female	
Never attended school	168(66.40)	129(67.88)	297(67.04)
Ungraded	47(18.58)	24(12.63)	71(16.03)
Kindergarten	3( 1.19)	3( 1.58)	6( 1.35)
1st thru 6th grade	10( 3.95)	9( 4.74)	19( 4.29)
7th or 8th grade	8( 3.16)	4( 2.11)	12( 2.71)
High school	17( 6.72)	20(10.53)	37( 8.35)
College	0( 0 )	1( .53)	1( .23)
<b>Total</b>	<b>253(57.11)</b>	<b>190(42.89)</b>	<b>443(100.00)</b>

$$\chi^2_6 = 6.38, P = .40$$

TABLE 3.11.3.1A. Total Number of Years Spent in School as Related to Sex of the Patient. Percentages Given in Parentheses.

Total No. of Years Spent in School	SEX		Total
	Male	Female	
Never attended school	88(34.37)	44(27.16)	132(31.59)
1 - 5 years	29(11.33)	19(11.73)	48(11.48)
6 - 7 years	18( 7.03)	14( 8.64)	32( 7.66)
8 years	23( 8.98)	10( 6.17)	33( 7.89)
9 - 11 years	28(10.94)	12( 7.41)	40( 9.57)
12 years	29(11.33)	20(12.35)	49(11.72)
13 years	9( 3.52)	11( 6.79)	20( 4.78)
14 - 20 years	32(12.50)	32(19.75)	64(15.31)
<b>Total</b>	<b>256(61.24)</b>	<b>162(38.76)</b>	<b>418(100.00)</b>

$$\chi^2_7 = 11.09, .10 < P < .20$$

TABLE 3.11.3.2A. Highest Grade Completed as Related to the Sex of the Patient. Percentages Given in Parentheses.

Highest Grade Completed	SEX		Total
	Male	Female	
Never attended school	88(34.11)	44(26.67)	132(31.20)
Ungraded	46(17.83)	18(10.91)	64(15.13)
1st - 5th grade	12( 4.65)	14( 8.48)	26( 6.15)
6th - 7th grade	12( 4.65)	17(10.30)	29( 6.86)
8th grade	19( 7.36)	11( 6.67)	30( 7.09)
9th - 11th grade	15( 5.81)	7( 4.24)	22( 5.20)
12th grade	37(14.34)	23(13.94)	60(14.18)
1st year college	13( 5.04)	11( 6.67)	24( 5.67)
2nd - 5th year college	16( 6.20)	20(12.12)	36( 8.51)
<b>Total</b>	<b>258(60.99)</b>	<b>165(39.01)</b>	<b>423(100.00)</b>

$$\chi^2_8 = 17.25, P \leq .025$$

TABLE 3.12.1.1A. History of Vocational Assistance Status as Related to the Sex of the Patient. Percentages Given in Parentheses.

Has Patient Ever Had Vocational Assistance	SEX		Total
	Male	Female	
Yes	80( 9.04)	59( 8.51)	139( 8.81)
No	805(90.96)	634(91.49)	1,439(91.19)
<b>Total</b>	<b>885(56.08)</b>	<b>693(43.92)</b>	<b>1,578(100.00)</b>

$$\chi^2_1 = .08, .70 < P < .80$$

TABLE 3.13.1A. Recreational Activities as Related to the Patient's Sex. Percentages Given in Parentheses.

Attends Activities	SEX		Total
	Male	Female	
Yes	402(39.57)	249(34.25)	651(37.35)
No	614(60.43)	478(65.75)	1,092(62.65)
Total	1,016(58.29)	727(41.71)	1,743(100.00)

$\chi^2_1 = 4.89, .025 < P < .05$

TABLE 3.14.1A. Need for Assistance or Service as Related to the Sex of the Patient. Percentages Given in Parentheses.

Assistance Needed	SEX		Total
	Male	Female	
Yes	477(47.18)	349(45.38)	826(46.40)
No	534(52.82)	420(54.62)	954(53.60)
Total	1,011(56.80)	769(43.20)	1,780(100.00)

$\chi^2_1 = .50, .40 < P < .50$

# **APPENDIX 3**

## **DEFINITIONS USED**

## 1 SEVERITY CODE

Items on ability to walk, to feed oneself, to dress oneself, to speak and ability to care for one's toilet needs (items 5D through 5H on the questionnaire) were combined to yield a severity code. Individual responses to each of these items were weighted, as given below, the weights then summed to derive a severity score.

TABLE 1A.1. Individual Weights Used to Derive the Severity Code.

Item	ASSIGNED WEIGHT			
	0	1	3	5
5D (Walking)		a	b, c, d	e, f
5E (Feeding)		a	b	c, d
5F (Dressing)	a	b	c, d	
5G (Speaking)	a	b	c, d	
5H (Toilet care)		a	b	c, d

From Table 1A.1 we see, for example, that an individual who could walk without help (item 5D.a) could feed himself completely (item 5E.a), could dress himself completely (item 5F.a), could speak clearly (item 5G.a), and could care for his toilet needs completely (item 5H.a) received a severity code of 3. On the other hand, if a patient was confined to a wheelchair or bed, could feed himself only poorly or not at all, could dress himself only poorly or not at all, could speak only poorly or not at all and could care for his toilet needs only poorly or not at all, the severity score for such a patient would be a maximum of 21.

A minimum score of 3 was defined as a mild handicap, scores of 3 through 20 were defined as a moderate handicap and a maximum score of 21 was defined as a severe handicap.

Individuals for whom we did not have information on all five items were not given a severity score. There were a total of 162 such individuals. Included in this group were individuals who were considered too young by the respondent for an evaluation on one or more of the five items of interest. See sections 3.5.2 through 3.5.6 for specifications of these age restrictions.

Because of difficulty in evaluating a patient on the above mentioned items, particularly young patients, this measure may be quite unreliable for those under five. Possibly the measure could have been improved if it had only been computed for individuals over age 5. In this manner, the response to items 5D through 5H should have become essentially independent of age.

Table 1A.2. below gives the actual distribution of severity scores.

TABLE 1A.2. Severity Score as Obtained From the Response to Items 5D through 5H. Percentages Given in Parentheses.

Severity Score	Frequency
3	628 (31.71)
4	253 (12.78)
5	87 ( 4.39)
6	120 ( 6.06)
7 or 8	110 ( 5.56)
9 or 10	100 ( 5.05)
11	60 ( 3.03)
12	22 ( 1.11)
13	74 ( 3.74)
14 thru 20	254 (12.83)
21	271 (13.67)
Total	1,979 (100.00)

The weights used in deriving this severity measure were arbitrary. Walking ability, feeding ability, and toilet care status were weighted more heavily than dressing or speaking ability.

Other items in addition to the five used for the severity measure could have been included. This would have, however, in part defeated our effort of trying to keep the measure as simple as possible, but yet define groups that actually differ in terms of severity of their handicap. We believe we have accomplished this because of the manner in which this measure correlates with other items on the questionnaire. Although this measure could possibly be improved in several ways, we feel it is adequate for our purposes in this study.

## 2 URBAN - RURAL STATUS

Patients having home addresses in the five-county area of Anoka, Dakota, Hennepin, Ramsey and Washington counties were considered to be residing in an urban area. Patients with home addresses anywhere else in the state were considered to be residing in a rural area. As with the severity measure, this particular definition was chosen because of its simplicity. Better, but more complicated, definitions could have undoubtedly been derived. For example, the area around Duluth might also have been included in our definition of an urban area, as well as certain other areas in the state. Although desirable to include such areas it was not practical in terms of the address information we had available for each patient.

It should also be emphasized that this urban-rural definition was based upon the home address of the patient and does not always reflect the facilities available to him, particularly when a patient is not living at his home address. However, in those cases where we were particularly interested in the facilities available to a patient, this definition was restricted to those living at home. Whenever this restriction was introduced it is mentioned in the text.

### **3 AGE OF THE PATIENT**

Since questionnaires arrived over a period of several months and since date of birth was the only information routinely available, an arbitrary decision had to be made as to how to compute an individual's age from such information. The rule used was to assume that all questionnaires had been filled out on January 1, 1958. This arbitrary decision does introduce discrepancies into the age distribution. In a few cases an individual's age may be incorrectly stated in this manner by more than one year.

Again, this procedure was adopted because of its simplicity. Technically it would have been possible to determine an individual's age exactly at the time the form was filled out. However, this would have been quite a tedious and time consuming task.

Table 3A.1 below gives the date of birth for the 2,141 patients for whom we have completed questionnaires. The patient's age as recorded in this report was determined from this distribution.