

**CHILDHOOD DISABILITY:
PARENTS' PERCEPTIONS AND EXPERIENCES
IN SAUDI ARABIA**

Fathi Akhdar

ProQuest Number: U555322

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U555322

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

ACKNOWLEDGEMENTS

The author acknowledges all the loving support from his family during the time of the study, and records his sadness that his parents did not live to see the final product.

The author thanks the RKH Programme of the Kingdom of Saudi Arabia for financial and other support including the setting up of a Child Disability Centre for putting into practice the findings of the study.

The author acknowledges with thanks the support of his supervisors and of the Centre for International Child Health, London, in providing all the necessary facilities for the study.

ABSTRACT

Worldwide, at least one child in ten is born with, or acquires, a physical, mental or sensory impairment that will interfere with their capacity for development unless some special assistance, support, or care is provided.

In addition to "number counting", this study is one of very few which investigates disability from the families' viewpoint and which identifies the problems and strengths experienced both at home and in using services. The study is also one of the rare investigations that identify the challenge to health workers if they are to provide long-term care in true close collaboration with parents. The current study is also important because very little work has been done on any community aspect of health problems in Saudi Arabia. There has been an urgent need for the development of culturally appropriate community based enquiry in the Kingdom. This study has developed an approach which can now be used for a number of other health problems in the country. Six key components of a community health enquiry in Saudi Arabia in the 1990s are identified.

A large-scale prevalence study was conducted contacting 1120 households with 2696 children achieving a 90% response rate with 2432 children seen for screening at the school or welfare clinic. It is recognized that the non-respondents may have led to under-reporting of prevalence rates. The non-respondents were 78 children now living outside the area, and 186 who dropped out of school whose parents reported that they were all right, but refused testing. 31 children with impairment considered severe by both the parents and the author were identified. The author had many contacts with each family over the study period. These contacts ranged from accompanying the family to appointments for medical, therapy and other sessions, to in-depth interviews. As the interactions progressed, the parents would disclose more information and it became possible to understand their feelings and the emotional aspects of living with a disabled child. The number of contacts varied from 20-25; and 20-25 hours were spent with each mother and father together. In keeping with Saudi culture and practice, the father answered all the questions in the early interviews. During the many contacts, the families explored their deeper feelings and the way they reacted to the problems that confronted them. Throughout the process the family needed a great deal of support in the form of understanding, kindness, caring and being there when needed. But, by the very expression of their hopes and fears (difficult though it was at times), the families seemed to have been helped to come more to terms with their child's impairment. Thus, the study became a help to the families themselves. Further information was obtained from key informants, teachers, children surveyed in the schools, grandparents and 25 religious leaders (Imams). The practical difficulties of undertaking such a study in Saudi Arabia are not negligible and some of the challenges such a study presents are described.

Overall, this study has developed a practical procedure for community enquiry in Saudi Arabia which others are likely to find useful. Only one other community-based enquiry has been done in the Kingdom. This study has also identified community-based prevalence rates for both minor and severe impairments, again for the first time.

On the subject of recognition the study has distinguished between family recognition and recognition by the services, identified factors affecting recognition, particularly emphasising the "cultural component" of recognition in Saudi Arabia and the importance of parents noticing "something is wrong". Need for action has been identified on four fronts: better perinatal care; improving general knowledge so that parents and grandparents recognise impairments early; better recognition of the legitimising role of traditional healers in recognition for the family; and training so they can recognise impairments better and know more fully what can be done to help; and better surveillance at health clinics and in schools.

Reactions have been separated into early and later. Particularly important reactions found include the finding of concealment of epilepsy and beliefs that the child with epilepsy is a changeling exchanged for a fairy child. Also important is the finding that children with developmental delay are respectfully accepted by most families in the belief that they are closer to God. Parents' incomprehension of disorders unknown to them is clear from this study, coupled with anger and disbelief as they perceive an impairment treated only with headache pills (aspirin for juvenile rheumatoid arthritis). A framework for action on reactions is described, in the family (counselling services and improving general knowledge for parents, siblings and grandparents); in the community (by improving general knowledge of impairments, their causes, and the many things that can be done to help); with traditional healers (developing liaison and recognising their important role in helping families to express their reactions); with health professionals (training to understand psychosocial matters and perhaps using case studies of the type found in this study); and with education professionals (training to understand how the role of the school can help a child cope with disability (or can cause worse problems with insensitive reactions from school pupils or teachers). Teachers can learn how their support for impaired children can greatly help families and the affected child. Teaching teachers by stories may be a practical way forward.

Acceptance is presented as a continuing process of parental, child and community factors positively facilitating acceptance of the impairment and of the child, or negatively delaying it. Acceptance is changing in Saudi Arabia. In the future it is hoped epilepsy may become better understood and carry less stigma so children do not have to have this impairment kept concealed. Developmental delay may become less accepted in future as academic achievement becomes more important. It is suggested that acceptance can only follow recognition. Acceptance also has to take place after the early reactions such as shock. When acceptance begins this is the first step towards starting the process of coping.

Coping, practical help with dealing with difficulties in daily living, was found to be one of the keys to enable families and the community to live with and alongside impairment and to enable normalisation and integration. Yet coping does not occur simply from provision of aids. Coping is also to do with feeling part of everyday life; living with others and being accepted at least to some extent in family and outside. Support from the social network helps coping; so can religion, not just belief, but the whole pattern of life associated with religious practice in Saudi Arabia; and finding something the child with impairment can be valued for. Two types of coping style were evident - treating the child as normal (even with severe impairment), and concealing the problem. A third key component of coping was ready availability of services when they were needed, services which recognise the burden and can alleviate it at appropriate times.

On services, the study has shown the key role of traditional healers in Saudi Arabia in helping recognition, enabling reactions to be expressed and facilitating family acceptance. The study has documented the changing views on the relevance of education to children with impairment and in health care, the need for better screening services, better prevention services, better health promotion services, as well as improvement developing an integrated education, traditional and health care system.

The study has identified the need to provide culturally appropriate services and support for disability in Saudi Arabia, marrying sophisticated high technology with a traditional approach to life and living and bringing up children. It has shown the key role of faith, fatalism and religion as a way of life both positively and negatively influencing acceptance, reactions, coping and use of services, especially those from traditional healers.

The study has shown the strengths and a number of weaknesses in the current services and provided an important new dimension in gathering parents' views of them. Suggestions are made to link together the best parts and strengthen the weaker so in future there may be an integrated service for disability building on the best of tradition and bringing in new knowledge where it is needed.

DEFINITIONS (see also section 1.3.2)

The World Health Organisation (WHO, 1980; Helander, 1984) suggests the following definitions for childhood disability:

IMPAIRMENT (in the context of health experience)

Any permanent or transitory loss or abnormality, of psychological, physiological or anatomical structure or function.

DISABILITY (in the context of health experience)

Any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal for a human being, resulting from an impairment.

HANDICAP (in the context of health experience)

A disadvantage for a given individual, resulting from an impairment or disability, that prevents or limits the fulfilment of a role that is normal, depending on age, sex, social and cultural factors for that individual.

These definitions are discussed in the Introduction (section 1.3.2, Problems of definition).

CONTENTS

1. INTRODUCTION AND OBJECTIVES	1
1.1 The need for the study	1
1.2 Magnitude of the problem of disability as shown in previous studies ...	2
1.2.1 Global prevalence rates of disability	2
1.2.2 A high proportion of people with disability in developing countries and in rural areas	2
1.2.3. Severity of disability	3
1.2.4 Lack of access to health services for people with impairment in developing countries	4
1.2.5 Quality of life of people with disabilities in developing countries	4
1.2.6 Causes of impairment	4
1.2.6.1 Genetic causes	4
1.2.6.2 Perinatal causes	5
1.2.6.3 The association of malnutrition with impairment	6
1.2.6.4 Communicable and non-communicable diseases causing impairment	6
1.2.6.5 Accidents as a cause of impairment	7
1.3 Problems of definition of disability	7
1.3.1 Cultural variation in the meaning of disability	7
1.3.2 Limitations of the "pathology model" of the disability process ..	8
1.3.3 Terminology and social context	8
1.3.4 The concept and practice of Community Based Rehabilitation ..	9
1.3.4.1 Experience of CBR from round the world	10
1.3.4.2 Experiences of CBR in Saudi Arabia	11
1.4 Objectives of the Study	11
2. LITERATURE REVIEW	13
2.1 Magnitude of the problem of disability	13
2.2 Mortality and quality of life of disabled people in developing countries ...	16
2.3 Recognition from the literature	17
.....	17
2.3.1 Perinatal recognition, often by health workers, later recognition dependent on parents noting something wrong or being noticed in school	17
2.3.2 The important "cultural component" of recognition of an impairment	17
2.3.3 Population screening for developmental impairment	18
2.3.4 Role of recognition in prevention strategies	19
2.4 Reactions to the impairment and to the child	19
2.4.1 What is meant by reaction to an impairment?	20
2.4.2 What range of reactions are found to impairment?	20
2.4.3 Denial by all families at the beginning	21
2.4.4 Other reactions	21
2.4.5 Later reactions from the family and other people	22
2.4.5.1 From crisis to strength	22
2.4.5.2 Stigma (see also discussion section 4.3.8.1) and religious belief (see section 4.3.6.3) mediating reactions	23
2.4.6 Variations in family reactions	23

2.5	Acceptance	24
2.5.1	What is acceptance?	24
2.5.2	Factors facilitating acceptance	25
2.6	Coping	27
2.6.1	Definitions of coping	27
2.6.2	Key factors related to coping with impairment	27
2.6.2.1	Coping by Parents	27
2.6.2.2	Coping by children	29
2.6.2.3	Recognising variability in coping depends on a child's personality, the family members and the nature of the situation	30
2.6.3	Recognising support mechanisms in coping	30
2.6.3.1	A strong family and informal social network	30
2.6.3.2	Support outside the family	31
2.7	Services (from the literature)	32
2.7.1	History of rehabilitation and community care	32
2.7.2	Current problems with the health services	34
2.7.2.1	Lack of services	34
2.7.2.2	Problems in health services for parents	35
2.7.2.3	Health workers do not understand the cultural background of families	35
2.7.2.4	Focus on expensive rehabilitation and cure rather than prevention and health promotion	36
2.7.3.1	Early intervention and prevention of secondary dysfunction	36
2.7.3.2	Changes in the professional role	37
3.	THE KINGDOM OF SAUDI ARABIA	40
3.1	History	40
3.2	Law and Government	40
3.3	Geography	41
3.4	Health	41
3.4.1	Prevalence of impairment	43
3.5	Education	44
3.5.1	The founding of special education in the Kingdom of Saudi Arabia	44
3.6	Social welfare	50
4.	METHODS	51
4.1	Why this Study?	51
4.1.1	The opportunity for a fresh look at care of disabled people for decision makers and managers in Saudi Arabia	51
4.1.2	The need for a study of disability from the families' point of view	52
4.2	Methods available for the Study	53
4.2.1	Introduction	53
4.2.2	Limitations of previous studies of children with impairments	53
4.3	Advantages and disadvantages of different methods of obtaining the information needed	54
4.4	Methods needed for Community Health Enquiry in Saudi Arabia	59
4.5	Selection of Survey Site and culturally specific procedures; a limited geographical area and a closed community; description of KAMAH (The King Abdulaziz Military Academy Hospital)	61

4.6	Identification of the children with impairments	67
4.6.1	Letters to all households in the KAMA Camp	67
4.6.1.1	Recruitment into the Study	67
4.6.1.2	Follow-up of the non-respondents to the household letter	68
4.6.1.3	Overall response rate from household survey	69
4.6.2	School Screening	69
4.6.2.1	Overall response rate in school sample	69
4.6.2.2	Procedure for school screening	69
4.6.2.3	Checking completeness of the school screening population	70
4.6.2.4	Non-respondents from school sample	70
4.6.3	Welfare Clinic screening of children under 5	71
4.6.3.1	Numbers screened at the child welfare clinic	71
4.6.3.2	Procedure at welfare clinics	72
4.6.4	Orientation of nurses involved in screening and screening procedures	72
4.6.4.1	Screening procedures and schedules	73
4.6.4.2	Audiology Tests	74
4.6.4.3	Vision Testing	75
4.6.4.4	Severity of individual impairment	76
4.6.5	Referral	79
4.7	The questionnaire and its pilot study	80
4.8	The Interviews	82
4.9	Key Informants	84
4.10	Constraints on the Study	85
4.10.1	Selection of important daily living and social activities	85
4.10.2	Approach to the care providers	86
4.10.3	Problems with administering IQ tests	86
4.11	Overview of the Methods	88

5.	RESULTS	92
5.1	Introduction to the Results	92
5.2.1	Minor impairments	92
5.2.2	Population prevalence rates for minor and severe impairment	95
5.2.3	Severe impairment	96
5.3	The steps towards the recognition of the disability	99
5.3.1	Age of diagnosis, place of delivery, the role of the health system and the cultural complexities of withholding information from one or both parents	99
5.3.1.1	Age of diagnosis and the role of health services	99
5.3.1.2	Recognition and place of delivery	102
5.3.1.3	Condition at Birth	105
5.3.1.4	Maturity (gestation) at birth	106
5.3.1.5	Type of delivery	106
5.3.1.6	The role of the visibility of the impairment at birth in recognition	107
5.3.1.7	Recognition of impairment but health services delay in later childhood in identifying cause, effect and implications	107
5.3.1.8	The cultural complexity of withholding information from one or both parents	108
5.3.2	Reasons for parental suspicion of impairment	109

5.3.3	The understanding of diagnosis in the cultural setting of Saudi Arabia	114
5.3.3.1	The cultural wish to ignore impairment when diagnosis is uncertain, or the problem minor	114
5.3.3.2	Parents' difficulty in understanding diagnostic labels	114
5.3.4	Key components of recognition shown in the current study	115
5.4	Reactions to the impairment and to the child	116
5.4.1	Pathways to recognition and varying reactions	116
5.4.2	First reactions	118
5.4.2.1	Shock	119
5.4.2.2	Depression	120
5.4.2.3	Guilt	122
5.4.2.4	Grief, anger and attribution to fate	123
5.4.3	Later reactions	125
5.4.3.1	Ignoring the impairment, ignoring the child and concealment (and later concern about future prospects)	125
5.5	Acceptance	127
5.5.1	Introduction	127
5.5.2	Factors contributing towards acceptance by the parents and family	127
5.5.2.1	Religious belief that hardship is rewarded by not complaining	127
5.5.2.2	Facing the reality	130
5.5.2.3	Physical attractiveness in the child	130
5.5.2.4	Attractive personality in the child (e.g. sense of humour)	131
5.5.2.5	Religious devotion by the child	131
5.5.2.6	Creating for the child an environment where he can achieve	132
5.5.2.7	Accepting the child for what they <u>can</u> do	132
5.5.2.8	Extended family support	134
5.5.3	Family factors delaying acceptance	136
5.5.3.1	Emotional exhaustion and prolonged questioning	136
5.5.3.2	Over-burdened mothers	136
5.5.3.3	Denial of the impairment, especially in the very young and for minor impairments	137
5.5.3.4	Dealing with the visibility of the impairment	139
5.5.3.5	Overcoming stigma, labelling and insensitivity in the community	140
5.5.3.6	Too high expectations	140
5.5.3.7	Too low expectations of suitability for marriage	140
5.5.3.8	Over-dependence on the mother in late childhood and adolescence, or over-delegation of care to others	141
5.5.4	Child factors affecting acceptance	143
5.5.4.1	Introduction	143
5.5.4.2	Acceptance of the impairment by the child	143
5.5.4.3	Non-acceptance of the impairment by the child	143
5.5.5	Positive community factors leading to greater and earlier acceptance	145
5.5.5.1	Neighbourhood support	145
5.5.5.2	Employment providing self reliance and improved social adjustment	145

5.5.6	Negative community factors delaying acceptance	145
5.5.6.1	Stigma, labelling and insensitivity in the community	145
5.5.6.2	Pressure from the community on parents to deny the child's impairment	146
5.5.6.3	Lack of support from health professionals	146
5.5.7	Conclusions on parental acceptance	147
5.5.7.1	The distinction between acceptance of the child and acceptance of the child's impairment	147
5.5.7.2	Emotional problems	148
5.6	Coping with the needs of daily living	148
5.6.1	Introduction	148
5.6.1.1	Introduction	148
5.6.1.2	Sleeping	149
5.6.1.3	Feeding/Eating	149
5.6.1.4	Dressing	151
5.6.1.5	Toileting	151
5.6.1.6	Moving around	152
5.6.1.7	Factors related to the impairment which affected social adjustment	152
5.6.1.8	Disabled child's behaviour leading to social difficulties	157
5.6.1.9	Play and leisure activities	159
5.6.2	Sharing the care of the child or unwilling to leave the child in the care of others	160
5.6.2.1	Unwilling to share the care	160
5.6.2.2	Sharing in care by other family members	160
5.6.2.3	Parents transferring responsibility to others	161
5.6.3	Worries, problems and exhaustion	161
5.6.3.1	Emotional demands on the mother	161
5.6.3.2	The relationship between the parents' involvement in care of the child with the disability and exhaustion	161
5.6.3.3	Parents' worries and concerns about the future	162
5.6.3.4	The problem of low expectations	165
5.6.3.5	The problem of uncertainty (and a lack of purpose)	165
5.6.3.6	Worry about integration into the community	165
5.6.3.7	Avoiding thought about the future	166
5.6.4	Styles of coping	167
5.6.4.1	Two approaches to coping and four strategies of coping in Saudi Arabia	167
5.6.4.2	Coping well (positive passive coping)	169
5.6.4.3	Coping by ignoring the problem (negative passive coping)	170
5.6.4.4	Assertive coping (using services/action to ensure coping)	170
5.6.4.5	Coping by denial and concealment (defensive coping)	170
5.7	Parents' experiences of services both traditional and modern	171
5.7.1	Introduction	171
5.7.2	Parents' experience of traditional healers	172
5.7.3	Parents' experiences of schooling	173
5.7.3.1	Introduction	173
5.7.3.2	Recognition of minor learning difficulties in school	174
5.7.3.3	Current education for the severe impairment group and mainstream school performance	174
5.7.3.4	Special institutions: seen as an alien environment	175
5.7.3.5	Conflict between traditional and modern in the choice of education in developmental delay	175

5.7.4	Parents' experiences of the medical services	176
5.7.4.1	Medical services for minor impairments	176
5.7.4.2	Medical services consulted by the parents for severe impairment	176
5.7.4.3	Breaks in medication and irregular attendance for treatment and reasons for this in children with severe disability	178
5.7.4.4	Strengths and satisfaction, weaknesses and dissatisfaction in the medical services as perceived by the parents	180
5.7.4.5	Conclusions of parents' experiences of medical care services	180
6.	DISCUSSION	182
6.1	Introduction to discussion	182
6.2	Recognition of the impairment	182
6.2.1	Defining recognition	182
6.2.2	Prevalence rates	183
6.2.2.1	Overall prevalence of disability	184
6.2.2.2	Types and prevalence of disability	184
6.2.3	Factors affecting recognition as shown in other studies and in the current investigation	188
6.2.3.1	The timing of the discovery of the impairment, and the roles of health professionals, parents and families, traditional healers and schools	188
6.2.3.2	Perinatal factors affecting recognition	189
6.2.3.3	The importance of parents noticing "something is wrong" in the process of recognition	190
6.2.3.4	Pre-school surveillance	191
6.2.3.5	The important role of schools in recognising impairment	192
6.2.3.6	The important "cultural component" of recognition of an impairment, especially in Saudi Arabia	192
6.3	Reactions to the impairment and to the child	193
6.3.1	What is meant by reaction to an impairment?	193
6.3.2	Early reactions	194
6.3.2.1	First reactions of shock, profound depression, parents blaming themselves and prolonged mourning for the child they feel they have lost, Why me?	194
6.3.2.2	Uncertainty of diagnosis affecting reactions by family and professionals	195
6.3.2.3	Denial of the disability	196
6.3.2.4	Struggle to get the disability recognised and understood	197
6.3.2.5	Role of health professionals in early reactions	197
6.3.3	Late reactions	198
6.3.3.1	Stressful life events following impairment	198
6.3.3.2	From crises to strength	199
6.3.3.3	Religious belief mediating reactions	199
6.3.4	Reactions by different members of the family	200
6.3.4.1	The impact of disability on the family	200
6.3.4.2	Reactions by parents	200
6.3.4.3	Reactions by siblings	201
6.3.5	Reactions by people outside the family	202
6.3.5.1	Stigma and labelling	202
6.3.5.2	Reactions by health workers	203

6.3.6	Theories of reactions to disability developed from other work and their linkage to findings in the current study	203
6.3.7	Action needed to tackle reactions in the family and the wider society in Saudi Arabia	203
6.4	Acceptance of a child with disability	205
6.4.1	Defining acceptance	205
6.4.2	The process of acceptance	206
6.4.3	Positive factors facilitating the acceptance of a disability in a child as shown in other studies and in the current investigation	207
6.4.3.1	Appropriate levels of expectations of the child by the family	208
6.4.3.2	Good mother/child, and family/child interaction	208
6.4.3.3	Social support and acceptance by others in both family and community	208
6.4.3.4	Normal daily living	210
6.4.3.5	Being a success	212
6.4.3.6	Acceptance by others helps the child accept the situation	212
6.4.4	Negative factors hindering acceptance	214
6.4.4.1	Too high expectations and difficulties with acceptance in the family	214
6.4.4.2	Lack of good parent/child interaction	214
6.4.4.3	Negative attitudes to disability in the community	215
6.4.4.4	Negative expectations by health workers	215
6.4.5	Implications for helping parents during the period of learning to accept their child with an impairment	216
6.5	Coping with a child with an impairment	217
6.5.1	What is coping?	217
6.5.2	Key elements for recognising challenges to coping	219
6.5.2.1	Recognising the separate problems that parents and the children with impairment need to cope with	219
6.5.2.2	Recognising subgroups of vulnerable families barely coping	224
6.5.2.3	Recognising variability in coping depending on a child's personality, the nature of the situation and the child's age	225
6.5.2.4	Prevention of secondary disability through health promotion	226
6.5.2.5	Recognising the range of strategies developed by parents	227
6.5.3	Practical procedures in coping	227
6.5.3.1	Finding solutions to problems of everyday living	227
6.5.3.2	Discipline	227
6.5.3.3	Facing worries about the future of the disabled child	228
6.5.3.4	Successfully mastering life events	228
6.5.3.5	The contribution to coping of strong family and informal social networks and positive attitudes in the community	230
6.5.3.6	The contribution of religious support to coping	230
6.5.3.7	The contribution to coping of a strongly developed self concept	231
6.5.4	Coping overall	232
6.6	Parents and services they use for the child with an impairment	233
6.6.1	Introduction	233
6.6.2	Parents' and the traditional healer services	233

6.6.3	Parents and the education services	234
6.6.3.1	Introduction	234
6.6.3.2	Current problems with the education services shown from this study	234
6.6.4	Parents and the medical care services	237
6.6.4.1	Medical care services and <u>recognition</u> of an impairment: current role and its limitations; future opportunities	237
6.6.4.2	Medical care services and <u>reactions</u> to an impairment: current role, its limitations and future opportunities	239
6.6.4.3	Medical care services and <u>coping</u> with an impairment: current role, limitations and future opportunities	239
6.6.4.4	Medical care services and <u>prevention</u> of impairment and disability	244
6.6.5	Future developments towards an integrated service combining health services, education services, social care and support services and traditional services working together throughout the life cycle	247
6.6.5.1	Summary of the need for change	247
6.6.5.2	Integration of recognition processes	248
6.6.5.3	Integration of support for reactions to the impairment	248
6.6.5.4	Integration of acceptance processes	249
6.6.5.5	Integration of services for prevention and health promotion	249
6.6.5.6	Integration of support for coping	250

7.	SUMMARY AND CONCLUSIONS BY THEMES	251
7.1	Summary and conclusions	251
7.2	Key findings of the present study	256

1. INTRODUCTION AND OBJECTIVES

1.1 The need for the study

There have been several "number counting" studies designed to measure the global size of the problem of disability (e.g. WHO, 1981). Such studies have not been able to capture the reality of disability as it confronts each family and those trying to help (Krefting and Krefting, 1990). The starting point for the present research was the conclusion of an earlier review (McConachie and Mitchell, 1985) that in order to design interventions more effectively, detailed information is needed on the parental, family and society dimensions of five topics, recognising; reacting; accepting; and coping with the disability; and parental views on services. The current study is one of very few studies from developing countries which investigate disability from the families' viewpoint, and which identify problems and strengths experienced both at home and in using health, education and other services. This study is also one of the rare investigations that identify the challenges to health workers if they are to provide long term care in true close collaboration with parents, bearing in mind that work with disabled children and their parents often takes place in an atmosphere laden with emotion. The current study is also important because very little work has been done on any community aspect of health problems in Saudi Arabia. There is an urgent need for the development of culturally appropriate community based enquiry for Saudi Arabia, which can be used in the Kingdom for other health problems. This study has developed approaches to working with families in the cultural situation of Saudi Arabia which may well be found valuable by others.

1.2 Magnitude of the problem of disability as shown in previous studies

1.2.1 Global prevalence rates of disability

Disability is a global problem of large proportions. In 1975, the International Society for Prosthetics and Orthotics carried out a survey of 33 countries and estimated that in a population of 2 billion there were 14 million people who are physically disabled (James, 1984). A common estimate worldwide of the total number of disabled people is about 400 million or 10 per cent of the world population (UNICEF, 1980). This figure has been challenged, but data from many countries and regions suggest at least one child in ten is born with or acquires a physical, mental or sensory impairment that will interfere with their capacity for normal development unless some special assistance, support and care is provided (UNICEF, 1980; James 1984). Although this seems to be a high prevalence, some consider that it is probably a minimum estimate.

1.2.2 A high proportion of people with disability in developing countries and in rural areas

Out of the world's 400 million disabled people, it has been estimated that 140 million are children and 120 million of these children live in developing countries (Hesperian Foundation, 1983; Wood, 1989).

Some Examples of Prevalence Studies

An extensive "key informant" survey in Bangladesh (Mia et al, 1979) produced a figure of 0.8% for disabled children. A slightly lower percentage (0.7%) is reported by Richardson's (1983) study in Nepal. Freye (1989) gives a figure of 5% for "easily identifiable" children with disabilities, based on a Botswana Ministry of Education figure for school-age disability. Tareen (1982) contrasts this with a US Office of Education figure for school age disability of 10% and

remarks "There is an apparent gap between the reported prevalence and visibility of disabilities". Periquet's (1984) study in Bacolod, Philippines, could discover only 3% in practice. A national sample survey of locomotor, visual, hearing and speech disabilities in India (Government of India, 1982) discovered 1.8% of the population as having these disabilities. (See also literature review section 2.1)

The uneven distribution of children with an impairment in different parts of the world is due mainly to differences in the socioeconomic state of a country's development; poverty; varying patterns of disability related diseases; and the total population (International Children's Centre, 1980). To a poor family, a disabled child adds a financial burden which increases their state of poverty (Lilione Fund Foundation, 1987). In rural areas, significantly more children were screened as positive than in urban areas in the Bangladesh Ten Question rapid epidemiological disability appraisal (Zaman, et al 1990).

1.2.3. Severity of disability

International organisations (e.g. UNICEF, 1980; ILO, 1982) have given a breakdown by severity of the 10 per cent of the population with a disability in the world as follows;

1% are in an advanced state (totally dependent for their daily needs)

1.5% - 3% require active rehabilitation, and

6% have moderate manageable disabilities (Rehabilitation International, 1981; WHO, 1981)

There is a need to recognise minor impairments as well as severe impairment. Severe impairment can be seen as the tip of the iceberg but it is impairment that is recognised early with ensuing appropriate action.

1.2.4 Lack of access to health services for people with impairment in developing countries

It has been calculated that 98% of disabled people have no access to services in their lifetime (Thorburn and Roecher, 1986). Most of them live in villages where no rehabilitation is available (International Children's Centre, 1980), or where rehabilitation services are only just beginning and at present reach only 2% of persons with a disability (Grant, 1985). It is estimated that, at present, no more than 2 - 3% of these people who could benefit from rehabilitation are receiving active services (Helander et al, 1989).

1.2.5 Quality of life of people with disabilities in developing countries

A poor quality of life is reflected in the general standard of living of children with impairments. Mortality is greater than among able-bodied children. The social and physical barriers may impede the quality of life more than the impairment itself. (See also literature review section 2.2)

1.2.6 Causes of impairment

1.2.6.1 Genetic causes

In Saudi Arabia clinical experience suggests that more genetic forms of impairment are now being seen probably because of the more widespread and better perinatal care now available in hospitals resulting in the survival of some babies with impairments who previously would have died. However, there are no reliable figures for Saudi Arabia. Genetic disorders causing impairments are known. However, the etiology and pathology may be highly complex (Hall 1992).

1.2.6.2 Perinatal causes

It is now becoming recognised that much disability is due to preventable conditions (Marfo, 1986).

Perinatal causes of disability are important particularly in developing countries where coverage with good perinatal care is low and a large proportion of deliveries are conducted by unskilled personnel (Ebrahim, 1982; Mavalanker et al, 1991). Lack of care during pregnancy and delivery is a major preventable cause of impairment. The prevention of asphyxia is a crucial issue in the prevention of impairment (Shah, 1989).

As the pattern of perinatal death changes, new causes of disability are appearing in different countries (Misra et al, 1993). Kernicterus, disappearing in Western countries, is becoming increasingly common in Saudi Arabia (Taha and Almahdi, 1984).

Low birth weight (< 2500 g) has a high incidence in many countries on account of maternal under-nutrition, anaemia, high parity, malaria, short birth interval, etc (Escobar et al, 1991). Many can be ascribed to foetal malnutrition (Sommer et al, 1981). The incidence of cerebral palsy and other motor or mental impairments is higher in low birth weight infants compared to those born with an adequate birth weight (see Zubrick et al, 1988).

In Saudi Arabia low birth weight continues to be a problem (Taha and al Mahdi, 1984) due to a combination of early age of pregnancy, infections and undernutrition and, as the current study (see results below) shows, a high proportion of impairments occur in the perinatal period.

1.2.6.3 The association of malnutrition with impairment

In Saudi Arabia the current concern is in the field of inappropriate nutrition, rather than a shortage of calories (Al-Othaimen et al, 1988). There are no nationwide statistics of the nutritional status of Saudi children (Sebai and Reinke, 1981), but a preliminary report on 840 preschool children indicated a prevalence of moderate or severe wasting of 6 per cent, and of moderate or severe stunting of 24 per cent (Serenius, 1988). In addition there are two further problems which are related to nutrition and possible impairment. One is that there are many births to women who are very young due to an early age of marriage. Another is the second generation effect of poor nutrition. These two factors mean that short stunted women may be giving birth to much larger babies than their pelvis is able to deliver easily. This means there is a risk of impairment occurring at birth.

Nevertheless, malnutrition can be directly associated with impairment. Iodine deficiency is a serious problem (e.g. Halpern et al, 1991) and is associated with deafness and cretinism, and worldwide millions are at risk (Sadarwalla and Wraith, 1989). This particular form of micro-nutrient deficiency is no longer being reported in Saudi Arabia although in other countries high prevalence rates continue since their identification in the 1960s (Jali, 1991).

1.2.6.4 Communicable and non-communicable diseases causing impairment

In Saudi Arabia some diseases such as cerebral malaria, T.B., Meningitis, and measles do continue to pose a problem, although tuberculosis is rapidly declining (unpublished data without detailed statistics, Ministry of Health, 1989, 1990) (see Badr, 1984).

In Saudi Arabia polio continues to be a problem (Ramia et al, 1987), although precise data are not available.

Measles survivors suffer from xerophthalmia causing blindness, middle ear infections, resulting in deafness, encephalitis which may lead to permanent brain damage and severe malnutrition. In Saudi Arabia measles continues to be a problem (Sebai, 1981).

The reason for the persistence of poliomyelitis in Saudi Arabia is thought to be inadequate maintenance of the cold chain, poor availability of services and lack of take-up of services by families.

A number of non-communicable diseases can also cause impairment.

1.2.6.5 Accidents as a cause of impairment

Accidents in the home and road traffic accidents are also important causes of impairment (Osberg and Discala, 1992). One of the study children has tetraplegia following a road accident. Road traffic accidents can be reduced by effective legislation, but this has not yet been introduced in Saudi Arabia (Mufti, 1986; Marwah, 1990).

1.2.7 Lack of data on impairment and disability in Saudi Arabia

The prevalence of disability in Saudi Arabia is not known (Sebai, 1981; Serenius, 1988).

1.3 Problems of definition of disability

1.3.1 Cultural variation in the meaning of disability

Although the terms defined by WHO (see Definitions) appear to be simple and straightforward, there is a great deal of controversy among the users of these terms (see Rodriguez, 1989). No definitions will ever be ideal. Definitions are often prepared by committees trying to reach a

compromise. Over time, new experience and new ideas lead to new definitions. "Disability" does not have meanings which are similar in all cultures. Within the same culture there is often disagreement about what disability actually is (Baily 1992).

1.3.2 Limitations of the "pathology model" of the disability process

Criticism comes particularly from people with a disability. A model of the disability process linked with pathology is open to criticism (see Wood, 1989). Concentration on the pathology alone will lead to reduction in the understanding of the disability (Helander, 1984).

1.3.3 Terminology and social context

Some terms may have negative meanings. Terms like "impairment", "disability", "handicap" and similar expressions like "deficient", "limiting", "dependency" have a negative connotation. They may contribute to perpetuating both disabled and able-bodied people's view of disabled people as being chronically affected, incurably ill, and inferior, forever segregated from normal life and for whom there are no expectations of contributing to a family or to society. Not only can disabled people become separated from everyday life because of the stigma and emotional isolation, but they may also be isolated physically because of the practical difficulties. For example, many buildings have no access for wheelchair users and braille notices are rare. Thus the attention may be on the individual and the impairment but also on the organisation of society which excludes disabled people. The type of terminology which focuses on the pathological conditions or describes people as objects of charity or pity (e.g. we are going to help them) puts them at a disadvantage.

Thorburn (1992) suggests that functional definitions still locate the causes of disability at the level of the individual, whereas the cause of disability often lies within the society which

frequently puts people with an impairment at a disadvantage. Alternative definitions have been proposed by disabled people. They read:

Impairment Lacking part or all of a limb, or having a defective limb, organ or mechanisms and functioning of the body;

Disability Disadvantages or restriction of activity caused by a social organisation which takes no or little account of people who have physical impairments and excludes them from the mainstream of social activities.

Throughout this thesis, only the terms "impairment" and "disability" are used. The word handicap with its negative and confusing connotations is avoided.

1.3.4 The concept and practice of Community Based Rehabilitation

- 1. What families do already is important and valuable.**
- 2. Health workers need special skills to work sensitively and effectively with families to support what they are doing already and to extend it.**
- 3. The needs of children with a disability and their families varies through the life cycle, and the role, skills and knowledge required by families and their health workers will be different at each stage. This means that training, support and supervision also vary through the life cycle of the child.**
- 4. Community based rehabilitation (CBR) also recognises that health services may at times need to take over from the family when care is needed which the family simply cannot provide.**

Support in the form of medical care, rehabilitation, help with daily living, as well as financial, social and emotional support are all part of the support from services for community care, including respite care in times of stress, holidays and illness, although this may take place in the community.

1.3.4.1 Experience of CBR from round the world

New projects and programmes are in action in many countries. In 1961 Huckstep developed methods of treatment and rehabilitation appropriate to the resources of rural Uganda (Huckstep, 1983). Hardy (1983) reports that "faced with the lack of available places in the few local specialised institutions, and dissatisfied with sending children abroad, in 1970, parents of children with a disability in Bahrain formed an association and opened a small multi-purpose centre."

Dixon (1981) reports from China with reference to the early 1970's that Chinese families with disabled children find themselves the focus of a network of community-based supportive services. During the same period Levitt et al (1976) were introducing paediatric physiotherapy in South African villages. Meanwhile, Thorburn (1991) was training community-based rehabilitation aides in the West Indies.

In some cases, the initiative has gone towards preventive action and the development of appropriate technology (Doyal 1983). There has been growing recognition of the limitation of the conventional institution-centred model of rehabilitation (O'Toole, 1988).

The Mexican experience led to the book "The Disabled Village Child" by Werner (1987). Project Projimo in Western Mexico is a rural rehabilitation programme. The main purpose of the programme is to give families the understanding and skills they need to help disabled children and adults develop their full potential and improve their self-esteem. The project is structured

to develop self-reliance in all who participate: workers, parents, and children. It is a village-based rehabilitation centre and programme and is directed by local people from poor working families, most of them disabled, and has the participation, in many different ways, of most of the community. Projimo is a Spanish word for neighbour in the most kindly sense, such as "love your neighbour", but P.R.O.J.I.M.O. is also a Spanish acronym meaning rehabilitation programme organised by disabled youth of Western Mexico (PCMR, 1979).

1.3.4.2 Experiences of CBR in Saudi Arabia

In Saudi Arabia Families have always looked after children with a disability, particularly those with certain types of impairments. Up to now there has been little institutional support. The current study is a first step towards improving this situation.

1.4 Objectives of the Study

- 1.4.1 To develop a culturally appropriate community based method of enquiry about impairment and disability amongst children in Saudi Arabia.**
- 1.4.2 To identify prevalence rates of minor and severe impairment.**
- 1.4.3 To find out how parents recognised impairment in their child.**
- 1.4.4 To identify the range of reactions to the impairment in the family and how reactions are affected by the way the impairment came to be recognised.**
- 1.4.5 To identify factors affecting acceptance of the impairment and of the disabled child by the family, and how recognition procedures and reactions affect the process of acceptance.**

- 1.4.6 To identify strategies for coping with the disability and how the processes of recognition, reaction and acceptance affect them.**
- 1.4.7 To identify what services are being used by families who have a child with an impairment, both traditional and modern, and ways in which current service provision could be improved.**

2. LITERATURE REVIEW

2.1 Magnitude of the problem of disability

As already described in the Introduction (section 1.2), international organisations such as WHO, UNICEF (1980) and ILO (1982) commonly use the figure of 10% as an average to represent the proportion of disabled people in the world with disabilities. They use the following breakdown: 1% have severe impairments; 1.5 - 3% require rehabilitation, and 6% have moderate manageable impairments (WHO, 1981, 1984). This is made up as shown in Table 2.1.

There is a major information gap in the Third World in the area of disability (Rehabilitation International, 1981). In the case of childhood disability, there have been studies of prevalence, but most have not yielded consistent and reliable data (Thorburn, 1991) for valid comparison of results. Consequently, the information is of questionable value for planning or extrapolation. Reasons for this situation include failure to use uniform (or any) definitions of impairment, disability and handicap, lack of sub-classifications within these areas and lack of criteria for levels of severity within categories of disability. The screening instruments used have been inconsistent and assessment tools have not been suitably adapted for cultural differences; sampling methods in some cases have been inadequate, either in selection or in size (Thorburn et al, 1992).

Table 2.1 Rehabilitation Needs - Global Estimate			
Needs of survey population of people with a disability in developing countries	Percentage total population	Percentage of the disabled population	Millions of people with a disability in developing countries (1985 = 400 million)
1. Severe disability needing care and rehabilitation	1%	10%	40 million
2. Rehabilitation only: Disabled people not needing care but needing rehabilitation			
(* Schooling: children and adults)		(8%)	(32 million)
(Job placement)		(22%)	(68 million)
Rehabilitation (total)	1.5-3%	30%	120 million
3. Care only: moderate disability and rehabilitation needs met or not feasible	6%	60%	240 million
Total	10%	100%	400 million

* The total number of children and adults needing schooling is about 32 million or 8% of the population of disabled people. This number is not added to the total as they are also included in the group needing training and jobs. Both schooling and jobs are included in the "rehabilitation only" total.

While it is difficult to compare the results of the various studies because different methods were used, it appears reasonable to conclude that 7 - 10% of the population in developing countries have an impairment, less than in industrialized countries, probably due to under-reporting. In one longitudinal study of a national sample of Jewish children born in 1975 and followed to age 7 in Israel, a rate of 6-9% was found (Palti, et al and Ornoy, 1992). Estimates are often based on the studies conducted in western countries.

The Disability Statistics Compendium (1990) assesses how disability concepts and definitions are used in countries to identify persons with a disability and how this affects statistical findings. Statistics presented in the compendium indicate that the percentage of persons with a disability ranges from a low of 0.2 to a high of 20.9 per cent for 63 surveys from the 55 countries, including data from all types of definitions, age ranges and data collection systems and recognising their lack of comparability.

Why is there such variation in the percentage of prevalence of disabled people?

The high degree of variability in disability rates is at least partly determined by the selection and use of varying impairment and definitions and codes used to describe disability. A major reason for this is the effect of the high degree of variation in surveys used by data collection programmes. In some cases people with a disability were screened into the disability survey by using a checklist that asked about persons in the households having specific impairment (e.g. Bahrain, 1980 and Peru, 1981 population censuses). In other cases, a general question asking whether any person in the household was impaired has been employed as the survey screening device (e.g. Egyptian population census, 1986). Some data collection programmes screened people into the survey either by asking a general disability question (Canadian population census, 1986) or by using a checklist of specific conditions (United States population census; New Zealand, 1980; Finland, 1978 and Norway, 1983 living conditions surveys; and the disability survey of Spain, 1986). Some countries assess disability through census questions about economic activity. In some censuses, disability is one category in a checklist of reasons for not attending school among children and youths (Chamie, 1989).

A consequence of the different approaches to identification techniques is that there are notable regional differences in percentage of people with a disability (Haggard, 1990). The countries of Africa and Asia, which generally implement impairment screens in their censuses, surveys and registration systems in order to identify persons with a disability, report lower rates than do the countries of Europe and North America, which generally use disability persons (with the

exception of the Caribbean countries which, until now, are still using impairment screens). This suggests that regional comparisons of disability rates may be very misleading unless the methodological differences between data collection systems are clearly stated. Since high false positive and false negatives continue to be reported, the investigation of factors that could lead to screening inaccuracies is important (Harris, 1987). These findings emphasise the necessity for international guidelines on survey standards for data collection and disability, so that rates may be more comparable, and more meaningful, both within and across countries.

The apparent gap between the reported prevalence and visibility level of disabilities may be explained in terms of stigma attached to abnormalities of all kinds. The mortality rate of people with a disability is higher than that of able-bodied in developing countries, not only because of their extreme vulnerability, but also as a result of active neglect on the part of parents and society. Studies using census and key informant methodologies, have found these methods biased and inaccurate and likely to under-enumerate. It has been found that people with impairments that are physically not obvious are most likely to be overlooked by the census enumerator or key informants (Chamie, 1989; Thorburn et al, 1992).

Pilot studies carried out in Pakistan and eight other developing countries on small samples (approximately one thousand children in each of the nine countries) suggest that a "ten question" questionnaire provides a sensitive screen for severe mental retardation in 3-9 year old children but it does generate false positives (Belmont, 1984; Zaman et al, 1990). Visual defects in children under 5 are generally detected by family and friends, not by screening, but detection by the medical profession could be improved by increased awareness and observation and quick referral (Hall and Hall, 1988).

2.2 Mortality and quality of life of disabled people in developing countries

Quality of life associated with later childhood and adult disability is of growing interest (Doyal, 1983). The importance of quality of life within early childhood services focuses on the fact that

the nature of the environment can dramatically increase or decrease the disability problem associated with young children. Quality of life is relevant to all domains of functioning (see, for example, Mitchell (1987)).

2.3 Recognition from the literature

Issues in recognition hinge on who first notices an impairment, where, and at what age (Zubrick et al, 1988). The timing is likely to be either perinatal or somewhat later; the place is likely to be either home, hospital, school or a screening session in a clinic, and the person involved is likely to be a health worker, school teacher, or parent or grandparent or family member (Dworkin, 1989).

2.3.1 Perinatal recognition, often by health workers, later recognition dependent on parents noting something wrong or being noticed in school

In the perinatal period, it is the health workers who often detect the impairment (Hertzig, 1981). Anomalies such as limb deformities are usually recognised at birth, or in the first days or weeks of the child's life. Parent of young children are likely to be the first to appreciate marked slowness in development (see Martin et al, 1981). Parental concern when present can lead rapidly to formal recognition. However, Rona et al (1991) find it difficult to agree that parental awareness alone would uncover the sizable level of appropriate referrals identified by their study.

2.3.2 The important "cultural component" of recognition of an impairment

The recognition of disability may stem from a number of sources, including child-rearing practices, religious and traditional beliefs, and concepts of disease causation (Bostock, 1976). Recognition is also influenced by such factors as information level, knowledge, attainment skills, acquisition and experience with the child with a disability (Leininger, 1985). Waxler

(1974, 1979) has developed a "social labelling" perspective on recognition which holds that "the societal definitions of cause and results and expectations" determine much of what is impairment. This perhaps suggests that any concept of disability must change and are dependent on a variety of social, economic, psychological and biological factors (see Burack et al, 1988; Goodman, 1990).

2.3.3 Population screening for developmental impairment

Much attention has been given to early detection (Bennett and Guralnick, 1991). The concept of total population screening of young children for developmental impairment has a long history.

Frankenburg et al (1988) have drawn attention to four common pitfalls made in the evaluation of developmental screening tests: the incorrect administration of the test; the failure to use reliable outcome measures; attempting to predict later status; and inappropriate generalizations and conclusions. In the 'Ten Questions', because of the nature of the questions, sensitivity to the child's behaviour depends on the child's care-giver and whether that behaviour is regarded as a problem. Thorburn et al (1992) mentioned that this awareness is high for some impairments (fits, and motor and hearing disabilities), but concern is not high to prompt action on the part of the care-giver in the less visible problems, particularly speech and cognitive disabilities.

A National Health and Development Screening Programme for children was instituted in the Federal Republic of Germany in 1972 (Drillien and Drummond, 1983). In 1977, a standard development check list, based on age, was set up in an attempt to produce more reliable results. However, (Drillien and Drummond, 1983) reported "in spite of an almost perfect offer of routine screening examinations to families, case finding is not nearly complete" (Fyro and Bodegard, 1987; Heydahhal, 1988). In France screening has been "obligatory" (at 8 days, 9

months and 2 years) in that postnatal benefits were dependent on screening attendance (Drillien and Drummond, 1983).

Previous studies have stressed the importance of early recognition of language disorders in order to avoid subsequent intellectual, emotional and social difficulties but still, for various reasons, diagnosis of a developmental language disorder is often delayed (Jensen et al, 1988).

Children with motor difficulties, so-called "clumsy" children, are more likely today to be identified by teachers and health care professionals (Stephenson et al, 1990).

2.3.4 Role of recognition in prevention strategies

Preventive strategies can be considered at two different levels: primary and secondary. Primary prevention is concerned with averting the conditions which give rise to impairments (Becker et al, 1989). Secondary prevention has to do with early identification of conditions which are likely to place a child's development at serious risk and the institution of measures to ameliorate or reduce the severity of any disability which might result from such factors (Brooks, 1984).

2.4 Reactions to the impairment and to the child

The study of the process of adaptation to disability has been a concern of rehabilitation researchers for many years. Although the literature abounds with theoretical discussions and the results of clinical impressionistic studies, there is generally little agreement within the field on the nature of the concept of adaptation to disability (Antonak and Livneh, 1991). However, several models that have been proposed (e.g. Livneh, 1986; Pepper, 1977) share a common theme, that of a sequence of stages or phases which define the process of change in psychosocial functioning upon encountering the impairment. In these models, adaptation is thought to involve the gradual, developmental process of acceptance. The Reactions to Disability and

Impairment Inventory (RIDI) by Livneh and Antonak (1990) may furnish researchers with a more useful multidimensional measurement device. The RIDI provides information on eight patterns of psycho-social reactions to the reactions of disability, namely: shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement and adjustment. The data of Antonak and Livneh suggest that anxiety, depression, internalized anger and externalized hostility are all prerequisites to reaching the final state of adaptation, which they define as acceptance and coping. They found that these reactions do not occur in any constant fixed sequence, but may depend on several factors, such as individual characteristics, culture and family factors.

2.4.1 What is meant by reaction to an impairment?

Reactions are defined in section 6.3.1. Reactions will vary at different stages of the life cycle. Many studies of parental reactions to diagnosis refer only to readily recognisable syndromes (e.g. Down's syndrome or congenital abnormalities such as spina bifida) (Cottrell and Summers, 1990).

2.4.2 What range of reactions are found to impairment?

There have been many generalisations and often contradictory statements. Many studies are said to show that parents find the birth of a child with an impairment an overwhelming shock from which they never recover and about which they feel guilt, chronic sorrow and a variety of other negative emotions (Copley and Bodensteiner, 1987). On the other hand, there are studies taking an opposite view. Byrne (1988) has suggested that at least three different categories of research on reactions can be found: those which examine family stress and coping strategy and those that are concerned with service needs.

2.4.3 Denial by all families at the beginning (see also Discussion 6.3.2.3.)

One of the reasons that denial occurs may be that parents have a desire for "normalisation" of everyday life (Dossa, 1992). Families can become isolated after a child is labelled with an impairment (see also Winfield and Cormak, 1986). Florain et al (1989) noted that some parents refused to recognise that certain characteristic behaviour in their children was abnormal and these parents tended to state that causes other than impairment were responsible for it.

2.4.4 Other reactions

Sloper and Turner, (1993) described families in which the child was unwanted by the mother and overfed in order to relieve her guilt. The degree of impairment suffered by a family seems to be a function of the state of the child, the reactions of the family and measures society is prepared to take to help (Goddard and Rubisslow, 1977).

Children, too, react to their own impairment; reactions are not the preoccupation only of parents or other people in the community (Cunningham et al, 1991). In the Ontario Child Health Study children with both chronic illness and associated disability were at greater risk for psychiatric disorders and considerable risk for social adjustment problems (Cadman et al, 1987). Coleman and Lindsey (1992) have pointed out, impairment during adolescence is likely to be associated with a negative self-image and the inability to attain emotional independence.

2.4.5 Later reactions from the family and other people (see also sections 4.3.6 - 4.3.8)

2.4.5.1 From crisis to strength

The onset of disability in a member of the family initially invariably produces a state of crisis for that family (Mitchell, 1987; Hoare, 1987; Livingstone, 1988). However, effective child and parent functioning can occur.

The literature concerning the effect on parents of caring for a child with an impairment is inconclusive. For example, some studies indicate that a general stress pervades the entire family, often with negative outcomes for marital relationships (Tew et al, 1975; see also Cooke et al, 1986 and Hirst, 1991), while other studies have indicated that, although under stress, families remain relatively intact and there are no negative effects on marital relationships (Freston, 1971). Indeed, a detailed study of 125 families including an 11 year old child with spina bifida, found that when the child's impairment was severe, while the family was significantly more restricted in some social activities, there was no significant association with any objective measures of family stress (Hirst, 1985).

External attitudes affect the family's behavioural response to the child which can either increase or decrease adjustment (Nolan and Pless, 1986; Cadman et al, 1987). A strong family with informal social backing and positive attitudes in the community can provide stimulating factors for active participation in the community by people with a disability. Several variables in the family environment, both positive and negative, have proved to be significant indicators of the adjustment of both the child with a disability and the family (Breslau and Marhsall, 1985), and a self report questionnaire has been developed (Rosenbaum et al, 1987).

2.4.5.2 Stigma (see also discussion section 4.3.8.1) and religious belief (see section 4.3.6.3) mediating reactions

Religious belief can also influence parental and sibling acceptance of the child with an impairment (Simeonsson and McHale, 1981).

Certain stigma are particularly important in the Middle East. Epilepsy carries great stigma. It was thought to be brought about by demons (Fareed, 1970). On the whole, in Middle Eastern culture, all people with a disability are negatively perceived and their chances of becoming fully rehabilitated into the society are much slimmer than in some other societies (Reiter et al, 1989) (see also Weller and Aminadal, 1989).

2.4.6 Variations in family reactions

Family life is invariably disturbed when the child with an impairment is living at home. Thus when discussing the impact of a child with a disability upon family life, differing views based upon the individual and social models of disability once again emerge (McGee and Stanton, 1990). The precise impact of the disability upon family life depends upon the position within the family of the person with an impairment. The presence of disability has an important effect upon the relationships and opportunities of the family as a whole (e.g. Fitzpatrick and Barry, 1990).

2.5 Acceptance

2.5.1 What is acceptance?

The meaning of "best acceptance" varies from one study to another but typically includes comparison on such factors as degree of client independence and reported client satisfaction (Intagliata et al, 1981).

Successful acceptance of the diagnosis of impairment means the death of a fantasy and the imaginary ideal child and the transfer of maternal and paternal love to the newly perceived child's reality (Stokes, 1976). The need to approach community adjustment at a variety of levels has been noted (Fraser, 1986). Family environment and daily living variables have also been studied (see Fraser and Rao, 1991).

Acceptance can also be approached from both an individual and a societal perspective. From an individual perspective, acceptance has to do with the problems and needs of the individual as these relate to his or her ability to function at maximum levels, physically, psychologically and socially. From a societal perspective, acceptance represents a set of problems having to do with social integration and performance of social and economic roles, for example, with peers and teachers (see Armstrong et al, 1992).

Allen (1983) has emphasised that social integration will not take place merely as a consequence of residence within an existing community. Firth (1987) said that little attention has been given to the social contact young people may have or lack either with their peers or with adults other than their carers. Social integration does seem to be a common practice in many countries (Victora et al, 1990).

2.5.2 Factors facilitating acceptance

Attitudes towards people with a disability vary according to level of education, rural or urban residence and socio-economic status (Nader, 1984). The treatment accorded to a person with a disability is determined by the prevailing attitudes (Judson and Burden, 1980).

Various child characteristics and community factors appear to mediate the degree of stress experienced by the family (Bernheimer et al, 1983; see also Bromley and Blacker, 1991). Children with an impairment have been mainly the woman's responsibility and "care by the family" or "by the community" can be seen as synonymous with "maternal care" (Wasserman and Allen, 1985).

Some factors facilitating acceptance

Physical attractiveness

Pless and Nolan (1991) found a strong positive correlation between children's physical attractiveness, their peer relationships and their teacher's appraisals of both their academic performance and their social adjustment.

Bracegirdle (1990) noted that both adults and children seem to enjoy interacting with attractive children more than unattractive children, so the former have more opportunity to practice social skills and receive more reinforcement of their efforts. A child who is not attractive but also has a visible impairment is additionally burdened with a stigma that is an attribute which is deeply discrediting.

Duty and religious and social expectations of care

The belief system of the parents seems to be an important factor affecting a child's acceptance (Reiter et al, 1986; Al Radi and Al Mahdi, 1989).

Stimulation and achievement and internal patterns of family life

It is well recognised that if the perceptual and cognitive functions of most children with a disability are enriched and nurtured, their capacity to learn from experiences will be improved (Allen and Zigler, 1987; Kashani et al, 1988; Walender et al, 1988). Such children may become more likely to be accepted. There have been many studies of "the effects of a disabled child on their family". The child's disability may produce effects on other family members, altering the family structure and influencing their life choices (Turk, 1964; Eiser, 1990). All families experience varying degrees of discomfort when discussing the child's disability among themselves. Background factors existing even prior to the establishment of the family, such as social class membership, ethnic origins, religious affiliation and financial status have their effects too (Freeston, 1971; Cooke et al, 1983). However, Hewett et al (1970) concluded that the "internal patterns of family life seem to be disrupted less than one might expect by the presence of a young disabled child". There is, however, little descriptive data with which to make comparisons with family life with able bodied children (Dunlop and Hollingsworth, 1977).

Other factors in acceptance

A family's acceptance and functioning is also affected by the age of the child at the onset of his symptoms; the sex and birth order; the severity of his condition; the parents' personalities and the prior losses they have already had to deal with; the special meaning the affected child has for them; and the support they can offer each other (Nolan and Pless, 1986; Cadman et al, 1987)

The over-involved family is not necessarily the best in accepting a child with a disability. This has been found to be particularly true for children with a severe disability (see, for example, Hatfield, 1987).

2.6 Coping (from the literature)

2.6.1 Definitions of coping

"Coping is to do with a multitude of daily interactions with individuals who teach, work, live with and care for people with a disability" (Mittler, 1988). There is a need to distinguish between subjective burdens involved in providing care, and the material burden which results in adverse effects on the household (e.g. Pauline and McMillen, 1992).

Even amongst families of the child where familial adjustment and acceptance occurred relatively early in the child's life, there are different problems that keep requiring new acceptance as the child grows older, and affecting the coping capabilities of the family (Goodyer, 1990).

2.6.2 Key factors related to coping with impairment

2.6.2.1 Coping by Parents

The birth of a child which physical impairment generates crisis throughout the family as a whole (Rimmerman and Portowicz, 1987). Parents are said frequently to experience feelings of loss, low self-esteem, and a sense of constant and often pervasive psychological and physical burden (Waisbern, 1980). Other stress-creating sources often reported in the literature include the demands on time, the prolonged burden of care, the stigma, and the long-term uncertainty. Further to these sources of stress, the indirect impact of reduction in social contacts, the concomitant adjustment problems of siblings, financial constraints, and the reduction in the use of professional services can be added (Waisbern, 1980; Wikler, 1981; Davidson and Dosser, 1982). In recent years, there has been a departure from the traditional approaches, based on the deficit model which assumed that all families with children with impairments had inherent problems, which tended to focus upon parental stress and coping in a one-dimensional method.

There is increasingly a tendency to examine multifaceted factors associated with parental coping resources (Cole, 1986; Dunst, 1986; Rimmerman, 1989). Two of the most frequent approaches cited in the current literature are studies of: (a) the individual family member, personal psychological resources (e.g. the ability to control the stress or life event); and (b) the external social resources (e.g. assistance received from relatives, friends and community organizations) (Rimmerman and Stanger, 1992).

Most previous studies (Cole, 1986) have dealt with parents' reactions to the crisis or the impact of the child with an impairment on the individual members of the family as a whole; only a few authors have focused on parents' perception of how to utilize their social support system. In fact, parental perception of the external social support system has been reported in the literature on children's developmental disability to be a buffer against stress and a vital resource for proper socialization over the life cycle (Blacker, 1984; Kazak and Marvin, 1984; Rimmerman, 1989).

Locus of control is one of the key concepts used by medical psychologists in explaining parental perception of and their ability to enhance their exploitation of social resources. Locus of control reflects the individual's perception of how much control he or she can exercise over life events. They have, in other words, strong faith in their own ability to plan and act upon their environment. At the other extreme are individuals who exhibit an 'external' locus of control, who tend to be characterized as fatalistic, passive, sceptical, and therefore less motivated to act on their own behalf or upon their own environment (Rimmerman and Stanger, 1992).

The concept of locus of control, which searched for a basic indicator to explain the rehabilitation motivation toward adjustment, gained special attention in rehabilitation studies (Pinkard, 1984). Recently, Antonovsky (1987) proposed the construct 'sense of coherence' (SOC), which is defined as "a global orientation that expresses the extent to which one has a pervasive, enduring, dynamic feeling of confidence that one's internal and external

environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected".

Although these concepts attracted some attention from psychologists and social scientists, they are still subjective. The mother's ability to mobilize her own social resources, at an early stage, decreases child-related stress and increases her competence to nurture her child (Blacher, 1984). In addition, this period may be characterized by early professional efforts to strengthen and stabilize the mother's social support network and to facilitate mother's coping (Intagliata and Doyle, 1984).

Within the immediate family, one member, most often the mother, assumes the role of principal care giver and is most profoundly affected by the acts and lapses of the child with an impairment (Fisman and Wolf, 1991). The presence of a child with an impairment in a family often results in problems of adjustment (McCormick et al, 1986) and stress (Dyson, 1991). In one study families with a disabled child were more likely to have longer spells as one parent families (Gallimore et al, 1989). The parents' reputation is affected by the presence of a child with an impairment (Voysey, 1975; Simeonsson and McHale, 1981).

2.6.2.2 Coping by children

There is growing evidence that social isolation occurs particularly with visible impairments (Rutter et al, 1970; Anderson, 1973; Altman, 1981; Hornby and Murray, 1983). Among the teenage children, the most commonly mentioned problems were shyness, lack of self-confidence and self-consciousness (see Kashani, 1986). Thomas et al (1988) have pointed out that impairment during adolescence is likely to be associated with a negative self-image and the inability to attain emotional independence.

2.6.2.3 Recognising variability in coping depends on a child's personality, the family members and the nature of the situation

The degree of difficulty in the family seems to be a function of the child, the reaction of the family and the extent to which society is prepared to help (Jenkins and Smith, 1991). However, there is one way in which their lives are almost inevitably different and that is in their need to have much more contact with the various services (Atkinson, 1992).

2.6.3 Recognising support mechanisms in coping

2.6.3.1 A strong family and informal social network

Developments in the field of disability have produced a marked upsurge of interest in the families of children with an impairment. Most authorities recognise that the place for a disabled person is with his family and community (Tysk, 1989). There is a growth of literature by parents who are caring for their child with a disability (Albrecht and Levy, 1981). Parents also need to be loved and to be valued (Brudenell, 1986). Groups of parents are now meeting together with a professionally trained leader. In the western world this has been found to be a most successful means of helping parents to learn about ways of helping the child, themselves and other members of the family (McAndrews, 1976). Often, the mother is most involved and having recognised more immediately than the others the true extent of the child's disability, she is the most perturbed when the child is withdrawn and refuses contact (Breslau, 1981; Cooke and Lawton, 1984; Fisman and Wolf, 1991; see also Bailey et al, 1992).

Siblings may share the parents' concern about the welfare of their disabled brothers and sisters (Craft et al, 1990). However, they have substantially less direct contact with the disability and the child (Abramovitch et al, 1987). Like fathers they may underplay or disavow the presence of the child's incapacity and consider that the child is faking or lazy (Lobato et al, 1991).

On the other hand, they are not exposed directly and intensively to the disability, the child or the concern of parents as first and second tiers of involvement and as the care providers (Dunn, 1988). Although Hewett (1970) found no harmful effects on siblings, evidence from other studies (McAndrew, 1976) indicated that brothers and sisters can be adversely affected by the presence of a child with a disability in the family.

Other children in a family that has a child with an impairment have been thought to be in danger emotionally because the disable family member is given all the love and attention (see, for example, Lobato et al, 1991).

Two models in the literature have attempted to explain the psychological value of social networks. One point of view is that social supports have a direct effect on adjustment (Eiser, 1990). The second point of view suggests that social support mediates the relationship between stress and adjustment, that is it serves as a buffer for the individual (Wallender et al, 1988). The latter model seems to be receiving most attention in research at this time (Erickson and Upsher, 1989; Gown et al, 1989; Harris and McHale, 1989). Social impairment results from the child perceiving the social environment as traumatic and uncontrollable (Cohen, 1989).

2.6.3.2 Support outside the family

Coping needs to include a community dimension aiming at appropriate integration of people with a disability into the socio-economic and cultural life of the community, for example, social support (Flynt and Wood, 1989) and for parental belief systems (Frey et al, 1989).

Terwogt et al (1990) have defined integration as the process of developing the participation of children and young people in their communities, an integral part of this process being their involvement in the social and educational life. However, Staples (1983a,b) argues that there

is disagreement about the contribution of support from outside the family and he thinks that when people speak of "community support", it is suggested that we should read "support by women". Cooke and Lawton (1984) describe the support from outside received by families with children with a disability as negligible.

2.7 Services (from the literature)

2.7.1 History of rehabilitation and community care

Community rehabilitation and care of disabled people are no recent invention, but rather a re-discovery and refinement of practices dating back at least 2,500 years (Miles, 1983).

At the borders of the Middle East, Hippocrates (5th Century B.C.) in what is present day Greece, seems to have been among the earliest to separate the rehabilitation of disability from notions of magic and evil. Mentally retarded persons are mentioned in the writings of Confucius (6th Century B.C.) and Zoroaster.

In the West, the town of Gheel in Belgium began in the 5th Century A.D. a remarkable tradition of community care for the mentally disordered, lasting up to the present time.

There was then the remarkable rise of Arab psychiatry after the inception of Islam (partially filling the one thousand year gap which tends to appear in Western histories of rehabilitation from about 200 A.D. onwards). The same period saw some debate on the civil rights of mentally retarded persons among the Muslim Jurists of the 8th and 9th centuries closely paralleling debate in the 1980s on the same subject.

Abbott and Sapsford (1988) recognise that disability is not a "thing" but to a large extent a "construction"; its nature varies from time to time and from place to place. They note that all

societies have some people who are less competent than others, but in most they are not specially picked out as a group in need. Mental disability is no longer feared as a social problem in the way that the nineteenth century faced it; the people with disability are no longer seen as a threat to society, but rather as just another problem group for whom social provision has to be made.

The Medieval system of handling deviants can be seen as one based on the community and the family. In the Middle Ages the Christian Church advocated charity towards those unable to care for themselves with love, understanding and respect as well as physical care. The period from the sixteenth to the eighteenth century made a gradual transition to a system based on institutions.

Although the charitable view has never died out within the church, another view began to surface in the sixteenth century. For instance, Calvin and Luther both denounced people with mental disability as possessed by Satan and without a soul, fit only for destruction. However, by the seventeenth century informed knowledge about people with mental disability was growing and the distinction between mental impairment and mental illness was becoming clear. By the end of the seventeenth century a change in social attitudes to marginal groups, including the mentally disabled was taking place; thus began the period of the 'Great Confinement' when idiots, criminals and the unemployed were seen as a threat to society and were locked away.

During the eighteenth century, Houses of Correction and Poor Law institutions were developed in England. In the United States the early settlers found no cause to provide special treatment for people with disabilities.

During the nineteenth century a radical shift in practice came about. First the severely affected and then the mildly impaired came to be seen as a distinct and serious 'problem class' which needed special control. By the turn of the century, biological theories relating to heredity and

evolution, both reflecting and magnifying a growing fear of mental disability as a social evil, came to play a dominant part in determining the ways in which society viewed disability and the methods of handling it. This occurred at the time of rapid urbanisation and social change. The latter part of the twentieth century has seen another transformation in views about rehabilitation, with emphasis on care in the community, primary prevention and avoiding secondary sequelae to impairment.

2.7.2 Current problems with the health services

2.7.2.1 Lack of services

Despite growing awareness of disability worldwide, in developing countries people with a disability have not received the priority they deserve. In a Jamaican study (Thorburn, 1991; Thorburn et al, 1992) it has been estimated that amongst children in Jamaica with impairments, 62% need special education, 30% need community based services, 21% need specialist referral and 6% require medical treatment. The vast majority of these needs are not met. In part this is because most developing countries are still struggling to provide basic health care and reduce mortality.

However, care facilities may also not be utilised. There are elaborate explanations about their inaccessibility to the child with impairments, often because of deep-rooted fear and beliefs, originating from old cultural and religious convictions (Chen, 1981). Culture has a strong influence on utilisation of services as Parry (1983) has pointed out.

One starting point for analysis of services is to begin with the concept of need. McConchie (1991), Davis and Rushton (1991) and Burden (1978) identified five distinct but overlapping groups of need: the need for information; support; advice; access to resources; and opportunity for social interaction. For example, between 66% and 70% of children with juvenile

rheumatoid arthritis may use remedies that are not part of generally accepted medical therapy (Wood et al, 1990).

2.7.2.2 Problems in health services for parents

Parents of children with impairments have become increasingly critical of many of the professionals involved in their lives. Indeed, they describe relationships as one of mistrust, frustration and alienation.

Bernheimer et al (1983), Fisman and Wolf 1991 and Dyson (1991), provide information about stress encountered by parents of children with a disability as they have sought services and information regarding diagnosis, treatment and prognosis, from care providers who have little or no experience of children with an impairment and limited knowledge of how community services contribute to parental stress.

2.7.2.3 Health workers do not understand the cultural background of families

Extensive research has been conducted to identify and measure the therapeutic variables that constitute an effective therapeutic relationship (e.g. Bostock, 1976). Care providers rarely have preparation or training in how to relate to parents (Mittler and McConachie, 1983). Several studies have demonstrated that care providers are unable to predict parental compliance. There has been little research into the extent of, and explanation for, non-compliance by parents of children with impairments (Cadman et al, 1984). Health workers need to gain better information on daily living.

Thus, many people with a disability have their needs met (or not) by professionals who very often do not provide the appropriate service in an acceptable fashion (Guralnick et al, 1987).

Medical coverage, custodial needs and care of the chronically ill are all issues as well as the quality of home care (Hall, 1992).

2.7.2.4 Focus on expensive rehabilitation and cure rather than prevention and health promotion

In the past there has been almost total focus on rehabilitation only rather than action on prevention and health promotion. It could be that the Kingdom of Saudi Arabia has been paying the most for the least effective intervention (Pringle, 1985).

2.7.3.1 Early intervention and prevention of secondary dysfunction

Early intervention for infants and toddlers with impairments and their families is increasingly recognised as an essential component of a modern society's rehabilitation services (Mitchell, 1987).

In the Honeyland project (Burden, 1978; Burden, 1980), parental stress and effects of intervention were evaluated. Results suggest that compared to a control group who received no intervention, mothers involved in this project showed less evidence of depression two years after the commencement of the project (Sloper et al, 1983).

Specific programmes have been identified to reduce secondary dysfunctioning. These comprise ongoing education and counselling for the child, family and community about chronic illness and its management, use of techniques to reduce stress, facilitation of social support mechanisms for fathers, and consideration of school performance (Perrin and MacLean, 1988).

In developed as well as developing countries the importance of early detection and subsequent intervention as a means to prevent or reduce developmental disabilities is increasingly

recognized. Implementation of that recognition in the form of comprehensive services, however, is likely to vary greatly from one country to another (Ar Rigada, 1990; Gonzalez, 1977). In a review of problems and strategies to reduce childhood disability in developing countries, Richmond et al (1983) pointed out that a given country, or a region within that country, will be at one of three epidemiological phases reflecting socio-economic conditions and health care availability. These are: (a) poor socio-economic conditions, lack of any organized health care system and significant health indicators of infant mortality and infectious disease; (b) public health provisions are established to some extent contributing to reduce fertility, infant mortality and infectious disease and its sequelae with the result of potential improvement in socio-economic conditions of the community; and (c) while applicable to relatively few countries, is characterized by an overall state of excellent health in the population with health resource utilization being largely a matter of personal choice.

In Saudi Arabia, economic development is proceeding irrespective of cultural change. This view is widely held, but there are no published studies of this phenomenon. As Serpell (1988) points out for Zambia, an approach to early detection (or indeed detection) which identifies impairments by functional characteristics is likely to be more successful and "culture fair" than impairment defined categorically.

2.7.3.2 Changes in the professional role

Communicating a diagnosis of impairment to parents, when the diagnosis and prognosis are unclear, is problematic. This is discussed in the light of information received from mothers of such children who attended a counselling and support group. It is concluded that dissatisfaction with diagnosis is not inevitable, if similar guidelines to those suggested for children with Down's Syndrome are used. It is essential that parents are involved in management and feel they have something practical to do to help their children. Clinics must

organize themselves to avoid swamping parents with information and to provide regular on-going support (Cottrell, 1990).

Numerous studies have reported on the way in which parents have been informed of their child's disability (e.g. Cunningham et al, 1984; Quine and Pahl, 1987). Cunningham and Sloper (1977) wrote that parents of children who have the Down's Syndrome want to be told as soon as possible after diagnosis. Telling a parent that their child has a major physical and mental impairment is often difficult and several studies report a high level of parental dissatisfaction (e.g. Tarron, 1981). However, providing such a service is much more difficult when the child has cerebral palsy because the diagnosis, though suspected, may be uncertain for many months (Ellenberg and Nelson, 1981), and it is often difficult to predict the eventual severity of the condition (Barabas and Taft, 1986), or the presence of other associated problems such as a mental impairment and epilepsy.

A high level of dissatisfaction was found among parents of children who had recognized perinatal problems but dissatisfaction was not found to be proportional to the severity of the child's impairment (McKay and Hensey, 1990).

Illingworth and Illingworth (1984) have argued that where there is suspicion about the child's motor development, it is unwise to inform the mother until the diagnosis is certain. Parents realize that there is no easy way to give such bad news (Ballard, 1978; Appleton, 1978), but Hewitt (1970) showed that parents are often the first to suspect that something is wrong and that much bitterness and anger are engendered when their worries are ignored. The period of uncertainty that is often inevitable before a definite diagnosis of cerebral palsy can be made is especially difficult for some families; their child is not a person but a 'question mark' (MacKeith, 1973). This particularly applies to children who have had recognized perinatal difficulties and are therefore considered 'at risk'.

Taylor (1982) points out that when such bad news is first given to parents, much of what is said will be denied and most of the information given will not initially be assimilated so that follow-up is essential. Ballard (1978) has pointed out "that it matters a lot to us parents to see that professionals are concerned and affected by the pain we experience".

3. THE KINGDOM OF SAUDI ARABIA

3.1 History

The Arabian Peninsula supported agricultural, herding and hunting cultures for thousands of years. Located on the ancient trade routes, the ancestors of the Saudi Arabians were in contact with many civilizations including those of Mesopotamia, Egypt, Greece, Rome, Byzantium, India, Persia and China.

The Qur'an (Koran) was revealed to the Prophet Muhammad in the western Arabian caravan city of Makkah (Mecca) beginning about 613 A.D. The birth of a new faith, Islam, was one of the most important events in history and affects every aspect of present day life in Saudi Arabia.

3.2 Law and Government

The Shari'a, the Islamic code of law based on the Qur'an, is the basis of the legal system of Saudi Arabia, the Qur'an itself is considered the constitution of the land and provides the country with ethical values and guidance.

Saudi Arabia is a monarchy. Executive and legislative authority are exercised by the King and the Council of Ministers within the framework of Islamic law. The Kingdom's ministries and all other government agencies are ultimately responsible to the King.

3.3 Geography

Saudi Arabia, with an area of about 870,000 square miles, occupies the largest part of the Arabian Peninsula. It is roughly one-third the size of the continental United States, and the same size as all of Western Europe.

3.4 Health

Health services in Saudi Arabia have made great progress in recent years resulting in improvement of the health standards of population, notably in the areas of immunization, endemic disease control and improved access of all population groups to health care facilities.

During the last twenty-year period (1970 to 1990) many health care projects came into operation. The number of hospitals in operation between 1970 - 1990 increased by 243%, and the number of hospital beds by 337%; during the same period, the number of primary health centres (Ministry of Health) increased from 519 to 1648, an increase of 217%. The number of hospital beds per population reached 3.35 beds/thousand and the physician/population ratio was 1.9 physicians/1000 population by 1990 (Figure 1).

PROGRESS OF HEALTH SERVICES

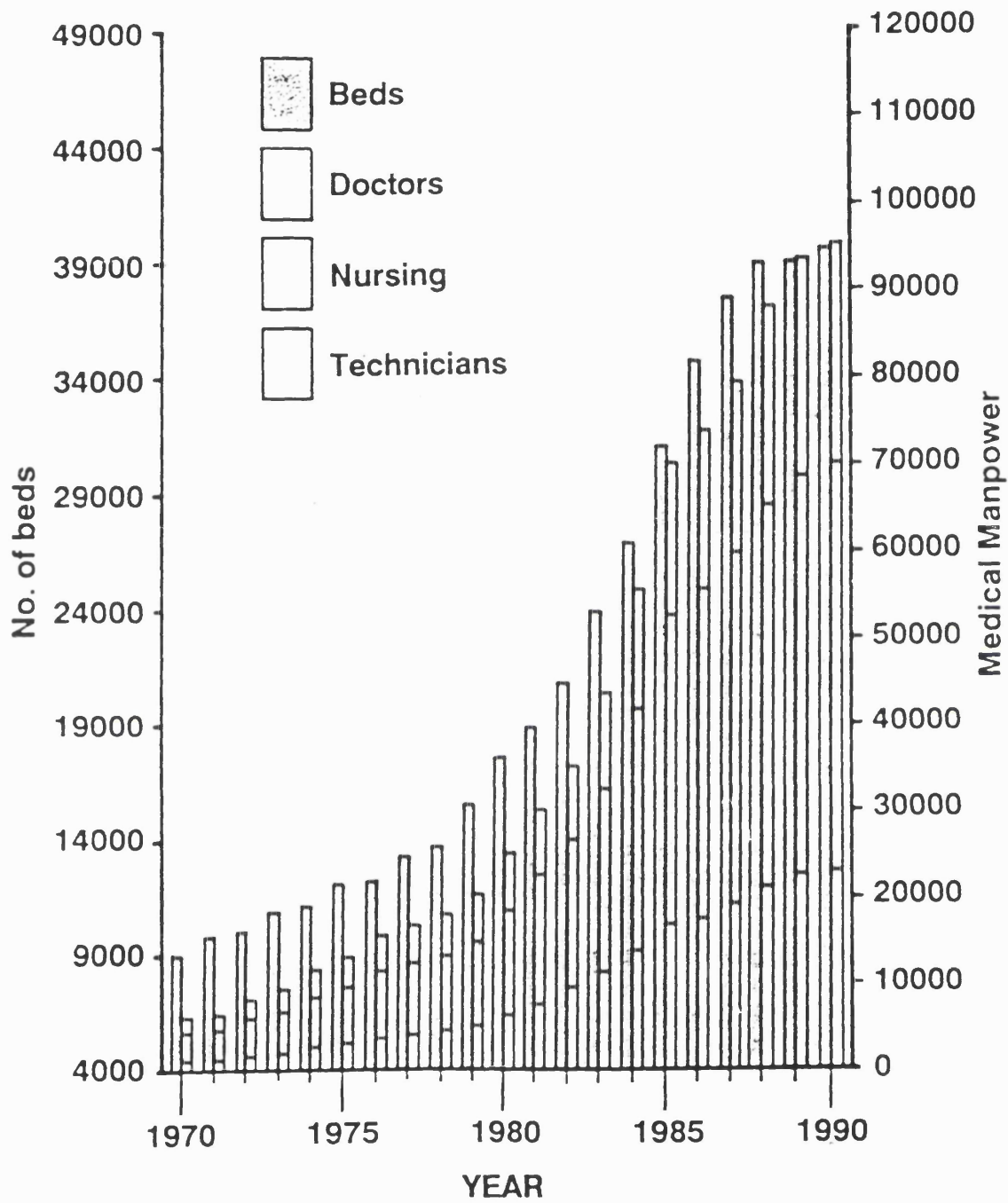


Figure 1

3.4.1 Prevalence of impairment (see also results section 5.2 and discussion section 6.2.2.2)

There are no accurate data for incidence or prevalence of impairment. There is a lack of rubella vaccination so congenital cases still occur, although in the Western Region of Saudi Arabia despite the lack of a rubella vaccination programme, a high percentage of women have been exposed to the "wild" virus through natural transmission before adolescence.

The information on which to base valid judgements of the medical needs of the Kingdom's population is presently patchy and out-of-date (Serenius, 1988). The ministries have a poorly developed system of documentation and information flow. Most of the available information rests in the files of the high-ranking officials.

It is not possible to make an accurate estimate of the number of blind people in the Middle East Region, because of lack of information and because each country defines blindness in relation to its own social and economic conditions. Therefore, the magnitude of the problem is not known in detail. The lack of specialised personnel who can conduct and analyse statistics is considered another problem.

In Saudi Arabia, as socio-economic conditions improved, trachoma and concurrent conjunctivitis have become progressively less severe. However, with the control of the avoidable blindness in the Kingdom over the coming few years, it is anticipated that glaucoma will become the leading cause of blindness. The fourth leading cause of blindness encountered in Saudi Arabia is injury.

Hospital data reveal that the majority of disabled children presenting for rehabilitation come from the South West Province of the Kingdom of Saudi Arabia. This is likely to give an erroneous impression of prevalence. There has been poor coverage of services south west of

the Kingdom until recently, so disabled children referred from that region tend to be institutionalised and appear in the register.

Generally lacking, however, has been a synthesis of elements of community based rehabilitation services matching the epidemiological pattern of impairment combined with health education on prevention and health promotion and bringing together a combined intersectoral initiative.

3.5 Education

Growth in student numbers is shown in Figure 2. During the period 1970 - 1990 the number of students in elementary and secondary schools more than doubled, while the number in higher institutions and universities increased over fourfold. In 1975, higher institution and university students made up 2.5% of the total student body, while by 1988 they made up 3.6% of the total student body.

3.5.1 The founding of special education in the Kingdom of Saudi Arabia

Special education in the Kingdom of Saudi Arabia began in 1378H (1958), through independent efforts by devoted people who educated a hundred blind students using braille in special evening classes in one of the schools in Riyadh. The Ministry of Education provided use of a Government building. During the day, these same students were enrolled in regular programmes in Government institutions.

Due to the success of this venture, two years after it began the Ministry of Education adopted special education, incorporated it into its programme, and opened its first Institute for the training of the blind. It was called "The Institute of Light for the Education and Training of the Blind in Riyadh". This Institute was the cornerstone laid by the Government for formal special education and was established in the year 1380H (1960).

Growth in Student Numbers

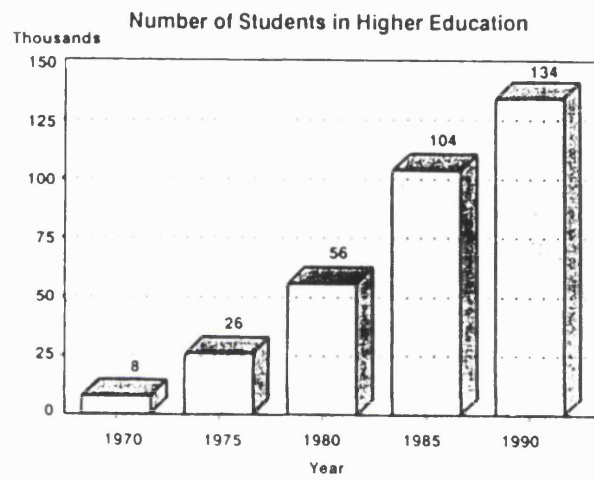
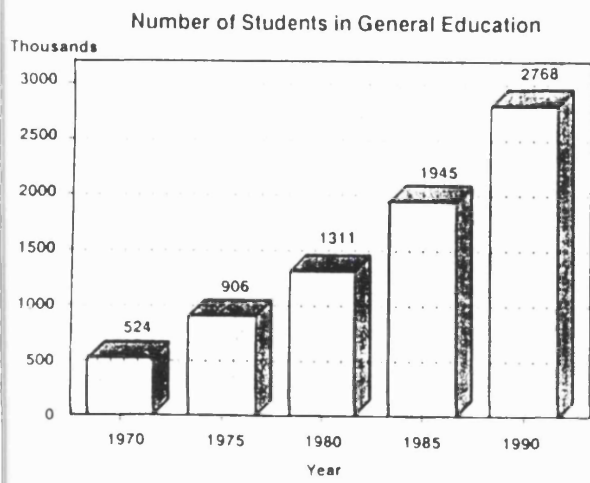


Figure 2

Since that time, education has incorporated special education. In the year 1964, the first two Institutes for the education of deaf children was opened, viz "The Institute of Hope for Boys and Girls in Riyadh". Both took day care and residential pupils. By that time there were already five institutes for the blind in this country. In the year 1971 the first institute for the training and care of mentally retarded boys and girls was opened in Riyadh. By this time the number of institutes for the blind and for the deaf children had reached eleven.

The Ministry of Education continued in its effort to open special institutes each year, according to the needs of the provinces of such forms of education, until the number of special institutes during the year 1980/81 reached the following: 10 institutes for the blind, for boys and girls at different levels; 11 institutes for the deaf and for the hard of hearing for boys and girls; 6 for the mentally retarded boys and girls, and special classes for the mentally retarded in the public school system (at Riyadh, Jeddah, Medina and Dammam).

In the year 1972 the Ministry of Education issued a Resolution to found the first administration of special education to encompass the responsibilities of planning special education programmes and supervising their progress.

In the year 1972 the administration was promoted to a General-Directorate, with specialised departments, and was named "The General-Directorate of Special Education Programme" (Hamdan, 1980; Hardy, 1983).

The distribution of students in special education institutions by region is shown in Figure 3, by stage of education in Figure 4 and by type of disability in Figure 5.

Distribution of male and female students of special education institutions according to geographical regions

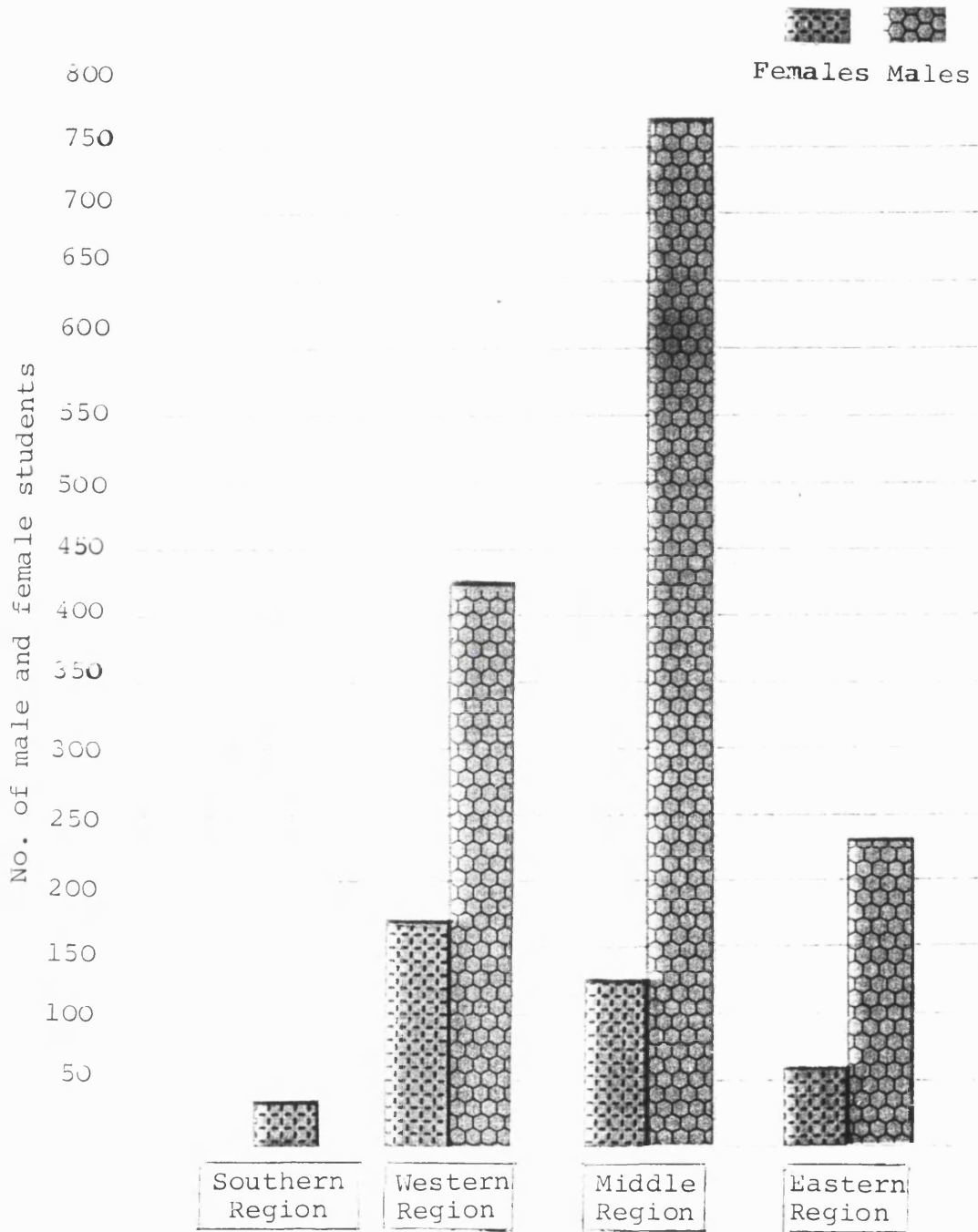


Figure 3

Distribution of male and female
 at different departments
 and stages of special education
 institutions

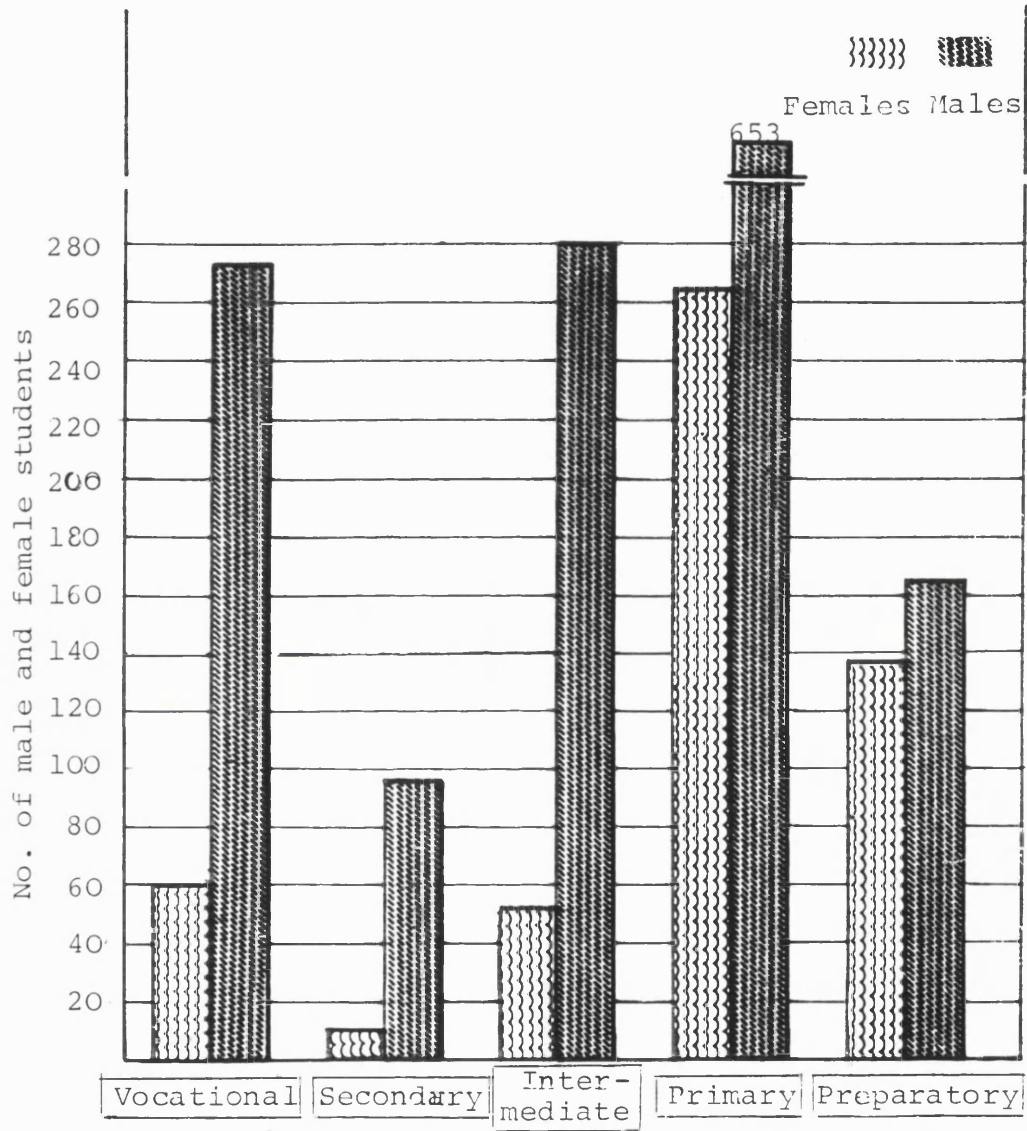


Figure 4

Distribution of handicapped groups
at the vocational and social
rehabilitation centres
in the Kingdom

severely handicapped

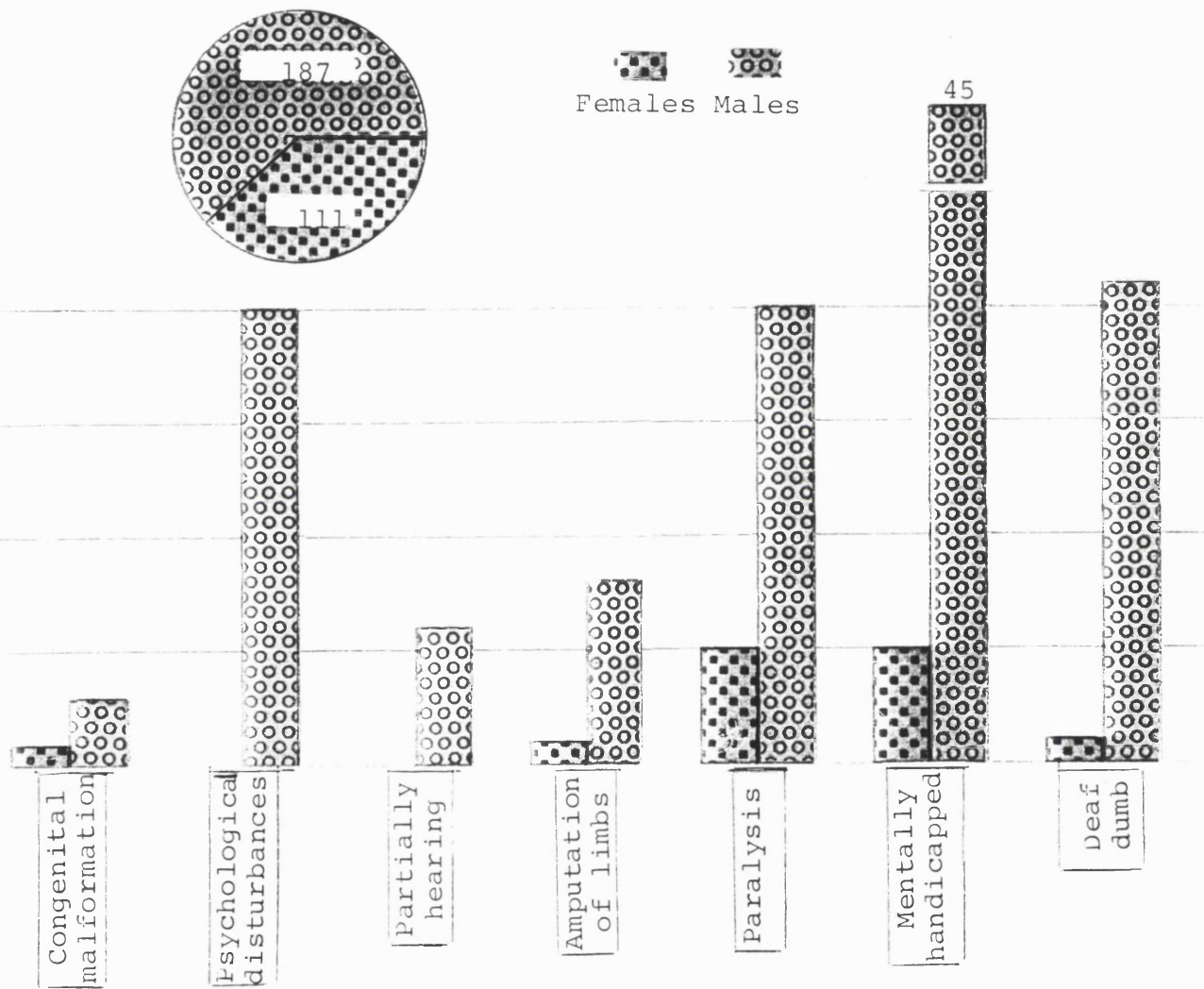


Figure 5

3.6 Social welfare

4. METHODS

The cumulative number of employees covered by social insurance increased from 145 thousand in 1393 to about 4 million in 1408, of which 90.2 percent were employed in the private sector.

The cumulative number of establishments covered by social insurance increased about thirteen-fold, rising from 1,062 in 1393 to 13,283 in 1408.

The provision of care for disabled children has reached a point in Saudi Arabia where care providers and planners require guidance, support and clarification of key issues. With the new idea of community based rehabilitation there is now the opportunity for a fresh look at the care of disabled children and their integration in the community.



KAMAH - Place of Study

4. METHODS

4.1 Why this Study?

4.1.1 The opportunity for a fresh look at care of disabled people for decision makers and managers in Saudi Arabia

The provision of care for disabled children has reached a point in Saudi Arabia where care providers and planners require guidance, support and clarification of key issues. With the new idea of community based rehabilitation there is now the opportunity for a fresh look at the care of disabled children and their integration in the community.

In Saudi Arabia the questions that need answering before an effective child disability intervention programme can be designed are the following:

- (i) What is the size of the problem; in terms of prevalence, type of impairment and severity?
- (ii) What are the specific cultural aspects of Saudi Arabian family life which affect adjustment to disability including:
 - recognition of an impairment;
 - reactions to the impairment in the family;
 - acceptance of the impairment and acceptance of the child, or the lack of acceptance;
 - coping strategies families develop;
 - use of services?
- (iii) What are the services for disability and what happens in practice?

- (iv) What is needed to close the gap between the guidelines for the provision of services on the one hand, and the needs of the parents coping with a disabled child?

- (v) What needs to be changed in the training of health workers and other professionals so that there is better understanding of the problems of disabled people face both in terms of the individuals impairment and its social consequences.

4.1.2 The need for a study of disability from the families' point of view

The study of strategies commonly employed by families will help identify the mechanisms of care currently operating in Saudi Arabia within its own special culture. No policies for the care of disabled children will work unless they are rooted in the experience and aspirations of Saudi families with such children. If the actions, problems and achievements of families with a child with a disability are not recognised then it is highly likely that the services provided empirically will be inappropriate.

By focusing on the identification of needs from the families' point of view, a more precise definition of needs can be obtained which can then be used to develop a practical framework for community based rehabilitation for disabled children. Only by first identifying families' current care and concerns can appropriate new services be evolved in the future. If rehabilitation services are not rooted in the informal network of caring in the community it may well be that the community will not participate in interventions which may be considered by the professionals to be best for the child.

In the past, care of children with impairments has suffered from professionally dominated and centrally administered strategies and service programmes. Professional carers who intervene often have not recognised what families are already accomplishing on their own and thus have failed to support them in the excellent work they have been doing already.

4.2 Methods available for the Study

4.2.1 Introduction

No single method can be employed to obtain every kind of information on disability (see Chamie, 1989). The challenge in this as in any other study, is to find methods for obtaining different categories of information (e.g. Wood, 1989) appropriate for Saudi Arabia (see Robertson 1988).

4.2.2 Limitations of previous studies of children with impairments

Some limitations of previous studies are summarised :

Previous studies of children with impairments have tended to focus on either the mentally or physically affected, or to be categorised by medical diagnosis (e.g. Mia et al, 1979; Cohen et al, 1986). There has been much concern with developing guidelines for censuses and surveys to gather numeric data on prevalence but there is a growing concern about the lack of action on this data (e.g. Chamie, 1989). In the current study a holistic approach to disability is taken. The focus is on families who have a child with an impairment and how they manage; and not simply on any specific type of impairment (see Schmid 1981).

Some studies of the family who have a child with an impairment have assumed and then over-emphasised serious disruption of internal family relationships and the relationships with the outside world (see Literature Review section 2.6.2.1, see also Discussion section 6.5.2.1). The current study takes as its starting point that in most families there will be coping strategies which will have had a positive effect on the family and enabled them to manage having a person with an impairment within them. One of the aims of the current study is to identify those positive coping strategies that families have developed, to enable professionals to

recognise them and to share with other families how progress can be made using the existing strengths of the families.

Where there is a disabled child in the family, effects on other siblings have been studied either by observing or interviewing the siblings. In this study it was not feasible to interview siblings. Parents were simply asked about the relationship. The limitations of this are recognised.

This study differs from many others in that where possible it is based on joint interviews with both parents. This is important because very often the two parents do have rather different views of what is happening with the child. In Saudi Arabia, it is important to address questions on family matters to the father. He is the one who is assumed to hold the responsibility for the family and should know about all family matters including everything to do with a child with an impairment. In practice, his wife, who takes care of the child, will know many details the father does not know, but it is still necessary to direct questions as if he knows all the answers. He will make reference to his wife as needed. Since he is not with the child for large parts of the day, it is very important that the interviewer asks the father questions in such a way that the mother's knowledge and opinions are elicited. The questions need to be attuned to each family to obtain the details and depth of the mother's contribution (see Keilhofner 1982). The way in which the mother was increasingly allowed to contribute directly to the discussion is described in the interview section 4.8. This was done by the husband actively encouraging his wife to tell the author about what had happened.

4.3 Advantages and disadvantages of different methods of obtaining the information needed

In developed countries disabled persons are identified from computerised data available from service records and registries containing information on all causes of a specific kind of disorder, or from organised studies that follow a birth cohort of several thousand children. In most

developing countries these sources of data are not readily available or valid (Nelson and Ellenburg, 1986).

In developing countries, any method of case identification must be at once inexpensive, simple, rapid (because of the large numbers of children to be screened or evaluated), and accurate. It is the requirement of accuracy that is most difficult to satisfy (see Bell et al, 1981).

Two low-cost methods have been found to be unsatisfactory because they miss too many children. One of these is the National Census Interview. This method tends to under-enumerate people with disabilities that are not highly visible (such as hearing loss and mental retardation) and also disabilities in women and children (Chamie, 1989). The other method is to ask a key informant in the community (e.g. community healers, teachers, midwives) to identify all disabled persons in the community. This method, studied in several countries, has been found to be inaccurate (Thorburn et al, 1992). A third approach involves door-to-door household surveys for screening children for disabilities and a follow-up evaluation of selected children. A pilot study took place in 10 communities in 9 developing countries. Two screening questionnaires, the Ten Questions (TQ) and the Childhood Disability Questionnaire (CDQ) were developed for identifying five types of impairments, i.e. motor disabilities, vision, hearing, mental retardation and seizures. House to house survey was conducted on 1000 children whose ages ranged from 3-9 years. The screening was followed by professional assessment by physicians and psychologists of those children found to be positive on the screen plus a random sample of negatives. The diagnosis served as the criterion against which the questionnaires were validated. It was found that the TQ was sensitive (100%) for detecting severe mental retardation in most study sites. The specificity of the screen was found to be less satisfactory. The CDQ which was a longer questionnaire, did not do as well.

The Rapid Epidemiological Assessment of Childhood Disability (REA) was a follow-up. The study made several advances. Children as young as 2 were included, and medical and

psychological assessment procedures were more thoroughly structured to enable better cross country comparison. Potential risk factor information was also collected. This study has been conducted in Bangladesh, Jamaica and Pakistan. The results are just being published (e.g. Zaman et al, 1990). Clearly, resources were not available for this type of identification. Surveys of all kinds are difficult to carry out in Saudi Arabia. There are many religious and cultural practices governing individual behaviour especially between the sexes, and there are also regulations associated with maintaining state security. Some of the difficulties in designing appropriate surveys for the Saudi Arabian situation are described in Section 4.4 below.

Closed questionnaires can be quick to administer and easy to analyse (e.g. screening for disability in census and survey modules, Chamie, 1989). However, the value of closed questionnaires often contained in so-called knowledge, attitude and practice studies (KAP) needs to be seriously questioned. Much of the information sought is often too sensitive to be accurately obtained in a tightly structured standardised method. Getting answers which can be reproduced in tables is meaningless if the statistics obtained are unreliable and do not reflect the real situation. This method was not suitable for the study of parents' reactions in the sensitive cultural situation of Saudi Arabia.

A postal questionnaire is not a useful method in Saudi Arabia. It is not a usual channel of communication in Saudi Arabia. If a questionnaire plopped on the floor through a letter box, people would be suspicious. Very few would answer, and those that did would merely write superficial replies.

Semi-structured interview method places a heavy dependence upon the researcher as the main instrument for sensitive observation, participant experience and the use of a process of constant clarification and validation of data with the people in the study (see Sandow, 1979).

The method leans on observation as well as exchanging words. Many new phenomena may be observed as insight is gained by talking with people and seeing their reactions as well as hearing what they say. People often hesitate to express their opinions in a direct way (see Leininger, 1985). A structured interview may fail to obtain an authentic answer in such a situation. A semi-structured interview may allow the interviewer flexibility, so that hesitations may be observed and taken into account in the subject's reply. Haile (1986) points to the value of participatory research in which the "social distance" between the researchers and the subjects is reduced, so that there is a process of reciprocity in which the most valuable information is obtained. This is of particular value in participatory research. Nichter (1984) has also explored the value of participatory research and Ware (1984) presents participatory research "rooted in the local culture". Adieniye et al (1984) similarly pointed to the need for culturally appropriate research sensitive to local values and priorities. One disadvantage can be difficulty in ensuring that the same aspects of subjects are covered in different interviews. A good check-list of topics can help to avoid this.

This study used informal observation and semi-structured interviews to obtain the information from key informants. In this study nurses, teachers and grandparents were seen as key informants. During the surveillance sessions the staff were interviewed informally. At every opportunity family members were asked about customary ways of:

- (i) coming to recognise a problem;
- (ii) reacting to impairment;
- (iii) facing the phases of acceptance;
- (iv) coping with everyday life;
- (v) using services both traditional and modern.

In-depth qualitative methods include in-depth interviews, participant observation, the interviewing of "key informants" and case studies as well as participatory action research. Their advantage is that they can be sensitive instruments to elicit information. One of the main

concerns in dealing with qualitative research is to what extent the information obtained from a relatively small sample is relevant to a larger population group.

The researcher lived in the study community for nine months before beginning the study. As a result of a number of invitations to peoples' homes, and enquiry by my own family about what they saw in the females' and childrens' areas, it was possible to obtain a good informal view of the living standards of the people.

Campbell and Stonel (1979) suggest that more reliable information can be obtained by methods which are sensitive to language and use concepts which are easily understood by the population in question. Even open-ended questionnaires and other qualitative methods may not necessarily succeed in obtaining information which reflects reality. This may be either because the respondents themselves do not know the reasons why they do or do not do certain things or because they are reluctant to reveal the real reasons to a relative stranger. This may be because of embarrassment and perceived differences in status between investigator and respondent or for a whole range of other reasons. Qualitative methods rely heavily on the ability of the investigator to establish rapport.

The unstructured interview allows the interviewer flexibility in establishing a relationship of trust with the respondent so that ways of enlisting authentic replies can be explored. He/she needs to make pertinent observations and to follow up on needs which may come up in discussion while using a specific instrument for example, a check list. This method was the basis of the interviews with families but was developed specifically for the Saudi Arabian culture as described below.

Focus Group Discussion can be a useful adjunct to research on children with a disability but group methods were not appropriate for this study. One problem is the requirement for open communication, which is difficult in Saudi Arabian traditional communities because of the

gender segregation. Focus groups would have required separate gender groups but it was important that both parents were to be present at the interviews.

Often incomplete records can be a useful but limited source of information. Use of routine data is limited by how robust the information is that is routinely collected. However, school records can be more reliable and in this study were used to identify children who had learning difficulties as judged by the recorded results of school performance.

Much research currently taking place is termed action research. One objective of this type of research is to look for opportunities for social change. The aim of the research is to facilitate the gaining of knowledge by individuals in the community, when knowledge is part of an empowerment for action (Al-Lamki and Ohlin 1992; Dossa 1992). In the current study this was not a crucial component or a major objective. Nonetheless some families were certainly strengthened by realising that with information gleaned in discussion during the interview, they were in a stronger position to request help needed for their child.

4.4 Methods needed for Community Health Enquiry in Saudi Arabia

There have been only two studies of disability in Saudi Arabia. One is on the pattern of impairments (frequency of types) encountered in institutions, the other is on pattern of provision (the number) of special schools and other services. Both studies were very formal and provide little insight into the everyday life of disabled adults or children. There is no study of families.

There has been only one community health study set up in Saudi Arabia. It is a longitudinal study currently being followed through. It started in 1970 (see Sebai, 1981).

Any unknown enquirer who visits someone's home is normally turned away. "Good" people do not arrive uninvited. "Good" people are always already known to the head of the household.

A visitor normally comes as a special guest. Visitors have special food, a special chair (or mat) and are only seen by the most important members of the household. They sit in the "best area", and never go into the area where the cooking is done, or where the family sleeps or where the children play. Conversation takes place with the father, the head of the household, away from all other members of the household. House to house surveys and enquiries are totally unknown and unacceptable.

There are difficulties involved in conducting community based work in Saudi Arabia. There is a need to find appropriate methods for working effectively with the acceptance of health workers and local people. This study has shown there are six essential components for conducting a community survey. These are listed below and are described:

- 1) Gaining the confidence of the community where the community survey is to be done, explaining what is being done and using the normal communication channels for reaching families, in this case those who have a child with a disability.
- 2) Being seen to be an acceptable person in Saudi society.
- 3) Using the normal culturally appropriate ways of relating and talking to people including talking to the family through the father.
- 4) Recognising that sensitive issues are better discussed by people of similar background of the same sex and respecting the cultural and religious views concerning interview and physical examination of girls.
- 5) Aiming that by the end of the study not one family should complain! This is particularly important in the early stages of community based research, as the reputation of health studies in the community will depend on the way in which the early studies are conducted. Where the community is learning to accept community based research, it becomes particularly important that nobody feels ruffled by the experience.
- 6) Realising that seeing people at a "recognised place" (clinic), may be more acceptable than an unknown visitor coming to the home.

In the current study all these six procedures were used as described below. The major part of the study is based on families seen separately in a clinic setting and interviewed in depth using a semi-structured approach.

4.5 Selection of Survey Site and culturally specific procedures; a limited geographical area and a closed community; description of KAMAH (The King Abdulaziz Military Academy Hospital)

In order to obtain some assessment of prevalence of disability, it was decided to identify a closed community with little movement of people in and out, and which is representative of the Saudi Society. The advantage of finding a closed community was that prevalence rates may be more accurate since all family health records and families can be found locally. In addition, cooperation could be enhanced through agreement with the military commander. The site selected is described below.

The hospital is located 50 to 60 miles West of Riyadh. It is a closed community of Saudi People and although a military complex it is representative of all social classes of Saudi Society. The staff working in KAMA comprise over a thousand families with a variety of educational and occupational backgrounds. By virtue of its location KAMA represents both urban and rural families, the latter coming from 5 villages in its surrounds (Saudi, Al Auyaynah, Salboukh, Al Julesulah and Haka). In KAMA the standards of education vary from highly qualified academic teaching staff to ordinary soldiers and their families with six to nine years' schooling.

As all the buildings in the study area are standard well-equipped homes built by the government there is a certain similarity in people's homes.

As a study site the Non Commissioned Officers' (NCO) clinic was unsuitable because it represented only one lower social group and was located in a rural area. The officers' clinic represented only an upper class society. The military factory was also ruled out because the

labour force lived dispersed throughout the city of Riyadh and there were no means of tracing them. Their families had access to medical facilities all over Riyadh and thus family records were spread all over the city making tracing of information difficult. Although detailed comparison with the general population is not possible since country-wide demographic data do not exist, KAMA is reasonably representative of the population overall. This is because:

- both military and civilian families live in the area;
- although the area belongs to the Ministry of Defence the area is not strictly military, except for the cadets who live separately unaccompanied by their families;
- the Ministry of Defence staff and the population are all Saudi nationals and come from all the geographical areas of Saudi Arabia;
- all social classes are represented, whereas in other strictly military areas there is a hierarchical military division and only one group (e.g. officers) may be found;
- since the site is 50 miles from Riyadh, people living in the area would find it difficult to use other health facilities;
- although it is true that many of the families resident in KAMA are nuclear families, this is now more the normal pattern in Saudi Arabia. Many extended families are being broken up in this way because of the manner of the country's development, the quest for employment and the vast area of the country;
- some grandparents live with their families;
- schools are available from preschool to secondary school and thus educational facilities are available in the area for all age groups;
- the population is entirely Saudi Arabian nationals;
- demographic data is available and reliable from this area but not obtainable for the rest of Saudi Arabia.

The entire population of the area is accessible and traceable as all military and civilian personnel must register for accommodation. Hence all children could be identified. The houses are

numbered and the streets classified according to social and economic status. Medical records for all personnel and their dependents are maintained in KAMA.

The co-operation of the Academy commander, his chief of staff, community leaders and the school heads was sought and received with enthusiasm.

A total of 1120 families reside in KAMA amounting to a population of 8241 (see Table 4.1). Of these 33% (2696) are children up to 15 years of age, and 16% (1304) are women in the age group 15 to 45 years. There are 14% (1121) women in the age group 34 years and below against 38% (3120) males in the same age group. The high ratio of males is due to the cadets in the Academy who are not accompanied by their families. They were all excluded from the study because they live isolated from the KAMA community in separate barracks whereas all other residents live with their families.

<p align="center">Table 4.1 KAMA community profile (from security registration data) Total population: 8241</p>				
Children aged 0-15	Females aged 16-45	Women aged 34 and below	Males in the same age group	Total
2696 (33%)	304 (16%)	1121 (14%)	3120 (38%)	8241
1152 (0-5); 1544 (6-15)				

Every study has to seek formal permission and in Saudi Arabia as everywhere this must be done in a culturally appropriate way - in this case from the director of the Military Hospital in Riyadh. A letter was written stating that the author was examining growth and development in children. It was explained that new research is identifying how growth and development can be monitored to recognise any delay or disability early and to treat it effectively so that families can be helped early.

The author then visited the authorities for unofficial and informal talks, and allowed himself to be questioned as to the why and how of the proposed study.

Once permission was granted, the author moved to KAMA where he lived for nine months from mid-June 1986 to March 1987 in the community working at the hospital in the paediatric department and the child welfare clinic.

The first step was to create awareness of the study (i) among the personnel of the hospital, (ii) among the community leaders and (iii) in the community itself.

By living in the community, the author found it possible to identify organisations used by families with disabled children. He was also able to develop a working relationship with these organisations which helped provide initial contact and referrals, and also helped provide a picture of the range of disability and the number of children with a disability in the community.

Prior to commencing the study the author set about creating awareness among the population. Contacts were established with community leaders with the encouragement of the administration, by means of official letters and through personal contacts.

Living in the community with one's family was essential. Being seen to go to the mosque, to the market and around was important, and having a daughter the same age as those to be

examined was invaluable. In order to obtain the trust of parents the author and his family resided in the study area for nine months, prior to the commencement of the study.

For this study, representations were made to the community leader so that he could use existing communication channels to inform the families. Contact was thus made with families through their usual channels. In this case it meant that the community leader wrote a letter to all families saying that this study was taking place.

At the same time the administrator of the hospital which provides medical care for all the families living in the community also wrote a letter explaining what the study was about. The same channels of communication were used to invite families to attend an assessment clinic.

If a family did not attend the clinic as requested then again the cultural norm was followed and the heads of the households concerned were met in their places of work. It was essential to invite people to come to the clinic since coming to a clinic is more usual in Saudi society than having a doctor visit the home (see below).

The cultural and religious attitudes of Saudi society concerning interview and physical examination of girls by a male needed to be taken into account. According to the teachings of Islam a girl who has reached puberty must not be seen, communicated with, or be touched by a male who is not an immediate member of the family. However, they can be seen for medical reasons in a hospital. Hence special arrangements were made for school-girls to attend the hospital escorted by their teachers and female nurses.

In Saudi Arabia doctors can discuss matters which are sensitive in normal circumstances. At a clinic the author was able to talk to any member of the family as a doctor, not as a male member of society with the constraints it entails. However, care had to be exercised throughout.

The author was concerned to obtain from parents as frank and as complete a picture as possible of their child's disability, their attitude and the care provided and their recognition and behaviour towards the children. The most satisfactory means of achieving this seemed to be face to face interview but it could not be in parents' homes.

If the author visited families at home he would be treated as a male guest and visitor. He would be received by the male head of the household but would have no opportunity to speak to the female head of the household, and it would have been an insult to the husband to ask to see and speak to the wife. To overcome this, the procedure of interviewing a family at the clinic was adopted. In Saudi Arabia, in accordance with tradition the wife is not allowed to drive. However, also in line with tradition, the father cannot take his children to the hospital without their mother. So an appointment at the hospital guarantees the attendance of the whole family, with little chance of absence of any of the adult family members.

The hospital chosen has a link with the main military hospital in Riyadh, thus assisting with any referral needed. The spacious size and convenient layout of the hospital was also a factor in selecting it. The clinic was an ideal setting for these interviews. It has a large waiting area necessary for registration of each child, several screening rooms, a dental area and an audiology room. The waiting area is well designed with air conditioned separate areas for men and women and allows plenty of space for children to play without disturbing others. It was possible to organise each session to run smoothly, by planning the use of this space, by careful organisation, and the cooperation of everyone concerned.

When families came bringing their child with a disability to the clinic, the usual cultural practice of interchange of information was followed. Initially, the husband spoke on behalf of the wife and child for all or most of the consultation. The child was examined only when essential, and with respect of family sensitivity.

As in all studies it is essential that families participating in the study should have the opportunity not to collaborate. The basic ethical requirement is that the family should understand what the study is about, and that there should be no pressure to participate. In addition observing local customs concerning confidentiality of patient treatment records, morbidity statistics and census information was most important.

4.6 Identification of the children with impairments

Three sources of data were used to identify the children:

- (i) Letters to all households in the KAMA Camp (Section 4.6.1);
- (ii) Screening of all school children (Section 4.6.2);
- (iii) Screening of all under-fives in the Child Welfare Clinics (Section 4.6.3)

4.6.1 Letters to all households in the KAMA Camp

The household population was obtained from a complete list of all the families in KAMA. This list is maintained by the housing department at KAMA and is based on the register of all the heads of the households and their dependents. The next step was to select the required population (0-15 years old) from this list.

4.6.1.1 Recruitment into the Study

Distribution of initial letter to households

The plan was to examine every child under 15 in the chosen community of 1120 families. However, it would not be acceptable to begin a total population screening without first showing commitment to helping the families who want support. Therefore, the procedure entailed the

distribution of a letter from the hospital through the academy commander to all the families, asking parents to contact the author if any of their children had problems relating to vision, hearing, movement, behavioural or learning problems or any problems related to growth and development.

He advised them to cooperate with the screening programme of growth and development being set up by the study.

Many hundreds of families telephoned or called in to obtain further information about the study. This is the normal procedure when people hear that there is a good traditional healer in the vicinity or a good new doctor.

4.6.1.2 Follow-up of the non-respondents to the household letter

The following steps were taken by the author to enhance the response rate:

- if there was no response, the parents were telephoned or visited;
- The reasons for non-response were discussed.

It was found that 78 children (49 boys and 29 girls) were registered in the community but now lived away with their extended family. In this community many young people leave at the age of 13 upwards, the girls frequently for marriage, the boys to return to their grandparents, particularly if they do not wish to stay at school. Some boys had gone elsewhere to find employment. It is recognised that these non-respondents may have led to under-reporting of prevalence rates.

4.6.1.3 Overall response rate from household survey

Table 4.2 Response rate in household survey

Number of households contacted	1120
Number of children in households	2696
Children excluded (now outside area)	78
Dropped out of school but living in KAMA and parents report all right, refused testing at school (see below)	186
Number who came for screening at school or welfare clinic (see below)	2432
Response rate	$2432/2696 = 90\%$

4.6.2 School Screening

4.6.2.1 Overall response rate in school sample

From the registration data, 1544 6-15 year olds were known to be present in the KAMA population. 1280 of these were seen in the schools. A further 264 were no longer at school (a response rate of 83%).

4.6.2.2 Procedure for school screening

In order to determine the level of needs for child health screening and to identify disabled children in school, all local schools were recruited in the study. Five types of screening were performed: hearing; vision; general physical examination; school records and teachers' reports

of difficulties with learning or poor academic progress. All the children were brought to the hospital by bus, all the girls accompanied by their teachers. The teachers were very helpful in providing clues regarding slow learners. A questionnaire was designed for completion by class teachers in the school, for all children attending normal primary schools in KAMA when they were aged five to 15 years. Information about slow learners was confirmed from results of school tests given to the students over the academic year. Following screening and identification of children with learning difficulties, the intention had been to refer these children for psychological testing. However, all parents refused "IQ" testing except for 2 who are included in the special group.

4.6.2.3 Checking completeness of the school screening population

A check was made with census data to ensure that children not attending school (e.g. mentally retarded) were not missed. A confirmatory check was made with all school children by asking about information on any disabled brothers or sisters.

4.6.2.4 Non-respondents from school sample

The non-respondents from the school sample were found to be those who were no longer in school. There were 264 non-respondents comprising 144 boys and 120 girls aged 13 upwards. The reasons for their leaving school was as follows:

1. 78 (49 boys and 29 girls) were registered in the community and visited frequently but lived with their extended families. The children were not visited but their fathers were seen and none expressed concern about their children's growth or development. Although it is common for children to be brought up by members of their extended families, particularly their grandparents it is possible that a reason for sending the child away from the community with its emphasis on formal education, could be that the

child had an impairment which could be stigmatising in KAMA, but would not be in the rural area. Thus it is possible that the numbers for prevalence of both severe and less severe impairments are underestimates. Some of the girls had been married at 13 or 14 years old and others were engaged. Some boys had left to find work elsewhere.

2. 186 (95 boys and 91 girls aged 13 upwards) had dropped out of school. They were otherwise reported by their families as having no problems and screening was refused. Parents did not perceive problems. Many people in Saudi Arabia have little education so slow academic learning is no disadvantage, but it is possible that this might have been a reason for drop out.

4.6.3 Welfare Clinic screening of children under 5

4.6.3.1 Numbers screened at the child welfare clinic

1100 were screened personally by the author at the child welfare clinic by special arrangement to see a few each day from the daily clinic held at the hospital. The screening included a full physical examination and a developmental screening examination. In addition 52 under five children were seen from Nursery school. Altogether 1152 under fives were screened which is the total population registered in KAMA (see Table 4.3). This was a response rate of 100% for under fives.

Table 4.3 Screening population response rates				
	Children 0-5	Children 6-15		Total 6-15
		M	F	
Screened at nursery school	52	680	600	1280
Screened at Welfare Clinic	1100	-	-	-
Dropped out of school	-	95	91	186
Registered but lived outside city	-	49	29	78
Total population in KAMA	1152	1544		1544
Response rate	100%	1280/1544		83%

4.6.3.2 Procedure at welfare clinics

Nearly all the children attended the child welfare clinics. Children considered to have developmental problems by their families, health care workers, doctors and others, were referred to the author at the clinic. Children with hearing and vision problems were referred to specialised clinics for evaluation. Hearing and vision screening procedures are described below. Of the special group with severe impairment found through the welfare clinic, more than half had already received some treatment.

4.6.4 Orientation of nurses involved in screening and screening procedures

Three training workshops were conducted by the author for training a study team of 10 nurses who were trained in screening procedures, especially audiology and vision testing. They also facilitated girls' attendance and examination at the clinic.

4.6.4.1 Screening procedures and schedules

A standard screening schedule was used. Each item in the four main areas of development (gross motor; vision, fine motor and adaptive; comprehension and communication; social and self-help skills) as well as some aspects of behaviour, a physical examination and some indicators of neurological dysfunction comprised the screening procedure. In order to minimise the numbers of unnecessary referrals, the test times selected for the first three screening examinations used were those appropriate for infants younger than the ages of screening. For example, tests applied at eight weeks were appropriate for six-week-old infants, those applied at 20 weeks were appropriate for 16-week-old infants, and those applied at 39 weeks appropriate for infants of 32 to 36 weeks. At two years, a more detailed assessment of development was carried out with items appropriate for age.

Three different schedules were designed for the screening at the child welfare clinic of 20 weeks or older infants. These covered the age ranges (a) 16 to 44 weeks, (b) 48 weeks to two years, and (c) two and a half to 4 years. A neuro-developmental component was added to the school medical examination and used for all children entering into the programme.

Further assessment of suspect or impaired children

Clinics for more detailed assessment of infants and children with neuro-developmental delay or defects were held at KAMA Hospital. The author was free to request referral to other specialities on the basis of screening results.

4.6.4.2 Audiology Tests

For babies up to six months of age, a history was taken and mothers were asked about the infant's response to sound. Their responses during neurological examination were also observed (startle reflex to loud noise, eye blink response).

In the screening the following tests were used for testing hearing:

- (1) **Startle reflex: for infants up to 3 months of age.**
The infant suddenly jerks up when exposed to loud sound.
- (2) **Eye blink response for infant up to 4-6 months.**
The infant blinks when exposed to loud sound.
- (3) **Calibrated noise makers for children aged between 7 - 36 months. Hearing was tested by visual response to audiometry and play audiometry using calibrated noise makers.**

From 36 months onwards full audiograms were done.

The Audiogram Screening

The test was operated by a basic level health worker who had training in audiometry, using an audiometer. The screening time was 3 - 10 minutes per child. The time taken for examination of test and conditioning of response was considerable. (Sound frequencies used for screening were 30 db; 50 db; 80 db.)

Hearing loss was classified as follows:

- (i) **With a hearing loss of 30-40 decibels (db), the child was diagnosed as mildly affected. Children with this degree of hearing impairment have difficulties hearing from a distance of 20 feet. They are able to cope in ordinary school, but many require a hearing aid.**

- (ii) With a hearing loss of 41 - 55 decibels, the child was moderately affected, and will have difficulty in hearing a conversational voice within a distance of 20 feet.
- (iii) With a hearing loss of 56 - 70 decibels, the child was moderately to severely affected and will not hear a conversational voice until loud and spoken from a distance of 2 feet.
- (iv) With a hearing loss of 71-90 decibels, the child was severely affected and can hear a loud voice only close to the ear.
- (v) With hearing loss above 90 decibels, the child was profoundly deaf and may hear only certain very loud sounds.

4.6.4.3 Vision Testing

For under five children parental history of any visual problem in the child was noted, and children tested for following of a moving finger.

(i) **Testing visual acuity (over 5s):**

The 'E' test was used as follows. A line was drawn 6 metres from the chart. The child to be tested stood behind the line, holding the cut-out "E". The health assistant pointed at the different "E"s, starting at the 6/60 letters, proceeding to the 6/6 line. The child tested was asked to hold the cut-out "E" so that its "legs" point the same way as the "E" on the chart. Each eye was tested separately, the nurse ensuring that there was full occlusion of the eye not being checked. All children who had 6/9 vision or poorer in either or both eyes were referred to the ophthalmologist.

(ii) **The diagnosis of squint (all ages):**

This was made by using the cover test. Children who failed the cover test were also referred to the ophthalmologist.

4.6.4.4 Severity of individual impairment

In response to the letter from the head of the community to all households 400 parents made contact. From these 400 children, 31 were identified who had impairments which the parents and the author considered severe. In all cases the diagnosis had already been made and the children had received medical attention and in some this was continuing. In others the parents had not kept appointments and the doctors had not followed them up. This group formed the basic group for detailed study.

Severity ratings as described in other studies (for example, Hirst and Cooke, 1988) were not suitable for this study so the following criteria were employed.

Three children with hearing impairment were considered to be in the severe group, both by their parents because of the lack of response in conversation and because their measured hearing loss was more than 70 decibels.

Epilepsy was considered a severe impairment because the parents perceived it as such and the condition carries a serious stigma. The diagnosis was confirmed by the neuro-paediatrician. The number of fits was not a criteria of measuring severity because of the stigma, and not because of the severity of the medical condition. Six children were identified as having epilepsy. During the evaluation, the physicians took considerable time in elucidating that care was taken to make sure the history indeed coincided with epilepsy, as opposed to benign disorders such as febrile convulsions, or breath-holding attacks.

One child with the speech problem was considered as having a severe impairment because defective speech is considered a very serious problem in Arab society. Speech is a sign of manhood. People think that marked defective speech at 8 years of age indicates the likelihood

of continued backwardness, not only in the development of acceptable verbal communication and social maturity, but also in scholastic attainment.

The severity of the impairment was obvious in a number of children, and a neurological examination was not needed for confirmation. This applied to 3 children with cerebral palsy; 3 with poliomyelitis; 1 child with hemiplegia, and 1 with tetraplegia; another with osteogenesis imperfecta, another juvenile rheumatoid arthritis and one of the 3 children with Down's syndrome, who was profoundly hypotonic (floppy). In all these children there were particularly obvious problems with movement. Four had to be carried (the two children with cerebral palsy, the child with Down's syndrome and the one with juvenile rheumatoid arthritis), another child was wheelchair-bound (tetraplegic), one could only crawl although no longer a baby (osteogenesis imperfecta); and the other four walked with conspicuous limps (poliomyelitis 3, hemiplegia 1). One child (with mild cerebral palsy) was clumsy in all her movements.

Ten children with developmental delay were included in the group with severe impairments. These children were not categorised through I.Q. or developmental testing, since parents always rejected these tests, as explained. The children were identified mainly because of their observed slow responses. They had difficulty in communication, and their concentration span was short.

At the time of the study only one of the children in this group was attending an ordinary school although some of the children were known to the teachers.

Thus for the 31 children, the classification of the impairment as severe came from the parents', the teachers' and the doctors' assessments rather than through screening tests.

Completeness of identification

The question of whether or not the 31 children include all the children in the KAMA catchment area with severe impairments can be answered in the following ways.

1. Since the KAMA community is a closed community all families have to be registered with the accommodation and medical services. Thus a medical record is available for every individual, including infants. All children's medical records were examined, including those of the children that did not attend. Nevertheless, many of the medical records were incomplete and no conclusion about the absence of impairments could be drawn from them.
2. School records were also studied with the teachers and this helped to confirm the developmental delay in some of the severe group and also identified those with less severe learning difficulties.
3. No other children with severe impairment were identified from the 400 who sought help from the author, from questioning the siblings nor from any of the key informants.
4. It is possible but unlikely that children with severe impairment were amongst the 264 who were not seen.

In the KAMA community, as elsewhere, people do not want to be officially labelled by the school or health services. Once a problem is identified officially and labelled, it is stigmatising. However, as in most communities it is difficult for secrets to be kept from others, and it is unlikely that any children with severe impairment were not known.

Although it is certain that no children with severe impairment were missed from the 90% seen, it is possible, that there might have been such children amongst the 264 who were not seen.

All of the 186 children who had dropped out of school had parents who were living in KAMA. They were interviewed, but the parents did not want their children examined or tested and insisted they were alright. It is possible that there were children with impairments amongst this group, and this might have been a reason for the child dropping out of school. If it were so, it was not obvious.

4.6.5 Referral

A referral network was established during the social preparation of the project. Initial co-ordination with secondary level institutions (health, special education, social welfare) was started in order to ensure their participation in the referral process.

All the children with impairment, minor or severe, were referred to the specialist clinics for confirmation of diagnosis and a plan of management. 117 (4.3%) showed hearing problems; 144 (5.3%) had visual defects and 31 (1.1%) had severe impairment. In the case of 61 children with learning problems further testing was refused.

Later the author took over the role of coordinator in the team working with other medical branches and especially with para-medical colleagues, e.g. the psychologist, the teacher, the speech therapist and the physiotherapist. After the identification stage of the impairment, the author stepped back into the background and took over the role of adviser and observer of the entire rehabilitation plan.

4.7 The questionnaire and its pilot study

The 31 children with severe impairment and their families were the main focus of the study and informal semi-structured interviews were conducted, with their families.

A questionnaire was developed in such a way that time could also be spent on observation and on interpreting the ways in which questions were being answered.

Questions centred on the five key areas for study: (1) initial recognition of the impairment, (2) reactions, (3) acceptance, (4) coping with daily living, and (5) use of services traditional and modern.

1. How do parents and families first recognise that the child "has something wrong" and does it worry them? What are the traditional beliefs and taboos which exist with regard to disability?
2. What are the reactions of parents and families after recognising "there is something wrong"? What are the pathways towards diagnosis and treatment or their avoidance?
3. Family's acceptance; the degree to which the parents achieve a balance between the needs of the disabled child and those of the rest of the family, including social life.
4. Family coping: the aim was to collect information on how families cope with children who have a disability and their daily living. What factors hinder families giving fully the help they want to give to a child with a disability?
5. Use of services: After diagnosis, what actions are taken by parents and the health services immediately and at a later date? What needs does the family have for outside

help? In what ways are these needs being met by the existing medical and educational service and the traditional system?

What services did the family use, including the extent and function of informal networks as they are an important part of the support and strength in the community.

The questionnaire also included questions and conversations to discover the extent to which and why the parents of the child with a disability considered community based rehabilitation desirable or not. What sort of reasoning underlies the generally held assumption that disabled children should be brought up in the "normal" community as far as possible.

The questionnaire was field tested in three different situations:

- (i) at a clinic for the non-commissioned officers (NCO)
- (ii) at an officers' clinic
- (iii) with the staff of military forces near Al Kharaj hospital.

They found the questions unclear and confusing. The result was that answers were given at random. At the Officers' clinic some of the questions were found offensive. Even though polite answers were given, the subjects found the interview a waste of their time. The wording of the questions and the approach was changed as a result of this experience. 10 families were interviewed in the military forces, five from the upper grades and five from the lower grades. The experience was similar to those of the NCO and officers' clinic. However this pilot study enabled the author to change the method of interview as well as the wording to suit the special aspects of Saudi culture.

4.8 The Interviews

The study attempted to make the interviews as much like a conversation as possible. The main focus was on the following:

- a) Facts related to the recognition of the impairment, such as the mode of detection;
- b) Reactions, steps to acceptance;
- c) The family's mechanisms for coping with particular problems of everyday living with a child who has a disability;
- d) Use of any type of service, traditional and modern.

Thus the interview was oriented to give insight into how the family functioned and coped with the disability; and could also begin to sense the unmet needs of that family. The topics covered by the interview are listed above. The procedure was as follows:

The Interview Procedure

Families had been invited to come to the clinic at an appointed time. Families that did not keep their appointments were telephoned by the author. The timing of the call was carefully chosen to be the "social time" of day which is after the siesta. The first interview was concerned with questions about practical coping.

During the interview, families put forward their opinions and often wanted to tell anecdotes in their own way. They were encouraged and time was always allowed for them to do so.

The family were left alone while a paediatrician examined the data and made recommendations for future action, investigations, referral, etc. The family would then return for further discussion. At this stage the family often expressed the need for more information in certain

areas and their own areas of concern. This was useful for setting the scene for future interviews. A further interview took place each time the family came for a follow up or to see a specialist. Some discussion took place in the waiting room during a clinic session and was always informal. While sharing a hospital vehicle to accompany the family to the main hospital to see specialists and other therapists or while waiting for such people in KAMA, valuable informal discussion revealed further important information.

The author had several contacts with each family over the study period. These contacts ranged from accompanying the family to appointments for medical, therapy and other sessions, to in-depth interviews. The number of contacts varied from 20 to 25 per family, and as the parents opened up more it provided the author with opportunities for in-depth understanding of the hopes and frustrations of the families and to understand their feelings and the emotional aspects of living with a disabled child. The help, the author was able to give the parents and their children through referral to specialist services reinforced his position and facilitated the communication process. Each interview took from 40 minutes to 1 hour and on average 20-25 hours were spent with each mother and father together.

Throughout the process the family needed a great deal of support in the form of understanding, kindness, caring and being there when needed. But, by the very expression of their hopes and fears (difficult though it was at times), the families seemed helped to come to terms with their child's impairment. Thus the study became a help to the families themselves.

From the initial interview a list was made of problems discussed and a set of questions listed to obtain a full account of what was happening or had happened to these children and their problems. At each interview the children and problems were discussed in turn and the listed questions discussed. At subsequent interviews the reception was more friendly, although sometimes parents seemed a little concerned about what they had said at the previous

interview. As the family came to trust the author more, the mother was allowed more frequently to contribute directly to the discussion.

Generally, families were but fleetingly interested in the aims, object or credentials of the study. More often than not, parents seemed grateful for the opportunity of talking about themselves. Their ability to express themselves varied greatly. Though certain parents needed time and reassurance before they could speak freely, the general response was positive, friendly and spontaneous.

It was quite likely that in the early stages of interviewing the study was involved mainly with parents' superficial feelings. But as interviewing progressed, it was possible to discover and discuss more deeply held ideas. Dealing with these hidden factors often alleviated some of the problem of disability, because these hidden factors often contained particular elements that could be identified as significant determinant factors in the environment.

4.9 Key Informants

Those key people in the community who have the knowledge and personal experience to answer some of the questions being raised in the study were identified.

These key informants included teachers, children surveyed in the schools, and grandparents living in KAMA with their sons and daughters as part of the extended family. The old were especially informative about traditional and cultural beliefs, but were also happy to give their views on the child with a disability. In addition to this 25 of the religious leaders (Imams) were met and discussions held with them. These discussions centred on their practice in relation to a child with an impairment. Their views are also incorporated into the individual case studies when parents (all of whom had visited traditional healers) described their role.

However, the informant may only know a part of the total social situation. Thus, the use of several informants, who represent different sectors of the community, was important. The use of several informants also helped to verify information. Moreover, the study was careful not to ignore less verbally expressive individuals as they may have a different perspective on the community.

The school-teachers and the students were strongly motivated to identify children with any health problems, taking a special interest in disability. The teachers were very helpful in providing clues regarding slow learners and the author verified this information through results of tests given to the students over the academic year.

Information was sought on customary practices which take place:

- i) at the time of recognition
- ii) during the phase of reactions
- iii) in the process of acceptance
- iv) in the everyday coping
- v) in the use of services traditional and modern

4.10 Constraints on the Study

4.10.1 Selection of important daily living and social activities

The attempt to produce a "social measure of disability" used to identify coping behaviour (see below) raises the problem of producing a list of all the activities in which human beings may be expected to engage. The list devised of priority daily living activities for this study was based on a subjective selection of the more important daily and social activities. A number of

supplementary questions were also devised to explore the nature of the problem of living with a specific disability and the particular capacity of the individual child.

4.10.2 Approach to the care providers

There is an understandable reluctance on the part of care providers to answer questions and possibly expose themselves to criticism. The demands of the study required maintaining effective rapport with the health workers at all times over a long period.

4.10.3 Problems with administering IQ tests

Although it was planned to carry out IQ tests on those children identified as having learning difficulties, the majority of the parents refused to allow their children to be submitted to IQ tests and the teachers were also reluctant to permit the tests.

Table 4.4

The children with severe impairment : by name in alphabetical order

(N = 31)

Abdu	Developmental delay
Abdulah	Epilepsy
Abdulaziz	Cerebral palsy
Ahmed	Juvenile rheumatoid arthritis
Amna	Cerebral palsy
Eman	Deafness
Fahad	Hemiplegia
Fawzia	Poliomyelitis
Hanan	Epilepsy
Hadeel	Developmental delay
Halel	Epilepsy
Hamed	Epilepsy
Ibrahim	Developmental delay at 13 yrs
Karim	Epilepsy
Laila	Osteogenesis imperfecta
Mohammed	Tetraplegia (car accident)
Nabiha	Developmental delay
Nada	Down's syndrome (not disclosed)
Nawal	Developmental delay
Nema	Rubella syndrome
Naila	Developmental delay
Nora	Rubella syndrome
Reem	Mild cerebral palsy
Saad	Deafness
Saeed	Epilepsy
Salman	Poliomyelitis
Salima	Down's syndrome recognised at 4 years
Thamer	Severe stutter
Turki	Deafness
Wadha	Poliomyelitis
Waleed	Developmental delay

4.11 Overview of the Methods

This chapter first considered (Section 4.1) the question "why this study?" Three reasons were identified. First, the current opportunity for a fresh look at care of people with a disability in Saudi Arabia where care providers require guidance, support and clarification on the key issues in the context of the new concept of community based rehabilitation. Secondly, the context of five major disability topics on which information is required in Saudi Arabia before an effective child disability programme can be designed. The present study can make a useful contribution. Thirdly, the need for a study of disability from the families' point of view, to identify the experience and aspirations of Saudi families, their problems and achievements in daily life with a child who has a disability. By first identifying families' current care and concerns, appropriate new services can be evolved rooted in the informal network of caring already in the community. Also by focusing on identification of needs for care from the families' point of view, a definition of community based needs can be obtained which can then be used to develop practical community based rehabilitation. In the past professional carers have not always recognised what families are already accomplishing and thus failed to support them.

Methods were chosen in a three stage process (section 4.3). First, limitations of previous studies of people with a disability were identified (their focus on limited types of impairment or similar syndromes; their excessive emphasis on family disruption rather than on coping strategies; their frequent ignoring of siblings; and their frequent dependence on information from only one parent). Secondly, advantages and disadvantages of different methods of obtaining the information needed were analysed; for closed questionnaires (quick, easy to analyse but insensitive and misleading if used for inappropriate topics, leading to unreliable statistics which do not reflect the real situation at all); also for semi-structured interviews, requiring observation as well as exchange of words, and insights from seeing people's reactions and hesitations. There are advantages in this format for reducing "social distance" between

researcher and subject so that there is a more accurate reciprocal exchange of information. A good check list of topics to be covered is essential to ensure that the same aspects of a subject are covered in different interviews. In-depth qualitative methods are also discussed and the use of records. Action research (as empowerment for action) was not a main aim of this study but nonetheless some families were certainly strengthened by the process of the study to request the help they needed.

Thirdly, the choice of methods was determined by what would be best for a community health enquiry in Saudi Arabia in the 1990s. Only two studies of disability have ever been done (frequency of types of impairment, and on the number of special schools and other services). Both are formal and provide little insight into families and disability. Only one community health survey has ever been done in Saudi Arabia. Surveys of all types are difficult to carry out due to cultural and religious practices governing individual behaviour, especially between the sexes, and also due to security regulations.

An important component of the present study is its new identification of the challenges to designing appropriate surveys in Saudi Arabia. As described in detail in section 4.4.1, these include traditional expectations of unknown visitors and uninvited guests (any unknown enquirer is normally turned away, "good" people do not normally arrive uninvited). Visitors come as a special guest, they have a special chair or mat; a special place; and special food. They are only seen by the most important members of the household. Conversation takes place with the father away from other family members. House to house surveys and enquiries are totally unknown and unacceptable. A postal enquiry will be seen as suspicious as it is not the usual channel of communication. Thus, to summarise section 5.4.2, six key components of community health enquiry in Saudi Arabia in the 1990s are identified:

1. Gaining the confidence of the community by using the normal communication channels for getting in touch with families who have a child with a disability.

2. **Being seen to be an acceptable person in Saudi society.**
3. **Using the normal more culturally appropriate ways of relating and talking to people including talking to the family through the father**
4. **Recognising the cultural and religious views concerning the interview and physical examination of girls.**
5. **Realising that seeing people at a recognised place (clinic) may be more acceptable than an unknown visitor coming to the home.**
6. **Aiming that by the end of the study not one family should complain. This is particularly important in the early stages of community based research as the reputation of health studies in the community would depend on the way in which the early studies were conducted.**

Finally, observing confidentiality, ethics and consent (as in all epidemiological studies).

In section 4.5 the rationale for choosing the survey site is described, the way formal permission was sought, and the characteristics of the site, the King Abdulaziz Military Academy Hospital (KAMAH).

In section 4.5.3 the procedure for preparing the hospital and the community for data collection is described. In 4.6.4 the training workshops for the nurses involved in screening (and who also facilitated the attendance and examination of girls at the clinic) are described and details of audiology tests, vision tests and screening schedules.

In section 4.6 the procedure for identification of the children with a disability is described. Three sources were used. First, a letter from the head of the community was sent to all 1120 households (with 2693 children). 2432 attended for screening, a response rate of 90%. (78 lived outside the area and were excluded, a further 186 were declared alright by parents and refused screening). The second source of screening was school children, of whom 1280 6-15 year olds and 52 under 5s at nursery school were screened. This was out of a total population of school children of 1544, a response rate of 83%. (264 children had left school, 78 lived outside, and 186 had dropped out and the parents refused screening of them). Of the screened school children, teachers identified 56 with learning difficulties. The parents were seen at the school. All refused to be seen by the psychologist or referred to confirm a problem. The third source was under fives screening. 1100 children were screened out of a population of 1152 and the others were seen at nursery school $N = 52$. This gave a response rate of 100%. Overall, 353 children were identified with impairments in a population of 2696 (13%) and the 31 with very severe impairments were studied in detail by interview with their parents.

Section 4.7 describes the development of the questionnaire including its pilot study. The interview procedure is described in section 4.8 with its special cultural components for Saudi Arabia; in a confidential environment, in a conversation including frequent mention of the Prophet and quotations from the Koran and the Hadith and using anecdotes and stories to explain situations. The several interviews with each family during the study and the opportunity this gave for an in-depth understanding to develop, are described. In section 4.9 the role of key informants is described and in section 4.10 the main constraints on the study. Finally, in section 4.11 the population is summarised and the 31 children with very severe impairments who form the bulk of the results are listed in alphabetical order by name to facilitate reference later in the text.

5. RESULTS

5.1 Introduction to the Results

The sections describing results and discussion are each organised similarly into five main subheadings; recognition of the impairment, reactions, acceptance, coping with daily living, and use of services.

The Results are described in two sections

- i) minor impairments detected in 322 children;
- ii) severe impairments in 31 children.

5.2.1 Minor impairments

Only minor impairments which might affect development were included. Children with minor physical defects were either referred directly to a specialist or the defect was so minor that no action was needed. Minor medical problems (such as skin lesions, dental caries and so on) which were treated on the spot or referred are not included.

Impairments were identified in the following three categories:

- vision
- hearing
- learning problems

Table 5.1 Frequency of minor impairment							
	Age <5	Age 6-15	N	Rates in <5	Rates in 6-15	Total per 100 children (N = 2432)	Total as proportion of population (N=8241)
Vision)		26	123	149	26/1152	123/1280	6.1%
Squint)					(2.3%)	(9.6%)	1.8%
Visual Acuity)							
Hearing	30	87	117	30/1152 (2.6%)	87/1280 (6.8%)	4.8%	1.4%
Learning Difficulties	NA	56	56	NA	56/1280 (4.4%)	4.4%	0.7%
Total	56	266	322	4.9%	20.8%	13.2%	3.9%

As expected, the highest proportion of impairments was found in the age group 6 to 15 years because impairments and defects are easier to detect in older children. Visual defects were more common compared to hearing and learning difficulties. Eight of the children had both hearing and visual problems. However, their visual impairments were minor and they are classified under hearing impairment.

The visual impairments were squint, defect in visual acuity or both. Parental concern was noticeable when both squint and defective vision were present and four of 16 (25%) parents had taken action, see Table 5.2). Parents were not concerned with poor visual acuity (only 7% had taken action), and surprisingly also in some cases of squint (29% had taken no action). No gender difference was apparent (see Table 5.2).

Table 5.2 Parental action in children with minor impairment affecting the eyes							
Age Group		Squint	Action taken	Poor visual acuity	Action taken	Both	Action taken
0-5	Boys	5	3	12	2	2	2
	Girls	1	-	14	1	2	2
6-15	Boys	1	-	51	5	7	-
	Girls	10	9	39	-	5	-
Total action taken			12/17 (71%)	8/116 (7%)	4/16 (25%)		

Impairment of hearing was due to either chronic otitis media or wax in the ear. Here also parental concern was variable. Only 17% had taken action for otitis media, and none for wax causing impaired hearing (see Table 5.3). No gender difference was apparent.

Table 5.3 Minor hearing impairment					
Age group		Otitis media	Action taken	Wax in the ear	Action taken
0-5 years	Boys	13	-	6	-
	Girls	9	6	2	-
6-15 years	Boys	46	9	-	-
	Girls	41	4	-	-
Total action taken		109	19/109 (17%)	0/8	0/8

Parents of children with learning difficulties (seen at the school) had not taken any action and as explained did not want their child to be referred. The reason being that if labelled in childhood, the child would have social problems, but after the age of 15 as adults it would not matter that they had failed at school.

5.2.2 Population prevalence rates for minor and severe impairment

Population prevalence rates are expressed either per 1000 of the child population or as a percentage or per 1000 of the total population for comparison with other studies. Although the numbers are small the prevalence rate for all impairments in children was 145/1000 children and for severe impairment 12.7/1000 (see Table 5.4).

Table 5.4 Population prevalence rates			
	Per 1000 child population (N = 2432)	% total population (N = 8241)	per 1000 total population (N = 8241)
Minor visual impairment (N = 149)	61	1.8	18
Minor hearing impairment (N = 117)	48	1.4	14
Minor learning difficulties (N = 56)	23	0.7	7
<hr/>			
Total minor impairments (N = 322)	132	3.9	39
<hr/>			
Epilepsy (N = 6)	2.5	0.07	0.73
Poliomyelitis (N = 3)	1.2	0.04	0.4
Deafness (N = 3)	1.2	0.04	0.4
Speech problem (N = 1)	0.4	0.01	0.1
Developmental delay (N = 7)	2.9	0.08	0.8
Cerebral palsy (N = 3)	1.2	0.04	0.4
Rubella syndrome (N = 2)	0.8	0.02	0.2
Others (N = 6)	2.5	0.07	0.73
<hr/>			
Total severe impairment (N = 31)	12.7	0.37	3.76
<hr/>			
Total all impairments (N = 353)	145	4.28	42.8

5.2.3 Severe impairment

The 31 children with severe disability were identified from replies to the initial letter without recourse to clinical assessment since all were previously known to the health services. The

families arrived with full details of the hospital diagnosis. Screening procedures were important for recognition of these children in the present study.

The 31 children with severe impairment, with types of deficits, the diagnostic category and the family background are summarised in Table 5.5. The children's first names only are used. This is done to emphasise the human nature and reality of each child, and so the reader's closeness with and opportunity for understanding the child and the parents is not obscured through codes and confusing initials. (Since all the names are common Islamic names, the use of the children's names does not assist in their identification).

Table 5.5 Children with severe impairment; age at diagnosis, family background, problems

No.	Name	Age at diagnosis	Age/inter view	Sex	Social class	Father Education	Clinical diagnosis	Develop-mental delay	Speech	Vision	Hearing	Loco-motion	Epil-epsy	Toilet-ing	Feeding
1	Karim	2 years	4	M	M	Graduate	Epilepsy	-	-	-	-	-	+	-	-
2	Hanan	2.5 years	4	F	M	Secondary	Epilepsy	-	-	-	-	-	+	-	-
3	Halel	1 year	6	M	M	Secondary	Epilepsy	-	-	-	-	-	+	-	-
4	Saeed	1 year	10	M	M	Secondary	Epilepsy	-	-	-	-	-	+	-	-
5	Abdulah	1 year	9	M	L	None	Epilepsy	-	-	-	-	-	+	-	-
6	Hamed	1 year	10	M	M	Secondary	Epilepsy	-	-	-	-	-	+	-	-
7	Saad	2 years	15	M	H	Graduate	Deafness	-	-	-	+	-	-	-	-
8	Eman	2 years	10	F	H	Graduate	Deafness	-	-	-	-	-	-	-	-
9	Turki	2.5 years	8	M	L	None	Deafness	-	-	-	+	-	-	-	-
10	Thamer	3 years	8	M	L	None	Severe Stutter	-	+	-	-	-	-	-	-
11	Fawzia	1 year	9	F	L	None	Polio	-	-	-	-	+	-	-	-
12	Salman	2 years	15	M	M	Secondary	Polio	-	-	-	-	+	-	-	-
13	Wadha	1.5 years	15	F	L	None	Polio	-	-	-	-	+	-	-	-
14	Ahmed	5 years	10	M	M	Secondary	Juv. Rheum. Arthritis	-	-	-	-	+	-	-	-
15	Mohammed	4 years	5	M	L	None	Tetraplegia	-	-	-	-	+	-	-	+
16	Fahad	1 year	3	M	M	Secondary	Hemiplegia	-	-	-	-	+	-	-	-
17	Laila	At birth	4	M	M	Secondary	Osteogenesis Imperfecta	-	-	-	-	+	-	-	-
18	Hadeel	1 year	4	M	H	Post Graduate	Develop. delay	+	-	-	-	-	-	-	-
19	Abdu	1 year	9	M	M	Secondary	Develop. delay	+	-	-	-	-	-	-	-
20	Nawal	1 year	9	F	L	None	Develop. delay	+	-	-	-	-	-	-	-
21	Ibrahim	13 years	15	M	M	Primary	Develop. delay	+	-	-	-	-	-	-	-
22	Waleed	9 years	9	M	M	Primary	Develop. delay	+	-	-	-	-	-	-	-
23	Nabiha	6 years	11	F	L	None	Develop. delay	+	-	-	-	-	-	-	-
24	Naila	3 years	10	F	M	Primary	Develop. delay	+	-	-	-	-	-	-	-
25	Salma	4 years	5	F	M	Primary	Down's syndrome	+	-	-	-	-	-	-	-
26	Nada	At birth	1	F	M	Primary	Down's syndrome	+	+	-	-	+	-	+	-
27	Reem	1 year	12	F	H	Graduate	Cerebral palsy (mild)	-	-	+	-	+	-	-	+
28	Amna	1 year	9	F	M	Primary	Cerebral palsy	+	+	-	-	+	-	+	+
29	Abdulaziz	1 year	4	M	M	Graduate	Cerebral palsy	+	+	-	-	+	-	+	+
30	Nora	At birth	2	F	M	Graduate	Rubella syndrome	+	-	+	+	-	-	-	-
31	Nema	At birth	2	F	M	Graduate	Rubella syndrome	+	-	+	+	-	-	-	-

5.3 The steps towards the recognition of the disability

5.3.1 Age of diagnosis, place of delivery, the role of the health system and the cultural complexities of withholding information from one or both parents

5.3.1.1 Age of diagnosis and the role of health services

The age and stage of the child's life at which the impairment was recognised makes a difference to the parent-child relationship and the process of adaptation to the impairment.

Table 5.6 shows the time of medical diagnosis for severe impairment.

When diagnosed	Number
Antenatal period	0
Perinatal period	5
Before aged 5 years	13
After aged 5 years	13
Total	31

In the current study, no child's impairment was diagnosed during antenatal screening even in the case two children born with rubella syndrome. No amniocenteses were carried out. Since abortion is only permitted in Saudi Arabia to safeguard the mother's life, this was an expected finding.

It was the child's clinical features in the perinatal period that led to the recognition of severe impairment at birth for five children: two children with rubella syndrome (Nora and Nema),

one with Down's syndrome (Nada), and one with osteogenesis imperfecta (Laila)(see Box 1). One child (Reem, see Box 2) had a stormy neonatal period and suspicion of permanent impairment was present from birth. This child was born in the USA. Two children with low birth weight and asphyxia born in hospitals in Saudi Arabia, where suspicion might have been present, were only diagnosed after the condition was obvious to the parents and family.

Box 1

Obvious impairment visible from birth (Laila, osteogenesis imperfecta)

Obvious impairment, visible at birth, immediately alerted her parents that all was not well. Laila was delivered at home with the help of elderly members of the family and neighbours. She was born with deformity of the limbs.

Laila's mother did not admit to her feelings about her daughter's deformity, though obviously these would have called forth tremendous anxiety in any parent. She said her distress about the child's abnormally deformed limbs was alleviated by the hope of treatment.

When Laila fractured her right humerus aged seven days, the parents sought medical treatment. The fracture (unlike the deformity) was recognised as a "normal" problem. Laila's mother also said it gave her the hope that the child's whole condition could be recognised and treated.

Besides the limb deformity, she had bowing of the long bones, deformity of the ribs, blue sclerae and a high palate. Chest X-ray showed multiple old rib fractures present and marked reduction in bone density. Skeletal X-ray showed bowing of most of the long bones with evidence of fracture of various stages. The orthopaedic surgeon warned the parents that nothing could be done to strengthen the bones at this stage, but that if there were multiple fractures and deformities when the girl was somewhat older, he could provide some support for the long bones and get her walking and stop the fractures. She has extra fragility of her long bones and is very prone to spontaneous painful fractures of her limbs. Clinical and radiological diagnosis of osteogenesis imperfecta was made.

The parents were told the diagnosis, but the condition was unknown to them and is still not understood. The parents recognise that the child was born with a condition about which they know nothing, but that their child may have further fractures, a condition they can recognise and act on.

Box 2

Perinatal events leading to suspicion of impairment from birth (Reem, mild cerebral palsy)

Reem was born at a centre with high standards of care (Willford Hall S.A.F. Medical Centre in the USA) at 30-31 weeks gestation with an occiput to frontal position. She was immediately diagnosed as having respiratory distress syndrome and intracranial bleeding. She developed hydrocephalus which subsequently arrested. From the first day of life, medical staff shared their concerns for Reem's survival and future with her parents. She was followed up regularly at the Tidwater Child Development Centre in the USA. Towards the end of her first year, she was diagnosed as having a cerebral palsy (spastic diplegia) with mild developmental delay. She was also found to have a congenital nystagmus with exotropia, retrolental fibroplasia and myopia.

Her parents had recognised that there would be something wrong throughout her life and were familiar with the meaning of the diagnosis of cerebral palsy and the outlook, mainly through the US media. Although she had many medical problems, her parents were relieved that the condition did not seem to be as severe as they had expected.

However, the diagnosis and its recognition left them feeling depressed. The paediatrician took immense trouble both during and after Reem's in-patient treatment to ensure that the parents were fully informed about the diagnosis and prognosis, and that they understood as far as possible how cerebral palsy had occurred, and what the implications were. Reem's parents felt greatly indebted to the consultant for his understanding. This kind of help was of crucial importance in facing their difficulties. The parents said that early recognition had reduced their feelings of isolation and brought relief in the realisation that other parents had similar and more difficult problems, yet with the same thoughts and emotions. The early recognition had helped them to encourage the child's development and to get appropriate professional help. Reem did well in school and her father sometimes wondered if he was putting too much pressure on her. However, he said that her mother would give her the love and affection needed, and that he was giving her the realistic guidance. Reem came from a high social (grade) class family.

Three children with cerebral palsy had their impairment recognised at a similar period in infancy. However, the family direction was completely different. For Reem, born in the USA, the family felt they had been supported by the services and had easy access for further care as needed. The other parents felt neglected by the services after diagnosis. The families felt they had been abandoned just when they were recognising new difficulties with the child all the time.

Altogether, few of the children's impairments were recognised at birth. Salima's Down's Syndrome might have been detected at birth had she been born in hospital. She was diagnosed at the age of 4 years. Other children's impairments might have been recognised at birth with sophisticated technology where it was available (for example, neonatal screening for the cases of hearing impairment (Saad, Eman and Turki)). Earlier diagnosis and intervention would have been helpful for the 3 children with hearing impairment, for one child with developmental delay (Ibrahim) who attended school, but had severe learning, social and psychological difficulties because of this, and Fahad whose hemiplegia was not recognised until one year (see Box 5), and Thamer (Box 3), where earlier diagnosis of the cause of speech problems would have been helpful.

When an apparently normal baby has been delivered and mother and baby have gone home with the family thinking all is well, the unexpected presentation of an impairment at a later stage can come as a shock. Hadeel's mother was reassured throughout the pregnancy that everything was as it should be and her daughter was born following a normal delivery. It was only when certain milestones were not reached that the parents came to learn from friends and family that the child had an impairment.

5.3.1.2 Recognition and place of delivery

One of the reasons for late diagnosis in some impairments present from birth, could be the place of delivery. Table 5.7 shows the place of delivery in relation to the medical diagnosis; 66% (20/31) were born at home.

Table 5.7 Place of delivery		
	Type of Impairment	Number of children with impairment
A Home Delivery	Down's syndrome	1
	Polio	3
	Osteogenesis imperfecta	1
	Juvenile rheumatoid arthritis	1
	Epilepsy	6
	Deafness	3
	Speech problem	1
	Developmental delay	4
		—
	Total home delivery	20
B Hospital Delivery	Rubella syndrome	2
	Down's syndrome	1
	Tetraplegia	1
	Hemiplegia	1
	Mild cerebral palsy	1
	Cerebral palsy	2
	Developmental delay	3
		—
Total hospital delivery	11	

Interestingly, none of the children born at home were delivered by traditional midwives but by female family members and neighbours. These women have no training but have given birth themselves and have taken an interest in childbirth.

There was no significant difference in place of delivery according to father's grade (social class) (Table 5.8).

Table 5.8 Place of delivery according to grade							
Grade	Lower		Middle		Higher		Total
Place of delivery							
Home	(5)	71%	(12)	63%	(3)	60%	(20) 65%
Hospital	(2)	29%	(7)	37%	(2)	40%	(11) 35%
Total	(7)		(19)		(5)		(31)
$\chi^2 = NS$							

5.3.1.3 Condition at Birth

The child's condition at birth should alert medical staff to the need for follow up. Table 5.9 shows that 20 of the 31 children had some evidence of problems at birth (severe asphyxia, possible trauma or anomalies). In 2 cases there was severe asphyxia but in 13 others the case notes had "birth trauma" recorded. Parents told the investigator that there were signs such as blueness, or failure to cry in those cases, but there are no records of Apgar scores, since many were home deliveries.

Table 5.9 Condition at birth (from case notes and history)

Condition at Birth	Type of Impairment	No. of Children (N=31)	
			%
1. Severe birth asphyxia Possible birth trauma	Cerebral palsy	2	
	Epilepsy	6	
	Developmental delay	<u>7</u>	
Total asphyxia and trauma		15	42
2. Anomalies	Rubella syndrome	2	
	Down's Syndrome	2	
	Osteogenesis imperfecta	<u>1</u>	
Total anomalies		5	16
3. No reported problem		<u>11</u>	42
4. Total		<u>31</u>	100

5.3.1.4 Maturity (gestation) at birth

Table 5.10 shows maturity (gestation) at birth. The three children with cerebral palsy had been preterm babies and were born in hospital.

Table 5.10 Maturity (gestation) at birth			
Maturity	Type of Impairment	No. of Children	%
Full Term	Deafness	3	
	Rubella syndrome	2	
	Down's syndrome	2	
	Polio	3	
	Osteogenesis imperfecta	1	
	Juvenile rheumatoid arthritis		1
	Tetraplegia	1	
	Hemiplegia	1	
	Developmental delay	6	
	Epilepsy	6	
	Speech problem	1	
Total full term		27	87
Preterm (all born in hospital)	Developmental delay	1	
	Mild cerebral palsy	1	
	Cerebral palsy	2	
Total Preterm		4	13
Total		31	100

5.3.1.5 Type of delivery

26 of the 31 children were delivered normally. All three cases of cerebral palsy were delivered by caesarian section.

5.3.1.6 The role of the visibility of the impairment at birth in recognition

Medical conditions which were easily apparent to parents alerted the parents immediately that all was not well. Mental impairment associated with typical morphological features is usually recognised early at least by health workers. Nada who had (Down's Syndrome) was recognised by the health workers in this way.

Four children were recognised at birth as having potential problems and this was confirmed, the forewarning, made the process of recognition easier.

With Nora and Nema (rubella syndrome) the parents themselves saw that their children had cataracts, and the health professional told them that surgery was needed. After surgery, the parents felt glad their child had been saved from blindness and expected the services to go on helping them as they had already saved the sight. The care providers were seen as competent as well as caring.

5.3.1.7 Recognition of impairment but health services delay in later childhood in identifying cause, effect and implications

Thamer's case (Box 3) illustrates delayed recognition of speech defect, but there was no recognition of the child's emotional problems nor the families social problems and intervention was inadequate.

Box 3

Recognition of impairment without recognition of the cause, effect and implications (Thamer, who has age-appropriate speech, but only speaks to a restricted range of people.)

He was a physically well-developed boy aged 8 years, the second of four children. He had started school at 6, but as his voice had never been heard inside or outside classroom, his teacher began to wonder whether he could in fact talk.

According to his mother, Thamer had always been a very shy child who would not speak outside the home or to strangers, and he did not even speak to all members of his wider family. At school, Thamer appeared alert and cooperated with age-appropriate tasks in the classroom. Although he played with the other children, this was mostly by way of parallel play, and he tended to withdraw as soon as they made any demand on him. He occasionally opened his mouth in singing, but no sounds would be heard. The other children referred to him as the child who did not talk and it was evident that they did not bother to talk to him.

The child was receiving speech therapy during the day. He showed no apparent improvement. The mother tended to focus attention on the problems of speech and speech development (and also upon emotional difficulties). Emotional problems were widespread both in the child and the family. The marital relationship was very poor, the relationship between the child and father and elder brother was noticeably disturbed. This state of affairs seemed to suggest that the emotional needs of both the child and the family require very careful attention and understanding, more perhaps than the existing services could provide. Speech therapy was mistakenly regarded as the only kind of therapy required. Because of the obviously doubtful value of speech therapy to the child, help of any other kind was delayed. The speech therapist tended to work in isolation from other agencies.

5.3.1.8 The cultural complexity of withholding information from one or both parents

In the case of Nada with Down's Syndrome the condition had been recognised by the medical authorities at birth, but the information had been kept from the mother. This was done in the expectation that, not knowing the truth, the mother would grow to love the child and be unwilling to part with her when later she learned of her daughter's condition. However, this caused deep distress to the mother (who had noticed something wrong which

was evaded by her husband) and suffering to the father because of "living a lie" in the crucial early days of the child's life.

Box 4

To illustrate where the paediatrician and the father had not disclosed the disability to the mother (Nada, Down's syndrome)

Nada's mother gave birth to a girl, following a normal pregnancy and normal delivery. She was not her first baby. Culturally and legally in Saudi Arabia the father has to be informed first. The normal routine is that the care providers and the father go immediately to the mother for discussion. The medical staff informed her husband that they thought the baby had a disability and it would be in the mother's best interest if she was not told. The health workers assumed the father would be very worried by the look of the child. So they hastened to explain to him that the problem was an impairment, a well-recognised problem, with known characteristics including the appearance. In the interview the mother said, in retrospect, that she knew that there was something that was not quite right about their daughter, but she could not put her finger on what it was. When she asked her husband what he thought, he always evaded the issue, and reassured her that everything was as it should be. When the baby was three days old the truth came out. The mother was not only confronted with the fact that her daughter had a disability, but discovered that her husband had known all along, and had kept it a secret from her. Because a professional had advised the husband about keeping the news from his wife, he thought it not his place to question it. The father said he continued to suffer from the living of those lies of the crucial first days, for the next six months.

5.3.2 Reasons for parental suspicion of impairment

Table 5.11 shows the reasons that led parents to think something might be wrong with the child. The majority of problems noticed by parents were either developmental delay; "backwardness since babyhood", or mobility problems, accounting for 9 of the 31 cases (29%). Seizures was the next most frequent category (6 children had epilepsy). Being born with a deformity accounted for another 5 children. Slow language or speech development was of concern in 3 hearing impaired children, also the child with severe stutter and one of the children with developmental delay; 3 developed their impairment after illness or an accident.

Table 5.11 Reasons that parents thought "something might be wrong" with the child

Reason	Type of Impairment	No. of Children	Total
1. Born with visible impairment	Rubella	2	4
	Down's syndrome	1	
	Osteogenesis imperfecta	1	
	Total		
2. Condition at birth	Mild cerebral palsy	1	1
	Total		
3. Parent concern during child's development			
3.1 Slow general development compared with expectations			6
3.2 Slow motor progress	Cerebral palsy	2	
	Hemiplegia	1	
3.3 Slow language development			3
	Severe stutter	1	15
	Developmental delay	1	
	Down's syndrome	1	
	Total		
4. Something happened			
4.1 Fits	Epilepsy	6	11
4.2 Illness	Poliomyelitis	3	
	Juvenile rheumatoid arthritis	1	
4.3 Accident	Tetraplegia	1	
	Total		11
Overall Total			31

Case studies of parents' concern during the child's development

Recognition of mental impairment in children who have no other pathological condition is expected to be dependent upon observed delay in developmental milestones, noticed usually first in the family, (and sometimes later at school).

The diagnosis of hearing impairment in two children was suspected 6-12 months earlier by parents, the delay being caused by professionals in making a diagnosis. Two children with slow development were also recognised by parents long before professional help was appropriately given. These case studies are described in Box 5 below.

Box 5

General developmental delay presenting as slow language development (Abdu)

His early history was uneventful; pregnancy and birth were normal and there has been no serious illness, though he was said to have been rather slow and lethargic as a baby.

The mother said she began to worry about the child's failure to develop speech when he was about 2 and that she took him to the doctor in the hospital, who told her that speech would probably develop in time. She says that she took him back several times, but the doctor said that the child was physically normal. Eventually the doctor referred the child to the speech therapist and, at her request, an appointment was made with the ENT doctors. Subsequent testing revealed fairly normal hearing.

There was clear evidence that the child heard and responded to sounds and this seems to have confused the parent. The mother herself was known to have spoken very late, after school-age, as reported by the maternal grandmother and this fact was seized upon as a possible reason for the child's failure to develop speech himself.

Slow development (Naila, developmental delay)

Naila's mother said she knew that something was wrong with her child in the first few months of life. She had no professional guidance as to the nature of the condition and type of management needed.

Attention to mothers' comments is of particular relevance for these children who show no overt clinical signs, who are often dismissed as "slow developers" and their mothers as "worriers".

However, there were still delays in diagnosis and lack of advice and support for parents once diagnosis had been made. The point to be made is that the pattern of identification of impairment in these children is likely to remain constant. Their identification depends to a much greater extent on the strategy of increasing suspicions.

Failure to develop speech (Saad, deafness)

Parents said they began to worry about the child's failure to develop speech when he was about 2 and they took him to their doctor, who told them that speech would probably develop in time. They say that they took him back several times, but the doctor said that their child was physically normal. Eventually, the doctor referred the child to the ear, nose, throat specialist at their request. Subsequent testing revealed loss of hearing. Deafness was not suspected until the child was 2 years old. The suspicion was confirmed only when the child was 2¹/₂ years of age.

Abnormal responses (Eman, deafness)

Eman is also a child born deaf. The parents say that they first noticed abnormal responses to sound at 12 months, took her to their doctor, who told them not to worry and that "speech may be rather backward". They took her again at 18 months, when she was referred to a consultant, who is reported to have said that hearing was probably somewhat affected due to enlarged adenoids and tonsils which were then removed. When the parents went again to the consultant after the operation, they were told that they must be patient. A further visit when the child was 24 months elicited the finding that the child was totally deaf.

Lack of hearing suspected (Turki, deafness)

Turki is also a child born deaf. Deafness was suspected at about the age of 2¹/₂ by his parents. The diagnosis was confirmed by the medical attendant, but no other provision was made since the parents took no further action.

Now at the age of 7 he has not been attending any school; his mother has so far refused to allow him to go to a special school because of the stigma. The parents will be accused of her not being able to look after the child and of putting him away. He plays with other children, who are inclined to 'baby' him but he has become more independent and can communicate with his playmates. This he would do as long as he is away from his mother. At home, the very reverse happens. His father is still trying to get him a place at a special school, but he is still on the waiting list.

Parents noticing delay in development (Ibrahim)

Ibrahim was able to sit by himself at 6/12 months, walked at 2¹/₂ years and was talking by the time he was 3.5 years old. He left school after the second grade after failing end of year class tests for 3 successive years. He is not in school any more. He has attended evening classes. When he was at school his parents had presumed that Ibrahim was learning in the school by his regular attendance. This lack of capacity to learn in an ordinary school had been overlooked. Although he is often a dull child, he seems curious.

At the age of 13 Ibrahim was presented by his parents at the local hospital for general weakness. Since then doctors with different skills and specialists debated whether the diagnosis was Marfan's syndrome or tuberous sclerosis and the child has been admitted as an "interesting case". This also required many sophisticated and expensive medical tests. And nothing has been done in the form of rehabilitation therapy to benefit Ibrahim. The parents have little interest left in the child's education, and they provide very little discipline.

To illustrate the gradual onset of recognition of disability which passed unnoticed until it was well established (Fahad, hemiplegia)

Developmentally: Fahad began sitting at 1 year, walking at 18 months with support; walking with a typical hemiplegic gait affecting the right side.

He started walking unaided at 20 months. The muscle tone increased in (R) arm; he was then talking with a few words with meaning. The child is bright, happy and alert. He was referred by the doctor to the physiotherapist. The physiotherapist commented (in English) that "this boy needs a lot of encouragement at home to use his right hand to avoid laziness thus affecting his normal development". Quite clearly the hemiplegia was not recognised.

To illustrate the unrecognised seriousness of a disease and disability (Ahmed, juvenile rheumatoid arthritis)

The disease started when Ahmed was 5 years of age. The child started to complain of recurrent pain in the back and neck and stiffness. Also he used to develop a fever every night. This continued for 35 days before he was admitted to hospital. He had no history of skin rash or sore throat.

The progress in hospital, since admission, was encouraging. Ahmed was febrile, but free from symptoms except for morning stiffness. Therefore it was decided to discharge him home on medication. The final diagnosis was Juvenile Rheumatoid Arthritis.

Ahmed was discharged on aspirin 450mg tablets daily for one month, to come for follow-up in two weeks time for measuring blood aspirin level. Ahmed's father was not at all pleased with the management. The parents think aspirin is merely for a headache, and so the parents bring the child very irregularly to the hospital.

5.3.3 The understanding of diagnosis in the cultural setting of Saudi Arabia

5.3.3.1 The cultural wish to ignore impairment when diagnosis is uncertain, or the problem minor

For some children with minor impairment, the impairment was "recognised", and recorded in their notes but not followed by any effective action. Several parents said they assumed (hoped) the child would grow out of the problem.

5.3.3.2 Parents' difficulty in understanding diagnostic labels

To understand why parents have difficulty in understanding some of the diagnostic labels given to their children, the frequency of the condition and everyday understanding of it needs clarification. Down's syndrome is rare and has not been recognised as a problem in Saudi Arabia until very recently. Cerebral palsy is an unknown phrase. No one knows what it means. Juvenile rheumatoid arthritis may as well be in another language for all the understanding that most people have of it. The other diagnostic categories which are unclear in the Saudi Arabian context are Rubella, Down's Syndrome, Osteogenesis Imperfecta, Juvenile Rheumatoid Arthritis, and Cerebral Palsy.

Some conditions are well recognised by parents but the cultural environment still requires concealment of others. I found the following. Poliomyelitis is easily recognised (it is common) and not hidden. Spinal injury leading to paralysis (tetraplegia) following an accident, is also openly understood. Thamer, with a speech problem, was recognised but reticence in communication was regarded as a feminine quality by his father.

Developmental delay is recognised but usually ignored until picked up by school teachers. Epilepsy is well recognised but carries a stigma and thus the diagnosis was hidden in all six

cases. Some diagnoses are not understood at all. Even two years after the diagnosis being made in three of the children with severe disabilities (Nada, Down's syndrome; Amna, cerebral palsy; Abdulaziz; cerebral palsy), their parents admitted that they still had been unable to achieve an understanding of the diagnosis. They were not sure of the meaning or the implications of the disability.

Although parents may understand the impairment and openly recognise such a problem, (for example, Polio myelitis) prevention is not understood. Immunisation is totally unknown in many families. The lack of understanding of immunisation also made it particularly difficult to explain prevention of congenital rubella to Nora and Nema's parents.

5.3.4 Key components of recognition shown in the current study

Parents' recognition varied from total failure to a vague realisation, to certainty of the impairment. Differences occurred because of variation in the parents' understanding of the child's condition depending on whether they think the impairment is serious, the onset was sudden or gradual, the condition well known or obscure, the diagnosis clear or unclear; and whether or not the parents feel they need to conceal the impairment.

Screening services provided at birth, during the pre-school period and during schooling should have had an important role in the recognition of impairment but were relatively ineffectual for the cases in the current study. As shown only 5 of the 31 severe impairments were picked up at birth and 10 cases that might have been identified were missed. Pre-school screening services were hardly mentioned by respondents and the role of the school was more in the context of picking up failure than in recognising needs for special help. There is clear opportunity for improving screening services in Saudi Arabia.

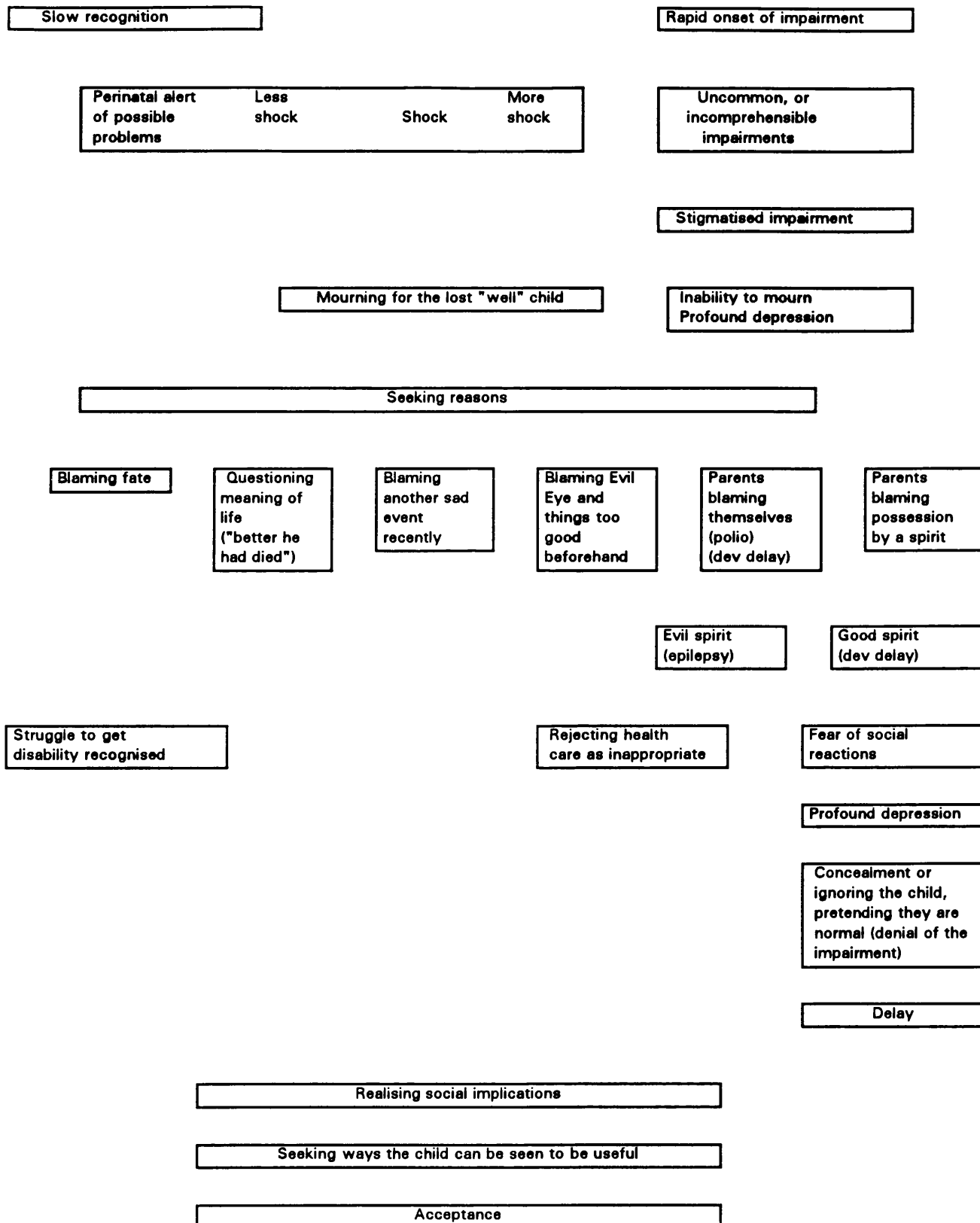
5.4 Reactions to the impairment and to the child

5.4.1 Pathways to recognition and varying reactions

Different pathways to recognition of disability affected parents differently (see Figure 2). In this study, the variation of parents' reactions to impairment and disability is examined according to the time period when they were informed or became aware as the particular condition progressed. Reactions are different if there is a perinatal alert, or if the impairment appears late and is totally unexpected. Reaction to incomprehensible conditions or those carrying a profound social stigma, as some impairments do in Saudi society, is very different from conditions which are well accepted.

Figure 2

A model of the sequence of reactions found in the present study



5.4.2 First reactions

Table 5.12 shows the first dominant reaction that parents of the children with severe impairments described.

Table 5.12 Parents' first reactions once disability is diagnosed			
Reaction	Medical diagnosis	No. of Children	(%)
Particular Shock	Rubella (Neem, Nora)	2	
	Cerebral palsy (Abdulaziz, Amna)	2	
	Deafness (Saad, Eman, Turki)	3	
	Down's syndrome (Nada, Salima)	2	
	Osteogenesis imperfecta (Laila)	1	
	Epilepsy (Abdulah)	1	
		Total	11 (35)
Depression	Epilepsy (Hanan, Hael, Hamed, Karim, Saeed)	5	
	Speech problem (Thamer)	1	
	Mild cerebal palsy (Reem)	1	
		Total	7 (23)
Guilt Feelings	Develomental delay (Abdu, Hadeel, Ibrahim, Nabiha, Nawal, Naila, Waleed)	7	
	Polio (Fawzia, Salman, Wadha)	3	
			Total
Grief	Juvenile rheumatoid arthritis (Ahmed)	1	
		Total	1 (3)
Questioning Life	Tetraplegia (Mohammed)	1	
	Hemiplegia (Fahad)	1	
			Total
Total		<u>31</u>	<u>100</u>

5.4.2.1 Shock

In the present study all the families said they experienced shock yet certain families were more shocked than others. A third (11/31) of the families expressed shock as their first dominant reaction.

Shock occurred when a newborn child was suddenly given an unexpected firm diagnosis of impairment (e.g. cerebral palsy, rubella). Also where the impairment is incomprehensible (e.g. in Saudi Arabia rubella syndrome or osteogenesis imperfecta) and where the parents had evergrowing awareness that there was something severely wrong but which others (especially professionals) did not seem to recognise (the children with undiagnosed deafness). Shock also particularly occurs when an impairment carries a profound social stigma (e.g. epilepsy), but only one amongst such parents described first reaction as particular shock (see Box 6). The others described profound depression as their first dominant reactions.

Box 6

The first reaction of shock on being told about the impairment

"I felt as if I would faint, as if I lost consciousness of everything, stunned, though others did not seem to be aware of what I was going through. People would talk to me, I did not hear them.

Often study parents said "I felt my chest narrow" (Arabic "*Ana hasaet dag sadry*"). Everyone knows this means someone feels unhappy, strung up, deeply concerned. This reaction was shown to all types of impairment in the present study except paralysis (of tetraplegia, hemiplegia and polio) and developmental delay.

Shock seemed less likely in impairments where parents only gradually become aware of a problem, such as in developmental delay, and with disabilities that are more common, more

well known and thus less unexpected. 30 per cent of beds in hospitals in Saudi Arabia are occupied by people injured in car accidents (Ministry of Health, 1981), so hemiplegia, tetraplegia etc are now well known. The difficulties for the child with hemiplegia gradually became obvious over a period of one year, giving time for the parents to adjust without a phase of acute shock.

5.4.2.2 Depression

In a number of families a dominant early reaction was profound depression, lowered self-esteem, and a feeling of worthlessness. This was mentioned by seven of the 31 parents, that is the five children with epilepsy (see box 7) one of the families who had a child with speech problems (Thamer); and the family with a child with mild cerebral palsy (Reem). The other family with a child with epilepsy expressed depression also, but secondary to shock. Reem's family were in America, away from home and away from their family with their first child. They were trying to keep the diagnosis a secret from the family. This led to their feeling of depression because of being unable to share their sorrow with anyone.

It seems profound depression is more likely when the parents are trying to conceal the impairment, either because they fear the social reactions (epilepsy or Thamer with speech problems) or because they are away from the wider family. Profound depression may also have been due to the marital conflict situation which isolated Thamer's mother.

Box 7

Profound depression as reaction to diagnosis of epilepsy and thinking the child has been possessed by a Jinn or a fairy, who even marks the EEG (e.g. Hanan)

The profound depression in response to a diagnosis of epilepsy was probably largely a response of the social stigma of epilepsy. The parents think their child has been possessed by others. They think their child has been taken by a fairy or the Jinns, who in return have given their own child. Parents want their own child back. They go to traditional healers to do this. The traditional healers are part of the society, they are not usually separately identified. They take whatever is given to them for their work; no-one bargains with a traditional healer. They treat by reciting verses from the Quran and by giving herbs to the child. In the oral literature it is well known that parents can get their own child back through the help of traditional healers in this way. From medical literature it is well known that half the cases of seizures will subside and fade away anyway which may explain the apparent success of traditional treatment in the past.

Parents do not want to tell people the child has epilepsy as other people will be afraid of him. Their child is not a human being, the child is now a fairy. Even when the EEG is shown to parents they think that "the fairy is making the traces on the oscillograph". They think "the fairy is causing something in the brain to make the traces".

Box 8

Profound depression as a reaction to speech problems because of the cultural attributes of speech in the male in Arab society (Thamer)

For the child with speech problems in which the parents showed profound depression this was also a reflection of the cultural attributes to speech, particularly for the male in Arab society. Arabs are famous for their talking, which is highly valued in the society. For a child not to be able to talk is seen as a major "disfigurement". It is assumed that something is wrong in the child far deeper than the impairment itself.

When it is a boy, as in this particular case, a speech defect is of even greater concern. One of the outward signs of maleness is being able to speak well, whether in poetry, in recitation, or in giving speeches. A father will say to his child "Speak up, don't be like a girl". In a girl less speech is seen as part of femininity, and as part of the passivity which is valued in Saudi society.

In addition the mother of the child with speech difficulties was having to cope with knowledge of this impairment with little support from her husband or her eldest son, both of whom were often away.

5.4.2.3 Guilt

Immediate guilt feelings were found in the parents of the three children who had contracted polio (Salman, Wadha and Fawzia). Gradual onset of guilt feelings was observed in all the seven families with developmental delay. Parents blamed themselves for the child's disability and critically looked back on their attitudes and behaviour towards the child, e.g. consanguineous marriages, failing to attend antenatal care, inadequate immunisation of the child (see Box 9).

Box 9

Disability seen as punishment of the father (Hadeel)

Hadeel's father finds all forms of disability or deformity repellant. In the past he would make hurtful statements and often joked about anyone who he thought was not "normal". When his daughter was born mentally disabled, his first reaction was to run away and pretend that it had not happened. He did not run away though. He stayed and devoted many long years in an effort to provide a home for her to live in. He did not even question whether she would be more appropriately cared for within an institution. He felt that this was God's punishment for how he had behaved towards disabled persons in the years before his daughter was born. He lives with the daily belief that fate took steps to punish him.

5.4.2.4 Grief, anger and attribution to fate

Other dominant first reactions were grief and anger and questioning the meaning of life (see Box 10). Ahmed's father exhibited increasing grief as Ahmed's condition progressed and appeared incurable. In Salima's family (Down's syndrome, recognised at 4 years) the anger was directed almost entirely at the care provider. Attribution to fate and superstition can be one way parents find a reason for the impairment (see Box 10).

Box 10

Prolonged mourning for the well child lost; attribution to the Evil Eye, grief and resentment: "The doctors only prescribed aspirin as for headaches" (Ahmed, juvenile rheumatoid arthritis)

This prolonged mourning particularly referred to the child who had juvenile rheumatoid arthritis. The child is clever. The family were very proud of him, especially the father.

"Now we have lost him. Doctors took him in to the hospital and discharged him like a piece of cloth. He is good for nothing now." "They have not done their job properly. They give him aspirin you can buy from any supermarket or shop. Everyone knows aspirin is for headaches".

In Saudi society people fear the Evil Eye. With this child the father thinks that because he was top of the class something evil has caused this problem. Because the mourning for this child was prolonged this led to emotional stress within the family.

Questioning the meaning of life as a reaction to the impairment (Mohammed, tetraplegia; Fahad, hemiplegia)

Mohammed was severely injured in a car accident. He was unconscious, he might have died. So the parents at this stage said to me that if he had died then this anguish would be all finished and in some ways it would have been easier for them. To have survived that situation and to cope with the child alive but with such a grave impairment was very difficult for them.

With Fahad, the child with the hemiplegia the parents said they were always thinking and remembering that they had a beautiful child who they thought they had lost and every day they would look and feel sorry because of the impairment. The child is intelligent, can play with other children and is in every way fine except for the hemiplegia which causes the parents deep grief.

To illustrate the superstition of the influence of sad events on each other (Salman, polio)

Salman and his sister fell ill about the same time. The sister died, but Salman recovered with residual paralysis of his right leg. This is part of a commonly found belief in Saudi Arabia of the influence of sad events on each other. The reference to his sister's fatal illness came unexpectedly during the interview. The brief discussion about polio was preceded by talk of by Salman's sister's sickness and elaborate commentary of children's health problems, including the general neglect of children, and women's ignorance about doctors. It was at this point that the polio problem was recounted, followed by a discussion about his sister's death. It must weigh heavily on the parents' minds.

5.4.3 Later reactions

Once the impairment is apparent, parents seem to show opposing secondary types of response; either ignoring the problem (developmental delay) combining this with concealment (epilepsy) or struggle to get the disability recognised and diagnosed (most cases).

5.4.3.1 Ignoring the impairment, ignoring the child and concealment (and later concern about future prospects)

Nearly all (302) families whose children had minor impairment knew of it, and nearly all had chosen to ignore it. About half (44) of study parents of children with visual problems said that when they were told about the results they did not want their child to wear glasses, whether a girl or a boy. "Glasses are for old people. They are not right for a child. They are also dangerous when a child is playing. They might break and damage the eye." One of the parents of a child with hearing difficulties said that hearing aids on children are not liked at all. They said they would rather the child coped with difficulties than wear an object on the ear. All the 56 parents of children with learning difficulties said that labelling a child with learning difficulties carries great stigma in Saudi Arabia. They said they thought that such children would be sent to a special home for "stupid" people. They would prefer to hide the impairment as long as possible, perhaps until they can be married. One father said "What is in the pot will come out on the plate ... Time will tell; we will go on as we are till the problem becomes very noticeable."

There is also the view that children with learning difficulties have a special close relationship with God. They are a blessing to the family. Even with severe developmental delay the impairment tended to be ignored and the child was well looked after. For all the children with epilepsy the families went to great lengths to conceal the problem. For one child the reaction was to totally ignore her (see Box 11). As the children grow older, families are likely to face situations to which there will be a large range of reactions. One particular concern is marriage prospects.

Box 11

Ignoring the child entirely (Hadeel, developmental delay)

Hadeel was ignored by her parents. Her father was brilliant and very well educated abroad to a PhD. All the time he tended to value intelligent people. He made fun of people who were not bright and could not tolerate anyone who was at all slow. Hadeel was diagnosed early with developmental delay. The father knew the meaning of the diagnosis and so accepted referral to find out exactly what was wrong with his daughter. Once the diagnosis was confirmed and the problem made known to him, he ignored her and she was not his child any more.

5.5 Acceptance

5.5.1 Introduction

The acceptance of a child with a disability, like reactions, is also affected by a number of factors unrelated to the impairment itself. These include the recognition by the parents and the pattern of relationships within the family, and the attitudes to the impairment in the wider community. This section identifies factors contributing towards acceptance and factors which delayed acceptance.

5.5.2 Factors contributing towards acceptance by the parents and family

5.5.2.1 Religious belief that hardship is rewarded by not complaining

Acceptance of developmental delay because of respect for their "closeness to God"

One reason that it is easier for the mothers of children with developmental delay, both minor and severe, to be patient is that Saudi society values such children (see Box 12).

Box 12

Religious compensation and coping strategies with Waleed (developmental delay)

Waleed's mother said that he was "taken into religion" by his grandfather. It seemed to be some way of compensating for the disability. She and the grandfather would ask him to recite certain verses from the Quran. She said it was good in the village for people to see this boy with a disability could recite the verses so nicely. Also the grandfather particularly appreciated the child saying the verses because children with developmental delay are considered to be close to God. Waleed did not reject this role but conformed to it. The attribution of the word "taib" or "good" to the child helped the family to recognise his achievement and facilitated his acceptance. They are seen as "dervishes", eg. Waleed's Grandfather referred to him as a dervish not intelligent, but very good and close to Allah, more spiritual than others. He was considered to be as such because he did not care about this life. The family take blessing from Waleed. The dervish look apathetic in the way of people with a mental handicap but this is interpreted as being because they can see something we cannot see. They are thought to be nice people, very spiritual, with a gift similar to telepathy keeping them in touch with things of the Spirit. They are so devoted they do not think about life in the same way as others. Just occasionally the term dervish is used as an abuse, a polite way of saying someone is stupid, but always good ("*taib*"). It is thought there is always a good component to be found in such a person.

Attitudes to poor "mothering"

Where mothering and caring does not take place the whole family may be deeply criticised (Box 13).

Box 13

Lack of mothering criticised as it reflects on the neighbours also (Hadeel) (Mosques as a social force in the care of disability)

Hadeel's parents said they felt in peoples' eyes their disregard by others because they had rejected their child. Nothing was said overtly, it was the way people looked. People considered the family "does not fear God", because they are seen that they do not take care of the child. The father was told by the Imam (the leader of the prayers in the mosque) that this was what people were saying. The Imam had been told this by the men after daily prayers.

(Men come five times a day to pray. In social gathering between prayers, people sit and talk, and greet one another. The men must make sure they do not interfere in other people's affairs. When they talk of their concern for Hadeel with the Imam, they say it is woman-talk. They have heard of the problems through their wives and their children. This is the usual way information spreads. When there are problems that people feel they are not really supposed to know about they say "I learned it from the Harem", or "the children told me". This then enables people to talk about social problems but at the same time saying that it is a rumour. The Imam could then go to Hadeel's parents and help by letting them know what has been said. This process is an important role of the mosque in Saudi culture.)

Overall Hadeel's situation shows how much the society values the usual mothering that is shown to a disabled child. These mothers are considered to be heroes. Their self-esteem is greatly enhanced in their motherhood. In life good things will happen to them. "After death they will have more reward than will be due than to even someone who has been a martyr (Shahid)".

It needs to be recognised that all the praise and reward for care of the child with an impairment only applies to the children with severe physical disability or developmental delay and not to the stigmatised situation of epilepsy.

5.5.2.2 Facing the reality

Mohammed's father explained that once faced with the disability, he had no choice and said

"Well, all I can say is, I have faith in Allah".

The parents of the children with congenital rubella and osteogenesis imperfecta were realistic.

They said the reason for their realistic approach was because they had seen effective interventions from the medical services, particularly treatment of cataract, palliative treatment, and the management of fractures.

5.5.2.3 Physical attractiveness in the child

Personal attributes of the child influence acceptance (see Box 29). Wadha was, however, the only one of her age group being prepared for marriage.

Box 14

Physical attractiveness affecting acceptance (Wadha, poliomyelitis)

In Wadha's case where her exceptional physical attractiveness heightened her chances of marriage, her impairment (due to polio) was more readily accepted by her parents and the community.

Cousin marriage is usual in Saudi Arabia, but if there is an impairment usually the family would not mention the subject of marriage. However in Wadha's case more than one cousin had been asking to marry her. She is also a very shy girl. This is seen as an addition to her beauty, people think shyness and timidity is very good, a feminine attribute which they value.

5.5.2.4 Attractive personality in the child (e.g. sense of humour)

Abdu's great sense of humour amongst his school friends, teacher and family made him very acceptable within this immediate circle and his family (Box 15).

Box 15

A case to illustrate that talent alone in the disabled child will improve his acceptance by family and community (Abdu)

The parents think that Abdu is really intelligent and amusing and his humorous acts help to hide his disability.

He has a particular type of verbal humour which makes him popular at school.

5.5.2.5 Religious devotion by the child

The parents told me that Waleed (developmental delay) was reared by his paternal grandfather who felt it would be beneficial for Waleed if he became devout in religion (see Box 16).

Box 16

Religious devotion helping acceptance (Waleed)

If a child is very good he can lead the prayers. He can become well respected in the Mosque as somebody who is devout. He does not have to go to school to learn, to acquire esteem in another way, no one need label him as disabled if he can do these things in the Mosque situation. This was why the grandfather did not want Waleed to go to an ordinary school. He had begun to learn some verses of the Quran by heart and function well in a devotional setting of the Quranic school (see also Box 12).

5.5.2.6 Creating for the child an environment where he can achieve

Relatively normal lifestyles

Enabling the child to be in an achieving environment came about in several different ways. In fourteen families there was a positive family environment which encouraged a relatively normal lifestyle with minimal change from what is usual. This was so for the seven children with developmental delay, for the six children with epilepsy (because of the need for concealment) and for the child with mild cerebral palsy, overall a total of fourteen in the sample. Another way to show "normality" was preparation for marriage at the customary age.

5.5.2.7 Accepting the child for what they can do

Nema's mother said:

"Well I naturally wish Nema was normal, but it is not good to keep longing for her to do things that I know she cannot do. I have just got to accept her for what she can do."

One child, Waleed, spent his first five years in a village where he was well adjusted. Later in Riyadh and at school he and his parents became aware that he was a failure. He was sent back to the village. Living in the village again was not simply a practical change. The new environment touched Waleed personally and brought about a growth of his own identification and his views of the impairment. The parents said that it was only after Waleed's return from the modern western life of KAMA to the family in their village that they resolved his problems. He was helped because he had moved back into a familiar and less complex environment where he could effectively carry out his expected domestic chores.

Box 17

Helping acceptance by changing the environment (Waleed, developmental delay)

Waleed was born in a village, where the streets were unpaved, there was no electricity and camels were common. His father was a government employee, who left for Riyadh soon after Waleed was born. His first five years were spent in the village, where his farmer grandfather helped to raise him in a very religious home.

Waleed's mother was concerned that Waleed should receive a formal education, although neither parent had expected very much from school attendance.

At the age of nine, Waleed was good natured and obliging, but when left alone would often stare into space. Although he developed a close relationship with his father, he had few school friends. His academic progress was very limited and he failed all his annual examinations and tests. His reading and number skills were several years behind his chronological age.

Thus both educationally and socially school made him feel out of place. There was general recognition that by staying in this environment, Waleed's self esteem would be impaired and so he was returned to his village.

On his return, he recognised that he had lost some of the village skills. He said:

"I had been so long at the school and the farm animals were exciting for me to see, the goats, the hens, the calves, the dogs. But I had lost the skill to look after them. Some hens died because I did not look after them properly."

"I spent my time catching birds in the desert. In the desert there was a big tank of water, and there I learned to swim. Early in the morning I would go out and look for things to sell: fruit, eggs, or hens. Whatever I found, I sold to the "bagal" (grocer)."

Once the child was recognised as not being very clever or with learning difficulties, all the 56 parents said they had taken their children to the traditional healer. This is for a blessing, a process to "help them on their way". It may also help the family to accept the child for what he is able to do.

5.5.2.8 Extended family support

The extended family in the community studied did not provide much in the way of practical help and support except at delivery (e.g. in Nada's case). The support is important, similar to that of the traditional healers. Grandparents provided moral support, relieved stress and helped with the acceptance of the child. For example, Waleed's grandparents always referred to him as a "good boy" (good - indicating someone who is likeable but simple and most of all, accepted).

Nada's grandmother also gave particular emotional support and companionship.

Box 18

Grandmother support to help acceptance of Nada, Down's syndrome

Nada's parents began to cope. The mother said the grandmother was very supportive. She said the children in the house were too young to understand. All they knew was that they had a little baby sister whom they loved even if she did have funny eyes! However, the family still had not told relatives and friends, and Nada's mother found she could not go outside the house because she felt she could not face the neighbours. It was the grandmother who helped her to do so.

However, for some children there was very little interaction with the extended family, for instance, Amna and Abdulaziz, where the grandparents lived far away.

Table 5.13**Factors contributing towards acceptance of the child and the impairment***

Factors	No.
1. Religious belief (all cases of developmental delay except Hadeel)	6
2. Facing the reality (e.g. Mohammed, tetraplegia) or experience of good services (rubella (2 cases), osteogenesis imperfecta (1))	4
3. Physical attractiveness in the child (Wadha, polio)	1
4. A pleasant personality in the child (Abdu, developmental delay)	1
5. Religious devotion of the child (Waleed, developmental delay)	1
6. Bringing up the child in an achieving environment	
(a) positive near normal environment	12
(b) adjusted environment using services for support	4
(c) Changing the environment through a job (Ibrahim)	1
(d) Changing the environment to a rural area (Waleed)	1
Total achieving environment	18
7. Extended family support (Nada, Waleed)	2
8. Neighbourhood support (all neighbours except for Hadeel)	30

* Some children's parents showed more than one of these characteristics.

5.5.3 Family factors delaying acceptance

5.5.3.1 Emotional exhaustion and prolonged questioning

The process of parents coming to terms with their child's impairment can be prolonged and emotionally exhausting.

Box 19

Prolonged and emotional exhaustion, delaying acceptance (Ahmed)

Ahmed's father explained his severe mental distress due to his son's impairment. He said that his resignation to the impairment eventually exhausted his capacity for worry. He had worried so much and for so long that he could no longer do anything except the practical necessities without really thinking about what he was doing.

"Well, I have got so much trouble and nobody to share it with me. I have got it so hard now that I really do not seem to have any more feelings left".

He did not take Ahmed shopping any more. He simply delivered him from place to place.

5.5.3.2 Over-burdened mothers

There were considerable problems when mothers felt they must do everything for the child and that no one else should help as it will reflect badly on the quality of their mothering.

The mothers of children with epilepsy also provided nearly all the care because they felt their children would not be appreciated by the community. As described above, at the same time the burden increased the mother's esteem for herself in being able to provide total care for her child. Reward in after life is also expected according to Islam. In providing total care the mother could also conceal her child's condition, thus avoiding a stigma being placed on her family. Yet the burden was excessive.

Apart from the children with severe impairment the other group in whom the mothers were very over-burdened with providing nearly all the care were the children with epilepsy. This was associated with the need to conceal the problem.

5.5.3.3 Denial of the impairment, especially in the very young and for minor impairments

Pretending that the child does not have an impairment

When most of the study parents were asked about how they came to accept the child, 24 (77%) had very little to say. For example, Wadha's father said "She has never been disabled as far as we are concerned, because she has never been that bad. She does exactly as others do. She only walks lamely, but still can walk." This was denial of the impairment in the form of minimising it. This avoided labelling and consequences for the child's future especially her marriage prospects. It also showed the parents' total acceptance of their daughter.

Denying the cause of the impairment

Ahmed (juvenile rheumatoid arthritis) is an example of this situation. His father denied the medical cause and was considerably occupied with 'shopping around' to identify why the impairment had happened and to find what could be done about it.

Box 20

Denying the cause of the disability and delaying the acceptance (Ahmed)

Ahmed's father produced what he believed to be rational explanations of the impairment. He felt it had come about because of 'spiritual evil', he did not believe anything could be done. Denying the real consequences of the child's impairment he refused rehabilitation and greatly reduced the potential benefits of it to the child and his family.

Salman with poliomyelitis was in a similar situation in some ways. The parents could not or did not want to recognise that lack of immunisation had been the cause of the problem. They tried to connect the problem with the death of his sister just around the time that Salman's illness occurred.

Minor impairment tends not to be accepted. All the study parents of young children with visual problems said the problems were too minor to justify a lot of time on consultations, etc. Minor impairments may be "doctor exaggeration", not really relevant to daily living.

Denial of the impairment while the child is young, and the impairment is not so noticeable

It is often the case that when a child is very young an impairment is not so apparent as when the child is older. This was particularly the case with the children who had developmental delay, where the problem did not really show badly until they were at school. One of the reasons why developmental delay is not well recognised in Saudi Arabia is because it is not an important factor in daily living in a society where education is not crucial for esteem.

The mothers of two children, with cerebral palsy, said their children "had a normal infancy". They found the impairment was, to some extent, more acceptable when the children were young and they needed only to face the implications as they grew older (see Box 21).

Box 21**Denying the impairment (Abdulaziz and Amna)**

Abdulaziz's mother said:

"You do not realise that your child is going to be that disabled and you do not face up to it. You will not see it. I went through a period when I did not want to go to meetings of the disability clinic at Riyadh military hospital mostly because I did not want to see the older children. I think you go through a phase when you think abnormalities will never be like that. This is not going to happen to me".

Amna's mother said:

"I must confess that the disability clinic depresses me terribly. I have only to see the various children there and you cannot but wonder if your own child will be like that."

Pretending the child is not there, ignoring him and over-delegation of care to others

This occurred with only one child, Hadeel, where both parents rejected the child entirely. The child was perceived as an intruder, a strange person, an unknown persona, a foreigner, encroaching on the family group.

Thamer's father also rejected him and maltreated him - he beat him - but his mother loved him.

5.5.3.4 Dealing with the visibility of the impairment

Overall, visibility is important because it can delay acceptance (for example the socially unacceptable drooling in Amna and Abdulaziz both of whom had cerebral palsy).

5.5.3.5 Overcoming stigma, labelling and insensitivity in the community

Socio-cultural factors influence every community. Certain aspects of the impairment such as; clumsiness in mild cerebral palsy, seizures in epilepsy, drooling in cerebral palsy and limb deformity in tetraplegia are labelled socially unacceptable in these situations. The process of coming to terms with the child's impairment can become prolonged and painful.

5.5.3.6 Too high expectations

Too high expectation showed in a number of ways. Some children were so severely disabled that they could not even go to a special school, Salman's (polio) parents had very high expectations, for him to go on to higher education. This presents a formidable challenge because the university refuses admission to those with physical impairment.

In Ibrahim's case (developmental delay) despite his failure in tests on several occasions his parents wanted him to continue as they felt that he could achieve more. In fact it was too much for him. The school eventually expelled Ibrahim. The parents then put him in the night school to try and ensure that he achieved what they expected.

5.5.3.7 Too low expectations of suitability for marriage

Parents of children with severe disabilities assumed that marriage was an area of normal life from which their children will be excluded. This was particularly so because they saw their children as physically unattractive in such an intimate relationship. It is not just the parents who thought like this. The neighbours, the community, the parents' of the cousins who they might have married also thought the same way.

5.5.3.8 Over-dependence on the mother in late childhood and adolescence, or over-delegation of care to others

Very close emotional ties exist between the parents and the severely disabled children particularly between the mother and the child. It was very hard for the parents to accept that the developing adolescent needed to become more independent emotionally. It is made even more difficult by the nature of their physical status. The children were dependent on their parents for daily living activities. The adolescent may be babied and protected and so may find it almost impossible to develop any meaningful autonomy at all.

Table 5.14 Family factors delaying acceptance of the impairment.

Factors	No.
1. Prolonged emotional exhaustion (Ahmed, Juvenile rheumatoid),	1
2. Denial of the impairment. All children with developmental delays (which the child young and the impairment not noticeable)	6
3. Dealing with visibility aspects	
Wadha (polio)	1
Ahmed (juvenile rheumatoid arthritis)	1
Amna (Cerebral palsy)	
Abdulaziz (Cerebral palsy)	
4. Overcoming stigma and labelling in the community	
All children with epilepsy	6
Mohammed (paraplegia)	
Abdulaziz (CP), Amna (CP), Fawzia (Polio)	2
Reem (mild CP)	1
5. Too high expectations	
Salman (Polio)	
Amna (CP)	
6. Too low expectations	1
Wadha (Polio)	
7. Over-dependence on the mother	
All children with epilepsy	6
Nada (Down's Syndrome)	1
Mohammed (Tetraplegic)	1
Amna and Abdul Aziz (CP)	2
Hadeel (developmental delay)	1
Thamer	1

5.5.4 Child factors affecting acceptance

5.5.4.1 Introduction

How a child reacts to an impairment will influence his personal growth. If the child feels inferior to his peers or is treated as if he has an illness, the coming to terms with the disability is much delayed.

5.5.4.2 Acceptance of the impairment by the child

The parents said that as Wadha became older and arrangements were progressing in the usual way for marriage, it was obviously a great help to her self-esteem. Salman (polio) also had high self-esteem. Since he was good at his studies and had the ability to attend university if he would be allowed. Waleed (developmental delay) was accepted by the grandfather and this greatly increased his self-esteem. Abdul (development delay) was appreciated as a joker which greatly enhanced his self-esteem. Reem received a prize in her class which greatly helped to improve her perception of herself. Ibrahim's low self-esteem was raised when as a result of night school he was able to attend vocational training.

5.5.4.3 Non-acceptance of the impairment by the child

Feelings of frustration, inadequacy and open rebellion are made more likely by parents who refuse to accept the fact of the child's medical diagnosis (Ahmed's father) or the child as a person (Hadeel's parents). Children said to be spiritually possessed and treated as inferior, i.e. those with epilepsy and developmental delay, find it difficult to come to terms with their impairment.

Table 5.15 shows some of the ways in which a lowering of self-esteem occurred.

Table 5.15 How children were treated in the family		
Condition	Type of Impairment	No of children (N = 31)
Treated as chronically sick	Polio (Fawzia, Wadha, Salman)	3
	Deafness (Iman, Turki, Sa'ad)	3
	Developmental delay (Naila)	1
Treated as spiritually possessed	Epilepsy	6
Treated as a stranger	Speech problem (Thamer)	1
Negative attitude to child	Developmental delay (Hadeel)	1
Treated as inferior	Developmental delay	5
Intimate contact with sympathy	The rest of the group	11

Emotional problems were apparent in several children. One cause was the need to compete with other children (Salman and Reem). Hadeel knew she was rejected. Thamer knew he was badly treated by his father and brothers. The personality development of the disabled child depended on the severity of the disability and how much intervention including counselling followed. It was obvious that those with impairments like the rubella syndrome (Nora and Nema), cerebral palsy (Amna and Abdulaziz), and Down's syndrome (Nada) had received less functional help and therefore fared poorly compared with those with other impairments.

5.5.5 Positive community factors leading to greater and earlier acceptance

5.5.5.1 Neighbourhood support

The families reported that almost all the neighbours were highly supportive of them. The Prophet has said that people cannot believe in God unless they take care of their neighbours. Neighbours gave excellent practical help and support to families. In Hadeel's case the neighbours were concerned about what was happening as it reflected on them as well as on the family. Neighbours did not go and interfere, but stood by and admired the way in which mothers were coping and thus gave the mothers the support they needed. There was one exception, Fawzia (see 5.5.6.1).

5.5.5.2 Employment providing self reliance and improved social adjustment

In another situation Ibrahim was able to find an achieving environment through the job that he obtained. From being over-dependent, isolated, and with poor self-esteem he became well adjusted and more self-reliant socially.

5.5.6 Negative community factors delaying acceptance

5.5.6.1 Stigma, labelling and insensitivity in the community

Insensitivity and ignorance in the community can affect the disabled child's ability to cope with the impairment. For instance, Fawzia (poliomyelitis) experienced name calling, not only from her peers but from one of her teachers who referred to her as the "lame one". Neighbours also referred to Fawzia's lameness as laziness in a derogatory manner. Although her impairment

was slight, the community's attitudes have reinforced any negative feelings the parents had towards their daughter.

5.5.6.2 Pressure from the community on parents to deny the child's impairment

In five out of seven developmentally delayed children who were attending the ordinary schools, there were strong pressures by the extended family and the clan upon parents "to deny their children's impairment and to make the child normal" (by pushing them hard).

Denial was expressed as insistence on mainstream schools for children with learning difficulties regardless of their progress or educational abilities. Four of the seven with developmental delay were attending ordinary schools. One child (Naila) was at special school. One was of pre-school age and one (Hadeel) was excluded from school. The emphasis was placed on the achievement of independence by the child in preparation for them to take their place in "the normal world of work and social interaction".

The parents did not wish to change their own lifestyle and wanted things to be considered normal. If the child was going to a special school, they would not look like an ordinary family.

5.5.6.3 Lack of support from health professionals

Health professionals had done little for most of the children. They had given a diagnosis, said they were sorry and nothing more. This was apparent from the records and parents' reports. There was little attention to any social or psychological problems or worries, and thus very little support.

5.5.7 Conclusions on parental acceptance

5.5.7.1 The distinction between acceptance of the child and acceptance of the child's impairment

Distinction needs to be drawn between acceptance of the child and acceptance of the impairment. Only one child was clearly rejected and all 30 others, even when the child was unresponsive, were lovingly cared for by their families. Although the effect of the impairment on the family was complex, the following four patterns were distinguishable.

(a) Rejection of the child (Hadeel) because of the impairment

The parents were unable to distinguish their daughter from her impairment, even after the passage of time. As stated earlier, this occurred in only one child.

(b) Family resources diminished

The emotional and physical demands that the child placed on the family because of their impairments took up time and energy. This was the case in four of the children, the two children with cerebral palsy (Amna and Abdulaziz), the child with tetraplegia (Mohammed) and one of the children with Down's syndrome (Nada).

(c) "Strain" on the family

Where the cause of the impairment was not established for some time, or where the prognosis was vague, such as in the children with developmental delay, and those with rubella syndrome, the confusion in the family's mind led to emotional problems. The families' expectations and roles were ambiguous, depending on the current manner in which their children's impairments were seen and the difficulty of trying to adapt to uncertain expectations.

This was particularly accentuated in one child (Ahmed), who had juvenile rheumatoid arthritis, where the diagnosis was not firmly established and the condition was unknown. In this family the emotional stress was severe.

The impairment in the six children with epilepsy was understood, however. The stress in these families seemed to be due to their being obliged to conceal the impairment.

(d) Realistic adjustment

In the families where the diagnosis, although unwelcome, was straightforward and visible, the child and the impairment were more readily accepted.

5.5.7.2 Emotional problems

Even more important than the physical work was the emotional demand on the family. It is shown by the strain put on the family when the expectations and roles are ambiguous as in the case of developmental delay. Emotional stress was greater when the impairment carried a stigma, e.g. epilepsy (requiring concealment) and was also great when acceptance was delayed for any reason.

5.6 Coping with the needs of daily living

5.6.1 Introduction

5.6.1.1 Introduction

Coping has to do with the everyday processes of living. The needs of daily living revolve around a variety of routines such as washing, dressing, grooming, toileting, feeding and sleeping. Other aspects of coping enquired into were moving around; communication and social adjustment; discipline; play and leisure; sharing the care of the child; and worries and concern

about the future. Ten aspects of coping are considered in this section, and specific problems with each described as well as the solutions which families have already found and opportunities for the future. The routines need to blend harmoniously with similar routines of other members of the family. The first requirement is of course for independence so that the child is able to perform all these routines for himself with as little help as possible.

5.6.1.2 Sleeping

Three children had particular sleeping problems, Nada, with Down's syndrome, and Amna and Abdulaziz with severe cerebral palsy. It is very difficult for them to adjust to the usual family sleeping patterns.

5.6.1.3 Feeding/Eating

Eating was an issue for four children. The difficulties with feeding included clumsiness, difficulty in swallowing food, and socially unacceptable guttural noises accompanying eating. Although some of the children took a long time to feed, this was not as important as the problems listed above.

Box 22

Difficulties in feeding Nada (Down's syndrome); Abdulaziz, Amna (cerebral palsy); Reem (Down's syndrome)

Nada was a "floppy" child, her difficulties in feeding were associated with slowness in swallowing, and she consequently took a long time to feed. At the age of 12 months she was being fed at two to three hour intervals during the day and at four to six hour intervals at night. She could only feed when seated on her mother's lap.

Abdulaziz and Amna had difficulty in swallowing. The food had to be in liquid or very soft form and was often projected out of the child's mouth due to tongue thrust. The meal was very messy and the child had to wear protective clothing all the time. The guttural noises that accompanied eating were quite distressing for the family even though they had got used to them. Both these children are served their food separately from the family. Their mothers feed them before the rest of the family eat.

Reem was 12 years old with mild cerebral palsy. The parents said when eating, the girl often used both hands rather than one. She had difficulty getting the pieces of food into her mouth. She swallows and masticates well. In spite of her clumsy way of eating, she eats with the rest of the family. Eating with the right hand is the traditional Arabic practice. When Reem ate clumsily, the siblings began to laugh and her mother cried. Her father usually told her in a calm but sad voice that this was not the way one did things. The parents felt, through the laughter, the cutting and hurt, of their child's impairment.

Using this incident as the point of departure, the father then informed the author that the girl began to deprive herself of various types of food, to avoid distress. Knowing her own limits, she had not eaten food requiring skill (e.g. mangoes) until now.

There were also social sequelae. The self-inflicted prohibition of certain foods and the subsequent eating alone in a special room both show the socially disabling effect of her impairment.

When Reem had to accept a prize at the school, she was invited to a party. The eating utensils were placed in front of her, and she had barely touched them when she was assailed with great fright. How would she use them? Would it not be better for her to simply sit in her place and not expose herself to ridicule and pity? So she did not eat.

5.6.1.4 Dressing

There were seven children with particular problems with dressing.

Box 23

Difficulties in dressing (Nada, Abdulaziz and Amna (CP), Mohammed (tetraplegia), Ibrahim (developmental delay))

Dressing can be a worrisome experience for many children who have disabilities. They often cannot support themselves or do not understand if you want them to hold out an appropriate arm. As the children grow older it becomes increasingly difficult to manoeuvre them around to get the clothes in the right position.

An additional aspect of problems of dressing is where the children are incontinent or have "accidents". They will need to change clothes several times a day and this is an additional caring activity required, usually performed by the mother. The social implications of difficulties in dressing are shown by Amna. Amna's mother did not want people to come and see the child because sometimes she was not clean. The mother was very particular about this and did not want anybody to see the child in this situation.

Ibrahim's new job meant a new type of clothing. He began wearing Western clothing and learned quickly to get in and out of it. The only thing to which he did not adapt well was the tie. At first his brother tied it for him, and later bought him a clip-on tie. So Ibrahim learnt a new form of dress and the parents proudly recount Ibrahim's skill at dressing himself independently. His parents treated Ibrahim's ability to cope with Western dress, as an adjustment to the new environment. It was a form of social education.

5.6.1.5 Toileting

Five children had difficulties, again the children with the most problems were Abdulaziz, Amna and Nada. They were doubly incontinent. The others who required help getting to the toilet were Mohammed and Laila. Most of the children could cope with getting to and using to the toilet.

5.6.1.6 Moving around

Ten children had particular difficulty moving around. All the children needed to be carried except for Mohammed (tetraplegia) in his wheelchair. The four children with severe impairments (Abdulaziz, Amna, Mohammed and Nada) and also Laila (osteogenesis imperfecta) had particular difficulty in moving around.

5.6.1.7 Factors related to the impairment which affected social adjustment

Communication presented a particular difficulty for seven of the children; the three with deafness as a problem (Eman, Saad and Turki); Abdulaziz, Nada and Amna (the three profoundly disabled children); also Thamer with his speech difficulty.

Mothers demonstrated to a remarkable degree adaptations to deal with these communication difficulties. Even when the child's disability was so profound that there was little reward or feedback, the mothers talked to them continually in the hope of eventually gaining some response. The children were being treated very much in the same manner as the other children in the family. In some ways this is not surprising as all the mothers were also bringing up other children. Yet the difficulties in communication must not be under-estimated. If anything, the contrast between Mohammed, who was severely disabled physically but without any communication problem and the three profoundly disabled children, Abdulaziz, Nada and Amna show the contrast most strikingly.

i) Types of social adjustment within the family

Five types of social adjustment within the family could be identified from the study (see Table 5.16).

The first group were well received by the family and happily adjusted. This group comprised most of the children (N = 20).

In the second group, those with deafness (N = 3) and with speech problems (N = 1), the child often felt "picked on". There were often arguments with siblings, sometimes the child would start a fight, sometimes resisting discipline; and becoming moody from time to time.

In the third group, consisting of three children, Mohammed (tetraplegia), Fawzia (polio) and Reem (mild cerebral palsy), the children tended to stay in one room for a fair proportion of the time or watched television for hours seeming to exclude themselves from the family.

In the fourth group, made up of the three profoundly disabled children (Amna and Abdulaziz with cerebral palsy and Nada with Down's syndrome), communication was impossible. They were no longer part of the family and were rarely included in family activities.

One child had a different pattern (Hadeel with development delay), there was rarely any communication. She constantly disagreed with her parents; and almost always resisted family plans or broke family rules; she tended to be destructive and cried frequently, often without apparent reason.

Table 5.16 Social adjustment within family

Social Adjustment	Type of Impairment	No. of children	%
1. Gets along well with the family members	Most of the study sample	20	64
2. Not as well-liked as other members of the family	Deafness (Eman, Saad, Turki) Speech Problems (Thamer)	3 1 (4)	13
3. Often keeps to self	Paraplegia (Mohammed) Polio (Fawzia) Mild cerebral palsy (Reem)	1 1 1 (3)	10
4. So withdrawn he/she cannot be reached	Cerebral palsy (Amna and Abdulaziz) Down's syndrome (Nada)	2 1 (3)	10
5. Very isolated	Developmental delay (Hadeel)	1 (1)	3
Total		31	100

ii) Relationships with siblings

All the children in the study had at least three siblings, with seven in the largest family (Ibrahim) and in most of the families, four.

Brothers and sisters were involved in custodial care of their sibling with a disability and were fully recognised in this role by their parents and the community. Parents reveal that the older female siblings tended to have the heaviest caretaking responsibilities, which is as would be expected in the culture of Saudi Arabia. However, even when the older sisters are involved in helping, they do not necessarily take total care of the child. Sometimes an older sister helps by doing some of her mother's tasks, freeing her for the care of the disabled child.

Nine parents stated that there was expression of jealousy in the siblings towards the children with impairment. Parents inadvertently increased sibling jealousy when they tried to compensate for the child's impairments and show excess tenderness. The brothers and sisters may also have noticed a more relaxed disciplinary attitude towards the affected child.

Overall, the nature of child's impairment largely appeared to govern what the other children in the family did.

iii) Relationship to peers

Five types of relationship were noted (see Table 5.17). In the first group, comprising most of the sample (N = 19), the child with an impairment was well liked and participated in many peer activities. The child would seek out other children for companionship.

In the second group (Fawzia with polio and Reem with mild cerebral palsy), there were a few close friends but not a wide circle of friends; they tended to avoid organised activity.

In the third group five children were shy and had trouble in making or accepting friendships with peers. They tended to withdraw if any critical comments were made.

In the fourth group two children rarely take part in social activity and interact minimally. One was Thamer with speech impairment and the other Mohammed (tetraplegia).

In the fifth group of these severely impaired children there was no contact at all with the peer group.

Table 5.17 Relationship to peers

Relationship to Peers	Type of Impairment	No of Children	Total	%
1. Well-liked and participates in many peer activities	Most of the study group	19	19	61
2. Has some difficulty initiating friendships but can respond to others	Polio (Fawzia)	1	2	7
	Mild Cerebral palsy (Reem)	1		
3. Has trouble in making or accepting friendship	Rubella syndrome (Nora & Nema)	2	5	16
	Deafness (Turki, Saad & Eman)	3		
4. Is a loner	Speech Impairment (Thamer)	1	2	7
	paraplegia (Mohammed)	1		
5. No contact with peers	Severe Down's syndrome (Nada)	1	3	9
	Severe cerebral palsy (Amna and Abdulaziz)	2		
Total		31	31	100

5.6.1.8 Disabled child's behaviour leading to social difficulties

i) Patterns of anti-social behaviour

Some of the disabled children's social behaviour related to social isolation, lack of interaction, lack of comprehension, lack of communication, autistic behaviour, lack of confidence and rebelliousness (specifically mentioned for Hadeel, the child with developmental delay, who was rejected by the parents). These behaviours were detrimental to the individual child's social integration and are listed below.

Table 5.18 Behaviour leading to social difficulties

Eats in isolation	Reem (mild cerebral palsy) preferred this, because of her clumsiness
General social isolation	Fawzia (poliomyelitis) isolated herself because of name calling; Mohammed (tetraplegia) had very low self-esteem
Unpredictable behaviour	The three deaf children's behaviour was unpredictable as they did not understand what was going on
Lack of comprehension	Intellectual difficulties isolated the children from their peers (5 children with developmental delay and one child with Down's syndrome (Salima))
Withdrawal in company	Three children were withdrawn in company, Thamer (speech problem), Nora and Nema (rubella)
Rebellious	Hadeel (developmental delay) reacted rebelliously to her parents' rejection
Lack of self confidence	All the (6) children with epilepsy (and also Ibrahim - developmental delay) were always waiting for a signal as to what they should do to behave appropriately. They had become dependent on their siblings and parents because of the way they had been brought up

ii) **Child rearing patterns in relation to discipline**

The parents in general took a keen interest in the behaviour of their child. They took great pains to teach appropriate behaviour because they felt that, if neglected, it would hinder the development and acceptance of the child.

A third of the parents mentioned their main aim was to correctly channel their child's social behaviour. (This was particularly mentioned for the children with developmental delay and epilepsy.) Another third of the study group mentioned their concern to reduce behaviour that gets in the way of development. Thus, two thirds of the sample were concerned about child rearing with regard to control of behaviour, showing the importance of discipline. For two further children, Nora and Nema (both with the Rubella syndrome), the parents specifically mentioned "getting rid of unacceptable behaviour".

In some cases parents made excuses for the child by saying that they could not learn until they could talk (the three with deafness and Thamer with speech problems).

iii) Child maltreatment

Two children were maltreated, Thamer and Hadeel (see Box 24).

Box 24

Child maltreatment (Thamer)

Although his father and elder brother were often away on business, when they were present, they showed thoroughly unpleasant behaviour towards Thamer; they would beat him or push him away and would also be unpleasant to his mother on these occasions. His siblings were also treated in this way, but it was Thamer who was abused most.

5.6.1.9 Play and leisure activities

The child's play activities took place mainly in school for those who attended. The next most frequent play would be with siblings at home, and infrequently with friends.

Parents do attempt to reduce the time their child spent in spectator activities and encouraged them in more active leisure pursuits. They felt participation would increase acceptance by the peers and play a part in the cycle of social interaction. For boys with developmental delay, there was encouragement to participate in activities such as wrestling and football. However, for boys with epilepsy and all girls, there was discouragement of active play.

Not surprisingly, those children who were physically impaired had greater difficulty in being accepted into the ordinary play situations. The impairments particularly prevented them from participating fully in active boys' games (Ahmed with juvenile rheumatoid arthritis, Salman with polio, and Fahad with hemiplegia). The girls with some physical impairment were Laila, with osteogenesis imperfecta, Fawzia with polio lameness, Wadha with polio and Reem with mild cerebral palsy, but their physical problems restricted their play less than the boys since in the Saudi society girls do not engage in active play. Lack of stimulation for the profoundly impaired children was clearly occurring.

5.6.2 Sharing the care of the child or unwilling to leave the child in the care of others

5.6.2.1 Unwilling to share the care

Parents of the study children stated that up to the age of one year there was no difference in rearing a child with a disability compared with a normal child. At one year problems would become more obvious. The children with a severe impairment continued to be dependent even after the age of one.

5.6.2.2 Sharing in care by other family members

The role of brothers and sisters has already been described. Members of the extended family may help particularly for short periods. However, if there is a problem in the extended family,

sharing the care with them may also become difficult. For example, with the three children with deafness, the extended family did not like the idea of a special school. With Naila (developmental delay), she was in the special school and the extended family did not like it, despite the views of the teachers and some neighbours and friends, who suggested that this was a good thing for Naila.

5.6.2.3 Parents transferring responsibility to others

In the study group, Eman (deafness), Saad (deafness) and Naila (developmental delay) were at special schools, Turki (deafness) was on the waiting list and Waleed (developmental delay) had been sent back to his village to stay with his grandparents.

5.6.3 Worries, problems and exhaustion

5.6.3.1 Emotional demands on the mother

Even where parents were exhausted physically and emotionally a sense of accomplishment seemed to compensate them. Most compensated for their hard work through a religious approach of recognition of their caring.

5.6.3.2 The relationship between the parents' involvement in care of the child with the disability and exhaustion

Feelings of achievement was seen in seven cases, Reem with mild cerebral palsy, Salman and Wadha with polio, and Abdu, Naila, Waleed and Ibrahim with developmental delay.

Great exhaustion but low feelings of achievement were apparent in five families (Ahmed, juvenile rheumatoid arthritis; Abdulaziz and Amna (cerebral palsy); Nada (Down's syndrome) and Mohammed (tetraplegia).

5.6.3.3 Parents' worries and concerns about the future

The parents of the children in the study were asked what they thought was the children's main problem in developing normally. Nearly a third of the sample (N = 9) mentioned the problem of social integration and the stigma (largely associated with epilepsy), but also for Eman and Saad (with deafness) and Naila (with developmental delay). The problems of social isolation also featured largely for the same group of children. Mobility was a particular problem for seven children.

Educational difficulties were mentioned by all the parents whose children had developmental delay (5 of the 7 children with developmental delay were in normal school, one child, Hadeel, was not in school as she was too young) and also for Salman (poliomyelitis) with high expectations for this child. No special anxiety was mentioned by the parents of the one child with developmental delay in a special school (Naila).

Table 5.19 Parents' views on the affected children's main problem

Problem	Type of Impairment	No of. children	% ¹
Social stigma Integration	Epilepsy	6	19
	Deafness (Eman & Saad)	2	
	Developmental Delay (Naila)	<u>1</u>	
	Total	9	29
Communication	Deafness (Turki)	1	
	Speech problem (Thamer)	<u>1</u>	
	Total	2	6
Social Isolation	Developmental Delay (Hadeel)	1	
	Rubella syndrome	2	
	Polio (Fawzia & Wadha)	2	
	Mild cerebral palsy (Reem)	<u>1</u>	
	Total	6	19
Mobility	Cerebral palsy		
	Amna & Abdulaziz)	2	
	Down syndrome (Nada)	1	
	Paraplegia (Mohammed)	1	
	Hemiplegia (Fahad)	1	
	Juvenile Rheumatoid Arthritis (Ahmed)	1	
	Osteogenesis Imperfecta (Laila)	<u>1</u>	
	Total	7	22
Education	Developmental delay	6	
	Polio (Salman)	<u>1</u>	
	Total	7	22
Non-Specific	The rest of the study sample	<u>4</u>	13
	Total	31	

There is a huge gap in the provision of supportive services to those caring for a severely disabled child at home.

1. Some parents had more than one concern for the future

Table 5.20 The common problems parents tackled in coping with a child's disability

The Problem	Type of Impairment	No.of Children	%
Need to change work			
(a) Wants to move to the capital so the child can attend special school daily rather than residentially	Deafness Development delay (Naiwal) Hemiplegia (Fahad) Tetraplegia (Mohammed)	(3) (1) (1) <u>(1)</u>	
	Total	6	19
(b) Blamed by tradition, told by the elders they are not being parents (because they have transferred responsibility to the special schools)	Deafness	2	6
c) Interpersonal problems			
Between spouses	Speech problems (Thamer)	(1)	3
Other family members (do not accept special schools)	Deafness Developmental delay Naila (school)	(3) (1)	9
Conflict problems in family	Developmental delay (Hadeel)	<u>(1)</u>	<u>3</u>
	Total	6	19
TOTAL		14	44

Parents were also asked what were the main problems they themselves had had to face. Need to change the husband's work, being blamed through traditional ideas on parenting, and interpersonal problems were particularly mentioned (see Table 5.20).

5.6.3.4 The problem of low expectations

Underestimating the possible potential of a disabled child can be a considerable problem. It assumes that failure will be inevitable for that child with the result that parents do not set targets for the child. Effects that failure has on acceptance of the child by the parents are described in section 5.5.3.8.

The prime example of this problem of low expectations was Hadeel, a child with developmental delay. However, for the children with severe impairments (cerebral palsy, Amna and Abdulaziz, and Nada with Down's syndrome) there also tended to be an assumption of low expectations for the future. The same was also the case with Mohammed (tetraplegia), despite the fact that the parents know that he is intelligent.

5.6.3.5 The problem of uncertainty (and a lack of purpose)

Another potentially damaging feature which these children and their families have to overcome is uncertainty about their future. This situation was particularly found in the severely impaired children. Amna and Abdulaziz with cerebral palsy and Nada with Down's syndrome and with Mohammed with tetraplegia. However, nine parents seemed completely unaware of possible future problems, or appeared to be shelving them. This was the case with five of the children with developmental delay, the two with Down's syndrome and the two with cerebral palsy and one with tetraplegic.

5.6.3.6 Worry about integration into the community

Where there is uncertainty about suitable integration now in the community, this also raises questions about the future. Some parents already foresaw difficulties ahead, for a number of

others future problems were not a concern, and for several day-to-day living was the predominant worry.

5.6.3.7 Avoiding thought about the future

Parents of children with epilepsy were unable to reconcile themselves to the future and alternated between shame, sympathy and affection for the child with the impairment. Parents also felt little was apparently being done for their child's epilepsy and lost confidence in the care provider. At least one family seemed to be shelving the problem of the future.

Fahad's parents seemed unaware of future problems or appeared to be shelving them. The parents of Nada, Amna and Abdulaziz were able to see the future, but could not find any answers. Children with developmental delay did not feature as future concerns for parents. The parents of Laila, Ahmed and Ibrahim were concerned with the present rather than hopes or fears for the future.

Table 5.21 Parents views of problems relating to the future of their disabled child

1. 7 parents showed evidence of positive realistic planning for the future of their children. The medical diagnoses in the children were developmental delay, rubella syndrome, deafness and limited cerebral palsy.
2. 9 parents seemed unaware of future problems or appeared to be shelving them. The medical diagnoses were developmental delay, Down's syndrome and cerebral palsy.
3. 2 were able to see future problems which appeared bleak and they could not envisage the answers. These were the parents whose children had tetraplegia and hemiplegia.
4. Future problems of children with epilepsy and polio did not loom too large in the minds of the parents.
5. 4 parents were concerned with the present and immediate future of the child's disability in the case of osteogenesis imperfecta, juvenile rheumatoid arthritis, speech problems and developmental delay.

5.6.4 Styles of coping

5.6.4.1 Two approaches to coping and four strategies of coping in Saudi Arabia

Two basic coping approaches were evident. The first group brought the child up according to the norms for the family and society, even though the child might have very severe impairment. The second group segregated and excluded the child from normal life, either through a segregated school or through ignoring the child. The four strategies employed by the parents were coping well (positive passive), coping by ignoring the problem (negative passive), assertive coping (using services or action) or coping by denial and concealment (defensive coping).

The role of the home, community and institutions in helping or hindering coping is shown in Table 5.22.

Table 5.22 Summary of type of coping strategy* and the role of home, community and institution

	Coping helped or hindered at home	Coping helped or hindered in the community	Coping helped or hindered in institutions
<p>Coping well (positive passive coping)</p> <p>N = 22</p>	<p>Mohammed but hindered by the physical environment</p> <p>Very young profounded disabled N = 3 OK at home i.e. Amna, Abdulaziz, Nada</p> <p>Epilepsy N = 6 ok at home</p> <p>Development delay (6) ok at home</p> <p>Ahmed himself OK</p>	<p>Hadeel helped by Iman and neighbours</p>	<p>Development delay (1) (Naila)</p>
<p>Coping by ignoring the problem (negative passive coping)</p> <p>N = 7</p>	<p>Deafness ignored</p> <p>Hadeel ignored</p> <p>Ahmed's juvenile arthritis ignored</p> <p>Thamer's speech problem ignored</p>		<p>All institutionalised children socially cut off from friends and relatives at home</p>
<p>Assertive coping (using services/action to ensure coping)</p> <p>N = 4</p>		<p>Reem (helped by good services)</p>	<p>Deafness, all helped</p>
<p>Coping by denial/concealment (defensive coping)</p> <p>N = 16</p>	<p>Ahmed's impairment</p>	<p>Epilepsy (6) Dev. delay (7) Thamer (speech problem)</p>	

* Some families showed more than one strategy

5.6.4.2 Coping well (positive passive coping)

Many children (19) were coping well in one way or another. 17 were coping well enough in the home environment (even if not in the community). These were the 6 with epilepsy, 6 of the 7 with developmental delay, the very young profoundly disabled (3), Mohammed (tetraplegia) and Ahmed himself (although his parents ignored the impairment). Hadeel was helped in the community (although not at home), and the one development delay child (Naila) in an institution was also coping well there. Parents who are coping well are aware that their child has an impairment but however sad, they are not disheartened by the situation (see Box 25).

Box 25

Coping positively, but hampered by the physical environment

Architectural and mobility barriers seriously affect the patterns of social interaction of physically disabled children and subsequently their self-image. The severely disabled children experienced a baby-like dependency. The disruptive consequences of this dependency, particularly in the case of Mohammed (paraplegia) had far-reaching effects on his self-esteem and self-concept. Mohammed's redefinition of roles took place through social interaction with his family, friends and members of the community. The important difficulty for him was that his disability affected his interaction with others. Therefore he could not rely on old patterns and role expectations.

The parents' general problem was with understanding, i.e. the clarity of the diagnosis, degree and cause of impairment, the possibility of improvement and the future of the disabled child. For disabled children with developmental delay, polio and mild cerebral palsy, admission to ordinary schools was anticipated. For others, the possibility of admitting the child to a special school was a dilemma partly due to the fragmented care received.

5.6.4.3 Coping by ignoring the problem (negative passive coping)

In the home situation the deaf children were ignored, as was Thamer's speech problem. The social cutting off of children in institutions from their family, friends and relatives can also be seen as a form of ignoring the problem.

Parents adopting this coping style do not differ from the group above in their recognition of disability. However, they may dramatise their child's impairment to provoke feelings of empathy in their social circle. Alternatively they may passively ignore the problem. Acceptance of developmental delay was harder for Hadeel's highly educated parents (e.g. Hadeel), presumably because of their high aspirations for their child and their view of the child as a reflection of their own status, although no generalisation can be made from this one case.

5.6.4.4 Assertive coping (using services/action to ensure coping)

Reem's parents showed another strategy for coping. They differed in that they did not consider the impairment as a flaw although they were aware of it. Their approach was to try to change or improve the situation through improving the child's quality of life by providing for all basic needs in the best way possible. They understood her problem and were striving to make the best of the situation. Reem was at the top of her class for academic achievement.

5.6.4.5 Coping by denial and concealment (defensive coping)

These parents deny their child's impairment since a disabled child is viewed as being inferior to a non-disabled child, and every effort is made to conceal the disability (e.g. children with epilepsy). Children who had developmental delay were also concealed in public and so was Thamer (speech problem). Ahmed's impairment was denied for its medical causation and

ascribed to the supernatural instead. Denial and concealment was not necessary in the home situation for the children with developmental delay who coped there very well.

In the case of epilepsy, the parents felt that by concealment of the condition they were coping as well as protecting the child and siblings from name calling and stigma. This was one of the reasons why the parents had more frequent contact with the traditional healers than other parents of disabled children, but this was also due to their belief that impairment was due to an "evil eye". Hope is not lost because the parents believe their "lost" or "possessed" child will be returned to them as normal eventually.

Although families generally coped fairly well with their epileptic child they gave a false impression to outsiders regarding the child's condition. The children tended not to be regular attenders at clinics and were poor compliers of medication.

5.7 Parents' experiences of services both traditional and modern

5.7.1 Introduction

Parents tended to turn to all forms of treatment, traditional and modern, for their children's disability. Everyone of the study children had been taken to a traditional healer, and for every family the services of these healers had been of great value.

Just over half (18) of the 31 study children were of school age and at a stage of using the education services (13 were in main stream schools - 11 at primary school, 2 at intermediate level - half were doing well or better than average). Three children were in special school and 1 awaited special school. Two children had been taken out of school. It needs to be noted that a third of the deaf (1 out of 3) were not in special school nor were 86% (6/7) of those with

developmental delay. All except the families of the very severely impaired were anxious about the education of their children.

Medical care services used are described. Little had been done for minor impairments but all except Salman (poliomyelitis) had consulted medical services for severe impairment. Medication was regularly reviewed for the rubella children, but never for the children with epilepsy. Three children still awaited further referral. Seven had been admitted to hospital and treated, usually the paediatrician had been the first point of contact. Breaks in medication and irregular attendance are analysed together with the strengths and satisfaction, as well as the weaknesses and dissatisfaction of the medical services as seen by the parents.

5.7.2 Parents' experience of traditional healers

Traditional practitioners are part of the local community, culture and traditions, and continue to have a high social standing in many places, exerting considerable influence on local health practices. Many treat children with impairments by means of traditional medicines, charging fees for the treatment or occasionally providing services free of charge to try to help the families concerned. Some healers have a religious background and a few are quite famous (see Box 26).

Box 26

One well known traditional healer with modern medicine linkages who had been seen by all the children with developmental delay, and those with epilepsy

One traditional religious healer is an Associate College Professor. It is said that he exorcised a genie following recitation of verses from the Quran. Since that time, he has been given permission by the King to practice traditional medicine openly and he now works in Medina. His office is always very crowded. He never charges for his services. He gives water and olive oil at the time he is reciting the verses from the Quran. All the children with developmental delay and epilepsy had been to see this man. Sometimes he refers children with epilepsy to paediatric neurologists who are known to him.

All the 31 respondents whose children had severe impairment and all 56 with a child with minor learning difficulties had previous experience of treatment by a traditional healer. Some had seen the traditional healer regularly, particularly those with children suffering from developmental delay and with epilepsy. When this was found 25 traditional healers were interviewed to get an insight into their methods of work, and the results are summarised in Appendix 2.

Religious reasoning is often given for the occurrence of a problem as with Turki (deafness), "God did not want him to hear bad things", or with Salman, "It is God's will you should study theology" (rather than go to the civilian university, where the rules excluded those with a physical impairment).

Overall, the traditional healers will always give the parents a reason for how the impairment has arisen, in a way which fits into the cultural situation and that they can understand and readily accept.

5.7.3 Parents' experiences of schooling

5.7.3.1 Introduction

Most of the parents in the study (N = 28) felt that the educational needs of their children gave rise to anxiety. There was often little alternative to a mainstream school or to dropping out altogether, when the cultural pressures not to use special schools are taken into account. The advice given may be scanty and it may be very difficult in the cultural context for parents to follow the advice. The educational problems for the deaf children created a special dilemma. Parents were not sure whether to admit the child to a school for the deaf and sacrifice the integration possible in a mainstream school, or to face the risk of lower educational attainment if the child was kept in a mainstream school. The only parents who did not find education a

worry were those who had children with profound impairment (Amna, Abdulaziz, cerebral palsy, and Nada, Down's syndrome). They had come to terms with the situation.

5.7.3.2 Recognition of minor learning difficulties in school

All the children with minor learning difficulties had been recognised by the teachers through school performance. This shows how well teachers can act as the first level of recognition of learning difficulty. They could also be trained to be alert for hearing and vision problems.

5.7.3.3 Current education for the severe impairment group and mainstream school performance

13 children were currently in mainstream schools (see Table 5.23), and nearly half were doing well or better than the grade they were in. Three were in special residential schools and one had been on the waiting list for 2 years. There were no educational places for a 16 years old girl with severe cerebral palsy and one boy with developmental delay had been expelled from school.

Table 5.23 Mainstream school performance of children with severe impairment

Performance	Type of Impairment	No. of children N = 13 in school now	%
1. Working at expected or advanced level at the school	The rest of the group (Fawzia, Ahmed, Thamer, Reem, Salman & Wadha)	6	46
2. Is at grade level but achieving below the grade	Epilepsy (Saeed, Abdullah & Hamed)	3	23
3. May be one grade behind	Developmental delay (Abdu, Nawal & Nabiha)	3	23
4. More than one grade behind	Developmental delay	1	8
5. Never attended school	Developmental delay (Ibrahim) Cerebral palsy (Amna)	2	

The children differed a great deal in their work habits. Three of the children with epilepsy (group 2) were described as having difficulty in concentration but normally got their home work done though not as well as the other children. Those with developmental delay (group 3) were described as neglecting home work and rarely studying at home. On the other hand, six children had good study habits, worked efficiently and were creative and imaginative in their study. Two children had never been to school. There is a rule excluding entry to higher education for people with a physical impairment.

5.7.3.4 Special institutions: seen as an alien environment

Government legislation entitles children with impairments to admission in special schools. The legislation by itself does not provide the service. Such institutions are few. Turki (deaf) had been on the waiting list for 2 years for admission to a school for the deaf. Only 3 children with severe impairment out of 31 in this study were attending a special school. Two out of the three children who were deaf had been sent to special schools where intensive care and attention was provided. One child out of the seven with development delay had been sent to a special school.

5.7.3.5 Conflict between traditional and modern in the choice of education in developmental delay

The conflict between traditional and modern views on appropriate education in developmental delay was clearly apparent. Waleed's return to the village and its positive effect has been described. Naila shows the open conflict between generations on the matter (see Box 27).

Box 27**Conflict between the traditional and the modern: choice of education (Naila, developmental delay)**

The decision about Naila's school placement led to serious conflict within her family. Her parents opposed the traditional choice of her staying at home, whereas her grandparents and the rest of the extended family wanted her to do so. Her parents were convinced that if she studied at the special school, it would give her educational advantages which were important for her future in modern Saudi Arabia. The extended family held the view that she should not be sent away and that education did not matter for girls. The goal of attending special school was encouraged by the parents' friends and Naila's teachers. The decision that parents made had many implications, including that of cultural criticism, but it is significant that friends and teachers were able to persuade the parents that special school in the modernising Saudi Arabia was a positive step.

5.7.4 Parents' experiences of the medical services**5.7.4.1 Medical services for minor impairments**

Treatment of minor impairment comprised antibiotics for otitis media and the prescription of spectacles for vision problems or squint. Lack of follow-up of minor impairment was apparent from the study.

5.7.4.2 Medical services consulted by the parents for severe impairment

Parents of all children except one (Salman, poliomyelitis) had consulted medical professionals. Usually the paediatrician was the first point of contact, thereafter it was the relevant specialist (see Table 5.24).

Table 5.24 Medical Services parents had consulted

Whom Parents Consulted	Type of Impairment	No. of children	Total	%
Disabled child never checked	Polio	1	1	3
Ophthalmologist and Paediatrician and ENT Specialist	Rubella	2	12	39
	Developmental delay	7		
	Cerebral palsy	2		
	Mild cerebral palsy	1		
	Total			
Paediatrician only	Down's syndrome	2	10	33
	Juvenile rheumatoid arthritis	1		
	Hemiplegia	1		
	Epilepsy	6		
	Total			
Orthopaedic Surgeon	Polio	2	2	6
Orthopaedic Surgeon and Paediatrician	Ostogenesis Imperfecta	1	1	3
Team of Surgeons and Paediatricians	Tetraplegia		1	3
ENT specialist only	Deafness	3	4	13
	Speech problem	1		
	Total			
Total			31	100%

Medication was given and regularly reviewed for the two rubella children (Nora and Nema).

Medication was also given for the six children with epilepsy, but none of these children were reviewed again or followed-up.

Three children were on the waiting list for further referral, Turki (deafness) to a special school, Salman (poliomyelitis) to an orthopaedic surgeon and Hadeel (developmental delay) to a specialist with particular interest in disability.

In seven cases the children had been admitted to hospital and had received good follow-up treatment. All these families considered they had adjusted better to the impairment after the hospital admission and subsequent treatment. These were the rubella children (Nora and Nema); Fawzia and Wadha (poliomyelitis); Laila (osteogenesis imperfecta); Ahmed (juvenile rheumatoid arthritis) and Mohammed (tetraplegia). Six were operated on.

The majority of the children (28/31) were rehabilitated in the community though with varying parental opinions on the quality of these services, see below.

5.7.4.3 Breaks in medication and irregular attendance for treatment and reasons for this in children with severe disability

Irregular use (or in one case non-use) of medical services or medication advised was apparent in eighteen of the children.

For the six children with developmental delay (all except Naila, the one who did go to a special school), the parents said they did not want to see anyone at the medical centre because it would draw attention to the child's problems. They said there was no privacy. These parents obviously felt the social labelling would make things more difficult for them. They said there seemed no connection with the education services. They said different opinions caused worry and confusion. These children were all receiving treatment from traditional healers.

Three of the parents of the six children with epilepsy said they would not attend medical care as "people would then know" there was a problem of seizure. They also mentioned lack of privacy. Four families said they thought little was being done, they had lost confidence in the care provided. Children with epilepsy had been referred to the hospital only for presenting features of the disability such as recurrence of seizures. They had ceased further attendance when the presenting seizures had been appropriately treated. The parents seemed to alternate between shame, sympathy and affection for the disabled

child. Two sets of parents said they did not believe the medication could help at all. There also seemed to be an element of apathy. The parents seemed not to want to bother with medical services as if their problem was felt to lie in some other realm. For them it seemed more important to use the services of the traditional healer. These children were all receiving indigenous treatment.

For one child (Ahmed, juvenile rheumatoid arthritis) the parents said they resented the opinion expressed. They obviously failed to appreciate the condition. They then passed from one care provider to another "shopping around" for an alternative explanation and possible cure.

Four families discontinued treatment and follow-up because they found attendance difficult. Three parents said they had had problems with long waiting lists (Mohammed, tetraplegia; Abdulaziz and Amna, cerebral palsy; and Nada's, Down's syndrome). For the three with profound disability (Amna, Abdulaziz and Nada) the parents said they felt attendance was pointless, there was little that could be done. Amna's mother also said she thought that staff at the baby clinic did not have much experience of disability so had little to tell her. Amna's mother also had difficulties finding someone to look after her other children.

Salman (poliomyelitis) had never attended any medical services before the study started. His parents had not made any attempt to try to use the services, though once they were able to see the possibilities they were very keen to have the surgery for the child.

Difficulties due to the husband being at work were reported by all mothers. Women are not allowed to drive in Saudi Arabia, nor can they walk unaccompanied to a health facility. Hence the husband being at work prevents the women from getting any medical help if needed. Thus accessibility of health care is conditional on the presence of men at home. Visiting hours were also said to be at an awkward time.

5.7.4.4 Strengths and satisfaction, weaknesses and dissatisfaction in the medical services as perceived by the parents

Four of the families said the medical services had helped a great deal and met nearly all their needs (rubella syndrome, Nora and Nema; mild cerebral palsy, Reem; developmental delay, Naila).

Fifteen families said that most of their needs had been met, the services had helped them. This comprised the rest of the group except for the families with a child with epilepsy or developmental delay.

The six families with a child with epilepsy said the services had not helped at all. They said few services had been provided for their needs and little effort had been made by the services to help them.

All the parents said they felt they had been left to carry out the difficult task of bringing up the child alone without any firm guidance on ways to cope with the situation. They said they were not getting the services they needed.

The six families with the children with developmental delay (Hadeel, Abdu, Nawal, Ibrahim, Waleed, Nabiha) said the medical services seemed to make things worse. Nabiha's parents said they did not offer help to the family. It was difficult coping yet the medical people did not seem to realise the problems parents had. The services were certainly not meeting their needs.

5.7.4.5 Conclusions of parents' experiences of medical care services

Overall, it can be seen that the strengths of the medical care services were experienced only by the families of children who had been hospitalised.

Clear weakness in the provision of current medical care is apparent from the comments made by parents. They were worried about the future, yet there was little discussion on prognosis. Their emotional and social needs were largely unmet. Coordination of educational and medical services was so unsatisfactory that families of children with developmental delay had felt medical consultation made the situation worse. Insufficient use had been made of wider services such as vocational training (only started for Ibrahim because of this study); day care; physiotherapy; clinical psychology; speech therapy or various forms of educational support. There was an opportunity for leadership which had not been taken by the paediatricians in enabling access to this range of services from which many children would have benefitted. Rehabilitation was being seen more as care of the "sick" and medically oriented rather than a striving towards functional fitness for everyday living as far as possible. The lack of a well directed comprehensive coordinated provision of services; poor communication between care providers and parents, and the failure of care providers to acknowledge, let alone deal with parental feelings of discomfort or threat, was mentioned many times by the parents.

6. DISCUSSION

6.1 Introduction to discussion

This is a study of impairment and disability in a relatively privileged section of Saudi society. Even though care was taken to include all grades in the original sampling frame, the residents of the military academy (KAMA) enjoy better amenities compared to individuals in similar circumstances in the general population. Like parents everywhere, the Saudi parents of children with disability were seeking explanations and ways to rehabilitate their affected children.

This study has attempted to understand the feelings and anxieties of parents and how they have moved from recognition through reactions to acceptance and to coping. Each individual parent is unique, and each family's background is also unique. The same is also true about the affected children. These families' experiences are now discussed against the background of other studies.

This chapter is organised similarly to the Results into five sections, viz. Recognition, Reactions, Acceptance, Coping and Role of Services.

6.2 Recognition of the impairment

6.2.1 Defining recognition (see also Literature Review section 2.3)

It may be useful to distinguish recognition by the family and that by the health services. The present study has shown the important role of the family in recognising that "something is wrong" and "slow progress" in a child. This "family surveillance" is an important first step in

recognition. Only when "family recognition" has occurred will a child begin to be accepted for what he or she is able to do. Otherwise the child may be seen as a failure in not doing things that are expected. Family recognition determines service utilisation, because families will not initiate service use until they have recognised the impairment, particularly after a home delivery. Two thirds (20/31) of the children were born at home. Presence of any congenital disability will depend upon the recognition of abnormal appearance or behaviour. The delay in diagnosis ranged from birth to 13 years, for example, Down's syndrome diagnosed at the age of 4 years. Late diagnosis increases the shock of discovering an impairment in a child.

Recognition by the services (medical, social, educational or occupational) requires provision of key diagnostic procedures which will ensure an accurate assessment of the impairment and disability if present. Service recognition is also a form of labelling. In the present study even in those born in hospital, there was a measure of delay, but in general recognition of abnormality was early. Obvious impairments such as most cases of Down's syndrome and congenital rubella were diagnosed at birth. But hemiplegia and cerebral palsy took as long as 1 year to be confirmed. The more common an impairment, the greater are the chances of it being recognised (Hirst and Cooke, 1988). All services are limited by family recognition. Although some (surveillance) services precede family recognition, only when families also recognise the impairment can the services (traditional and modern) begin to help.

6.2.2 Prevalence rates

Some information on the size of the problem of disability internationally is shown in the introduction, section 1.2 and in the literature review section 2.1. Prevalence rates of some of the impairments in the present study are described in the results. In the cultural setting of Saudi Arabia the methods used in this study for obtaining an assessment of prevalence are practical and acceptable and as accurate as is possible.

6.2.2.1 Overall prevalence of disability

In industrial countries, a number of large-scale surveys indicate that about 10% of the population has some disability. In developing countries, some 100 studies, including surveys and official population counts, have been done. It is difficult to compare the results of the various studies because different methods were used. Nevertheless, it appears reasonable to conclude that 7 - 10% of the population in developing countries have a disability, which is less than in industrialised countries, but probably only because of under-reporting and lack of recognition of problems such as developmental delay (see literature review section 2.1). Numerically there are far more people with disabilities in the developing world because of large populations (see introduction section 1.2).

6.2.2.2 Types and prevalence of disability

Some comparative data is summarised below for minor impairments, poliomyelitis and road traffic accidents and for epilepsy, developmental delay and cerebral palsy.

1. Types and prevalence of disability: minor impairments, poliomyelitis and RTAs

i) Minor impairments

The total child disability rate in 0-15 year olds was found to be 3.9% for minor impairments in the present study. When severe impairment in children is included the child disability rate in 0-15 year olds is 4.3% of the total population. This compares with an under 15 rate of disability in the UK (surveyed in 1985-1986) of a slightly lower 3.2% of the total population (WHO, 1990) and with an Ethiopian study in 1981 showing a much lower 0-15 rate of 0.2% probably due to extensive under-reporting (WHO, 1990). In Bangladesh amongst 2-9 year olds screened with the rapid ten questions method 8.2% screened positive for disability (Zaman et

al, 1990). In Jamaica a prevalence of all types and levels of disability of 9.3% in children aged 2-9 was found, and serious disability at 2.5% of the child population (Paul et al, 1992).

For minor impairments, the current study found a prevalence rate in the child population of 6.1% (9.6% in 6-15; 2.3% in under 5) for minor visual impairment, 4.8% (6.8% in 6-15 and 2.6% in under 5) for minor hearing impairment and 4.4% for minor learning difficulties in children 6-15 years old.

Comparison with other studies is limited because of reporting of disability type lacking analysis by age group (e.g. Rodriguez, 1989; WHO, 1990). For all age groups a prevalence rate in the whole population of Spain of 2.4% is reported for vision problems; and 2.6% for hearing compared with the finding in the current study of 1.8% for seeing (when the child cases are expressed as a percentage of the total population); 1.4% for hearing (see Table 5.1).

In Jamaica (Paul et al, 1992) prevalence of hearing problem (all types) was found to be 0.9% of the child population (2-9 years) lower than in the present study, and 1.1% (of 2-9 year olds) for vision problems, again lower than the present study.

ii) Poliomyelitis (3 cases: Salman, Fawzia, Wadha)

Poliomyelitis still poses a serious public health problem in Saudi Arabia despite regular vaccination campaigns, though there is a lack of information on the extent of paralytic poliomyelitis. Poliomyelitis is also endemic in neighbouring countries. The incidence of this disease is frequent in the first years of life, demonstrating the importance of early vaccination (Serenius, 1988).

Three children in the present study had contracted poliomyelitis, a prevalence rate of $2/2696 = 0.1\%$ (1 per 1000) in the child population of KAMA of 2696 children (0.4 per 1000 total

population in KAMA). This is much higher than the EMRO reported rates of 3 per 100,000 population in 1986 and 1 per 100,000 in 1988 (Robertson et al, 1990). It has been estimated that during 1986, 1987 and 1988, there were 200,000 cases of paralytic poliomyelitis in the world. These are mostly children who belong to the 780 million people living in absolute poverty where polio vaccination is not available. With the current level of polio immunisation coverage it is estimated that 360,000 cases of paralytic poliomyelitis were prevented in 1988. The incidence of poliomyelitis in unimmunised infants is expected to be 5 per 1000 (Robertson et al, 1990).

iii) Road traffic accidents (RTA)

Mohammed's tetraplegia had been caused by a road accident. 30% of hospital beds in Saudi Arabia are occupied by people injured in car accidents (Ministry of Health, 1981; unpublished data). It is well established that seat belts reduce mortality and morbidity among children. Data are presented for 413 children injured severely in motor vehicle crashes to require hospitalization. Of the unrestrained children 4.5% died, compared with 2.4% of the belted children. Unrestrained children had a higher proportion of injuries in anatomical regions, were more severely injured, stayed longer in hospital, and were 15% more likely than belted children to have impairments (Osberg and Discala, 1992). Little evidence exists on the social and medical costs of this disability arising from RTAs, which may be prolonged or permanent.

2. Types and prevalence of disability: epilepsy, developmental delay and cerebral palsy

iv) Epilepsy

The prevalence of epilepsy in the population is said to range from 3.5 per 1000 in the industrial world to 15-50 per 1000 in the developing world (WHO, 1987, 1990). The present study found a rate of 0.7 per 1000 when expressing the child cases as a proportion of the total

population of KAMA. Clearly, this does not include adult cases which may explain the low prevalence found. It is unlikely that there were other child cases which were not disclosed to me. In Bangladesh (Zaman et al, 1992) serious seizure was found in 1.1% of the 3-9 year old population, more than the 0.25% of the child population found in the present study. In Jamaica 2% of the child population at 2-9 years old were found to have all types of seizure (Paul et al, 1992).

v) Developmental delay

Saudi Arabia is an example of a middle-eastern country where the problems of mental subnormality are coming to the forefront, although most of the cases of severe mental disability remain without adequate explanation.

The prevalence of moderate to severe mental retardation below 18 years (an IQ of less than 50 with major difficulties in intellectual and social function) is estimated to be approximately 3-4 per 1000 (WHO, 1990), very similar to that found in the present study of 2.9% per 1000 under 15, although WHO consider their own figures to be underestimates. In Bangladesh (Zaman, 1992) a lower proportion (0.5%) screened positive for serious learning problems. However, if delayed milestones (0.4%), comprehension problems (0.4%) and slowness (0.7%) are included, the Bangladesh total becomes 2.0% nearer the current study level of 2.9%

The prevalence of mild and moderate mental disability (an IQ of 50-70 with marginal performance at school in complex intellectual tasks) is estimated to be approximately 20-30 per 1000 (WHO, 1990). The current study found a rate of 23 per 1000 children under 15, which falls within these estimates.

vi) Cerebral Palsy

It has been suggested that cerebral palsy is a relatively frequent problem in Saudi Arabia. In one small clinical study it was the second most frequent neuro-paediatric disorder encountered (Al-Rajhi et al, 1991).

6.2.3 Factors affecting recognition as shown in other studies and in the current investigation

6.2.3.1 The timing of the discovery of the impairment, and the roles of health professionals, parents and families, traditional healers and schools

The timing of discovery that a child has an impairment explains the range of processes in recognition that have been found in this and other studies. In the perinatal period it is the health professionals who often play a major part in the process of recognition of an impairment. Severe congenital abnormalities such as limb deformities are usually recognised at birth, or in the first few days or weeks of a child's life. This was certainly the case in the present study (e.g. Laila with osteogenesis imperfecta, Nada's Down's Syndrome and the two children with rubella syndrome, Nema and Nora). On the other hand Fahad's hemiplegia and Salima's Down's syndrome were not diagnosed until late, in the latter case at the age of 4 years.

Some impairments, physical, sensory, or intellectual are likely to become apparent only later in the child's life, months or years after birth. Recognition processes at these stages are often highly dependent on the parents and family noticing that "something is wrong" and taking the child to be seen by health professionals. This parental and family recognition is most important and the cultural recognition of what is or is not appropriate for a particular child at a particular stage will determine in turn what the parents consider to be different from the usual pattern. The initial signs of learning difficulties are primarily recognised in the classroom and as the child gets older. Overall, recognition processes seem to hinge on health professionals in the perinatal

period; and later on parents and family and their cultural milieu of what is expected to be normal behaviour for the developing child, with an important role for classroom teachers to later pick up learning difficulties. Four of the children were identified as slow learners by the teachers before the parents became aware of something being wrong. The ages at diagnosis ranged from 3 to 13 years.

6.2.3.2 Perinatal factors affecting recognition

In the present study only 16% of the children with a disability were recognised in the perinatal period. Only one of them (osteogenesis imperfecta) was born at home. Even among those born in hospital (now estimated as 60% of deliveries in Riyadh, Serenius et al, 1988), only 36% had an impairment diagnosed at the time of birth. There is abundant literature on the fact that at least 50% of impairment originates in the perinatal period, i.e., it arises as a result of adverse factors operating during pregnancy, birth and the first few minutes, hours and weeks of life (see, for example, Astbury et al, 1990). Statistics indicate that the majority of impairments occur during the antenatal and perinatal periods and are usually due to birth insults. Thus it is of great concern that 42% (15/31) of children in the present study had a poor condition at birth with a history of asphyxia and trauma (Table 5.9 in section 5.3.1.3). Such birth insults include hypoxia and neonatal asphyxia, low birth weight, prematurity, depressed Apgar scores, delayed onset of respiration, bleeding during pregnancy, and pregnancy complications such as toxæmia and hypertension. Children with such a birth history need to be followed up, and the parents informed about the reason for such follow-ups. Similar follow-up is also indicated for children born pre-term.

Current limitations in availability of perinatal services

The crucial importance of the immediate perinatal period in the prevention of impairment is now well recognised. Thus it was particularly disconcerting in the present study to find some

apparent limitation in the perinatal care being provided to the families of the children studied. The 3 cases of cerebral palsy were all children who had been delivered by emergency caesarian section and all were preterm. It is also of concern that 15 children (half) had birth asphyxia or birth trauma; all the cases of epilepsy had a history of birth trauma and all the cases of developmental delay, and 2 of the 3 cerebral palsy cases had a history of birth asphyxia (see section 5.3.1.3 and Table 5.9).

Health professionals' dilemma in perinatal recognition

The question of health professionals own reactions when they find an impairment is an important issue, as illustrated in the present study by the concealment of Nada's Down's syndrome. The dilemma felt by the paediatrician between voicing recognition of the impairment and concealment because he thought that the impairment might interfere with the maternal bonding, is open to question.

6.2.3.3 The importance of parents noticing "something is wrong" in the process of recognition

This study has shown the importance of parents in the process of recognition of an impairment in Saudi Arabia (see section 5.3.2). Sheridan (1965) stresses that a mother's suspicions of unusual development in her child should never be ignored, since these can provide an effective early signal of delay (see also Voysey, 1975). It is suggested that if all parents of young children appreciated the significance of marked slowness in development, then parental concern, when present, would lead without delay or difficulty to formal recognition (Phillips et al, 1978).

For parents, the social process of recognising that they have a child with an impairment begins when they observe in the child a departure from what is, until then, regarded as usual

behaviour. The translation of this awareness into concern, initially or some time later, will depend on how serious the change from normal behaviour appears to be to the parents.

Recognition is also affected by social visibility (see Lansdown, 1990). Socially embarrassing conduct in public is quickly noticed. Covert behaviour, for example not coping academically, may go unnoticed for some time by parents because it is less visible socially. Surroundings and interpersonal relationships also influence whether there is early recognition of the impairment in the child.

In the current study the main reasons that parents thought something might be wrong (see section 5.3.2.1) were "slow progress" since babyhood, developmental delay or mobility problems (29%, 9/31); seizures (19%, 6/31); or speech problems (10%, 3/31). While some parents were extremely anxious and concerned about their children before they first came to see the doctor, others had come to realise only slowly the implications of the impairment. At the time of the first diagnostic examination parents were more concerned about the uncertainty of their situation. They did not have a clear picture of what was involved. Overall, it is clear that parents' recognition of an impairment in their child requires that they recognise that there is some sort of "flaw" in the child's development.

6.2.3.4 Pre-school surveillance

Pre-school surveillance is largely absent in Saudi Arabia. In other countries (see literature review) much attention has been given to early detection of impairment (Bax and Whitmore, 1987; Jarvis et al 1990). These early years are now recognised as even more crucial for facilitating the development of competence in children with an impairment than for the child without an impairment (Marfo, 1990). Not only may younger children be more receptive to therapy but families may be able to evolve "coping and caring strategies" as the child grows older.

6.2.3.5 The important role of schools in recognising impairment

School surveillance is largely absent in Saudi Arabia (Abu-Shaqara et al, 1991). Yet the initial signs of learning difficulties are primarily recognised in the classroom and careful assessment by the teachers in some studies have shown at least 50% of the children having learning difficulties during their first year at school. In the present study, delayed development came to be recognised in the schools in the case of 4 of the 6 severely impaired children.

6.2.3.6 The important "cultural component" of recognition of an impairment, especially in Saudi Arabia

"Recognition depends on the culture perceiving an abnormality". Anthropologists have long been in the forefront of those maintaining that "impairment" is functionally and conceptually related to a culture's defining criteria for "appropriate" and "deviant behaviour" (eg Lefley, 1987). It is now also recognised that there are cultural factors which shape the "social recognition" of impairment (Simeonsson and McHale, 1981). In the colloquial Arabic of Saudi Arabia, there are no equivalent terms for "juvenile arthritis" or "osteogenesis imperfecta"; causations such as congenital Rubella and Down's Syndrome are not understood.

In Saudi Arabia the effect of people's ideas about the causation of an impairment which in turn affect their social recognition of the impairment is exemplified by epilepsy. The recognition of epilepsy as a situation where the child has been exchanged with the child of a fairy, or is possessed by jinns is still a widely held belief (just as in earlier times in Europe). Every family in Saudi Arabia with a child with epilepsy in the present study wished to conceal this impairment and to work closely with traditional healers to attempt to get their own child back.

A "cultural" explanation can also be given for the fact that children with developmental delay were not "recognised as having an impairment" by the parents. "Schooling is not important to

many families in Saudi Arabia". Skills learnt through schooling are not particularly valued compared with skills learnt in other ways. Although developmental delay may not be important in present circumstances, in the future when schooling becomes a more important component of modern life in Saudi Arabia, children with developmental delay who are not given special help may become more disadvantaged than at present.

6.3 Reactions to the impairment and to the child

6.3.1 What is meant by reaction to an impairment?

Commonly, the birth of a disabled child evokes strong emotions in the family, such as grief, disbelief, rage, self disgust and hopelessness (Gath, 1977). It has been said that while parents of normal children frequently have such feelings towards their children, parents of children with a disability may experience these feelings with greater intensity and complexity (see Albrecht and Levy, 1981).

Reaction is also a continuous re-evaluating judgement about the child's impairment tending to be based on the consequences of the impairment, e.g. its visibility, rather than the diagnosis. It develops as parental recognition develops; as rehabilitation and social life become more or less possible. Reactions thus change continuously and are influenced by the course of the impairment and the outcome (Mahoney and Powell, 1988).

6.3.2 Early reactions

6.3.2.1 First reactions of shock, profound depression, parents blaming themselves and prolonged mourning for the child they feel they have lost, Why me?

In the current study first reactions of shock in the family were clearly apparent (section 5.4.2.1). "Reactions can often include extreme feelings of shock, helplessness, shame, embarrassment and guilt as well as feelings of frustration and rejection of the child. Some psychologists have seen this as part of the process of grief and mourning for a normal child who was never born. Others see it as a "narcissistic blow to the mother" (see Cooke and Lawton, 1984). Others see parents as in a state of chronic sorrow because they are faced with the life-long reality of their situation (e.g. Copley and Bodensteiner, 1987). Mourning for the "well" child they had lost was clearly apparent in the present study (section 5.4.2.4, Box 21).

However, this view is not unchallenged. Others have suggested that the birth of a child with an impairment does not necessarily promote adverse emotional reactions. Even where stress is present the problem is not the impairment but the fact that certain problems have not yet been resolved (Baldwin, 1986). Many writers have seen families gain in strength rather than weakness in the face of adversity (Howlin, 1988). In the present study this is certainly evident in most families who had a child with developmental delay and particularly Waleed. The processes by which this occurs are still not clearly understood (Sarson, 1988). Perhaps the secret lies in a combination of maintaining a sense of hope, emphasising the child's own personal worth and encouraging his coping with his infirmity (Cooke and Lawton, 1984; Marfo, 1990). This is part of the move towards coping behaviour, not just reaction (see section 6.5 (coping) and 6.4 (acceptance) below).

In the current study a model of the reactions found is shown in Figure 2. More shock seems likely when there is rapid onset of an impairment, when the impairment itself is unknown or

incomprehensible and when the impairment is particularly stigmatised in Saudi society. There seems to be less shock when there is slow recognition of an impairment or when there has been a perinatal alert of possible problems. Mourning for the lost "well" child particularly follows shock, and all usually seek reasons for the problem, (blaming fate; another recent sad event; the Evil Eye when things were Too Good; parent blaming themselves; or blaming possession by a Spirit either evil or good).

When parents fear the social reactions to the impairment, e.g. in epilepsy (exchange for a fairy child), then profound depression is likely, and concealment or ignoring the symptoms and pretending the child is normal follows. Alternatively with non-stigmatised impairments (e.g. deafness) parents may struggle to get the impairment recognised.

6.3.2.2 Uncertainty of diagnosis affecting reactions by family and professionals

Most studies of parental reactions to diagnosis of impairment refer only to readily recognisable syndromes, e.g. Down's syndrome or congenital abnormalities such as spina bifida (Cottrell and Summers, 1990). However, for many children seen at child development clinics, their diagnosis is much less certain and evolves over time as the child's developmental progress falls behind that which is expected. Quine and Path (1987) found that mothers of children, in whom the aetiology of impairment was uncertain, were significantly more likely to be dissatisfied than mothers of children where the diagnosis was known. In the present study where children were eventually diagnosed to have profound deafness, their mothers had expressed concern about hearing at ages varying from 1 year to 2.5 years, but the diagnosis could not be confirmed until much later. The uncertainty gave rise to much concern. The professionals could not be absolutely certain of diagnosis and were less than certain of prognosis.

6.3.2.3 Denial of the disability

Denial of the impairment was found in the present study in the concealment of epilepsy and the ignoring of developmental delay. This is well recognised. A third form of denial was found with Hadeel where both the child and the impairment were ignored. Institutionalisation can also be seen as a form of denial and was looked down upon by most parents in the study. When there is relative absence of signs associated with impairment, a sense of doubt may be created within the family as to whether the impairment is in fact present or not. Practical problems are seldom seen straight away as "disabling". Often parents have to struggle against the isolation of being labelled as disabled (see also Winefield and Cormak, 1986).

Block (1986) claimed that denial of mild disability interferes with rehabilitation. Denying the real consequences of a child's impairment and rejecting training may result in the child becoming overly dependent. This will interfere with rehabilitation, greatly reducing the potential benefits to the child and family. Thus in the present study some parents of children with minor impairment hoped that "if ignored, the child would become alright". Similarly children with developmental delay in the present study were not recognised as having problems.

Institutionalisation when seen as denial is a form of segregation of the child away from mainstream children. In the present study most families reacted strongly against the possibility of institutional care.

Denial can help avoid the threat to the social status and self-esteem of parents. It may be a method of parental defence. Denial may not actually help the parents bring into play their parental skills and deployment of competence in coping. Whenever the reaction is denial it means delay. It can deter parents from seeking medical help for the child's impairment. It can lead to a delay in seeking help because the parents do not worry that the signs and symptoms

the child is experiencing are due to impairment. It can also lead parents to resist medical treatment and rehabilitation which might reveal the presence of impairment. However, an alternative explanation of the present data is that the greater fear in impairment is not the diagnosis but the associated treatment and rehabilitation, for example the fear that a child would be sent away to a special school.

6.3.2.4 Struggle to get the disability recognised and understood

In the current study Ahmed's parents represent a frustrating search for answers and help to deal with his impairment. Shopping around with a variety of professionals may become an established way of life. When no answers are forthcoming, and when the professionals are unable to produce a definitive explanation as anticipated, feelings of anger, frustration, stress and anxiety are experienced by the family. The professional's own uncertainty concerning the child's impairment may be detected by the family, adding still further anxiety.

Some parents (e.g. Reem's) present an opposite picture to denial. They immediately realised (and were well informed) that their child had an impairment and sought appropriate help.

Appropriate advice and counselling given by health workers is helpful and sufficient time must be allowed for parents to take in and question what is being said. Quine's (1986) findings suggest that discussion on the aetiology of the impairment is important when counselling parents particularly the mother, so that some insight about the reasons is gained from the counselling when parents are first confronted by the impairment.

6.3.2.5 Role of health professionals in early reactions

Parents may need support to help them react to an impairment in an appropriate manner. This may require the help of health professionals, in "legitimising" the impairment (see Cunningham and Sloper, 1977a,b). This is one interpretation of the situation of Nada with Down's

syndrome. The mother desperately needed help to recognise her own fears. She also needed to have it confirmed by health professionals that there was a problem. Only when this was done could she move to the stage of reaction and then on to coping.

Robinson (1978) identified a number of dimensions of the problem, including poor communication between the care provider and parents as well as the failure of care providers to acknowledge parental feelings of discomfort or perceived threat. He also found that parents felt powerless with regard to decisions made about their child's future and some care providers behaved in an autocratic way.

6.3.3 Late reactions

6.3.3.1 Stressful life events following impairment

Hewett et al (1970) explain that the reactions experienced by the mother can be sporadic, that is, they may recur at different stages of the child's development. It is well known that a family who have a child with a disability often turns into a family with a disability (McAndrew, 1976). This is particularly true in Hewett's study on grief reaction to the birth of a child with an impairment. The degree of impairment suffered by the family seems to be a function of the state of the child, the reaction of the family and measures society is prepared to take to help (Goddard and Rubisslow, 1977).

The stress being experienced in caring for a child with impairment can be further exacerbated by other dimensions of the parents' lives. For example, if marital problems already exist, then they may have less chance to improve, although it is reported that in such circumstances some families have actually gained strength and the family bond has become stronger (e.g. Thamer with severe stuttering). Dorner (1975) has suggested that even though depression is found to occur more frequently in mothers of children with physical impairments than in the general

population, the most likely explanation for this is that the presence within the family of a child with a disability, increases the vulnerability of parents to other stressful life events, such as bereavement, isolation or marital problems (see also Mitchell 1987).

6.3.3.2 From crises to strength

The onset of disability in a member of the family invariably produces a state of crisis for that family. However, effective child and parent functioning can occur, and Naila's parents got her admitted to a special school in the face of opposition from the extended family. In the process they came much closer. Cooke and Lawton (1984) stated that in such circumstances the parents are somehow enabled, despite their deep worries and fears to continue functioning as parents, e.g. Nada's mother who suffered because information was withheld from her. But later she came to cope well. Despite the wealth of literature on negative effects of a child with impairment, it is recognised that the attitudes of parents to their child with the impairment is of paramount importance and if other assets in the family can also be acknowledged and developed, there may well be compensation for negative aspects of the situation in the family (Hegarty, 1988). For example, Ibrahim who went for vocational training, and Wadha who was acceptable for marriage because of her good looks.

6.3.3.3 Religious belief mediating reactions

The religious belief of the family is a factor which may influence parental and sibling acceptance of a disabled child (Simeonsson and McHale, 1981). In the present study the importance of the religious and spiritual dimension in the families' reactions to their affected child were important. On the one hand, the intense fear of a child who has epilepsy, on another the respect for a child with development delay as being nearer to God; also the great respect accorded to mothers caring for a child with a disability; and the considerable help felt by many families in ascribing the cause of the impairment to the will of Allah.

6.3.4 Reactions by different members of the family

6.3.4.1 The impact of disability on the family

In the present study, all members of families where a child had epilepsy were worried and were making every effort to conceal the impairment. On the other hand, in the case of deafness, the parents knew what the problem was and their life continued as normal. When a specific action has been taken, e.g. in the case of Naila who was admitted to a special school, or removal of cataract in the child with rubella syndrome, the family felt that they had played their part. The degree of disability suffered by the family seems to be a function of the child, the reaction of the family and the extent to which society is prepared to help (see also Goddard and Rubissow, 1977).

6.3.4.2 Reactions by parents

Parental reactions are described in sections 5.4, denial specifically in 5.4.3.1; and moves from crisis to strength in section 5.5. It is recognised that reactions to disability may vary according to the sex of the affected person and ethnic group. One explanation is the varying implication of disability for social performance within these sub-groupings (Kutner & Kutner, 1979). Another explanation is familial and cultural variations in the attitudes to disability. A new approach (Wasserman et al, 1985; Fraser, 1986) to investigating family reactions is the examination of parent/infant communication. This approach recognises that the development of interaction is dependent upon stimulation of the parents by the infant. Impairment may reduce the signalling ability of the child and thus cause a different affective and cognitive response by the parents. It is suggested that counselling and guidance can ameliorate such a situation. This is a clear example of relationship between recognition (of an interaction problem) and a possible route to help parents towards acceptance. In the present study, Thamer (speech

problem) is the example where the parents had not been helped to develop interaction with him at an appropriate early age.

A stressful emotional climate, anxieties and practical burdens can have an impact on the family (Anderson and Hinjosa, 1984). Ahmed is an example from the present study. The father was very distressed and always casting around for a cure. In some situations the disability may bring out the strong character of the parents (Voysey, 1975; Simeonsson and McHale, 1981). However, as noted above, many impairments, of varying types, are accommodated in the family without parents fully realising the effects, or ever spelling them out.

6.3.4.3 Reactions by siblings

It is now recognised that there may be negative consequences of disability for the brothers and sisters. The negative consequences for siblings in Saudi Arabia are usually those associated with concealing the impairment especially by the siblings of children suffering from epilepsy. It is culturally usual in Saudi Arabia for the older female sibling to have greater responsibility in caring for the child with a disability. Nema (rubella syndrome), Laila (osteogenesis imperfecta) and Abdulaziz (cerebral palsy) were largely cared for by their older sisters. In seven families the older siblings were expected to control the behaviour of the disabled child.

Some studies have indicated that the presence of a child with a disability adversely affects the behaviour of the siblings. Breslau (1981) found that siblings of children with a disability were less well adjusted than siblings of those without an impairment. There are also studies suggesting that religious belief, and parental values in general, influence sibling acceptance of the child with the disability. This area is complex as the nature of that influence, if it does occur, may be mediated by a number of other variables (Simeonsson and McHale, 1981). Hewett et al (1970) found no harmful effects on siblings. However, evidence from studies by Howlin (1988) indicated that brothers and sisters can be adversely affected by the presence

of a child with a disability in the family. It may be argued that all those studies were of families in a totally different culture from that of Saudi Arabia. In the present study parents of 9 study children reported jealousy among the siblings. Less frequently, just the opposite happens, the child with a disability is regarded as a failure and any other children in the family will be pushed too hard and expected to excel in compensation. These findings have been explained in terms of a process of "role reorganisation" that needs to take place in families when a child has an impairment (Simmeonsson and McHale, 1981).

6.3.5 Reactions by people outside the family

6.3.5.1 Stigma and labelling

Throughout history people with disabilities have been ridiculed, persecuted or totally ignored (Crocker, 1989). Some, for example Ogbue (1984), think that primitive man believed that only the fit should survive. Such treatment stems from a belief that the gods have no room in their kingdom for disabled people. All the children in the present study were subjected to stigma one way or another, but more particularly those with epilepsy, those who had drooling on account of cerebral palsy and those with the obvious facies of Down's syndrome. Since ancient times disability has caused fear and rejection.

Attitudes such as these, Altman (1981) argues, are important because they have an effect on interaction with the general public. An able-bodied person's reaction to disability both in public and private plays an important part in the development of the person who has a disability with regard to self-esteem and self-confidence, and in turn in the way they interact with society (Lyons, 1991). Persons who possess attributes that are viewed negatively by the prevailing group in a society tend to be devalued by that society (Wolfensberger, 1983). Such attributes might pertain, for example, to ethnicity, physical appearance or intelligence. They are often viewed as inferior, incompetent and incapable of normal social functions (Warren, 1985).

6.3.5.2 Reactions by health workers

One extreme example of the health worker's reaction is described in the case of Nada (Down's syndrome) where the disability was not disclosed to the mother. Reem is a contrasting case of openness and compassionate counselling. Educational and rehabilitation programmes, even when they exist, can be expected to have reduced impact where there is a stigmatising attitude (Hirst, 1983).

6.3.6 Theories of reactions to disability developed from other work and their linkage to findings in the current study

The present study shows that in Saudi Arabia reactions to disability are really very similar to other places. Shock, frequently accompanied by denial is the usual reaction. Defensive retreat is certainly one possible interpretation of some of the reactions seen. What did not come out in particular was much evidence of anger, although depression was clearly apparent. Certainly the present study emphasises that in certain cases active moves towards accepting an impairment and dealing with it may be shown more rapidly by the family than by the professionals.

6.3.7 Action needed to tackle reactions in the family and the wider society in Saudi Arabia

To consider approaches to helping with reactions it may be helpful to think what can be done for the families, for the community, for traditional healers, for the health professionals and for the education professionals.

For the family, counselling services and improving general knowledge needs to be provided for parents, siblings and grandparents:

- a) To improve their knowledge of the impairment and what can be done to help.
- b) Also to help parents and families in seeking appropriate services and to provide counselling in dealing with the stress which follows the impairment which may be worse than dealing with the impairment itself.
- c) Also to help the family (parents, siblings and grandparents) to progress from reaction to acceptance and coping and to help them disclose and publicly recognise the situation.

A similar strategy is needed with regard to the community. Contact that evokes aversion and fear, that reinforces negative stereotypes or that is experienced as burdensome, however, results in negative attitudes (Wright, 1985). Thus, contact must be planned carefully so as to occur in a social climate in which the person's abilities will be appreciated (Lyons, 1991).

A person's self-concept is determined to a large extent by the perceptions of others within the environment. This is illustrated with Wadha where her apparent physical attributes allowed her lameness to be overlooked by society. Social expectations and treatment accorded to the disabled are determined by prevailing attitudes. Hence, the decisive factor appeared to be the degree to which the child needs a "disabled" identity in order to protect him or herself within a normal environment (Albrecht and Levy, 1981). The visibility of an impairment influences how the disabled child copes with the disability. If the impairment is slight, or not easily recognisable, e.g. epilepsy or hearing loss, then the child's self-image tends to be more positive. It is of particular importance to the adolescent that the impairment is not too visible to their peers.

Liaison also needs to be developed with traditional healers since traditional healers play such an important role in helping families (parents, siblings and grandparents) to express their

reactions and in helping them to move towards acceptance. What is needed is recognition of their role.

Action is particularly needed to tackle reactions by health professionals. This study has shown very clearly the need for health professionals involved in helping families of affected children to understand fully the social and cultural milieu of the family. Unless the cultural situation is understood, the families' reactions cannot be understood and nor can meaningful help be given. When families feel the need to consult a traditional healer to "get their child back" in the case of epilepsy, it is unlikely that medication alone will be acceptable. In Saudi Arabia there is the added problem of short-term expatriate health workers who do not even have the language leaving aside an insight into the culture.

The school has its part to play. There can be extreme exacerbation by insensitive mishandling of the situation. This happens all too often (Lonsdale, 1978). What is needed is training for school teachers in how their reactions to impairment in the school influence the affected child and other pupils. Teachers need to realise that stress within families caused by their life with a child with an impairment can be partially alleviated by a well-coordinated system of support from health services and school.

6.4 Acceptance of a child with disability

6.4.1 Defining acceptance

Acceptance shapes parents' behaviour in important ways. Acceptance in both the parents and the child includes some or all of the following components:-

- a) Acceptance of the impairment, including social stigma, deformity, helplessness
- b) Acceptance of care facilities, treatment and rehabilitation available

- c) **Acceptance of separation from the family and the community in the case of institutionalisation**
- d) **At community level integration of the child and family into society is also a process of acceptance.**

Acceptance includes the adaptive skills required for acceptability; culturally acceptable behaviour; age appropriate behaviour and behaviour considered safe not dangerous. For the child to be accepted by society he has to be able to attain or achieve academic and social expectations as set by society. The child with an impairment thus has to overcome the environmental obstacles and barriers which become acutely apparent to him when he realises the restrictions due to his disabilities. These obstacles and barriers are present in the home, school, the services, in the community and in the wider society.

Acceptance is an essential precursor to coping. It is said that families in a rapidly modernising society such as Saudi Arabia find it difficult to adjust to the pace of change. Adjustment to the presence of people with a disability presents such a society with an even greater challenge to their capacity to accept and integrate concepts previously unknown to them.

6.4.2 The process of acceptance

The process whereby the parents come to terms with their child's disability can be prolonged and emotionally exhausting, (eg. Ahmed's juvenile rheumatoid arthritis). The process may include a number of stages before complete acceptance is achieved. The parents have to overcome the stigma associated with the impairment (see section 5.5.3.6), and this may take time. They must also have reached the stage of recognition of the impairment (see section 5.3) and be moving towards "coping" with various problems (see section 5.6).

The severity of a disability can influence parents' acceptance of their child as well as the child's impairment. This was the case with Mohammed (tetraplegia as a result of a road traffic accident), Nada (severe Down's syndrome) and Amna and Abdulaziz (severe cerebral palsy). The difference between acceptance of the child and the acceptance of the impairment is an important part of the process of adjustment on the part of the parents. Acceptance of each influences the family's ability to cope with the child's disability.

Parents' acceptance ranged from a low of utter despair, of being overwhelmed by the care-giving burden, and fear of the future, to a sense of satisfaction with their ability to fulfil a duty. On the whole, mothers of developmentally delayed children were more accepting and tolerant than others. This is due mainly to their religious belief that their hardship and patience will be rewarded by not complaining (see section 5.5.2.2).

Phases in acceptance

The process of parents' acceptance of a disabled child can be classified into three phases with parallel phases of contact with services. The initial phase occurs during the immediate period after diagnosis. Rehabilitation follows this, and the third phase is adjustment back to life in the community.

The literature on community adjustment (e.g. King et al, 1989) reports few, if any, agreed predictors of success. This has been attributed to a host of methodological inadequacies.

6.4.3 Positive factors facilitating the acceptance of a disability in a child as shown in other studies and in the current investigation

Factors facilitating acceptance found in the present study (section 5.5.2) were religious belief; facing the reality; physical attractiveness in the child; a pleasant personality in the child,

religious devotion in the child; neighbourhood and extended family support; having the child in an achieving environment and accepting the child for what they can do.

6.4.3.1 Appropriate levels of expectations of the child by the family

Waleed and Ibrahim illustrate that failure can be very stressful. The best situation for a child with an impairment is one which leads to a good match to the surroundings. Waleed's and Ibrahim's parents accepted that by changing their expectations they had by far the best "solution" for their child.

6.4.3.2 Good mother/child, and family/child interaction

Nada and Waleed had particularly good extended family support (see Results section 5.5.3.1 and Box 19). In a Canadian study (Katz and Chamiel, 1989) it was found that the child's success or failure in understanding the world and in mastering activities was determined not so much by physical limitations as by the more or less anxious attitude of the parents (see also Anderson, 1973). Cooke and Lawton (1984), reviewing the literature, concluded that there is some disturbance in the mother-child interaction system when the child is atypical in some ways. Rosenbaum et al (1992) found that developmental restrictions in the child can further increase levels of parental anxiety.

6.4.3.3 Social support and acceptance by others in both family and community

A sympathetic role played by other families is good for adjustment, allowing many children with disabilities to adjust successfully. The self concept of children who have disabilities is determined to a large extent by the acceptance of others within the environment. Reem will be acceptable when she can behave appropriately in public. One reason she found life so difficult was that inability to eat in a socially acceptable way was such a problem for her,

because of excessive drooling. Saudi culture is based on hospitality and food is involved in many social activities. If she could come to terms with her difficulties and realise they can be overcome, either through her own efforts or through proper training, acceptance would follow. It has been suggested that the two main factors in acceptance are the attitudes of the family and the ease with which a child's impairment can be reintegrated into society (Lefley, 1987).

Criticism came only for Hadeel's parents (see section 5.5.5.1). For four children a positive environment was created with professional support (section 5.5.5.2), for Ibrahim it was employment which improved social adjustment (section 5.5.5.3) and for Waleed changing the social environment (section 5.5.2.7).

Both theoretical and empirical analysers acknowledge that early parent-child interaction processes play a central role in mediating the development of competence in children. For children with a disability, the early years are, perhaps, even more crucial (Marfo, 1990).

Effects of acceptance by the community

Salman (poliomyelitis) and Wadha (poliomyelitis) are examples of good acceptance by the community. Wadha was a shy girl and good looking (see results section 5.5.2.4). Both the attributes are highly prized by the Saudi society. The community acceptance of disability is important. Only through it can there be integration of the people with a disability into the socio-economic and cultural life of the community. With such acceptance the person with a disability is turned from dependency to self-sufficiency and productivity. They are also no longer lonely, hopeless and desperate. Ibrahim (developmental delay) is the prime example of this in the current study (see section 5.5.5.3).

As a group, the children with epilepsy were in general somewhat "maladjusted". Although they were too young to feel the stigma directly, which their parents and siblings obviously did, the

children seemed to be aware of the restrictions on them and to be "lacklustre" people compared with other children.

Families are inevitably affected by community acceptance and will experience varying degrees of discomfort (e.g. see: Tong He Koh, 1976; Tukr, 1964; Cooke et al, 1986).

Allen (1983) has emphasised that social integration will not take place merely as a consequence of residence within an existing community. If social integration is to be a goal of care in the community, then attention will also need to be given to the development, maintenance and repair of relationships, (see also Firth, 1987).

6.4.3.4 Normal daily living

"Normal daily living" may need to be specified in detail to be sure it is available. Physical integration does not always mean that psychosocial integration has been achieved. Waleed in the present study is an example of this situation. He was part of the urban school but did not feel at home there. Integration at school depends on many factors such as the personality of the child with a disability, the teachers' attitudes towards these children, and how good are the school facilities to enable children with a disability to be accepted.

Several authors have written about the effects of specific impairments on experience (e.g. Lankhorst, 1989; Stensman, 1985). In the present study it was Mohammed (tetraplegia) who suffered an abrupt change in lifestyle when he became wheelchair bound after the car accident.

Quite minor changes in the environment can alter the behaviour of young children, regardless of their neurological status (Rosenbaum et al, 1992). It seemed from the present study that minor changes to Hadeel's (developmental delay) environment, such as simply taking her out

on visits, would make a huge difference. Minnes' (1988) study emphasises that behavioural variation is to a large extent determined by the immediate environment.

The major purpose of integration is to improve the social competence of the child by providing him with a model of a type he would not find in an institutional setting. The development of much social competence depends on modelling rather than an innate intellectual capacity. But to develop social competence there has to be exposure to social interactions. Some parents were reluctant to take their children out on a regular basis, partly because of a sense of shame (e.g. in the case of Hadeel, and partly because of institutionalisation as in the case of Naila). In the case of all the parents of children with developmental delay (except Hadeel and Naila), it was apparent that their primary aim was to achieve such social acceptance and integration of their child (but also they wanted the child treated as normal, no different from others).

The outcome is linked with the type of intervention because the type of intervention will determine which dimensions of the adjustment are to be emphasised (e.g. physical, social or cultural). Clinical methods of intervention will be concerned with the medical, whereas cultural and social methods of intervention will be concerned with social integration and competence. In this study the children with rubella syndrome (Nora and Nema) and osteogenesis imperfecta (Laila) were greatly helped towards acceptance by surgical intervention. Waleed is an example of cultural intervention where he returned home to the village and could cope better there. Ibrahim is an example of social intervention where his employment was seen as being productive. Reem (with cerebral palsy and visual problems) is the example where developmentally she is fine despite her physical problems. She topped the list for her class at school.

6.4.3.5 Being a success

Functioning in normal social roles is much influenced by the type of social setting the child belongs to. The fulfilment of social obligations may be of greater practical importance in one setting than in another. Not only the type of family unit the child belongs to but also the emotional climate and the relationships prevailing in the home influence the functioning of the child in normal roles (Coleman and Lindsay, 1992). In the peer group, children are more likely to seek contact when they perceive the child with an impairment as "being fun to be with" or "interesting" (Archie and Sherrill, 1989) just as Abdu was popular for his sense of humour.

6.4.3.6 Acceptance by others helps the child accept the situation

The study found that factors related to the child which influence acceptance centre on either acceptance of the impairment by the child (see section 5.5.4.2) or his non acceptance of the impairment (see section 5.5.4.3) (Varni and Setoguchi, 1992).

The more intelligent disabled children often feel more inadequate because they are more aware of their limitations. Concepts held by the person with an impairment regarding his/her competence are transmitted by means of both verbal and non-verbal messages. (Walker, 1983). This was seen in Fawzia (verbal) and Reem (non verbal). Social expectations and treatment accorded to people with a disability are determined by prevailing attitudes.

To a great extent the parents' and community's expectations of their child with an impairment will influence the child's acceptance of the problem. Particular personal attributes of the child may help. In Wadha's case where her exceptional attractiveness heightened her chances of marriage, her disability (polio) was more readily accepted by her parents and the community. In Western cultures, shy sensitive and reticent behaviour is usually viewed as immature and as reflecting fearfulness or a lack of self-confidence. Such behaviour becomes associated with

peer rejection or isolation by the peer group. Shyness/sensitivity would not lead to isolation by the peer group or rejection among Chinese children. Indeed, shyness/sensitivity would be positively evaluated and related to peer acceptance in the Chinese sample (Chen et al, 1992). Fraser (1986) has shown that parents will modify their interactions with children upon basis of sex of the child and upon the basis of physical attractiveness. Abdu's great sense of humour made him popular amongst his school friends, teachers and family, and made him acceptable within this immediate circle.

In religious groups the child may be accepted. For example, Waleed (developmental delay) was reared by his paternal grandfather who felt it would be beneficial for Waleed if he became more devout in his religion as his impairment was a result of some unexplained phenomenon.

As the child gets older, he may become more or less troubled, e.g. because of physical appearance or the inability to use their body effectively. Reem, Fawzia and Salman were more aware of their impairment as they became older. For Salman he began to realise that he might not achieve his ambitions. Fawzia became more socially isolated. It is the girls who tend to feel most particularly about problems of physical appearance. Ibrahim faced the problem that he behaved as a child and was accepted as such until he suddenly looked like an adult, when people no longer accepted him so well. In a traditional society there is a very abrupt gender separation at puberty. While he looked young, he could come and go amongst the women and other children as he pleased. As soon as he looked adult, this was not acceptable. It was a sudden change for him and difficult. It took time for him to adjust.

Built on the basis of family integration many countries have embarked on efforts to enhance further social integration including schooling. Parents attuned to normalisation believe people with a disability should be in regular school whenever possible (Welton, 1982). However, the particular problem with integration as a concept is that it is concerned with pupil rather than the school (Hegarty, 1988). It directs attention to the pupil as someone who needs to be

integrated rather than to the school which may have to change its practice before an appropriate education can be offered to that pupil.

6.4.4 Negative factors hindering acceptance

6.4.4.1 Too high expectations and difficulties with acceptance in the family

The expectations by the parents, the family and the professionals can have adverse effects on the child's rehabilitation and eventual acceptance by the community. This is illustrated by the cases of Mohammed (tetraplegia), Abdulaziz and Amna (cerebral palsy) and Nada (Down's syndrome). In all these children the disabilities were obvious and severe. In this study the negative factors working against acceptance were emotional exhaustion; denial; high visibility; too high expectations; too low expectations; negative attitudes (stigma) in the community (e.g. to epilepsy); and over-dependence on the mother or on caretakers.

In cases where parents could not accept the impairment itself their difficulties in accepting the child are clearly apparent. Parents of children with epilepsy could not accept the epilepsy itself because they felt that the seizures were due to some kind of 'evil influence'. In contrast, Laila (the child with osteogenesis imperfecta) was accepted because her parents were able to see the visible impairment and the cause had been clearly explained to them and understood.

6.4.4.2 Lack of good parent/child interaction

In the current study Hadeel was the particular example of poor parent/child interaction. Lack of close relationship between the parents and the child with a disability is one of the most devastating manifestations of disability. All members of the family need the rewards of interpersonal relationships so when the family does not accept the impairment and cannot provide the usual relationship this undermines the child's acceptance of himself.

Accommodation of a child's impairment within the family unit occurs through making adjustments to the impairment. Relationships, activities and expectations are modified but if the parents do not accept the impairment, accommodation cannot even begin. Not all families can rise to the challenge of living with a disabled child.

6.4.4.3 Negative attitudes to disability in the community

In the current study Hadeel (developmental delay) epitomises a new negative attitude in Saudi Arabia because of her educational failure. The children with epilepsy epitomise the traditional negative attitude. The negative attitude to speech problems and deafness also arose because of traditional expectations of verbal performance, especially amongst the boys.

6.4.4.4 Negative expectations by health workers

Blender (1981) argues that the attitudes of rehabilitation professionals towards the disabled should be of particular concern. He points out that many individuals including families, rehabilitation professionals and disabled people themselves hold negative expectations towards people with a disability. In the current study health professionals had merely given a diagnosis, said they were sorry and left it there. This was apparent from the records. There was no visible concern about the child as a person or in a family. There was no home visit (since there is no system for this). Taking the history, they were obviously not keen to know of social or psychological problems or worries of the parents. There was a narrow focus on clinical labels.

6.4.5 Implications for helping parents during the period of learning to accept their child with an impairment

i) Practical actions during acceptance

The implications for action are as follows: (i) working with religious leaders, (ii) creating an environment of success and (iii) providing counselling support.

In a highly religious society, the important role of religious leaders and religion itself in helping parents come to terms with a child with an impairment is apparent from this study.

It is also important for the parents to create a suitable environment for their child in which he feels he is able to achieve his maximum potential. By doing this the child's self-worth is increased and his self-concept enhanced. This is evident in Waleed's case where he returns to his home village and is able to integrate easily and is accepted.

Services have a key role in providing counselling support during the times of recognition and reaction and helping parents and the child move towards acceptance. Creating an environment of success (an achieving environment) by attention to daily living skills enables children to participate fully in most of the activities around them, providing counselling to listen to parents' worries and to identify social and psychological problems, starts the process of providing support.

Another approach is to recognise what happens in acceptance and to use techniques to facilitate acceptance.

ii) Age and lifecycle influences in acceptance

The age and life cycle influences on acceptance are outlined in section 5.5.7.1. The distinction is drawn between acceptance of the child and acceptance of the child's impairment. "Achieving as normal a life as possible" is a recurring theme in all aspects of acceptance. The study suggests that acceptance may only occur when the family has recognised and indeed been able to meet the extra demands made upon it in terms of energy and time and emotion in dealing with the impairment.

iii) Moving towards coping

At worst, parents do not recognise a problem, or they ignore it. In this situation children will never receive the appropriate rehabilitation that they need.

Only when recognition and reaction have taken place can acceptance begin and thereafter move towards coping with daily living and using appropriate services.

6.5 Coping with a child with an impairment

6.5.1 What is coping?

In families where there is a child with an impairment, daily activities of living become most important if everyday life is to proceed smoothly (Kirkham et al, 1986).

Coping provides us with a perspective for viewing the family as a "reactive, responding unit", rather than a "causal" agent in relation to disability (Perrin et al, 1987). Coping thus means the efforts parents make to adapt to and with their disabled child (Hatfield, 1987). However, it is

now recognised that the health of the child includes, in addition to the absence of signs of illness, the ability to "perform as usual on a day to day basis" (Winefield and Cormack, 1986).

Concepts of coping can also reflect the ways in which a partnership with the parents is perceived (see Appleton and Minchom, 1991). Four types of partnership have been identified. Each can be interpreted as having a different definition for coping.

Types of partnership with the parents

- 1) In the "expert model" where the professionals assess the problem, parents are expected to cope by fitting in with professional goals for management of the impairment. A particular problem may be a narrow focus of interest by professionals and a lack of fit between parental goals and professional goals.
- 2) In the "transplant (of expertise) model" parents are expected to undertake a treatment program as prescribed by professionals. Particular problems can arise with this model because of differences between families in parenting style and family relationships. Dependency may be increased because authority and power are seen to remain with the professional.
- 3) In the "consumer rights" model the focus is entirely on parents having the right to select appropriate services and appropriate interventions. The major drawback is that it is assumed that parents do have the expertise to make appropriate decisions on what is needed and that all the services are available. This model of coping comes to depend more on the service provision. It is assumed that it is the services that need to be highly flexible, not merely providing standard packages of assessment and care, in specific places, but providing individually tailored help according to parental wishes. This becomes

a concept of the services coping with-the-child (with-a-handicap) and-the-family rather than vice versa.

- 4) The fourth concept of coping picks up the "model of the social network". In this model parents, children and therapists are regarded as part of a social network of informal and formal developmental and social support for the family and the child. Overall it is this model which seems to have the most scope for practical action in the current situation in Saudi Arabia.

One of the foundations of partnership between parents and care providers lies in the recognition of how much they have in common and how much they have to learn from one another (Mittler and McConachie, 1983).

6.5.2 Key elements for recognising challenges to coping

6.5.2.1 Recognising the separate problems that parents and the children with impairment need to cope with

i) What parents (and other family members) need to cope with

This study's contribution to the topic of coping is the identification of some of the problems parents in Saudi Arabia face and the solutions they have found to daily living activities (sleeping; feeding/eating; dressing; toileting; moving around; communication and adjustment with siblings and peers; discipline; play; sharing the care of the child) and also parents' worries, problems and exhaustion and their concerns for the future (see section 5.6.1).

Four key problems for parents can be identified which require "coping": recognition of the problem; receiving appropriate advice; overcoming the social stigma attached to the impairment;

and coming to terms with the subsequent outcome for dealing with the child and his impairment.

The first stress which parents have to suffer is that of receiving the diagnosis. This is stressful because most parents are frightened by the implications of the diagnosis. A diagnosis of impairment often signifies an uncertain future, loss of a body-part or function, dependency and alienation from others. Receiving a diagnosis of impairment may be felt as a threat because of the implications for the future.

A number of studies provide information about stress encountered by parents of disabled children as they have sought services and information regarding diagnosis, treatment and prognosis (Bernhmeiner et al, 1983; see also Dyson, 1991; Fisman and Wolf, 1991). In the present study, the parents of the children with deafness had a considerable struggle to get the impairment recognised. For Ahmed (juvenile rheumatoid arthritis) the "shopping around" caused great distress. For the families of all the children there was the stress of the first reactions at the time of recognition (see section 5.4.2).

Additionally, the treatment of the impairment can be stressful. Wadha and Fawzia (both poliomyelitis) particularly experienced the stress of surgical treatment (as did the two rubella children, Nora and Nema) and Laila (with osteogenesis imperfecta). For the children with profound disability and their families it can be an enormous strain going to the hospital (away from their normal routine and facilities, being stared at, etc.). Also there is the stress to the parents of taking the responsibility, remembering and being part of the daily routine of giving the children regular medication, e.g. for epilepsy. This was the reason most families had stopped giving medication. There is also the stress of separation when part of the treatment is to send the child to a special institution (e.g. Naila (developmental delay); Saad and Eman (deafness)) and the stress from the social pressure in Saudi Arabia saying this is the wrong thing to do. Then also the stress of prognosis of a chronic impairment that will not improve.

Care providers who have little or no experience with disabled children and limited knowledge of the community can contribute to parental stress (Bernheimer et al, 1983). In the same vein, Robinson (1978) identified a number of dimensions of the problem, including poor communication between the care provider and parents as well as the failure of care providers to acknowledge parental feelings of discomfort or threat. He also found that parents felt powerless with regard to decisions made about their child's future and some care providers behaved in an autocratic way. Such stress can be well imagined when there are cultural and linguistic barriers between parents and care providers. The service offered can itself be inadequate. In the present study, mere attendance at a special school carried negative connotations for many parents. Other factors suggested in this study as being contributory to the distress were the relatively impersonal nature of the treatments and the limited contact with professionals.

The third challenge for coping is overcoming the social stigma attached to the impairment as experienced particularly by parents of children with epilepsy. The existence of a negative stereotype, usually due to lack of familiarity and general ignorance on the part of the public is an additional problem families have to face. Although negative attitudes to disability are widespread in Saudi society, variations exist between different sections of the population. The more educated (paradoxically) hold to the traditional stereotypes of disability and are influenced by it more than some of the less well educated. Families thus face a very real problem of labelling by singling out certain attributes, evaluating them as undesirable and devaluing the person who possesses them. The majority of the study families showed at least some positive aspects of coping.

The fourth challenge to coping is the challenge of daily living. Sleeping, feeding, mobility, social interaction, all flow through life more or less smoothly when there is no impairment to cope with. But with an impairment these activities can present formidable challenges (see results section 5.6).

Overall, effective adjustment depends on how the parents cope with life. It is not the absence of crisis but the manner in which the stresses of living are handled (Hornby and Murray, 1983). In the present study, the degree of disability suffered by the family seems to be a combination of the function of the child: (compare for example the children with profound disability and those with epilepsy); the reaction of the family (e.g. ignorance (Hadeel), concealment (epilepsy), denial (Wadha, Ahmed), hostility (Thamer)); and the extent to which society is prepared to help, e.g. with developmental delay (Goddard & Rubbissow, 1977). Families with disabled children lead lives which in many respects are very like those of families with only able-bodied children.

ii) What the children with impairment need to cope with

Recognising special problems of adolescence

There are specific periods during which parents of children with a disability and presumably children themselves experience heightened stress, particularly during adolescence and name calling by others. This was apparent in the current study with Reem (mild cerebral palsy) and Fawzia (poliomyelitis) (see section 5.5.3.6). In the present study the two particular qualities in the child mediating stress at adolescence were "being the joker" (Abdu, developmental delay, see section 5.5.2.5); and "knowing that he was clever" (Salman, poliomyelitis).

When parents in the Anderson et al (1982) study were asked to describe the kind of difficulties that their teenage children had in forming personal relationships, they most commonly mentioned shyness, lack of self-confidence, and self-consciousness. While these are problems that many young people have at this age, with their increased awareness of appearance, a person with a physical impairment is particularly prone to shyness and timidity in peer relationships (Reinhard and Weissenborn, 1990). Reem (cerebral palsy) and Fawzia (polio) are both academically doing well and yet the former does not wish to eat in company because of clumsiness, and the latter clings to her mother because of her lameness. Considerable

individual differences exist; whereas some families are truly disabled by their experiences, others emerge as largely stable or even strengthened (Dyson, 1991).

Social isolation particularly when an impairment is very visible

There is general consensus that visible impairments often evoke negative attitudes in those without them. Altman (1981) argues such attitudes are important because they affect interaction with the general public. Becoming socially isolated and alienated from able-bodied society may become a problem in western society for many teenagers with a disability (Reinhard and Weissenborn, 1990). Such a possibility was noticeable in the present study for all the children except Wadha (poliomyelitis, age 15) who was being prepared for marriage. In Saudi Arabia where arrangements for selecting a marriage partner begin early, the marriage partner is often known by the age of 7 to 9 for children with no impairment, and this was the situation with Wadha.

In persons with an impairment and for their families, self concept is influenced by a multitude of daily interactions with individuals who teach, work, live with and care for disabled persons (Mittler, 1988). In the present study Hadeel is one clear example.

A child's quality of life may be low due to lack of stimulation (e.g. Hadeel, the four profoundly disabled, all the developmentally delayed and the children with epilepsy). Messy eating as an example of poor quality of life in the family as found in Amna and Abdulaziz (both cerebral palsy) may need to be distinguished from an improved quality of life resulting from change of lifestyle (e.g. of a family moving away from the area, as in the case of Waleed being removed to the village or that of Ibrahim taking up vocational training).

A child may have restricted experience. In the current study lack of adjustment through sensory deprivation was obvious in all the 3 children with deafness, two in institutions (Saad

and Iman) and one (Turki) in the community, waiting to go to special school. Social deprivation was clearly apparent in Hadeel's (developmental delay, age 4) situation.

6.5.2.2 Recognising subgroups of vulnerable families barely coping

In each area of family life that the current study examined, a small proportion of families were experiencing difficulties and restrictions in activities and relationships. A common factor was extra demands caused by profound disability. These were the two children with cerebral palsy (Amna and Abdulaziz), Nada (Down's Syndrome) and Mohammed (tetraplegia). Others were coping with extra demands and pressures. For example, Ahmed's father was suffering considerable emotional distress. A common anxiety in the families was concern for the child's future. Many families adopted the strategy of "living from day to day" and felt distressed at being unable to anticipate the future.

One indicator of difficulty in coping was reports of children showing high levels of behaviour problems (see Prior et al, 1988). For example, Saad (deafness) had a behaviour problem each time he came home from the special school during holidays. (This probably arose from adjustment problems when he came home.) Ibrahim showed childish behaviour which with his adult size at puberty was incongruous and unacceptable. Thamer (serious stuttering) avoided interaction and became a loner. Where they occurred, the children's activities were restricted and their relationships with friends were poor.

Dorner (1975) has suggested that even though depression is found to occur more frequently in mothers of children with physical impairments than in the general population, the most likely explanation for this is that the presence within the family of a child with a disability increases the vulnerability of parents to other stressful life events (see Singhi et al, 1990). These include bereavement, isolation or marital problems as in Thamer's situation where there was already

marital stress. The implication of this is that it is the underlying problems which need to be tackled.

Overall a number of different subgroups of barely coping families can be seen; families of children with severe disabilities (with difficulties in their activities and relationships with other children); families of children with high levels of behaviour problems; families worried about the child's future, and families who had difficulty adjusting to the child and where the parent-child relationships continues to be poor.

6.5.2.3 Recognising variability in coping depending on a child's personality, the nature of the situation and the child's age

The progression of parents from recognition to acceptance to coping can depend on the nature of the situation, personality factors and age factors.

Some factors affecting progression by parents from recognition to acceptance to coping

Personality factors

For example, the pattern of motivation of the parents and the general attitude of the parents towards their child, towards the impairment, and towards the environment. In Wadha's (lameness) situation her parents gave her every encouragement and because of it she thrived and developed well. Hadeel's (developmental delay) and Reem's (mild cerebral palsy) parents demonstrate how the personality of parents can affect the progression from recognition to acceptance to coping. Hadeel's parents were negative whereas Reem's were encouraging from the beginning. The parents' motives, beliefs about their child's impairment, child rearing resources and their knowledge will all influence their appraisal of the impairment and, thus, their coping.

The nature of the situation

For example, the possibility of localising a source of physical danger, e.g. for the children with epilepsy. The parents of children with deafness were particularly worried about how their children would cope when they left school. How would they hear the 'phone, for example? How would they hear the call for prayers? Positive community examples are seen in Waleed (developmental delay) in the rural environment and negative examples in the attitude to epilepsy. Factors in both the physical and social environment will influence how a situation is appraised. A child's impairment is only part of a larger environment and whether or not the situation is appraised as threatening will depend, in part, on the nature of this larger environment.

Age factors

For example, physical demands (for lifting) become greater as the child gets older and heavier. Amna's parents were finding it increasingly difficult now she was older. Usually any lifting had to wait until her father came home. Difficulties will increase as her father gets older and becomes less able to lift her.

6.5.2.4 Prevention of secondary disability through health promotion

The concept of health promotion is now recognised as a critical concept for persons with impairments (Brooks, 1984). Examples of early intervention to prevent secondary disability were found in the case of poliomyelitis and rubella syndrome through surgery for Wadha, Fawzia, Nora and Nema. When developmental delay is considered no impairment, nothing is done and this becomes a future problem. There was no attention to prevention of secondary disability such as illiteracy. Similarly when Wadha's father understood that poliomyelitis surgery was like a fracture and he thought it "solved" the problem, no further attempt was made at

health promotion to prevent secondary disability. Similarly Salman (poliomyelitis) was only taken to the hospital very late indeed. Also when epilepsy is considered merely an evil-spirit possession, there may be no medication given.

6.5.2.5 Recognising the range of strategies developed by parents

Parents utilise various strategies in an attempt to cope with the impairment and lessen its emotional impact. They may take direct action such as information seeking (seen in Reem (mild cerebral palsy), the three children with deafness, Hadeel (developmental delay), Naila (developmental delay), the rubella children and Laila (osteogenesis imperfecta)). They may use defensive action, or wishful fantasies (e.g. Wadha (poliomyelitis denied by the father); 5 out of 7 cases of developmental delay (all except Hadeel and Naila); all epilepsy; Ahmed (juvenile rheumatoid arthritis)). Any of these coping modes are used by parents to either alter a stressful relationship in the environment of the child with a disability or to control their own emotional response to the situation.

6.5.3 Practical procedures in coping

6.5.3.1 Finding solutions to problems of everyday living

Parents had found some solutions to everyday problems such as feeding but for some daily routines like toileting, eating, dressing and sleeping there was much scope for further help.

6.5.3.2 Discipline

It is well recognised that children with certain impairments (e.g. hearing problems) are more likely to show behavioural difficulties. Freeman et al (1975) discovered that deaf children were

significantly more likely than normal children to be described by their mothers as disobedient, restless, possessive, overly dependent and fussy.

For Saudi Arabia in the future, attention is needed in the prevention of disciplinary problems (e.g. by avoiding exclusion of the deaf, by forming support groups who can meet and communicate in sign language) and also by tackling child abuse. One effective way of doing this is likely to be through support of the traditional system, via the Imam and the Mosque who already see their role as including protection of all children (such as Hadeel).

6.5.3.3 Facing worries about the future of the disabled child

Worries about the future were of concern to all parents in the study. Concerns varied across a range from social stigma, social isolation and lack of social integration; through to mobility, education, change of work to be nearer a special school, sharing the care of the child, being blamed for the impairment, conflict in the wide family and uncertainty.

What is needed is support and reassurance for families from health care providers; more realistic assessment for future needs of the child, more explanation of the aetiology, and more linkage with traditional healers so that hopes are not raised too much, but their help and support are also enlisted.

6.5.3.4 Successfully mastering life events

Effective coping was evident in direct manipulation of the environment, perception of the impairment and management of the impairment.

Procedures employed by parents for coping

- 1. Direct manipulation of the environment to reduce the child's impairment: e.g. Waleed went to the village; Ibrahim took up vocational training; and Salman wanted to get the legislative and physical barriers to attending higher education removed.**
- 2. "Perceptual redefining" of the meaning of the child's impairment to reduce its threatening properties: e.g. in developmental delay, ascribing the impairment to closeness to God and with Wadha, considering her to be as other girls regardless of the impairment.**
- 3. Managing a child's impairment so that it was no longer overwhelming: e.g. for Reem (mild cerebral palsy), early detection, starting to teach her from the beginning, putting her in the mainstream etc; and the rubella syndrome children (Nora and Nema), by improving their condition by surgery.**

Performance relies upon being able to carry out major social roles, keeping self-esteem and getting access to available resources. Parents who prepared effectively for their child's impairments were less threatened by it (as with Naila's parents when they admitted her to a special school for mentally disabled children). However, Ahmed's parents were unable to anticipate and they felt that they had no control over the situation. Coping requires knowledge and information; the availability of a helping network; and a well developed problem-solving capacity.

6.5.3.5 The contribution to coping of strong family and informal social networks and positive attitudes in the community

A strong family, informal social networks and positive attitudes of the community are factors which enable more active participation of disabled people in the community (Dunst et al, 1986; Frey et al, 1989). These factors need to be promoted. Strong psychological family resources can be strongly associated with good adjustment (Wallander et al, 1989).

In Naila's case her parents supported each other against the rest of the extended family. They recognised she could do some study at the special school and this would give her education which was important for her in Saudi Arabia today.

6.5.3.6 The contribution of religious support to coping

Important factors influencing the way in which a family may cope with the task of rearing a disabled child include background factors existing even prior to the establishment of the family, such as social class membership, ethnic origins, religious affiliation and financial status (Freeson, 1971; Cooke et al, 1983). Religious belief has been a most important factor in helping a family to accept disability and has been recognised to help (Burton, 1975) including in the present study.

Parents may take comfort in religious belief. Psychological stress has been found to be low in mothers with a positive belief system (see, for example, Frey et al, 1989). In the study one example was Mohammed's father. As has been emphasised in this study, great strength is derived through the teachings in the Koran and the extent to which Islam plays a part in the lives of the Saudis. It is in this context that many parents find considerable spiritual support and gain the help from traditional healers (see section 6.6.2).

Hill (1978) suggested that professionals who are concerned mainly with the physical aspects of disease may not be fully aware of its psychological and social consequences. This is similar to findings in the current study where the emotional and social consequences of the child's impairment were being neglected by the professionals.

6.5.3.7 The contribution to coping of a strongly developed self concept

Salman (poliomyelitis, age 15) was free, unrestricted by his parents, able to do whatever he wanted in the whole realm of activity within the family. Davis and Rushton (1991) noted that the term 'independent' living, causes problems of understanding. It is generally interpreted as meaning living without help. Problems relating to the provision of aids to daily living typically fall into three main categories; no provision; poor assessment of an individual resulting in an inappropriate or unsatisfactory aid; and difficulties with maintenance and repair.

It has been recognised that intellectual and social skills are not static concepts and may change in time or with environmental changes (Barry et al, 1975) with the result that a disabled person's self-concept is determined to a large extent by the perceptions of others and their social expectations. In the study the change in Ibrahim was particularly apparent after the start of vocational rehabilitation.

The treatment accorded to the disabled person is determined by the prevailing attitudes (Judson and Burden, 1980). If the disabled child's perceptual and cognitive functions are systematically enriched and nurtured, his capacity to bring impulses into harmony with environmental limitations, to learn from experiences and to resolve conflicts will be improved.

Kashani (1986) too has indicated the link between impairment and low self-esteem. Examples in the current study are Fawzia (poliomyelitis) because of name calling at school and Reem (mild cerebral palsy) because of her clumsiness. Parmenter (1988) recognises this situation and,

contends that persons with disabilities have to cope with "negative aspects of their personal condition" as well as the "negative socially assigned identity". Parmenter shows how deviance, as a creation of social order, does not enable persons with disabilities to establish a viable social position. In order to counter this situation, Parmenter develops a model comprising a "rational marriage" between objective and subjective indicators. The model consists of three components: (a) self (low value in Fawzia (poliomyelitis) and Reem (mild cerebral palsy), and high value in the clever Salman and Abdu (the joker)); (b) functional behaviours (problematic in the children with epilepsy, and well adjusted in the children with developmental delay); and (c) societal influences (positive for Waleed and his grandfather's help to him in teaching him the Quran; negative for children with epilepsy). "What becomes paramount is how that person (with a disability) grows and develops as an autonomous individual, with an opportunity to achieve his/her hopes and aspirations".

6.5.4 Coping overall

Parents struggle to make sense of their experiences, so do children with an impairment. Parents and children utilise various strategies in an attempt to cope with the impairment and to lessen its emotional impact. They use direct actions such as seeking information, they may also use defensive thought processes and even wishful thinking and fantasies. They strive towards normality in their relationship and activities with the child. In the results two approaches to coping in Saudi Arabia were found (Section 5.6.4). One group were brought up as usual even though sometimes profoundly disabled. The others were segregated and excluded from usual life. Four strategies of coping by parents were also distinguished (Section 5.6.4.1).

Coping is to do with a multitude of daily interactions with individuals who come in contact with the disabled person because they live together, or provide care, or teach or are work-mates (Mittler, 1988). In this the disabled are helped by a framework of support ranging from the

immediate family to the society at large. The objective of services is to build on such a framework.

6.6 Parents and services they use for the child with an impairment

6.6.1 Introduction

The results showed the key need to recognise the current importance of traditional services in enabling the parents with the children with severe impairment to give public recognition, express their reactions, receive support towards acceptance, and receive support for everyday coping. The changing views towards education for children with impairment was clear and the likely effect of improving general knowledge on demand for health care services. Practical provision and also some weaknesses were also described for the education services. Current strengths and weaknesses of the health care system are described. This section now identifies current strengths, current problems and possible future developments for each of the three types of service the parents had used. Future opportunities for improvement within an integrated system are identified.

6.6.2 Parents' and the traditional healer services

All the children had been taken to a traditional healer and the current strengths of traditional healing are amply illustrated by this study.

For every single phase of dealing with an impairment in a child (recognition, reaction, acceptance, coping and services utilisation), traditions, culture and traditional healers play an important part alongside religion. What seems clear is the need for a plan of action which not only brings world class technology to the family in need but at the same time also endorses the caring and support that is already happening. It may be that there is still a need to help

planners understand that technology alone is only part of dealing with disability. There is always an emotional dimension to impairment.

6.6.3 Parents and the education services

6.6.3.1 Introduction

In this section of the discussion education services are defined and concepts of need for services are described. Then four problems with the education services are outlined. These are parents' strong preference for normal schooling (see results section 5.6.3.3); lack of facilities in mainstream schools (see results section 5.6.3.2); exclusion of parents from decision making (in the study all the parents of the children in special schools (Eman, Saad and Naila) were excluded from decisions on their education); and the need for schooling to reflect the developmental level of the child rather than chronological age (in the study it is the 56 children with mild learning problems for whom this is a particular issue. Good aspects of current services and opportunities and challenges for mainstreaming education provision lead to suggestions for future developments focused on the opportunity for educational integration of children with disabilities, with the need to examine psychosocial as well as physical integration. The opportunities for schools in Saudi Arabia to have an important role in recognition, acceptance and coping are outlined.

6.6.3.2 Current problems with the education services shown from this study

- a) Parents' strong preference for normal schooling (see literature review section 2.7.4)**

Parents in the present study know only too well that the ordinary school offers considerable advantages for the disabled child, for instance, it has a "normalising" influence on the child and

allows early socialisation with children who live in the neighbourhood, so that he or she belongs to a neighbourhood and forms part of his local community (Barry et al, 1975). Thus in the present study many parents wished their child to go to ordinary school for just these reasons and could see no sense whatsoever in sending the child to a special school with the disadvantage of being cut off from other children in their neighbourhood. Parents in Saudi Arabia are thus faced with the decision either to keep the child at home or to try to use the already scarce special schools with their extensive criteria for admission (the child must be aged 5 or more, must not have multiple impairments etc). Many studies have found that children with disabilities have less opportunity to attend school and vocational training than able-bodied children (e.g. Moore, 1980; Davern and Schnorr, 1991).

b) Education service problems: exclusion of parents from decision-making

The existing education and care system for children with disability in Saudi Arabia has often forced parents into making desperate choices. The lack of involvement of parents in arrangements for care and education may be shown in a number of ways. For example the central Department of Special Education in Saudi Arabia has not yet reached the stage of involving parents in their children's programme in any way that could be defined as "involvement". What is needed for the future for education services for children with disability in Saudi Arabia is listed below:

Studies to determine the effectiveness of special class placement have been fraught with methodological difficulties that have made the findings difficult to interpret (Kaufman and Ribakow, 1987). Little attempt has yet been made to ensure that schools are positive in their approach to the integration of disabled children, nor is it yet ensured that the teachers feel competent to both teach and handle any medical emergencies that may arise (Eiser and Town, 1987). These are opportunities for future improvement of education services in Saudi Arabia.

Future needs in the education services in Saudi Arabia

- **Education services and recognition of impairment**

A school screening service.

- **Education services and reactions to impairment in the future**

The school can play a key role in teaching able bodied children not to over-react to disability and to accept children with impairments. The school can also help build up a disabled child's self concept so they can tolerate the reactions of others (for example, Abdu (developmental delay) was accepted by teachers and peers because of his sense of humour).

- **Education services and acceptance of impairment in the future**

Attendance of the disabled children at regular school is generally considered desirable by paediatricians and parents. School attendance serves at least two functions. It provides a standard of education necessary for individual self-esteem and increases the probability of successful integration into the adult workforce. It also provides the opportunity to develop social skills in the children's relations with their peers.

- **Education services and coping**

Practical teacher education on coping with impairments at school is needed, e.g. medicines and coping with epilepsy

- **Education services and prevention of impairment**

Through health education on how to reduce impairment occurring preconceptionally, antenatally, in childhood and in adult life.

In prevention of social disability through lack of education and under achievement.

6.6.4 Parents and the medical care services (see also literature review section 2.7)

The following sections examine the current limitations in medical care services for recognition, reactions, acceptance and coping.

6.6.4.1 Medical care services and recognition of an impairment: current role and its limitations; future opportunities

Uncertain diagnosis

Many parents were dissatisfied with the advice they had received and with the assessment process. In many children seen at child development clinics, the diagnosis was uncertain. Clarity evolves over time as the child's developmental progress falls behind that which is expected. Mothers of children, where the aetiology of impairment was uncertain, are likely to be significantly more likely to be dissatisfied than mothers of children where the diagnosis is clear (Quinel, 1987). Such an observation stresses the importance of sound clinical knowledge for establishing a diagnosis and making a comprehensive list of all deficits.

Failure to recognise parental stress at the time of receiving the diagnosis
(see also literature review section 2.7.2.2)

The first stress with which parents with disabled children cope is that of receiving the diagnosis. Impairment diagnosis often signifies an uncertain future, loss of a body part or function, dependency and alienation from others. Thus, receiving a diagnosis of impairment may be felt as a threat because of the implications for the future. Hence a compassionate personality and ability to communicate well are the necessary attributes of the clinician making the diagnosis.

Uncertainty about what services to use when impairment is recognised
(see also literature review section 2.7.2.2)

Most parents were uncertain of what course to take when they discovered that their child had an impairment. The diagnosing clinician was not much help because of the reasons described, and also because there is no comprehensive service yet in Saudi Arabia for dealing with disability. Parents experienced many problems associated with the services when seeking advice for their children.

For the future a comprehensive disability service needs to include the following components to improve recognition: better antenatal screening; better perinatal screening; better pre-school surveillance; and better school surveillance.

6.6.4.2 Medical care services and reactions to an impairment: current role, its limitations and future opportunities

Limitations of the current medical role in dealing with reactions (see also literature review section 2.7.2.3)

The medical care services in Saudi Arabia could help parents much more with their reactions to the impairment. In the previous section it was noted that the parental stress of receiving the diagnosis was not being recognised. In the section below the failure to recognise the stress of the treatment procedure is described. When services do not recognise parental distress they do not start the help needed to cope with these reactions.

6.6.4.3 Medical care services and coping with an impairment: current role, limitations and future opportunities

Current limitations on medical care for coping include limited care for minor impairments, failure to recognise the stress of treatment and the need for better information on daily living, more emphasis on the family rather than the individual, improved coverage and improved continuity of life.

i) Limited care given for minor impairment

For minor vision impairment, coping covered issue of glasses and treatment of squint. Parents reacted positively to the treatment of squint because of its cosmetic effect, and sometimes reduction of headaches when myopia had been corrected. Hearing problems in the 109 children with chronic otitis media tended not to be recognised and only treated with antibiotics.

ii) Failure to recognise the stress of the treatment

As noted above, the treatment of the impairment is usually very stressful. Physiotherapy, speech therapy and occupational therapy can be both physically and psychologically stressful for the parents and the child. Other factors suggested as contributory to the distress were the relatively impersonal nature of the treatments and the limited contact with professionals.

iii) Better information needed on daily living, to improve coping

Everyday practical problems of this type require more time and more energy expended on them than the "normal" child care tasks. In the present study, parents felt ill-informed and lacking in proper guidance on management of their child with a disability. In order for many parents to cope with their disabled child the greatest area of need was for practical solutions to problems of daily living. Such topics are not usually addressed adequately by specialists or primary physicians.

Toilet adaptations could be made more widely available, the "inhuman spaceman" image of aids could be tackled and visible environmental improvements introduced (ramps, wide doorways, lower pavements, wide checkouts, toilets for the disabled; wheelchair taxis, wheelchair buses, level platform/train doors and wheelchair lifts available as well as stairs and escalators.

Attention is also needed to care by mother substitutes so that in-service child carer training becomes a norm rather than an exception. Flexible rules of employment are needed so that parents can also play their part in bringing up their children. Women and men with experience in both child care and employment are needed to work to find the best solutions for Saudi Arabia.

Coping services particularly need to develop ways of helping families with support and reassurance to counteract their worries. Better explanation is needed of future needs, aetiology and close links established with the traditional healers who currently provide most of the support families receive.

Attention is needed to the various intervention strategies being tried out elsewhere to see which may be relevant for Saudi Arabia. For example, the use of an "opportunity group" for young children with developmental difficulties focused on providing a rich social and emotional environment to facilitate cognitive development (Campion and Wohlfarth, 1989) could be useful for Hadeel's situation but for the other children with developmental delay the traditional system was already providing a rich world of social and emotional experience and human relationships.

Other approaches such as skills training in coping styles (Kirkham et al, 1986) might have a role too but each needs to be carefully examined for the Saudi setting.

Opportunities to improve services for coping

Seven current problems could be systematically tackled:

- Better care for minor impairment
- Recognise stress of the treatment
- Better information and support practical aspects of daily living

This would include feeding, toileting, sleeping, play, aids, accessibility, training for mother substitutes, parental leave systems; and sources of reassurance for worries on aetiology and prognosis including linkage with traditional healer support

- **Focus on family rather than individual**

Families enter the rehabilitation partnership with their focus on a particular member of the family but also have an interest in the family as a whole. The professional health worker in contrast has been taught to be interested mainly in the individual "case" and only recently begun to be trained to see the wider family.

The family of a disabled person tend to see their member holistically, their commitment is generally lifelong and they see things from all sides (Burden, 1986; Mitchell, 1988; Mittler and McConachie, 1983). The health worker often sees the person with the impairment about a "narrow" problem, their commitment is temporary and they may see things only from their specialist point of view.

With such conflicting sets of role expectations and priorities, it is not surprising that sometimes problems arise in the relationship between parents and professionals. Both need to recognise that team roles of partnership in rehabilitation involve crossing into other professionals or individuals' boundaries.

- **Wider coverage**

Greater specialisation of medical care has been the tendency in Saudi Arabia rather than wider coverage. Response to disability problems has been through increased national spending and a multiplication of programmes. The success of these massive public programmes has been modest. Home care is a new option. As elsewhere it will be subject to debate about how medical coverage should be extended to meet the long term needs of the chronically ill, and concerns about quality of home care.

- **Improved continuity of care**

Continuity of care is of vital importance for the families as well as the child with impairment (Anderson and Hinjosa, 1984). In this way problems arising can be referred via the care provider to the appropriate service. In this way, patients feel they are receiving the best possible care with the opportunity to be referred elsewhere when the need arises. Once the child is lost to follow up, the route to consultation can be long and tedious with tests and investigations being unnecessarily repeated.

- **Action on the problem of transition from paediatric health care to adult health care**

After leaving the care of the paediatric health service, many teenagers with a physical impairment find difficulty in obtaining appropriate adult hospital services. It is a common experience that on moving out of the paediatric age group many disabled persons are rarely seen by the hospital services on a regular basis (Hirst, 1983).

- **Attention to the quality of interaction between families and care providers in the health, education and traditional sectors**

Opinions differ regarding the nature and extent of parental involvement in home treatment programmes (e.g. for the child with cerebral palsy, Hinjosa & Anderson, 1991) and their relevance for developing countries.

Mothers of more severely disabled infants can find that their involvement in home treatment makes their lives more manageable. Characteristics such as the child's age, the nature of the disability, and the severity of impairment may affect a mother's perception of the helpfulness of home intervention. Parental involvement in a home treatment programme may increase the parents' knowledge of their child's condition and can facilitate parent-child interactions (Baker

et al, 1991). Furthermore, parental involvement may relieve stress and improve the family's health. These studies imply that parental involvement in treatment may be perceived as an important adjunct to therapy (Beckman, 1991). Furthermore, many parents want to become involved in their child's therapeutic programme (Appleton and Minchom, 1991; Mahoney and O'Sullivan, 1990).

There may be a danger of a mass export of western treatment packages to developing nations rather than questioning what the parent is being asked to do. Parental involvement reflects western concepts of education and child rearing. In other countries families have very different demands, routines, expectations, concepts of play and use of toys, as this study has shown (McConachie, 1991). Thus what is needed by Saudi Arabia is a highly critical assessment of interventions in use around the world. In introducing a parental involvement programme, research would be needed to investigate creative ways to assist a child's development as an integral part of the day, focusing not necessarily just on the mother, but the father, grandparents, and maybe other close relations too, rather than making unrealistic demands on an already overburdened or less than interested mother.

6.6.4.4 Medical care services and prevention of impairment and disability (see also literature review sections 2.7.3.1 and 2.7.3.2)

Currently there is little stress on prevention of impairment in Saudi Arabia (Al Saif and Tabbara, 1986; Basalamah and Serebour, 1982). Medical care services can take a lead role in identifying the causes of impairment and providing health promotion activities as well as preventing secondary dysfunction.

Ways the medical care services could improve services for prevention of impairment and disability

- **Improve the general health of adult men and women about to have children thus reducing impairments of periconception and early pregnancy origin**

Immunisation against rubella in a woman before child bearing age is an example of such measures. This could be done by increasing the uptake of rubella immunisation in school girls and by screening for susceptibles and immunisation before pregnancy. Although the evidence showed that congenital rubella was numerically a small cause of perinatal and foetal problems, these problems are potentially preventable.

A new area of interest in prevention of impairment is the opportunity for health promotion in both parents in the period four months prior to conception (see e.g. Wynn & Wynn, 1991). This has implications possibly for marriage counselling, as well as the education of children. One slogan is "get fit and healthy before you go for a baby".

- **Improve antenatal care (not only for better screening) but to reduce impairments of pregnancy origin**
- **Improve delivery care and early neonatal care to reduce impairment of perinatal origin**

This was shown in the present study to be a particularly important need. An entire system of community based obstetric care is needed, with careful evaluation of home based deliveries. The management of neonatal crises has a considerable effect on the reduction of prevalence of disability due to perinatal causes. Education of grandparents is needed for them to be alert to problems antenatally, during the delivery and in the immediate post-partum period.

- **Promote immunisation and promote healthy development of children to reduce physical, intellectual, emotional and social impairment of childhood and adolescent origin**

- **Improve screening services and coping services so untreated impairment is avoided**

See section 4.6.4.2 and for coping services see section 4.6.4.5, so that treatment and care commence early and secondary disability resulting from untreated impairment or lack of education is avoided.

- **Improve public education on causes of impairment through the life cycle to promote environmental/safety issues (especially road traffic accidents) for prevention of impairment and disability**

- **Collaborate with education and employment sectors to seek gainful employment opportunities for children with disabilities to prevent social isolation and poverty**

Adults with disabilities have generally lower incomes than able-bodied adults and consequently they are more likely to suffer poverty. In some societies however, they receive disability benefit, their economic situation is less favourable than the able-bodied, thus their standard of living is lower.

No extensive empirical literature is available on the socialisation and integration of disabled persons in the workforce. However, in Dijkstra's study disabled persons were unable to become integrated and became jobless. The differences in turnover because of unsuccessful socialisation could be explained partly by biological and disability variables, and also by the degree of commitment to sheltered employment, often regarded as stigmatising. Sheltered employment is often the only labour market alternative left for many people with disability (Dijkstra, 1986).

6.6.5 Future developments towards an integrated service combining health services, education services, social care and support services and traditional services working together throughout the life cycle

6.6.5.1 Summary of the need for change

The effects of depriving disabled children of stimulation, security and, orientation are now universally recognised, but it took years of repeated research before it was accepted by institutions, that children with disabilities should not be left alone to look at blank ceiling for long periods of time.

Throughout recorded history, the problems of these children have been dealt with by their families, at the community level. That makes sense, in a profound way that we have only recently begun to appreciate. It is to that approach that studies are now returning, but with three major differences. First, we now understand that we must make the community as a whole accessible to children with disabilities. In the past, we expected the family somehow to struggle with the barriers in the community or to keep the disabled member at home. Secondly, Saudi Arabia has communication channels and resources that allow the country to bring world-class services to even remote villages. Finally, the services have recourse to many new technologies. There is no need for constructing "special places" (hospital, schools) far from population centres. Such services forced removal of the child from the family and from the community. In the past accessible design of public places was not an issue because people with disabilities were removed into institutions. That is why much of the community facilities in Saudi Arabia remain inaccessible.

6.6.5.2 Integration of recognition processes

As described above (section 6.2.4.5) action is needed to link three situations in which recognition processes occur: in the family; in the surveillance services (perinatally, pre-school and school); and with the traditional healers who help families formally recognise impairment.

One important situation is improved community education to help families (especially grandparents and parents) recognise impairments even better. Families (particularly parents as well as grandparents) need to know what medical and education services to turn to when they suspect a child may have an impairment.

A second important field is improvement of the surveillance services, in the medical service those dealing with perinatal and pre-school periods, and in the education service with school surveillance both through school health services and through training of teachers. Since traditional healers have been shown to be playing such a key role, they need to be integrated into the evolving programme of surveillance.

Traditional healers need training in recognising other impairments over and above those they already recognise well. They need formal appreciation of their important role in enabling the family to come together in a group and formally recognise that, even with an impairment, a child is still a child. Traditional healers need to have information on what medical and education services they can refer the family to when recognition of an impairment occurs.

6.6.5.3 Integration of support for reactions to the impairment

Support for reactions to impairment needs to take account of both the emotional reactions (shock, anger, denial, guilt etc, see sections 5.4.2 to 5.4.4) and the sociocultural context (of stigma and labelling, and low expectations (sections 5.5.3 and 5.5.6). It needs also to take

account of the process of recognition and what people think are the causes of the impairment. Only by considering all these aspects will appropriate support services begin to develop.

Action is needed to tackle reactions in the family; to improve their knowledge of impairment and what can be done to help it; to help parents and families know which services can provide support in the time of stress following diagnosis. Also to help the family progress from reaction to acceptance and coping and to help them disclose and publicly recognise the situation.

Action is also needed to tackle reactions in the community; creating positive attitudes through an environment of achievement and social acceptance for the person with a disability. When there is positive attitude and understanding, then perhaps concealment will be far less common.

6.6.5.4 Integration of acceptance processes

The keys to progress on acceptance seem to lie in the three fields of collaboration with religious and traditional healers; services which ensure success for the child; and recognition that acceptance changes with age and stage of the life cycle.

Services to ensure family support and "success" will enhance the child's self-esteem and self-acceptance as well as community recognition of achievement. Attention to daily living skills may be all important for this.

6.6.5.5 Integration of services for prevention and health promotion

This study has shown many severe impairments present solely through the lack of primary intervention. Immunisation services need attention in Saudi Arabia to enable better rubella coverage, and better poliomyelitis coverage in particular. Both children and adults need to be targeted. Road accident prevention is a very important topic for national focus. Particular

attention is needed on the quality of care provided at the time of delivery and this, as with other aspects of services, requires joint attention not only to the quality of medical care provided but to the knowledge of parents and grandparents so that they recognise need for special care in pregnancy and at or soon after delivery. Attention is also needed to health promotion in the periconception period, including focus on a good birth interval.

6.6.5.6 Integration of support for coping

When coping is seen as to do with the multitude of activities of daily living; combined with relevant medication; combined with the numerous individuals who teach, work, live with and care for people with a disability; co-ordination and cooperation as well as linkage between the health sector education and traditional healers become crucial. It is not surprising to find the "social network" model of coping (see section 5.6) which is the preferred model for Saudi Arabia at present. The concept of partnership rests on the assumption that children will learn and develop better on a basis of equality between parents and care providers than when they work in isolation. One of the foundations of partnership between parents and care providers lies in the recognition of how much they have in common and how much they have to learn from one another.

7. SUMMARY AND CONCLUSIONS, KEY ELEMENTS OF THIS STUDY AND RECOMMENDATIONS

7.1 Summary and conclusions

This study has developed a practical procedure for community enquiry in Saudi Arabia which others are likely to find useful. Only one other community based enquiry has been done in the Kingdom. The study has also identified community based prevalence rates for both minor and severe impairments, again for the first time.

The study is, in its broadest sense, a work describing child disability within Saudi Arabian Islamic culture, with its own special processes of communication and expected forms of behaviour held in common by both the author and the respondents. The study is based on recognition that all aspects of culture are important to an understanding of a child with disability. A holistic picture of child disability within the Saudi culture is presented. The study will allow expatriates working in Saudi Arabia to appreciate the cultural context and the way of life experienced by the parents of children with disabilities. Saudi professionals can also be sensitised to the experience of disability in the family, to promote their understanding of the problems and the solutions parents have found. The procedure used was a large screening study coupled with the gathering of extremely detailed descriptive information based on an extended and in-depth researcher-parent relationship. For the descriptive study an inductive approach is used that generates research questions rather than answering predetermined hypotheses. This is an exploratory approach building conceptual models and hypotheses from the analysis of the data rather than predicting answers and testing them. This approach can help professionals control the biases and the professionalism they often develop during their training. When a study begins with broad research questions, the study is less likely to

overlook phenomena that do not fit the original expectations. The data are contained within the use of language and expression, verbal and non-verbal, derived from observation within a framework of five topics. The study also recognises that human behaviour goes beyond that which can be observed. Significance is thus also drawn from the meanings and interpretation of events expressed by the parents. Understanding arises from information about parents' interpretations of their experience. Prevalence statistics are presented but even more importantly the everyday life events these statistics represent, are discussed. The depth and variety of data aids in the humanising of stereotypes of disabled children. The analysis is conducted on several levels. Content analysis reveals repetitive themes within the data. These substantive themes are then integrated to form a conceptual analysis of the data.

On recognition the study has distinguished between recognition by the family and recognition by the services, identified factors affecting recognition, particularly emphasising the "cultural component" of recognition in Saudi Arabia and the importance of parents noticing "something is wrong". Need for action has been identified on four fronts: better perinatal care; improving general knowledge so that parents and grandparents recognise impairments early; better recognition of the legitimising role of traditional healers in recognition for the family; training of healers so they can recognise impairments better and know more fully what can be done to help; and better surveillance at health clinics and in schools.

Reactions have been separated into early and later. Particularly important reactions found include the finding of concealment of epilepsy and beliefs that the child with epilepsy is a changeling exchanged for a fairy child. Also important is the finding that children with developmental delay are respectfully accepted by most families in the belief they are closer to God. Parents' blank incomprehension of disorders unknown to them is clear from this study, coupled with anger and disbelief as they perceive an impairment treated only with headache pills (aspirin for juvenile rheumatoid arthritis).

A framework for action on reactions is described. Action is needed to tackle reactions in the family (counselling services and improving general knowledge for parents, siblings and grandparents); in the community (by improving general knowledge of impairments, their causes, and the many things that can be done to help; with traditional healers (developing liaison and recognising their important role in helping families to express their reactions); with health professionals (training to understand psychosocial matters and perhaps using case studies of the type found in this study) and with educational professionals (training to understand how the role of the school can help a child cope with disability (or can cause worse problems with insensitive reactions from school pupils or teachers). Teachers can learn how their support for impaired children can greatly help families and the affected child. Teaching teachers by stories may be a practical way forward.

Acceptance was presented as a continuing process of parental, child and community factors positively facilitating acceptance of the impairment and of the child, or negatively delaying it.

Positive factors found in the Saudi context included religious belief that hardship is rewarded by not complaining, and the value given to developmental delay children as being close to God. In some cases neighbours showed concern, and also support from the extended family was shown to help acceptance. The compensating positive effects in the child of physical or personality attractiveness, religious devotion and achievement were seen. A positive environment facilitating acceptance was also created for some families by "facing the reality" and for a few through professional help. For others the positive environment was created by employment of the young person or putting them in some other achieving (not failing) environment, accepting the child for what they can do or managing them so that they do the usual activities for their age group.

Negative factors delaying acceptance found in the study were prolonged questioning of the diagnosis and emotional exhaustion; overburdened mothers, and overdependence on them or

over-delegation of care to others; denial of the impairment (common for minor impairment and the young); labelling and stigma in the community; too low expectations (e.g. of marriage); or too high expectations and poor performance. Lack of concern from health professionals about worries or problems was also a delaying factor for many parents. For the children negative factors included failure and new problems to be faced at adolescence.

Acceptance is changing in Saudi Arabia. In the future it is hoped epilepsy may become better understood and carry less stigma so children do not have to have this impairment kept concealed. Developmental delay may become less accepted in future as academic achievement becomes more important. With modernisation the village could become less accepting in future.

In Saudi Arabia certain actions are needed to help parents during the period of learning to accept their child with an impairment. These include recognising and building on the important role of religious leaders and religion itself in helping parents come to terms with a child with an impairment in the family. Another important field is work to create an environment of success for each child with an impairment. A third is to provide counselling support to parents and the child during the times of recognition and reactions, to help them move toward acceptance; recognising the factors that facilitate acceptance and those that delay it, and recognising that continuing support is needed through the life cycle as new situations arise. Only when full recognition of the facts, healthy reactions, and acceptance of their implications have occurred, will parents, the extended family and the child move towards positive coping based on understanding, anticipating problems, recognising low expectations and thus appreciating every slight improvement.

Overall analysis of acceptance needs to consider the age, the stage of development of the child, and the key transitional stages they are facing at a particular time (e.g. adolescence, going to a new school or college, or getting married). It needs to distinguish between acceptance of the child and acceptance of the impairment, and between acceptance socially and acceptance

academically. The "size" of the burden which each family has to accept also needs to be taken into account. In the end acceptance depends on families finding out what a child can do and appreciating every step towards such achievement. Acceptance will not take place while parents still do not recognise there is a problem. Acceptance can only follow recognition. Acceptance also has to take place after the early reactions such as shock. When acceptance begins this is the first step towards starting the process of coping.

Coping, practical help in managing difficulties in daily living, was found to be one of the keys to enable families and community to live with and alongside impairment and to enable normalisation and integration. The challenge to any country is to make resources available to enable families to find practical solutions to everyday problems.

Yet coping does not occur simply from provision of aids. Coping is also to do with feeling part of everyday life; living with others and being accepted at least to some extent in family and outside. Support from the social network helps coping, so can religion not just belief, but the whole pattern of life associated with religious practice in Saudi Arabia and finding something the child with impairment can be valued for. Two types of coping style were evident, treating the child as normal (even with severe impairment) and concealing the problem.

A third key component of coping was ready availability of services when they are needed, services which recognise the burden and can alleviate it at appropriate times.

On **services**, the study has shown the key role of traditional healers in Saudi Arabia in helping recognition, enabling reactions to be expressed and facilitating family acceptance. Their recognition is not of a medical diagnosis, but of a person and their family in need of special support. Their hope is with the family that the problem may fade away (unlike the permanent medical diagnosis), part of their support is in the shared belief that the impairment can affect anyone. Those who are patient with the problem, they teach, will be rewarded. The study has

documented the changing views on the relevance of education to children with impairment and in health care, the need for better screening services, better prevention services, better health promotion services as well as improvement developing an integrated education, traditional and health care system.

From these findings, the study has identified the current key role, previously unrecognised officially, of traditional healers in recognition, acceptance, reactions and coping with impairment. Practical suggestions are made to build on this important role in a future integrated service. The study has also identified the range of reactions experienced in current Saudi Arabia with a mix of traditional response and something of a modern negativism.

The study has identified the need to provide culturally appropriate services and support for disability in Saudi Arabia, marrying sophisticated high technology with a traditional approach to life and living, and the bringing up of children. It has shown the key role of faith, fatalism and religion as a way of life both positively and negatively influencing acceptance, reactions, coping and use of services, especially those from traditional healers.

The study has shown the strengths and a number of weaknesses in the current services and provided an important new dimension in gathering parents' views of them. Suggestions are made to link together the best parts and strengthen the weaker ones so in future there may be an integrated service for disability building on the best of tradition and bringing in new knowledge where it is needed.

7.2 Key findings of the present study

The study has developed a practical and culturally appropriate method of enquiry about disability in Saudi Arabia. The present situation in the care of children with disability (in the key fields of recognition, reactions, acceptance and coping is summarised in Table 7.1.

Table 7.1 Towards an integrated care service for disability

	Family parents and grandparents	Community	Medical care	Education sector	Traditional care
Recognition processes	<ul style="list-style-type: none"> ● Surveillance ● perinatally ● pre-school ● at school 	<ul style="list-style-type: none"> ● Surveillance ● perinatally ● pre-school ● at school 	<ul style="list-style-type: none"> ● Surveillance ● perinatally ● pre-school 	<ul style="list-style-type: none"> ● Surveillance at school 	<ul style="list-style-type: none"> ● Help families recognise impairments
	<ul style="list-style-type: none"> ■ Improve community education ■ Teach community recognition ■ Teach what medical and education services are available 		<ul style="list-style-type: none"> ■ Improve surveillance services ■ Train teachers better ■ Teach to refer to traditional healers 		<ul style="list-style-type: none"> ■ Improve recognition ■ Recognise role ■ Teach to refer to medical and education services
Reactions	<ul style="list-style-type: none"> ■ Recognise shock, anger, denial, guilt 	<ul style="list-style-type: none"> ■ Recognise stigma and labelling 	<ul style="list-style-type: none"> ■ Recognise support services are lacking ■ Improve knowledge of cause and effect ■ Train professionals to understand social/cultural situation and likely reactions; train to examine own attitudes ■ Train to refer to traditional healers 		<ul style="list-style-type: none"> ■ Recognise support ■ Support and facilitate this role
	<ul style="list-style-type: none"> ■ Recognise what people believe are the causes ■ Improve knowledge of what can be done to help, especially services for times of stress for parents, siblings and grandparents 				
Acceptance	<ul style="list-style-type: none"> ■ Recognise religious dimension 	<ul style="list-style-type: none"> ■ Recognise community values of achievement 	<ul style="list-style-type: none"> ■ Recognise factors facilitating or delaying acceptance ■ Create service which ensure success and enhance self esteem 		<ul style="list-style-type: none"> ■ Formally recognise key role in helping parents achieve acceptance
	<ul style="list-style-type: none"> ■ Create positive attitudes through enjoyable interaction ■ Create achievement ■ Create normal status for people with disability ■ Recognise acceptance changes with age and stage of life cycle 				
Coping	<ul style="list-style-type: none"> ■ Recognise problems ■ Find ways to share solutions found 	<ul style="list-style-type: none"> ■ Recognise their share in caring ■ Provide training for mother substitutes ■ Improve visible accessibility 	<ul style="list-style-type: none"> ■ Improve practical support for daily living and achievement ■ Provide reassurance ■ Use many disciplines for help 		<ul style="list-style-type: none"> ■ Improve knowledge of practical daily living ■ Improve referral
Prevention of Impairment	<ul style="list-style-type: none"> ■ Improve general health before conception ■ Improve knowledge of danger signs antenatally, in labour and postnatally, especially for grandparents 	<ul style="list-style-type: none"> ■ Improve general knowledge of health before conception and during pregnancy ■ Road safety action 	<ul style="list-style-type: none"> ■ Improve: <ul style="list-style-type: none"> ● antenatal care ● delivery care ● neonatal care ■ Promote immunisation for all age groups ■ More research on preventable causes of impairment 	<ul style="list-style-type: none"> ■ Avoid secondary illiteracy ■ Immunisation through school services ■ Seek gainful employment opportunities 	<ul style="list-style-type: none"> ■ Provide information so they can teach via the mosques
	<ul style="list-style-type: none"> ■ Promote immunisation and improve child development monitoring 		<ul style="list-style-type: none"> ■ Avoid secondary disability due to lack of services use 		

Table 7.2 Summary of Programme Recommendations

	Integration of services	Creating awareness
Education target groups	<ul style="list-style-type: none"> ● Traditional healers ● General population 	<ul style="list-style-type: none"> ● Health workers ● Parents ● Wider family ● School teachers
Professional training	<ul style="list-style-type: none"> ● Health workers ● Teachers ● Social workers 	<ul style="list-style-type: none"> ● Health workers ● Teachers ● Social workers
Resources	<ul style="list-style-type: none"> ● Ministry of Health ● Ministry of Education ● Ministry of Social Affairs ● Ministry of Pilgrimage and Endowment 	<ul style="list-style-type: none"> ● Ministry of Health ● Ministry of Education ● Ministry of Social Affairs ● Ministry of Pilgrimage and Endowment

Organisation	<ul style="list-style-type: none"> ● MOH initiated working party ● Representatives from other Ministries ● Outline plan of action ● Report to King ● 5 year plan of action and budget 	<ul style="list-style-type: none"> ● MOH initiated working party ● Representatives from other Ministries ● Outline plan of action ● Report to King ● 5 year plan of action and budget
Research	<ul style="list-style-type: none"> ● Repeat study in key sites nationwide ● Identify low cost high coverage options ● Try out alternative model programmes in selected areas 	<ul style="list-style-type: none"> ● Identify alternative approaches for improving knowledge on dissability (literature review, workshop) ● Assess relative effectiveness of different approaches

APPENDIX

Procedures when the family with a child with an impairment consults a traditional healer (help for recognition, reactions, acceptance and coping)

When the family met the traditional healer, the children were held closely, by the parents, and other relatives, who all came together for this important occasion. It is a social gathering, a bringing together of the family. While the verses from the Quran were being recited, the children were always being held and this was most important for the children with a profound disability who were drooling. The relatives normally tend to keep their distance and do not want to hold the child with an impairment but, in this important situation were welcomed as part of the family. The traditional healer talked with everyone in a language that they understood. He showed by his mannerisms that he felt the problems and yet was always optimistic for the future. There is hope. In the process of reciting the verses from the Quran, in an atmosphere of faith and yet also togetherness with the family, there was often much crying by both male and female members of the family and this can serve to release tension for all the family. In Saudi culture, it is very bad, particularly for a man, to cry in public. However, in this special situation, it was a release for everyone of the tensions and stresses that they were experiencing.

In talking with the families, the traditional healers particularly focused on family strengths. They gave plenty of time for acknowledgement of what families were doing that was working well, and they helped the family to acknowledge it themselves. The parents' self esteem and feelings of competence were greatly enhanced by this acknowledgement of their strengths. Many families said they felt able to tell the traditional healer how well they were coping with their own lives and how they could cope with the problems of their children. Acknowledgement of the strengths of the family, as well as dealing with the family's needs, and recognising areas in need of change, provided an excellent three way balance needed to build a truly helpful relationship with the family. The traditional healer had the effect of decreasing family anxiety about the child and increasing confidence in their ability to be effective care-givers. The healers' emphasis in this role is on coping, not just on rehabilitating the child. This in turn enhanced the willingness of families to participate in the activities suggested. Because the family's activities were being valued, there was also less stigma attached to what they were doing and this again enhanced the willingness of families to accept the future.

Throughout, there was no blame; there was no "parental genetics" that had caused this problem, it was always a question of the Will of Allah, a genie, and Something which is beyond the control of the parents. This may make it much more comfortable for them to live with the impairment.

As part of recognition of the family strengths, brothers and sisters came to visit the traditional healer as well and the traditional healer recognised the role that the brothers and sisters were playing. He focused on family strength through collaboration. The brothers and sisters may function as an adviser for the child with the impairment. While the siblings were there, the traditional healer would read some verses of the Holy Quran over them to protect them from such an impairment, but also to involve them in the whole process of dealing with the child's disability. This also reinforced the idea that everybody is susceptible, and can suffer a similar impairment.

The traditional healers do not think along the lines of disability, but rather focus on a lack of skills. Less stigma is attached to such an approach. They provide specific information relevant to each of the major areas of need felt by the family and, since they respond to the felt needs of the families, what they say is found to be useful and satisfying by the families.

For example, the traditional healers frequently emphasised that patience in this life will bring rewards later on. With the parents of Turki, the traditional healer said that maybe God did not want him to listen to bad things, but to better things in the future. This is why the child was deaf: so that he would not hear the bad things himself. By giving a religious reason for a particular impairment, he reassured the family.

To Salman, the traditional healer said "You are a clever boy and it is God's will that you should study theology, as this will be more beneficial than going to the civilian university".

BIBLIOGRAPHY

Abbott P, Sapsford R. Community care for mentally handicapped children. Open University Press, Milton Keynes, 1988:5-43

Abdurrahman MB. Parents' understanding of their children's illnesses. J Trop Paediatr Environ Child Health 1973;19:251

Abramovitch R, Stanhope L, Pepler C. The influence of Down's Syndrome on sibling interaction. J Child Psychol Psychiat 1987;28(6):865-879

Abu-Shaqara SM, Kazi G, Al Rushood A, Yassin S. Prevalence and causes of visual acuity defects in male school children in Al Khobar area. Saudi Med J 1991;12(5):397-402

Adekunle FA. Immunization: problems faced in a developing country. Africa Health 1980 Dec;30

Adeniyi D, Bridger WR. Involving communities in tropical disease control. J Public Health 1984;95:185-88

Al Lamkiz and Ohlin C. A community-based study of childhood handicap in Oman. J Trop Paediatrics 1992;38:314-316

Al Othaimen AI, Sawaya WN, Tannous RI. A nutritional survey of infants and pre-school children in Saudi Arabia. Saudi Med J 1988;9(1):40-48

Al Radi S, Al Mahdi MA. Group therapy: an Islamic approach. 1989; mimeographed, 7 pages

Al Rajeh S, Bademosi O, Awada A, Ismail H. Cerebral palsy in Saudi Arabia: a case control study of risk factors. Dev Med Child Neurol 1991;33:10468-52

Albrecht GL, Levy JA. Constructing disabilities as social problems. In: Albrecht GL, editor. Cross national rehabilitation policies: a sociological perspective. California: Sage Publications Ltd., 1981:11-32

Allen G. Informal network of care: issues raised by Barclay British. J Soc Work 1983;13:417-433

Allen L, Zigler E. Psychological adjustment of seriously ill children. J Am Acad Child Adoles Psychiatry 1987;25:708-712

Altman BM. Studies of attitudes towards the handicapped: the need for a new direction. Social Problems 1981;28:321-337

Anderson EM. The disabled school child: a study of integration in Primary Schools. London: Methuen, 1973:127-152

Anderson J, Hinjosa J. Parents and therapists in professional partnership. Am J Occup Ther 1984;38(7):452-461

Anderson NB, Rincover A. The generality of overselectivity in developmentally disabled children J Exp Child Psychol 1982 Oct;34(2):217-230

Antonak RF and Livneh H. A hierarchy of reactions to disability. Int Rehabil Res 1991;14:13-24

Antonovsky A. Unravelling the mystery of health. Jossey-Bess, San Francisco 1987:xii

- Appleton C. Help for parents of the handicapped (letter). *Br Med J* 1978;275:1348-1349
- Appleton PL, Minchom PE. Models of parent partnership and child developmental centres. *Childcare Health Dev* 1991 Jan-Feb, 17(1): 27-38
- Archie VW, Sherrill C. Attitudes toward handicapped peers of mainstreamed and nonmainstreamed children in physical education. *Percep Mot Skills* 1989 Aug;69(1):319-322
- Armstrong RW, Rosenbaum PL, King S. Self-perceived social function among disabled children in regular classrooms. *J Dev Behav Pediatr* Feb 1992;13(1):11-16
- Arrigada HM. Early stimulation programs in Latin America. *Int J Ment Health* 1990;18(3):19-39
- Atkinson FI. Experiences of informal carers providing nursing support for disabled dependents. *J Adv Nurs* 1992;17:835-840
- Badr I. Epidemiology and a proposed national programme for the control of trachoma in Saudi Arabia. *Saudi Med J* 1984 Jul;5(3):325-329
- Bailey DB, Blasco PM, Simeonsson RJ. Needs expressed by mothers and fathers of young children with disabilities. *Am J Ment Retard* 1992 Jul;97(1):1-10
- Baker BL, Heifetz LJ. Behavioral training of parents of mentally retarded children: one year follow-up. *Am J Ment Deficiency* 1980;85(1):31-38
- Baldwin S. Problems with need - where theory meets practice. *Disabil Handicap Soc* 1986;1(2):139
- Ballard REH. Help for coping with the unthinkable. *Dev Med Child Neur* 1978;20:517-521
- Barabas G, Taft LT. The early signs and differential diagnosis of cerebral palsy. *Paed Annals* 1986;15(3):203-214
- Barry C, Gavey C, Byrne MM. The education of physically handicapped children in normal school. *Child Care Health Dev* 1975;1:179-184
- Bax M, Whitmore K. The medical examination of children on entry to school: The results and use of neurodevelopmental assessments. *Dev Med Child Neurol* 1987; 29: 40-55
- Becker HA, Bergen AKS, Ingalsbe K, Sands D. Health promoting attitudes and behaviour amongst persons with disabilities. *Int Rehabil Res* 1989;12(3):235-250
- Bell NJ, Schoenrock C and Bensberg G. Changes over time in the community: findings of a longitudinal study. *Monogram Assoc Ment Def* 1981, Vol.4:195-206
- Bennett FC, Guralnick MJ. Effectiveness of developmental intervention in the first five years of life. *Pediatr Clin North Am* 1991;38(6):1513-1528
- Bernheimer LP, Marlene S, Young MS, Winton PJ. Stress overtime: Parents with young handicapped children. *J Dev Beh Paediatr* 1983 Sep;4(3):77-81
- Bishop DVM. Autism, Asperger's syndrome and semantic-pragmatic disorders: where are the boundaries? *Brit J Disorders Communication* 1989;24:107-121
- Blacher J. Sequential stages of parental adjustment to the birth of a child with handicaps: fact or artifact. *Ment Retard* 1984;22:55-68
- Block BP. Appropriate strategy for rehabilitating the rural blind: education of parents and

Dunst CJ, Trivette CM, Cross AH. Mediating influences of social support: personal, family and child outcomes. *Am J Ment Defic* 1986 Jan;90(4):403-417

Dworkin PH. British and American recommendations for developmental monitoring: the role of surveillance. *Pediatr* 1989;84:1000-1010

Dyson LL. Families of young children with handicaps: parental stress and family functioning. *Am J Ment Retard* 1991 May;95(6):623-629

Ebrahim GJ. Maternal and child health services (MCH) and the prevention of disability. *J Trop Paediatr* 1982;28:ii-iv

Eheart BK. Mother-child interactions with non-retarded and retarded preschoolers. *Am J Ment Deficiency* 1982;87:20-25

Eiser C. Psychological effects of chronic disease. *J Child Psychol Psychiatry* 1990;31(1):85-98

Eiser C, Town C. Teachers' concerns about chronically sick children: implications for paediatricians. *Dev Med Child Neurol* 1987 Feb;29(1):56-63

Ellenberg JH, Nelson KB. Early recognition of infants at high risk for cerebral palsy: examination at age four months. *Dev Med Child Neurol* 1981;15:524-527

Erickson M, Upsher C. Care taking burden and social support: comparison of mothers of infants with and without disabilities. *Am J Ment Retard* 1989;94:250-258

Escobar GL, Littenberg B, Petitti DB. Outcome among surviving very low birth weight infants: a meta-analysis. *Arch Dis Child* 1991;66:204-211

Fareed H. Disability in antiquity. New York: Philosophical Library, 1970:141-175

Firth H. A move from hospital to community: evaluation of community contacts. *Child Care Health Dev* 1987;13:341-354

Fisman S, Wolf L. The handicapped child: psychological effects of parental, marital and sibling relationships. *Psychiatr Clin North Am* 1991 Mar;14(1):199-217

Fitzpatrick C, Barry C. Cultural differences in family communication about duchenne muscular dystrophy. *Dev Med Child Neurol* 1990;32:967-973

Flynt S, Wood T. Stress and coping in mothers of children with moderate mental retardation. *Am J Ment Retard* 1989;94:278-283

Frankenburg WK, Thornton SM. Common pitfalls in the evaluation of developmental screening tests. *J Ped* 1988;113:1110-1113

Fraser BC. Child impairment and parent-infant communication. *Child Care Health Dev* 1986 May-Jun;12(3):141-150

Fraser WI, Rao JM. Recent studies of mentally handicapped young people's behaviour. *J Child Psychol Psychiatr* 1991;32(1):79-108

Freeman RD, Malkin SF, Hastings JO. Psychological problems of deaf children and their families: a comparative study. *Amer Ann Deaf* 1975;120:391-405

Freeston BM. An enquiry into the effect of a spina bifida child upon family life. *Dev Med Child Neurol* 1971;13:456-61

Freye KS, Greenberg MT, Fewell RR. Stress and coping among parents of handicapped children: a multidimensional approach. *Am J Ment Retard* 1989 Nov;94(3):240-249

Fyro K, Bodegard G. Screening tests for congenital hypothyroidism. *Acta Paediatr Scand* 1987;76:107-114

Gallimore R, Weisner T, Kaufman S, Bernheimer L. The social construction of the eco-cultural niches: family accomodation of developmentally delayed children. *Am J Ment Retard* 1989;94:216-230

Gath A. The impact of an abnormal child upon the parents. *Br J Psychiatry* 1977;130:405-410

Goddard J, Rubissow J. Meeting the needs of the handicapped children and their families: the evolution of honeylands, a family support unit in Exeter. *Child Care Health Dev* 1977;3:325-347

Gonzalez R. Ministering intelligence: a Venezuelan experience in the promotion of cognitive abilities. *Int J Ment Health* 1990;18(3):5-18

Goodman JE. Problems in etiological classification of mental retardation. *J Child Psychol Psychiatry* 1990;31:465-467

Goodyer IM. Family relationships and childhood psychopathology. *J Child Psychol Psychiatry* 1990;31:161-192

Goodyer IM. Family therapy and the handicapped child. *Dev Med Child Neurol* 1986 Apr;28(2):247-250

Government of India. A summary of three reports on survey of disabled persons. Ministry of Social Welfare 1982.

Gowen JW, Johnson-Martin N, Goldman BD, Appelbaum M. Feeling of depression and parenting competence of mothers of handicapped and non-handicapped infants. *Am J Ment Retard* 1989;94:259-271

Grant J. Disabilities: The preventable burden. *The state of the world's children* 1985: 20

Guralinick MJ, Bennett FC, Heiser KE, Richardson HB, Shibley RE. Training residents in developmental pediatrics. *J Dev Behav Pediatr* 1987 (8): 260-265

Hailes B. "Some parameters for qualitative audience Research" and "Terms and tools for EPI Communication Activities" In: Report from Mission to Cairo 1986 Feb 15-Mar 1. Bangkok: East Asia and Pakistan Regional Office, UNCF

Hall DMB. Child health, promotion, screening and surveillance. *J Child Psychol Psychiatr* 1992;33(4):649-657

Hall DMB, Hall SM. Early detection of visual defects in infancy. *Brit Med J* 19 Mar 1988;296:823-824

Hall J. Subjective measure of quality of life in Britain: 1971 to 1975: some developments and trends. *Social Trends* 1976:7 pgs

Halpern JP, Boyages SC, Maberly GF, Collin SJK, Eastman CJ, Morris JG. The neurology of endemic cretinism: a study of two endemias. *Brain* 1991;114(pt 2):825-841

Hardy JB., author. Education for the handicapped in the Arabian peninsula: issues and trends. University Teachers College E.D.D. University, Columbia: Microfilms International, 1983.

Harris V, McHale, S. Family life problems, daily care giving activities and psychological well-being of mothers of mentally retarded children. *Am J Ment Retard* 1989;94:231-239

Hatfield AB and Lefley HP, ed. Families of the mentally ill. Coping and adaptations. The Guilford Press, 1987: 60-84

Hegarty S. Meeting special needs in ordinary schools: an overview. London: Cassell Ltd., 1988:3-15

Helander E. Rehabilitation for all: Guide to the management of CBR. Provisional version RHB/84. I. WHO 1984 Geneva

Helander E, Mendis P, Nelson G. Training disabled persons in the community. WHO, Geneva, 1989.

Hertzig ME. Neurological "soft" signs in low birth weight children. *Dev Med Child Neurol* 1981; 23: 778-791

Hesparin Foundation. The project projimo: a village run rehabilitation programme for disabled children in Western Mexico. The Hesparin Foundation, California, 1983:1-64

Hewett S, Newson J, Newson E., authors. The family and the handicapped child: a study of cerebral palsied children in their homes. London: George Allen & Unwin, 1970:15-27,38-39

Heyerdahl S. Psychological problems in relation to neonatal screening programmes. *Acta Paediatr Scand* 1988; 77: 239-241

Hill CE. Differential recognitions of the rehabilitation process. *Soc Sci Med* 1978;12:57-63

Hinjosa J, Anderson J. MOthers' perception of home treatment programs for their preschool children with cerebral palsy. *Am J Occup Ther* 1991 Mar; 45 (3): 273-9

Hirst M. Dissolution and reconstitution of families with disabled young persons. *Dev Med Child Neurol* 1991;33:1073-1079

Hirst M. Young adults with disabilities: Health employment and financial cost's for family carers. *Child care, Health Dev.* 1985; 11: 291-307

Hirst M. Young people with disabilities: what happens after 16? *Child Care Health Dev* 1983;9:273-284

Hoare P. Children with epilepsy and their families. *J Child Psychol Psychiatry* 1987;28(5):651-655

Hornby G, Murray R. Group programmes for parents of children with various handicaps. *Child Care Health Dev* 1983 Jul-Aug;9(4):185- 198

Howlin P. Living with impairment: The effects on children of having an autistic sibling. *Child Care Health Dev* 1988; 14(6): 395-408

Illingworth CM, Illingworth RS. Mothers are easily worried. *Arch Dis Childhood* 1984;55:63-65

ILO. Community-based rehabilitation services for the disabled. A pilot experience in Indonesia. ILO, Geneva 1982

Intagliata J, Doyle N. Enhancing social support for parents of developmentally disabled children: training in interpersonal problem-solving skills. *Ment Retard* 1984;22:2-11

Intagliata J, Willer B, Wicks N. Factors related to the quality of community adjustment in family care homes. Monogram Assoc Ment Deficiency 1981;4:217-230

International Children's Centre (CIE). Screening and social integration of handicapped children: a document for policy makers. CIE, 1980; ICCHHS Washington

Jali LF. The principles and strategic steps in a simple nutritional message. Acta Pediatr Scan Suppl 1991;373:160-167

James WV. Technology for the disabled. World Health Forum 1984;5:256-258

Jarvis SN, Tamhne RC, Thompson L, Francis PM, Anderson J, Colver AF, Preschool vision screening. Arch Dis Child 1990;65:288-294

Jenkins JM, Smith MA. Marital disharmony and children's behaviours problems: Aspects of poor marriage that affects children adversely. J Child Psychol Psychiat 1991; 32(15): 793-810

Jensen TS, Andersen BB, Schmidt J, Ankehus J, Hansen E. Perinatal risk factors and first year vocalizations: influence on pre- school language and motor performance. Dev Med Child Neurol 1988;30:153-161

Judson SL, Burden RL. Towards a tailored measure of parental attitudes: an approach to the evaluation of one aspect of intervention projects with parents of handicapped children. Child Care Health Dev 1980;6:47-55

Kashani JH, Self-esteem of handicapped children and adolescents. Dev Med Child Neurol 1986 Feb;28(1):81-83

Kashani JH, Koenig P, Shepperd JA, Wilfrey D, Morris DA. Psychopathology and self-concept in asthmatic children. J Pediatr Psychol 1988;13:509-520

Katz S, Chamiel LM. Relationship between children's ages and parental attitudes, and their attitudes toward a child with physical disability. Int J Rehab Res 1989;12(2):190-192

Kaufman J, Hardy-Ribakow D. Home care: a model of a comprehensive approach for technology-assisted chronically ill children. J Pediatr Nurs 1987 Aug;2(4):244-249

Kazak AE, Marvin RS. Differences, difficulties and adaptations: stress and social networks in families with a handicapped child. Fam Rel 1984;33:67-77

Kielhofner G. Qualitative Research Part I. Paradigmatic grounds and issues of reliability and validity. Occup Ther J Res 1982;2(2):62-79

King SM, Rosenbaum P, Armstrong RW, Milner R. An epidemiological study of children's attitudes toward disability. Dev Med Child Neurol 1989;31(2):237-45

Kirkham MA, Schilling RF, Norelius K, Schinke SP. Developing coping styles and social support networks: an intervention outcome study with mothers of handicapped children. Child Care Health Dev 1986 Sep-Oct;12(5):313-323

Kutner NG, Kutner MH. Race and sex as variables affecting reactions to disability. Arch Phy Med Rehabil 1979;60:62-66

Lansdown R. Psychological problems of parents with cleft lip and palate: discussion paper. Journal of the Royal Society of Med 1990;83(7):448-450

Lefley HP. Culture and mental illness: the family role. In: Families of the mentally ill coping and adaptation. Eds. Hatfield AB, Lefley HP. England: The Cultural Press 1987:30-56

Leininger MM. Nature, rationale and importance of qualitative research methods in nursing. In Leininger MM (ed) *Qualitative research methods in nursing*. New York: Grunne & Stratton 1985; 1-28

Levitt E, Cohen S. Educating parents of children with special needs: approaches and issues. *Young Child* 1976 May;263-272

Lillion E. *Fund Foundation* 1987: 3

Livingstone MG. The burden on families of the brain injured: A review. *J Head Trauma Rehabil* 1988; 3: 6-15

Livneh H. A unified approach to existing models of adaptation to disability. Part 1: model of adaptation. *J Applied Rehab Couns* 1986;17(5):16-56

Livneh H and Antonak RF. Reactions to disability: an empirical investigation of their nature and structure. *J Applied Rehab Couns* 1990;21:13-21

Lobato DJ, Miller CT, Barbour L, Hall LJ, Pezzullo J. Preschool siblings of handicapped children: interactions with mothers, brothers and sisters. *Res Dev Disabil* 1991;12(4):387-99

Lonsdale G. Family life with a handicapped child: the parents speak. *Child Care Health Dev* 1978;4:99-120

Lyons M. Enabling or disabling? Students' attitudes towards persons with disabilities. *Am J Occup Ther* 1991;45(1):311-316

McAndrews I. Children with handicap and their families. *Child Care Health Dev* 1976;2(4):213-237

McConachie H. Home-based teaching: what are we asking of parents? *Child Care Health Dev* 1991 Mar-Apr;17(2):123-136

McConachie H, Mitchell DR. Parents teaching their young mentally handicapped children. *J Child Psychol Psychiatry* 1985;26(3):389- 405

McCormick MC, Charney EB, Stemmler MM. Assessing the impact of a child with spina bifida on the family. *Dev Med Child Neurol* 1986;28:53-61

McKay M and Hensey O. From the other side: parents' views of their early contacts with health professionals. *Child: Care, Health and Dev* 1990;16:373-381

Mahoney G, Powell A. Modifying parent-child interaction: enhancing the development of handicapped children. *J Spec Educ* 1988;22:82-96

McKeith R. The feelings and behaviour of parents of handicapped children. *Dev Med Child Neurol* 1973(15):524-527

Marfo K. Maternal directiveness in interactions with mentally handicapped children: an analytical commentary. *J Child Psychol Psychiatry* 1990;31(4):531-549

Marfo K, Walker S, Charles B. *Childhood disability in developing countries: issues in habilitation and special education*. London: Prager Ltd., 1986.

Martin JAM, Colley BJRT, Hennebert D, Holm C, Lurato S, de Jong EGA, McCullen O, Meyer ML, Moore WJ, Morgan A. Child deafness in European community. *Scand Audio* 1981; 10: 165-174

Marwah S, Alhabdan JM, Kutty MS, Parashar S. Road traffic accidents in university hospital in Saudi Arabia (a pilot study) Saudi M J 1990; 11(5): 389-391

Mavalankar DV, Trivedi CR, Gray RH. Levels and risk factors for perinatal mortality in Ahmed Abad, India. Bulworld Health Organ 1991; 69 (4): 435-442

Mia A, Hafizal MD, Shamsherali MD. Situation of physically handicapped children in Bangladesh: The disabled child a new approach to prevention and rehabilitation. Assign Child 1979, 53/54: 199-217

Miles N. Attitudes towards persons with disabilities following I.Y.D.P. with suggestions for promoting positive changes. A study conducted for the national council of social welfare, Mental Health Centre, Mission Hospital, Peshawar 1983 April: 1-86

Minnes PM. Family resources and stress associated with having a mentally retarded child. Am J Ment Retard 1988; 93 (2): 184-192.

Mitchell DR. Parents interactions with their developmentally disabled or at risk infants: A focus of interventioj. Aus NZ J Dev Disabl 1987; 13: 73-81

Mitchell DR, Pollock N. Play deprivation in children with physical disabilities: The role of occupational therapist in preventing secondary disability. Am J Occup Ther 1991; 451(10) 882-888

Mittler P. The concept of normalisation as a principle of education theory and practice. Int J Rehab Res 1988;11(3):261-268

Mittler P, McConachie H., editors. Parents, professionals and mentally handicapped people - approaches to partnership. London: Croom Helm, 1983:8-40

Moore MO. Social acceptance of the physically handicapped child in the ordinary school. Child Care Health Dev 1980;6:317-338

Morris RD. Classification of learning disabilities: old problems and new approaches. J Consulting Clin Psychiatry 1988;56:789-794

Mufti MH. Medico-legal aspects of seat belt legislation in Saudi Arabia. Saudi Med J 1986; 7:84-90

Nader A. Teacher attitudes toward the elementary exceptional child. Int J Rehabil Res 1984;7(1):37-46

Nichter M. Project community diagnosis: participatory research as a first step towards community involvement in primary health care. Soc Sci Med 1984;19:237-52

Nolan T, Pless IB. Emotional correlates and consequences of birth defects. J Pediatr 1986; 109: 148-154

O'Toole B. A community-based rehabilitation programme for pre- school disabled children in Guyana. Int J Rehabil Res 1988;11(4):323-324

Ogbue RM. Education and the handicapped child in Nigeria. ICPS Bull 1984 Dec:69-73

Osberg JS, Discala C. Morbidity among pediatric motor vehicle crash victims: the effectiveness of seatbelts. Am J Public Health 1992 Mar;82(3):422-425

Parmenter TR. An Analysis of the dimensions of quality of life for people with physical disabilities. In Quality of life for handicapped people (Ed) Brown RI. London: Croom Helm 1988

Parry G. Domestic roles. In: Watts FN, Bennett DH, editors. Theory and practice of psychiatric rehabilitation. John Wiley & Sons Ltd., 1983:241-266

Paul TI, Desai P, Thorburn MJ. The prevalence of childhood disability and related medical diagnosis. West Indian Med J 1992;41(1):8-11

Pauline H, McMillen N. A survey of transport for children in wheelchairs. Br J Occup Ther 1992, 55(5): 179-182

PCMR. The residential clusters of Eastern Nebraska. In Mental retardation: the leading edge. PCMR 1979, US Govt, Washington DC

Pepper GA. The person with a spinal cord injury: psychological care. Am J Nurs 1977;77:1330-1336

Periquet AO. Community based rehabilitation services: The experience of Bacolod, Philippines and the Asia Pacific Region. World Rehabilitation Fund, New York 1984 Monogram 26: 7-49

Perrin EC, Ramsey BK, Sandler HM. Competent kids: children and adolescents with a chronic illness. Child Care Health Dev 1987;13:13-32

Phillips CJ, Yuk-Ching H, Smith B, Sutton A. Severe mental retardation from social disadvantaged families. Child Care Health Dev 1978;12:69-91

Pinkard CM, Gross P. Modification of locus of control among rehabilitation counselling graduate students. Rehab Couns Bull 1984;27:39-45

Pless IB, Nolan T. Revision, replication and neglect: research on maladjustment in chronic illness. J Child Psychol Psychiat 1991;32(2):347-365

Pringle MK. The needs of children: A personal perspective. Hutchinson 1985: 148-162

Prior MTR, Glazner J, Sanson A, DeBelle G. Temperament and behavioural adjustment in hearing impaired children. J Child Psychol Psychiat 1988;29(2):209-216

Quicke JC. Pupils' knowledge of mental handicap: a study of second year pupils in a British comprehensive school. Int J Rehab Res 1989;12(1):17-26

Quine L, Pahl J. First diagnosis of severe handicap: a study of parental reactions. Dev Med Child Neurol 1987;29(2):232-242

Ramia S, Bakir TM, Al-Frayhand H, Bahakim. Paralytic poliomyelitis and non-polio enteroviruses in Saudi Arabia. J Trop Paediatr 1987 Aug;33:166-167

Rehabilitation International. Childhood disability: Its prevention and rehabilitation. Assign Child 1981 53/54: 43-75

Reinhard HG, Weissenborn M. Isolation and the mastering of anxiety in physically handicapped children and adolescents. Acta Paedopsychiatr 1990;53(4):298-304

Reiter A, Mar'i S, Rosenberg J. Paternal attitudes towards the developmentally disabled Arab communities in Israel: a cross-cultural study. Int J Rehabil Res 1986;9(4):355-362

Richardson SA. Physical impairment, disability and handicap in rural Nepal. Dev Med Child Neurol 1983;25:717-726

Richmond JB, Butler JA, Stenmark S. Reducing childhood disability in the 80's. Hosp Comm Psych 1983;34(6):507-514

Rimmerman A. The provision of respite care for children with developmental disability: changes in maternal coping and stress over time. *Ment Retard* 1989;27:99-103

Rimmerman A, Portowicz DJ. Analysis of resources and stress among parents of developmentally disabled children. *Int J Rehab Res* 1987;10:439-445

Rimmerman A, Stanger V. Locus of control and utilization of social support among mothers of young children with physical disabilities. *Int J Rehab Res* 1992;15:39-47

Robertson L. Qualitative research methods in occupational therapy. *Br J Occup Therapy* 1988 Oct;51(10):344-346

Robertson SE, Chan C, Kim Farley R, Ward N. Worldwide status of poliomyelitis in 1986, 1987 and 1988 and plans for global eradication by the year 2000. *Rapp trimest Statist Sanit Mond* 1990;43:80-91

Robinson EJ, Robinson WP. The roles of egocentrism and of weakness in comparing in children's explanations of communication failure. *J Exp Child Psychol* 1978 Aug;26(1):147-60

Rodriguez PG. Using the international classification of impairments, disabilities and handicaps in surveys: The case of Spain. *Work Health Stat Q* 1989; 42: 161-165

Rona RJ, Reynolds A, Allsop M, Morris RW, Morgann M, Mandalila S. Audit from pre-school developmental surveillance of vision, hearing and language referrals. *Arch Dis Child* 1991; 66: 921-926

Rosenbaum PL, Armstrong RW, King SM. Parental attitudes toward children with handicaps: new perspectives with a new measure. *J Dev Behav Pediatr* 1987 Dec;8(6):327-334

Rosenbaum PL, King SM, Cadman DT. Measuring process of care giving to physically disabled children and their families 1: Identifying relevant component of care. *Dev Med Child Neurol* 1992; 34:103-114

Rutter M, Graham P, Yule W. A neuro psychiatric study in childhood. *Clin Dev Med* 1970; 35-36:3-24

Sadow S. Action research and evaluation: can research and practice be successfully combined. *Child Care Health Dev* 1979;5:211-223

Sarason IG. Social support, personality and health. In: Janisse MP, editor. *Individual differences, stress and health psychology*. New York: Springer Verlag, 1988:109-128

Sardharwalla IB, Wraith JE. A clinical views of the mass screening of the newborn for inherited diseases: Current practice and future considerations. *J Inherit Metab Dis* 1989; 12(1): 55-63

Schmid H. Qualitative research and occupational therapy. *Am J Occup Ther* 1981;35(2):105-106

Sebai ZA. *The health of a family in a changing Arabia, Jeddah*. Tihama Publications 1981

Sebai ZA, Reinke WA. Anthropometric measurements among pre-school children in Wadi Turba, Saudi Arabia. *J of Trop Pediatrics* 1981; 15: 310-314

Serenius F. *Child health in Saudi Arabia: comprehensive summaries of Uppsala dissertations*. Uppsala: Faculty of Medicine, University of Uppsala, Sweden, 1988.

Serpell R. Assessment criteria for severe intellectual disability in various cultural settings. *Int J Beh Dev* 1988;1:117-144

Shah PM. Birth asphyxia: A crucial issue in prevention of developmental disabilities. WHO, Geneva. 1989

Sheridan MD. The handicapped child and his home. National Children's Home 1965; 7: 153-171

Simeonsson RJ. Early prevention of childhood disability in developing countries. Int J Rehab Res 1991;14:1-12

Simeonsson RJ, McHale SM. Review: research on handicapped children: sibling relationships. Child Care Health Dev 1981;7:153-171

Singhi PD, Goyal L, Pershad D, Singhi S, Walia BN. Psychosocial problems in families of disabled children. Br J Med Psychol 1990 Jun;63(2):173-182

Sloper P, Cunningham CC, Jotsdottir MA. Parental reactions to early intervention with their Down's syndrome infants. Child Care Health Dev 1983;9:357-376

Sloper P and Turner S. Risk and resistance factors in the adaptations of parents of children with severe physical disability. J Child Psychol Psychiat 1993; 34(2): 167-188

Sommer A, Tarwotjo I, Hussani G, Susanto D, Soegiharto T. Incidence, prevalence and scale of blinding malnutrition. Lancet 1981;1:1407-8

Staples J. Mentally handicapped: caring enough to try. Community Care 1983 May 19:16-17

Staples J. We can be there when they need us. Community Care 1983 May 26:15

Stephenson E, McKay C, Chesson R. An investigative study of early developmental factors in children with motor, learning difficulties. Br J Occup Therapy 1990; 53 (1): 4-6

Stokes BM. Helping parents to accept. Child Care Health Dev 1976;2:29-33

Sullivan PM, Vernon M and Scanlan JM. Sexual abuse of deaf youth. Am Annals Deaf 1987;3:256-262

Taha SA, Mahdi AH. Cerebral palsy in Saudi Arabia: A clinical study of 102 cases. Ann Trop Paediatr 1984; 4: 155-158

Tareen KI. Epidemiological study of childhood disability. Internal Report 1982 UNICEF, Punjab, Lahore

Tarron E. Parents' views on medical and social work services for families with young cerebral palsied children. Dev Med and Child Neur 1981;23:173-182

Terwogt MM, Schene J, Koops W. Concepts of emotion in institutionalised children. J Child Psychol Psychiat 1990; 31 (7): 1131-1143

Tew B, Payne E, Laurence KM. Some sources of stress found in mothers of spina bifida children. Br J Prev Soc Med 1975;29:27-30

Thorburn MJ. Parent evaluation of community based rehabilitation in Jamaica. Int J Rehabil Res 1992; 15: (2) 170-176

Thorburn MJ. The disabled child in the Caribbean: a situation analysis. West Indian Med J 1991 Dec;40(4):172-180

Thorburn M, Desai P, Paul TJ, Malcolm L, Durkin M, Davidson L. Identification of childhood

- disability in Jamaica: the ten question screen. *Int J Rehabil Res* 1992;15(2):115-127
- Thorburn MJ, Roecher A. A realistic approach to the preparation of personnel for rehabilitation services in developing countries. In *childhood disability in developing countries*. Ed. Marfo K, Walker S, Charles B. P Ger 1986; 73-81
- Trevelyan J. When it's difficult to say no. *Nurs Times* 1988;84:16-17
- Turk J. Impact of cystic fibrosis on family function. *Pediatr* 1964 Jul;67-71
- Tysk KE. Evaluation of care load for individuals with spastic tetraplegia. *Dev Med Child Neurol* 1989; 31: 737-745
- UN. Disability compendium. Statistics on special population groups series Y No. 4 Department of International Economic and Social Affairs Statistical Offices 1990. ST/ESA/Stat, ser Y/4
- UNICEF. Childhood disability: its prevention and rehabilitation. Report of Rehabilitation International to the Executive Board of UNICEF. Geneva: UNICEF, 1980 Mar 26. Report No. E/ICEF/L 1410:10-15
- Varni JW, Setoguchi Y. Screening for behavioral and emotional problems in children and adolescents with congenital or acquired limb deficiencies. *Am J Dis Child* 1992 Jan;146(1):103-107
- Voysey M. *A constant burden: the reconstitution of family life*. London: Routledge and Kegan Ltd., 1975:76-94,95-107
- Waisbren SE. Parents' reactions after the birth of a developmentally disabled child. *Am J Ment Deficiency* 1980;84:345-351
- Walker SA. A comparison of the attitudes of student and non-students towards the disabled in Ghana. *Int J Rehabil Res* 1983;6(3):313-320
- Wallander JL, Varni JW, Babani L, Banis HT, Wilcox KT. Children with chronic physical disorders: Maternal reports of the psychological adjustments. *J Pediatric Psychol* 1988; 13: 197-212
- Wallander JL, Varni JW, Babani L, Banis HT, Wilcox KT. Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *J Pediatr Psychol* 1989 Jun;14(2):157-73
- Ware H. Effects of maternal education, women's roles and child care on child mortality. In: Mosley WH, Chen LC., editors. *Child survival, strategies for research, population and development*. Review 10;(Suppl):191-214
- Warren MD. The Canterbury studies of disablement in the community: prevalence, needs and attitudes. *Int J Rehabil Res* 1985;8(1):3-18
- Wasserman GA, Allen R, Solomon CR. The behavioral development of physically handicapped children in the second year. *J Dev Behav Pediatr* 1985 Feb;6(1):27-31
- Waxler N. Cultural and mental illness. A social labelling perspective. *J Nerv Ment Dis* 1974; 159 (6): 379-395
- Waxler N. Is outcome of schizophrenia better in non-industrial societies: The case of Sri-lanka. *J Nerv Ment Dis* 1979; 167: 144-158
- Wells RD, Schwebel AI. Chronically ill children and their mothers: predictors of resilience and

vulnerability to hospitalization and surgical stress. *J Dev Behav Pediatr* 1987 Apr;8(2):83-89

Welton J. School in the welfare network. *Child Care Health Dev* 1982;8:271-281

Werner D. Disabled village children. *Hesperin Foundation* 1987; 228-318, 463-476

Wikler L, Wassow M, Hatfield E. Chronic sorrow revisited: Parent vs professional depiction of the adjustment of parents of mentally retarded children. *Am J Ortho Psychiat* 1981; Jan, 51(1): 63-70

Wilson S, Schreck A. Maternal perceptions of child behavior: handicapped versus nonhandicapped. *Spec Care Dentist* 1988 May- Jun;8(3):125-128

Winefield HR, Cormack SM. Regular activities as indicators of subjective health status. *Int J Rehabil Res* 1986;9(1):47-52

Wolfensberger W. Social role valorisation: A proposed new term for the principle of normalisation. *Ment Retard* 1983; 21: 234-239

Wood PHN. Measuring the consequences of illness. *World Health Stat Q* 1989; 42: 115-121

Wood STR, Malleson PN, Rovert S, Thomson PJ/ Unconventional remedies used for patients with juvenile arthritis. *Paediatrics* 1990; 85: 150-153

World Health Organization. CBR in the countries which have introduced the programme. May 1984:14

World Health Organization. Disability, prevention and rehabilitation. Geneva: WHO Technical Reports 1981;668:9-35

World Health Organization. Evaluation of the strategy for health for all by the year 2000: Sevent report on the world health situation. *Global Reviews, Vol 1; Geneva, WHO* 1987

World Health Organization. International classification of impairments, disabilities and handicaps. 1980, Geneva, WHO.

Zaman SS, Khan NZ, Durkin M, Islam S. Childhood disabilities in Bangladesh. Report on the epidemiological assessment of childhood disabilities in Bangladesh. *Bangladesh Proti Bondhi Foundation* 1992:1-35

Zaman SS, Khan NZ, Islam S, Banu S, Dixit S, Shrout P, Durkin M. Validity of the "Ten Questions" for screening serious childhood disability: results from urban Bangladesh. *Int J Epidemiol* 1990 Sep;19(3):613-620

Zubrick SR, Macarthey H, Stanley FJ. Hidden handicap in school-age children who received neonatal intensive care. *Dev Med Child Neurol* 1988; 30: 140-152