

PROJECT ON CO-ORDINATION OF SERVICES FOR
MENTALLY HANDICAPPED

VOLUME I

PARENTS

PROJECT ON CO-ORDINATION OF SERVICES FOR
MENTALLY HANDICAPPED

VOLUME I

PARENTS

THE HOSPITAL CENTRE

PROJECT ON CO-ORDINATION OF
SERVICES FOR THE MENTALLY HANDICAPPED

(June 1969 to September 1972)

ANALYSED DATA

VOLUME I

PARENTS

Compiled by

ALI BAQUER

Research Officer to the
Working Party

CONTRIBUTORS TO THIS VOLUME

Project Consultant

Representative of King's Fund

Research Officer

Research Assistant

Part-time Fieldworkers

Coders

Part-time Researchers

Computer Work

Secretarial Assistance

Lithograph Duplicating

Professor R.W. Revans

Janet Craig

Ali Baquer

Tim Eltham

Barbara Bellaby

Richard Fogg

Liz Crout

Valerie Mills

Felicity Sommerfeld

Paul Sommerfeld

Joan Trigwell

Liz Crout

David Smith

David Troon

Diana Cortazzi

Liz Crout

David Smith

Paul Sommerfeld

Frances Troon

Ray Banks - At the London Hospital Computer Centre

Sarah Stenning and Anne Woronow

Rose Crawford

The real contributors to this volume, however, are the representatives of the seven areas who helped to design, complete and analyse the questionnaires. Some of those who co-ordinated the research activities in their areas are:

Hounslow

Dr. P. Bennett

Peter Charles

Marjorie Hills

Dr. Curtis Jenkins

David Mason

Hull

Dr. O.C. Dobson
Dr. H. Jackson
Dr. W. Kell

E. Elliott
J.H. Gardham
Joe Graham
Mrs. Murphy
R.W. Shane
Miss Staines
Roy Wardell
V.L. Wilson

Nottingham

D.H. Carter
Miss Fletcher
Dr. Kenneth Mason
Miss A. Morton
Dr. W. Parry
J.A. Westmoreland

Oxford

J. Forshaw
Dr. E.P. Lawrence
D.W. Macintosh
I. Price
D. Purrett
F. Vidpond

East Sussex

Roy Borley
F. Candy
J.C. Matthews
Angela Wood
Miss J.R. Simpson
Susan Sheriff
M.G.W. Ternouth
Dr. J.A. Watson
Dr. R.G. Brims Young

West Suffolk

Mrs. C.E. Cooley
Mr. G. Elliston
T.H. Higham
B. Hird
R. Lloyd Jones
Dr. A.M. Lish
T.B. Maguire

FOREWORD

- AIMS** The two main objectives of this project, which was supported by the King's Fund from June 1969 to September, 1972, were to collect information on the service offered in seven diverse local authorities of the country and to involve the providers of service in a systematic examination of it. Both these aims have been achieved.
- METHOD** The representatives of Hounslow, Gateshead, Hull, Nottingham, Oxford, East Sussex and West Suffolk formed themselves into a Group under the chairmanship of Dr. M.G. Spark, a general practitioner. The Group now identifies itself as Revans' Participative Research Group (R.P.R.G.). The members of this Group helped the Research Officer, Ali Baquer, in the design of the study, construction of questionnaires, collection of data, and finally in suggesting the methods of analyses of the information gathered. Since the project was undertaken at a time when a great many organisational changes were taking place part-time researchers were employed to help on various aspects of the research.
- SAMPLE** A random sample of the mentally handicapped living in the community and under the age of 30 was drawn from the seven areas. The questionnaires were then administered on their parents, general practitioners, mental welfare officers, health visitors and school teachers. The records kept at the then mental health departments were also examined through the use of a questionnaire. The information thus collected was coded on standard 80 column data sheets and transferred on I.B.M. cards. The data was then processed on computer at the London Hospital Computer Centre.
- DATA** A selection from the computer analysis of the data is now being presented in 5 volumes:

Volume I consists information collected from the questionnaires addressed to the parents (THC 72/555) "table numbers prefixed by P"

Volume II presents an analysis of information collected from general practitioners (THC 72/556) "table numbers prefixed by G"

Volume III deals with the answers given by the mental welfare officers (THC 72/557) "table numbers prefixed by M.W.O."

Volume IV presents the replies of the health visitors and teachers (THC 72/558) "table numbers prefixed by H.V's and T"

Volume V comprises the findings from the records kept on the cases in

The final report, entitled "I Thought They were Supposed to be Doing That" consisting of the main findings, and a description of methods used, has been presented to the King's Fund to be considered for publication in a book form.

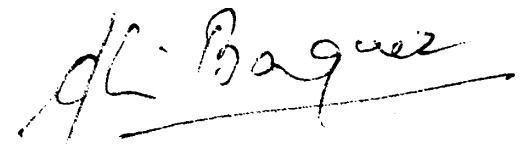
Apart from this book it is hoped that a number of other publications, in the form of articles and books, will be prepared by members of Revans' Participative Research Group as well as others interested in making use of the experience and findings of the project. It will be appreciated if copies of such articles/books could be sent to Miss Janet Craig, Assistant Director, The Hospital Centre, 24 Nutford Place, London, W1 who has agreed to co-ordinate the activities of the Group after the conclusion of the project on 30th September, 1972.

Copies of the five volumes of analysed data are being made available to the Library at the Hospital Centre, London and:

Town Clerks
Directors of Social Services
Medical Officers of Health

in the seven areas respectively.

Those wishing to make use of the data presented in these volumes are requested to acknowledge Revans and Baquer's project on "Co-ordination of Services for the Mentally Handicapped."


Ali Baquer,
Research Officer to the
Working Party.

September, 1972.
Hospital Centre,

NOTES ON INTERPRETING THE TABLES

1. "No Information" category.
This category means that no reply to the question was given or the response was irrelevant for this table.
2. Some of these tables are summary tables in that they total all the answers provided to a particular question. For many questions, the respondent gave more than one answer, for example, in the question, what kind of support is now being provided to the family, the respondent might list two or three types of support. Since the table will summarise the total number of each type of support provided, it is possible for the total of all types of support to exceed the number of cases being surveyed. This situation arises only where more than one answer has been given to the one question.
3. It will be necessary to remember the number of respondents applicable to each volume of the data, for they vary from volume to volume. Although there were 212 cases in our full sample, we only had usable returns from 204 parents, 147 general practitioners, 169 mental welfare officers, etc. The number of respondents applicable to each area is given at the commencement of each volume.

LIST OF ABBREVIATIONS USED

Areas

HO - Hounslow
GA - Gateshead
HU - Hull
NT - Nottingham
OX - Oxford
ES - East Sussex
WS - West Suffolk

Agencies

G.P. - General Practitioner
H.V. - Health Visitor
M.O.H. - Medical Officer of Health
M.W.O. - Mental Welfare Officer
L.E.A. - Local Education Authority
D.R.O. - Disablement Resettlement Officer
J.T.C. - Junior Training Centre
A.T.C. - Adult Training Centre

Others

S.N. - Sub-normal or mentally handicapped
S.S.N. - Severely Sub-normal or Severely Handicapped
E.S.N. - Educationally Sub-normal

RESPONSE TO PARENTS QUESTIONNAIRE

<u>Cases in each area.</u>		<u>Questionnaires completed</u>	
Hounslow	19		19
Gateshead	14		13
Hull	45		44
Nottingham	46		45
Oxford	23		23
East Sussex	45		40
West Suffolk	20		20
	<hr/>		<hr/>
TOTAL	212	TOTAL	204
	<hr/>		<hr/>

CONTENTS

	<u>Page</u>
List of Contributors	II and III
Foreword	IV and V
Notes on Interpreting the Tables	VI
List of Abbreviations Used	VII
Response to Parents Questionnaires	VIII

LIST OF TABLES

<u>Title</u>	<u>Table No.</u>
Parents living together or not	P1
Mother's age at time of survey	P2
Father's age at time of survey	P3
Mother's age at the birth of the Handicapped	P4
Family composition at time of survey	P5
Place of the handicapped in the family	P6
Presence of mental handicap amongst siblings	P7
Number of stillbirths reported and when they occurred	P8
Number of miscarriages and when they occurred	P9
Parents description of the handicap	P10
Number of handicaps mentioned by parents	P11
Age at which subnormality suspected	P12
Number of subnormal in the sample distribution by age and sex	P13
Reasons for suspicion of subnormality by parents	P14
Number of reasons mentioned	P15
Action taken by parents on suspicion	P16
Number of actions taken by parents	P17

<u>Title</u>	<u>Table No.</u>
Person who confirmed the handicap	P19
Length of time parents had to wait to see a specialist	P20
Manner of early assessment of handicap	P21
Satisfaction of parents with advice given on assessment of handicap	P22
Ability of parents to accept the advice	P23
Satisfaction of parents with the manner in which they were told that the child was handicapped	P24
Person who referred the child to subsequent specialist	P25
Diagnosis by subsequent specialist	P26
Age on first diagnosis	P27
Satisfaction with the specialist and his diagnosis	P28
Family doctor	P29
Problems faced by parents during the first three years of the child's life (A)	P30
Problems faced by parents during the first three years of the child's life (B)	P31
Number of problems encountered by the parents	P32
People who helped the parents during the first three years of the Child's life	P33
Help received by the parents in the first three years of the child's life	P34
Number of helps mentioned	P35
Help received from G.P.	P36
Type of help received from G.P.	P37
Number of types of help by G.P. mentioned	P38
How best G.P's could help parents	P39
Number of types of help that G.P's could provide parents	P40
Ease of access to G.P.	P41

Number of types of help received from H.V.	P43
Type of help received from the clinic doctor	P44
Number of types of help from the clinic doctor	P45
Have parents seen M.O.H.	P46
Person who arranged meeting with M.O.H.	P47
Advice given by M.O.H.	P48
Usefulness of M.O.H's advice	P49
Role of medical officer	P50
Number of roles mentioned for M.O.H.	P51
Access to M.O.H.	P52
Frequency of visits by Mental Welfare Officer	P53
Usefulness of visits by M.W.O.	P54
Role of M.W.O.	P55
Number of roles mentioned for M.W.O.	P56
Need for more visits by M.W.O's	P57
Help given by friends, neighbours, relatives	P58
Kind of help given by friends, neighbours, relatives	P59
Number of helps given by friends, neighbours, relatives	P60
Meetings with other parents	P61
Place of meetings with other parents	P62
Frequency of meetings	P63
Ways in which meeting parents help	P64
Membership of voluntary organisations	P65
Extent of activity in voluntary organizations	P66
Assessment of ways in which voluntary organizations can help	P67
Attendance at nursery	P68
What parents were told about the education of their child	P69

<u>Title</u>	<u>Table No.</u>
Age of child at the time of this decision	P71
Type of educational assessment made	P72
Type of educational report provided	P73
Person who helped parents to accept decision on education	P74
First type of school child was admitted to	P75
Age of child on first admission	P76
Satisfaction with first school	P77
Last type of school child was admitted to	P78
Age of child on leaving last school	P79
Satisfaction with last school	P80
Age on first admission to a special school, J.T.C., E.S.N. School	P81
Employment of handicapped	P82
Parents view of employment	P83
Provision of short term care	P84
Age on first admission for short term care	P85
Reason for first admission for short-term care	P86
Satisfaction with first short term care	P87
Age on last admission	P88
Reason for last admission	P89
Satisfaction with last short term care	P90
Parents perception of help given by subnormality hospitals	P91
Health of the handicapped	P92
Speech	P93
Eyesight	P94
Hearing	P95
Incontinence	P96

<u>Title</u>	<u>Table No.</u>
Problems with sleep	P98
Problems with feeding	P99
Mobility	P100
Washing	P101
Dressing	P102
Reasing	P103
Writing	P104
Can he tell the time?	P105
Money	P106
Friends	P107
Problems with sex life?	P108
Any other problems?	P109
Number of other problems	P110
Did Parents ask for help?	P111
Whom did the family ask for help?	P112
Did the parents get the help	P113
Advice on having more children	P114
Advice given by or asked from	P115
What advice was given	P116
Genetic counselling	P117
Genetic counselling arranged by	P118
Services required	P119
Number of services mentioned	P120
Accommodation	P121
Ownership	P122
Amenities:- First - Toilet	P123

TitleTable No.

Bathroom	P125
Play space	P126
Condition of the house and furniture	P127
Interviewer	P128
Duration of the interview	P129
Co-operation	P130
Who was present at the time of the interview	P131
Interviewer's comments:- Degree of satisfaction with services	P132
Interviewer's comments:- General ability to cope with the situation	P133
Interviewer's comments:- Degree of acceptance of the handicap	P134
Interviewer's comments:- Disposition towards the child	P135
Interviewer's comments:- General assesment of the home environment	P136
Interviewer's comments:- Assessment of integration of family	P137
Predominant problem as seen by interviewer	P138
Ease with which information was obtained from parents by interviewer	P139

PARENTS LIVING TOGETHER OR NOT

	HO	GA	HU	NT	OX	ES	WS
Not ascertained	-	-	-	3	1	-	-
Both alive and living together	16	9	36	37	15	31	15
Mother dead or divorced M.S. with father and spouse	-	1	-	-	-	1	-
Father dead or divorced, M.S. with mother and spouse	-	-	2	1	1	1	-
Parents separated, M.S. with mother	-	-	3	1	1	1	1
Parents separated M.S. with father	-	-	-	-	-	-	1
Both parents dead, M.S. with relatives	-	1	-	1	1	2	-
Mother dead or divorced, M.S. with father	-	-	1	1	2	1	1
Father dead or divorced, M.S. with mother	3	2	3	2	1	3	1
M.S. with other relations	-	-	-	-	1	-	1

MOTHER'S AGE AT TIME OF SURVEY

	HO	GA	HU	NT	OX	ES	WS
Not ascertained	-	2	1	1	4	3	-
20 - 24 years	-	-	1	-	-	-	-
25 - 29 years	1	-	1	2	-	2	3
30 - 34 years	2	1	4	4	3	4	2
25 - 39 years	2	1	7	6	-	4	1
40 - 44 years	1	2	6	5	2	7	2
45 - 49 years	3	-	10	8	4	3	4
50 - 54 years	4	3	4	6	2	7	2
55 - 59 years	4	2	4	5	6	6	2
60 - 64 years	2	2	4	5	1	3	2
Over 65 years	-	-	2	-	-	1	-
Not applicable - mother dead, divorced or separated	-	-	1	4	1	-	2

FATHER'S AGE AT TIME OF SURVEY

	HO	GA	HU	NT	OX	ES	WS
Not ascertained	3	3	5	2	3	7	1
20 - 24 years	-	-	-	-	-	-	-
25 - 29 years	-	-	1	1	-	1	-
30 - 34 years	3	1	2	2	3	3	3
35 - 39 years	1	-	5	4	1	4	3
40 - 44 years	2	2	6	10	3	3	1
45 - 49 years	-	1	11	4	1	6	1
50 - 54 years	1	1	2	5	4	6	3
55 - 59 years	4	2	2	7	2	4	3
60 - 64 years	2	2	6	-	3	4	4
Over 65 years	3	1	3	7	2	2	1
Not applicable - father dead, divorced or separated	-	-	2	4	1	-	-

MOTHER'S AGE AT THE BIRTH OF THE HANDICAPPED

	HO	GA	HU	NT	OX	ES	WS
15 - 19 years	-	-	1	2	-	1	-
20 - 24 years	5	2	10	13	3	7	6
25 - 29 years	4	2	11	7	4	7	2
30 - 34 years	1	2	9	5	3	12	5
35 - 39 years	7	3	9	10	3	7	4
40 - 44 years	2	1	4	4	4	1	1
45 - 49 years	-	-	-	-	1	2	-
Not ascertained	-	3	1	5	5	3	2

FAMILY COMPOSITION AT TIME OF SURVEY

	HO	GA	HU	NT	OX	ES	WS
Not ascertained	-	1	1	1	-	-	-
One sibling	6	-	6	14	2	12	7
Two siblings	6	3	11	8	6	11	5
Three siblings	1	4	7	6	2	6	2
Four siblings	2	2	9	6	6	1	-
Five siblings	1	1	3	4	2	4	1
Six siblings	1	1	4	1	1	1	-
Seven siblings	-	-	-	-	-	-	1
Eight or more siblings	-	-	1	1	1	-	-
Handicapped is the only child	2	1	3	5	3	5	4

PLACE OF THE HANDICAPPED IN THE FAMILY

	HO	GA	HU	NT	OX	ES	WS
First born	6	2	12	13	3	12	3
Second born	6	2	11	14	4	13	7
Third born	2	2	6	4	4	5	4
Fourth born	-	2	8	1	3	2	1
Fifth born	1	1	3	5	4	1	-
Sixth born	1	1	-	3	-	1	1
Seventh born	-	1	-	-	1	1	-
Eighth, ninth or tenth born	-	1	1	-	1	-	-
Handicapped is the only child	2	1	3	5	3	5	4
Not ascertained	1	-	1	1	-	-	-

PRESENCE OF MENTAL HANDICAP AMONGST SIBLINGS

	HO	GA	HU	NT	OX	ES	WS
One other sibling with mental handicap	1	1	1	5	3	2	2
Two other siblings with mental handicap	-	1	1	2	-	1	-
Three other siblings with mental handicap	-	-	-	1	-	-	-
Handicapped is the only child	2	1	3	5	3	5	4
Information on mental handicap of other siblings not available or no handicap reported	16	10	40	32	17	32	14

NUMBER OF STILLBIRTHS REPORTED AND WHEN THEY OCCURED

	HO	GA	HU	NT	OX	ES	WS
One stillbirth	1	1	2	2	2	3	2
Two stillbirths	-	1	-	-	-	1	-
Three stillbirths	-	-	-	1	-	-	-
No stillbirths reported	7	3	1	3	1	3	-
Stillbirth was before the birth of the handicapped	1	1	2	2	-	3	1
Stillbirth was after the birth of the handicapped	-	-	-	1	2	-	1
Stillbirths were before and after the birth of the handicapped	-	1	-	-	-	1	-
No information on stillbirths available	11	8	42	40	20	33	18

NUMBER OF MISCARRIAGES AND WHEN THEY OCCURRED

	HO	GA	HU	NT	OX	ES	WS
One miscarriage	2	2	9	7	4	4	3
Two miscarriages	1	-	2	1	2	2	1
Three miscarriages	-	-	1	1	-	-	-
Four miscarriages	-	-	1	1	-	-	-
Miscarriage was before the birth of the handicapped	-	1	4	7	4	5	1
Miscarriage was after the birth of the handicapped	3	1	6	2	2	1	2
Miscarriage was before and after the birth of the handicapped	-	-	3	1	-	-	1
No miscarriages reported	9	8	31	32	16	31	16
No information on miscarriages available	7	3	1	4	1	3	-

PARENTS DESCRIPTION OF THE HANDICAP

	HO	GA	HU	NT	OX	ES	WS
Nothing wrong	-	1	2	-	-	-	-
Medical problems only - illness, injuries, etc.	1	-	1	4	-	7	1
Physical problems only - slow to develop, walk, talk etc.	2	1	5	7	1	3	7
Social problems only - does not mix, has no friends, needs looking after	-	-	1	-	1	1	1
Educational problems - slow at school, cannot read, and write etc.	-	1	1	-	-	1	1
Mental problems - backward, retarded, subnormal	8	6	32	20	14	19	10
Categories of mental handicap mentioned - he is mongol, epilipsy, etc.	9	2	7	16	9	17	5
Behaviour problems - lazy mischievous	-	-	-	2	-	3	1
No information given or available	-	3	5	6	-	1	2

QUESTION: Could you please tell me what do you believe is wrong with your child?

NUMBER OF HANDICAPS MENTIONED BY PARENTS

	HO	GA	HU	NT	OX	ES	WS
One handicap	18	9	31	33	21	27	14
Two handicaps	1	1	9	7	2	12	4
Three handicaps	-	-	-	-	-	-	-
No information given or available	-	3	5	6	-	1	2

AGE AT WHICH SUBNORMALITY SUSPECTED

	HO	GA	HU	NT	OX	ES	WS
Less than 1 week	2	-	1	-	-	1	-
Two weeks	-	-	1	-	-	2	-
Three weeks	-	-	-	-	-	-	-
One month	-	-	-	1	-	1	-
1 - 3 months	-	1	7	6	2	4	-
3 - 6 months	-	-	2	4	2	3	3
6 - 9 months	-	-	3	1	1	4	2
9 - 12 months	-	1	3	2	1	2	2
12 - 18 months	-	1	2	1	-	3	2
18 - 24 months	3	-	1	1	-	2	-
2 - 2 $\frac{1}{2}$ years	-	-	2	2	2	2	-
2 $\frac{1}{2}$ - 3 years	1	-	3	1	1	1	-
3 - 3 $\frac{1}{2}$ years	3	-	1	-	1	-	-
3 $\frac{1}{2}$ - 4 years	-	-	-	2	-	1	-
4 - 5 years	-	-	-	-	-	-	-

QUESTION: How old was the child when you first suspected that he/she might be handicapped?

AGE AT WHICH SUBNORMALITY SUSPECTED - Cont'd.

	HO	GA	HU	NT	OX	ES	WS
At birth	6	2	7	13	6	3	4
Between birth and 5 years	9	5	33	34	16	29	13
5 - 9 years	2	6	9	9	5	9	5
10 - 14 years	2	-	1	1	-	-	1
15 - 19 years	-	-	-	-	-	2	-
20 - 24 years	-	-	-	-	-	-	-
Not known	-	2	2	2	2	-	1

NUMBER OF SUBNORMAL IN THE SAMPLE
DISTRIBUTION BY AGE AND SEX

M = Male
F = Female

	0 - 4		5 - 9		10 - 14		15 - 19		20 - 24		25 - 29		
	M	F	M	F	M	F	M	F	M	F	M	F	M
HOUNSLOW	1	1	1	1	1	2	2	1	1	2	3	3	
GATESHEAD	1	-	-	1	1	1	2	-	2	1	2	2	
HULL	2	1	3	5	6	5	4	4	6	2	4	2	2
NOTTINGHAM	-	-	6	3	5	4	8	5	6	4	2	2	2
OXFORD	-	-	2	2	2	3	3	1	4	4	1	1	1
EAST SUSSEX	2	2	4	3	2	5	3	4	6	2	3	4	2
WEST SUFFOLK	2	2	3	1	1	1	1	2	2	-	3	2	1
TOTAL	8	6	19	16	18	21	23	17	27	15	18	16	

REASONS FOR SUSPICION OF SUBNORMALITY BY PARENTS

	HO	GA	HU	NT	OX	ES	WS
Parents did not suspect	5	6	6	11	3	9	5
Connected with known syndromes e.g. mongolism	3	2	6	11	6	4	2
Connected with slow development of child	6	2	20	12	9	20	9
Connected with fits, convulsions, tantrums	2	-	5	3	1	5	-
Connected with education - admission to school, performance at school	1	1	6	4	2	4	2
Connected with behaviour problems	3	1	2	5	-	3	3
No specific reason for suspicion mentioned	-	-	1	1	-	-	-
Physical reasons	-	-	1	2	1	1	2
No information provided	-	2	2	1	1	-	-

QUESTION: What made you suspect it?

NUMBER OF REASONS MENTIONED

	HO	GA	HU	NT	OX	ES	WS
None mentioned	5	6	6	11	3	9	5
One reason mentioned	13	4	32	30	18	25	12
Two reasons mentioned	1	1	4	4	1	6	3
No information provided	-	2	2	1	1	-	-

ACTION TAKEN BY PARENTS ON SUSPICION

	HO	GA	HU	NT	OX	ES	WS
No action taken	7	6	10	9	9	9	9
Consulted friends, relatives, neighbours	-	-	-	-	-	-	-
Consulted voluntary organisations	-	-	1	-	-	-	-
Consulted other parents with handicapped children	-	-	-	-	-	-	-
Consulted own G.P.	3	2	22	19	8	21	10
Consulted other specialists	1	-	10	11	3	11	1
Consulted H.V.	-	-	-	-	-	2	-
Consulted clinic doctor	4	1	5	7	1	3	3
Consulted Mental Health Department	1	-	2	3	1	-	-
Consulted others	4	1	2	4	2	1	-
Not clear what action taken	1	3	3	1	1	1	-

QUESTION: What did you do about it?

NUMBER OF ACTIONS TAKEN BY PARENTS

	HO	GA	HU	NT	OX	ES	WS
No action taken by parents	7	6	10	9	9	9	9
One action taken	9	4	24	29	11	23	9
Two actions taken	2	-	6	6	2	6	1
Three actions taken	-	-	2	1	-	1	1
No information provided	1	3	3	1	1	1	-

PERSON WHO REFERRED THE CHILD TO A SPECIALIST IN THE
FIRST PLACE

	HO	GA	HU	NT	OX	ES	WS
No one referred, child never seen by a specialist	1	1	-	7	2	6	3
Not clear who referred	-	1	1	-	-	-	-
G.P.	1	3	22	16	6	18	8
Clinic doctor	2	2	3	6	1	1	2
M.O.H, M.W.O., H.V.	1	1	1	-	-	1	1
~ School Teacher, School Doctor, Headmaster	6	2	10	6	7	3	1
~ Hospital	7	-	5	5	4	6	5
Parents	-	-	-	3	1	3	-
Not known who referred	1	3	3	3	2	2	-

QUESTION: Who referred your child to a specialist in the first place?

PERSON WHO CONFIRMED THE HANDICAP.

	HO	GA	HU	NT	OX	ES	WS
No one confirmed the handicap	-	1	-	9	2	3	2
Not clear who confirmed the handicap	-	2	1	2	-	2	-
G.P.	1	1	-	-	-	1	1
Clinic Doctor	3	1	-	1	1	4	1
M.O.H, M.W.O.	1	2	13	3	1	2	1
Schoolmaster, School Teacher	1	1	2	1	1	1	-
School Doctor	2	2	3	6	6	5	2
Hospital Paediatrician	9	-	22	21	10	13	10
Consultant - Privately Consulted	-	-	3	1	1	7	2
Not known who confirmed the handicap	1	3	1	2	1	2	1

QUESTION: Who actually confirmed that the child was handicapped,
who was the specialist and what advice did he give you?

LENGTH OF TIME PARENTS HAD TO WAIT TO SEE A SPECIALIST

	HO	GA	HU	NT	OX	ES	WS
Did not see a specialist	2	2	-	7	6	6	2
Not clear how long	2	1	-	-	-	-	-
No waiting at all	9	6	11	24	7	26	15
Less than a month	-	1	22	2	3	1	-
Between 1 and 6 months	1	-	10	2	2	4	3
Between 6 and 12 months	-	-	-	-	1	-	-
Over a year	-	-	-	1	1	-	-
No information available	5	3	2	10	3	3	-

QUESTION: How long did you have to wait before your child was
 actually seen by a specialist?

MANNER OF EARLY ASSESSMENT OF HANDICAP

	HO	GA	HU	NT	OX	ES	WS
Assessment was not made at all	1	-	-	6	2	5	1
Not clear where the child was seen	2	1	-	1	-	-	-
Child admitted as an inpatient	6	1	6	5	3	12	9
Child seen as an outpatient	2	5	19	23	8	15	5
Child seen at home	1	-	-	-	1	2	2
Child seen at a clinic	2	-	1	1	-	1	-
Child seen at school	2	1	4	3	5	2	3
Child seen at the office of the M.O.H.	-	-	14	3	1	-	-
No information available	2	5	1	4	3	3	-

QUESTION: How was the assessment made? Was your child admitted to hospital for observation and investigation? Or was your child assessed as an out patient?

SATISFACTION OF PARENTS WITH ADVICE
GIVEN ON ASSESSMENT OF HANDICAP

	HO	GA	HU	NT	OX	ES	WS
No advice received	-	-	-	5	3	1	2
Unqualified satisfaction	7	8	28	23	13	19	6
Qualified satisfaction	5	-	3	2	2	5	7
Qualified dissatisfaction - asked for more advice, consulted others	3	-	6	11	3	12	5
Unqualified dissatisfaction	-	1	6	1	-	1	-
No information available	4	4	2	4	2	2	-

QUESTION: Were you satisfied with the consultation and advice given?

ABILITY OF PARENTS TO ACCEPT THE ADVICE

	HO	GA	HU	NT	OX	ES	WS
No advice received	-	-	-	5	3	1	2
No problems with accepting advice	-	5	9	4	3	1	-
Some problems - "nothing else could be done".	-	3	23	18	7	23	13
Neither accepted nor rejected the advice	-	-	-	1	-	-	-
Partial rejection of the advice - "something more could have been done".	-	3	10	10	6	13	6
Complete rejection of advice	-	-	2	1	-	-	-
No information available	19	2	1	5	3	2	-

QUESTION: Looking back, do you think you were able to accept
the advice given to you?

SATISFACTION OF PARENTS WITH THE MANNER
IN WHICH THEY WERE TOLD THAT THE CHILD
WAS HANDICAPPED

	HO	GA	HU	NT	OX	ES	WS
Parents have not been told	1	-	-	3	3	1	1
Unqualified satisfaction	5	8	32	18	10	18	5
Qualified satisfaction	-	-	2	2	2	3	7
Qualified dissatisfaction	3	1	7	17	5	16	6
Unqualified dissatisfaction	-	-	2	2	-	-	-
No information available	10	4	2	3	3	2	1

QUESTION: Were you satisfied with the manner in which you were told that the child was handicapped?

PERSON WHO REFERRED THE CHILD TO SUBSEQUENT SPECIALISTS

	HO	GA	HU	NT	OX	ES	WS
Child was not seen	9	3	29	22	15	17	9
OWN G.P.	3	2	5	8	3	5	3
Clinic doctor	2	-	1	-	-	2	-
Hospital - inpatient	-	-	1	-	-	-	1
Hospital - outpatient	-	-	2	3	-	-	-
School doctor	1	-	3	3	1	3	-
Parents cannot remember if the child was seen or not	-	-	1	2	-	-	1
Parents by their own efforts	1	-	1	-	-	4	1
Another specialist	-	-	-	3	-	4	3
M.O.H.	-	-	-	1	3	-	1
No information available	3	8	2	4	1	5	1

QUESTION: After this first referral your child was perhaps seen by other specialists. Could you please recall who these were and what happened?

DIAGNOSIS BY SUBSEQUENT SPECIALIST

	HO	GA	HU	NT	OX	ES	WS
Child was not seen	9	3	29	22	15	17	9
Parents recall that diagnosis was made only on general health care problems	1	-	2	5	1	5	2
Parents recall that diagnosis was made on mental handicap	2	1	6	6	5	8	1
Parents recall that diagnosis was made on both physical and mental handicap	2	1	3	7	-	4	5
Parents cannot recall what diagnosis was made	2	-	2	1	1	2	1
No information available	3	8	3	5	1	4	2

AGE ON FIRST DIAGNOSIS

	HO	GA	HU	NT	OX	ES	WS
Child was not seen	9	3	29	22	15	17	9
Child was between 0 and 4 years	4	1	6	10	3	8	6
Child was between 5 and 9 years	2	-	4	6	2	4	3
Child was between 10 and 14 years	1	-	2	3	1	4	-
Child was over 14 years	-	-	2	-	1	3	-
Child was seen but parents cannot remember the age	-	1	-	1	-	-	-
No information available	3	8	2	4	1	4	2

SATISFACTION WITH THE SPECIALIST AND HIS DIAGNOSIS

	HO	GA	HU	NT	OX	ES	WS
Child not seen at all	9	3	29	22	15	17	9
Very satisfied	4	1	6	10	2	8	6
Satisfied	1	-	7	6	3	10	2
Dissatisfied	-	-	-	2	2	1	-
Very dissatisfied	-	-	1	1	-	-	-
Satisfied with some and dissatisfied with others	1	1	-	-	-	-	2
No information available	4	8	2	5	1	4	1

FAMILY DOCTOR

	<u>HO</u>	<u>GA</u>	<u>HU</u>	<u>NT</u>	<u>OX</u>	<u>ES</u>	<u>WS</u>	
Family has the same G.P. as at the time the child was born	5	4	14	14	5	12	6	
Family has a different G.P.	13	8	31	29	18	28	14	
No information available	1	1	-	3	-	-	-	

QUESTION: Is he the same doctor you had at the time the child was born?

PROBLEMS FACED BY PARENTS DURING THE
FIRST THREE YEARS OF THE CHILD'S LIFE (A)

	<u>HO</u>	<u>GA</u>	<u>HU</u>	<u>NT</u>	<u>OX</u>	<u>ES</u>	<u>WS</u>	
<u>SLEEPING PATTERN</u>								
Problems with sleeping pattern	1	2	10	12	6	16	3	
No problem	16	9	35	31	15	22	16	
<u>FEEDING</u>								
Problems with feeding	10	4	18	26	5	14	7	
No problem	8	7	27	17	16	24	12	
<u>DRINKING FROM A CUP</u>								
Problems with drinking from a cup	2	4	10	17	4	10	7	
No problems	16	7	35	26	17	28	12	
<u>SITTING UP</u>								
Problems with sitting up	3	4	19	22	9	13	12	
No problem	15	7	26	21	12	25	7	
<u>INCONTINENCE</u>								
Problems with incontinence	9	4	28	24	5	18	9	
No problem	9	7	17	19	16	20	10	

QUESTION: Did you face any special problems in looking after the child
in the first three years of his/her life?

PROBLEMS FACED BY PARENTS DURING THE
FIRST THREE YEARS OF THE CHILD'S LIFE. (B)

	HO	GA	HU	NT	OX	ES	WS
<u>WALKING</u>							
Problems with walking	9	6	30	31	14	25	16
No problem	9	5	15	12	7	12	4
<u>TALKING</u>							
Problems with talking	9	8	36	35	16	30	12
No problem	9	3	9	8	5	7	7
<u>WEANING</u>							
Problems with weaning	4	4	7	8	3	6	5
No pbblem	14	7	38	35	18	31	14
<u>DRESSING</u>							
Problems with dressing	4	3	29	30	13	22	12
No problem	14	8	16	13	8	15	7
<u>OTHER PROBLEMS</u>							
Problems - not specified	3	1	4	7	5	8	-
No other problems	15	10	41	36	16	29	19
No information available	1	1	-	3	2	3	-

NUMBER OF PROBLEMS ENCOUNTERED BY
THE PARENTS

	HO	GA	HU	NT	OX	ES	WS
None	4	2	4	2	1	1	3
One problem	3	3	5	2	3	5	1
Two problems	2	2	5	3	1	5	2
Three problems	1	-	3	5	7	2	3
Four problems	1	1	7	3	1	7	2
Five problems	5	1	7	9	5	7	1
Six problems	-	-	3	1	-	4	3
Seven problems	1	1	7	11	1	3	2
Eight problems	1	1	1	3	1	3	3
Nine or more problems	-	1	3	3	1	1	-
No information available	1	1	-	4	2	2	-

PEOPLE WHO HELPED THE PARENTS DURING THE FIRST THREE
YEARS OF THE CHILDS LIFE

	HO	GA	HU	NT	OX	ES	WS
Nobody	10	2	32	17	10	16	7
Immediate family	1	2	6	8	5	9	4
Grandparents	4	3	4	5	1	9	2
Relatives, friends, neighbours	2	1	1	-	-	2	3
G.P.	2	1	2	3	2	1	2
Clinic doctor	2	-	-	-	1	1	1
Health visitor	-	1	2	1	2	3	2
Mental Health Department	-	-	-	-	1	-	-
Voluntary organisations	-	-	-	-	1	-	-
Others	-	1	3	4	1	1	2
No information available	-	4	-	11	2	2	2

QUESTION: Who helped you most in respect of the care of the
child during the first three years?

HELP RECEIVED BY THE PARENTS IN THE
FIRST THREE YEARS OF THE CHILD'S LIFE

	HO	GA	HU	NT	OX	ES	WS
No information available	-	5	1	14	-	1	1
Medical needs, illness, injuries etc.	2	1	2	3	2	1	5
Practical needs of management of the child, baby sitting, shopping etc.	8	6	13	7	3	19	6
Educational needs, admission to JTC etc, assessment of IQ	1	-	-	-	1	-	-
Arranging holidays, short-term care etc.	-	-	-	1	-	-	-
Social contacts - introduction to voluntary organisations, other parents with handicapped children, clubs.	-	-	1	1	-	-	-
General help and support to reduce anxiety, tension, etc.	3	3	8	3	4	9	1
Receiving help mentioned but type of help not clear	1	-	-	1	1	1	-
No help received	9	2	30	21	14	18	8

QUESTION: In what way do you think (name the person) mentioned above helped you?

NUMBER OF HELPS MENTIONED

	HO	GA	HU	NT	OX	ES	WS
Mentions ONE	5	3	7	7	7	14	10
Mentions TWO	5	2	4	3	2	5	1
Mentions THREE	-	1	3	1	-	2	-
Mentions FOUR	-	-	-	-	-	-	-
Mentions FIVE or more	-	-	-	-	-	-	-
No help	9	2	30	21	14	18	8
No information available	-	5	1	14	-	1	1

HELP RECEIVED FROM GP

	HO	GA	HU	NT	OX	ES	WS
No information available	-	-	1	5	-	-	-
No help received even when parents asked for his help	3	-	-	-	1	4	-
GP helped only when parents asked for his help	2	1	3	3	-	-	-
GP helped	6	5	9	17	5	14	7
No help received	7	7	32	21	17	20	13

QUESTION: Did your own doctor help you?

	HO	GA	HU	NT	OX	ES	WS
No information available	4	-	1	4	-	4	-
Help received, but type of help not ascertained	-	-	1	1	1	1	1
Was sympathetic and kind, listened to problems, gave advice	3	4	6	10	4	7	4
Attended to general medical needs, gave medication	4	3	6	4	1	6	2
Helped in referring the child to specialists in the hospital for diagnosis and treatment	2	-	2	6	-	2	2
Got in touch with MOH, HV, MWO, clinic doctor	-	-	-	1	-	-	-
Helped in arranging educational facilities, IQ testing, child guidance clinic, JTC, etc.	-	-	1	1	-	-	-
Helped to arrange the child to be seen for speech, eye sight and hearing defects	1	-	-	1	-	-	-
Introduced the family to voluntary organisations, parents of other handicapped children, gave literature to read on problems of having handicapped children	1	-	1	-	-	-	-
Helped in arranging holidays, short-term care etc.	-	-	-	1	-	6	-
No help received	2	2	32	21	15	20	17

NUMBER OF TYPES OF HELP BY GP MENTIONED

	HO	GA	HU	NT	OX	ES	WS
No information available	4	-	1	4	-	2	-
Mentioned ONE	6	5	8	17	6	12	5
Mentioned TWO	1	1	4	3	-	2	2
Mentioned THREE	-	-	-	1	-	-	-
Mentioned FOUR	1	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-	-
No help mentioned	17	7	32	21	17	20	13

	HO	GA	HU	NT	OX	ES	WS
No information available	-	-	2	9	1	-	2
Cannot help - they do not have the skills, you need special doctors for the mentally handicapped	1	-	7	1	-	5	1
Cannot help - unqualified negative response	1	-	-	5	1	-	-
Can help - unqualified positive response	-	-	-	5	-	-	1
Can help - by being kind and sympathetic, they can listen to problems, advise and support on problems connected with mental handicap	10	6	15	17	8	24	11
Can help by referring a child to specialists/hospitals for diagnosis and treatment	1	2	4	2	6	1	-
Can help by referring the child and family to agencies who could help like the MOH, HV, MWO, voluntary organisations	4	-	2	3	2	4	-
Can help by attending to the medical needs of the patients prescribing medication etc.	4	1	3	2	5	4	1
Can arrange holidays, short-term care, admission to institutions etc.	-	-	-	1	-	-	-
Don't know	2	7	8	1	3	3	5
Cannot help - they do not have the time; too busy, too many patients on their lists etc.	2	-	11	7	5	12	1

QUESTION: How best do you think family doctors could help parents with mentally handicapped children?

NUMBER OF TYPES OF HELP THAT GP'S COULD PROVIDE PARENTS

	HO.	GA	HU	NT	OX	ES
Mentioned ONE	12	3	19	22	12	29
Mentioned TWO	4	3	7	4	6	4
Mentioned THREE	1	-	-	1	-	-
Mentioned FOUR	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-
Parents said don't know	2	7	8	1	3	3
None mentioned	-	-	9	10	1	4
No Information	-	-	2	9	1	-

EASE OF ACCESS TO GP

	HO	GA	HU	NT	OX	ES	W
Difficult to contact	3	-	3	2	5	6	
Neither difficult nor easy	3	-	1	2	-	2	
Easy to contact	12	13	39	36	16	30	1
No access at all	-	-	-	-	-	-	
No information available	1	-	2	5	2	1	

QUESTION: Is it fairly easy for you to consult your own doctor about the mental handicap of the child?

TYPE OF HELP RECEIVED FROM HV

	HO	GA	HU	NT	OX	ES
No information available	-	-	1	8	1	-
Cannot help	-	-	-	-	2	-
Help received - type of help not ascertained	1	3	1	3	-	1
Help received - routine help mentioned, not any different from the help given to mothers with normal children	4	2	3	4	1	4
Help received - sympathetic, kind, gave advice and support on problems connected with mental handicap	4	2	12	4	1	5
Help received - HV got in touch with others (specialists, clinic doctor, child guidance clinic, GP etc.) to arrange assessment and treatment, medical care	1	-	6	2	2	-
Help received - HV got in touch with others (MOH, MWO, voluntary organisations JTC etc.) to obtain social support for the family	1	-	-	2	-	-
Help received - HV arranged or helped in arranging holidays, short-term care etc.	-	-	-	1	-	-
Don't know, can't remember	-	2	1	1	2	3
No help received	8	5	23	23	15	27

QUESTION: What help and advice did you get from your Health Visitor regarding your child?

NUMBER OF TYPES OF HELP RECEIVED FROM HV

	HO	GA	HU	NT	OX	ES
Mentioned ONE	11	5	18	11	4	10
Mentioned TWO	-	1	2	3	1	-
Mentioned THREE	-	-	-	-	-	-
Mentioned FOUR	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-
Parents said don't know	-	2	1	1	2	3
No help received	8	5	23	23	15	27
No information available	-	-	1	8	1	-

TYPE OF HELP RECEIVED FROM THE CLINIC DOCTOR

	HO	GA	HU	NT	OX	ES
No information available	4	3	1	7	-	-
No help received - they did not have the time, too busy	-	-	1	1	-	-
No help received - they did not know enough about mental handicap	1	-	4	1	2	-
Help received - type of help not ascertained	-	2	1	5	-	-
Help received - they were kind and sympathetic, listened to problems, gave advice on problems connected with mental handicap	1	3	3	2	-	2
Help received - they referred the child to specialists/hospitals for diagnosis and treatment	-	1	4	3	-	-
Help received - they referred the child and family to agencies who could help like MOH, HV, MWO, voluntary organisations etc.	2	1	2	-	-	-
Help received - they attended to medical needs	5	-	-	-	-	1
Parents said they don't know or can't remember	-	1	1	-	-	2
No help received	7	2	30	28	21	35

QUESTION: Did you receive any advice from the clinic doctor regarding the mental handicap of your child?

In what way do you think he/she helped you?

NUMBER OF TYPES OF HELP FROM THE CLINIC DOCTOR

	HO	GA	HU	NT	OX	ES
Mentioned ONE	6	7	11	8	2	3
Mentioned TWO	1	-	-	-	-	-
Mentioned THREE	-	-	-	-	-	-
Mentioned FOUR	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-
Parents said don't know or can't remember	-	1	1	-	-	2
No help received	7	2	30	28	21	35
No information available	4	3	1	2	-	-

HAVE PARENTS SEEN MOH

	HO	GA	HU	NT	OX	ES	W
No information available	-	1	1	8	-	-	
Seen only once	1	1	22	17	1	12	
Seen twice	2	3	3	2	-	2	
Seen thrice	2	-	-	1	-	1	
Seen four-times	1	-	-	-	-	-	
Seen five times or more	-	-	-	-	-	-	
Seen twice a year or more	3	-	-	-	1	1	
Seen once a year	4	1	-	1	-	-	
Seen - frequency of meetings not ascertained	3	-	-	3	-	7	
Don't remember if seen or not	-	-	-	-	-	1	
No, not seen	3	7	19	14	21	16	

PERSON WHO ARRANGED MEETING WITH MOH

	HO	GA	HU	NT	OX	ES
No information available	1	2	1	15	-	-
Parents efforts	3	-	2	-	-	4
MOH invited	4	1	4	3	-	7
GP arranged	-	-	3	3	1	2
HV arranged	-	1	3	2	-	-
MWO arranged	1	-	1	1	-	-
Clinic doctor arranged	4	1	2	-	1	2
Voluntary organisations arranged	-	-	-	-	-	-
School arranged	1	-	10	10	-	4
Cannot remember who arranged the meeting	2	1	-	1	-	5
MOH not seen at all	3	7	19	11	21	16

QUESTION: Who referred you to him?

ADVICE GIVEN BY MOH

	HO	GA	HU	NT	OX	ES
No information available	1	2	1	15	-	-
MOH seen but offered no advice	3	-	1	6	1	12
MOH seen but parents can't remember what advice was given	1	-	3	2	-	2
MOH seen and he explained problems connected with handicap, offered advice	3	2	-	3	-	4
MOH seen and he made arrangements for IQ assessment, test and speech therapy for speech, hearing defects, etc.	2	-	2	2	-	1
MOH seen and he arranged admission to JTC, advised etc. arranged transport	4	2	19	7	1	4
MOH seen and he arranged admission to institutions for long-term care	2	-	-	1	-	-
MOH seen and he referred the family to agencies which could give support	-	-	-	-	-	1
MOH arranged home visits of HV, MWO	-	-	-	-	-	-
MOH not seen	3	7	19	10	21	16

What advice did he give you?

USEFULNESS OF MOH'S ADVICE

	HO	GA	HU	NT	OX	ES	WS
MOH's advice was useful	7	4	16	8	1	8	8
MOH's advice neither useful or not useful	1	-	2	-	-	-	1
MOH's advice not useful	3	-	4	6	-	5	2
MOH's seen but parents can't remember the advice given	1	-	1	-	-	-	-
MOH not seen	3	7	19	10	20	16	9
No information available	1	2	1	17	2	1	-
No advice given	3	-	2	5	-	10	-

QUESTION: Did you find this advice useful?

ROLE OF MEDICAL OFFICER

	HO	GA	HU	NT	OX	ES	WS
No information available	-	2	1	19	2	-	4
To give advice to parents on problems connected with mental handicap	8	2	1	7	2	17	2
To make suitable arrangements for education and training of the child	3	3	10	6	-	7	5
To arrange facilities for diagnosis and treatment of the child	-	1	1	1	3	3	-
To arrange home visits by social workers, health visitors	2	-	1	1	-	3	-
To co-ordinate with other agencies who could help the child, like GP etc.	5	-	2	-	1	3	1
To arrange holidays, short-term care etc.	1	-	-	1	-	1	1
To make arrangements for long term care when the parents can't cope or are no longer there	1	-	-	1	-	1	-
To help in finding suitable employment	1	-	1	-	-	1	-
Don't know	3	6	15	8	11	4	10
MOH has no role, does nothing	-	1	14	6	5	8	-

NUMBER OF ROLES MENTIONED FOR MOH

	HO	GA	HU	NT	OX	ES	WS
Mentioned ONE	11	3	15	12	4	24	4
Mentioned TWO	5	-	1	1	1	3	1
Mentioned THREE	-	1	-	1	-	1	1
Mentioned FOUR	-	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-	-
Parents said don't know	3	6	15	3	-	4	9
None mentioned	-	1	13	14	16	8	4
No information available	-	2	1	15	2	-	1

ACCESS TO MOH

	HO	GA	HU	NT	OX	ES	WS
Difficult to contact	-	2	8	6	2	14	-
Neither difficult nor easy	2	-	-	1	-	1	-
Easy to contact	16	5	35	14	15	23	11
No access at all	-	1	-	3	-	-	2
No information available	1	5	2	19	1	-	1
Don't know	-	-	-	3	5	2	6

QUESTION: Is it fairly easy for you to get in touch with the Medical Officer
from the local authority Health Department?

FREQUENCY OF VISITS BY MENTAL WELFARE OFFICER

	HO	GA	HU	NT	OX	ES	WS	T
No information available	-	-	-	3	-	-	-	
Visits - THREE or more times a year	1	1	4	4	2	11	7	
Visits - TWICE a year	2	-	5	5	4	6	4	
Visits - ONCE a year	1	-	5	4	-	2	2	
Visits - ONCE in TWO years	1	-	2	1	-	-	-	
Visits - ONCE in THREE years	3	-	1	-	-	-	-	
Visits - occasionally	-	-	-	3	-	1	-	
Visits - regularly	1	2	-	9	10	1	1	
Visits - irregularly	5	4	14	8	2	10	-	
Visits - when needed or requested	-	1	-	1	2	1	1	
No visits at all	5	5	14	8	3	8	5	

QUESTION: Are you visited by a Mental Welfare Officer?

USEFULNESS OF VISITS BY MWO

	HO	GA	HU	NT	OX	ES	WS
No information available	1	2	1	3	1	-	-
Useful - MWO was kind, sympathetic, explained the problems supported the family	7	4	20	17	15	22	6
Useful - MWO got in touch with others who could help the child/family	-	-	1	3	4	1	1
Useful - MWO arranged assessment, holidays, short-term care	-	-	-	3	1	3	-
Useful - no specific reason given	-	1	-	1	-	-	6
Not useful - unkind, unsympathetic	-	-	-	-	-	2	-
Not useful - he did not take any action - no practical help	2	1	11	12	-	4	1
Not useful - no specific reason given	4	-	-	1	-	2	-
Mixed response - neither not useful, nor useful	2	-	-	1	-	-	-
Don't know	-	-	1	2	-	-	1
Had no visits at all	3	5	11	3	2	6	5

ROLE OF MWO

	HO	GA	HU	NT	OX	ES	WS	T
No information available	-	2	1	12	1	-	3	
Can't help - they do not know how to	-	-	1	1	-	-	-	
Can't help - unqualified negative response	-	-	6	-	-	1	-	
Can help - unqualified positive response	1	-	-	5	1	-	1	
Can help - by being kind and sympathetic, they can listen to problems, advise and support on problems connected with mental handicap	13	5	30	22	17	32	10	
Can help by referring the child to specialists for diagnosis and treatment	-	-	2	2	11	-	-	
Can help by referring child and family to other agencies who could help like HV, voluntary organisations etc.	3	2	3	4	3	4	1	
Can help by arranging admission to JTC and schools for training and education	2	-	2	4	2	2	1	
Can help by arranging holidays, short-term care, admissions to institutions etc.	-	-	1	5	1	4	2	
Don't know	3	6	10	1	3	4	4	

QUESTION: What do you suggest his role should be in relation to the families with handicapped children?

NUMBER OF ROLES MENTIONED FOR MWO

	HO	GA	HU	NT	OX	ES	WS	T
Mentioned ONE	14	4	27	27	14	30	11	
Mentioned TWO	1	1	3	4	4	6	-	
Mentioned THREE	-	-	2	2	1	-	- 2	
Mentioned FOUR	1	-	-	-	-	-	-	
Parents said don't know	3	4	10	2	-	4	3	
Mentioned none	-	2	2	7	4	-	2	

NEED FOR MORE VISITS BY MWOs

	HO	GA	HU	NT	OX	ES	WS
No need for more visits - we know where to get hold of them	2	1	13	9	9	7	14
No need for more visits - we get along well on our own. Don't need them	9	5	13	3	8	21	-
No need for more visits - no reason given	-	-	1	1	-	-	-
Would like more visits - no reason given	1	-	-	2	-	-	-
Would like more visits, it is nice to talk with someone who can give advice/cares	1	1	9	8	4	8	1
Would like more visits because they can arrange help	4	1	-	1	-	4	-
No need for any visits at all	1	-	1	15	1	-	-
No information available	1	5	2	5	1	-	4
Don't know	-	-	6	2	-	-	1

QUESTION: Would it help if he visited you more often?

HELP GIVEN BY FRIENDS, NEIGHBOURS, RELATIVES

	HO	GA	HU	NT	OX	ES	WS	T
--	----	----	----	----	----	----	----	---

No help given

8	7	23	22	16	16	6
---	---	----	----	----	----	---

Help given

11	5	21	19	6	25	14
----	---	----	----	---	----	----

No information available

-	2	1	5	1	-	-
---	---	---	---	---	---	---

QUESTION: Have you got any friends and neighbours or relatives who help you in any way with regard to your handicapped child?

KIND OF HELP GIVEN BY FRIENDS, NEIGHBOURS, RELATIVES

	HO	GA	HU	NT	OX	ES	WS
Help received - but kind of help not mentioned	1	1	-	2	-	1	1
Help received - general support "help in any way", "very kind, friendly"	2	1	5	10	4	10	8
Helped received - help in looking after the handicapped, baby sitting	12	2	19	11	4	19	11
Help received - in the way of clothing, financial assistance etc.	1	-	-	-	-	-	-
No help given	8	7	23	22	16	16	6
No information available	-	2	1	5	1	-	-

QUESTION: What sort of help do they give you?

NUMBER OF HELPS GIVEN BY FRIENDS, NEIGHBOURS, RELATIVES

	HO	GA	HU	NT	OX	ES	WS	TOT
Mentioned ONE	9	4	18	16	4	19	8	
Mentioned TWO	2	-	3	3	2	4	6	
Mentioned THREE	-	-	-	-	-	1	-	
Mentioned FOUR	1	-	-	-	-	-	-	
No help received	7	7	23	25	17	16	6	1

MEETINGS WITH OTHER PARENTS

	HO	GA	HU	NT	OX	ES	WS	T
Do not meet	4	6	9	15	11	19	7	
Meet other parents	15	7	35	30	12	21	13	
No information available	-	-	1	1	-	-	-	

QUESTION: Do you meet other parents with handicapped children?

PLACE OF MEETINGS WITH OTHER PARENTS

	HO	GA	HU	NT	OX	ES	WS
Meet at JTC/ATC etc.	5	6	7	2	3	3	6
Meet at local societies' office	1	-	13	15	1	6	5
Meet at coach picking points	1	1	4	6	2	-	-
Meet at functions	4	-	-	-	4	2	1
Meet at other places	2	-	11	2	2	6	1
Meet but places of meeting not specified	2	-	-	-	-	-	-
Meet at several places	-	-	-	5	-	5	-
Do not meet	4	6	9	14	11	18	7
No information available	-	-	1	2	-	-	-

QUESTION: Where do you meet them?

FREQUENCY OF MEETINGS

	HO	GA	HU	NT	OX	ES	WS	5
No information available	1	2	1	6	1	-	-	
Daily	-	-	9	9	1	1	-	
Weekly	2	-	8	6	2	3	1	
Fortnightly	1	-	1	-	-	-	-	
Monthly	2	-	1	6	2	4	-	
Annually	1	-	8	-	-	1	1	
Regularly, frequently	2	1	7	3	4	8	11	
Irregularly	4	4	1	2	2	5	-	
Frequency of meetings not specified	2	-	-	-	-	-	-	
Do not meet	4	6	9	14	11	18	7	

QUESTION: How often?

WAYS IN WHICH MEETING PARENTS HELP

	HO	GA	HU	NT	OX	ES	WS	TO
No information available	1	4	1	8	9	-	2	
<u>Meet</u> parents and it helps - no reason given	-	-	-	2	-	-	1	
<u>Meet</u> parents and it <u>does not</u> help - no reason given	1	-	2	6	1	-	2	
<u>Do not meet</u> but it would help - no reason given	-	-	1	-	-	-	-	
<u>Do not meet</u> and <u>it would not help</u> - no reason given	-	-	-	2	-	-	-	
<u>Meet</u> - it helps psychologically, can compare notes, exchange information	14	5	24	21	8	23	11	
<u>Do not meet</u> - <u>it would help</u> psychologically, can compare notes, exchange information, toys	2	1	4	1	-	9	1	
<u>Meet</u> - <u>it does not help</u> , they do not understand, we are all right as we are	1	-	1	2	1	-	1	
<u>Do not meet</u> - it would not help, they do not understand, we are all right as we are	-	2	10	3	1	8	1	
Not sure if meetings will be helpful or not	-	1	2	1	3	-	1	

QUESTION: Does it help to meet such parents?
In what way?

MEMBERSHIP OF VOLUNTARY ORGANISATIONS

	HO	GA	HU	NT	OX	ES	WS
Member of ONE organisation	8	-	13	14	2	14	11
Member of TWO organisations	1	-	1	4	2	2	1
Not a member	10	13	31	27	19	24	8
No information available	-	-	-	1	-	-	-

QUESTION: Are you a member of any voluntary organisations?

EXTENT OF ACTIVITY IN VOLUNTARY ORGANIZATIONS

	HO	GA	HU	NT	OX	ES	WS	TV
Member but not active	7	-	2	6	1	3	6	
Member very active	1	-	11	10	2	11	3	
Member how active not ascertained	-	-	-	1	1	-	2	
Member - active and hold a position	1	-	1	-	-	2	1	
Not a member	10	13	31	27	19	24	8	
No information available	-	-	-	3	-	-	-	

QUESTION: How active are you in these organisations?

ASSESSMENT OF WAYS IN WHICH VOLUNTARY ORGANIZATIONS CAN HELP

	HO	GA	HU	NT	OX	ES	WS
Do not help - reasons given	4	4	8	2	7	11	4
Do help - no reason given	1	-	-	1	1	1	-
Do help - arrange outings, clubs, holidays for the child	5	2	4	12	5	8	4
Do help - organise meetings for the parents	-	-	-	3	-	-	2
Do not help - no reasons given	1	5	3	15	4	5	2
No information available	4	1	-	4	1	-	1
Not a member or do not know how they can help	4	1	30	9	5	15	7

QUESTION: Do voluntary organisations in this area help you in any way?

ATTENDANCE AT NURSERY

	HO	GA	HU	NT	OX	ES	WS	T
Child attended for less than a year	1	-	3	2	4	3	-	
Child attended for between 1 - 2 years	2	-	6	3	3	3	3	
Child attended for over 2 years	1	1	6	3	3	3	1	
Child did not attend	14	12	29	37	12	31	16	
No information available	-	-	1	1	1	-	-	

QUESTION: We have so far been talking about your child when he/she was very young.
When he/she was under school age did he/she go to a day nursery or play group?

WHAT PARENTS WERE TOLD ABOUT THE EDUCATION OF THEIR CHILD

	HO	GA	HU	NT	OX	ES	WS
Parents told child "ineducable"	1	-	2	-	-	2	1
Needed special education	11	9	34	31	16	26	11
Could have normal education	3	1	1	5	-	1	4
Parents were not told anything	1	2	7	6	5	10	-
No information available	2	1	1	4	2	-	-
Parents not told anything - child too young	1	-	-	-	-	1	4

QUESTION: Now let us talk about the education and training of the child.
What type of education/training were you told he/she should receive?

PERSON WHO DECIDED ON EDUCATION

	HO	GA	HU	NT	OX	ES	WS
GP	-	-	-	-	-	3	-
Parents decided themselves/family	1	1	-	2	-	1	-
MOH, Medical doctor from Local Authority/MHD	7	6	29	8	7	16	2
School doctor/LEA/Teacher	1	3	4	25	5	8	8
Psychologist	-	-	-	-	2	-	1
"Specialist"	2	-	5	1	2	2	1
Clinic doctor	3	2	-	1	1	-	-
Don't know, don't remember	2	-	1	1	-	3	1
"No body" "they"	1	-	5	1	1	5	1
No information available	2	1	1	7	5	2	6

AGE OF CHILD AT THE TIME OF THIS DECISION

	HO	GA	HU	NT	OX	ES	WS
Child under 4 years	1	1	3	2	2	4	1
Between 4 - 5 years	7	4	7	12	14	3	10
Between 5 - 6 years	2	-	22	12	2	11	2
Between 6 - 7 years	4	2	2	5	1	3	1
Between 7 - 10 years	3	2	4	8	-	4	2
Over 10 years	1	1	3	2	-	7	-
Don't remember	-	1	1	-	-	4	-
No information available/not applicable	1	2	3	5	4	4	4

TYPE OF EDUCATIONAL ASSESSMENT MADE

	HO	GA	HU	NT	OX	ES	WS
No information available	-	-	1	4	3	-	1
Stanford-Binet test as revised by Terman-Merrill	1	-	-	-	-	-	-
Observation	1	-	2	2	-	2	-
Assessment made but no further details of the test given	10	12	35	34	15	8	14
Don't know, can't remember	1	1	-	3	2	11	-
No assessment made	6	-	7	3	3	19	5

QUESTION: What sort of assessment was made? Could you please describe it.

TYPE OF EDUCATIONAL REPORT PROVIDED

	HO	GA	HU	NT	OX	ES	WS	T
Written report	1	3	5	9	3	5	3	
Verbal report	7	9	30	21	12	10	11	
Don't know, can't remember	1	-	-	1	-	4	-	
No report	6	-	9	10	5	20	2	
No information available	3	11	1	5	3	1	4	

QUESTION: Did you get a written report or were you informed verbally?

PERSON WHO HELPED PARENTS TO ACCEPT DECISION ON EDUCATION

	HO	GA	HU	NT	OX	ES	WS
No information available	2	3	4	16	3	-	3
Own family	-	-	9	4	1	3	3
School, headmaster, teacher etc.	-	1	-	1	-	1	1
School doctor	1	-	-	-	-	1	-
Medical officer from Local Authority	1	3	5	3	1	-	1
Local Education Authority - its officer	-	-	-	1	-	-	3
Mental Welfare Officers, Health Visitors	1	2	1	-	5	3	1
Clinic doctor	1	-	-	-	-	-	-
Others	-	-	1	-	-	2	-
Can't remember, don't know	-	-	-	-	1	1	1
Nobody - child too young so no decision	13	4	25	21	12	29	7

FIRST TYPE OF SCHOOL CHILD WAS ADMITTED TO

	HO	GA	HU	NT	OX	ES	WS	T
No information available	-	2	1	-	2	-	2	
Attended ordinary school	6	7	18	15	7	10	9	
Attended ESN or special school	1	-	3	2	4	4	-	
Attended JTC	10	2	18	26	8	13	6	
Attended ATC	-	-	-	1	-	-	-	
Attended special care unit	-	-	1	-	-	-	-	
Attended school for physically handicapped/deaf	-	-	1	1	1	4	-	
Attended boarding school/home tutition/custodial care	-	-	-	-	-	2	-	
Attended school - type not ascertained	1	-	-	-	-	-	-	
Don't know, can't remember	-	-	-	-	1	4	-	
No school, too young	1	2	3	1	-	3	3	

QUESTION: Please tell me about the schools and training centres the child has attended, and for how long? Were you satisfied with the training

AGE OF CHILD ON FIRST ADMISSION

	HO	GA	HU	NT	OX	ES	WS	TOT
No information available	-	2	1	4	2	-	2	
Under 4 years	1	-	-	2	1	2	1	
Between 4 - 5 years	5	7	3	13	13	6	8	
Between 5 - 6 years	5	2	29	13	5	14	5	
Between 6 - 7 years	4	-	4	8	1	1	-	
Between 7 - 10 years	1	-	1	4	1	7	1	
Between 10 - 15 years	-	-	2	1	-	1	-	
Between 15 - 20 years	1	-	1	-	-	1	-	
Don't remember	1	-	1	1	-	5	-	
Never attended school, too young	1	2	3	-	-	3	3	

SATISFACTION WITH FIRST SCHOOL

	HO	GA	HU	NT	OX	ES	WS	TOT
Very satisfied	6	2	16	24	10	11	6	70
Satisfied	6	3	14	12	8	16	4	63
Dissatisfied	2	1	3	4	2	4	4	20
Very dissatisfied	1	-	7	1	1	3	1	14
Neither dissatisfied nor satisfied	2	-	-	-	-	-	-	2
Don't know, can't remember	-	1	-	-	-	3	-	4
Never attended	1	2	3	-	-	3	3	12
No further information available	1	4	2	5	2	-	2	17

LAST TYPE OF SCHOOL CHILD WAS ADMITTED TO

	HO	GA	HU	NT	OX	ES	WS	TO
No information available	6	4	12	11	5	10	6	
Attended ordinary school	1	-	-	1	-	1	2	
Attended ESN or special school	3	2	-	3	3	-	-	
Attended JTC	3	1	10	17	2	14	3	
Attended ATC	5	4	19	12	8	8	5	
Attended special care unit	-	-	-	1	-	-	-	
Attended school for physically handicapped/deaf	-	-	1	1	-	-	-	
Attended boarding school/home tuition/custodial care	-	-	-	-	-	3	1	
Attended school - type not ascertained	-	-	-	-	5	-	-	
Don't know, can't remember	-	-	-	-	-	1	-	
No school, too young.	1	2	3	-	-	3	3	

AGE OF CHILD ON LEAVING LAST SCHOOL

	HO	GA	HU	NT	OX	ES	WS	T
No information available	6	4	12	4	4	10	3	
Between 5 - 6 years	-	-	-	1	-	-	1	
Between 6 - 7 years	-	-	-	1	-	-	-	
Between 7 - 10 years	-	-	1	-	-	1	-	
Between 10 - 15 years	1	1	-	2	-	1	1	
Between 15 - 20 years	5	2	2	6	3	6	2	
Don't remember	1	2	-	16	1	1	-	
Never attended school, too young	1	2	3	-	-	3	2	
Still at school	5	2	27	16	15	18	11	

SATISFACTION WITH LAST SCHOOL

	HO	GA	HU	NT	OX	ES	WS	T
Very satisfied	4	3	15	15	12	10	8	
Satisfied	4	2	6	9	5	10	2	
Dissatisfied	-	-	3	7	-	6	1	
Very dissatisfied	1	-	5	-	1	1	-	
Don't know, can't remember	1	1	-	-	1	-	-	
Never attended	1	2	3	-	-	3	3	
No further information available	8	4	13	15	4	10	5	

AGE ON FIRST ADMISSION TO A SPECIAL SCHOOL, JTC, ESN SCHOOL

	HO	GA	HU	NT	OX	ES	WS	T
No information available	1	2	1	4	4	-	6	
Under 4 years	1	-	-	1	1	2	1	
Between 4 - 5 years	3	2	3	6	7	3	1	
Between 5 - 6 years	3	-	13	14	4	6	4	
Between 6 - 7 years	4	2	9	7	3	3	-	
Between 7 - 10 years	1	3	7	8	3	9	3	
Between 10 - 15 years	3	1	3	3	1	3	2	
Between 15 - 20 years	-	-	5	1	-	4	1	
Don't remember	1	1	1	1	-	6	-	
Never attended school, too young	2	2	3	1	-	4	1	

EMPLOYMENT OF HANDICAPPED

	HO	GA	HU	NT	OX	ES	WS	TO
No information available	1	-	-	12	3	1	-	
Person who helped get him/her a job not ascertained	-	-	-	-	-	-	1	
Family helped to get a job	2	-	-	2	-	-	2	
teacher helped	2	2	1	-	-	-	-	
social worker helped	-	-	-	2	1	1	-	
MOH helped	1	-	-	-	1	-	-	
No one helped - job found on his/her own	-	1	-	1	1	-	-	
Labour Exchange helped	-	1	-	2	1	1	-	
DRO helped	-	-	-	-	-	-	-	
Handicapped ont working/too young to work	13	9	44	27	16	37	17	

QUESTION: Is your son/daughter working somewhere?

Did anyone help him/she to find employment?

PARENTS VIEW OF EMPLOYMENT

	HO	GA	HU	NT	OX	ES	WS	T
Handicapped is working	5	4	4	4	-	4	3	
Think that handicapped <u>can</u> be employed, requested help but did not get it, are dissatisfied with lack of support	-	1	1	1	-	1	1	
Parents think that the handicapped <u>can</u> be employed, requested help and did not get it, satisfied with the situation	-	-	1	2	-	1	-	
Parents think that the handicapped <u>can</u> be employed but have not requested it	1	3	1	4	1	7	2	
Parents think that the handicapped <u>cannot</u> be employed	2	1	17	15	-	12	3	
Handicapped too young	8	4	21	7	1	14	9	
No information available	2	-	-	13	21	1	2	

QUESTION: Do you think he/she can be employed?

PROVISION OF SHORT TERM CARE

	HO	GA	HU	NT	OX	ES	WS	T
Had short term care ONCE	5	3	7	3	3	3	4	
Had short term care TWICE	3	2	2	4	3	4	2	
Had short term care THRICE	-	-	1	3	-	1	1	
Had short term care FOUR times	-	-	-	1	1	-	-	
Had short term care FIVE or more times	1	-	-	4	1	-	-	
Not ascertained if handicapped had short term care or not	-	-	-	-	-	-	-	
Never had short term care	8	8	35	28	14	30	12	
No information available	2	-	-	2	1	2	1	

QUESTION: Has he/she ever been admitted for short term care

Where and for how long? Who referred him/her?

AGE ON FIRST ADMISSION FOR SHORT TERM CARE

	HO	GA	HU	NT	OX	ES	WS	TO
No information available	3	-	-	5	1	2	1	
Under 4 years	3	1	2	-	-	3	5	
Between 4 - 5 years	-	1	-	6	1	-	-	
Between 5 - 6 years	-	-	-	1	1	-	-	
Between 6 - 7 years	1	-	1	1	-	1	-	
Between 7 - 10 years	1	1	4	3	3	2	1	
Between 10 - 15 years	-	2	2	2	3	1	-	
Between 15 - 20 years	1	-	1	1	-	-	-	
Over 20 years	2	-	-	-	-	-	1	
Not ascertained if handicapped had short term care or not	-	-	-	-	-	1	-	
Handicapped never had short term care	8	8	35	27	14	30	12	

REASON FOR FIRST ADMISSION FOR SHORT-TERM CARE

	HO	GA	HU	NT	OX	ES	WS	TO
Holiday	2	1	-	3	-	2	-	
Treatment, diagnosis	8	3	1	3	4	2	4	
In order to help family, to give mother rest	-	1	8	8	3	4	3	
Never had short term care	8	8	35	26	14	30	12	
No information available	1	-	1	4	2	2	1	

SATISFACTION WITH FIRST SHORT TERM CARE

	HO	GA	HU	NT	OX	ES	WS	TOT
Very Satisfied	2	1	4	7	4	3	3	
Dissatisfied	1	-	1	3	1	1	1	
Very dissatisfied	1	-	1	3	1	-	2	
Satisfied	4	4	3	1	2	3	1	
Neither satisfied nor dissatisfied	-	-	-	-	-	-	-	
Don't know, can't remember	1	-	-	-	-	1	-	
Never had short term care	8	8	35	26	14	30	12	1
No information available	2	-	1	5	1	2	1	

AGE ON LAST ADMISSION

	HO	GA	HU	NT	OX	ES	WS	TOT
No information available	7	3	7	4	4	6	5	
Under 4 years	1	-	-	-	-	1	1	
Between 4 - 5 years	-	-	-	1	-	-	1	
Between 5 - 6 years	-	-	-	1	-	1	-	
Between 6 - 7 years	-	-	-	-	-	-	-	
Between 7 - 10 years	-	-	1	4	1	1	-	
Between 10 - 15 years	1	1	1	3	1	-	-	
Between 15 - 20 years	-	1	1	4	3	1	-	
Over 20 years	1	-	-	1	-	-	1	
Not ascertained if handicapped had short term care or not	1	-	-	-	-	-	-	
Handicapped never had short term care	8	8	35	28	14	30	12	13

REASON FOR LAST ADMISSION

	HO	GA	HU	NT	OX	ES	WS	T
Holiday	2	-	-	3	-	1	-	
Treatment, diagnosis	3	1	-	-	1	1	2	
In order to help the family, to give mother rest	-	-	3	11	3	2	1	
Handicapped never had short term care	8	8	35	26	14	30	12	
No information available	6	4	7	5	5	3	4	

SATISFACTION WITH LAST SHORT TERM CARE

	HO	GA	HU	NT	OX	ES	WS
Very satisfied	1	-	-	8	3	2	2
Dissatisfied	-	1	-	-	1	-	1
Very dissatisfied	-	-	1	4	-	-	-
Satisfied	1	1	1	2	1	1	-
Neither satisfied nor dissatisfied	-	-	-	-	-	1	-
Don't know, can't remember	1	-	-	-	-	-	-
Never had short term care	8	8	36	26	14	30	12
No information available	8	3	7	6	4	6	4

PARENTS PERCEPTION OF HELP GIVEN BY SUBNORMALITY HOSPITALS

	HO	GA	HU	NT	OX	ES	WS
No information available	19	2	-	14	6	4	2
Assess handicap, make diagnosis	-	-	-	-	1	-	-
Provide holiday to the handicapped	-	-	1	1	-	-	-
Provide treatment and training to handicapped	-	4	15	2	2	2	4
Facilitate holiday and rest for family	-	2	4	17	3	1	3
Negative response - place to lock up patients	-	-	1	-	-	-	-
Have harmful effects on the handicapped - make him disturbed, frightened etc.	-	-	-	-	-	1	-
Have harmful effects on the family	-	-	-	-	-	-	-
Don't know	-	5	24	9	11	31	10
Nothing	-	-	-	3	-	1	1

QUESTION: What help do subnormality hospitals offer to the mentally handicapped and their families?

HEALTH OF THE HANDICAPPED

	HO	GA	HU	NT	OX	ES	WS
Sound	17	12	42	42	21	34	18
Poor	2	1	3	4	2	6	2
No information	-	-	-	-	-	-	-

QUESTION: How is his/her general health?

SPEECH

	HO	GA	HU	NT	OX	ES	WS
No defect	5	3	12	12	9	16	9
Slight defect	8	8	13	15	9	12	4
Severe defect	4	2	15	16	3	8	5
Total disability	2	-	5	2	2	4	1
No information	-	-	-	1	-	-	1

QUESTION: Any defect in speech?

EYESIGHT

	HO	GA	HU	NT	OX	ES	WS
No defect	7	11	32	30	14	22	16
Slight defect	4	2	10	11	8	12	1
Severe defect	-	-	2	5	1	6	3
Total disability	1	-	1	-	-	-	-
No information	7	-	-	-	-	-	-

QUESTION: What about his/her eye sight?

HEARING

	HO	GA	HU	NT	OX	ES	WS
No defect	12	13	43	39	22	40	18
Slight defect	-	-	1	3	-	-	1
Severe defect	-	-	1	3	1	-	1
Total disability	-	-	-	-	-	-	-
No information	7	-	-	1	-	-	-

QUESTION: And his/her hearing?

INCONTINENCE

	HO	GA	HU	NT	OX	ES	WS
Fully continent	14	10	33	40	19	27	13
Occasionally incontinent	-	2	4	2	-	6	1
Semi-incontinent	3	-	4	3	1	2	2
Totally incontinent	1	1	3	1	3	5	4
No information	1	-	1	-	-	-	-

QUESTION: Is he/she incontinent?

NUMBER OF HANDICAPS

	HO	GA	HU	NT	OX	ES	WS
Mentioned ONE	8	5	17	23	7	17	5
Mentioned TWO	4	5	12	14	9	16	5
Mentioned THREE	2	-	5	3	1	2	3
Mentioned FOUR	-	-	1	-	-	-	-
No problems mentioned	5	3	10	6	6	5	7

PROBLEMS WITH SLEEP

	HO	GA	HU	NT	OX	ES	WS
Yes problems - getting to sleep	-	-	6	4	2	2	-
Yes problems - waking up during the night	-	1	-	3	-	3	1
Yes problems - not specified	-	1	1	4	-	2	-
No problems	6	11	38	34	21	33	19
No information	13	-	-	1	-	-	-

QUESTION: Are there any problems with his/her sleep?

PROBLEMS WITH FEEDING

	HO	GA	HU	NT	OX	ES	WS
1. Yes problems - unable to feed himself	-	-	-	-	-	4	2
2. Yes problems - unable to drink from an ordinary cup	-	-	-	-	-	-	-
3. Yes problems - unable to use knife or fork	-	-	3	-	-	-	2
4. Yes problems - combination of 1 and 2	1	-	-	-	-	-	-
5. Yes problems - combination of 1 and 3	-	-	-	-	-	-	-
6. Yes problems - combination of 1, 2, and 3	-	-	1	1	1	-	-
7. Yes problems - not specified	2	1	1	5	-	2	1
8. No problems	11	12	39	39	22	34	15
9. No information	5	-	1	1	-	-	-

QUESTION: Are there any problems with feeding?

MOBILITY

	HO	GA	HU	NT	OX	ES	WS
No information	-	-	-	-	-	-	1
<u>Can</u> go out on his own	13	8	10	13	9	14	8
<u>Can not</u> go out on his own	5	4	34	26	6	14	3
Unable to use public transport	-	-	-	5	6	6	2
Uses a wheelchair	-	1	-	-	-	-	2
Unable to walk at all	-	-	-	1	1	2	2
Unable to sit without support	-	-	-	-	-	-	-
Is house bound, bed ridden	-	-	1	-	1	1	-
Child too young	1	-	-	1	-	1	2
Difficulty in negotiating steps	-	-	-	-	-	2	-

QUESTION: Can he/she go outdoors?

WASHING

	HO	GA	HU	NT	OX	ES	WS
<u>Can</u> wash himself	8	11	31	38	19	29	13
<u>Can not</u> wash himself	4	2	13	8	3	10	5
Too young	1	-	1	-	-	1	2
No information	6	-	-	-	1	-	-

QUESTION: Can he/she wash himself/herself?

DRESSING

	HO	GA	HU	NT	OX	ES	WS
<u>Can</u> dress himself	7	11	33	40	17	29	13
<u>Can not</u> dress himself	4	2	11	6	5	10	5
Too young	2	-	1	-	-	1	2
No information	6	-	-	-	1	-	-

QUESTION: Can he/she dress himself/herself?

READING

	HO	GA	HU	NT	OX	ES	WS
Yes - no problems	4	1	4	4	3	6	2
Yes - with some difficulty	3	4	4	8	5	8	4
No - can't read	4	7	36	33	15	21	9
Too young	4	1	1	1	-	5	5
No information	4	-	-	-	-	-	-

QUESTION: Can he/she read?

WRITING

	HO	GA	HU	NT	OX	ES	WS
Yes - no problems	4	1	3	2	3	5	1
Yes - with some difficulty	2	5	7	10	7	10	4
No - can't write	4	6	34	33	13	20	10
Too young	5	1	1	1	-	5	5
No information	4	-	-	-	-	-	-
QUESTION: Can he/she write?							

CAN HE TELL THE TIME?

	HO	GA	HU	NT	OX	ES	WS
Yes - can tell the time	6	5	9	19	8	18	7
No - can not	6	7	34	26	15	16	9
Too young	3	1	2	1	-	6	4
No information	4	-	-	-	-	-	-

QUESTION: Can he/she tell the time?

MONEY

	HO	GA	HU	NT	OX	ES	WS
Yes - no problem	5	4	6	8	3	6	4
Yes - some difficulty	4	8	12	13	5	12	5
No - does not understand	4	-	26	24	15	17	6
Too young	3	1	1	1	-	5	5
No information	3	-	-	-	-	-	-

QUESTION: Can he/she understand money?

FRIENDS

	HO	GA	HU	NT	OX	ES	WS
Yes - plays with other siblings	3	4	22	21	11	23	8
Yes - friends at school	-	3	15	14	7	9	6
Yes - friends in neighbourhood	6	5	6	9	3	5	6
Yes - goes to clubs, camps	-	-	-	1	1	3	-
No friends at all	7	1	1	-	-	-	-
No information	3	-	1	1	1	-	-

QUESTION: Has he/she got suitable frineds, playmates?

PROBLEMS WITH SEX LIFE?

	HO	GA	HU	NT	OX	ES	WS
Yes - problems	3	-	2	1	1	5	-
No problems	3	9	21	28	13	19	9
Too young	6	2	20	16	6	15	10
No information	7	2	2	1	3	1	1

QUESTION: Are there any problems regarding his/her sex life?

ANY OTHER PROBLEMS?

	HO	GA	HU	NT	OX	ES	WS
No Information	4	1	-	4	-	1	-
Yes - problems not specified	1	1	2	1	2	1	-
Yes - problems connected with physical well being and medical care of the handicapped	1	-	8	3	1	6	1
Yes - problems connected with psychological and emotional life of the handicapped	-	1	7	9	3	10	1
Yes - problems connected with behaviour of the handicapped, management	1	5	10	9	1	4	1
Yes - problems connected with the relationship between members of the family	2	-	-	3	4	8	2
Yes - problems with education and training of the handicapped	-	-	6	4	1	6	1
Yes - problems connected with inadequacy of housing, lack of playground, finances etc.	2	-	-	2	1	1	-
Yes - problems of isolation, loneliness of the handicapped	2	-	1	2	2	3	-
No other problems	6	8	19	19	11	12	15

QUESTION: Are there any other problems that he/she faces now which we have not talked about so far?

NUMBER OF OTHER PROBLEMS

	HO	GA	HU	NT	OX	ES	WS
Mentioned ONE	9	2	19	13	9	17	4
Mentioned TWO	-	1	6	10	3	10	1
Mentioned THREE	-	1	1	-	-	1	-
Mentioned FOUR	-	-	-	-	-	-	-
Mentioned FIVE or more	-	-	-	-	-	-	-

DID PARENTS ASK FOR HELP?

	HO	GA	HU	NT	OX	ES	W
Yes - type of help not mentioned	2	-	-	-	-	-	
Yes - holiday, clubs etc. for the handicapped	-	-	1	-	2	-	
Yes - wheelchair, glasses etc. for the handicapped	-	-	2	3	3	1	
Yes - employment of the handicapped	-	-	2	-	2	1	
Yes - other forms of help directed to the handicapped	1	2	4	10	1	2	
Yes - financial assistance to the family	1	-	3	6	-	1	
Yes - other forms of help for the family	1	1	3	4	2	4	
No help asked for	5	11	33	24	16	32	1
No information	9	-	1	3	-	-	

QUESTION: Have you asked for any help from any authorities or services with regard to problems faced by him/her, or by your family?

What were the problems for which you needed help?

WHOM DID THE FAMILY ASK FOR HELP?

	HO	GA	HU	NT	OX	ES	WS
Mental Health, MWO	-	-	9	12	6	2	1
MOH	-	-	-	-	-	-	-
GP, clinic doctor, hospital	1	-	2	1	1	-	2
Education Authority, school	-	-	1	2	-	1	-
Social Security	1	-	1	2	-	1	-
Employment Exchange, Ministry of Labour	-	-	1	-	-	-	-
Others	-	2	-	2	2	3	-
No information	16	11	32	31	16	33	1

QUESTION: Whom did you ask?

DID THE PARENTS GET THE HELP

	HO	GA	HU	NT	OX	ES	WS
Help asked for and received	2	1	10	13	7	2	
Help asked for and not received	2	1	4	8	3	7	
Help asked for and still waiting for a reply	-	1	1	1	-	-	
No information	15	11	32	29	16	32	1

QUESTION: What happened?

ADVICE ON HAVING MORE CHILDREN

	HO	GA	HU	NT	OX	ES	WS
Advice given when asked for	6	1	1	2	3	2	4
Advice given without having to ask for it	1	3	4	9	4	11	7
No information	11	8	39	35	16	26	9
No advice given	1	1	1	-	-	1	-

QUESTION: After the birth of this son/daughter, did you get any
advice on having more children?

ADVICE GIVEN BY OR ASKED FROM

	HO	GA	HU	NT	OX	ES	WS
GP	4	1	1	6	3	9	3
Clinic doctor	1	-	-	-	-	-	-
HV	-	1	-	-	-	-	1
MOH	-	-	-	-	-	1	-
Hospital	2	1	2	3	2	2	1
Paediatrician	-	-	1	-	1	1	-
Others	-	1	1	2	-	-	6
No advice was asked for	1	-	-	-	-	-	-

QUESTION: Whom did you ask?

WHAT ADVICE WAS GIVEN

	HO	GA	HU	NT	OX	ES	WS
Advice asked for but not given	-	-	-	-	-	-	-
Advised to have more children	3	1	3	7	4	7	5
Advised not to have more children	2	1	2	4	3	5	4
Not clear what advice given	1	1	-	-	-	1	-

QUESTION: What advice was given?

GENETIC COUNSELLING

	HO	GA	HU	NT	OX	ES	WS
Advice given but no investigation made	-	-	-	-	-	-	-
Advice given and investigation made - details of investigation not given	1	-	-	-	-	1	1
Advice given, investigation made - details of investigation given - clinical, chromosome testing etc.	1	-	1	2	-	2	1
No advice given	4	4	2	4	-	-	-
No information	13	9	41	38	23	37	18

QUESTION: Was any investigation or examination done to find out if you should have more children or not?

GENETIC COUNSELLING ARRANGED BY

	HO	GA	HU	NT	OX	ES	WS
GP	1	-	-	-	-	1	-
MOH	-	-	-	-	-	-	-
Clinic doctor	-	-	-	-	-	-	-
HV	-	-	-	-	-	-	-
Hospital	-	-	-	1	-	-	-
Paediatrician	-	-	1	-	-	-	-
Others	-	-	-	1	-	-	1
Parents arranged it on their own	-	-	-	-	-	-	-
No information	18	13	44	44	23	39	19

QUESTION: What sort of investigation was it?
Who arranged it and who did it?

SERVICES REQUIRED

	HO	GA	HU	NT	OX	ES	WS
None required	8	4	1	7	1	-	-
Medical attention, medical treatment for the handicapped required, more consultations with GP etc.	-	-	1	8	-	2	1
Holidays, clubs, leisure time activities for the handicapped	2	-	7	18	5	12	2
Services connected with the education and training of the handicapped	1	1	5	5	1	5	3
Finding suitable employment of facilities for work mentioned	1	-	3	3	1	7	7
Facilities for the care of the handicapped when parents are no longer able to look after the handicapped	2	1	3	6	8	7	5
Social work support for the family mentioned	1	2	-	4	2	1	1
Help with regard to housing, finances etc. mentioned	-	3	4	5	2	4	3
Help to remove the social isolation of the handicapped and the family mentioned	6	1	2	11	2	10	9
Don't know	-	-	2	1	1	4	1
No information	1	4	25	2	7	8	2

QUESTION: There are various services and facilities provided for mentally handicapped and their families. What could help you and your child to lead an easier life now and in the future?

NUMBER OF SERVICES MENTIONED

	HO	GA	HU	NT	OX	ES	W
None mentioned	1	4	25	2	7	8	
Mentioned ONE	7	3	12	15	9	16	
Mentioned TWO	3	-	6	13	5	9	
Mentioned THREE	-	2	1	6	1	7	
Mentioned FOUR	-	-	-	1	-	-	
Mentioned FIVE or more	-	-	-	2	-	-	
Don't know	-	-	-	-	-	-	
No Information	8	4	1	7	1	-	

ACCOMMODATION

	HO	GA	HU	NT	OX	ES	WS
Whole house	16	9	42	43	20	21	14
House shared with others	-	1	-	-	-	1	-
Bungalow	-	-	2	2	-	2	2
Self contained flat - upstairs	1	2	-	-	-	2	-
Self contained flat - downstairs	-	-	-	-	-	-	-
Rooms	-	1	1	-	-	-	-
Council house	-	-	-	1	3	13	2
Council flat	-	-	-	-	-	-	1
No information	2	-	-	-	-	1	1

OWNERSHIP

	HO	GA	HU	NT	OX	ES	WS
Owner occupied	10	2	13	15	10	14	9
Local Authority	7	9	24	17	13	18	5
Private rented (furnished)	1	-	-	1	-	-	1
Private rented (unfurnished)	1	2	8	12	-	6	5
No information	-	-	-	1	-	2	-

AMENITIES:

First - Toilet

	HO	GA	HU	NT	OX	ES	WS
Toilet inside upstairs	2	4	12	9	8	17	7
Toilet inside downstairs	6	5	11	13	9	13	6
Toilet inside both upstairs and downstairs	-	-	11	5	5	6	4
Toilet outside	1	2	10	12	1	3	2
Toilet Shared	-	1	1	1	-	-	-
No Information	10	1	-	6	-	1	1

CONVENIENCE OF TOILET

	HO	GA	HU	NT	OX	ES	WS
Toilet convenient for handicapped	-	5	19	19	12	31	5
Toilet inconvenient for handicapped	-	3	8	4	3	2	1
No response	19	5	18	23	8	7	14

BATHROOM

	HO	GA	HU	NT	OX	ES	WS
Bathroom in the house	8	11	32	24	23	38	1
No bathroom in the house	-	1	13	10	-	1	
Bathroom Shared in House	-	1	-	6	-	-	
No Information	11	-	-	6	-	1	

PLAY SPACE

	HO	GA	HU	NT	OX	ES	WS
Garden or yard available for play in safety	6	9	36	33	23	35	16
No place accessible for handicapped to play	1	2	5	3	-	1	1
No information	12	2	4	10	-	4	3

TABLE
CONDITION OF THE HOUSE AND FURNITURE

	HO	GA	HU	NT	OX	ES	WS
Good, - good furniture	7	8	23	20	13	12	12
Good, adequate furniture	1	-	7	9	1	5	2
Good, poor furniture	-	-	3	1	4	10	1
Adequate, adequate furniture	2	1	5	7	3	3	3
Adequate, poor furniture	1	2	1	3	1	4	1
Poor, adequate furniture	1	-	1	-	-	2	-
Poor, poor furniture	1	1	5	4	1	1	1
No information	6	1	-	2	-	3	-

INTERVIEWER

King's Fund researcher: B. Bellaby, P. Sommerfeld,
F. Sommerfeld, R. Fogg, V. Mills, E. Crout

Other workers from the services

HO	GA	HU	NT	OX	ES	WS
18	5	40	42	11	1	20
1	8	5	4	12	39	-

DURATION OF THE INTERVIEW

	HO	GA	HU	NT	OX	ES	WS
Half an hour or less	-	-	1	-	-	-	-
Between 30 - 45 minutes	1	-	4	1	3	5	-
Between 45 minutes - 1 hour	3	5	14	9	4	6	-
Between 1 hour - $1\frac{1}{4}$ hours	4	4	13	11	4	11	1
Between $1\frac{1}{4}$ - $1\frac{1}{2}$ hours	5	-	8	12	8	6	5
Between $1\frac{1}{2}$ - $1\frac{3}{4}$ hours	4	-	2	3	-	5	3
Between $1\frac{3}{4}$ - 2 hours	1	-	2	2	1	5	5
2 hours or more	-	2	-	2	3	-	6
No information	-	2	1	6	-	2	-

CO-OPERATION

	HO	GA	HU	NT	OX	ES	WS
Both parents cooperative	2	5	14	20	6	11	5
Mother cooperative, father uncooperative	-	1	4	2	3	-	-
Father cooperative, mother uncooperative	-	5	14	-	4	1	-
Both parents uncooperative	1	4	15	11	4	-	-
Only mother interviewed - cooperative	10	4	29	18	13	25	13
Only mother interviewed - uncooperative	-	-	2	5	-	1	-
Only father interviewed - cooperative	-	-	1	2	-	-	2
Only father interviewed - uncooperative	-	2	-	1	-	-	-
Sibling or other relation of handicapped interviewed - cooperative	-	2	-	-	3	-	-

WHO WAS PRESENT AT THE TIME OF THE INTERVIEW

	HO	GA	HU	NT	OX	ES	WS
Both parents present all the time	6	5	14	16	6	12	5
Mother not present	-	-	2	5	-	-	2
Father not present	11	4	29	19	13	26	13
Both parents not present - interview with a sibling or relative	-	1	-	2	4	-	-
No information	2	3	-	3	-	2	-

INTERVIEWER'S COMMENTS:

DEGREE OF SATISFACTION WITH SERVICES

	HO	GA	HU	NT	OX	ES	WS
Very satisfied, no complaints	-	1	2	5	4	1	-
Generally satisfied, minor irritations only	-	-	2	1	-	-	-
Dissatisfaction with one particular service only e.g. schooling	1	-	3	9	1	3	-
Generally dissatisfied with provision of services	1	1	3	7	1	5	-
Very dissatisfied - evidence of bitter feelings toward services	1	-	2	-	-	-	-
No thumbnail sketch provided by interviewer	9	2	2	2	7	12	-
No information	7	9	31	22	10	19	2

INTERVIEWER'S COMMENTS

GENERAL ABILITY TO COPE WITH THE SITUATION

	HO	GA	HU	NT	OX	ES	WS
Coping very well - hardly any or no problems	1	3	7	6	-	2	2
Coping fairly well - minor problems only	1	3	11	10	1	5	3
Barely managing to cope - lack of support by one partner	-	-	-	1	-	-	1
Barely managing to cope - lack of support by services	-	-	-	1	1	-	-
Barely managing to cope - one or both parents below average I.Q.	-	2	1	-	-	-	-
Unable to cope - one or both parents subnormal	1	-	1	4	1	-	-
Unable to cope - other reason	2	1	1	2	-	1	-
No information	5	2	22	20	13	20	1

INTERVIEWER'S COMMENTS

DEGREE OF ACCEPTANCE OF THE HANDICAP

	HO	GA	HU	NT	OX	ES	WS
Accepted the handicap well	3	5	8	6	1	5	
Have difficulty in accepting handicap	1	-	2	6	3	2	
Have not accepted - lack of understanding	1	2	3	1	-	2	
Have not accepted - believe child is normal	1	-	2	1	1	1	
Have not accepted - believe further provision of services would remove handicap	-	-	-	2	-	2	
No information	4	4	28	28	11	16	1

INTERVIEWER'S COMMENTSDISPOSITION TOWARDS THE CHILD

	HO	GA	HU	NT	OX	ES	WS
Good to excellent disposition towards child	4	7	26	24	8	6	12
Fair disposition towards child - some resentment at curtailment of social life	-	-	1	1	-	-	-
Fair disposition - other reason	-	-	1	1	1	-	-
Rejection by one parent	-	-	1	-	-	1	-
Rejection by both parents	-	-	-	-	-	-	-
Rejection by one or more siblings	-	-	-	1	-	-	-
Overprotection by one or both parents	-	-	1	1	1	7	-
No information	6	4	13	16	6	14	8

INTERVIEWER'S COMMENTS

GENERAL ASSESSMENT OF THE HOME ENVIRONMENT

	HO	GA	HU	NT	OX	ES	WS
Good to excellent physical surroundings, caring, sensitive parents	1	5	13	15	1	3	7
Fair environment - good physical surroundings but indifferent parents	1	-	-	1	1	2	-
Fair environment - caring sensitive parents but poor physical surroundings.	-	1	4	3	1	-	4
Poor environment - poor physical surrounds and indifferent or antipathetic emotional climate	-	1	3	5	-	-	-
No information	8	4	23	20	13	23	9

INTERVIEWER'S COMMENTS
ASSESSMENT OF INTEGRATION OF FAMILY

	HO	GA	HU	NT	OX	ES	WS
Whole family life revolves around child	-	1	4	7	2	1	3
Child treated in similar normal fashion to other siblings	1	2	9	5	1	4	3
Child isolated from rest of family by overprotective parents	-	-	1	-	-	1	-
Child has created tensions in family life which have not been resolved	1	-	-	2	1	4	-
Child situation has led to emotional and/or physical separation of parents	2	-	-	1	1	-	1
No information	6	8	29	29	11	18	13

PREDOMINANT PROBLEM AS SEEN BY INTERVIEWER

	HO	GA	HU	NT	OX	ES	WS
Lack of sufficient support by services	-	1	-	6	1	9	-
Social isolation of family	-	1	-	2	1	1	2
Financial/housing problems	1	-	2	2	1	1	1
Parents inability to cope with situation	1	-	2	1	1	-	-
Parents unwillingness to cope with situation	-	-	-	1	-	-	-
Lack of information provided by GP's, hospitals, services etc.	1	-	1	9	-	3	-
Fear of what the future holds	-	-	6	4	3	-	-
No information	7	9	32	19	9	14	17

EASE WITH WHICH INFORMATION WAS OBTAINED FROM PARENTS BY INTERVIEWER

	HO	GA	HU	NT	OX	ES	WS
Parents co-operative, gave helpful, factual and complete answers	3	1	19	14	5	6	4
Parents tended to ramble and be irrelevant	1	-	1	1	-	1	2
Parents did not know or could not remember on many points	-	1	2	3	2	2	1
Interviewer had great difficulty in gaining answers to questions	2	-	1	3	1	2	-
No information	4	9	20	23	8	17	13



54001000030802

