

Depth interview guide

1. HOUSEHOLD/FAMILY
 - Household composition
 - Age/sex/employment status of household members
 - History of separation/widowhood (where relevant)
 - Other children/family members in area
 - Tenure
 - Residence at address/in area
2. CHARACTERISTICS/CIRCUMSTANCES OF THE HANDICAPPED PERSON
 - Age/sex
 - Position in family (if other children)
 - Day time activity
 - Type/severity of handicap
 - History of handicap
 - Accompanying physical disabilities
 - Behavioural problems
3. HISTORY OF RESIDENCE AT HOME
 - Detailed history of mentally handicapped person living at home; reasons for any changes; feelings about changes.
 - Reason for decision to live at home
 - in childhood/at outset of handicap
 - when left school/in adulthood
4. EXPERIENCE OF OTHER FORMS OF CARE
 - Details of other forms of care used; when; for how long; what type.
 - Views about other types of care experienced; aspects approved/disapproved
5. KNOWLEDGE/AWARENESS OF OTHER FORMS OF CARE
 - Knowledge of local provision; sources of information; contact with/visits to; how initiated; views about.
 - Knowledge/awareness of alternatives available outside area; sources of information; views about
 - Awareness of different forms of care (prompted where necessary); views about.

6. INDEPENDENCE/ABILITIES OF HANDICAPPED PERSON

- Brief check of abilities/needs/social skills; degree to which independent; level of help required.
- Feelings about level of independence/dependency
- Whether had training in self care/daily activities/social skills; when; who provided; how responded.
- Whether parents have tried to encourage greater independence; (i.e. through extending daily activities; clubs; holidays; encouraging greater separation).
- Views about further training/preparation; potential for greater independence.

7. EXPECTATIONS FOR MENTALLY HANDICAPPED PERSON IN ADULTHOOD

(Reference to time when son/daughter in late teens/ early twenties).

- What expectations did they have for son/daughter in relation to
 - day time activities
 - social activities
 - where they would live
- To what extent did they think about handicapped person 'leaving home' like other children of his/her age; did they think about it; when
- To what extent did they explore/think about other possibilities at that time; what; what happened.
- What are the factors that made it 'different' for handicapped son/daughter: than for other children
- Why do they feel it is more difficult to see handicapped person move on;
IF OTHER CHILDREN WHO HAVE LEFT HOME
How did they feel when other children left home; did this raise any feelings about son/daughter staying or leaving home.

8. FEELINGS ABOUT SEPARATION FROM HANDICAPPED PERSON

- To what extent have they seen separated from their handicapped son/daughter: reference to previous mention of care; holidays; staying with relatives etc.
- Were there any problems/ difficulties for son/daughter/for them while away.
- How did they feel when son/daughter went away; while he/she was away; when they came back.

9. VIEWS/FEELINGS ABOUT HOME CARE

- What have been the rewards/stress of caring at home:
 - in the past
 - at present
- What have been the effects of home care on
 - the handicapped person
 - the parents
 - other children
- To what extent have other family members (outside household) been involved; how do they feel about that.
- To what extent have they received help/support from service agencies/self-help groups.
- Have there been times when 'decision' to care at home was in question/times when it was too much; when; what happened; how did they feel; what kept them going.
- Are there any circumstances/alternatives that might have changed decision to care at home: what, why.

10. CONSIDERATION OF ALTERNATIVES

- To what extent have they considered their son/daughter living elsewhere; in past; at present: reasons; when.
- Have they explored any other options at all; with other relatives/friends; with formal agencies; self-help groups.
- What sort of alternatives are they looking for/thinking about; what are the essential features; important features.
- What do they feel when question of son/daughter living elsewhere is raised.
- Do they know of other mentally handicapped people who have moved from home; who; what happened; how did they feel.

11. CONSIDERATION OF/PROVISION FOR FUTURE

- Extent to which future has been considered; what has been considered; feelings about.
- Specific plans/provision made; what; when; why; feelings about.
- Hopes for future; what arrangements they would want
- Difficulties of thinking about the future; ways in which might be helped.

12. VIEWS ON PROVISION NEEDED

- Do they have any thoughts about the kinds of provision that are needed; what; what features are important.
- Are there ways in which parents could be helped to plan for the future; mentally handicapped people could be helped to prepare for the future
- If a suitable alternative had existed would they still prefer to care for their son/daughter at home or would they like them to have opportunity of living elsewhere; what would be suitable.
- General views on help/services needed for parents caring for adults at home.

QUALITATIVE RESEARCH: Some further reading

Walker, Robert (Ed): Applied Qualitative Research, 1985 Gower

Patton, Michael Quinn: Qualitative Evaluation Methods, 1980, Sage

or Practical Evaluation, 1982, Sage

Burgess, Robert G (Ed): In the Field Contemporary Social Research No 8
1984, George Allen and Unwin

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<u>1. THE PARENTS</u>	<u>5. PROVISION OF HOME CARE</u>	<u>7. SEPARATION (Contd)</u>
1.1 Characteristics/circs.	5.1 Role/contribution of mother	7.4 Importance of a break
1.2 Marital history/difficulties	5.2 Role/involvement of father	7.5 Attitudes/feelings about separation (in past)
1.3 Other children	5.3 Role/involvement of siblings (in or outside H/H)	7.6 MHA attitudes towards separation (in past)
1.4 Parents health	5.4 Involvement of other family/friends	<u>8. ALTERNATIVES TO HOME</u>
<u>2. MENTALLY HANDICAPPED</u>	5.5 Involvement of statutory/agencies	8.1 Knowledge of local provision/sources
2.1 Age/sex/position in family	5.6 Involvement/contact with MENCAP or other vol.	8.2 Reactions to forms of care experienced
2.2 Type/severity of handicap; other physical/behavioural problems	<u>6. HOME CARE - Reasons and effects</u>	8.3 Reactions to local forms of care not experienced
2.3 History of handicap	6.1 Responsibilities/obligations/seeds of responsibility to care at home	8.4 Reactions to other forms of care (seen or heard about)
<u>3. ACTIVITIES (MHA)</u>	6.2 Rewards of home care	8.5 Type/form/features of care wanted (or not wanted)
3.1 Day time activities	6.3 Parents need for MHA/sense of loss if away	8.6 MHA reactions to care (experienced or known)
3.2 Social activities	6.4 Inhibitors to moving on/legitimisation/letting go	8.7 Feelings about care by other children
3.3 Friends	6.5 Importance of home to MHA/feelings about moving from home	<u>9. THE FUTURE</u>
3.4 Other activities/interestes	6.6 Comments on other parents letting go	9.1 Extent to which thought about/plans for/preparation
<u>4. INDEPENDENCE</u>	6.7 Comparison with non-handicapped children	9.2 Views about timing/reasons for putting off
4.1 Abilities	6.8 Stresses/restrictions of home care	9.3 Parents wanting to let go/MHA to go
4.2 Changes in abilities/potential for change	6.9 Critical points where home care in question	9.4 Comments about MHA happiness if/he/she moved
4.3 Training/preparation from outside home	6.10 No trouble being at home	9.5 Discussion with MHA
4.4 Efforts to develop inside home/attitudes to independence	<u>7. SEPARATION</u>	9.6 MHA - better off not living
4.5 Anxiety about/effects of risk taking/over protection	7.1 Living away	<u>10. SUGGESTIONS FOR HELPING PARENTS</u>
4.6 MHA attitudes towards greater independence	7.2 Short stay (short/vol. only)	10.1 In relation to care/longer term future
4.7 Perception of child or adult	7.3 Holidays/other experience (relatives)	10.2 Other suggestions (eg support/services)
4.8 Comments/reactions to general philosophy of normalisation		<u>11. MISC/OTHER</u>
		11.1 Feelings about handicap
		11.2 Public attitudes to