

RESEARCH MONOGRAPH 2 -- May 1962

Report on a Survey of Respiratory and Severe Post-Polios

Prepared by

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RICHARD D. BURK, M.D.
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DONOVAN L. CLARK, Assistant in Research



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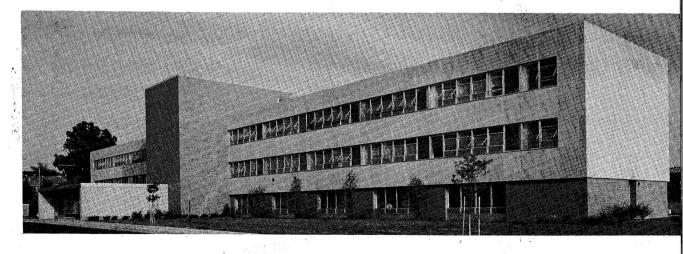
OF THE COLLEGE OF MEDICINE
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NATIONAL FOUNDATION'S SUMMARY OF POLIO PATIENTS USING MAJOR RESPIRATORY AIDS AS OF JANUARY 1, 1959

Alabana .	u	Missouri / 35 #
Alkene //	•	Montaga / 5
A ris ons ,		Nebraska / 31
Arimmen	10	Towards / //
California	353	New Hampshire 5
Colorado	29	New Jersey 15
Connecticut	19	New Mexico
Delaware		New York 116
District of Columbia	5	North Garolina 22
Plorida [©]	34	North Dakota 2
Georgia 🕅	17	Ohio 147
Bawa11	0	Oklahoma 22
Idaho	10	Oregon 26
Illinois	86	Pennsylvania 42
Indiana	39	Rhode Island 3
Iowa	26	South Carolina 4
Kazosa	13	South Dakota 4
Len tucky	16	Tennessee 29
Louisjana	29	7exas : 187
Naine	11	Utah 6
Haryland .	16	Vermont 2
Massagupe : te	65	Virgina 12
niohigen	108	Washington 23
Nimossota	56	West Virginia 16
Miseiselpyi	11	Nisconsin 37
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INTRODUCTION

This report presents the findings of a survey that was initiated by Editors of the TOOMEY j GAZETTE: Mrs. (L. A.) Sue Williams and Mrs. (J. S.) Gini Lauri. The T.j.G. was started in the form of a news letter as a means of communication among severely disabled polio victims. It was named after the late Dr. John A. Toomey of the Cleveland City Hospital in recognition of his service to polio patients. Presently, the GAZETTE has grown to a sizable periodical with a circulation nearing five thousand. Among those receiving it are about two thousand people with severe paralytic residuals, mostly of poliomyelitis.

Concerned about the lack of economic support in the amounts needed to adequately care for people with long-term post-polio disabilities, Editors of the T.j.G. developed this survey in order to obtain specific information from their readers. Two-part questionnaires were distributed to over 1400 people. As a result of sending several waves of these questionnaires, adequate responses were received from 806 people, a return rate of about 55 per cent. Although the questionnaires were not systematically planned, they include a considerable amount of useful information as shown in the Appendix.

Others are similarly concerned about the problems confronting postpolios, and coordination of their efforts has been undertaken by the
Office of Vocational Rehabilitation. In order to estimate the problems,
it was recommended that findings of the T.j.G. survey be analyzed and

a report prepared for the use of those concerned. The Social Research section of The Ohio Rehabilitation Center was asked to carry out these operations, which were in part supported financially by the OVR.

Presentation of data is organized under four main headings: Demographic and Family Characteristics, Medical Characteristics, Economic Characteristics and Vocational Characteristics. Certain limitations of the data need to be pointed out, especially the high rate of "no response" to some questions and the inconsistency in answering others. In general, however, the data presented should be revealing of the characteristics and conditions of the post-polio severely disabled.

DEMOGRAPHIC AND FAMILY CHARACTERISTICS

As mentioned before, the survey includes people from most parts of the country. Table 1 shows that only five states are not represented; namely, Alaska, Delaware, Hawaii, New Hampshire and Vermont. This can be attributed to the fact that these states had the smallest numbers of people for inclusion in the survey as indicated by the T.j.G mailing list and the National Foundation's 1959 records of polios depending upon breathing aids.

Table 1
Number of Respondents by States of Residence

State	No. of Respon- dents	State	No. of Respon- dents	State	No. of Respon- dents		No. of Respon- dents
		1 2				1 X 2	
Ala.	4	Ind.	27	Neb.	14	S.C.	4
Alas.	0	Iowa	14	Nevada	2	S.D.	1
Ariz.	8	Kansas	6	N.H.	0	Tenn.	1 9
Ark.	1	Ky.	14	N.J.	9	Texas	38
				2 W			
Cal.	156	La.	8	N.M.	4	Utah	4
Col.	16	Maine	3	N.Y.	57	Ver.	0
Con.	, 12	Ma.	12	N.C.	13	Va.	12
Del.	0	Mass.	16	N.D.	2	Wash.	27
Fla.	23	Mich.	42	Ohio	86	W. V.	4
Ga	īĭ	Minn.	19	Okla.	10	Wis.	17
Hawaii	- 0	Miss.	3	Oregon	18	Wyo.	3
Idaho	5	Mo.	12	Pa.	21	D. of C.	
Ill.	30	Mon.	2	R.I.	2	Army P.O	
0 خادخادیار	J0	MOIL		T1.		234.114)	
		N.		*			

Age

The youth of respondents is evident in Table 2. About 75% of the men and 73% of the women are in their twenties and thirties.

Ages for all respondents range from 9 to 59 years with a median of 36 for men and 33 for women.

Table 2

Age of Respondents by Their Sex

Age	М	ale	Fema	ale	Total		
	No.	%	No•	%	No. %		
Less than 15 years 15 - 19 years 20 - 24 years 25 - 29 years 30 - 34 years	14 18 57 62 79	4.0 5.1 16.1 17.6 22.4	17 22 63 76 91	3.8 4.9 13.9 16.8 20.1	31 3.8 40 5.0 120 14.9 138 17.1 170 21.1		
35 - 39 years 40 - 44 years 45 - 49 years 50 years and over Not indicated	64 32 11 10 6	18.1 9.1 3.1 2.8 1.7	100 46 18 16 4	22.1 10.1 4.0 3.5 0.9	164 20.3 78 9.7 29 3.6 26 3.2 10 1.2		
Total	353	100.0	453	100.1	806 99•9		

Sex and Race

As indicated in Table 2, women respondents exceed men by about one hundred. However, this does not necessarily reflect a higher proportion of females in the population surveyed. It can be simply the result of lower rates of response to the questionnaires among men.

It should be noted also that only ten people, five men and five women, identified themselves as non-whites. Racial background was not indicated by eleven respondents.

Religion

Only eleven people did not indicate their religious preferences on the questionnaires. A proportionate distribution of males and females among religions can be seen in Table 3, with the great majority of both sexes being Protestants.

Table 3
Religion by Sex of Respondents

Religion]	Male		male	į	Total		
				No.	%	No.	%	No.	%		
None Protestant Catholic Jewish Not indicated				21 252 60 12 8	2.6 31.2 7.4 1.5 1.0	21 328 88 13	2.6 40.7 10.9 1.6 0.4	42 580 148 25	5.2 71.9 18.3 3.1 1.4		

Educational Levels

The structure of the questionnaires did not allow for a distinction in responses between those who have not received any formal education and those who simply did not indicate their present educational levels. There were 485 respondents for whom present levels of education

were not indicated. However, all but 29 have indicated their preparalysis achievements.

Table 4 shows the high educational levels of respondents. About 74% completed high school with 40% continuing for partial or complete college or graduate work before paralysis. It can be noticed also that the proportion of men continuing education beyond high school is larger than that for women, especially for those completing their graduate training.

Table 4

Present Educational Levels by Sex of Respondents

Educational	Ma	ale	Fem	ale	Total		
Levels	No. %		No.	%	No.	%	
Partial grade school Complete grade school Partial high school Complete high school Partial college	3 16 14 100 56	0.8 4.5 4.0 28.3 15.9	8 19 22 173 59	1.8 4.2 4.9 38.2 13.0	11 35 36 273 115	1.4 4.3 4.5 33.8 14.3	
Complete college Partial graduate work Complete graduate work Other education None indicated	76 5 24 46 13	21.5 1.4 6.8 13.0 3.7	89 4 7 56 16	19.6 0.9 1.5 12.4 3.5	165 9 31 102 29	20.5 1.1 3.8 12.6 3.6	
Total	353	99•9	453	100.0	806	99•9	

Post-paralysis educational achievements of respondents are presented in Table 5, which shows a comparison of their educational status

before and after disability. About 40% pursued higher levels of education after paralysis. The most frequently mentioned means of continuing education was tutoring, which was indicated by 59 respondents. Means following in order of frequency of mention are: correspondence as indicated by 53 respondents, home study by 35, regular attendance by 23 and other means, including telephone, by 17. The use of a combination of these means was indicated by 111 respondents.

Table 5

Education Before and After Paralysis

Education After		E	duca	tion	Bef	ore	Para	lysi	ន		Total
Paralysis		1	2	3	4	5	6	7	8	9	
O-None indicated 1-Partial grade school 2-Complete grade school 3-Partial high school 4-Complete high school 5-Partial college 6-Complete college 7-Partial graduate work 8-Complete graduate work 9-Other education	29 5 5 13 4 4 0 1 2	0 2 10 4 20 6 5 0 2	0 0 20 5 42 15 5 2 0 6	0 0 0 22 31 13 11 1 0 8	0 0 0 0 167 6 7 0 2 23	0 0 0 0 71 14 2 1		0 0 0 0 0 0	0 0 0 0 0 0 0 0 0 22 3	0 0 0 0 0 0 0	29 11 35 36 273 115 165 9 31 102
Total	72	49	95	86	205	94	127	6	25	47	806

It was interesting to note that 171 respondents indicated a knowledge of other languages. Among this group 46 individuals mentioned that they knew two or more languages. In order, the most frequently mentioned were Spanish, French, German and Latin.

Marital Status

Half of the respondents reported that they were married before paralysis. As shown in Table 6, only 11 or 1.4% were reported as being divorced.

Table 6

Pre-Paralysis Marital Status by Sex of Respondents

Marital Status	M	ale	Total			
	No.	%	No.	%	No.	%
Single Married Divorced Not Indicated	183 164 3 3	51.8 46.5 0.8 0.8	199 239 8 7	43.9 52.8 1.8 1.5	382 403 11 10	47.4 50.0 1.4 1.2
Total	353	99•9	453	100.0	806	100.0

A comparison of the data presented in Tables 6 and 7 demonstrates a considerable difference in the divorced and separated categories before and after paralysis. While no separations and 11 divorces were reported before paralysis, the post-paralysis picture includes 9 separations and 72 divorces. Paralysis was mentioned as a factor in about 80%, or 64, of the 81 cases presently separated or divorced. It should be noted also that 36 persons, or about 10% of those who were single,

married after the onset of disability. Of these post-paralysis marriages, six resulted in divorces or separations of which four were attributed to the disability.

Table 7

Present Marital Status by Sex of Respondents

Marital Status	Ma	le	Fema	ale	Total		
	No.	%	No.	%	No.	%	
Single Married Separated Divorced Widowed Not Indicated	161 155 (2) 28(25) 2 5	45.6 43.9 0.6 7.9 0.6 1.4	185 208 7(4) 44(33) 0 9	40.8 45.9 1.5 9.7 0.0 2.0	346 363 9 72 2 14	42.9 45.0 1.1 8.9 0.2 1.7	
Total	353	100.0	453	99•9	806	99.8	

Figures between parentheses indicate the numbers of people who mentioned that paralysis was a factor in divorce or separation.

Number of Children

Over half of the respondents have no children; of these, about 91% are single. Similar distributions in the number of children exist between men and women, as manifested in Table 8. Over 30% of the respondents have one or two children and about 17% have three or more children.

Table 8

Number of Children by Sex of Respondents

Number of Children	1	Male		Total			
	No.	%	No.	%	No	. %	
None One Two Three Four and over	192 30 68 40 23	54.4 8.5 19.3 11.3 6.5	226 56 97 56 18	49.9 12.4 21.4 12.4 4.0	418 86 165 96 41	51.8 10.7 20.5 11.9 5.0	
Total	353	100.0	453	100.0	806	99•9	

It should be mentioned also that 52 men and 40 women reported having children born after paralysis. Children are mostly of younger ages, as should be expected from the age distribution of the parents, as shown in Table 2. In describing ages of their children, 240 respondents reported having children under 10 years of age, 284 reported having children of ages between 10 and 19 and only 36 reported having children 20 years of age or over.

Of the 384 people having children, 340 or 89% indicated that their children live with them. A higher proportion of the married (90%) than of the widowed and divorced (47%) have their children with them. Twenty-one of the divorced and separated reported that their children are living with their spouses. Only 5% of the parents mentioned that their children are living with relatives or others.

Parents' Occupation

Occupations reported by respondents for their parents include the general categories of the Census. It was not possible, however, to determine the parent for whom the occupation was reported.

Table 9
Parents' Occupations

Occupation	No.	%
Professional and technical Managerial, Official and Proprietary Clerical and Sales Craftsmen and Foremen Operatives and Mine Workers	44 34 38 50 31	16.9 13.1 14.6 19.2 11.9
Service Workers, excluding Domestics Farmers and Farm Managers Laborers, including Farm Private Household Workers	13 31 16 3	5.0 11.9 6.1 1.1
Total	260	99.8

If the serial order in which occupational categories are presented in Table 9 corresponds generally to the socio-economic hierarchy, it would indicate that the respondents come from higher socio-economic backgrounds as compared to the total population. Thirty per cent of the reported occupations for parents are professional, technical, managerial, official or proprietary while only 12% can be classified as service work, labor or private household work.

Respondents Places of Residence

About as many respondents indicated that they live in their own homes as those indicating they live with their parents. As shown in Table 10, the majority of the single people live in their parents! homes while the majority of the married live in their own homes. It is worth mentioning that some younger respondents probably did not make the proper distinction in their answers between their parents! homes and their own. The table also reveals a high proportion of those divorced, separated or widowed who are not living in their own homes.

Table 10
Residence by Marital Status

	e	* * * * * * * * * * * * * * * * * * *	Mar	ital S	tatus	5					
Residence	Sin	gle	Marr	ied Di	epara vorce Widov	ed or		in- ated	Total		
	No.	%	No.	%	No.	%	No.	%	No.	%	
Respondents home Parents home Other Not indicated	24 273 26 23	6.9 78.9 7.5 6.6	295 24 20 24	81.3 6.6 5.5 6.6	25 33 10 15	30.1 39.8 12.0 18.1	3 2	21.4 21.4 14.3 42.9	333	43.0 41.3 7.2 8.4	
Total	346	99•9	363	100.0	83 :	100.0	14	100.0	806	99•9	

In specifying the types of their housing the great majority (712) indicated that they lived in houses. Apartments were second highest

in mention (49). Forty respondents reside in hospitals or nursing homes. Of those living in hospitals and nursing homes, the highest proportion is among the divorced and separated, which may partially explain such a post-paralysis marital status.

Of the 508 who mentioned that their bedrooms were originally built for that purpose 115 or 23% did not indicate satisfaction with the adequacy of their rooms. The rest who were satisfied with their rooms included 122 who had rooms specially built for their needs. A total of 186 persons have their beds in converted living, dining or other rooms and 58 or 31% expressed no satisfaction with such arrangements.

It is interesting to note that 116 or 14% of the respondents changed community of residence sometime after paralysis. Reasons for such changes were not sought in the questionnaires. It is probably in large part due to normal reasons of geographical mobility of families.

MEDICAL CHARACTERISTICS

This part of the report includes a presentation of data related to such factors as the lapse of time since onset of disability, etiology of paralysis, the degree of involvement, residual capacities and health practices. It should be kept in mind that these data represent the respondents estimates of their own conditions.

Lapse of Time Since Onset of Disability

The lapse of time between onset of disability and responding to the survey questionnaires ranged from one year or less to 51 years. Table 11 shows that more than 70% of the cases reported a lapse of less than 10 years. It appears from comparing this distribution with the range of ages that the onset of disability in the majority of cases occurred at an early age.

Table 11

Lapse of Time Between Onset of Disability and the Survey

Lapse of Time		No. %
Less than 5 years From 5 to 9 years From 10 to 19 years 20 years and over Not indicated	5 1	63 7.8 10 63.3 91 23.7 27 3.3 15 1.9
Total	8	06 100.0

Etiology of Disability

In the great majority of cases, 766 or about 95% of the total, disability was a result of poliomyelitis. Cord injury was reported as the cause of paralysis in 23 cases or 2.8% of the respondents. Multiple sclerosis and muscular dystrophy are frequent among the other causes reported by 17 persons. The small number of people reporting causes other than poliomyelitis renders cross-tabulation of etiology with other variables unnecessary.

The Degree of Disability

Degrees of disability were determined on the basis of impairment in breathing functions and the involvement of extremities. Since measurement of extremity involvement was not precise, as will be explained later, combining the two criteria was felt unwarranted, hence they will be presented separately.

a. <u>Breathing Involvement</u>. Evaluation according to this criterion was made on the basis of respondents' reports about their dependence upon breathing aids. Table 12 shows the degrees of dependence.

Table 12
The Degree of Dependence upon Breathing Aids

Degree of Dependence	No.	%	
None at present Night only Night and part of day Full time Other	$ \begin{array}{c} 318 \\ 159 \\ 189 \\ 137 \\ 3 \end{array} $	39.4 19.7 23.4 17.0 0.4	600
Total	806	99•9	

Among the 102 people indicating the use of frog-breathing, 75 said they use it less than 6 hours a day. Of these, 56 use it less than 3 hours. The other 27 mentioned that they use frog-breathing for periods extending from 6 hours to more than 15 hours daily.

In responding to the question about the frequency of aspiration 49 persons described it as being often. Seventy people indicated that aspiration is necessary only when they have colds and 687 did not mention the use of aspiration.

A higher proportion of males (63.7%) than females (58.7%) are dependent upon breathing aids. It is interesting to note also that among men dependent upon breathing aids those reporting involvement of upper extremities are less in proportion than those reporting involvement of lower extremities. This finding, however, can be due to the lack of precision in determining involvement.

extremities were collected by means of <u>yes</u> and <u>no</u> answers to questions asking whether or not the respondents could move the different parts of their extremities. It should be pointed out that an indication of movement does not mean the absence of limitation. As there were no direct means of determining limited mobility of the parts in question, respondents who answered affirmatively throughout were classified as having no involvement. Those who answered at least one question negatively were classified according to the set of extremities to which the immobility pertained, i.e., upper or lower. Those whose negative answers applied to at least one part in both sets were classified as having an involvement of the upper and the lower extremities. The results obtained are presented in Table 13.

Table 13
Involvement of Extremities

Extremities Involve	eđ.	No.	%
None Uppers Lowers Uppers and Lowers		91 1 154 1	7.3 1.3 9.1 2.3
Total		806 10	0.0

In the section which follows, the writers have tried to define the severity of these disabilities more clearly by relating involvement of the extremities to other variables, especially residual capacities.

Residual Capacities

Residual capacities of respondents were determined through a series of questions regarding gross functions and abilities to perform activities of daily living. Tables 14 through 21 present the relationships of these residual capacities to the involvement of extremities. Again, it should be borne in mind that reported ability to move all extremities constituted "no involvement" as far as these tabulations are concerned, since opportunity to indicate weakness or partial paralysis was not provided.

a. <u>Feeding and Dressing</u>. Table 14 shows that 234 or 29% of the respondents have no ability to feed themselves. This of course is an important factor in the need for attendants. While 216 or

or about 27% indicated an ability for feeding themselves with assistive devices, an additional 35 can do so if ideally equipped.

Table 14
Involvement of Extremities and Capacity for Feeding

Capacity for		In	volv	ement	of E	xtrem	Lties	3		
Feeding	N	one	Up	pers	Lo	wers	I	Both	To	tal
	No.	%	No.	%	No.	%	No.	%	No.	%
No ability Able with assis-	1	1.7	36	39.6	2	1.3	195	38.8	234	29.0
tive device Able without	10	16.9	27	29.7	33	21.4	146	29.1	216	26.8
assistive device Able if ideally	47	79•7	23	25.3	116	75•3	135	26.9	321	39.8
equipped	1	1.7	5	5•5	3	1.9	26	5.2	35	4.3
Total	59	100.0	91	100.1	154	99•9	502	100.0	806	99•9

Capacity for dressing is a personally important activity of daily living and was therefore included in the questionnaires. Results are presented in Table 15 which shows that about 83% of the total group are unable to perform this activity. The personal importance of the activity is reflected in the completeness of responses; only one person failed to indicate whether or not he could dress himself.

Table 15
Involvement of Extremities and Capacity for Dressing

Capacity for		In								
Dressing	None		Up	Uppers		Lowers		Both	Total	
DIODDING	No.	%	No.	%	No.	%	No.	%	No.	%
Unable Able Not indicated	22 37 0	37•3 62•7 0•0	80 11 0	87.9 12.1 0.0	101 53 0	65.6 34.4 0.0	467 34 1	6.8	135	83.1 16.7 0.1
Total	59	100.0	91	100.0	154	100.0	502	100.0	806	99•9

b. <u>Writing and Typing</u>. Among the severely disabled, correspondence assumes increased importance. It is significant to note (Table 16) that nearly one half of the respondents have the capacity for writing without assistive devices. It is equally important to point out that about 32% have no ability in this regard.

Table 16
Involvement of Extremities and Capacity for Writing

Capacity for			In	volv	rement	of E	xtremi	ities			
Writing		N	one	Up	pers	Lo	wers	В	oth	Tot	tal.
		No.	%	No.	%	No.	%	No.	%	No.	%
No ability Able with assis-		4	6.8	39	42.9	8	5•2	206	41.0	257	31.9
tive device Able without		7	11.9	17	18.7	20	13.0	104	20.7	148	18.4
assistive device Able if ideally		48	81.4	32	35.2	125	81.2	178	35•5	383	47.5
equipped	:	0	0.0	3	3•3	1	0.6	14	2.8	18	2.2
Total		59	100.1	91	100.1	154	100.0	502	100.0	806 :	100.0

An evaluation of the ability to type was also sought in the questionnaires. However, it was not possible to determine whether a negative answer meant a physical inability or simply the lack of skill.

As shown in Table 17, among those who can type 35% require an assistive device and an additional 9% can do so if ideally equipped. This can mean an electric typewriter, a mouth stick, a letter guard, an attendent to insert and remove paper, etc.

Table 17
Involvement of Extremities and Capacity for Typing

Capacity for		In	volv	ement	of E	xtremi	ties		2	14 19
	N	one	Ur	pers	Lo	wers	E	oth	To	tal
Typing	No.	%	No.	%	No.	%	No.	%	No.	%
No ability Able with assis-	11	18.6	24	26.4	14	9.1	174	34•7	223	27.7
tive device Able without	9	15.3	36	39.6	40	26.0	200	39.8	285	35•4
assistive device Able if ideally	37	62.7	19	20.9	90	58.4	72	14.3	218	27.0
equipped Other or not	2	3.4	11	12.1	8	5.2	52	10.4	73	9.1
indicated	0	0.0	1	1.1	2	1.3	4	0.8	7	0.9
Total	59	100.0	91	100.1	154	100.0	502	100.0	806	100.1

c. Reaching. Limitations in the above activities can in large part be explained through the ability, or more precisely the inability, to reach beyond the lap board area. Table 18 reveals that about 75% have a limited capacity for reaching, being unable to reach beyond that area. Implications as to the capacity for dressing are obvious. It also points out the need for some assistance in bringing feeding and writing utensils to the lap board.

Table 18
Involvement of Extremities and Capacity for Reaching
Beyond Lapboard Area

Compositer for	14		In								
Capacity for Reaching		Ne	one	Up	pers	Lo	wers	Ε	oth	Тс	tal
		No.	%	No.	%	No.	, %	No.	%	No.	, %
Unable Able Not indicated	:	18 37 4	30.5 62.7 6.8	80 11 0	87.9 12.1 0.0	71 83 0	46.1 53.9 0.0	68	86.1 13.5 0.4	199	74.6 24.7 0.7
Total	,	59	100.0	91	100.0	154	100.0	502	100.0	806	100.0

d. Transfer Activities. Ability to transfer from bed to chair, Table 19, is an important index of the degree of independence versus reliance upon attendants. The table indicated that 502 persons have reported involvement of both upper and lower extremities, yet about 40% of them require no assistance in transfering from bed to chair. A similar proportion, 42%, of the 154 with involvement in the lower extremities only can transfer unassisted. The significance of this comparison is the implied loss of function in the upper extremities for the 58% of those reported as having involvement in the lower extremities only, yet requiring assistance in transfer activities.

Table 19

Involvement of Extremities and Number of Persons
Required for Assistance in Transfer from Bed to Chair

		In	volv	ement	of E	xtremi	ties			15 H
Number of	No	one	Up	pers	Lo	wers	E	Both	То	tal
Persons Assisting	No.	%	No.	%	No.	, %	No.	, %	No.	%
None required One person More than one Not indicated	31 10 2 16	52.5 16.9 3.4 27.1		28.6 44.0 20.9 6.6	39 34	41.6 25.3 22.1 11.0	29 152	5.8 30.3	118 207	40.1 14.6 25.7 19.6
Total	59	99•9	91	100.1	154	100.0	502	100.0	806	100.0

Table 20 presents the methods of transfer activities. The most frequently mentioned method was the use of hydraulic lifts which was reported by 310 persons, constituting about 38% of the respondents. It should be noted that of those for whom no involvement of extremities is indicated, over 20% are dependent upon lifts, slides, rolls or other devices for transfer.

Table 20

Involvement of Extremities and Method of Transfer from Bed to Chair

Method of	-,,	In	3							
Transfer	None		Up	pers	Lowers		Both		Total	
	No.	%	No.	%	No.	, %	No.	%	No.	, %
Own power Hydralic lift Slide, roll, other Not indicated	0 4 8 47	0.0 6.8 13.6 79.7	3 18 5 65	19.8 5.5	56 33	0.6 36.4 21.4 41.6	232 47	46.2 9.4	310 93	38.5
Total	59	100.1	91	100.0	154	100.0	502	100.0	806	100.0

e. Ambulation. Information related to wheelchair ambulation is included in Table 21. About half of the respondents cannot propel a wheelchair while 21% of them can do so. Of particular interest are the 27% who made no indication in this respect. It is probable that a significant proportion of these are ambulatory in a normal, independent fashion. In fact, on another part of the questionnaire, 93 respondents indicated ability to walk independently. Also of medical

interest are the 19 persons who can propel their wheelchairs backward only. This is frequently the finding among patients with extensive arm weakness and the retention of partial function in one lower extremity.

Table 21
Involvement of Extremities and Wheelchair Activities

Wheelchair		In	volv	ement	of E	xtremi	lties			
Activities	N	one	Up	pers	Lo	wers	В	oth	To	tal.
·	No.	%	No.	%	No.	%	No.	%	No.	%
Can [‡] t propel wheelchair Propels wheelchair Requires powered chair Other/not indicated	0	35.6	19	20.9	68	1.3	60	11.9	168	2.1
Total	59	100.0	91	100.1	154	99•9	502	99•9	806	99•9

f. Other Activities. In responding to questions about outdoor activities 112 said they rarely go outdoors, and 116 do not go out socially. Among those who do go out socially the need for assistance was apparent, and major reliance for such assistance is upon family members. Of particular interest is that none affirmed the use of agencies for assistance in social transportation.

Possession and Use of Equipment

Responses to possession and use of equipment give an added insight into the degree of disability as well as the degree of functional capacity retained. Table 22 presents some of the more standard items of equipment and their use by respondents.

Table 22
Possession and Use of Equipment

Equipment	None	Uses	Has but
	Indicated	Regularly	Never Uses
Telephone Typewriter Standing table Lift Reading rack Page turner	244	537	25
	336	404	66
	709	62	35
	426	342	38
	509	267	30
	714	55	37
Ramp Elevator Feeders Generator Aspirator Portable aspirator	459	346	1
	780	23	3
	567	198	41
	700	90	16
	665	115	26
	389	388	29
Respirator batteries	532	243	31
Corset	352	391	63
Artificial muscle	782	21	3
Hand splint	554	168	94
Leg braces	626	107	73
Other	597	200	9

Upper extremity involvement is implied in 168 cases who regularly use hand splints and in the 198 who depend upon a feeder apparatus. In addition, 388 persons require regular use of a portable aspirator. Only 107 regularly use leg braces while 73 persons possess such braces but

never use them. Of the 346 people having a ramp only one person reported that he never uses it. This implies that a significant proportion of the respondents are wheelchair bound. However, no direct questions were asked respondents about usual modes of ambulation. It should be noted also that the table reveals the possession of a rather sizable amount of equipment that is never used, of which the two largest single items are leg braces and hand splints.

The average number of items per person was also computed. As would be expected it varied considerably with dependence upon or independence of breathing aids. For example, the number of persons independent of and dependent upon breathing aids who indicated possession of 9 or more pieces of equipment are 46 and 196 respectively.

Need for Attendants

The degree of disability was reflected also in the need for attendants. Such needs were indicated by 720 respondents or over 90% of the total. The majority depend upon members of their own families, but 234 persons or about one third of the 720 indicated that their attendants were volunteers other than family members, were hired help or a combination. Over half of the 806 respondents mentioned that attendants slept in the same room or within sound of a buzzer. It is also significant to note that 145 persons require turning in bed one or more times every night.

Only 40 people indicated they were residing in a hospital or nursing home, and of these, 15 or 37% had been in such residence for 5 years or more.

Medical Care: Availability and Use

With a large proportion of the group indicating dependence upon breathing aids it was felt important to show the arrangements made for emergency care and the distance to respiratory centers or other appropriate facilities. Table 23 presents findings about these arrangements as related to the degree of disability. It should be pointed out that among the 124 persons depending full time upon breathing aids, 41 or about 30% have no emergency arrangements, 22 would have to travel 50 miles or more for such services and 7 would have to travel 200 miles or more.

Table 23

Degree of Breathing Involvement,

Arrangements and Distance for Emergency Treatments

Distance from		Deper	idenc	e Upor	n Bre	eathing	g Aid	ls		
Treatment Center		Independent Night Night and Full of Aid Only Part of Day Time								
	No	%	No.	%	No.	%	No	%	No	. %
Less than 50 miles 50 miles or over No arrangement Not indicated	78 23 166 54		27 62	17.0° 39.0	40 74	36.0 21.2 39.2 3.7	22 41	44.5 16.1 29.9 9.5	112 343	13.9 42.6
Total	321	100.0	159	100.1	189	100.1	137	100.0	806	100.1

The questionnaires also included items seeking information about past and present use of respiratory and rehabilitation centers. Respiratory centers refer to units that were largely sponsored by the

National Foundation and strategically located on the basis of both geographic areas and population distributions. About 43% or 343 respondents indicated present use of respiratory and/or rehabilitation centers. Of the 388 persons not using either services at present 227 or 58% used these centers in the past.

In responding to questions about physical therapy obtained, nearly half of the group indicated that they are receiving such services. Of these, 215 persons receive therapy daily or weekly. It should be mentioned also that therapy is received by a larger proportion (55%) of those dependent upon breathing aids than those independent of these aids (37%). Among those administering physical therapy to respondents, family members were the most frequently mentioned. In comparison to the 179 receiving therapy given by family members, 68 received therapy from attendants, 41 from registered physical therapists and 36 from local agencies. Other means including volunteers and a combination of various means were mentioned by 71 respondents.

ECONOMIC CHARACTERISTICS

While available information on the respondents monthly earnings and other sources of income is not exhaustive, it will afford some insight into their general economic condition. Estimates for two sources of income were available in the data collected: earnings and economic assistance. Economic characteristics will also include discussion of the amounts of services needed and presently obtained as well as the housing situation of respondents.

Respondents' Earnings

Questions about respondents' earnings were explicitly seeking the average monthly earnings resulting from employment or other work. Over two thirds of the respondents did not indicate any earnings; nearly 20% earned less than 100 dollars per month, and over 13% reported monthly earnings of more than 100 dollars. As shown in Table 23, the proportions of men exceeded those of women at every level of earnings. For example, while 22.9% of the men earned more than 100 dollars monthly, only 6% of the women reported such earnings.

Table 24
Average Monthly Earnings by Sex

A CONTRACTOR OF THE PARTY OF TH			A								
None Sex Indicated			Less than \$100		\$100 - \$199		\$200 & over		Total		
		No.	%	No.	%	No.	%	No.	%	No.	%
Male Female	11		56.9 75.0	71 86	20 . 1	21 13	5•9 2•9	60 14	17.0 3.1	353 453 1	
Total	•	541	67.1	157	19.5	34	4.2	74	9•2	806 1	.00.0

As would be expected, earnings are highly dependent upon working status. As exhibited in Table 25, about 98% of those indicating no employment or work activity reported no earnings. However, a reversal in the picture can be seen by comparing the earnings of people working full time with the earnings of those reporting part-time work. While the majority of the first group (73%) earned less than 100 dollars per month, 74% of the latter group indicated monthly earnings of more than 200 dollars. Some explanation for this reversal can be found in the type of work undertaken. For example, a higher percentage of professional, technical and managerial people reported part-time work engagements as compared to those in occupations such as clerical and sales, in which a higher percentage reported either full-time work or home projects.

Table 25

Average Monthly Earnings by Present Working Status

		A-							
Present Working Status	one cated		s than 100	\$100- \$200 \$199 or				Total	
	No.	%	No.	%	No.	%	No.	%	No. %
Full Time Part Time Home Project Not indicated	3 2 12 524	4.7 2.7 9.1 97.8	47 10 92 8	73.4 13.5 69.7 1.5	8 7 18 1	12.5 9.5 13.6 0.2	6 55 10 3	9.4 74.3 7.6 0.5	64 100.0 74 100.0 132 100.0 536 100.0
Total	541	67.1	157	19.5	34	4.2	74	9.2	806 100.0

The relationships between the average monthly earnings and the present educational levels present a consistent picture. Excluding

the apparently heterogenous category of "other educational pursuits", Table 26 shows that the higher the level of education the higher the proportion of respondents reporting monthly earnings. Furthermore, the table shows that considerably larger proportions of those with higher levels of education have higher monthly earnings. For example, while nearly half of the people who received partial graduate training or completed their graduate degrees earn \$200 or more per month, only about 13% of those with partial or complete college training and 2% of those receiving no college training reported such earnings.

Table 26
Average Monthly Earnings by Present Educational Levels

Educational Levels		ne cated	Le	ess the \$100		100 - 199		00 & ver	To	tal
	No.	%	No.	%	No.	%	No.	%	No.	%
Partial/complet	:e									
graduate work Partial/complet	12	30.0	6	15.0	3	7•5	19	47.5	40	100.0
college work Below college	169	60.3 76.9				6.1 2.8		12 . 9 2 . 3	280 355	100.0
Other educa- tional pursuits Not indicated	59 28	57.8 96.6		28.4 0.0	3	2.9 3.4	11 0	10.8	102 29	99•9 100•0
Total	541	67.1	157	19.5	34	4.2	74	9.2	806	100.0

Differences in the degree of involvement corresponded to some, although slight, differences in earnings. Among the 318 persons independent of breathing aids, 117 or 37% reported earnings. Of these, 39 or 33% earned \$200 or more per month. On the other hand, 30% of those

Financial Benefits and Assistance

Sources of income, other than earnings, for which information was available include veterans, social security and insurance benefits as well as financial assistance provided by public and other agencies and groups. Estimates of the total amounts of income from these sources and specifically from Veterans Administration and Social Security were obtained from responses to the first part of the questionnaire. More comprehensive questions regarding the sources, types and purposes of assistance were included in the second part of the questionnaire.

a. Amounts of Benefits and Assistance. Estimates of the total amounts of veterans' and social security benefits in addition to the economic help received from other sources ranged from none to \$500 or more. Although not explicitly stated, the structure of the questions seeking these estimates strongly implies a monthly basis.

Table 27 presents the distributions of the total amounts of benefits and/or assistance obtained and shows their relationships to respondents' monthly earnings. It can be noticed that about 42% of the group received neither benefits nor assistance. In fact, only 301 persons or 37% of the total 806 have indicated income from such sources. Over one third of this group received less than \$100 per month.

The table shows that among those for whom no earnings or monthly sums of less than \$100 were indicated, 40% received benefits or assis-

tance as compared to 22% of those earning \$100 or more per month. It is also important to point out that no benefits or assistance were indicated for 331 or 61% of the 541 for whom no earnings were reported.

Table 27
Total Benefits and/or Assistance and the Average Monthly Earnings*

and/or Assistance	No.	ne cated	Less than \$100- \$100 \$199				\$200 ove	6 G 21 1	Total		
	No.	%	No.	%	No.	%	No.	%	No.	%	
None Less than \$100 \$100-\$199 \$200-\$299 \$300 or more Not indicated	210 66 57 43 34 131	26.0 8.2 7.1 5.3 4.2 16.3	57- 34- 19- 13- 11- 23	7.1 4.2 2.4 1.6 1.4 2.9	16 2 4 1 4 7	2.0 0.2 0.5 0.1 0.5 0.9	53 3 5 3 2 8	6.6 0.4 0.6 0.4 0.2 1.0	336 105 85 60 51 169	41.7 13.0 10.5 7.4 6.3 21.0	

^{*} Percentages in this table are computed using the total number of respondents (806) as a base.

Marked differences exist between men and women in the proportions receiving benefits and/or assistance as well as in the total amounts obtained. As manifested in Table 28, 46.5% of the males are receiving benefits and/or assistance, and amounts of \$200 or over are received by slightly more than half of them. On the other hand, only 30.3% of the females receive financial benefits and/or assistance and only 5.8% of these reported total amounts of \$200 or over. These sex differentials are probably a function of veterans and social security benefits for which the eligible males outnumber the females. Equally possible, of course, is that some able husbands of female respondents earn enough to meet contingent needs unassisted.

Table 28

Total Benefits and/or Assistance by Sex

	, A.	1	Sex				
Total Benefits and/or Assistance	M	ale	Fer	Female			
Assistance	No.	%	No.	%	No.	%	
None Less than \$100 \$100-\$199 \$200-\$299 \$300 or more Not indicated	110 37 42 42 43 79	31.2 10.5 11.9 11.9 12.2 22.4	226 68 43 18 8 90	49.9 15.0 9.5 4.0 1.8 19.9	336 105 85 60 51 169	41.7 13.0 10.5 7.4 6.3 21.0	
Total	353	100.1	453	100.1	806	99•9	

It is interesting to note also that by grouping respondents according to their major pre-paralysis occupational categories, the highest proportion of those receiving benefits and/or assistance, about two thirds, was found among craftsmen, foremen and operatives. People who had professional, technical and managerial occupations followed with slightly over half of them reporting such incomes. The lowest proportion among the major occupational groups represented was found among the clerical and sales workers, of whom only one third received benefits and/or assistance.

Present independence of or dependence upon breathing aids seemed to have no relationship to the amounts of benefits or assistance obtained or the proportions of people receiving them. Involvement of extremities as reported in the questionnaires also exhibited no influence in this respect.

As has been mentioned before, estimates of the amounts were specifically obtained for veterans and social security benefits. Other sources were grouped together as shown in Table 29. If it can be assumed that a large proportion of those who did not indicate assistance from other sources do in fact receive none, there would be no appreciable differences in the distributions presented in Table 29 except in the amounts of payments. A higher proportion of people received \$200 or more from Social Security or other sources than from the Veterans Administration.

Table 29

Amounts of Benefits and/or Assistance by Sources

						
Amounts of	4.7	Sources	of Bene	efits or .	Assista	ance
Benefits and/or Assistance	r "	V.A.	Social	Security	Other	Sources
	No.	%	No.	%	No.	%
None Less than \$100 \$100 to \$199 \$200 or more Not indicated	659 13 89 14 31	81.8 1.6 11.0 1.7 3.8	621 81 47 32 25	77.0 10.0 5.8 4.0 3.1	485 74 52 30 165	60.2 9.2 6.4 3.7 20.5
Total	806	99•9	806	99•9	806	100.0

b. Sources and Types of Benefits and Assistance. Several sources of financial benefits or assistance were named by the respondents. Among these, as shown in Table 30, the National Foundation is by far the most frequently mentioned. County and state assistance come second and family and relatives third in the frequency of mention as sources of

financial support. These three sources are also represented in the same order in providing regular assistance. In fact the survey findings show that the National Foundation occupies the most prominent position in all types of assistance. However, the highest proportion of regular assistance (90%) is provided by Social Security. It is followed by the Veterans' Administration with 76%, county and state agencies with 57%, family and relatives with 55% and the National Foundation with 30% of the support being in regular form. In order, the two sources most frequently mentioned for past (discontinued) assistance are the National Foundation and insurance.

Table 30 also indicates that a higher proportion of people are receiving benefits or assistance in the form of regular payments.

Past support was second, followed by "occasional" and "one shot" forms.

Table 30 Sources of Benefits and Assistance by Their Regularity

Sources of		Reg	gularity	of A	ssist	ance		
Assistance	Regu-	Tempor- ary	Occa- sional	One Shot	Past	Combin- ation	Not ind.	Total
Family & Relatives Church & Community Employer pre-paraly National Foundation		13 5 2 40	66 60 6 210	12 71 16 66	44 51 15 636	0 12 0 19	22 23 2 88	351 272 47 1522
County & State Insurance Social Security Veterans' Adm.	288 59 131 161	27 15 3 5	50 64 8 5	22 34 0 6	76 105 0 19	5 6 0 1	40 24 4 16	508 307 146 213
Total	1352	110	469	227	946	43	219	3366

c. Purposes of Benefits and Assistance. The predominant purpose, as shown in Table 31, is medical and hospital care followed by equipment and attendant care. The table reports figures representing all benefits and assistance mentioned by respondents regardless of the degree of regularity. In other words, the figures include present as well as past support. The National Foundation is highest in providing aid for attendant care, equipment and medical and hospital care. For housing and child care the family and relatives are providing more support than any other source. In general, family assistance is fairly well distributed among the different purposes. This is also characteristic of support from church and community, Veterans' Administration and state and county agencies. Insurance benefits were largely used in meeting costs of medical and hospital care as well as purchasing equipment.

Table 31
Purposes of Benefits or Assistance by Their Purposes

		Purposes								
Sources	Atten- dants	Chil- dren	Hous- ing			& care Other	Total			
Family & Relatives Church & Community Employer pre-paraly National Foundation		42 17 5 4	76 31 4 8	42 67 6 486	67 53 4 660	56 72 27 35	351 272 47 1522			
County & State Insurance Social Security Veterans Adm.	105 15 17 35	39 2 32 12	38 2 10 16	63 23 1 20	184 250 5 60	79 15 81 70	508 307 146 213			
Total	602	153	185	708	1283	435	3366			

The highest regular support is provided for the purposes of medical and hospital care, equipment and attendants. The same pattern is exhibited in the occasional assistance and to some extent in the other major forms of support.

It is important to notice that among the forms of assistance past is most frequently mentioned for medical and hospital care and is second in mention for equipment and attendant care.

Table 32
Purposes of Benefits or Assistance by Their Regularity

				Purpose	S		
Regularity	Atten- dants	Chil- dren	Hous- ing	Equip- ment	Med. & Hosp.care	Other	Total
Regular Temporary Occasional One Shot	263 29 24 12	81 7 23 7	100 9 15 20	320 12 121 76	342 43 237 77	246 10 49 35	1352 110 469 227
Past Combination Not indicated	241 6 27	27 3 5	28 2 11	124 8 47	465 22 97	61 2 32	946 43 219
Total	602	1 53	185	708	1283	435	3479

d. Needs for Financial Assistance. Respondents were also asked to indicate their needs for financial assistance. As shown in Table 33, the most prominent need is that for attendant care followed by equipment.

Table 33
Needs for Financial Assistance

	Needs	No. Indica- ting Need	Percent of Total
	Attendant care	335	41.6
	Equipment	157	19.5
	Setting up home business	132	16.4
316	}		
	Education	109	13.5
~	Vocational guidance	75	9•3
	Other purposes	.104	12.9

The figures presented in the table above also emphasize the potential for vocational rehabilitation among these people. In spite of the possibility of overlap among the three categories, there are significant numbers expressing the needs for setting up a home business, education and vocational guidance.

In discussing needs for financial assistance, it is felt important to mention that 346 persons have some type of hospitalization insurance; 255 mentioned that they have other hospitalization arrangements. Of the remaining 205, no hospitalization coverage was reported by 188, and 17 persons failed to indicate whether or not they have any arrangements.

Types of Services and Changes in Use

The three major types of services being used by respondents are attendance, housekeeping and nursing. A considerable number of the people performing these services live in with the respondents. Included are 59 attendants, 57 housekeepers and 6 nurses. Quarters for help living in were described by 103 respondents as being a private

room and by 7 as a connecting apartment. Advertising, mentioned by 122, was the most often used means of securing the needed help. Help was also found by 101 persons through friends. Other means used included hospitals and employment agencies.

In regard to the use of the three major types of services, Table 34 shows that attendants were used by a greater number of people, followed by housekeepers and nurses both registered and practical. While the increase in use follows the sameorder, the elimination of each of these three services exhibits a reversed pattern. In other words, nursing services were eliminated by a larger number of people, followed by housekeepers and attendants.

Table 34

Types of Services and Changes in Use

			T,	ypes o	f Serv	ices		
Use of Services		ten- nce		ouse- ping	Nu	rsing	Oti	her
	No.	%	No.	%	No.	%	No.	%
Increased No change Reduced	125 69 31	15.5 8.6 3.8	103 60 33	12.8 7.4 4.1	41 20 6	5.1 2.5 0.7	55 33 .9	6.8 4.1 1.1
Eliminated None indicated, or not determined	64 517	7.9 64.1	66 544	8 . 2	85 654	10.5	34 675	4.2 83.7
Total	806	100.0	806	99•9	806	99•9	806	99•9

Half of the people reducing and eliminating any of these services indicated financial reasons for doing so. Other reasons given include

"children growing older" and "receiving further rehabilitation" and a combination of these factors.

Adequacy of Services

In evaluating the adequacy of the services obtained, as presented in Table 35, nearly half of the respondents indicated that it was at minimum or below. People who reduced or eliminated their help because of financial reasons constituted a large proportion of those dissatisfied with the adequacy of their help.

Table 35

Estimates of the Adequacy of the Services Obtained

			di a constantina
Degree of	Adequacy	No.	%
Adequate Minimum Inadequate Unsafe Not indicated		414 155 71 40 126	51.3 19.2 8.8 5.0 15.6
Total		806	99•9

As would be expected, the amounts of attendance and nursing services measured in the number of hours provided are related to the degree of disability. A higher proportion of those dependent on breathing aids reported the use of such services and for more hours than those independent of such aids. The total number of service hours ranged from none to more than 200 per week with about 70% of those receiving services reporting less than 80 hours.

The types and amounts of services provided by the family are of

Cost of Services

Total salaries paid by respondents for the services they obtained ranged from less than \$40 to \$180 per week. The weekly salaries paid by two thirds of those using hired help are less than \$60 and between \$60 and \$100 for 12% of them. Table 36 presents a comparison of the salaries paid for the three major types of service.

Table 36
Weekly Salaries Paid by Types of Service

Weekly Salaries		Atten- dance	House- keeping	and St. St.	Nursing
Less than \$20 \$20 to \$39 \$40 to \$59 \$60 and over Not indicated		25 80 77 32 592	39 59 32 4 672		10 8 14 10 764
Total	1	806	806		806

These figures do not necessarily indicate the rates of pay for the different types of service. They largely reflect the numbers of hours of services obtained, as has been mentioned before. It should be pointed out that one hundred persons are presently utilizing two of these services and 25 mentioned all three.

OCCUPATIONAL CHARACTERISTICS

Although more than a third of the respondents did not indicate having been employed either before or after disability, the number for whom jobs were reported is large enough to warrant a survey of post-onset changes in occupation and working status as modulated by other characteristics. Respondents who may be unemployed are considered briefly in the section which follows.

Changes in Occupation after Onset

Table 37 shows the occupations reported before and after onset of disability. The categories used are those established by the U.S. Bureau of the Census.

Of the 336 respondents who did not indicate employment either before or after onset, about 68% are females and 9% are children of less than working age. Two hundred-seventeen or nearly 65% report involvement in upper and lower extremities and 60% are presently dependent upon breathing aids. Less than a high school education was indicated by 63%. Singly or in combination, factors such as household responsibilities in the case of females, youthful age, early onset, interrupted education and severity of disability may preclude employment for many.

Of the 216 who were employed before onset but who did not specify

an occupation at the time of the survey, 78% had less than high school education. Eight per cent were women reporting children born after onset. Involvement of upper and lower extremities was indicated by 64%, and 68% depend on breathing aids.

Table 37
Occupation Before Onset and at Present by Sex of Respondent

			Se	ex of	Res	onden	t	
Occupation	Ве	Ma fore	ele Pre	esent	Ве	Fem efore	ale Pre	esent
	No.	%	No.	%	No.	%	No.	%
Professional & technical Managers, officials and	62	17.6	51	14.4	58	12.8	45	9•9
proprietors except farm Clerical & sales Craftsmen & foremen	10 46 41	2.8 13.0 11.6	60	5.9 17.0 0.8	91	0.9 20.1 0.7	3 65 1	0.7 14.3 0.2
Operatives & mine workers	13	3.7	0	0.0		0.9	0	0.0
Service except private household	1 3	0.8	1	0.3	10	2.2	1	0.2
Farmers & farm managers	13	3.7	2	0.6	0	0.0	0	0.0
Laborers including farm								
laborers & foremen	8	2.3	1.	0.3	0	0.0	0	0.0
Domestic	0	0.0	0	0.0	0	0.0	0	0.0
Not indicated	157	44.5	214	60.6	283	62.5	338	74.6
Total	353	100.0	353	99•9	453	100.1	453	99•9

Although representation in the professional, managerial and clerical categories alters considerably after onset, a greater proportional number of changes seems to have occurred within the smaller groups representing the other occupations. The exact proportions and directions of change for any group, however, remain to be seen in Table 38.

Percentages are computed from the total number of respondents in each group before onset. The occupational categories listed above will henceforth be reduced to four by reason of small representation in some and none in others.

Table 38

Changes in Occupation and Employment Status after Onset

Occupation		Pres	ently Er	nploye	ed.			
before Onset of Disability		ned in pation				nged pation		Employed Present
	No.	%	No.	%	No.	%	No.	%
Professional & Managerial Clerical & Sales Craftsmen &	49 34	36.6 24.8	71(47) [*] 91(54)	53.0 66.4	20 16	14.9 11.7	65 87	48.5 63.5
Operatives Other Occupations None Indicated	1	1.6 2.9	3(2) 4(1) (104)	4.9 11.8 23.6	11	29.5 32.4	42 22 336	68.9 64.7 76.4

^{*} Figures within parentheses total 104 and represent among the respondents who entered each occupation, the number who did not indicate an employment before onset.

Proportionally high after onset, the totals in the professional-managerial and clerical-sales categories should not obscure the displacement of a great number who were originally within those groups. It must be noted that proportions of change in status recorded for any of the groups may be influenced in part by factors other than disability. Education is a noteworthy example and will be treated later.

The directions of change are further illustrated in Table 39. The respondents representing the four occupational categories at present

are distributed according to their occupations before onset.

Table 39

Occupation before Onset of Disability and at Present

			0ccu	patio	n be	fore	Onse	t			e eng	 Ag S
Occupation at Present		0		1		2	3			4	Tot	al
	No.	%	No.	. %	No.	%	No.	%	No.	%	No.	%
O-None indicated 3 1-Professional .	 36	76.4	65	48.5	87	63.5	42	68.9	22	64.7	552	68.4
& Managerial .	47 54	10.7	49	36.6 13.4	16 34	11.7 24.8	6 11	9.8 18.0	2	5•9 23•5	120 125	14.9
3-Craftsmen & Operatives . 4-Other occupations	2	0.5	Ó	0.0	0	0.0	1	1.6	ļ	2.9	4	0.5
		· · · · · · · · · · · · · · · · · · ·		99.9								

Since an accounting has been attempted for respondents who may never have been employed and for those who had been employed previously, some description is justified of the group who did not indicate employment before onset but who are working now. Numbering 104, forty-six per cent are males of whom 18% are married. Completion of high school and/or partial or complete college training or other education after onset was reported by 63%. Since 48% range in age from 20 to 29, and with the lapse of time for all respondents averaging about ten years since onset, it can be safely assumed that a large proportion of the group were of less than working age at the time of onset.

Occupation and Age

The largest proportion (29%) of the professional . . . managerial groups range in age from 30 - 34. About 26% are under thirty and 45% over thirty-four. Similarly, in the clerical and sales groups 28% are from 30 - 34 years of age while 31% are under thirty and nearly 41% are thirty-four or over. The few respondents representing the other occupational categories after onset are generally in their twenties and thirties. The youngest person reporting employment is fourteen years of age and the oldest 58.

Employment and Education

Findings of this survey clearly demonstrate the relationship of educational level and employment status. As the level of education increased, the proportions of respondents indicating no employment decreased markedly. Listed below as proportions of the totals at their levels of education are the respondents who reported employment at the time of the survey.

Table 40

Proportion Reporting Post-Onset Employment by Their Educational Levels

Educational Levels	Per	Cent Employed	• ;
Less than high school High School Partial or complete college Graduate training		12% 24% 38% 70%	

Working Status and Severity of Disability

of the 270 employed respondents who indicated their working status, nearly half reported home projects. About 27% were employed part time and 24% full time. The following distributions result when the same respondents are grouped by disability: among those who indicated involvement of upper and lower extremities, 85 or 56% were engaged in home projects, and the remainder were almost evenly divided between part- and full-time jobs. Twelve or 55% of those reporting upper involvements had home projects, nine held part-time work and only one indicated a full-time job. Those reporting lower involvements were uniformly distributed with 38% indicating home projects and 62% divided equally between the two remaining categories. While the dependent and independent in breathing were almost evenly represented in full- and part-time work, the former were about 57% of the 130 who reported home projects.

Occupation and Present Working Status

In closing this report it seems appropriate to focus on the respondents as they are presumably now at work. Occupations and current working status are presented in Table 41. Home projects are seen to predominate, especially among the clerical and sales group. Some of the more frequently mentioned projects were television monitoring, bookkeeping, typing and telephone soliciting. Among the professional and managerial groups many continue to operate businesses from their homes, some to practice law and medicine and others to teach.

Perhaps lesser involvements or programs of rehabilitation have enabled a large number of return to part- and full-time work. Again, much of what could be relevant to such determinations is imprecisely known.

Table 41
Present Occupation by Working Status

		Working	Status		
Occupation	Not Ind.	Full Time	Part Time	Home Project	Total
	No. %	No. %	No. %	No. %	No. %
Professional & Managerial Clerical & Sales Craftsmen & Operatives Other Occupations Not Indicated	7 1.3 5 0.9 0 0.0 0 0.0 524 97.8	24 37.5 32 50.0 1 1.6 3 4.7 4 6.3	23 31.1 0 0.0 2 2.7	41 31.1 65 49.2 3 2.3 0 0.0 23 17.4	125 15.5 4 0.5 5 0.6
Total	536100.0	64 100.0	74 100.0	132 100.0	806 100.0

A brief description of current activities other than work will provide a final note. Avocational interests were recorded under three headings: affiliation, hobbies and volunteer activities. As would be expected, hobbies proved most popular. Of 806 respondents, 579 or 72% had hobbies, 222 or 28% mentioning one, 158 or 19% mentioning two and the remainder more than two. About 196 or 24% of the respondents listed volunteer activities, and 155 or about 19% reported membership in fraternal or honorary organizations.

This publication reports the findings of a survey of people with respiratory and other severe post-polio disabilities. The survey was initiated by Editors of the TOOMEY j GAZETTE, and the findings were analyzed and reported by the Social Research section of the Ohio Rehabilitation Center.

Several waves of a two-part questionnaire were mailed to some 1400 people on the T.j.G mailing list. A return of about 55 per cent was obtained which included responses from 806 individuals. Findings are presented and discussed in four major sections covering demographic and family, medical, economic and vocational characteristics of the respondents.

Demographic and Family Characteristics

Included were 453 females and 353 males. The great majority, about 73%, range in age from 20 to 39 years. Only ten respondents identified themselves as non-white. The present educational levels reported are much higher than those in the average population. In fact, only 10% did not complete high school while 38% have completed college. A comparison of the educational levels before paralysis and at the time of survey shows remarkable achievements on the part of many of the individuals.

Some items descriptive of family composition were also included in the questionnaires. Half of the respondents were married before paralysis while 47% were single. The major change in marital status after paralysis was in the proportions of the divorced and separated which increased from 1.4% to 10% of the respondents. The majority of these attributed their separations or divorces to the disability. Most of those having children indicated that their children live with them.

The high socio-economic status of respondents' families as compared to the general population is evident in the parents' occupations. About 30% of the respondents' parents are in professional, technical, managerial, official and/or proprietary occupations. However, a number of the other census occupational categories were represented in similar proportions to those present in the U.S. employed population.

The great majority of respondents (84%) lived in either their parents' homes or their own. The dwelling units indicated by most were private houses. At the time of survey, forty individuals resided in hospitals or nursing homes. About 115 or 23% of the respondents were not satisfied with the adequacy of their rooms.

Medical Characteristics

The disability in 95% of the cases is a result of poliomyelitis. Cord injury accounted for about 3% and miscellaneous causes for the remainder. The lapse of time since onset varied from less than one year to 51 years with 87% of the cases falling between 5 and 20 years. Responses showed about 60% of the cases depend upon breathing aids in varying degrees. Involvement of the upper and lower extremities was reported by 62%, upper only by 11% and lower only by 19%. The remain-

der indicated no extremity involvement. It should be remembered that the ability to move all extremities constituted "no involvement" since opportunity to indicate weakness or partial paralysis was not provided.

Residual capacities for activities of daily living were related to extremity involvement in order that the severities of respondents' disabilities could be better defined. Twenty-nine per cent have no ability to feed themselves. About 40% are able to do so without assistance, and nearly 31% can or could feed themselves with assistive devices. Inability to dress was reported by 83%. The ability to write unassisted was indicated by 48% and the ability to type by 27%. Writing and typing with assistive devices was specified by 18% and 35%, respectively. About 32% are unable to write and 28% cannot type. Nearly 75% are unable to reach beyond the lap board area, which may in part explain the limitations in the above activities. The ability to transfer from bed to chair with no one assisting was reported by about 40%. An additional 40% can transfer with help. Almost half of the respondents cannot propel a wheel chair. Of the 27% who made no indication in this respect, some are probably able to walk independently.

The need for attendants is also a measure of the degree of disability.

Over 90% of the respondents indicated this need, the majority depending upon family members and about a third upon volunteers, hired help or a combination.

The survey also covered medical services used. Forty-three per cent presently use respiratory and/or rehabilitation services. A specific service in question was physical therapy, received by nearly half of all

respondents. Arrangements for emergency care were indicated by about 46%, but of the 137 persons depending full-time on breathing aids, at least 30% have no emergency arrangements. In many cases the distance to the center of treatment seemed greater than emergency would allow. Nearly 14% of the respondents would have to travel fifty miles or more for emergency care.

Economic Characteristics

Estimates of income were based on earnings, benefits and economic assistance. While over two-thirds of the respondents did not indicate any earnings, 13% earnedmore than \$100 monthly. More men earned, and earned more, than women. Although higher earnings were reported by more part-time workers than full-time, a larger proportion of the former indicated professional, technical or managerial occupations. Earnings related consistently to levels of education: the higher the level, the larger the proportion reporting earnings and the greater the earnings. The degree of involvement corresponded only slightly to differences in earnings.

Forty-two per cent of the respondents received neither benefits (V.A., Social Security, insurance, etc.) nor assistance. More than a third of the 37% who indicate such incomes receive less than \$100 per month. Twenty-one per cent did not respond.

Sources of benefits or assistance most frequently mentioned were the National Foundation, county and state agencies, family and relatives. The same sources provide the most regular assistance. The pre-

dominant purposes of assistance are medical and hospital care, purchase of equipment and payment for attendants. Most prominent among remaining needs for financial assistance are attendant care and equipment.

The services most used by respondents are attendance, housekeeping and nursing. When services are reduced or eliminated, nursing and housekeeping usually precede attendance. The adequacy of all services obtained is minimum or below according to nearly half of the respondents, especially those who reduced or eliminated services for financial reasons.

The number of service hours varies from none to more than 200 per week and, as expected, corresponds to the degree of disability. Seventy per cent of those receiving service report less than 80 hours weekly. More than two-thirds of the respondents are helped by family members in most activities of daily living.

Salaries paid for services ranged from less than \$40 to \$180 per week; two-thirds were less than \$60, and 12% were between \$60 and \$100 weekly. The variation largely reflects the number of service hours obtained. Salaries over \$60 were most often paid for attendant care.

Vocational Characteristics

More than a third of the respondents did not indicate employment either before onset or at the time of survey. About 19% were employed in both instances. Twenty-seven per cent were employed before onset but not at the time of survey, and 13% were not employed before onset but are now.

Considered separately, the occupational groups least affected by disability were professional and managerial, with about 37% of their original number remaining, and clerical and sales, 25% remaining. Of 95 persons formerly employed as craftsmen, foremen, operatives, service workers, farmers or laborers, only two have the same classifications at the time of survey. Sixty-five persons changed occupations sometime after onset.

The importance of education is again apparent in the proportion at each level who indicated employment at the time of survey. Of those reporting less than a high school education only 12% were employed; high school, 24%; partial or complete college, 38%; graduate training, 70%.

The degree of disability was seen to correspond with present working status. Among those who were employed and who reported involvements which included the upper extremities, a greater proportion were engaged in home projects than among those who reported involvement of lower extremities only. With one exception, the remaining proportion in each category of extremity involvement was almost equally divided between part- and full-time work. Dependence upon or independence of breathing aids did not bear significantly on working status.

The highest proportion (65%) of the part-time workers were in the professional and managerial categories. Clerical and sales workers formed the largest proportion among those reporting full-time employment (50%) and home projects (49%).

Some Implications

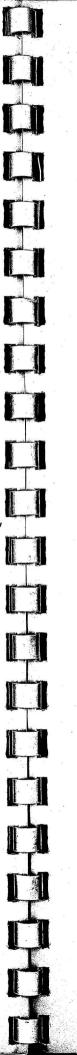
Implications in these findings are several. The vocational achievements of a large proportion of those included in the survey should be of interest from the rehabilitation point of view. It is particularly important to note that vocational outcome was not determined by the degree of disability alone. Further analysis of the available data may help to disclose the important factors associated with the levels of vocational achievement. Education is very likely prominent among these factors. An assessment both of the means employed by some to continue their studies and of the restrictions faced by others could be very useful in furthering special education.

The majority of post-paralysis separations and divorces were attributed to disability. These findings accentuate the need for a comprehensive study of the impacts of disability upon family relations. Although data pertaining to the dynamics of family relations are lacking, further analysis of the available data should be carried out in an attempt to study some of the factors related to the success or failure of marriages stressed by disability.

Findings also suggest that many need but cannot afford more care.

It is obvious that long-term disabilities require long-term aid. A comparison of the costs of institutional and home care would be important from an economic point of view. This survey did not provide sufficient data for such a comparison. If further study would reveal that some have at least the potential for adequate self-care, rehabilitation to that end might free other family members for work which could partially obviate long-term financial assistance.

It is clear that the needs of people surveyed as well as others in similar situations are many and varied. This again raises the often discussed question of the adequacy of health, social, economic, educational and vocational services available at community levels and of enhancing the effectiveness of their coordination.



APPENDIX

T J G C E N S U S Part I

Male Female Religion Race Children: If you have children, please indicate their ages What is the occupation of your spouse or parent? Are you receiving Veterans payments? Yes No How much? Are you receiving Social Security payments? Yes No How much? Is any other agency helping you? Yes No How much? What agency? Can you propel a wheelchair? Yes No With one foot? Two feet? With one arm? With both arms? Backwards? Forwards? Manual? Power-driven?
What is the occupation of your spouse or parent? Are you receiving Veterans payments? Yes No How much? Are you receiving Social Security payments? Yes No How much? Is any other agency helping you? Yes No How much? What agency? Can you propel a wheelchair? Yes No With one foot? Two feet? With one arm? With both arms? Backwards? Forwards?
Are you receiving Veterans payments? Yes No How much? Are you receiving Social Security payments? Yes No How much? Is any other agency helping you? Yes No How much? What agency? Can you propel a wheelchair? Yes No With one foot? Two feet? With one arm? With both arms? Backwards? Forwards?
Are you receiving Social Security payments? Yes No How much? Is any other agency helping you? Yes No How much? What agency? Can you propel a wheelchair? Yes No With one foot? Two feet? With one arm? With both arms? Backwards? Forwards?
What agency? Can you propel a wheelchair? Yes No With one foot? Two feet? With one arm? With both arms? Backwards? Forwards?
With one arm? With both arms? Backwards? Forwards?
With one arm? With both arms? Backwards? Forwards?
Manual: Fower-driven:
If you have use of your arms or hands, do you do the following? Feed yourself with assistive device ? Without assistive device ? Type with assistive device ? Without assistive device ? Write with assistive device ? Without assistive device ? Reach beyond lapboard area? Yes No Dress yourself? Yes No
Ideally, if someone would set you up with breathing aids and assistive devices, could you feed yourself? Yes No; Type? Yes No Write? Yes No
If you use an assistive device, is it: (1) Sling? (2) Warm Springs feeder? (3) Artificial muscle? (4) Hand splint? (5) Abdominal breather? (6) Other
If you are now living at home, indicate the hours per week you employ any of the following, now and in the past: (1) Housekeeper, now past (2) Attendant, now past (3) Homemaker service, now past (4) Visiting nurse, now past (5) Driver or pusher, now past (6) Baby sitter, now past (7) Secretary, now past (8) Nurse, PN, now past (9) Nurse, RN, now past (10) Other , now past
If you have <u>reduced</u> the amount of help you employ, what was the reason? (1) financial (2) Further rehabilitation (3) Children growing older (4) Other

당시한 휴리적인 10 등 전쟁을 가지면 하지만 하는데 되어 하시고 있다면 현업을 취임 중심다
If you are now living in a <u>Hospital</u> or <u>Nursing Home</u> , please indicate: (1) Since onset, have you lived at home? Yes No How long?
(2) Would you have been able or willing to remain at home if attendant care had been provided? Yes No
(3) Is it private? City? County? State? Veterans ? Church? Other?
(4) How long have you lived in this hospital or nursing home? (5) What is the cost per day? (6) How many other respos there now? How many other quads?
How many hours per day are you left alone?
In your present setup, is the help you receive: (1) Adequate for your needs? Yes No (2) Bare minimum? Yes No (3) Inadequate? Yes No (4) Too little for safety? Yes No (5) Worse than that? Yes No
Would your problem be solved if you could go to live in an ideal type residence-nursing home? Yes No In the future? Yes No
If necessary financial assistance could be obtained for you, describe oriefly where your needs would be the most vital:
Attendant care
Setting up a home business
Vocational guidance
Education
Equipment $oxed{}$
Other
Since onset of paralysis, have you been a patient in a (1) Respiratory Center? Yes No Name of Center
(2) Rehabilitation Center? Yes No Name of Center Other

Are	e you still associated in any way with a (1) Respiratory Center? Yes No Name of Center
	(2) Rehabilitation Center? Yes No Name
Do	you have any arrangements with a Respiratory Center or Hospital for emergency treatment? Yes No Name of Center or Hospital Approximately how many miles from you?
	you have hospitalization insurance? Yes No not, what arrangements do you have for paying for your hospitalization?

TJG CENSUS Part II

The information you give on this questionnaire will be of great help to all totally disabled and will aid TJG in future issues. We will appreciate your answering as many questions as apply to you. Leave blank, if they do not apply. Simply mark an "X" in the spaces provided, if they do apply. The questions are arranged so that the more personal questions are on the second page. The second page, therefore, may be done more privately, or not answered at all, if you are sensitive.

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more personal questions are on the second page. The second page,
therefore, may be done more privately, or not answered at all, if you
are sensitive.
737773 A COUPT TO A COUPT TO A COUPT A
BREATHING INVOLVEMENT:
Vital capacity: reclining sitting frogging?
Dependence on aid: neverformerlyat present? If at
present, check the following: full time night & part of day
night only 1 to 3 hrs. unassisted 3 to 12 hrs. un-
assisted average hrs. of frog breathing
Equipment: Day: Lung chestpiece rocking bed pos. pres.
oral p.p. trach
Night: Lung chestpiece rocking bed pos. pres.
oral p.p. trach
If your trach is open, are you aspirated?: Often only with colds
Do you take care of mucus by: aspirator frogging increase
resp. pres other?
SLEEPING:
Do you sleep on your back side abdomen?
Are you moved during the night never once twice
thrice more?
Do you have someone sleeping in your room nearby room within
sound of buzzer?
Are you attended by your family an attendant other
CONTROL TITLE CONTROL OF TEXAS OF A TOMAS
INVOLVEMENT OF LEGS & ARMS: Can you move rt. hand rt. arm left hand left arm ? Can you move rt. foot rt. leg left foot left leg ?
can you move rt. nand rt. arm left hand left arm !
wiggle toesfingers?
Can you feed yourself dress yourself propel wheelchair
type write?
Do you use mouthstick balance feeders slings toes
other
Can you walk walk assisted stand alone use leg braces
EQUIPMENT:
If you do not have the following special equipment, leave blank. If
you have it, and use regularly, mark with an "X." If you have it,
never use it, "XX."
Telephone typewriter standing table lift reading
rack page turner ramp elevator feeders

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 	generator aspirator portable respirator respirator
	batteries corset artificial muscle hand splint
g ^(A)	leg braces other
TTO	OTTIVO -
HO	SING:
	Do you live in a house apartment hospital rest home
	other ?
~ -1	Is your room a bedroom converted other - dining room living room ?
	Was it specially built for your needs shared with another patient a ward ?
	Personal Property of the Prope
	Is it large enough for your needs? Are you in the same com-
. 1	munity as pre-paralysis ?
	If you live at home, is it your home parent's home boarding other
	Office
ACT	IVITIES:
110.	How do you transfer from bed to chair: hydraulic lift slide
	roll ? carried by one person more than one own muscle power?
	Do you get up in your chair: daily on special occasions
	never ? Can you sit comfortably for about: 1 hr 2 hrs.
	3 hrs. 4 hrs. 5 hrs. more ?
	Do you get outdoors every in good weather once a week
	rarely ?
	Do you go out socially: yes no . Who assists you in social transportation: family agency friends other
	Do you have physical therapy: daily weekly at home at a
	hospital? No Who gives you your therapy: family a
	local agency volunteer other
	Do you take a tub bath? Yes No . If yes, do you have special
	arrangements?
HEI	<u>P</u> :
	Do you employ a nurse ? hrs. per week ? salary per week ?
	Do you employ an attendant ? Male ? Female ? hrs. per
	week? weekly salary?
	Do you employ a housekeeper ? hrs. per week _ ? salary per week
	? Does he or she live in: attendant ? housekeeper _ ?
	nurse ? If so, does he or she have own room ? trailer ?
	connecting apartment ?
	How have you found your help: employment agency? friends?
	advertise? through the hospital? social worker? other
	Does your family help with your physical care? Yes No Who?
	Father ? Mother ? Wife ? Husband ? Children ? Other
	Does your family care for you: evenings ? weekends ? weekdays
	Does your family care for you: evenings ? weekends ? weekdays ? With your dressing ? feeding ? grooming ? Do they set
	up for typing? reading? telephoning? etc.?

If not employed, do you have plans or ideas	for self-	-support? Ye	s
If employed pre-paralysis, what did you do			?
HOBBIES: "Ham" ? Stamp collecting ? Painting	? Chess	? Music	?
Voicepondance ? Other			?
VOLUNTEER ACTIVITIES:			
			- 102

If you are able and willing to enlarge on any of these questions asked, on a separate sheet of paper, we would be more than pleased. Consider, also, the following questions: Would you give us an approximate schedule of your average day? The daily schedule of your help? Have you any special claim to fame in the "horizontal" world? Have you designed or made any special equipment? Any suggestions about legislation for the totally disabled? Income tax reduction? Federal or State aid? Would you write to your Congressman to help support legislation for the totally disabled? What suggestions do you have ??????

FINANCIAL ASSISTANCE:
Indicate the assistance you have received since you were discharged
from your initial hospitalization by entering the appropriate letters in
columns below:
Regular assistance - "R" Occasional assistance - "O" Temporary
assistance - "T" One Shot Deal - "S" Past assistance, now dis-
continued - "P"
atten- child- equip- hosp, house- hous- med.
Rec'vd for: dant ren ment care keeper ing trt. Other
Rec'vd from:
Church
Community
County/state
Employer, pre-
paralysis
Fraternal/lodge
Insurance
Nat. Foun.
Relatives
Social Sec.
Veteran, ex- Serviceman
Other, specify
Are you at present investigating other agencies for support? Yes No Specify
MARITAL STATUS:
Single Married: before paralysis after ? widowed ? Divorced: before paralysis after ? If after, was paralysis
a factor? Yes No
Children: 1 2 3 4 5 6 7 ? Any born post-
paralysis? Yes No
Are the children living with you? Yes No With husband
wife relatives?
EDUCATION:
Pre-paralysis: grade school high school college Other
After paralysis: grade school high school college other
(If after paralysis: by tutor home study correspondence telephone other)
What fraternal or honorary organizations
Trained in any language other than your own
EMPLOYMENT:
If presently employed, what do you do
part time ? full time ? home project ? Are your average
earnings per month: under \$50? under \$100? more than \$100
more than \$200?